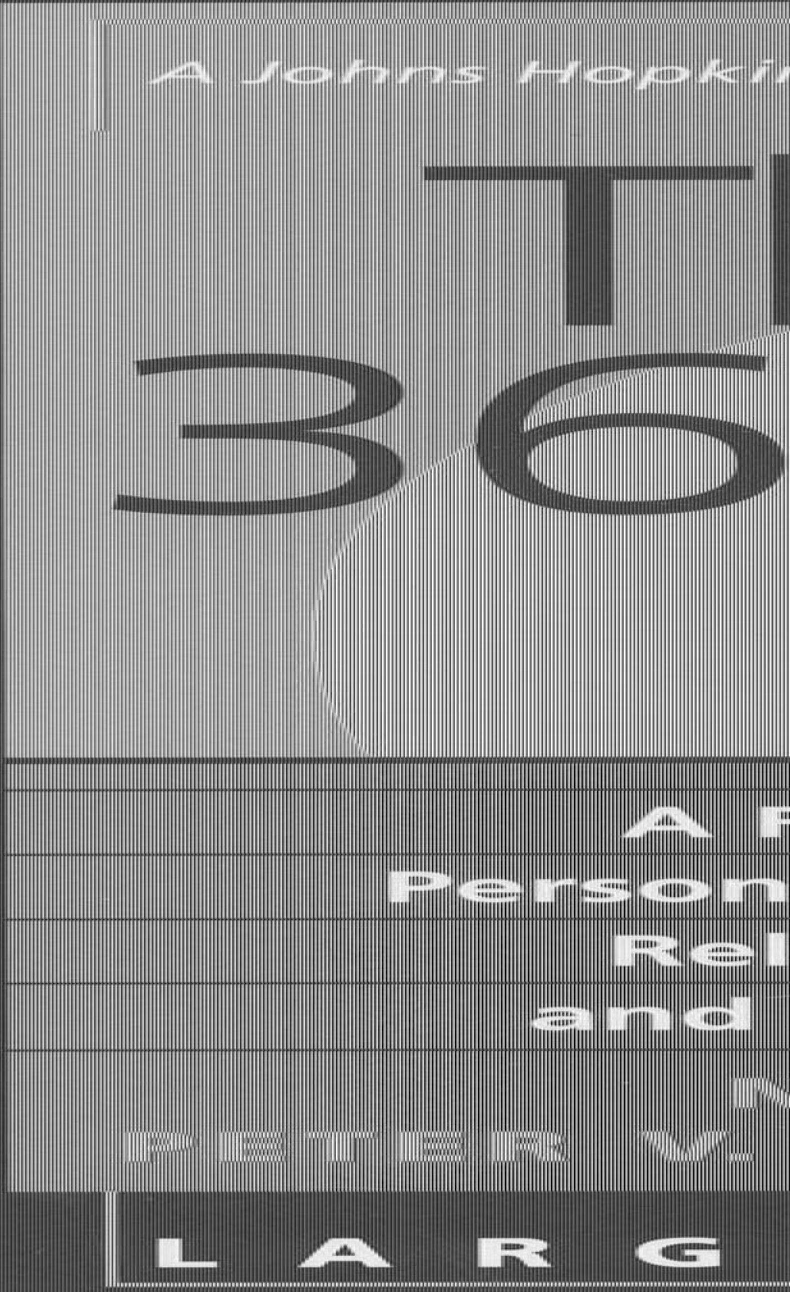

A Johns Hopki

Th
36

A P

Person

Rel

and

N

PETER V.

LARG

Nancy L. Mace, M.A.

is retired. She was a consultant to and member of the board of directors of the Alzheimer's Association, and an assistant in psychiatry and coordinator of the T. Rowe and Eleanor Price Teaching Service of the Department of Psychiatry and Behavioral Sciences of the Johns Hopkins University School of Medicine.

Peter V. Rabins, M.D., M.P.H.

is professor of psychiatry, with joint appointments in medicine, mental hygiene, and health policy and management, director of the geriatric neuropsychiatry section, and director of the T. Rowe and Eleanor Price Teaching Service of the Department of Psychiatry and Behavioral Sciences of the Johns Hopkins University School of Medicine.

A Johns Hopkins Press Health Book

First edition 1981
Third edition 1999. Large print edition 2000
Printed in the United States of America on acid-free paper
9 8 7 6 5 4 3 2 1

The Johns Hopkins University Press
2715 North Charles Street
Baltimore, Maryland 21218-4363
www.press.jhu.edu

Words from "Joy Is Like the Rain" by Sister Miriam Therese Winter
© 1965 by Medical Mission Sisters, Philadelphia, Pa.
Reprinted by permission of Vanguard Music Corp.,
1595 Broadway, New York, N.Y. 10019
Further reproduction prohibited

Library of Congress Cataloging-in-Publication Data will be found
at the end of this book.
A catalog record for this book is available from the British Library.

ISBN 0-8018-6521-2 (pbk.—large print)

**This Large Print Book carries the
Seal of Approval of N.A.V.H.**

This book is dedicated to everyone who gives a "36-hour day" to the care of a person with a dementing illness.

Contents

Foreword

I welcome with enthusiasm the third edition of this book for families and friends of patients with dementing illnesses. It has served well in its prior appearances and should accomplish even more with this edition, as here the most recent advances in scientific and clinical knowledge about these conditions are brought forth. As I have watched, with pride in Johns Hopkins psychiatry, each of the editions of *The 36-Hour Day* appear, I have been impressed by both the information and the comfort it brought to those who would help their relatives. But even more impressive has been the unanticipated good that emerged from responses to the book by its audience. Like any doctor, I know how useful is information related to palliation, prevention, and cure and spend most of my efforts transmitting it, but the reception and employment of any information depends on a commitment to employ it in service. We have learned from readers that this book has strengthened their dedi-

What is new, then, in this edition? The entire text has been reviewed and updated. There is new information on the financing and delivery of care, reflecting the current health care marketplace. The latest information on the genetics of Alzheimer disease is reviewed. This has special importance for family members, who may be concerned about their risk of developing the disease. There is new information about research and about the other dementias. Unfortunately, there is still no cure for Alzheimer disease and related dementias. However, several new drug treatments hold promise for improving the quality of life for persons with dementia (and so for their caregivers as well), and these are discussed.

You will see that Alzheimer's disease and other disorders named for a clinician or researcher no longer carry an " 's"; hence, they are referred to as, for example, Alzheimer disease or Down syndrome. This reflects the current medical usage. Of course, organizations are referred to by their official names, which may include the " 's" (for example, Alzheimer's Association).

The appendixes have been brought up to date. Appendix 1 mentions some recent books, videos, and Web sites that families may find educational or emotionally comforting or both, as well as a list of current books for professionals.

Appendix 2 now includes not only the latest address and telephone numbers for U.S. organizations but also, where available, Web site addresses; international organizations and Web sites of interest to readers are also listed.

and shared their comments. Our friends and colleagues, translators of foreign editions, physicians, dentists, and others have answered our questions and offered suggestions. Over time we have considered this information and tested it against the experience of caregivers and professionals. This process of learning, growth, testing, and reshaping created the revised edition. It would be impossible to list every name and would violate the privacy of many. Nevertheless, we are indebted to the generosity of this worldwide community.

The Alzheimer's Association has distributed countless copies of the book, and its board members and staff have contributed to the revisions. Kathryn Ling, Tom Kirk, Joan Dashiell, and Nancy Lombardo, Ph.D., made generous contributions of time to the second edition. For the third edition, Patricia Pinkowski, director of the Library and Information and Referral Services, researched current information and Paul McCarty, a former member of the board of directors, assisted in updating the nursing home issues.

David Chavkin reviewed the accuracy of sections on nursing home reform legislation, Medicare, and Medicaid. Staff members at the National Senior Law Center also advised us on legal issues. The staff of the National Citizens Coalition for Nursing Home Reform, particularly Barbara Frank, Ruth Nee, M.S.W., Sarah Burger, M.S.W., and Elma Holder, M.S.P.H., reviewed the sections on nursing homes and nursing home law. Gene Vandekieft assisted us in understanding insurance issues. Katie Maslow, M.S.W., of the Office of Technology Assessment, U.S. Congress, and Lisa Gwyther, M.S.W., of Duke University, long supporters of the first edition, shared expertise in many areas. Jean Marks, M.S.W., and her staff in the New York City chapter of the Alzheimer's Association shared their experiences of confused people living alone and of minority families. Ray Rasco also provided information on confused people who live alone. The Internal Revenue Service Information Department and John Kenneally provided information about tax law. Thomas Milleson, D.D.S., and Richard Dixon, D.D.S., gave us guidance in dental care. Carter Williams, M.S.W., and Mildred Simmons helped us understand the role of physical restraints. Mary Barringer, R.N., and Jean Marks helped us with incontinence care. Thomas Price, M.D., gave us information about multi-infarct dementia. Glenn Kirkland, M.S., reviewed the entire manuscript and gave us extensive valuable comment; he also researched the "gadgets" that might be useful to families. Laura Del Genis supplied information on nutrition. For the third edition, the staff of the Johns Hopkins University Press updated facts and figures and appendixes.

A good editor is vital to a good book, and *The 36-Hour Day* has had the good fortune to have two good editors dedicated to its success. Anders Richter, editor to the first edition, facilitated many of the foreign language editions. It was he who initiated the writing of the second edition. Wendy Harris has carried on the tradition of energy, skill, and dedication in the editorial management of *The 36-Hour Day.* We are indebted to both of these fine editors.

Preface to the First Edition

Although this book was written for the families of people with dementing illnesses, we recognize that other people, including those suffering from these conditions, may read this book. We welcome this. We hope that the use of such words as *patient* and *brain-injured person* will not discourage those who have these illnesses. These words were chosen because we want to emphasize that the people who suffer from these conditions are ill, not "just old." We hope the tone of the book conveys that we think of you as individuals and people and never as objects.

This book is not intended to provide medical or legal advice. The services of a competent professional should be obtained when legal, medical, or other specific advice is needed.

At present, not all professionals are knowledgeable about dementia. We frequently refer to trained personnel who can help you, but we recognize that you may

LARGE PRINT edition

The 36-Hour Day

1

Dementia

For two or three years Mary had known that her memory was slipping. First she had trouble remembering the names of her friends' children, and one year she completely forgot the strawberry preserves she had put up. She compensated by writing things down. After all, she told herself, she was getting older. But then she would find herself groping for a word she had always known, and she worried that she was getting senile.

Recently, when she was talking with a group of friends, Mary would realize that she had forgotten more than just an occasional name—she lost the thread of the conversation altogether. She compensated for this too: she always made an appropriate answer, even if she secretly felt confused. No one noticed, except perhaps her daughter-in-law, who said to her best friend, "I think Mother is slipping." It worried Mary—sometimes depressed her—but she always denied that any-

wasn't, because he had just been there. Then when she complained to her daughter-in-law that she never came, she thought the woman lied when she said, "But Mother, I was just here this morning." In truth, she could not remember the morning.

People came and poked and pushed, and shoved things in and out and over her. They gave her needles and they wanted her to blow into their bottles. She did not understand and they could not explain that blowing in the bottles forced her to breathe deeply to strengthen her lungs and improve her circulation. The bottles became part of her nightmare. She could not remember where she was. When she had to go to the bathroom, they put rails on her bed and refused to let her go, so she cried and wet herself.

Gradually, Mary got better. The infection cleared and the dizziness passed. Only during the acute phase of her illness did she imagine things, but after the fever and infection had passed, the confusion and forgetfulness seemed more severe than before. Although the illness had probably not affected the gradual course of her memory loss, it had weakened her considerably and taken her out of the familiar setting in which she had been able to function. Most significantly, the illness had focused attention on the seriousness of her situation. Now her family realized she could no longer live alone.

The people around Mary talked and talked. No doubt they explained their plans, but she forgot. When she was finally released from the hospital, they took *her to her daughter-in-law's house. They were happy about something that day, and led her into a room. Here at last were some of her things, but not all. She thought perhaps the rest of her things had been stolen while she was sick. They kept saying they had told her where her things were, but she couldn't remember what they said.*

This is where they said she lived now, in her daughter-in-law's house—except that long ago she had made up her mind that she would never live with her children. She wanted to live at home. At home she could find things. At home she could manage—she believed—as she always had. At home, perhaps, she could discover what had become of a lifetime of possessions. This was not her home: her independence was gone, her things were gone, and Mary felt an enormous sense of loss. Mary could not remember her son's loving explanation—that she couldn't manage alone and that bringing her to live in his home was the best arrangement he could work out for her.

Often, Mary was afraid, a nameless, shapeless fear. Her impaired mind could not put a name or an explanation to her fear. People came, memories came, and then they slipped away. She could not tell what was reality and what was memory of people past. The bathroom was not where it was yesterday. Dressing became an insurmountable ordeal. Her hands forgot how to button buttons. Sashes hung inexplicably about her, and she could not think how to manage them or why they hung there.

couraged for a while, until nature heals us or the trouble goes away.

Mary's old ways of coping with trouble remained. Often when she felt nervous, she thought of going for a walk. She would pause on the porch, look out, drift out, and walk away—away from the trouble. Yet the trouble remained and now it was worse, for Mary would be lost, nothing would be familiar: the house had disappeared, the street was not the one she knew—or was it one from her childhood, or where they lived when the boys were growing up? The terror would wash over her, clutching at her heart. Mary would walk faster.

Sometimes Mary would react with anger. It was an anger she herself did not understand. But her things were gone, her life seemed gone. The closets of her mind sprang open and fell shut, or vanished altogether. Who would not be angry? Someone had taken her things, the treasures of a lifetime. Was it her daughter-in-law, or her own mother-in-law, or a sister resented in childhood? She accused her daughter-in-law but quickly forgot the suspicion. Her daughter-in-law, coping with an overwhelming situation, was unable to forget.

Many of us remember the day we began high school. We lay awake the night before, afraid of getting lost and not finding the classrooms the next day in a strange building. Every day was like that for Mary. Her family began sending her to an adult day care center. Every day a bus driver came to pick her up in the morning, and every day her daughter-in-law came to get her in the *afternoon, but from day to day Mary could not remember that she would be taken home. The rooms were not dependable. Sometimes Mary could not find them. Sometimes she went into the men's bathroom.*

Many of Mary's social skills remained, so she was able to chat and laugh with the other people in the day care center. As Mary relaxed in the center, she enjoyed the time she spent there with other people, although she could never remember what she did there well enough to tell her daughter-in-law.

Mary loved music; music seemed to be imbedded in a part of her mind that she retained long after much else was lost. She loved to sing old, familiar songs. She loved to sing at the day care center. Even though her daughter-in-law could not sing well, Mary did not remember that, and the two women discovered that they enjoyed singing together.

The time finally came when the physical and emotional burden of caring for Mary became too much for her family and she went to live in a nursing home. After the initial days of confusion and panic passed, Mary felt secure in her small, sunny bedroom. She could not remember the schedule for the day but the reliability of the routine comforted her. Some days it seemed as if she were still at the day care center; sometimes she was not sure. She was glad the toilet was close by, where she could see it and did not have to remember where it was.

Mary was glad when her family came to visit. Sometimes she remembered their names; more often she did

> *not. She never remembered that they had come last week, so she regularly scolded them for abandoning her. They could never think of much to say, but they put their arms around her frail body, held her hand, and sat silently or sang old songs. She was glad when they didn't try to remind her of what she had just said or that they had come last week, or ask her if she remembered this person or that one. She liked it best when they just held her and loved her.*

Someone in your family has been diagnosed as having a dementia. This could be Alzheimer disease, vascular dementia, or one of several other diseases. Perhaps you are not sure which condition it is. Whatever the name of the disease, a person close to you has lost some of his intellectual ability—the ability to think and remember. He may become increasingly forgetful. His personality may appear to change, or he may become depressed, moody, or withdrawn.

Many, although not all, of the disorders that cause these symptoms in adults are chronic and irreversible. When a diagnosis of an irreversible dementia is made, the patient and his family face the task of learning to live with this illness. Whether you decide to care for the person at home or to have him cared for in a nursing home, you will find yourself facing new problems and coping with your feelings about having someone close to you develop an incapacitating illness.

This book is designed to help you with that adjustment and with the tasks of day-to-day management of a so tiny that neither you nor the afflicted person is aware of any change, but all together they can destroy enough bits of brain tissue to affect memory and other intellectual functions. This condition used to be called "hardening of the arteries," but autopsy studies have shown that it is stroke damage rather than inadequate circulation that causes the problem. In some cases, treatment can reduce the possibility of further damage.

Alzheimer disease and vascular dementia sometimes occur together. The diagnosis and characteristics of these diseases are discussed in detail in Chapter 17.

People who have dementing illness may also have other illnesses, and their dementia may make them more vulnerable to other health problems. Other illnesses or reactions to medications often cause delirium in people with dementing illnesses. The delirium can make the person's mental functions and behavior worse. It is vital, for his general health and to make his care easier, to detect and treat other illnesses promptly. It is important to have a doctor who is able to spend time with you and the patient to do this.

Depression is common in older people, and can be the cause of memory loss, confusion, or other changes in mental function. Dementia caused by depression is reversible. The depressed person's memory frequently gets better when the depression is treated. Although depression can also occur in a person with an irreversible dementia, depression should always be treated.

Several other uncommon conditions cause dementia. These will be discussed in Chapter 17.

The dementing diseases know no social or racial lines: the rich and the poor, the wise and the simple alike are affected. There is no reason to be ashamed or embarrassed because a family member has a dementing illness. Many brilliant and famous people have contracted dementing illnesses. Although dementias associated with the final stage of syphilis were common in the past, this is very rare today.

Severe memory loss is *never* a normal part of growing older. According to the best studies available, 5 percent of older people suffer from a severe intellectual impairment and a similar number may suffer from milder impairments. The diseases become more prevalent in people who survive into their 80s and 90s, but about 80 percent of those who live into very old age never experience a significant memory loss or other symptoms of dementia. A slight forgetfulness is common as we age but usually is not enough to interfere with our lives. Most of us know elderly people who are active and in full command of their intellect in their 70s, 80s, or 90s. Margaret Mead, Pablo Picasso, Arturo Toscanini, and Duke Ellington all were still active in their careers when they died: all were past 75; Picasso was 91.

As more people in our population live into later life, it becomes crucial that we learn more about dementia. It has been estimated that 4 million people in the United States have some degree of intellectual impairment. A study estimated that Alzheimer disease alone cost the United States $100 billion in 1998.

The Person with a Dementing Illness

The person with a dementing illness has difficulty remembering things, although he may be skillful at concealing this. His ability to understand, reason, and use good judgment may be impaired. The onset and the course of the condition depend upon which disease caused the condition and upon other factors, some of which are unknown to researchers. Sometimes the onset of the trouble is sudden: looking back, you may say, "After a certain time, Dad was never himself." Sometimes the onset is gradual: family members may not notice at first that something is wrong. Sometimes the afflicted person himself may be the first to notice something wrong. The person with a mild dementia is often able to describe his problem clearly: "Things just go out of my mind." "I start to explain and then I just can't find the words."

People respond to their problems in different ways. Some people become skillful at concealing the difficulty. Some keep lists to jog their memory. Some vehemently deny that anything is wrong or blame their problems on others. Some people become depressed or irritable when they realize that their memory is failing. Others remain outwardly cheerful. Usually, the person with a mild to moderate dementia is able to continue to do most of the things he has always done. Like a person with any other disease, he is able to participate in his treatment, in family decisions, and in planning for the future.

the family members themselves. Many of the ideas offered here were developed by family members who have called or written to share them with others. These ideas will get you started.

At some point you may find that you will need additional help in caring for an impaired person. Chapter 10 discusses the kinds of help that may be available and how to locate them.

You and the impaired person are part of a family that needs to work together to cope with this illness. Chapter 11 discusses families and the problems that can arise in families. Chapter 12 discusses your feelings and the effects this illness may have on you. Caring for yourself is important for both you and the confused person who is dependent on you, and is discussed in Chapter 13.

Chapter 14 is written for young people who know someone with a dementing illness. Perhaps, as a parent, you will want to read this section also and plan a time to discuss it with your son or daughter. The entire book is written in such a way that a young person will be able to understand any other sections he may want to read.

Chapter 15 discusses legal and financial matters. Although it may be painful to plan ahead, it is most important to do so. Perhaps now is the time to get started with things you may have been avoiding.

A time may come when the impaired person cannot live alone. Chapter 16 discusses nursing homes and other living arrangements. There is a shortage of good nursing home beds in many states and nursing home care can you, but we know that simple solutions are not yet at hand.

This book often focuses on problems. However, it is important to remember that confused people and their families do still experience joy and happiness. Since dementing illnesses develop slowly, they often leave intact the impaired person's ability to enjoy life and to enjoy other people. When things go badly, remind yourself that, no matter how bad the person's memory is or how strange his behavior, he is still a unique and special human being. We can continue to love a person even after he has changed drastically, and even when we are deeply troubled by his present state.

help you find the best possible medical care in your community.

In the course of a dementing illness, you may need the special skills of a physician, neuropsychologist, social worker, nurse, or recreational, occupational, or physical therapist. Each is a highly trained professional whose skills complement those of the others. They can work together first to evaluate the impaired person and then to help you with ongoing care.

The Evaluation of the Person with a Suspected Dementia

When a person suffers from difficulty in thinking, remembering, or learning or shows changes in personality, it is important that a thorough evaluation be made. A complete evaluation tells you and the doctors several things:

1. the exact nature of the person's illness,
2. whether or not the condition can be reversed or treated,
3. the nature and extent of the disability,
4. the areas in which the person can still function successfully,
5. whether the person has other health problems that need treatment and that might be making her mental problems worse,
6. the social and psychological needs and resources of the sick person and the family or caregiver, and
7. the changes you can expect in the future.

Procedures vary depending on the physician or hospital. However, a good evaluation includes a medical and neurological examination, consideration of the person's social support system, and an assessment of her remaining abilities. You may not have a choice of physician or other service, but you can learn what is important in an evaluation and insist that the person receive a complete work-up.

The evaluation may begin with a careful examination by a physician. The doctor will take a *detailed history* from someone who knows the person well and from the sick person if possible. This will include how the person has changed, what symptoms the person has had, the order in which the symptoms developed, and information about other medical conditions. The doctor will also give the person a *physical examination,* which may reveal other health problems. A *neurological examination* (asking the person to balance with her eyes closed, tapping her ankles or knees with a rubber hammer, and other tests) may reveal changes in the functioning of the nerve cells of the brain or spine.

The doctor will do a *mental status examination,* in which he asks the person questions about the current time, date, and place. Other questions test her ability to remember, to concentrate, to do abstract reasoning, to do simple calculations, and to copy simple designs. Each of these reveals problems of function in different parts of the brain. When he does this test, he will take into consideration the person's education and the fact that the person may be nervous.

The doctor will order *laboratory tests,* including a number of blood tests. The *CBC* (complete blood count) detects anemia and evidence of infection, either of which can cause or complicate a dementing illness. *Blood chemistry tests* check for liver and kidney problems, diabetes, and a number of other conditions. *Vitamin* B_{12} *and folate level tests* check for vitamin deficiencies, which might cause dementia. *Thyroid studies* evaluate the function of the thyroid gland. Thyroid problems are among the more common reversible causes of dementia. The *VDRL test* can indicate a syphilis infection (syphilis was a common cause of dementia before the discovery of penicillin), but a positive VDRL test does not necessarily indicate that the person has ever had syphilis. The blood tests usually involve inserting one needle, which is no more unpleasant than a pin prick.

The *lumbar puncture* (LP), or spinal tap, is done to rule out infection in the central nervous system (for example, tuberculosis) and it may reveal other abnormalities. It is usually done after a local anesthetic has been injected into the back and has few complications. It may not be done if there is no reason to suspect these conditions.

The *EEG* (electroencephalogram) records the electrical activity present in the brain. It is done by attaching little wires to the head with a pastelike material. It is painless but may confuse the forgetful person. It aids in the diagnosis of delirium and can offer evidence of abnormal brain functioning, but occasionally is normal in a person with dementia.

CT scans, MRI scans, PET scans, and SPECT scans are advanced radiological techniques that help the physician identify changes in the brain which may indicate strokes, Alzheimer disease, and many other conditions that can cause dementia. They are often important to a diagnosis. Because they are expensive, the doctor may use them only when he needs this additional information. These tools are described in more detail on pp. 528–29.

These tests involve lying on a table and placing one's head in an object that looks like a very large hair dryer. It is painless but may be noisy. It may confuse an already impaired person. If so, a mild sedative can be prescribed to help the person relax.

For some procedures, such as the lumbar puncture and dye injections for the CT scan, you will be asked to sign an informed consent form. This lists all the possible side effects of the procedure. Reading this can make the procedure seem alarming and dangerous, but in fact, these are safe procedures. If you have any concerns about possible side effects, ask a doctor to explain them to you.

The history, physical and neurological exams, and laboratory tests will identify or rule out known causes of dementia. Other evaluations in addition to the medical assessment are done to understand the person's abilities and help you to plan for the future.

A *psychiatric and psychosocial evaluation* is based on interviews with the person and her family. This provides the basis for the development of a specific plan for the care of the individual. It may be done by the doctor, nurse, or social worker who works with the physician. It includes helping the family evaluate their own emotional, physical, and financial resources, the home in which the person lives, the available community resources, and the patient's ability to accept or participate in plans.

It is important that the physician determine whether the patient is depressed. Depression can cause symptoms similar to dementia and it can make an existing dementia worse. Whenever there is a question about depression, a psychiatrist experienced in geriatrics should see the patient. Depression is quite common and usually responds well to treatment.

An *occupational therapy evaluation* helps to determine how much the person is able to do for herself and what can be done to help her compensate for her limitations. It is done by an occupational, rehabilitation, or physical therapist. These therapists are important members of the health care team. Their skills are sometimes overlooked because in the past they were consulted only in cases where there was the potential for physical rehabilitation. However, they are able to identify the things that the person can still do, and to devise ways to help the person remain as independent as possible. Part of this assessment is an *ADL* (activities of daily living) evaluation. The person is observed in a controlled situation to see if she can manage money, fix a simple meal, dress herself, and perform other routine tasks. If she can do part of these tasks, this is noted. These therapists are familiar with a variety of appliances that can help some people.

Neuropsychological testing (also called cortical function testing or psychometric testing) may be done to determine in which areas of mental function the person is impaired and in which she is still independent. This testing takes several hours. The tests evaluate such things as memory, reasoning, coordination, writing, and the ability to express oneself and understand instructions. The testing psychologist will be experienced in making people feel relaxed and will take into consideration differences in education and interests.

The final part of the evaluation is your *discussion with the doctor* and perhaps with other members of the evaluating team. The doctor will explain the findings to you and to the patient if she is able to understand at least part of what is happening.

At this time the doctor should give you a specific diagnosis (he may explain that he cannot be certain) and a general idea of the person's prognosis (again, he may not be able to tell you exactly what to expect). The findings of other tests, such as the ADL evaluation, the psychological tests, and the social history, will also be explained to you. You should be able to ask questions and come away with an understanding of the findings of the evaluation. The doctor may make recommendations such as the use of medications or community support services or he may refer you to someone who can advise you about community services. You, he, and the afflicted person may identify specific problems and set up a plan to cope with them.

A complete evaluation may take more than one day.

You may want to arrange to spread the evaluation over more than one day so that the patient will not get too tired. It usually takes several days for the laboratories to report their findings to the doctor and for him to put all these data together into a report.

Evaluations may be done either with the patient admitted to the hospital or on an outpatient basis. Several factors, including your insurance coverage, the general health of the patient, and your convenience, affect the decision to do an inpatient or outpatient evaluation.

Sometimes family members and occasionally professionals advise against "putting a confused person through the 'ordeal' of an evaluation." We feel that every person with problems in memory and thinking should be fully evaluated. An evaluation is not an unpleasant ordeal. Staff accustomed to working with people with dementia are usually gentle and kind. It is important that they make the person as comfortable as possible so that they will be able to measure her best performance.

As we have said, there are many reasons why a person might develop the symptoms of dementia. Some of these are treatable. If a treatable problem is not found because an evaluation is not done, the afflicted person and her family may suffer unnecessarily for years. Certain diseases can be treated if they are found promptly, but can cause irreversible damage if they are neglected.

Even if it is found that a person has an irreversible dementia, the evaluation will give you information about how best to care for the impaired person and how best to manage her symptoms. It gives you a basis upon which have been given differing diagnoses, discuss this frankly with the doctor. It is important that you feel certain that an accurate diagnosis has been made. Occasionally a physician will make a diagnosis of Alzheimer disease without doing a complete evaluation. It is not possible to make an accurate diagnosis without a complete assessment and tests that rule out other conditions. If this happens to you, we suggest you consider getting a second opinion.

You may hear about people with similar symptoms who are "miraculously" cured, or you may hear statements like "senility can be cured." Considerable confusion has arisen because some of the causes of dementia are reversible and because dementia and delirium (see Chapter 17) are sometimes confused. There are some unscrupulous individuals who offer bogus "cures" for these tragic illnesses. An accurate diagnosis and a doctor you trust can assure you that all that can be done is being done. You can also keep informed about the progress of legitimate research through the Alzheimer's Association and from the major research institutes.

The Medical Treatment and Management of Dementia

Dementing illnesses require continuing medical attention. The availability of professional services varies. You, the caretaker, will provide much of the coordination of care. However, there are times when you will need the help of professionals.

The Physician

You will need a physician who will prescribe and adjust medications, answer your questions, and treat other, concurrent illnesses. The physician who provides continuing care will not necessarily be the specialist who provided the initial evaluation of the person. He may be your family doctor, part of a geriatric team, or someone with a special interest in geriatric medicine. This doctor does not have to be a specialist, although he should be able to work with a neurologist or psychiatrist if necessary. The doctor you select for continuing care must:

1. be willing and able to spend the necessary time with you and the sick person,
2. be knowledgeable about dementing illnesses and the special susceptibility of patients with dementia to other diseases, medications, and delirium,
3. be easily accessible,
4. if possible, be able to make referrals to physical therapists, social workers, and other professionals.

Not all doctors meet these criteria. Some doctors have large practices and do not have the time to focus on your problems. It is impossible for any one person to keep up with all the advances in medicine, so some doctors may not be skilled in the specialized care of people with dementia. Finally, some doctors are uncomfortable caring for people with chronic, incurable diseases. However, no physician should give you a diagnosis without following through with referrals to professionals who can give you the help and follow-up you need. You may have to talk with more than one doctor before you find the one who is right for you. Discuss your needs and expectations honestly with him, and talk over how you can best work with him. Doctors have been trained to keep the patient's problems confidential. Because of this, some doctors are reluctant to talk to other members of the family or will talk to only the patient's spouse. There may be good reasons why you need to know about the patient. Physicians who work with many families of dementia patients find that conferring with the whole family is important. Discuss this problem frankly with the doctor and ask him to be as open as he can be with the whole family.

The Nurse

In addition to the knowledge and experience of a physician you may need the skills of a registered nurse who can work with the physician. The nurse may be the person whom you can reach most easily and who can coordinate the work that you, the doctor, and others do to provide the best possible care. She may be the person who understands the difficulties of caring for an ill person at home. She can observe the person for changes in her health status which need to be reported to the doctor and she can give you support and counsel. After talking with you, the nurse can identify and help solve many of the problems you face. She can teach you how to provide practical care for the person (coping with catastrophic reactions, giving baths, helping with eating problems, managing a wheelchair). She can teach you how and when to give medicine and how to know whether it is working correctly. A nurse may be available to come to your home to assess the patient and offer suggestions for simplifying the person's environment and minimizing the effort you need to expend.

A licensed vocational (practical) nurse may also be helpful to you.

Your physician should be able to refer you to a nurse, or you can locate this help by calling your health department or a home health agency such as the Visiting Nurse Association.

Medicare or health insurance may pay for nursing services if they are ordered by a physician (see pp. 310–13).

In some areas an occupational therapist or physical therapist may be available to help.

The Social Worker

Social workers have a unique combination of skills: they know the resources and services in your community and they are skilled in assessing your situation and needs and matching these with available services. Some people think of social workers as "just for the poor." This is not true. They are professionals whose skills in helping you find resources can be invaluable. They can also provide practical counseling and help you and your family think through plans. They can help families work out disagreements over care.

Your physician may be able to refer you to a social worker, or, if the sick person is hospitalized, the hospital social worker may be able to help you. The local office on aging may have a social worker on the staff who will help anyone over 60.

Most communities have family service agencies staffed by social workers. To locate local social service agencies, look in the telephone book yellow pages under "social services organizations" or under the listings for your state and local governments. You can write to the national office of Family Service America (see Appendix 2). They accredit private agencies and can provide you with the names of your nearest agencies.

Social workers work in a variety of settings, including public social service agencies, some nursing homes, senior citizen centers, public housing projects, and local offices of the state department of health. Sometimes these agencies have special units that serve elderly persons. There are social workers in private practice in some communities. Some social workers will arrange supportive services for a relative who lives out of town. Social workers are professionally trained. In many states they must also be licensed or accredited. You should know the qualifications and training of the person you select.

Fees for social services vary, depending on the agency, the services you need, and whether or not you are using other services of that agency (such as a hospital). Some agencies charge according to your ability to pay.

It is important to select a social worker who understands the dementing illnesses.

3

Characteristic Problems of Dementia

In chapters 3 through 9 we will discuss many of the problems that families may encounter in caring for a person with a dementing illness. Although, as yet, nothing can be done to cure some dementing illnesses, it is important to remember that *much can be done to make life easier for you and the person with a dementing illness.* The suggestions we offer come from our clinical experience and from the experiences that family members have shared with us.

Each individual and each family is different. You may never experience many of these problems. The problems you will face are influenced by the nature of the specific disease, by your personality, by the sick person's personality, and, often, by other factors, such as where you live. We do not want you to read through this section as if it were a list of what lies ahead of you. It is a comprehensive list of problem areas for you to use as a reference when a specific problem arises.

The Brain, Behavior, and Personality: Why People with Dementia Do the Things They Do

The very nature of brain injuries can make them difficult to live with. The brain is a vast, complex, mysterious organ. It is the source of our thoughts, our emotions, and our personality. Injury to the brain can cause changes in emotions, personality, and the ability to reason. Most dementing illnesses do their damage gradually, so the effects are not seen suddenly, as are the effects of a major stroke or head injury. Consequently, the behavior of a person with a dementing illness often seems puzzling in contrast to behaviors due to other illnesses. It is not always evident that many of the visible symptoms (changes in personality, for example) are the result of a disease, because the sick person often looks well.

You may wonder which behaviors are caused by the disease and which are deliberate or willful, or family members may disagree about this. In the following chapters we will discuss some of the behavior problems you may face and suggest ways you can respond. Understanding that the damage to the brain causes these behaviors will help you cope with them.

The brain is an incredibly complex organ composed of billions of microscopic neurons, or brain cells. All the tasks of the brain—thinking, talking, dreaming, walking, listening to music, and hundreds of others—are carried out when these cells communicate with one another. This communication is accomplished by a chemical, manufactured inside the cell, that jumps the tiny gap from one cell to the neighboring cell. Because it is known that some of these chemicals are in short supply in the brains of people with Alzheimer disease, scientists are studying the chemicals in an effort to alleviate the symptoms of Alzheimer disease.

Different parts of the brain carry out different tasks. When a person has a stroke and cannot speak, we know that the stroke occurred in the speech center of the brain and destroyed cells that are necessary for the person to talk. A stroke often causes extensive damage, but to only a few areas of the brain. In dementia, damage is done in many areas and affects many aspects of mental function. While a stroke does all its damage at once, Alzheimer disease gradually does more and more damage. This means that different cognitive abilities are damaged *unevenly* and the person will be able to do some things but not others. For example, he may be able to remember things from long ago but not from yesterday.

Our brains do thousands of tasks and we are usually not aware of most of them. We assume that other people's brains, like ours, are working as they should—but with a person who has a dementia we cannot make this assumption. When the person does something odd or inexplicable, it is usually because some part of the brain has failed to do its job. In addition to controlling memory and language, the brain enables us to move our various body parts, filters out the things we don't want to pay attention to, gives feedback on the things we do, enables us to recognize familiar objects, and coordinates all the activities it is carrying out. *When brain damage is* *uneven, the person may do things that don't make sense to us.*

> *John Barstow can remember he was angry with his wife, but he cannot remember her explanation of why she did what she did. In fact, he may not even remember what she did that made him angry.*

Researchers think that our brain stores and processes memories of emotions differently from memories of fact. It is possible for the dementia to damage one without damaging the other as much. Old social skills and the ability to make customary social remarks are often retained longer than insight and judgment. Thus, a person may sound fine to the doctor but in fact be unable to responsibly care for himself.

It may be that damaged nerve cells, like a loose light bulb, connect sometimes and fail other times. This may be why a person can do something one day and not another. Even when we do something that seems simple, the brain must carry out many tasks. *If the dementia prevents the brain from performing any one of the steps in a task, the task will not get done.*

> *"I asked my sister to make us both a cup of tea, but she ignored me. Then half an hour later, she went to the kitchen and made herself a cup of tea."*

Obviously this sister was still able to do this task but probably was not able to understand or act on language even though she heard the request.

Behavior problems are caused by the damage to the *brain and are not something the person can control or prevent.* Behavior that upsets you is almost never deliberate and almost never intended to "get your goat." Because the brain itself is damaged, the person has a severely limited ability to learn things or understand explanations. It is futile to expect the person to remember or learn and frustrating to both of you to try to teach him. The person does not want to act like this and *is trying as hard as he can.*

> *Mrs. Robinson helped out in her older daughter's kitchen, but when she visited her younger daughter she only sat and criticized. The younger daughter felt that Mrs. Robinson had always preferred the older sister and that her refusal to help was a less than subtle reminder of her preference. In fact, the mother had been familiar with the older sister's kitchen before she became forgetful, but could no longer learn new information, even things as simple as where the dishes were kept in her younger daughter's unfamiliar kitchen.*

A person's feelings also affect his behavior. The person with dementia probably feels lost, worried, anxious, vulnerable, and helpless much of the time. He may also be aware that he fails at tasks and feel that he is making a fool of himself. Imagine what it must feel like to want to say something nice to your caregiver but all that comes out are curse words. Think how frightening it must be if a familiar home and familiar people now seem strange and unfamiliar. If we can find ways to make a person mother, his response will be based on the faulty understanding of the situation. A person who was usually placid may respond calmly, a person who was usually irritable may respond with anger, but whatever the response, it will be appropriate to the message *received,* not necessarily the message you gave.

The final step in communication is the person's answer. Things can go wrong here, too. What comes out may not be what the confused person intended. This too can sound like an intentional evasion, insult, or foolish answer.

There is much that we do not know about this process. Neuropsychologists study the mind and try to understand these complex cognitive processes. Often a neuropsychologist can figure out why a particular person acts as he does, and sometimes can devise a way around the disability. Although there is still an enormous amount to learn about how this process works, when people with a dementing illness say or do things that don't make sense or that seem nasty or deliberate, it is almost certainly the brain damage at work. *The person you are caring for is also often miserable and is doing the best he can.* In the rest of this book we will show you many ways you can help.

You may not be able to figure out what the person understood or intended. Because the brain is so complex, even the best experts are often at a loss. In addition, most families do not have access to a neuropsychologist. Do the best you can, regard problems as the brain damage at work, not as something you did or something the confused person intended. Affection, reassurance, and calm are best, even when things make no sense.

Caregiving: Some General Suggestions

Be informed. The more you know about the nature of dementing illnesses, the more effective you will be in devising strategies to manage behavior problems.

Share your concerns with the patient. When a patient is only mildly to moderately impaired, he can take part in managing his problem. You may be able to share with each other your grief and worries. Together you may be able to devise memory aids that will help him remain independent. Mildly impaired people may benefit from counseling that can help them accept and adjust to their limitations.

Try to solve your most frustrating problems one at a time. Families tell us that the day-to-day problems often seem to be the most insurmountable. Getting mother to take her bath or getting supper prepared, eaten, and cleaned up can become daily ordeals. *If you are at the end of your rope, single out one thing that you can change to make life easier, and work on that.* Sometimes changing small things makes a big difference.

Get enough rest. One of the dilemmas families often face is that the caregiver may not get enough rest or may not have the opportunity to get away from his caregiving responsibilities. This can make the caregiver less patient and less able to tolerate irritating behaviors. If things are getting out of hand, ask yourself if this is happening to you. If so, you may want to focus on finding ways to get more rest or more frequent breaks from your caregiving responsibilities. We recognize that this is difficult to arrange. We will discuss this in Chapter 10.

Use your common sense and imagination; they are your best tools. Adaptation is the key to success. If a thing cannot be done one way, ask yourself if it must be done at all. For example, if a person can eat successfully with his fingers but cannot use a fork and spoon appropriately, don't fight the problem; serve as many finger foods as possible. Accept changes. If the person insists on sleeping with his hat on, this is not harmful; go along with it.

Maintain a sense of humor; it will get you through many crises. The sick person is still a person. He needs and enjoys a good laugh too. Sharing your experiences with other families will help you. Surprisingly, these groups of families often find their shared experiences funny as well as sad.

Try to establish an environment that allows as much freedom as possible but also offers the structure that confused people need. Establish a regular, predictable, simple routine for meals, medication, exercising, bedtime, and other activities. Do things the same way and at the same time each day. If you establish regular routines, the person may gradually learn what to expect. Change routines only when they aren't working. Keep the person's surroundings reliable and simple. Leave furniture in the same place. Put away clutter.

Remember to talk *to* the confused person. Speak calmly and gently. Make a point of telling him what you are doing and why. Let him have a part in deciding things as much as possible. Avoid talking *about* him in front of him, and remind others to avoid this also.

Have an ID necklace or bracelet made for the confused person. Include on it the nature of his disease (e.g., "memory impaired") and your telephone number. This is one of the single most important things you can do. Many confused people get lost or wander away at one time or another and an ID can save you hours of frantic worry.

Keep the impaired person active but not upset. Families often ask if retraining, reality orientation, or keeping active will slow down or stop the course of the disease. Likewise, they may ask if being idle hastens the course of the disease. Some people with dementing illnesses become depressed, listless, or apathetic. Families often wonder whether encouraging such a person to do things will help him to function better.

The relationship of activity to the course of dementing illnesses is not clear. Research continues in this area. Activity helps to maintain physical well-being and may help to prevent other illnesses and infections. Being active helps the ill person to continue to feel that he is involved in the family and that his life has meaning.

It is clear that people with dementing illnesses cannot learn as well as before because brain tissue has been damaged or destroyed. It would be unrealistic to expect them to learn new skills. However, some individuals can learn simple tasks or facts if they are repeated often enough. Some impaired people who feel lost in a new place eventually “learn” their way around.

At the same time, too much stimulation, activity, or pressure to learn may upset the confused person, may upset you, and may accomplish nothing. The key to this is balance:

1. Accept that lost skills are gone for good (the woman who has lost the ability to cook will not learn to fix a meal), *but* know that repeatedly and gently giving information that is within the person’s abilities will help him function more comfortably (the person going into a strange day care setting will benefit from frequent reminders of where he is).
2. Know that even small amounts of excitement—visitors, laughter, changes—can upset the confused person, *but* plan interesting, stimulating things within his capabilities—a walk, visiting one old friend.
3. Look for ways to simplify activities so that a person can continue to be involved within the limits of his abilities (the woman who can no longer fix a whole meal may still be able to peel the potatoes).
4. Look for things the person is still able to do and focus on them. A person’s intellectual abilities are not all lost at once. Both of you will benefit from carefully assessing what he can still do and making the best use of those abilities. For example,

   Mrs. Baldwin often cannot remember the words for things she wants to say but she can make her meaning mildly demented person may devise reminders for himself, while a severely impaired person will only become more frustrated by his inability to use the aid. People who are able to read may be able to do chores if you write out instructions. Writing down names and often-used phone numbers also helps. If you are going out, write down where you are going. If you will be gone at mealtime, leave a written reminder to eat.

Have clocks and calendars in view to help the confused person remember what time it is. Mark off the days as they pass. It is often helpful to put a simple list of the day's activities where the person can easily see it. A regular daily routine is much less confusing than frequent changes.

Leave familiar objects (pictures, magazines, television, radio) in their usual places where the person can see them easily. A tidy, uncluttered house will be less confusing to an impaired person and misplaced items will be easier to find. Some families have found that putting labels on things helps. Labeling drawers "Mary's socks," "Mary's nightgowns" may help.

Remember, however, that with progressive dementing illnesses the person will eventually be unable to read or will not be able to make sense out of what he reads. He may be able to read the words but unable to act on them. Some families then use pictures instead of written messages. For example, it may help to put a picture of a toilet on the bathroom door if the person is in an unfamiliar place or has trouble remembering where the bathroom is.

People are often more confused at night and may get lost going to the bathroom. Strips of reflector tape on the wall from the bedroom to the bathroom help. Night lights will help him see where he is.

Pictures of family members and close friends may help the more confused person remind himself of who these people are. If you are visiting someone in a nursing home, you might try taking along a family picture album. Looking at the pictures may stir bits of pleasant memory in the confused mind.

Overreacting, or Catastrophic Reactions

Even though Miss Ramirez had told her sister over and over that today was the day to visit the doctor, her sister would not get into the car until she was dragged in, screaming, by two neighbors. All the way to the doctor's office she shouted for help and when she got there she tried to run away.

Mr. Lewis suddenly burst into tears as he tried to tie his shoelaces. He threw the shoes in the wastebasket and locked himself, sobbing, in the bathroom.

Mrs. Coleman described several incidents similar to this one, in which her husband had mislaid his glasses.

"You threw out my glasses," he told her.

"I didn't touch your glasses," she answered.

"That's what you always say," he responded. "How do you explain that they are gone?"

"You do this to me every time you lose your glasses."

without clothes on and she feels she has lost her privacy and independence. This is overwhelming for a person who cannot remember doing the thing before, who can't remember how to do all these tasks, and whose mind cannot process all these activities at once. One way to react to this is to refuse to take a bath.

We use the term *catastrophic reaction* to describe this behavior. (The word *catastrophic* is used in a special sense; it does not mean that these situations are necessarily very dramatic or violent.) *Often a catastrophic reaction does not look like behavior caused by a brain illness. The behavior may look as if the person is merely being obstinate, critical, or overemotional.* It may seem inappropriate to get so upset over such a little thing.

Catastrophic reactions are upsetting and exhausting for you and for the confused person. They are especially upsetting when it seems as if the person you are trying to help is being stubborn or critical. The person may get so upset that he refuses necessary care. Learning how to avoid or lessen catastrophic reactions is a major key to easier management of them.

Sometimes catastrophic reactions and forgetfulness are the first behaviors family members see when they begin to realize that something is wrong. The mildly impaired person may benefit by being reassured that his panic is not unusual and that you understand his fear.

The things that can help prevent or reduce catastrophic reactions depend on you, on the impaired individual, and on the extent of his limitations. You will gradually learn how to avoid or limit these reactions.

- feeling frustrated;
- being treated like a child.

Anything that helps remind the confused person about what is going on, such as following familiar routines, leaving things in familiar places, and written instructions (for people who can manage them), can help to reduce catastrophic reactions. Because catastrophic reactions are precipitated by having to think of several things at once, simplify what the confused person has to think about. Take things one step at a time, and give instructions or information step by step. For example, when you help a person bathe, tell the person one thing at a time. Say, “I’m going to unbutton your shirt” and then reassure him, “It’s all right.” Say, “Now I’m going to slip your shirt off. That’s fine. You’re a big help. Now take a step up into the tub. I will hold your arm.”

Give the confused person time to respond. He may react slowly and become upset if you rush him. Wait for him. If a person is having frequent catastrophic reactions, try to reduce the confusion around him. This might mean having fewer people in the room, having less noise, turning off the television, or reducing the clutter in the room. The key is to simplify, to reduce the number of signals the impaired, disoriented brain must sort out.

Find things the impaired person can realistically do. If strange places upset him, you may not want to take him on a trip. If he gets tired or upset quickly, plan shorter visits with friends.

Plan demanding tasks for the person's best time of day. Avoid asking him to do things when he is tired. Know what his limits are and try not to push him beyond them.

You can avert some catastrophic reactions by simplifying the task facing the impaired person. Mr. Lewis's family recognized that tying shoelaces had become too difficult for him but that he needed to remain as independent as possible. Buying him slip-on shoes solved the problem. Mrs. Coleman's husband often lost things because he forgot where he put them. She found it helpful to ignore his accusations and help him find his glasses. Knowing that accusing her was his way of reacting to his forgetfulness made it easier for her to accept the insult.

Simplify tasks for him. Do the parts he finds difficult yourself. Families often worry that they are doing too much for a person and might make him more dependent. A good rule of thumb is to let a person do for himself until he shows the *first signs* of frustration, then assist him *before* he becomes more upset. Urging him on will usually only upset him more.

If a person seems more irritable than usual, check carefully for signs of illness or pain. *Even minor illness or discomfort can make the person's thinking worse.* Have the person's medications been changed in the past three weeks? Reactions to medication sometimes cause these outbursts.

Reconsider your approach. Are you unintentionally rushing him? Did you misunderstand him? Did you ignore his protests? Are your behavior and voice communicating your own frustration to him? Although it is easy to treat a person who is so dependent like a child, this may make him angry and precipitate an outburst.

When the person does become upset or resistant, remain calm and remove him from the situation in a quiet, unhurried way. Often the emotional storm will be over as quickly as it began and the confused person will be relieved that the upset is over. His short memory may work to your advantage: he may quickly forget the trouble.

As a person with cognitive impairment becomes upset, his ability to think and reason temporarily declines even more. It is useless to argue with him, explain things to him, or even get him to complete a task when he is in the grip of a catastrophic reaction. Arguing, explaining, or restraining him may make things worse. Help him calm down and relax so that he can think as well as possible. Take him away from what upset him, if possible.

You may lose your temper with a person who is having catastrophic reactions or is unable to do what seems like a simple task. This usually will make the person's behavior worse. Occasionally losing your temper is not a calamity; take a deep breath and try to approach the problem calmly. The person will probably forget your anger much more quickly than you will.

Try not to express your frustration or anger to the confused person. Your frustration will further upset him when he cannot understand your reaction. Speak calmly. Take things one step at a time. Move slowly and quietly. Remember that the person is *not* being obstinate or doing this intentionally.

ing will help you, this may be an indication of your own depression. (See pp. 368–70.) In fact, some things can be found that will reduce catastrophic reactions in most people with dementia.

Combativeness

Mrs. Frank was having her hair done. The beautician was working on the back of her head and Mrs. Frank kept trying to turn around. When this happened the beautician would turn Mrs. Frank's head back. Then Mrs. Frank began batting at the beautician's hands. She looked as if she were about to cry. Finally, Mrs. Frank turned around in the chair and hit the beautician.

Mr. Williams stood close to a group of nurses who were talking. He bounced up and down on his toes. The nurses ignored him even though he bounced faster and faster. When he began to shout, one of the nurses took his arm to lead him away. He pulled away from her but she held on. When she did not let go, he struck her.

When a person with dementia hits (or bites, pinches, or kicks) another, it is upsetting for everyone. Sometimes this happens frequently and the caregiver or nursing home may feel they cannot continue to provide care.

Combativeness is almost always an extreme catastrophic reaction. It often can be prevented by being alert to the person's signals that his stress level is rising. Perhaps if the beautician had talked to Mrs. Frank about what she was doing and showed her in a mirror how her self to others, and the problems he has in understanding what people say to him.

Problems the Impaired Person Has in Making Himself Understood

The nature of communication problems and whether or not they will get worse depend on the specific disease. Do not assume that things will get worse.

Some people have only occasional difficulty finding words. They may have trouble remembering the names of familiar objects or people. They may substitute a word that sounds similar, such as saying "tee" for "tie" or "wrong" for "ring." They may substitute a word with a related meaning, such as saying "wedding" for "ring" or "music thing" for "piano." They may describe the object they cannot name, such as "it's a thing that goes around" for "ring" or "it's to dress up" for "necktie." Such problems usually do not interfere with your ability to understand what the person means.

Some people have difficulty communicating their thoughts.

> *Mr. Zuckerman was trying to say that he had never had a neurological examination before. He said, "I really have not, not really, ever have been done, I have never . . ."*

In some language problems the person cannot communicate the whole thought but he can express a few of the words in the thought.

> *Mr. Mason wanted to say that he was worried about missing his ride home. He could say only, "Bus, home."*

Sometimes people are able to ramble on quite fluently, and it seems as if they are talking a lot. They will often string together commonly used phrases, so what they say at first seems to make sense, but upon reflection the listener may not be sure he understood the thought being expressed.

> *Mrs. Simmons said, "If I tell you something, I might stop in the middle and . . . I'll be real sure about what I've done, . . . said, . . . sometimes I stop right in the middle and I can't get on with . . . from . . . that. In past records . . . I can be so much more sure of the . . . After I get my bearing again I can just go on as if nothing happened. We thought it was high time to start remembering. I just love to . . . have to . . . talk."*

In these examples, it is possible to understand what the person is saying if we know the context.

When the limitations in ability to communicate frustrate the confused person and frustrate you, they can lead to a series of catastrophic reactions. For example, the impaired person may burst into tears or stamp out of the room when no one understands him.

Sometimes a person is able to conceal language problems. When a doctor asks a person if he knows the word for a wristwatch (a common question used to evaluate language problems), the patient may say, "Of course I do. Why do you ask?" or "I don't want to talk about it.

been diagnosed as having had a stroke that interferes with language function, he should be seen by a stroke rehabilitation team as soon as he has recovered from the acute phase of his illness. Much can be done to rehabilitate people who have had strokes.

If the person is having difficulty finding the right word, it is usually less frustrating for him to have you supply the word for him than it is to let him search and struggle for the word. When he uses the wrong word and you know what he means, it may be helpful to supply the correct word. However, if doing so upsets him, it may be best to ignore it. When you don't know what he means, ask him to describe it or point to it. For example, the nurse did not know what Mrs. Kealey meant when she said, "I like your wrong." If the nurse had said, "What?" Mrs. Kealey might have become frustrated in trying to express herself. Instead, the nurse asked, "Describe a wrong." Mrs. Kealey said, "It's a thing that goes around." "Point to it," said the nurse. Mrs. Kealey did and the nurse responded, "Oh, yes, my ring." If the person gets lost in the middle of what he is saying, repeat his last few words—this may help get him started again.

When a person is having trouble expressing an idea, you may be able to guess what he is trying to say. *Ask* him if you are guessing correctly. You might guess wrong, and if you act on an erroneous guess you will add to the confused person's frustration. Say, "Are you worried about catching the bus home?" or "Are you saying you have never had an examination like this before?"

mother, try saying, “You must miss your mother” or “Tell me what your mother was like.”

Problems the Impaired Person Has in Understanding Others

Often people with brain impairments have difficulty comprehending or understanding what you and others tell them. This is a problem that families sometimes misinterpret as uncooperative behavior. For example, you may say, “Mother, I am going to the grocery store. I will be back in half an hour. Do you understand?” Your mother may say, “Oh yes, I understand,” when in fact she does not understand at all and will get upset as soon as you are out of sight.

People with dementing illnesses also quickly forget what they did understand. When you give them a careful explanation, they may forget the first part of the explanation before you get to the rest of it.

People with dementia can have trouble understanding written information even when they can still read the letters or words. For example, to determine exactly what a person can still comprehend, we may hand him a newspaper and have him read the headline, which he may be able to do correctly. Then when we hand him the written instructions “Close your eyes,” he does not close his eyes although he correctly reads the words aloud. This indicates that he cannot understand what he is repeating.

Jan told her mother that lunch was in the refrigerator. She left a note on the refrigerator door to remind her *mother. Her mother could read the note but could not understand what it said, so she didn't eat her lunch. Instead she complained that she was hungry.*

This can be infuriating until you consider that reading and understanding are two different skills, one of which may be lost without the loss of the other. It is not safe to assume that a person can understand and act upon messages he can hear or read. You will need to observe him to know whether he *does* act upon them. If he does not act on instructions, assume he has a problem in understanding language.

The person who can understand what he is told in person may not be able to comprehend what he is told over the telephone. When a person with a dementing illness does not understand what you told him, the problem is not inattentiveness or willfulness, but an inability of the malfunctioning brain to make sense out of the words it hears.

There are several ways to improve your verbal communication with a person who has a dementing illness.

1. Make sure he does hear you. Hearing acuity declines in later life and many older people have a hearing deficit.
2. Lower the tone (pitch) of your voice. A raised pitch is a nonverbal signal that one is upset. A lower pitch also is easier for a hearing-impaired person to hear.
3. Eliminate distracting noises or activities. Both because of a possible hearing deficit and because of the impaired person's inability to sort things out, he may

be unable to understand you when there are other noises or distractions around him.

4. Use short words and short, simple sentences. Avoid complex sentences. Instead of saying, “I think I’ll take the car to the garage tonight instead of in the morning because in the morning I will get caught in traffic,” just say, “I’m going to take the car to the garage now.”
5. Ask only *one* simple question at a time. If you repeat the question, repeat it exactly. Avoid questions like “Do you want an apple or pie for dessert or do you want to have dessert later?” Complex choices may overload the person’s decision-making ability.
6. Ask the person to do one task at a time, not several. He may not be able to remember several tasks or may be unable to make sense out of your message. Most of the things we ask a person to do—take a bath, get ready for bed, put on a coat so we can go to the store—involve several tasks. The impaired person may not be able to sort out these tasks. We help him by breaking down each project into individual steps and asking the person to do one step at a time.
7. Speak slowly, and wait for the person to respond. The impaired person’s response may be much slower than what seems natural to us. Wait.

You can improve communication with the person and your understanding of his needs without the usual forms of conversation. People communicate through both what they say and the way they move their faces, eyes, hands, and bodies. Everyone uses this nonverbal make his hands and fingers do certain familiar tasks. He may understand what he wants to do, and although his hands and fingers are not stiff or weak, the message just does not get through from the mind to the fingers. Doctors use the word *apraxia* to describe this. An early sign of apraxia is a change in a person's handwriting. Another, later indication is a change in the way a person walks. Apraxias may progress gradually or change abruptly, depending on the disease. For example, at first a person may seem only slightly unsteady when walking, but he may gradually change to a slow, shuffling gait.

It can be difficult for a person not trained to evaluate dementing illness to separate problems of memory (can the person remember what he is supposed to do?) from problems of apraxia (can the person not make his muscles do what they are supposed to do?). Both problems occur when the brain is damaged by disease. It is not always necessary to distinguish between them in order to help the person manage as independently as possible.

When apraxia begins to affect walking, the person may be slightly unsteady. You must watch for this and provide either a handrail or someone to hold on to when the person is using stairs and stepping up onto or down off of a curb.

Losses of coordination and manual skills may lead to problems in daily living such as bathing, managing buttons or zippers, dressing, pouring a glass of water, and eating. Dialing a telephone requires good coordination, and a person who does not appear to have any motor

A relaxed atmosphere often helps make the person's clumsiness less apparent. It is not unusual for a person to have more difficulty with a task when he is feeling tense.

Sometimes a person can do something one time and not another time. This may be a characteristic of the brain impairment, not laziness. Being hurried, being watched, being upset, or being tired can affect an impaired person's ability to do things—just as it does any person's. Having a brain disease makes these natural fluctuations more dramatic. Sometimes people can do one task with no problem, such as zipping up trousers, and be unable to do another similar task, such as zipping up a jacket. It may seem that the person is being difficult, but the reason may actually be that one task is impossible because it is different in some way.

Sometimes a person can do a task if you break it down into a series of smaller tasks and take one step at a time. For example, brushing your teeth involves picking up the toothbrush, putting the toothpaste on it, putting the toothbrush in your mouth, brushing, rinsing, etc. Gently remind the person of each step. It may help to demonstrate. You may have to repeat each step several times. Sometimes it helps to put a familiar tool, such as a spoon or comb, into the person's hand and gently start his arm moving in the right direction. Beginning the motion seems to help the brain remember the task.

An occupational therapist is trained to assess what motor skills the person has retained and how he may make the best use of them. If you can obtain an occupational therapy evaluation, this information can help you give the confused person the help he needs without taking away his independence.

In the later stages of some of the dementing diseases, extensive loss of muscle control occurs and the person may bump into things and fall down. This will be discussed in Chapter 5.

People with dementing illnesses may have other physical conditions that also interfere with their ability to do daily tasks. Part of the problem may be in the muscles or joints and another part of the problem in the impaired brain. Such complicating conditions include tremors (shaking), muscle weakness, joint or bone diseases such as arthritis, or stiffness caused by medications.

There are many techniques and devices to help people with physical limitations remain independent. When you consider such techniques or devices, remember that most of them require the ability to learn to do something a new way or to learn to use a new gadget. People with dementing illnesses may not be able to learn the new skills needed.

Some people have tremors. These are shaking movements of the hands or body. These can make many activities difficult for a person, but an occupational therapist or physical therapist may be able to show you how to minimize the effects of tremors.

Some people with neurological conditions, especially Parkinson disease, have difficulty starting a movement or may get "stuck" in the middle of a movement. This can be frustrating for both of you. If this is a problem, here are some helpful hints:

1. If the person becomes "glued to the floor" while walking, tell him to walk toward a goal or to look at a spot on the floor a few feet in front of him. This may help him get going again.
2. It may be easier to get out of a chair that has armrests. Also, try raising the sitting person's center of gravity by raising the chair seat two to four inches. A firm seat is needed. Use a firm pillow or a higher chair such as a dining room chair or a director's chair. Avoid low chairs with soft cushions. Instruct the person to move forward to the edge of the chair and spread his feet about one foot apart to give a wider base to stand on. Ask the person to put his hands on the armrests and then to rock back and forth to gain momentum. On the count of 3, have him get up quickly. Have him take time to get his balance before he begins to walk.
3. Sitting down in a chair may be easier to do when the person puts his hands on the armrests, bends forward as far as possible, and sits down slowly.

Muscle weakness or stiffness may occur when a person does not move around much. Exercise is important for memory-impaired people.

Occasionally a person who is taking one of the major tranquilizers or neuroleptic drugs will get stiff and rigid or may become restless. These may be side effects of the medication. They can be very uncomfortable. Notify your doctor. He can change the dosage or give another medication to overcome this effect.

Loss of Sense of Time

The uncanny ability normal individuals have for judging the passage of time is one of the first losses of a dementia patient. He may repeatedly ask you what time it is, feel that you have left him for hours when you are out of sight for a few minutes, or want to leave a place as soon as he has arrived. It is not hard to understand this behavior when you consider that in order to know how much time has passed, one must be able to remember what one has done in the immediate past. The person who forgets quickly has no way to measure the passage of time.

In addition to this defect of memory, it appears that dementing diseases can affect the internal clock that keeps us on a reasonably regular schedule of sleeping, waking, and eating. It will be helpful to you to recognize that this behavior is not deliberate (although it can be irritating). It is the result of the loss of brain function.

The ability to read a clock may be lost early in the course of the disease. Even when a person can look at the clock and say, "It is 3:15," he may be unable to make sense out of this information.

Not being able to keep track of time can worry the forgetful person. Many of us, throughout our lives, are dependent upon a regular time schedule. Not knowing the time can make a person worry that he will be late, be forgotten, miss the bus, overstay his welcome, miss lunch, or miss his ride home. The confused person may not know just what he is worried about, but a general feeling of anxiety may make him ask you what time it is. And, of course, as soon as you answer him, he will forget the whole conversation and ask again.

Sometimes a person feels that you have deserted him when you have been gone only briefly. This is because he has no sense of how long ago you left. Setting a timer or an old-fashioned hourglass or writing a note—"I am in the backyard gardening and will be in at 3 P.M."—might help the person wait more patiently for your return. Be sure to select a cue (timer, note) that he can still comprehend. Perhaps you can think of other ways to reduce this behavior. For example,

> *When Mr. and Mrs. Jenkins went to dinner at their son's house, Mr. Jenkins would almost immediately put his hat and coat on and insist that it was time to go home. When he could be persuaded to stay for the meal, he insisted on leaving immediately afterward. His son thought he was just being rude.*

Things went more smoothly when the family understood that this was because the unfamiliar house, the added confusion, and Mr. Jenkins's lost sense of time upset him. The family thought back over Mr. Jenkins's life and hit upon an old social habit that helped them. In earlier years, he had enjoyed watching the football game after Sunday dinner. Now his son turned on the TV as soon as Mr. Jenkins finished eating. Since this was an old habit, Mr. Jenkins would stay for about an hour, giving his wife time to visit, before he got restless for home.

Symptoms That Are Better Sometimes and Worse at Other Times

Families often observe that the person can do something one time but not another time.

> *"In the morning my mother does not need as much help as she does in the evening."*
>
> *"My wife can use the bathroom alone at home, but she insists she needs help at our daughter's house."*
>
> *"My husband does not get as angry and upset at day care as he does at home. Is this because he is angry with me?"*
>
> *"Bill said a whole sentence yesterday, but today I can't understand a thing he says. Was he trying harder yesterday?"*

Fluctuations in ability are common in people with dementing illnesses. Well people also have fluctuations in ability, but they are less noticeable. People with dementia have good days and bad days; some are better in the morning, when they are rested; some have more problems in less familiar settings; some do better when they feel more relaxed. Some fluctuations have no explanation. Whatever the likely reason, such fluctuations are normal and do not signal a change in the course of the disease.

People with dementia are more vulnerable than others to minor changes in health. (See Chapter 6.) An abrupt change in the ability to do something or in overall level of function may indicate a medication reaction or a new illness. If you suspect this kind of change, it is important to contact the person's physician.

The brain damage itself accounts for some changes in ability. It is possible that damaged nerve cells that fail most of the time do work occasionally. It is also possible that less damaged or undamaged areas can intermittently take over and temporarily "fix" a defective system.

All of these causes for variation in ability are beyond the person's deliberate control. People with dementia are usually trying as hard as they can. You can help them the most by learning which things in their environment bring out their best and which things cause more disability.

4

Problems in Independent Living

As a person begins to develop a dementing illness, she may begin to have difficulty managing independently. You may suspect that she is mismanaging her money, worry that she should not be driving, or wonder if she should be living alone. People with dementing illnesses often appear to be managing well, and they may insist that they are fine and that you are interfering. It can be difficult to know when you should take over and how much you should take over. It can also be painful to take away these outward symbols of a person's independence, especially if the confused person adamantly refuses to move, to stop driving, or to relinquish her financial responsibilities.

Part of the reason that making these changes is so difficult is because they symbolize giving up independence and responsibility, and therefore all of the family members may have strong feelings about them. (We will discuss these role changes in Chapter 11.) Making necthat you must consider: the emotional and psychological adjustments involved in such a major change, and the financial changes that will be involved. A person's job is a key part of her sense of who she is. It helps her to feel that she is a valued member of society. The impaired person may resist giving up her job or may insist that nothing is wrong. Her adjustment to retirement may be a painful and distressing time. If these things happen, a counselor or social worker can be invaluable in helping you.

It is important that you consider the financial future of the impaired person. (This will be discussed in Chapter 15.) Retirement can create special problems. Individuals who are forced to retire early because of a dementing illness should be entitled to the same retirement and disability benefits as a person with any other disabling *disease.* In some cases, benefits have been denied on the erroneous grounds that "senility" is not a disease and the impaired person has been forced to resign or take an early retirement. This can substantially reduce her income. If this happens, you may want to obtain legal counsel.

Federal law (the Social Security Disability Act) provides assistance (Social Security Disability Income—SSDI—or Supplemental Disability Income) to people who become disabled. To receive SSDI the disabled person must have worked 20 out of the past 40 calendar quarters and she must no longer be able to do gainful work because of a medically determinable physical or mental illness that will result in death or that has lasted illness. No test score can determine this, but occupational or physical therapists may be able to evaluate driving skills. To decide whether the time has come, look at the skills that a person needs to drive safely and evaluate whether the confused person still has these skills—both in the car and in other situations.

1. *Good vision:* A person must have good vision, or vision corrected with glasses, and be able to see clearly, both in front and out of the corners of her eyes (peripheral vision) so that she sees things coming toward her from the sides.
2. *Good hearing:* A person must be able to hear well or have her hearing corrected with a hearing aid, so that she is alert to the sounds of approaching cars, horns, and so forth.
3. *Quick reaction time:* A driver must be able to react quickly—to turn, to brake, and to avoid accidents. Older people's reaction time, when it is formally tested, is slightly slower than that of young people, but in well older people it is usually not slow enough to interfere with driving. However, if you see that a person seems slowed down or reacts slowly or inappropriately to sudden changes around the house, this should alert you to the possibility of the same limitations when she is driving.
4. *Ability to make decisions:* A driver must be able to make *appropriate* decisions rapidly and *calmly.* The ability to make a correct decision when a child darts in front of the car, a horn honks, and a truck is ap-

pair the driving ability of people with a brain injury. This is a dangerous combination, and you must intervene.

If you are concerned about a person's driving ability, you might first approach the problem by discussing it frankly with her. Even though a person is cognitively impaired she is still able to participate in decisions that involve her. How you initiate such a discussion may affect her response. People with brain impairments are sometimes less able to tolerate criticism than when they were well, so you will want to use tact in such a discussion. If you say, "Your driving is terrible, you are getting lost, and you're just not safe," a person may feel she has to defend herself and may argue with you. Instead, by gently saying, "You are getting absent-minded about stoplights," you may be able to give a person an "easy way out." Giving up driving can mean admitting one's increasing limitations. Look for ways to help the person save face and maintain her self-image at the same time you react to the need for safety. Try offering alternatives: "I'll drive today and you can look at the scenery." As a last resort some families have sold the car and told the impaired person that it could not be repaired.

Sometimes families are pleasantly surprised.

Walt was a strong-minded, independent man. The family knew that his driving skills were poor but felt it would break his heart to lose his independence. They also anticipated a terrible fight over driving. However, a neighbor notified the Department of Motor Vehicles. When Walt came home from his driving test, he tossed

When You Suspect that Someone Living Alone Is Getting Confused

You need to be alert to the possibility that the person's ability to function alone may change suddenly: some minor stress or even a mild cold can make her worse. Or, you may not notice the gradual, insidious decline until something happens. Families often wait too long before taking action.

When things do go wrong, the person may react by trying to "cover up." Some confused people do not realize they have problems; others may blame the family or withdraw. Close family members may also deny that there are problems. Therefore, it can be difficult to know for sure what is going on. Here are some questions to consider when deciding whether a person who is living alone is in need of help:

Changes in Personality or Habits

Is she uncharacteristically apathetic, negative, pessimistic, suspicious, or unusually fearful of crime?

Does she insist that everything is fine, or not admit that there are any problems when you know there have been problems?

Is the person able to manage her own personal care and grooming? Some forgetful people wear dirty clothes, forget (or refuse) to bathe or brush their teeth, or in other ways neglect themselves.

Has she become isolated? Does she say she is going out when she does not?

Telephone Calls

Have her conversations become increasingly vague? (Details require more memory.)

Do conversations ramble, or does she seem to forget what she was saying? Does she repeat herself?

Does she become "edgy" when talking on the telephone, more than she used to? Is she less tolerant of frustration?

Are you getting fewer phone calls from her, too many calls, or calls late at night?

Does she repeat the same story at each conversation as if it were new?

Letters

Has she stopped writing letters or notes, or are her letters uncharacteristically rambling? Has her handwriting changed?

Meals and Medications

Is the person eating her meals and taking her medications correctly? A forgetful person may not eat, or may eat only sweets even when you have provided a hot meal. The person may take too much medicine or forget her medicine. This can make her mental impairment worse and can jeopardize her physical health. If the person is safe in other ways, she may be able to live alone if someone else helps daily with food and medicine, but it has been our experience that people who forget to eat properly are experiencing sufficient cognitive impairment that they probably cannot safely live alone.

Is the person forgetting to turn off the stove or burning the food? People who appear to be managing well often forget to turn off the stove. Has she stopped cooking? Are pots burned? Is the person using candles or matches? It can be hard to believe that a person is really a danger to herself when she looks so well, but fire is a real and serious hazard. Cases of severe or even fatal accidental burns are not uncommon. If you suspect that the person is forgetting to turn off the stove, you must intervene.

Other Problems

Is the person wandering away from home? She could get lost or be robbed or assaulted. Is she wandering around outside at night? Such behavior is dangerous. Have her friends or neighbors called you with concerns about her behavior or safety? Has she failed to keep appointments or not come to family events? Has she given you confusing reports of a mishap, such as a car accident? Did she retire from work early or abruptly?

Is the person keeping the house tidy, reasonably clean, and free of hazards? Forgetful people may spill water in the kitchen or bathroom and forget to clean it up. A person can slip and fall on a wet floor. Sometimes people forget to wash the dishes or forget to flush the toilet or in other ways create unsanitary conditions. If the house is badly cluttered, they can trip and fall. A confused person may pile up newspapers and rags, which become a fire hazard. Does the house smell of urine? This is a signal that the person is unable to manage alone or is ill.

Is the person keeping herself warm? A forgetful person may keep her house too cold or dress improperly. Her body temperature can drop dangerously if she does not keep herself warm. In hot weather the confused person may dress too warmly or may be afraid to open the house for adequate ventilation. This can lead to heat stroke.

Is the person acting in response to "paranoid" ideas or unrealistic suspiciousness? Such behavior can get her in trouble in the community. Sometimes people call the police because of their fears and make their neighbors angry. Sometimes, too, confused elderly people become the targets of malicious teenagers. Such problems may occur in suburban neighborhoods as well as in the inner city.

Is the person showing good judgment? Some confused people show poor judgment about whom they let in the house and can be robbed by the people they invite in, or they may give away money or do other inappropriate things.

Who is paying the bills? Often the first indication family members have that something is wrong is when the heat or water is shut off because the bill has not been paid or because the person will not let the meter reader in. The person may stop balancing her checkbook or her spending habits may change.

Such clues indicate that *something* may be wrong—

but not necessarily that the person has a dementing illness. Once you are aware that there may be a problem, it is essential to get a complete assessment for the person. These changes can indicate many other treatable conditions.

What You Can Do

Contact the Alzheimer's Association chapter in your community. Most chapters have had experience helping families who live at a distance and can give you valuable information. Talk to neighbors and other family members to get as complete a story as possible. If the person lives in a city, talk to a close friend of the person, an apartment house neighbor, or a doorman. If she lives in a rural area, talk to the mail carrier, bank manager, clergyperson, or neighbor. They may be aware of problems. Give these people your telephone number and ask them to alert you if there are problems.

Visit in person to assess the situation and to arrange for a diagnosis. Talk to the Alzheimer's Association and the office on aging in your relative's town. They will be able to tell you about local resources.

Sometimes a person can continue to live independently for a while if you can arrange for supervision. Perhaps her physician can give you an idea of how able the person is to continue functioning alone. In major cities there are social workers who will, for a fee, function as a stand-in relative, taking a person for appointments, helping with the checkbook, and keeping an eye on things. You should check the credentials of any per-help make the move easier. A move from independent living to living with someone else may mean giving up one's independence and admitting one's impairment. Moving means more losses. It means giving up a familiar place and often many familiar possessions. That place and those possessions are the tangible symbols of one's past and reminders when one's memories fail.

The confused person is dependent upon a familiar setting to provide her with cues that enable her to function independently. Learning one's way around in a new place is difficult or impossible. She feels dependent upon familiar surroundings to survive. The person with a dementing illness may forget the plans that have been discussed or may be unable to understand them. You may reassure your mother that she is coming to live in your house—which is very familiar to her—but all her damaged mind may perceive is that a lot of things are going to be lost.

As you make plans for this person to live with someone, there are several things to consider.

1. *Take into careful consideration the changes that this move will mean in your life, and plan, before the move, for financial resources and emotional outlets and supports for yourself.* If the impaired person is to move in with you, what effect will this have on her income? States may consider room and board as income and reduce Public Assistance benefits to people living with someone. You will also want to review such things as whether you can claim the person as your dependent on your income tax.

If the person is coming to live with you, how does the rest of the family feel about this? If there are children or teenagers in the family, will their activities upset the confused person or will the “odd” behavior of the confused person upset them? How does your spouse feel about this? Is your marriage already under stress? Having a person with dementia in the home creates burdens and stresses under the best of circumstances. If the ill person and her spouse are both moving in, you must also consider how the spouse will interact in the household. All of the people affected need to be involved in the decision and need the opportunity to express their concerns.

Assuming the care of a forgetful person may mean changes in other things: leisure time (you may not be able to go out because there is no one to sit with Mother), peace (you may not be able to read the newspaper or talk to your wife because Mother is pacing the floor), money (you may have increased medical bills, or bills for remodeling the bedroom), rest (the confused person may wake at night), visitors (people may stop visiting if the person’s behavior is embarrassing). These are the things that make life tolerable and that help to reduce your stress. It is important to plan ways for you and your family to relax and get away from the problems of caring for a sick person. Remember also that other problems are not going to go away: you may still worry about your children, come home exhausted from your job, have the car break down, etc.

Is the person you are bringing into your home someone you can live with? If you never could get along with your mother and if her illness has made her behavior worse instead of better, having her move in with you may be disastrous. If you have had a longstanding poor relationship with the person who is now sick, that poor relationship is a reality that can make things more difficult for you.

2. *Involve the person as much as possible in plans for the move, even if she refuses to move.* The impaired individual is still a person, and her participation in plans and decisions that involve her is important, unless she is too severely impaired to comprehend what is happening. Confused people who have been hoodwinked into a move may become even more angry and suspicious and their adjustment to the new setting may be extremely difficult. Certainly the extent and nature of the impaired person's participation depend on the extent of her illness and her attitude toward the move.

Keep in mind that there is a key difference between making the decision, which you may have to do, and participating in the planning, which the confused person can be encouraged to do. Perhaps Mr. Sawyer's story will continue like this:

> *"After we talked it over with Mother, she still absolutely refused to consider a move. So I went ahead with the arrangements. I told Mother gently that she had to move because she was getting forgetful.*
>
> *"I knew too many decisions at once would upset her, so we would just ask her a few things at a time:*

Reassure yourself that after an adjustment period the person usually will settle into her new surroundings. Signs on doors may help her find her way around an unfamiliar home. An additional sedative for a brief time may help her sleep at night. Try to postpone other activities or changes until after everyone has adjusted to the move.

Occasionally an impaired person never really adjusts to moving. Don't blame yourself. You did the best you could and acted for her well-being. You may have to accept her inability to adjust as being the result of her illness.

5

Problems Arising in Daily Care

Hazards to Watch For

A person with a dementing illness is less able to take responsibility for his own safety. He is no longer able to evaluate consequences the way the rest of us do, and, because he forgets so quickly, accidents can easily happen. He may attempt to do familiar tasks without realizing that he can no longer manage them. For example, the disease may affect those portions of the brain which remember how to do simple things, such as buttoning buttons or slicing meat. This inability to do manual tasks is often unrecognized and causes accidents. Since the person also cannot learn, you will have to take special precautions to guard against accidents. Because a person seems to be managing well, you may not realize that he has lost the judgment he needs to avoid accidents. Families may need to take responsibility for the safety of even a mildly impaired person.

Accidents are most likely to occur when you are cross or tired, when everyone is hurrying, when there is an argument, or when someone in the household is sick. At these times you are less alert to the possibility of an accident and the impaired person may misunderstand or overreact to even the slightest mishap with a catastrophic reaction.

Do what you can to reduce confusion or tension when it arises. This is difficult when you are struggling with the care of a person with a dementing illness. If you are rushing with him to keep an appointment or finish a job, *stop,* even if it means being late or not getting something done. Catch your breath, rest a minute, and let the confused person calm down.

Be aware that mishaps can be warning signs of impending accidents: you banged your shin on the edge of the bed, or dropped and broke a cup, and the impaired person is getting upset. This is the time to create a change of pace before a serious accident occurs. Alert others in the household to the relationship between increased tension and increased accidents. At such times, everyone can keep a closer eye on the impaired person.

Be sure you know the limits of the impaired person's abilities. Do not take his word that he can heat up his supper or get into the tub alone. An occupational therapist can give you an excellent picture of what the person can do safely. If you do not have this resource, observe the person closely as he does various tasks.

Have an emergency plan ready in case something does happen. Whom will you call if someone is hurt? How will you get the upset person out in case of a fire? Remember that he may misinterpret what is happening and resist your efforts to help him.

Change the environment to make it safer. This is one of the most important ways to avoid accidents. Hospitals and other institutions have safety experts who regularly inspect for hazards. You can and should do the same thing. Go thoughtfully through your home, yard, neighborhood, and car, looking for things a person with a dementing illness could possibly misuse or misinterpret that might cause an accident.

In the House

A neat house is safer than a cluttered one. There are fewer things to trip over or knock over, and hazards are more easily seen. Knickknacks or clutter may distract or confuse an impaired person.

Remove things that cause problems. If a person tries to use the iron and leaves it on, causing a fire hazard, put it away where he cannot find it. Whenever possible take the easiest path to safety without conflict. Does the impaired person have access to power tools, lawn mower, knives, hair dryer, sewing machine, or car keys when he can no longer safely use them? You must put these in a locked closet.

Are all medications kept out of reach of a person who may forget that he has already taken them? Buy a metal file box and equip it with an inexpensive lock to keep medications safely away from the forgetful person and visiting grandchildren.

Are things stored on the stairs? Clutter is always dangerous, particularly when a person is confused, clumsy, or misinterprets what he sees. Are extension cords stretched across the floor where a person might trip on them?

Lower the temperature on your water heater so that water is not hot enough to scald the person who accidentally turns it on. People with dementing illnesses can lose the ability to realize that hot water is too hot and they can burn themselves badly. If hot water pipes are exposed, cover them with insulation.

If the confused person readjusts the furnace or water heater, you may need to lock the basement door.

If you have stairs, install gates at the top. The confused person can easily get "turned around" and fall down the steps, especially at night. Check the handrails; be sure they are sturdy. Handrails should be anchored into the stud and not into drywall or plaster. They will not hold a person's weight if they are not securely fastened. Install handrails if there are none. As the person becomes unsteady on his feet, he will need them. Put away rugs that slip. If stairs are carpeted, check to see that the carpet is securely tacked down.

Remove furniture with sharp corners or sharp finials. Put away or block off large areas of breakable glass; a person can fall against a glass china cabinet and be badly cut. Put away rocking chairs that tip over easily. Put away coffee tables and fragile antiques.

Use stable chairs that are easy to get out of (see p. 73). Check to see if fingers or toes could get caught in parts of recliners. Furniture upholstery should be easy to clean; you may have to wipe up spills. Fabric, draperies, and cushions should be flame resistant.

A confused person can easily lean too far out of a window or over a balcony rail and fall—a particular danger in high-rise buildings. Install security locks on windows and balcony doors. There are inexpensive devices that enable you to lock a window in an open position so that a person cannot get out but fresh air can get in, or open the window a little at the top and a little at the bottom and secure it.

Block off hot radiators by putting a sturdy chair in front of them. You may want to put a gate around a floor furnace.

Can the person lock himself in a room so that you cannot get in? Remove the lock, take the tumblers out, and replace the knob, or tape the latch open.

Never keep insecticides, gasoline, paint, solvents, cleaning supplies, etc., in other than their original, clearly labeled containers. Store them safely out of reach of the confused person. Childproof (and patient-proof) cabinet latches are available at hardware stores. Mildly confused people may try to use such materials inappropriately.

Impaired people forget what can be eaten and what cannot; they may drink solvents by mistake. These people may also eat other inappropriate items. Put small things such as pins and buttons out of reach. Give away poisonous houseplants. Some people will eat chips of loose paint from walls or furniture. Watch for any behavior that involves putting things in the mouth.

If you live in an apartment or condominium building that has a doorman or security staff, let these people know that this member of your family is forgetful and may have trouble finding his apartment. These staff may be willing to alert you if the person tends to wander away.

Outdoors

Both adults and children can easily put a hand through the glass in a storm door. Storm doors should be covered with a protective grillwork. Sliding glass patio doors should be well marked with stick-on decals.

Check to see if a confused person might fall off a porch or deck. If there are steps, paint them bright, contrasting colors, attach outdoor no-skid tape to the edges, and install a banister.

Check for uneven ground, cracked pavement, holes in the lawn, fallen branches, thorny bushes, or molehills that the person can trip over.

Take down the clothesline so the person will not run into it.

If you have an outdoor grill, never leave it unattended while the coals are hot. Make sure the coals are out and cold. If you have a gas barbecue, be sure the confused person cannot operate it.

Lock up garden tools.

Check yard furniture to be sure it is stable, will not tip or collapse, and has no splinters or chipped paint.

Fence in or dispose of poisonous flowers.

Outdoor swimming pools are very dangerous. Be sure that your or your neighbor's pool is securely fenced and locked so that the confused person cannot get to it. You may have to explain carefully the nature of the person's impairment to the owner of the pool, making certain that the confused person is not ever assumed to be competent around a pool. Even if he has always been a good swimmer, a person with dementia may lose his judgment or his ability to handle himself in the water.

In the Car

Problems with driving are discussed in Chapter 4. Never leave a confused person alone in a car. He may wander away, fiddle with the ignition, release the handbrake, be harassed by strangers, or run the battery down with the lights. Some automatic windows are dangerous for confused people and for children, who may close the window on their head or arm.

Occasionally a confused person will open the car door and attempt to get out while the car is moving. Locking the doors may help. If this continues to be a problem, you may need a third person to drive while you keep the impaired person calm.

Smoking

If the person smokes, the time will come when he lays down lighted cigarettes and forgets them. *This is a serious hazard.* If it occurs, you must intervene. Try to discourage smoking. Many families have taken cigarettes completely away from a patient. Things may be difficult for a few days or weeks, but much easier in the long run. However, some people forget they ever smoked, and do not complain when you take their cigarettes away. Other families allow the impaired person to smoke only under their supervision. All smoking materials and kitchen or fireplace matches must be kept out of reach of the forgetful person. (The person who has cigarettes but not matches may use the stove to light his cigarette and may leave the stove on.)

Hunting

The use of firearms requires complex mental skills that are usually lost early in dementia. Guns must be put in a safe place. If necessary, ask your doctor or clergyperson to explain to the confused person's hunting buddies that hunting is now too dangerous for him. Ask the local police or sheriff's department if they can help dispose of a gun or rifle if you do not know how to do so.

Highways and Parking Lots

Highways are dangerous. If you think the confused person may be walking along a highway, notify the police immediately. They do not mind being alerted unnecessarily. This is much better than not alerting them and having a tragedy occur.

People driving in parking lots often assume that pedestrians will get out of their way. People with dementia may not anticipate cars coming or may move slowly. Be especially alert to entrances into enclosed garages. These often put the pedestrian directly into the path of cars.

Meal Preparation

When you must prepare meals in addition to all your other responsibilities you may find yourself taking short cuts such as fixing just a cup of coffee and toast for yourself and the confused person. If preparing meals is a job you had to take on for the first time when your spouse became ill, you may not know how to serve good nutritious meals quickly and easily and you may not want to learn to cook. There are several alternatives. We suggest you plan a variety of ways to get good meals with a minimum of effort.

There are Eating Together programs for people over 60 and Meals-on-Wheels programs in most areas. Both services provide one hot, nutritious meal a day. You can find out what meal services are available through a social worker or by calling the local office on aging. Meals-on-Wheels programs bring a meal to your home. Eating Together programs, funded under the Older Americans Act, provide lunch and often a recreation program in the company of other retired people at a community center. Transportation is often provided.

Many restaurants will prepare carry-out meals if requested. This helps when a person can no longer eat in public.

There are numerous inexpensive cookbooks on the market that explain the basic steps in easy meal preparation. Some are written for the man who is "bacheloring." Some are in large print. An experienced homemaker can show you how to prepare quick, easy meals.

The home economist in your county extension office or a public health nurse can give you good, easy recipes for two. She also has helpful information on budgeting, shopping, meal planning, and nutrition, and she can help you understand and plan menus for special diets.

Some frozen dinners provide well-balanced meals, but these are often expensive. Many, however, are low in vitamins and high in salt, and lack the fiber older people need to prevent constipation.

Problem Eating Behaviors

Forgetful people who are still eating some meals alone may forget to eat, even if you leave food in plain sight. They may hide food, throw food away, or eat it after it has spoiled. These are signals that the person can no longer manage alone and that you must make new arrangements. You may manage for a time by phoning at noon to remind him to eat lunch now, but this is a short-term solution. Confused people who live alone are frequently malnourished. Even when they appear overweight, they may not be getting the proper foods. A poor diet can worsen their confusion.

Many of the problems that arise at mealtime involve catastrophic reactions. Make mealtime as regular a routine as possible, with as little confusion as you can arrange. This will help prevent catastrophic reactions. Fussy or messy eaters do better when things are calm.

Check that dentures are tight fitting if the person uses them to eat. If they are loose, it may be safer to leave them out until they can be adjusted.

keep the snacks in the container. Others persuade the person to "trade" their old, spoiled food for fresh food.

If the person has a complicating illness, such as diabetes, which requires a special diet, it may be necessary to put foods he should not eat where he cannot get them and allow him only those foods he should have. Remember, he may lack the judgment to decide responsibly between his craving and his well-being. Since a proper diet is important to his health, you may have to be responsible for preventing him from getting foods he should not have, even if he vigorously objects. A locksmith can put a lock on the refrigerator door if necessary. Childproof locks will secure cabinets. But before you invest in locks, ask yourself whether you need to keep all those sweets in the house anyway.

Nibbling

Sometimes a person seems to forget that he ate and will ask for food again right after a meal. Sometimes people seem to want to eat all the time. Try setting out a tray of small, nutritious "nibbles" such as small crackers or cheese cubes. Sometimes people will take one at a time and be satisfied. If weight gain is a problem, put out carrots or celery.

Eating Things He Should Not Eat

People with dementing illnesses may be unable to recognize that some things are not good to eat. You may need to put out of sight foods like salt, vinegar, oil, or Worcestershire sauce, large amounts of which can make lows before giving him the next bite. You may have to tell him to swallow.

Not Eating, or Spitting Foods Out

Some of the medications often given to people with dementia make the mouth and throat dry, which makes many foods unpalatable or hard to swallow. Your pharmacist can tell you which drugs have this effect. Mix food with juice or water and offer the person a sip of water with each bite.

Sometimes the mouth and throat can be so dry it is painful and the person may be cranky. Offer fluids frequently.

Not Swallowing

Sometimes a person will carry food around in his mouth but not swallow it. This is due to forgetting how to chew or swallow. This is an apraxia (see p. 69) and is best handled by giving the person soft foods that do not require much chewing, such as chopped meat, gelatin, and thick liquids.

If the person does not swallow pills, crush the pill and mix it with food.

Malnutrition

People with dementia can easily become malnourished, even when their caregivers are doing the best they can. Malnutrition and dehydration contribute to the person's overall poor health, increase his suffering, and shorten his life. Malnutrition affects the way the entire body functions; for example, how quickly a person recovers from an illness or how quickly a wound heals. Some people can be overweight and still not be getting the proteins or vitamins they need. People who have difficulty swallowing or who have had a stroke are especially at risk of malnutrition.

Many of the residents of nursing homes suffer from malnutrition, and some are not getting enough fluids. Insist that the nursing home evaluate the person's nutritional status and treat any problems.

Weight Loss

People with dementia lose weight for all the same reasons that any other person does. Therefore, if he loses weight, the first step is to consult the person's physician. Weight loss often indicates a treatable problem or a disease unrelated to the dementia. Do not assume that it signals a decline. It is important that the physician search carefully for any contributory illness. Is the person constipated? Has the person had a new small stroke? Is the person depressed? Depression can account for weight loss even in a person who has a dementia. Poorly fitting dentures or sore teeth or gums often contribute to weight loss. Weight loss very late in the illness may be a part of the disease process itself. Certainly all other possible causes should be considered.

When a person is still eating and yet losing weight, he may be pacing, agitated, or so active that he is burning up more calories than he is taking in. Offer nutritious, substantial snacks between meals and before bedtime. Some clinicians think that several small meals and several snacks help prevent this kind of weight loss.

Sometimes all that is needed to get a person to eat better is a calm, supportive environment. You may have to experiment before you find the arrangement that best encourages the person to eat. Be sure the food tastes good. Offer the person his favorite foods. Offer only one thing at a time and do not rush him. People with dementia often eat slowly. Frequently offer snacks. Gently remind him to eat.

Eating problems often arise in nursing homes. Most people eat better in a small group or at a table with one other person in a quiet room. Perhaps the nursing home will set aside space to serve a few confused people on the unit instead of in a large, noisy dining room. Sometimes nursing home staff members are too rushed to coax a person to eat; a familiar family member may have better success. Homemade goodies may be more appealing than institutional food. We have had one patient respond by having her back gently stroked while she was being fed. One patient responded to a low dose of medication given one hour before meals.

You may give a person who is not eating well a liquid high-calorie diet supplement like Ensure, Mariteme, or Sustacal. You can purchase these by the case from most pharmacies and discount warehouses. They contain vitamins, minerals, and proteins the person needs. They come in different flavors; the person may like some flavors or products better than others. Offer this as the beverage with a meal or as a "milk shake" between meals. Consult your physician about using them.

Choking

Sometimes people with coordination problems begin to have trouble swallowing. If the person has difficulty changing his facial expression, or if he has had a stroke, he may also have trouble chewing or swallowing. When this occurs, it is important to guard against choking. Do not give the person foods that he may forget to chew thoroughly, such as small hard candy, nuts, carrots, chewing gum, or popcorn. Soft, thick foods are less likely to cause choking. Easy to handle foods include chopped meat, soft-boiled eggs, canned fruit, and frozen yogurt. Foods can be ground in a blender. Seasoning will make them more appealing. You can mix a liquid and a solid (for example, broth and mashed potatoes) to make swallowing easier.

If the person has trouble swallowing, be sure he is sitting up straight with his head slightly forward—never tilted back when he eats. He should be sitting in the same position in which a well person would sit at a table. He should remain sitting for fifteen minutes after he eats.

Do not feed a person who is agitated or sleepy.

Foods like cereal with milk may cause choking. The two textures—solid and liquid—make it hard for him to know whether to chew or swallow.

Some fluids are easier to swallow than others. If a person tends to choke on fluids like water, try a thicker liquid, like apricot or tomato juice. A nurse can help you cope with this problem.

First Aid for Choking

A nurse or the Red Cross can teach you a simple technique that can save the life of a choking person. It takes only a few minutes to learn this simple skill. Everyone should know how to do it.

If the person can talk, cough, or breathe, *do not interfere.* If the person cannot talk, cough, or breathe (and he may point to his throat or turn bluish), *you must help him.* If he is in a chair or standing, stand behind him, then reach around him and lock or overlap your two hands in the middle of his abdomen (belly) below the ribs. Pull hard and quickly back and up (toward you). If he is lying down, turn him so he is face up, put your two hands in the middle of his belly, and push. This will force air up through the throat and cause the food to fly out like a cork out of a bottle. (You can practice where to put your hands, but you should not push hard on a breathing person.)

When to Consider Tube Feeding

People with dementia stop eating for many reasons. They may have difficulty swallowing due to an apraxia, to ulcers in the esophagus, esophageal obstruction (narrowing), or overmedication. They may dislike the food being offered, not recognize it as food, lose the sense of feeling hungry or thirsty, or be sitting in an uncomfortable position. People with dementia may stop eating when they are experiencing a concurrent illness; they *may* resume eating when they recover. Even severely impaired people may suffer from a depression that causes them to stop eating. However, some people reach a point in their illness when they are no longer able to eat or swallow. Good care, even in the last stage, requires that a physician carefully review the person's medical status. Then, if weight loss cannot be stopped, you and the doctors are left with an ethical dilemma. Should you allow the insertion of a nasogastric (NG) tube (a tube that goes through the nose into the stomach) to feed the patient or of a feeding tube directly into the stomach (a gastrostomy)? Or should you allow the patient to die? Only you can make this decision.

It is helpful if you can talk about this issue before it arises. We discuss these ethical dilemmas on pages 198–203. Here we will discuss the options you have for sustaining life.

Many physicians believe that a gastrostomy tube (a tube placed through the abdominal wall directly into the stomach) is more comfortable for the patient than the more familiar nasogastric tube (a tube that goes through the nose, down the esophagus, and into the stomach). Patients are less likely to pull gastrostomy tubes out and these tubes need to be changed less often. New surgical procedures make inserting them safe and easy. However, these tubes do require a surgical opening through the abdomen and this may present a slightly higher risk to the patient. If the person has dementia, You may have to exercise with the impaired person. The kind of exercise you do depends on what you and the impaired person enjoy. There is no point to adding an odious exercise program to your life. Consider what the person did before he got sick and find ways to modify that activity so that it can continue. Sometimes an exercise project can also be a time for you and the impaired person to share closeness and affection without having to talk.

How much exercise can an older person safely do? If you or the impaired person has high blood pressure or a heart condition, check with the doctor before you do anything. If both of you can do normal walking around the house, climb steps, and shop for groceries, you can do a moderate exercise program. Always start a new activity gradually and build up slowly. If an exercise causes either of you stiffness, pain, or swelling, do less of it or change to a gentler activity. Check the person's feet for blisters or bruises if you begin walking.

Walking is excellent exercise. Try to take the person outside for a short walk in all but the worst weather. The movement and the fresh air may help him sleep better. If the weather is too rainy or cold, drive to a shopping mall. Make a game of "window shopping." Be sure both of you have comfortable, low-heeled shoes, and soft, absorbent cotton socks. You may gradually build up the distance you walk, but avoid steep hills. It may be easier for a forgetful person to walk the same route each day. Point out scenery, people, smells, etc., as you walk.

Dancing is good exercise. If the person enjoyed dancpeople with dementia enjoy the camaraderie with other people who are also confused. Some in-home visitor programs offer occupational or recreational therapy services for the ill person. These professionals can help you plan exercises or activities the person will enjoy. Both visiting at home and day care offer social activities and opportunities for success and fun. If at all possible, involve the person in such a program.

People with dementia often lose the ability to entertain themselves. For some, idleness leads to pacing or other repetitive behaviors. The person may resist your suggestions of things to do. Frequently, this is because he does not understand what you are suggesting. Try beginning an activity and then inviting him to join you. Select simple, adult activities rather than childish games. Select an activity that will be fun rather than one that is supposed to be "therapeutic." Look for things that the person will enjoy and that he will succeed at (like sanding wood, playing with a child, cranking an ice cream maker).

The amount of activity a person can tolerate varies widely. Plan activity when the person is rested; help whenever the person becomes anxious or irritable, and break the activity down into simple steps.

Previously enjoyed activities may remain important and enjoyable even for seriously impaired people. However, the things the person used to enjoy, such as hobbies, guests, concerts, or going out to dinner, can become too complicated to be fun for someone who is easily confused. These must be replaced by simpler joys, although it can be hard for family members to understand that simple things can now give just as much pleasure.

Music is a delightful resource for many confused people. Sometimes a severely impaired person seems to retain a capacity to enjoy old, familiar songs. Some people will sing only when someone sits close by and encourages them. Others may be able to use a simple tape deck or radio with large knobs. Very impaired people are sometimes still able to play the piano or sing if they learned this skill earlier.

Some memory-impaired people enjoy television. Others get upset when they cannot understand the story anymore. The quick shifts from one scene to another precipitate catastrophic reactions in some people.

Most confused people enjoy seeing old friends, although sometimes visitors upset them. If this happens, try having only one or two people visit at a time, instead of a group. It is often the confusion of several people visiting at once that is upsetting. Ask visitors to stay for shorter periods, and explain to them the reason for the person's forgetfulness and other behaviors.

Some families enjoy going out to dinner, and many people with dementing illnesses retain most of their social graces well. Others embarrass the family by their messy eating. It is helpful to order for the confused person and select simple foods that can be eaten neatly. Remove unnecessary glasses and silverware. Some families have found that it helps to explain to the waitress discreetly that the person is confused and cannot order for himself.

stuffed toy can be either childish and demeaning or comforting; much depends on the attitude of the people around the confused person.

As the dementing illness continues and the person develops trouble with coordination and language, it is easy to forget his need to experience pleasant things and to enjoy himself.

Never overlook the importance of hand holding, touching, hugging, and loving. Often when there is no other way we can find to communicate with a person, he will respond to touching. Touch is an important part of human communication. A backrub or foot or hand massage can be calming. You may enjoy just sitting and holding hands. It's a good way to share some time when talking has become difficult or impossible.

Meaningful Activity

Much of what a well person does during the day has a purpose that gives meaning and importance to life. We work to make money, to serve others, to feel important. We may knit a sweater for a grandchild or bake a cake for a friend. We wash our hair and clothes so we will look nice and be clean. Such purposeful activities are important to us—they make us feel useful and needed.

When the person with a dementing illness is unable to continue his usual activities, you need to help him find things to do that are meaningful and still within his abilities. Such tasks should be meaningful and satisfying to him—whether they seem so to you or not. For example, folding and refolding towels might have meaning for some people but not for others. Seeing themselves as "volunteers" rather than "patients" is important to some people. This provides both a sense of worth and the benefit of participation. The person may be able to spade a garden for you and for the neighbors or may be able to peel the vegetables or set the table when no longer able to prepare a complete meal. Confused people can wind a ball of yarn, dust, or stack magazines while you do the housework. Encourage the person to do as much as he can for himself, although you can simplify the tasks for him.

Personal Hygiene

The amount of help a person with a dementing illness needs in personal care varies with the extent of his brain damage. The person with Alzheimer disease will be able to care for himself in the early stages of the disease, but may gradually begin to neglect himself and will eventually need total help.

Problems often arise over getting a person to change his clothes or take a bath. "I already changed," the person may tell you, or he may turn the tables and make it sound as if you are wrong to suggest such a thing.

> *A daughter says, "I can't get her to change clothes. She has had the same clothes on for a week. She sleeps in them. When I tell her to change, she says she already did or she yells at me, 'Who do you think you are, telling me when to change my clothes?' "*

acutely uncomfortable experience. When we offer to help with something a person has always done for himself—something everybody does for himself and does in private—it is a strong statement that this person is not able to do for himself any longer, that he has, in fact, become like a child who must be told when to dress and must have help.

Changing clothes and bathing involve making many decisions. A man must select among many socks, shirts, and ties for an outfit that goes together. When he begins to realize he can't do this, when looking at a drawer full of blue, green, and black socks becomes overwhelmingly confusing, it can be easier just not to change.

Such factors as these often precipitate catastrophic reactions involving bathing and dressing. Still, you are faced with the problem of keeping this person clean. Begin by trying to understand the person's feelings and his need for privacy and independence. Know that his behavior is a product of his brain impairment, and is not deliberately offensive. Look for ways to simplify the number of decisions involved in bathing and dressing without taking away his independence.

Bathing

When a person refuses to take a bath, part of the problem may be that the business of bathing has become too confusing and complicated; for others it is anxiety or the fact that the caregiver must intrude into the person's private space. Look for ways to reduce these factors. Be calm and quiet; simplify the task. Wrap the

You have control of the water (and the mess). The seat is safer and the controlled flow of water is less upsetting to the confused person.

Never leave the person alone in the tub. Use only two or three inches of water. This helps the person feel more secure and is safer in case he slips. Put a rubber mat or no-skid decals on the bottom of the tub. People can often continue to wash themselves if you gently remind them one step at a time of each area to wash.

Sometimes it is embarrassing for a family member to see that the genital area is thoroughly washed, but rashes can develop, so see that this is done. Be sure that you or the confused person has washed in folds of flesh and under breasts.

Use a bathmat that will not slip for the person to step out onto and be sure there are no puddles on the floor. It may be helpful to replace bathmats with bathroom carpeting that does not slip, soaks up puddles, and is washable. If the person still dries himself, check to see that he doesn't forget some areas. If you dry the person, be sure he is completely dry. Use body powder, baby powder, or cornstarch under women's breasts and in creases and folds of skin. Cornstarch is an inexpensive, odorless, and nonallergenic substitute for talcum powder. Baking soda is an effective substitute if the person resists using a deodorant.

While the person is undressed, check for red areas of skin, rashes, or sores. If any red areas or sores appear, ask your physician to help you manage them. Pressure sores or decubitus ulcers develop quickly on people who sit or lie down much of the time. Use body lotion on dry skin. There are unscented lotions for men.

Dressing

If all of the person's socks will go with all of his slacks, he doesn't have to decide which is right to wear with what.

Hang ties, scarves, or accessories on the hanger with the shirt or dress they go with. Eliminate belts, scarves, sweaters, ties, and other accessories that are likely to be put on wrong.

Lay out a clean outfit for the confused person. Laying out clothes in the order in which he puts them on may also help.

Put away out-of-season or rarely worn clothes so they do not add to the decisions the person must make. If the person refuses to change clothes, avoid getting in an argument. Make the suggestion again later.

As the disease progresses, it becomes difficult for a person to get clothes on right side out and in the right sequence. Buttons, zippers, shoelaces, and belt buckles become impossible to manage. If the person can no longer manage buttons, replace them with Velcro tape, which you can purchase in a fabric store. People can often manage this after their fingers can no longer cope with buttons. One wife, sensitive to her husband's need to continue to dress himself independently, bought him clothes that were reversible. She bought attractive t-shirts, which don't look bad if they are worn backward and which don't have buttons, pants with elastic waistbands, and tube socks. (Tube socks don't have heels, so it takes less skill to put them on.) Slip-on shoes are easier than shoes with laces or ties.

Women can look pretty in reversible, slip-on blouses and reversible, wrap-around or elastic-waistband skirts or slacks. Loose-fitting clothing is easier to manage.

Select clothing that is washable and that doesn't need ironing; there is no reason to add to your work load.

Sometimes "busy" patterns confuse and distract the impaired person. Select colors with considerable contrast; these are easier for the older person to distinguish.

Women's underwear is difficult for a confused person to manage, and a mystery to many husbands. Buy soft, loose-fitting panties. It won't matter if they are on backward or wrong side out. Skip the slip; it is not necessary. If you must put a bra on a woman, ask her to lean forward to settle her breasts in the cups. Pantyhose are difficult to put on, and knee socks or garter belts are bad for people with poor circulation. Short cotton socks may be best to wear at home.

Tell the person, one step at a time, what to do or what you are doing. Go with what works. If the person is dressed oddly, let it be.

Grooming

Have the person's hair cut in an attractive, short style that is easy to wash and care for. Avoid a style that requires setting. People who have always gone to the beauty shop or barber shop may still enjoy doing so. If this is too upsetting an experience, it may be possible to arrange for a beautician or barber to come to your home.

It may be safer (and easier on your back) to wash hair in the kitchen sink rather than the tub unless you have a sprayer attached to the bathtub. Invest in a hose attachment for the sink. Be sure you rinse hair well. It should squeak when rubbed through your fingers.

You will need to trim fingernails and toenails or check to see that he can still do this. Toenails can curl back against the toes and be quite painful.

Encourage the person to get dressed and to look nice. Moping around in a bathrobe will not help his morale. If a woman has always worn makeup, it may be good for her to continue to wear simple makeup. It is not difficult for a husband to put powder and lipstick on his wife. Use pastel colors and a light touch on an older woman. Skip the eye makeup.

When the bath and dressing are finished, encourage the person to look in the mirror and see how nice he looks (even if you are exhausted and exasperated). Get the rest of the family to compliment him also. Praise and encouragement are important in helping him continue to feel good about himself even when a task he has always been able to do, such as dressing, has become too much for him.

Oral Hygiene

With all the other chores of caring for a chronically ill person it is easy to forget what we can't see, but good oral hygiene is important for the person's comfort and for his health. A person who appears to be able to care for himself in other ways may, in fact, be forgetting to care for his teeth or dentures.

Dentures are particularly troublesome. If they don't fit just right or if a person is not applying the denture adhesive properly, they interfere with chewing. The natural response is to stop eating those things one can't chew. This can lead to inadequate nutrition or constipation. Dentures should be in place when a person is eating. If they don't fit properly or are uncomfortable, insist that the dentist fix them. If a person forgets to take his dentures out and clean them, or if he refuses to let you do it, he can develop painful sores on his gums which also interfere with a proper diet.

Since you want the person to be as independent as possible, you can assume the responsibility of remembering, but let the person do as much of the actual care as possible. One reason people stop caring for their teeth or dentures is that these are actually complicated tasks with many steps and they get confused about what to do next. You can help by breaking down the job into simple steps and reminding the person one step at a time. If you take over the care of the person's dentures, you must remove them daily, clean them, and check the gums for irritation. The dentist can show you how to do this. If the person has his own teeth, you may have to brush them for him and check the mouth for sores.

Some dentists recommend foam applicators instead of brushes for cleaning teeth. You can clean the teeth more gently with these. If the person will not unclench his teeth, try to clean the outside of the teeth.

Make oral care a part of a regular, expected routine and do it calmly; you will get less resistance. Select a time of day when the person is most cooperative. If the person does get upset, stop, and try again later. Someone else may be better able to get the person's cooperation.

Healthy teeth or properly fitting dentures are critically important. People with dementing illnesses tend not to chew well and to choke easily. Dental problems make this worse. Even mild nutritional problems caused by sore teeth can increase the person's confusion or cause constipation. Sores in the mouth can lead to other problems and can increase the person's impairment. (See pp. 182–83.)

Bathroom Supplies

Medical supply houses carry a variety of bathroom aids which make the bathroom safer and easier for the impaired person.

Raised (built-up) toilet seats make it easier for an impaired person to get off and on the seat and easier to transfer a person from a wheelchair to the toilet. The seat should fasten securely to the toilet so it does not slip when the person sits on it. Padded (soft) toilet seats are more comfortable for the person who must sit for some time. This is especially important for the person who develops pressure sores easily.

You can rent portable commodes that can be placed near a person's bed or on the ground floor, so that the

Incontinence (Wetting or Soiling)

People with dementing illnesses may begin to wet themselves or have their bowel movements in their clothing. This is called, respectively, urinary incontinence and bowel or fecal incontinence. The two are really separate problems, and one often occurs without the other. There are many causes of incontinence, so it is important to begin by assessing the problem.

Urinating and moving one's bowels are natural human functions. However, ever since childhood we have been taught that these are private activities. Many of us have also been taught that they are nasty, dirty, or socially unacceptable. In addition, we associate caring for our own bodily functions in private with independence and personal dignity. When another person has to help us, it is distressing for both the helper and the disabled person. Often, too, people find urine or bowel movements disgusting and may gag or vomit when cleaning up. It is important for both family members and professional caregivers to be aware of their own strong feelings in these areas.

Urinary Incontinence

Urinary incontinence has many causes, some of which respond well to treatment. Ask yourself the following questions.

If the person is a woman, is she "leaking" rather than completely emptying her bladder, especially when she laughs, coughs, lifts something, or makes some other lead to dehydration. A first step in addressing incontinence is to be sure that the person is getting enough fluid to adequately stimulate the bladder to work. Both too little and too much fluid can be bad. If you are uncertain how much fluid the person should get, ask your doctor or nurse. A doctor or nurse can also determine if the person is dehydrated.

If the problem is that the person moves slowly or uses a walker or is clumsy and cannot get to the bathroom in time, you can bring the toilet closer to the person. For example, if a person must go upstairs to the toilet, renting a commode for the ground floor may solve the problem. You can improvise a portable urinal that will help when you travel. You can also simplify clothing so the awkward person can manipulate it faster. Try Velcro tape instead of zippers or buttons. Can the person easily get up out of his chair? If he is sunk in a deep chair, he may not be able to get up in time.

Sometimes people cannot find the bathroom. This often happens in a new setting. A clear sign or a brightly painted door may help. People who urinate in waste baskets, closets, and flower pots may be unable to locate the bathroom or unable to remember the appropriate place. Some families find that putting a lid on the waste basket, locking closet doors, and taking the person to the bathroom on a regular schedule help. Remember that older people may have been taught as children to urinate outdoors or in a can by the bed. If so, it may be easier to supply them with a can than to clean up the waste basket.

ask them to use a commode in a room that is not a bathroom. It is often this involuntary "no go" response that leads families to say, "He wouldn't go when I took him and then he wet his pants. I think he is only being difficult."

Sometimes, if a person has trouble urinating, it may help to give him a glass of water with a straw and ask him to blow bubbles. This seems to help the urine start. Ask a nurse to show you how to press gently on the bladder to start the flow of urine.

Sometimes a person asks to go to the bathroom every few minutes. If this is a problem, it is helpful to have a urologist see the person to determine whether there is a medical reason why the person feels he needs to urinate frequently. A urinary tract infection or certain medications can give a person this feeling or can prevent his completely emptying his bladder. (If his bladder is not completely empty, he will soon feel the need to urinate again.) If you have ruled out medical reasons and are sure the person is emptying his bladder when he urinates, take him to the toilet every two to three hours and try to distract him in the interim period.

Some doctors and nurses may still dismiss incontinence as inevitable. It is true that some people with dementia will eventually lose independent control of their functions, but many do not, and many causes of incontinence can be controlled. Even when the person has lost independent function, there is much you can do to make your work load easier and to reduce embarrassment for him. If you are having problems, ask for a one size fits all; for others, size is by hip or waist measurement. The type of filler used determines how much urine the brief will absorb. Products with a “gelling property,” or super-absorbent polymers, usually hold much more than fiber-filled materials.

There are both disposable and washable garments. Some washable garments are not lined with soft materials, so the protective layer comes in contact with the skin and is uncomfortable. Many families find disposable liners are better because they hold larger volumes of urine. Liners with “gel” hold more urine with less bulk than fiber-filled materials.

Several products consist of an outer, washable pant that holds a disposable pad. The ideal is a soft, cool material in which the absorbent pad tends to draw urine away from the crotch so that the person’s skin feels dry. It is helpful if the garment is designed so that the pad can be changed without lowering the garment and so that the garment can be lowered for toileting.

The leg of the pant should fit snugly, to prevent leakage, but should not bind. Adult briefs may leak around the legs of a thin person. Families have found that using a toddler-size diaper plus the absorbent section of an adult brief helps. Using a safety pin to attach the brief to the undershirt of a bedfast person will help contain a bowel movement. Some briefs have greater absorbency in the front, while others are more absorbent toward the back. Experiment to find the one that works best for you.

Garments that don’t fit or that are too saturated may leak. Don’t expect the garment to hold more than one urination. Pads may say how much fluid they will hold. A full bladder may empty eight to ten ounces (one cup) of urine.

In large cities, there are adult diaper services that save you the burden of washing these garments.

Disposable pads are made to protect bedding, and you can also buy rubberized flannel baby sheets. These are much less unpleasant than the older rubber sheets you may remember from your childhood.

Use a draw sheet on the bed. This is a regular sheet folded in half lengthwise and tucked in across the bed. It holds a plastic pad in place between it and the bottom sheet. Should the patient have an accident, you have only the draw sheet and the pad to change. Absorbent bed pads used in combination with a draw sheet and rubber pad will help keep the bed dry. Look for pads with a polymer (gelling) effect and an embossed back to keep them from slipping. Follow the manufacturer’s washing and drying instructions.

It is not a good idea to use plastic pants, plastic bags, or rubber sheets that are not shielded by a layer of cloth next to the skin. They cause moisture to stay in contact with the skin and lead to irritation and rawness.

Problems with Walking and Balance; Falling

As the person’s illness progresses, he may become stiff or awkward and have difficulty getting out of a chair or out of bed. He may develop a stooped or leaning posture or a shuffling walk. He will need close supervision when he is at risk of falling.

> *A family member writes, "His steps are very slow now. As he walks, he often raises his feet high, for he has little sense of space. He clutches door frames or chairs. Sometimes he just grasps at the air. His gaze is unfocused, like that of a blind man. He stops in front of mirrors, and he talks and laughs with the images there."*

> *A wife says, "He sometimes falls down. He trips over his own feet or just crumples up. But when I try to lift him—and he is a big man—he yells and struggles against me."*

Any of these symptoms *may* be caused by medications. Discuss with the doctor any change in walking, posture, stiffness, repetitive motions, or falling. He needs to be sure that there is not a treatable cause for them, such as medications, a delirium, or a small stroke. These same symptoms will occur when the dementing process has damaged the areas of the brain which control muscle movements. But do not assume this is the cause until the doctor has eliminated other causes.

Watch for the time when the person can no longer safely negotiate stairs, or trips, or has other difficulties walking. If a person is unsteady on his feet, have him take your arm, if he will, rather than your grasping his. Hold your arm close to your body. This maximizes your ability to keep your balance. Or you may steady him by walking behind him and holding his belt.

ing means that the person has another illness or a medication reaction. This should be investigated promptly by a physician.

The gradual loss of the ability to walk or stand is the result of progressive brain damage; the person has forgotten how to walk. Keeping people as active as possible helps to maintain their muscle strength and general health, but there is no evidence that exercise or activity can postpone or prevent the loss of the ability to walk.

Even though a person cannot walk, he may be able to sit up. Sitting in a chair much of the day enables him to continue to be a part of family or institutional life. If the person has a tendency to fall forward or out of the chair, you can prop him with pillows or use a waist restraint. You can purchase a waist restraint made for support or you can make one. It is a padded belt several inches wide, which can be adjusted so that it will not be tight. It should be easy to unfasten from the back in an emergency.

An alternative is a lounge chair or a Gerichair (you can rent or purchase these from medical supply houses). When a lounge chair is kept in the reclined position, it protects the person from falling forward. You may prop him with pillows so that he is comfortable. You may want to move the person from chair to chair to bed so that his position changes. Use pieces of "egg crate" foam (available from a medical supply house) to cushion him.

Some people eventually become unable to sit. They usually have contractures—stiffened tendons that do not allow their joints to fully open or extend. Contractures may be postponed or reduced by keeping people physically active and with physical therapy, but they can occur late in Alzheimer disease or following a stroke, even when the person's joints are moved and exercised by others.

When patients are no longer able to move voluntarily and are confined to bed, they require almost constant physical attention. They are at high risk of developing bedsores or pressure sores (see pp. 173–74) and of getting food, saliva, and other substances into their lungs because they cannot swallow or are lying down.

Bedbound patients should be carefully moved from one side to the other every two hours. Your doctor may recommend more frequent turning. Care must be taken to avoid putting undue pressure or weight on any one part of the body, because these patients tend to have brittle bones and fragile skin. Satin or silk sheets and pajamas can make it easier to move someone who cannot move independently. When the person is lying on his side, he should be propped up with a pillow. A pillow or pad is sometimes necessary between the knees to prevent sores from forming. Skin must be kept clean and dry.

Moving a totally bedbound person requires skill and training. Visiting nurses and physical therapists can be helpful in teaching you how to move and turn the person.

Wheelchairs

If the time comes when the person needs a wheelchair, your doctor or a visiting nurse can give you guidance in selecting and using one. Your library will have several books with information about maneuvering wheelchairs. Wheelchairs can be uncomfortable for people who sit in them for long periods. The seats of many chairs are hard and can cause pressure sores. Chairs that do not support the body correctly can cause muscle and nerve damage as well. Sometimes people slump in the chair or are left sitting with an arm hanging so that fingers go numb. The right kind of chair can help avoid these problems. There are different kinds of wheelchairs. A qualified person should help you select a chair that is comfortable and supports the user. You will also need a chair that meets your needs in weight (Can you lift it?), portability (Will you need to take it in the car?), and width (Will it go through your doorways?). Ask a physical therapist or nurse to show you how to help someone in and out of the chair and how to support the person correctly.

Medicare will pay for one wheelchair (for each person) that is properly fitted according to a physical therapist's prescription. A prescription-fitted wheelchair can reduce pain, pressure sores, and other problems. Families tell us that they have had to advocate strongly to have these wheelchairs paid for.

Changes You Can Make at Home

There are many changes you can make at home which might make life easier for you and for the confused person. While they may help, gadgets are not the total solution. When you consider changes, ask yourself whether you can live with them comfortably. Also, remember that people who have dementing illnesses may not be able to learn even simple new things and sometimes cannot adjust to minor changes. You might purchase a new telephone that is easy for you to operate, only to find that the ill person cannot learn to use it; or you might rearrange the furniture and then realize this upsets the person more.

Some of the products we will mention here are sold for other purposes. It takes a bit of imagination to apply them to the care of people with dementia. It is important to remember that no single suggestion will work in all situations. However, most of these are helpful and low in cost. Some of these products and some medical supplies, like walkers and wheelchairs, may be available secondhand.

Products that promote safety.

These include no-skid mats (for bathtub, under rugs, and elsewhere), grab rails (for bath, hall, bedroom), a temperature control on the water heater, fire and smoke alarms, and shower seats. We discuss these elsewhere in the book. Look for them in hardware stores, electronics stores, or medical supply houses.

Long-reach lighters work like cigarette lighters but have a long nozzle. They make lighting a gas stove safer and make it unnecessary to have matches lying around. Some people with dementia will be unable to learn to operate them—which is another safety advantage. Sound-activated switches can turn on a light when you or the patient gets up at night. Timers can be put on an electric stove so that it will operate only between certain hours and will shut off automatically.

Gadgets that make life easier for older people.

These include recliners, special cushions for thin people or those with sensitive skin, all sorts of lights (to make vision easier, some clip onto a cabinet to increase light in bath or bedroom), heating pads, magnifying glasses for people with vision problems, amplifiers and lights that alert people with hearing problems to sounds such as the telephone or doorbell. Catalogs advertised in magazines that cater to older people carry many such products.

Tools that help people with arthritis.

Many devices are available to enlarge the size of handles on dinnerware, pens and pencils, and any other item that must be grasped. There are also long reaching devices for getting things off the floor or down from a high shelf. There are several devices for opening jars. These are usually advertised in magazines aimed at an older audience.

Devices that allow you to record telephone calls.

In combination with a tape recorder, a "record adapter" or "record control" will turn on the tape recorder when the telephone is picked up and turn it off when the phone is hung up. These will allow you to monitor calls the confused person is getting or making. There are also telephones that have large numbers for people with coordination or vision problems and telephones that are voice activated for people who the bathroom may help the person find his way without your having to get up).

Gadgets that provide sound for you or him.

A headset will allow you to listen to music while the person listens to television (or vice versa). A clock radio will play soothing music at bedtime and then turn itself off. Some gadgets play "white noise," soothing background sounds that help some people fall asleep. Test them before purchasing.

Gadgets for security.

You might consider some of these same low-cost devices for security. Lighting stores and electronics stores carry small switches that will turn on your house lights from outside as you approach.

Gadgets that monitor sounds.

Originally designed for parents of small babies, these systems enable you to hear what is going on while you are in another room or in the yard. You place a small transmitter in the ill person's pocket and carry a small receiver with you which picks up the sounds of whatever the person is doing.

Home videos.

Home video use is limited only by one's imagination. Some people with dementia enjoy watching films (especially from their own era); nursing homes use videos for staff training; staff members sometimes videotape each other interacting with patients, and then study the film for ways to improve care; home movies can be converted to videotape so that family members can reminisce together. You can tape yourself giving a message to the person, for example, "John, this is Mary, your wife. I have gone to work. Mrs. Lambe will be with you until I come home at six. She will fix your lunch and then you will go for a walk. I want you to stay with her. I love you. See you at six."

Should Environments Be Cluttered or Bare?

How cluttered should the environment be? People with dementia often have difficulty focusing on one thing in a cluttered room. Order, routine, and simplicity are helpful to the person who has trouble concentrating or thinking. However, some environments are so barren that they add to sensory deprivation and disorientation. Some people urge families to put away many things; others say that patients need stimulation. Some people argue that pictures on the wall or wallpaper cause hallucinations or disorientation. How do you know what is right? The answer depends on the individual person and the kind of clutter or interest the room offers.

Observe your patient: Does he tend to grab at everything in the bathroom? Does he put his hands into serving dishes or play with the condiments in the center of the table? Does he seem unable to decide what food to eat first or what piece of tableware to pick up? If you observe these things, try simplifying. Remove unnecessary things from the bathroom; leave serving dishes in the kitchen or put only one item of food on his plate at a time. An occasional person will talk to the pictures on the wall or try to pick the flowers off the wallpaper. However, most people will not do this. One woman in a nursing home was proud of the wallpaper "her husband put up." If a picture or mirror is distressing the person, remove it; but there is no reason to remove it if she just talks to it and is not distressed by it.

In general, people, animals, noise, lights, and action in a room are more distracting than the decor. If the person is restless, irritable, or having difficulty attending to you, consider reducing these distractions, but be sure that plenty of meaningful, focused, one-to-one interactions are provided in their place.

Things a person has to choose between (like several bottles of shampoo in the shower or several kinds of food on a plate) cause more problems than things that are "just there," like several cushions on the sofa. If the person stacks the pillows or carries them around, there is no need to put them away. Remove things only if they are causing a problem.

In contrast to family homes, nursing homes may not offer enough stimulation, interest, or environmental cues. Whatever the setting, observe the person's response to it. People who pace, fiddle, or repeat the same thing over and over may stop if they are helped to do an activity they can focus on.

There are many ways we can help a confused person function by changing the physical environment. We can also use the environment to keep the person away from certain areas. For example, as we age, we need more light to see; therefore, be sure that there is enough light. People with dementia are doubly handicapped because they may not think to turn on a lamp or go over to the window for light. Colors with considerable contrast are easier to see than pastels or colors similar in intensity. To the person with some visual impairment, it may be impossible to see light-colored food on a white plate. If the bathroom rug is deep blue, the person may have more success targeting the white toilet than if the rug is also white.

Just as color can be used to help people notice things, it can be used to hide things. Paint a door (frame, baseboard, and all) to match the adjoining walls if you want the person to ignore it. A curtain over a door also helps.

Hearing aids magnify background noise, and people with dementia often cannot learn to compensate for this. Eliminate background noise wherever possible, unless the person is enjoying it and focused on it.

6

Medical Problems

People with dementing illnesses can also suffer from other diseases ranging from relatively minor problems, like the flu, to serious illnesses. They may not be able to tell you they are in pain (even if they are able to speak well) or they may neglect their bodies. Cuts, bruises, or even broken bones can go unnoticed. People who sit or lie for long periods of time may develop pressure sores. Their physical health may gradually decline. *Correction of even minor physical problems can greatly help people who suffer from dementing illnesses.*

You may have experienced a feeling of mental "dullness" when you were sick. This phenomenon can be worse in people with dementing illnesses, who seem to be especially vulnerable to additional troubles. A delirium can be brought about by other conditions (flu, a minor cold, pneumonia, heart trouble, reactions to medications, and many other things) and it may look like a sudden worsening of the dementia. However, the delirium (and the symptoms) usually goes away when the condition is treated. You should check routinely for signs of illness or injury and call them to the attention of your doctor.

People who cannot express themselves well may not be able to answer yes or no when you ask them specific questions such as, “Does your head hurt?” Even people who still express themselves well may fail to recognize or may be unable to report pain.

All indications of pain or illness must be taken seriously. It is important to find a physician who is gentle, who understands the patient’s condition, and who will take care of general medical problems. Do not let a doctor dismiss a patient because she is “senile” or “old.” Insist that her infection be treated and her pains diagnosed and relieved. Because of the person’s vulnerability to delirium, it is wise to check with the doctor about even minor conditions, such as a cold.

Signals of illness include:

- abrupt worsening of behavior (such as refusal to do things she was previously willing to do),
- fever (a temperature over 100° F). When taking a temperature, use the new liquid-crystal thermometers that are placed against the skin or thermometers with a plastic-coated “probe.” These are available in drug stores. Confused people may bite a glass thermometer. Older people may not have a significant fever even when they are seriously ill. *Lack of a fever does not mean that the person is well.*

If a person begins to lose weight, this may indicate the presence of a serious disease. It is important that your doctor determine the cause of any weight loss. A person who has lost 10 percent of her weight needs to be seen by a physician as soon as possible.

Pain

Families ask if people suffer pain as part of a dementing illness. As far as is known, Alzheimer disease does not cause pain and multi-infarct dementia causes pain only very rarely. People with dementing illnesses do suffer pain from other causes, such as stomach and abdominal cramps, constipation, hidden sprains or broken bones, sitting too long in one position, flu, arthritis, pressure sores, bruises, cuts, sores or rashes resulting from poor hygiene, sore teeth or gums, clothes or shoes that rub or are too tight, and open pins.

Indications of pain include a sudden worsening of behavior, moaning or shouting, refusal to do certain things, and increased restlessness. All signals of pain must be taken seriously. If the person cannot tell you where or whether she is in pain, a physician may have to search for a specific site and cause of the pain.

Falls and Injuries

People with dementing illnesses may become clumsy; they can fall out of bed, bump into things, trip, or cut themselves. It is easy to overlook serious injuries for several reasons: (1) older people are more vulnerable to broken bones from seemingly minor injuries, (2) they may continue to use a fractured limb, (3) people with dementia may not tell you they are in pain or may forget they have fallen. A bruise may not be in evidence for several days. Even minor head injuries can cause bleeding within the skull; this must be treated promptly to avoid further brain damage.

Check the person routinely for cuts, bruises, and blisters that may be caused by accidents, falls, pacing, or uncomfortable clothing. Feet and mouth are frequently overlooked sites of pain. Changes in behavior may be your only clue to an injury.

Pressure Sores

Pressure sores (decubitus ulcers) develop when a person sits or lies down for prolonged periods. They can be caused by tight clothing, swelling, or inadequate nutrition. Older people's skin may be quite vulnerable to pressure sores. Pressure sores begin as red areas and can develop into open sores. They are more common over bony areas: heels, hips, shoulders, shoulder blades, spine, elbows, knees, buttocks, and ankles. Fragile skin can easily be torn and bruised, even in routine washing. You must watch for red spots or bruises, especially over hips, tailbone, heels, and elbows. If any reddening appears, make sure the person does not lie on that spot. Continue to turn her so other sores do not form. Contact your doctor or visiting nurse. Prompt attention can prevent a minor bruise from progressing to something more serious.

Encourage the person to change position: ask her to change the TV channel, go for a walk, set the table. Ask her to come into the kitchen to see if the cake is baking correctly or to come to the window to see something.

Pressure sores are always a risk in people who are no longer able to move or are bed- or chairbound. Develop a schedule in which you move the patient from one side to the other or change her position every two hours.

If the person does not change position enough, you can protect vulnerable areas. Medical supply firms sell "flotation" cushions that the person can sit or lie on. If the person is hospitalized, save the foam mattress from the hospital. There are air cushions, water cushions, gel pads, foam pads, and combinations of these. Select one that has soft, washable covers and shields against spills and odors. Stores also sell heel and elbow pads (these are made of a synthetic fleecelike material) that protect these bony areas. Use these *in addition* to frequent turning.

Dehydration

Even people who can walk and appear to be able to care for themselves may become dehydrated. Because we assume that they are caring for themselves we may not watch for the signs of dehydration. Watch for this problem especially in people who have vomiting, diarrhea, or diabetes, or are taking diuretics (water pills) or heart medication. Symptoms include: thirst or refusal to stipation can lead to a bowel impaction, in which the bowel becomes partially or completely blocked and the body is unable to rid itself of wastes. You should consult a doctor or nurse if you suspect this. (A person can have diarrhea accompanying a partial impaction.)

Many factors contribute to the development of constipation. One important factor is that most Americans eat a diet high in refined, easy-to-prepare foods and low in fiber-containing foods that encourage bowel activity. Often when a person has a dementing illness or her dentures fit poorly or her teeth hurt, she makes further changes in her diet that aggravate the problem of constipation. The muscles of the bowel that move wastes along are believed to be less active as we age, and when we are less physically active, our bowel is even less active. Some drugs and some diet supplements (given to people who are not eating) tend to increase constipation. Ask the pharmacist whether the drugs the person is taking can cause constipation.

If a person has a dementing illness, you cannot assume that she is able to keep track of when she last moved her bowels even if she seems to be only mildly impaired or if she tells you she is taking care of herself. If a confused person is living alone, she may have stopped eating things that take preparation skills and may be eating too much cake, cookies, and other low-fiber, highly refined foods. It may be impossible to find out how regularly her bowels move. If you suspect that she may be getting constipated, you will need to keep track for her. Do this as quietly and unobtrusively as possible, so

Ask your doctor whether you should add more fiber by giving psyllium preparations (sold under various brand names, such as Metamucil). Do not use any such product without medical supervision.

Medications

Medications are a two-edged sword. They may play a vital part in helping the patient to sleep, in controlling her agitation, or in the treatment of other conditions. At the same time, people suffering from a dementing illness (and older people in general) are susceptible to overmedication and to reactions from combinations of drugs. This includes over-the-counter drugs, unguents, creams, and suppositories. A sudden increase in agitation, a slow stooped walk, falling, drowsiness, incontinence, apathy, sleepiness, increased confusion, leaning, stiffness, or mouth or hand movements may be a side effect of medication and should be called to the doctor's attention. Physicians cannot always eliminate all the side effects of the medication and at the same time get the needed results. You and your physician must work together to achieve the best possible balance. Many people will need behavior-controlling medications to help them through some phases of their illness. However, because these can cause serious side effects, including more confusion, they must be used cautiously. Behavior-controlling drugs are best used when they are targeted to specific symptoms such as sleeplessness, hallucinations, suspicions, and severe irritability. They do not work well for controlling aimless wandering or restlessness. Whenever the physician raises the dosage of a behavior-modifying drug, ask yourself if there are any nondrug changes you can make that might also help. (See pp. 43–46, 206–7.) Perhaps if you had more time to yourself, you could tolerate more restlessness on her part. Could you respond more calmly to her behavior or divert her before problems develop? Ask whether the drug can be given so that it has its strongest effect at the person's worst time of day.

Your pharmacist is highly trained in the effects and interactions of drugs. Some pharmacists now have special training in geriatric pharmacology. Much of the responsibility for medications, however, will fall to you. Here are some ways you can help.

Be sure that all of the physicians involved in the person's care know about all of the medications she is taking. Some combinations of drugs can make the person's confusion worse. You may want to take all the patient's prescription drugs and over-the-counter medications to your pharmacist and ask him to make up a card listing all of them. Ask the pharmacist if any of these medications should be listed on the patient's identification bracelet. Whenever the physician prescribes a new drug, ask him to review all the medications to see whether any can be discontinued. This will help reduce drug interactions. Ask him to start the new drug in as low a dose as possible, and to increase the dose later if necessary. People with brain injuries like dementia often develop side effects at low or regular adult doses. Ask whether this drug stays in the body the shortest time and whether another, similar drug would have fewer side effects.

Ask what side effects to watch for. Side effects can appear even three weeks or a month after the person began taking the drug. By then, you and the doctor may not attribute new symptoms to the medication. Ask if there are any possible side effects that you should report to your doctor immediately.

Some drugs must be taken before meals, some after. Some have a cumulative effect (that is, they gradually build up their effectiveness) in the body, some don't. Older people and people with a dementing illness are especially sensitive to incorrect dosages, so it is imperative that you see that the patient gets her medications in the amounts and at the times the doctor specifies. If a medication makes the person drowsy, ask if it can be given at bedtime when it will help her sleep and not be given in the morning when she should be active.

Find out what you should do if you miss a dose or accidentally give a double dose. Your pharmacist can give you information about side effects and medication interactions.

Some patients do not understand why you want them to take a medication and may have a catastrophic reaction. Avoid arguing about it. Next time, tell the person one step at a time what is happening: "This is your pill. Dr. Brown gave it to you. Put it in your mouth. Drink some water. Good." If the person becomes upset, try again later to give her the medicine. Some people will take pills more easily if you routinely put each dose in

Store medications where the confused person cannot reach them.

This section has been written to meet the needs of families caring for someone at home. In a nursing home, there are fewer reasons for using powerful, and sometimes dangerous, behavior-modifying drugs.

Dental Problems

It is important that the person receive regular dental check-ups. Painful cavities, abscesses, and sores in her mouth may be hard for you to find, and she may not be able to tell you about them. She may refuse to let you look in her mouth. Even mildly forgetful people may neglect their teeth or dentures and develop oral infections because oral problems can increase confusion or worsen behavior. The person's teeth must be pain-free and dentures must fit well. Poor teeth or ill-fitting dentures can lead to poor nutrition, which can significantly add to the person's problems. If the person is in a nursing home, be sure that arrangements are made for continued dental care.

People with dementia tend to lose dentures and partial plates. Ask the dentist to consider alternatives that cannot be removed and lost. Because people with dementia have a shortened life expectancy, treatments that last for many years may be less important than ease of management (for example, a fixed crown versus a removable bridge).

Many people resist going to the dentist. Look for a dentist who understands these patients and who works slowly and gently. Some dentists say they rarely have problems with confused patients. If the dentist recommends a general anesthetic during dental care, carefully weigh the need for the care against the risks of the anesthetic.

Before the person enters a nursing home, ask the dentist to put the person's name on her dentures (don't do this yourself). Sometimes dentures get mixed up, and this will ensure that the facility can identify hers.

Vision Problems

Sometimes it appears that the person cannot see well or is going blind. She may bump into things, pick her feet up very high over low curbs, be unable to pick up her food on her fork, or become confused or lost in dim light. One of several things may be happening. She may have a problem with her eyes such as farsightedness or cataracts. Have her checked by an ophthalmologist. A correctable vision problem should be corrected, if possible, so that her impaired brain can get the best possible information from her eyes. If she is both not seeing well and not thinking well, she will be even less able to make sense out of her environment and will function more poorly. Do not let a physician dismiss her vision problems because she is "senile." Even if he cannot help, he should explain to you what the problem is.

Brain-impaired people may be less able to distinguish between similar color intensities. Thus, light blue, light where she is unable to manage contact lenses. If she continues to wear lenses, you must watch for irritations of the eye and be sure she cares for her lenses properly.

Hearing Problems

Failing to hear properly deprives the confused brain of information needed to make sense of the environment, and hearing loss can cause or worsen suspiciousness or withdrawal (see Chapter 8). It is important to correct any hearing loss if possible. A physician can determine the cause of the hearing loss and help you select an appropriate hearing aid. As with vision problems, it can be difficult for you to separate problems in thinking from problems in hearing. People with Alzheimer disease develop problems understanding or comprehending what is said to them (see pp. 64–68). An audiologist and your physician should be able to distinguish between this and the type of hearing loss that can be corrected.

Since the ill person cannot learn easily, she may not be able to adjust to her hearing aid. Hearing aids amplify background noises. This can be upsetting to the wearer. You may want to purchase a hearing aid with the agreement that you can return it if it does not work out.

If the person uses a hearing aid, you must be responsible for it and must check regularly to see that the batteries are working.

In addition to correcting the loss with a hearing aid, here are some things you can do:

1. Reduce background noises, such as noise from appliances, the television, or several people talking at once. It is difficult for the impaired person to distinguish between these and what she wants to hear.
2. Lower the pitch of your voice; high-frequency sounds are harder to hear.
3. Give the person clues to where sounds are coming from. It can be hard to locate and identify sounds, and this may confuse the person. Remind her, "That is the sound of the garbage truck."
4. Use several kinds of clues at one time: point, speak, and gently guide the person, for example.

Visiting the Doctor

Visits to the doctor or dentist can turn into an ordeal for you and the patient. Here are some ways to make them easier.

The forgetful person may not be able to understand where she is going or why. This, combined with the bustle of getting ready to go, may precipitate a catastrophic reaction. Look for ways to simplify things for her.

Some people do better if they know in advance that they are going to the doctor. Others do better if you avoid an argument by not bringing up the doctor visit until you are almost there. Instead of saying, "We have to get up early today. Hurry with your breakfast because today is your visit to Dr. Brown, and he has to change your medicine," just get the person up with no comment, serve her breakfast, and help her into her coat. When you are almost there, say, “We are seeing Dr. Brown today.”

Rather than get in an argument, ignore or downplay objections. If the person says, “I am not going to the doctor,” instead of saying, “You have to go to the doctor,” try changing the subject and saying something like “We will get an ice cream while we are downtown.”

Plan your trip in advance. Know where you are going, where you will park, how long it will take, and whether there are stairs or elevators. Allow enough time without rushing, but not so much time that you will be early and have a longer wait. Ask for an appointment at the person’s best time of day. Take someone with you to help while you drive.

Talk to the receptionist or nurse. She may be able to tell you whether you have a long wait. If the office is crowded and noisy, she may be able to arrange for you to wait in a quieter place. Take along some snacks, a package of instant soup (the receptionist can get you hot water), or some activity the person enjoys doing. If the receptionist knows that you have a long wait, you may be able to take a short walk if you check in frequently with her. Never leave a forgetful person alone in the waiting room. The strange place may upset her or she may wander away.

The doctor may prescribe a sedative for the patient if other methods fail. Usually, however, your being calm and matter-of-fact and giving the person simple information and reassurance are all that is needed.

be calm and reassuring with her. Write out things the nurses need to know and ask that your notes be put in the chart. Mention things that will help them cope with her, such as nicknames, family whom she might ask about, things she will need to have done for her (like filling out the menu and opening milk cartons), and how toileting is managed.

Hospitals are often short-staffed and nurses often work under pressure. They may not be able to spend as much time with the confused person as they would like. They may not be trained to work with dementia patients.

It is usually comforting for the person to have someone she knows to be with her as much as possible and to accompany her to tests and treatments. A family member can help with meals, see that the person gets enough fluid, and reassure her about what is going on. Some hospitals will let family members stay overnight with confused patients. *But,* sometimes a family member's own anxiety and nervousness upset the patient or get in the way of the staff. Calmness—or nervousness—is contagious. The confused person will be influenced by your feelings. You may want to ask someone else to spend time with the person to give you a break. If you cannot go with the person for tests, explain to the staff how important it is to comfort and reassure her.

We recommend you consider hiring a sitter to stay with the person full-time or to be with the person when you or other family members cannot. If possible, arrange a schedule for children, family, or understanding close friends to be with the person.

Familiar clothing, a familiar blanket, and large photos of family members help reassure the person. Some families write a letter to the person that nurses can use to reassure her when she is anxious. It might read like this:

> *Dear Mom: You are in the hospital because you broke your hip. You will be coming back home to our house soon. Ted or I will come to see you every night right after you have your supper. The nurses know you have trouble remembering things and they will help you. I love you. Your daughter, Ann.*

If the person must be restrained, ask that the restraint be as mild as possible. For example, mittens can be used to keep the person from pulling out tubes. This is usually less frightening than tying her hands.

Do not be alarmed if the person's confusion worsens in the hospital. In most cases the person's level of impairment will return to what it was before the hospitalization.

Seizures, Fits, or Convulsions

The majority of people with dementing illnesses do not develop seizures. Because they are so uncommon, you are not likely to have to face this problem. However, seizures can be frightening for you if you are not prepared to deal with them. Various diseases can cause seizures. Therefore, if the person does have a seizure it may not be related to the dementia.

Seizures are frightening and unpleasant to watch, but they are usually not life-threatening nor are they indications of danger to others or of insanity. They can become less frightening for you as you learn how to respond to them. Find a nurse or experienced family member with whom you can discuss your distress and who can knowledgeably reassure you.

Jerking Movements (Myoclonus)

Patients with Alzheimer disease occasionally develop quick, single jerking movements of their arms, legs, or body. These are called myoclonic jerks. They are not seizures; seizures are repeated movements of the same muscles, while myoclonic jerks are single thrusts of an arm or of the head.

Myoclonic jerks are not a cause for alarm. They do not progress to seizures. The only danger they may present is inadvertent hitting of something and possible accidental injury. At present there are no good treatments for the myoclonus associated with Alzheimer disease. Drugs can be tried, but these usually have significant side effects and offer little improvement.

The Death of the Impaired Person

Whenever you have the responsibility for an ill or elderly person, you face the possibility of that person's death. You may have questions you are reluctant to bring

One daughter said, "I don't know what I would do. What if one of the children found her?"

Perhaps you have heard of someone who found a husband or wife dead, and you wonder how you would handle this. Most families find it reassuring to plan in advance what they will do first, second, third.

- When the person dies, you can dial 911 or the local emergency number. Emergency personnel or paramedics usually will arrive promptly. Paramedics may routinely begin resuscitation efforts. If you do not want this to happen, you may not want to call them right away.
- You can select a funeral director or mortician in advance. When death occurs, you have only to call him.
- You might call your clergyperson or physician. Discuss in advance whether they can respond to an emergency call late at night.
- Some people want a little time to say goodbye; others do not. If you do, the thing to do first might be to sit a little while with the person or cry, and then call someone.

Some families value the peacefulness and privacy that death at home allows, but families often worry about what dying looks like and about what to do. If you want the person to be able to die at home, a home care nurse can show you what care is needed and give you guidance on how to conserve your own energy. Also, there are books available on this.

from the way you and your family member would have wished. Most of these problems revolve around how much and what kinds of life-sustaining interventions should be used. You must have a durable power of attorney for health care (see p. 430). This helps, but it does not guarantee that your wishes will be honored.

When Should Treatment End?

When a person has a chronic, terminal illness, the person's family faces the question of whether it would be better to allow life to end or to prolong suffering. This is a difficult question, one that doctors, judges, and clergy struggle with, as do seriously ill people and their families. Each of us must make the decision based on our own background, beliefs, and experiences.

There are no "better" or "worse" choices, as long as the person receives gentle care and is kept comfortable. We describe some of the options, to help you select the kind of care that will be right for you and your family member. Some families want to be sure that everything possible has been done; others have felt hassled or upset by medical interventions they did not want.

Occasionally a physician, a social worker, or a nursing home has strong opinions about life support and resuscitation and will follow those opinions regardless of your wishes. Some act out of fear of lawsuits and some continue a practice because it is "the way we have always done it." Ask your physician and the nursing home what steps they will take. Will they routinely transfer the patient to a hospital? Will they insert tubes or give life-sustaining drugs? What procedures, if any, do they consider "routine" and carry out without your explicit consent? Will they discourage your presence in the patient's room? If an ambulance is summoned, will the paramedics automatically try to resuscitate the person? Will the hospital automatically try resuscitation? Are they open and responsive to your questions, or do they avoid your questions or dogmatically state positions?

You might ask a clergyperson or a friend to help you make the necessary phone calls to ask these questions. If there is a local hospice organization, they may be able to tell you what the usual practices in your community are.

If you are not comfortable with the procedures in your hospital or nursing home, write out instructions for the care you want the person to receive. Request that these instructions be placed in the person's chart at the nursing home and hospital. Make one copy for the person's doctor and one copy for the nursing home to send with the patient to the hospital, and sign each copy. Ask the doctor and the nursing home directly if they will honor these instructions. Go with the person to the hospital if possible.

Occasionally, a family will feel so strongly opposed to the care available in a hospital or nursing home that they transfer the person to another nursing home or take her home to die.

What Kind of Care Can Be Given at the End of Life?

When a person has a chronic, terminal illness, the person's family must often make decisions about when to allow treatment and when to accept the declining course of the disease. There are few right or wrong answers, and there are many things that are not understood about the last stages of life. The questions that families often face include whether to use tubes to feed a person who has stopped eating and whether to treat concurrent illnesses with antibiotics or surgery. (You may have faced similar issues earlier in the illness, such as whether to restrain an ambulatory person who might fall.)

As you make these decisions, be cautious about accepting dogmatic opinions from "experts." Like the rest of us, professionals can easily confuse personal values with fact in this emotion-laden area.

When you consider questions about life-support interventions for terminally ill people, such as feeding tubes, oxygen, treating illnesses such as pneumonia with antibiotics, or surgery for acute problems, recognize that many things are not known about these difficult issues, and we sometimes understand even less about the effects of life-supporting interventions on patients with dementia. It is difficult to know whether an abrupt decline is part of the dementing illness or whether, if treated, the person might continue comfortably for some time. It is just as difficult to determine when a person with dementia is "terminally ill" or to predict when a person with late-stage dementia will die. These uncertainties add to the family's burden. Neither you nor the doctors may be able to say whether an intervention will help or will be distressing to a patient close to death.

ably need to find a way to stop it, even if you must use a medication that has side effects. If it is not dangerous you should strongly consider letting it continue. This may be easier to tolerate if you get away from the person once in a while.

The Six *R*'s of Behavior Management

Some families tell us that the ill person does some things that create serious problems. Do not assume that you will face all or even most of the problems listed in this chapter. But if you do face problems, one of the first places to seek help is the Alzheimer's Association support group in your area. It was from families that we learned many of the things we suggest in this book. Most Alzheimer's Association chapters publish newsletters. You can subscribe to several. They contain excellent ideas.

One husband does not call these "problems." He calls each difficulty a "challenge." This helps him approach it with a positive outlook. You will find that you solve problems better when you are not exhausted; find some time for yourself. Behaviors have different causes in different people and different solutions will work in different households. Some families have found these six *R*'s helpful in thinking through a problem.

Restrict. The first thing we often try is to get the person to stop whatever he is doing. This is especially important when the person might harm himself or someone else. But trying to make the person stop may upset him more.

Reassess. Ask yourself: Might a physical illness or drug reaction be causing the problem? Might the person be having difficulty seeing or hearing? Is something upsetting him? Could the annoying person or object be removed? Might a different approach upset the person less?

Reconsider. Ask yourself how things must seem from the patient's point of view. People with dementia are often unaware of the extent of their impairment. When you try to bathe or dress someone who does not understand that he needs help, he may get upset. The person's anxiety is understandable when things are going on that he can't make sense of.

Rechannel. Look for a way that the behavior can continue in a safe and nondestructive way. The behavior may be important to the person in some way that we cannot understand. One man who had been a mechanic continued to take things apart around the house, but he could not get them back together. His wife had an old automobile carburetor steam cleaned and gave it to him. He was able to enjoy taking it apart for several months, and he left the household appliances alone.

Reassure. When a person has been upset, fearful, or angry, take time to reassure him that things are all right and that you still care for him. While the person may not remember the reassurance, he may retain the feeling of having been reassured and cared for. Putting your arm around the person or hugging him is a way of reassuring him.

Take time to reassure yourself as well. You are doing until a crisis occurs. Families are often shocked and distressed by the extent of the problem when they finally learn of it.

You may wonder what the person is still able to do for himself and what needs to be done for him. If he is still employed, has responsibility for his own money, or is driving, he may not realize or may be unwilling to admit that he can no longer manage these tasks as well as he once could. Some people recognize that their memory is slipping. Different people cope with this in different ways. While some people don't want to admit that anything is wrong, others find relief and comfort in talking about what is happening to them. Listen to their thoughts, feelings, and fears. This can be comforting and can give you a chance to correct misconceptions.

Others may successfully conceal their impairment by keeping lists. They may use conversational devices, such as saying "Of course I know that" to cover their forgetfulness. Some people get angry and blame others when they forget things. Some people stop participating in activities that they have always enjoyed. One woman said, "I have a dementia. My memory is terrible." But when her family found out that she had sent a bad check to the IRS, she insisted that she could not make mistakes like that. Her family could not understand how she could know about her forgetfulness and "lie" about the check. Families often ask why a person forgets one thing and remembers another. It can be difficult to understand the quirks of memory, but it is likely that she was honestly trying as hard as she could. Memory is complex, and contradictions like this are common. The ill person cannot help herself.

A frequent characteristic of the dementing illnesses is that personality and social skills appear nearly intact while memory and the ability to learn are being lost. This condition enables a person to conceal his illness for a long time. One can talk with such a person about routine matters and fail to recognize that his memory or thinking is impaired. Psychological testing or an occupational therapy evaluation can be helpful in such situations because the evaluation will give you a realistic measure of how much you can expect from the impaired individual and what things the person can still do. Because dementing illnesses can be so deceiving, even to people close to the person, the assessment these professionals can give is most important to you in helping you and your family plan realistically. These professionals may also talk over their findings with the impaired person and show him ways he can remain as independent as possible.

Wandering

Wandering is a common and frequently serious problem that deserves thoughtful consideration. Wandering behavior can make it difficult to manage a person at home. It can make it impossible for day care centers or nursing homes to care for a person. The impaired person is endangered when he wanders into busy streets or into strange neighborhoods. When a confused per-continuous pacing and wandering can cause the person's feet to swell.

Some people wander at night. This can be dangerous for the impaired person and exhausting for you.

Many of us can sympathize with the confused person's experience of becoming disoriented. We may have lost our car at a parking lot or gotten "turned around" in a strange place. For a few minutes we feel unnerved until we get hold of ourselves and work out a logical way to find out where we are. The person with a memory impairment is more likely to panic, is less able to "get hold of himself," and may feel that he must keep his disorientation a secret.

When wandering is made worse by a move to a new home or by some other change in the environment, it may be because it is difficult for a confused, memory-impaired person to learn his way around in a new setting. He may not be able to understand that he has moved and may be determined to go "home." The stress of such a change may impair his remaining abilities, which makes it harder for him to learn his way around.

Aimless wandering may be the person's way of saying, "I *feel* lost. I am searching for the things I feel I have lost." Sometimes wandering behavior is the person's way of trying to communicate feelings.

> *Mr. Griffith was a vigorous man of 60 who kept leaving the day care center. The police would pick him up several miles away hiking down the highway. Mr. Griffith always explained that he was going to Florida.*

Florida represented home, friends, security, and family to Mr. Griffith.

Wandering may be the person's way of expressing restlessness, boredom, or the need for exercise. It may help to fill the need of an active person to be "doing something." It may signal a need to use the toilet.

A constant or agitated pacing or a determination to get away may be difficult to manage. Sometimes this is a catastrophic reaction. Something may be upsetting the person. He may not be able to make sense out of his surroundings or may be misinterpreting what he sees or hears. Sometimes this agitated wandering appears to be a direct result of the brain damage. It is hard to know exactly what is happening to the brain, but we do know that brain function can be seriously and extensively disrupted. Remind yourself that this is not a behavior that the person can control.

Night wandering can also have various causes, from simple disorientation to a seemingly incomprehensible part of the brain injury (see p. 222).

The Management of Wandering

The management of wandering behavior depends on the cause of the wandering. If the person is getting lost and if you are sure he can still read and follow instructions, a pocket card may help him. Write *simple* instructions on a card he can carry in his pocket and refer to if he is lost. You might put at the top of the card the written reminder "stay calm and don't walk away." You might write on the card "call home" and put the telephone number, or write "ask a clerk to show you to the men's wear department and stay there. I will come for you." You may need different cards for different trips. This will make it possible for a mildly confused person to help himself.

It is essential that you get the person a bracelet with his name and your phone number on it, and the statement "memory impaired." A bracelet that is securely fastened (so the patient cannot take it off) and too small to slip off is probably safer than a necklace. This information will help anyone who finds the person if he gets lost. You can have an inexpensive bracelet engraved in a store that engraves mugs, key rings, etc. Have a "memory impaired" bracelet made *now* if there is any possibility that the person will wander or get lost. This is so important that some clinics require that their patients have such identification. A lost, confused person will be afraid and upset, and this can cause him to resist help. He may be ignored or assumed to be crazy by the people around him. Under stress he may function more poorly than he usually does.

You can purchase bracelets with medical information on them from pharmacies. You may want the person to wear one, especially if he has a heart condition or some other serious health problem. You can order a Medic Alert bracelet reading "*Alzheimer/memory impaired.*" These bracelets also have a telephone number that can be called for further information about the person. Medic Alert maintains a trust fund to help low-income famialone to adjust or asking the family not to visit at first may add to the person's panic.

When a confused person finds himself in a new place, he may feel that he is lost, that you cannot find him, or that he is not supposed to be where he is. Reassure the disoriented person often about where he is and why he is there. "You have come to live with me, Father. Here is your room with your things in it," or "You are at the day care center. You will go home at 3:00."

When we give this advice, families sometimes tell us, "It doesn't work!" It doesn't work in the sense that the person may continue to insist that he doesn't live there and keep trying to wander away. This is because he is memory impaired and does not remember what you told him. He still needs to be gently and frequently reassured about his whereabouts. It takes time and patience to get him to accept the move and gradually come to feel secure. He also needs this frequent reassurance that you know where he is. A gentle reassurance and your understanding of his confusion help reduce his fear and the number of catastrophic reactions he has. Our experience with people who are hospitalized for their dementia is that, even with difficult people, frequent gentle reassurance about where they are sometimes helps them become comfortable (and easier to manage). However, this may take several weeks.

A move often upsets a person with a dementing illness, causing him to wander more or making his behavior worse for a period of time. It is helpful to know that this is usually a temporary crisis.

to forget that he may have lost the judgment that would keep him from stepping over the side of a swimming pool or in front of a car.

Other people are also an environmental hazard to the confused person who wanders. In addition to those who don't understand are the cruel and vicious who seek out older and frail persons to harass, torment, or rob them. Unfortunately, there seem to be enough such people, even in the "nicest" neighborhoods, for you to recognize this hazard and protect the confused person from them.

There are physical devices to restrain a person in a chair or bed. The decision to use a restraint should be made jointly between you and the health care professional who knows the person best, and these should be used *only after all other possibilities have been tried.* (We are addressing here the use of restraints at home. The use of restraints in a nursing home involves other issues and will be discussed in Chapter 16.) The most familiar restraint is the Posey restraint. A patient can turn, shift position, or roll to the side in a Posey. Poseys can be rented from a medical supply house. It is very important that a Posey be properly applied; a nurse should show you how to use it.

A Gerichair is like a recliner with a tray on it that prevents the person from getting up. It will elevate a person's feet. A person can eat, sleep, or watch television in a Gerichair. These can also be rented or purchased.

Nurses occasionally find that a restraint, especially at night, provides a confused person with a firm reassurance that he must stay where he is. However, restraints further agitate other people.

Either a chair or a Posey restraint may help to keep a person still and safe long enough for you to take a bath or fix supper. Using restraints or a Gerichair gives the person's feet a chance to recover.

Very agitated people can hurt themselves fighting against the bed while in restraints or may tip over a chair in which they are restrained. People cannot be left unsupervised for long periods in either Poseys or Gerichairs. *Never* leave a person alone in the house while he is restrained, because of the possibility of a fire. You should be able to release any restraining device quickly in case of emergency.

People with dementing illnesses can be difficult to manage, and wandering can be a serious problem. The responses vary with each person. One confused woman was only looking for the bathroom when she wandered away. A sign solved the problem. Another man got a screwdriver and took the door off its hinges when he found that he could not operate the lock.

You may reach a point when the wandering behavior is more than you can manage or when a person cannot be kept safely in a home setting. If this time comes, you will have done all you can and will need to plan realistically for institutional care for the person. Many places will not accept a patient who is agitated, combative, or a wanderer. See Chapter 16 for a discussion of placement issues.

plan a regular activity program—a long walk, for example—in the late afternoon. This may make the person tired enough to sleep better at night. A car ride makes some people sleepy. Day care centers are one of the best ways to keep a person active during the day.

See that the person has used the bathroom before going to sleep.

Older people may not see as well in the dark and this may add to their confusion. As our eyes age, it becomes more difficult to distinguish dim shapes in poor light. The confused person may misinterpret what he sees, so he thinks he sees people or thinks he is in some other place. This can cause catastrophic reactions. Leave a night light on in the bedroom and bathroom. Night lights in other rooms may also help the person orient himself at night. Reflector tape around the bathroom door may help. Try renting a commode that can sit right beside the bed.

Many of us have had the experience of waking from a sound sleep and momentarily not knowing where we are. This may be magnified for the confused person. Your quiet reassurance may be all that is needed.

Be sure the sleeping arrangements are comfortable: the room is neither too warm nor too cool, and the bedding is comfortable. Quilts are less likely to tangle than blankets and sheets. Bedrails help some people remember they are in bed. Other people get upset and try to climb over them, which is dangerous. You may want to rent bedrails and see if they help. Bedrails are available for most beds.

A whole day of trying to cope with confusing perceptions of the environment may be tiring, so a person's tolerance for stress is lower at the end of the day. You are also more tired and may subtly communicate your fatigue to the confused person, causing catastrophic reactions.

Plan the person's day so that fewer things are expected of him in the evening. A bath (which is often difficult), for example, might be scheduled for morning or midafternoon if this works better.

Sometimes there are more things going on at once in the house in the evening. This may overstimulate the already confused and tired person. For example, are you turning on the TV? Are more people in the house in the evening? Are you busy fixing supper? Are children coming in? Being tired may make it harder for him to understand what is going on and may cause him to have catastrophic reactions.

If possible, try to reduce the number of things going on around the person at his worst times of day or try to confine the family activity to an area away from the impaired person. It is also important to try to plan your day so that you are reasonably rested and not too pressed for time at the times of day that you observe are worst for the confused person. For example, if he gets most upset while you are getting supper, try to plan meals that are quick and easy, that are left over from lunch, or that you can prepare in advance. Eat the larger meal at midday.

Edna Johnson's father-in-law was at his worst just at the time her sons came in from school and her husband

> *would shout, "Mother, you have already folded that towel five times."*
>
> *Mrs. Andrews had trouble with baths. She would wash just one side of her face. "Wash the other side," her daughter would say, but she kept on washing the same spot.*
>
> *Mr. Barnes paces around and around the kitchen in the same pattern, like a bear in a cage.*

It seems as if the damaged mind has a tendency to "get stuck" on one activity and has difficulty "shifting gears" to a new activity. When this happens, gently suggest that the person do a specific new task, but try not to pressure him or sound upset, because you can easily precipitate a catastrophic reaction.

In the case of Mrs. Weber's mother-in-law, ignoring the problem worked well. As Mr. Weber came to accept his mother's illness, the behavior ceased to bother him.

Mrs. Andrews's daughter found out that gently patting her mother's cheek where she wanted her to wash next would get her out of the repetitious pattern. In this example, a stroke had lessened her mother's awareness of one side of her body. Touch is a very good way to get a message to the brain when words fail. Touch the arm you want a person to put in a sleeve; touch the place you want the person to wash next; touch a hand with a spoon to get a person to pick it up.

Mr. Barnes's wife found ways to distract him from pacing by giving him something to do. "Here, Joe, hold this," she would say, and hand him a spoon. "Now hold this," and she would take the spoon and give him a potholder. "Helping" would enable him to stop pacing. It kept him busy and perhaps also made him feel needed.

Distractibility

People with dementia may "get stuck" or be too easily distracted. The person may look elsewhere or grab at other things while you are trying to get his clothes on; he may eat the food on someone else's plate; he may walk off while you are talking to him. Part of our brain filters out things we do not want to pay attention to—this is how you "tune out" unimportant noises, for example. When the dementing illness damages this ability, the person may be equally attracted to everything that is happening, no matter how unimportant it may be.

If you can identify the things that distract him—people, animals, and sudden noises are common distractions—and reduce them, he may be better able to focus on one activity, such as dressing. Put his plate a little farther from the other plates; have fewer visitors at once; visit in a calm, quiet area. If he is distracted by the television or radio, turn it off. Plan eating and other activities in an area where other people are not moving about and talking.

Clinging or Persistently Following You Around

Families tell us that forgetful people sometimes follow them from room to room, becoming fretful if the caregiver disappears into the bathroom or basement, or that they constantly interrupt whenever the caregiver tries to rest or get a job done. This can be distressing. Few things can irritate more than being followed around all the time.

This behavior can be understood when we consider how strange the world must seem to a person who constantly forgets. The trusted caregiver becomes the only security in a world of confusion. When one cannot depend on himself to remember the necessary things in life, one form of security is to stick close to someone who does know.

The memory-impaired person cannot remember that if you go in the bathroom, you will be right back out. To his mind, with his confused sense of time, it may seem as if you have vanished. Childproof door knobs on the bathroom door may help give you a few minutes of privacy. Sometimes, setting a timer and saying, "I will be back when the timer goes off" will help. One husband got himself a set of headphones so he could listen to music while his wife continued to talk. (Then he got her a set because he discovered that she enjoyed the music.)

It is most important that you try not to let annoying behaviors such as these wear you down. You must find other people who will help with the person so you can get away and do the things that relax you—go visiting or shopping, take a nap, or enjoy an uninterrupted bath.

Using medication to stop behaviors like this is often unsuccessful and the side effects can be disabling. Unless the behavior places the person with dementia or someone else in danger, medication should be used only after other attempted solutions have failed.

Find simple tasks that the person can do, even if they are things that you could do better or things that are repetitious. Winding a ball of yarn, dusting, or stacking magazines may make a person feel useful and will keep him occupied while you do your work.

Mrs. Hunter's mother-in-law, who has a dementing illness, followed Mrs. Hunter around the house never letting her out of her sight and always criticizing. Mrs. Hunter hit upon the idea of having her mother-in-law fold the wash. Since Mrs. Hunter has a large family, she has a lot of wash. The older woman folds, unfolds, and refolds (not very neatly) and feels like a useful part of the household.

Is it being unkind to give a person made-up tasks to keep her occupied? Mrs. Hunter doesn't think so. The confused woman needs to feel that she is contributing to the family and she needs to be active.

Complaints and Insults

Sometimes people with dementing illnesses repeatedly complain, despite your kindest efforts. The confused person may say things like "You are cruel to me," "I want to go home," "You stole my things," or "I don't like you." When you are doing all that you can to help, you may feel hurt or angry when the confused person says such things. When he looks and sounds well or when

Of course, you may get angry sometimes, especially when you have heard the same unfair complaint over and over. To do so is human. Probably the confused person will quickly forget the incident.

Sometimes the impaired person loses the ability to be tactful. He may say, "I don't like John," and you may know he never did like this person. This can be upsetting. It helps for those involved to understand that the person is unable to be tactful, that while he may be being honest he is not being purposefully unkind.

Perhaps you can cope with these remarks, but what about other people? Sometimes people with dementing illnesses make inappropriate or insulting remarks to other people. These can range from naïve directness, such as telling the pastor's wife she has a run in her stocking, to insults, such as shouting at the neighbor who brings dinner, "Get out of my house, you're trying to poison us."

Confused people may tell casual friends or strangers stories such as "My daughter keeps me locked in my room." When you take a confused person to visit, he may put on his coat and say, "Let's go home. This place stinks."

Each brain-impaired person is different. Some will retain their social skills. In others a tendency toward bluntness may emerge as open rudeness. Some are fearful and suspicious, leading them to make accusations. Catastrophic reactions account for some of this behavior. The confused person often misjudges who the person is that he is speaking to or he misjudges the situation.

place, perhaps due to a catastrophic reaction, remove him gently. It may be best to say nothing. While this can be embarrassing, you do not necessarily owe strangers any explanation.

Distraction is a good way to get a confused person out of what might become an embarrassing situation. For example, if he is asking personal questions, change the subject. When a person is telling others that you are keeping him prisoner or not feeding him, try distracting him. Avoid denying directly, as this can turn into an argument with the confused person. If these are people you know, you may want to explain to them later. If they are strangers, ask yourself whether or not it really matters what strangers think.

Sometimes there is a gossip or insensitive person in a community who may build upon the inappropriate remarks of a person with a dementing illness. It is important that you not be upset by such gossip. Usually other people have an accurate estimate of the truth of such gossip.

Taking Things

Confused people may pick up things in stores and not pay for them or may accuse the sales clerk of stealing their money. One wife reported that her husband was stealing and butchering the neighbors' chickens. He did not realize that they were not his own and was proud to be helping with dinner.

If a person is taking things in stores, he may be doing so because he has forgotten to pay for them or because he does not realize that he is in a store. Several families have found that giving the person things to hold or asking him to push the shopping cart, so that his hands are occupied, will stop the problem. Before you leave the store, check to see if he has anything in his pockets. You may want to dress him in something that has no pockets the next time you go shopping.

If the person continues to do this, you might ask your doctor for a brief letter explaining that the person has Alzheimer disease and sometimes forgets that he has put things in his pockets. If the person does take something and you discover it later or if he is caught by store personnel, you can show them this letter.

The wife of the man who took chickens had her clergyperson explain things to the neighbors and then arranged to replace any chickens that turned up on her dinner table.

Forgetting Telephone Calls

Forgetful people who can still talk clearly often continue to answer the telephone or to make calls. However, they may not remember to write down telephone messages. This can upset friends, confuse people, and cause you considerable inconvenience and embarrassment.

Inexpensive telephone call recorders (sold at electronics stores) will record all telephone conversations. (See pp. 163–64.) Attaching the device to an extension phone the impaired person does not often use may be

Alzheimer disease. She was wearing her daughter out with demands: "Get me a cigarette," "Fix me some coffee." The daughter could not tell her mother to do these things herself because she started fires.

Sometimes people with dementing illnesses can be demanding and appear to be self-centered. This is especially hard to accept when the person does not appear to be significantly impaired. If you feel that this is happening, try to step back and objectively evaluate the situation. Is this behavior deliberate or is it a symptom of the disease? The two can look very much alike, especially if the person had a way of making people feel manipulated before he developed a dementing brain disease. However, what is often happening with an impaired person is *not* something he can control. Manipulative behavior really requires the ability to plan, which the person with a dementing illness is losing. What you experience are old styles of relating to others which are no longer really deliberate. An evaluation can be helpful because it tells you objectively how much of such behavior is something the person can remember to do or not to do.

Some demanding behavior reflects the impaired person's feelings of loneliness, fright, or loss. For example, when a person has lost his ability to comprehend the passage of time and to remember things, being left alone for a short time can make him feel that he has been abandoned and he may accuse you of deserting him. Realizing that this behavior reflects such feelings can help you not to feel so angry and can help you respond to the *real* problem (for example, that he feels abandoned) instead of responding to what seems to you like selfishness or manipulation.

Sometimes you can devise ways for the confused person to continue to feel a sense of control over his life and mastery over his circumstances which are not so demanding of you.

> *Mr. Cooper's daughter was able to find an "apartment" for her father in a sheltered housing building where meals, social services, and housekeeping were provided. This reduced the number of emergencies but enabled Mr. Cooper to continue to feel independent.*

> *A medical evaluation confirmed for Mrs. Dietz's daughter that her mother could not remember her previous requests for a cigarette for even five minutes. With the help of the physician, she was able to deal with her mother's addiction to cigarettes and coffee.*

Families often ask whether they should "spoil" the person by meeting his demands or whether they should try to "teach" him to behave differently. The best course may be neither of these. Since he cannot control his behavior, you are not "spoiling" him, but it may be impossible for you to meet endless demands. And since the impaired person has limited ability, if any, to learn, you cannot teach him, and scolding may precipitate catastrophic reactions.

If the person demands that you do things you think he can do, be sure that he really can do these things. He may be overwhelmed by the tasks. Simplifying them may make him willing to do them. Sometimes, being very specific and direct with the person helps. Saying "I am coming to see you Wednesday" is more helpful than getting into an argument over why you don't visit more often. Say, "I will get you a cigarette when the timer goes off. Do not ask me for one until the timer goes off." Ignore further demands until then.

You may have to set limits on what you realistically can do. But before you set limits, you need to know the extent of the impaired person's disability and you need to know what other resources you can mobilize to replace what you cannot do. You may need to enlist the help of an outside person—a nurse or social worker who understands the disease—to help you work out a plan that provides good care for the sick person without leaving you exhausted or trapped. (See Chapter 10.)

When demands make you feel angry and frustrated, try to find an outlet for your anger which does not involve the impaired person. Your anger can precipitate catastrophic reactions, which may make him even more recalcitrant.

Stubbornness and Uncooperativeness

"Whatever I want him to do, he won't do it," said one daughter-in-law. Said another, "Whenever it's time to dress Dad, he says he has already changed his clothes. He won't go to the doctor, and whatever I serve for dinner he won't eat."

When the Sick Person Insults the Sitter

When a family is able to arrange for someone to stay with the impaired person, he may fire the sitter or housekeeper. He may get angry or suspicious, insult her, not let her in, or accuse her of stealing. This can make it seem impossible for you to get out of the house, or mean that the impaired person can no longer live in his own home. Often you can find ways to solve the problem.

As with many other problems, this situation may arise out of the impaired person's inability to make sense out of his surroundings or to remember explanations. All he may recognize is that a stranger is in the house. Sometimes the presence of a "babysitter" means a further loss of his independence, which he may realize and react to.

Make sure the sitter knows that it is you, not the confused person, who has the authority to hire and fire. This means that you must trust the sitter absolutely. If possible, find a sitter the person already knows or introduce the person to the sitter gradually. The first time or two, have the sitter come while you remain at home. Eventually the person may become accustomed to the idea that the sitter belongs there. This will also give you an opportunity to teach the sitter how you manage certain situations and to evaluate how well the sitter relates to the confused person.

Be sure the sitter understands the nature of a dementing illness and knows how behaviors such as catastrophic reactions are handled. (Hiring a sitter is discussed in Chapter 10.) Try to find sitters who are adept at engaging the person's trust and who are clever about managing the person without triggering a catastrophic reaction. Just as there are some people who are naturally good with children and others who are not, there are some people who are intuitively adept with confused people. However, they are often hard to find. If the person will not accept one sitter, try another. Ask yourself if your reluctance to use a sitter is part of the problem.

Be sure the sitter can reach you, another family member, or the doctor in the event of a problem.

Often the confused person will adjust to the presence of a sitter if both you and the sitter can weather the initial stormy period.

Introduce the sitter as a friend "who wants to visit with you" and not as a sitter. If the person is suspicious of the sitter, his doctor may be able to reduce the suspiciousness with medication or can write a signed note to the impaired person reminding him to stay with the visitor.

In all events, consider your own health. Even if a sitter does upset the person with dementia, it is essential that you get out from time to time if you are to continue to be able to give care. (See Chapter 10.)

Using Medication to Manage Behavior

This chapter has listed many ways to control problem behaviors. You may hear different things about using medications to control problem behaviors. Some people depression is neither natural nor necessary. Fortunately, this kind of depression responds well to treatment, so the person can feel better whether or not she also has an irreversible dementing illness.

> *Mrs. Sanchez was irritable and often whined about her health. She said she "just wanted to die," and she was losing weight. It seemed that there was never a time when she cheered up. Because she had a serious memory problem, the doctor said she had Alzheimer disease. A psychiatrist determined that she was also depressed. When that was treated with medication, her mood—and her memory—improved. She gained weight. From time to time the doctor had to change her medication to manage her depression. She gradually became more forgetful and ultimately it was clear that she did have Alzheimer disease as well as depression. Treating her depression enabled her to live as full a life as possible and made caregiving much more pleasant for her family.*

Researchers are trying to understand why we get depressed, but the total answer is not yet in. We obviously feel sad or low when something bad happens to us. But this does not completely explain the phenomenon of depression. For example, researchers are linking some depressions to changes in the brain. It is important that a physician assess the nature of each depression and determine whether it is a response to a situation or a deeper despondency, and then treat the depression appropriately. Indications of a deeper despondency include weight loss, a change in sleep patterns, feelings that one has done something bad and deserves to be punished, or a preoccupation with health problems.

It may be impossible for a depressed person to "snap out of it" by herself. Telling her to do so may only increase her feelings of frustration and discouragement. For some people, trying to cheer them makes them feel that they are not understood.

You can encourage a depressed or discouraged person to continue to be around other people. If she has memory problems, be sure that the activities she tries are things she can still do successfully and are of some use, so that she can feel good about herself for doing them. Help her avoid tasks that are too complicated. Even small failures can make her feel more discouraged about herself. Have her set the table for you. If she doesn't have that much energy, have her set just one place. If that task is too complicated, have her set out just the plates.

If groups of people upset her, encourage her not to withdraw completely but instead to talk with one familiar person at a time. Ask one friend to visit. Urge the friend to talk to the depressed person, to meet her eyes and involve her.

When a person is feeling discouraged, it may be helpful for her to talk over her concerns with a knowledgeable counselor, clergyperson, physician, psychiatrist, or psychologist. This is possible only when she can still communicate well and remember some things. This person must understand dementia and adjust the treatment accordingly.

Complaints about Health

If the person often complains about health problems, it is important to take these complaints seriously and have a doctor determine whether there is a physical basis for the complaints. (Remember that chronic complainers can get sick. It is easy to overlook real illnesses when a person often focuses on things with no physical basis.) When you and the doctor are sure that there is no physical illness present, he can treat the depression that is the underlying cause of the problem. Never let a physician dismiss a person as "just a hypochondriac." People who focus on health problems are really unhappy and need appropriate care.

Suicide

When a person is depressed, demoralized, or discouraged, there is always a possibility that she will harm herself. While it may be difficult for a person with Alzheimer disease to plan a suicide, you do need to be alert to the possibility that she will injure herself. If the person has access to a knife, a gun, power tools, solvents, medications, or car keys, she may use them to kill or maim herself. Statements about suicide should always be taken seriously. Notify your physician.

Alcohol or Drug Abuse

Depressed people may use alcohol, tranquilizers, or other drugs to try to blot out the feelings of sadness. This can compound the problem. In a person with a dementing illness it can also further reduce her ability to function. You need to be especially alert to this possibility in a person who is living alone or who has used medications or alcohol in the past.

People who are heavy drinkers and who also develop a dementing illness can be difficult for their families to manage. The person may be more sensitive to small amounts of alcohol than a well person, so even one drink or one beer can significantly reduce her ability to function. These people often do not eat properly, causing nutritional problems that further impair them. They may also act nasty, stubborn, or hostile.

It helps to recognize that the brain impairment may make it impossible for the person to control her drinking or her other behaviors, and that you may have to provide this control for her. This will include taking steps to end her supply of alcohol. Do so quietly but firmly. Try not to feel that her unpleasant behavior is aimed at you personally. Avoid saying things that put the blame for the situation on anybody. Do what needs to be done, but try to find ways for the person to retain her self-esteem and dignity. There should be no liquor in the house unless it is locked away. One family was able to arrange with the local liquor store to stop selling to the patient.

You may need help from a counselor or physician to manage the behavior of a person with a memory problem who also abuses alcohol or drugs.

Apathy and Listlessness

Sometimes people with brain diseases become apathetic and listless. They just sit and don't want to do anything. Such people may be easier to care for than people who are upset, but it is important not to overlook them.

As with depression, we are not sure why some people with dementia become apathetic and listless. It is probably due to the effects of the disease on specific areas of the brain. It is important to keep people with dementia as active as possible. People need to move around and to use their minds and bodies as much as possible.

Withdrawing may be a person's way of coping when things get too complicated; if you insist on her participation she may have a catastrophic reaction. Try to reinvolve her at a level at which she can feel comfortable, can succeed, and can feel useful. Ask her to do a simple task, take her for a walk and point out interesting things, play some music, or go for a car ride.

It often seems that getting the body moving helps cheer a person up. Once a person gets started doing something, she may begin to feel less apathetic. Perhaps she can peel only one potato today. Tomorrow she may feel like doing two. Perhaps she can spade the garden. Even if she spades for only a few minutes, it may have probably the result of misunderstanding what is happening. For example,

> *Mr. Jones adored his small grandson. One day the grandchild tripped and fell and began to cry. Mr. Jones grabbed a knife, began to yell, and would allow no one near the child.*
>
> *Mr. Jones had misinterpreted the cause of the child's crying and overreacted. He thought someone was attacking the child. Fortunately, the child's mother understood what was happening. "I will help you protect the baby," she said to Mr. Jones. She gave Mr. Jones a job to do: "Here, you hold the door for me." Then she was able to pick up and quiet the child.*

Forgetfulness is an advantage, since the person may quickly forget the episode. Often you can distract a person who is behaving this way by suggesting something you know she likes.

> *Mrs. Williams's mother-in-law often got angry and nasty when Mrs. Williams tried to prepare supper. Mr. Williams began distracting his mother by spending that time each day visiting with just her in another part of the house.*

Once in a while a person experiencing a catastrophic reaction will hit someone who is trying to help her. Respond to this as you would to a catastrophic reaction. When at all possible, do not restrain her. If this occurs frequently, you may need to ask the doctor to help you review what is upsetting the person and if necessary to consider prescribing medication.

Anxiety, Nervousness, and Restlessness

People with dementing illnesses may become worried, anxious, agitated, and upset. They may pace or fidget. Their constant restlessness can get on your nerves. The person may not be able to tell you why she is upset. Or she may give you an unreasonable explanation for her anxiety. For example,

> *Mrs. Berger was obviously upset over something, but whenever her husband tried to find out what it was, she would say that her mother was coming to get her. Telling her that her mother had been dead for years only caused her to cry.*

Some anxiety and nervousness may be caused by the changes within the brain. Other nervousness may come from real feelings of loss or tension. The real feelings that result from not knowing where one is, what one is expected to do, and where one's familiar possessions are can lead to almost constant feelings of anxiety. Some people sense that they often do things wrong and they become anxious about "messing up." Longing for a familiar environment ("I want to go home.") or worrying about people from the past ("Where are my children?") can create anxiety. Reassurance, affection, and distraction may be all you can offer. Medication only occasion-

One woman was restless much of the time. She paced, fidgeted, and wandered. Her husband stopped telling her to sit down and instead began handing her a deck of cards, saying, "Here, Helen, play some solitaire." He took advantage of her lifelong enjoyment of this card game, even though she no longer played it correctly.

Sometimes this behavior is the result of frequent or almost continuous catastrophic reactions. Try to find ways to reduce the confusion, extra stimulation, noise, and change around the confused person. (Read the sections on catastrophic reactions and on wandering.) Medications may help very agitated or restless people.

False Ideas, Suspiciousness, Paranoia, and Hallucinations

Forgetful people may become unreasonably suspicious. They may suspect or accuse others of stealing their money, their possessions, and even things nobody would take, like an old toothbrush. They may hoard or hide things. They may shout for help or call the police. An impaired person may begin accusing her spouse of infidelity.

People with a dementing illness may develop unshakable ideas that things have been stolen from them or that people are going to harm them. Carried to an extreme, these ideas can make the person fearful and resistant to all attempts at care and help. Occasionally they develop distressing and strange ideas that they seem to remember and insist upon. They may insist that this is not where they live, that people who are dead are alive and are coming for them, or that someone who lives in the house is a stranger and perhaps dangerous. Occasionally a person will insist that her husband is not her husband—he is someone who looks like her husband, but is an impostor.

A person with a dementing illness may hear, see, feel, or smell things that are not there. Such hallucinations may terrify her (if she sees a strange man in the bedroom) or amuse her (if she sees a puppy on the bed).

These behaviors are upsetting for families because they are strange and frightening and because we associate them with insanity. They may never happen to your family member, but you should be aware of them in case you have to respond to such an experience. When they occur in the presence of a dementing illness, they are usually the result of the brain injury or a superimposed delirium (see pp. 276–79, 505–6) and are not symptoms of other mental illness.

Misinterpretation

Sometimes these problems are due to the confused person's misinterpretation of what she sees and hears. If she sees poorly in the dark, she may misinterpret the moving curtains as a strange man. If she hears poorly, she may suspect conversations to be people talking about her. If she loses her shoes, she may misinterpret the loss as a theft.

Is the person seeing accurately in the dark or is she often what happens when a person becomes unrealistically suspicious. Sometimes you can help by giving the confused person accurate information or writing down reminders. You may have to repeat the same information frequently, since the person will tend to forget quickly what you say.

Failure to Recognize People or Things (Agnosia)

People with dementing illnesses may lose the ability to recognize things or people, not because they have forgotten them or because their eyes are not working but because the brain is not able to put together information properly. This is called *agnosia*, from Latin words meaning "to not know." It can be a baffling symptom. For example,

> *Mrs. Kravitz said to her husband, "Who are you? What are you doing in my house?"*

This is not a problem of memory. Mrs. Kravitz had not forgotten her husband; in fact, she remembered him quite well, but her brain could not figure out who he was from what her eyes saw.

> *Mr. Clark insisted that this was not his house, although he had lived there many years.*

He had not forgotten his home, but, because his brain was not working right, the place did not look familiar.

You can help by giving the person other information. It may help to say "I guess it doesn't look familiar, but this is your house." Hearing your voice may help her remember who you are. Help her focus on one familiar detail. “Here is your chair. Sit in it. It *feels* familiar.”

“You Are Not My Husband”

Occasionally a person with a dementing illness will insist that her spouse is not her spouse or that her home is not her real home. She may insist that it looks just like her real house, but someone has taken the real one away and replaced it with a fake one. We do not understand exactly what is happening but we do know that this distressing symptom is a part of the brain damage.

Reassure the person, “I am your husband,” but avoid arguing. Although this may seem heartbreaking, it is important for you to reassure yourself that it is not a rejection of you (the person *does* remember you). It is just an inexplicable confusion of the damaged brain.

“My Mother Is Coming for Me”

Someone with a dementing illness may forget that a person she once knew has died. She may say, “My mother is coming for me,” or she may say that she has been visiting with her grandmother. Perhaps her memory of the person is stronger than her memory of the death. Perhaps in her mind the past has become the present.

Instead of either contradicting her or playing along with her, try responding to her general feelings of loss, if you feel that this is what she is expressing.

Telling the confused person outright that her mother has been dead for years may upset her terribly. Her constant focus on these memories probably means that they are important to her. Ask her to tell you about her mother, look through a photo album from those years, or retell some old family stories. This responds to her feelings without hurting her again and again.

Sometimes people feel that this idea is "spooky" or that the impaired person is "seeing the dead." It is much more likely to be just another symptom like forgetfulness, wandering, or catastrophic reactions.

Perhaps you will decide that this issue is not worth the argument.

Suspiciousness

If a person is suspicious or "paranoid," one must consider the possibility that her suspicions are founded on fact. Sometimes when a person is known to be unusually suspicious, real causes for her suspiciousness are overlooked. In fact, she might be being victimized, robbed, or harassed. However, some people with dementing illnesses do develop a suspiciousness that is inappropriate to the real situation.

Paranoia and suspiciousness are not really difficult to understand. We are all suspicious; it is necessary to our survival. The innate naïveté of the child is carefully replaced by a healthy suspicion. We are taught to be suspicious of strangers who offer us candy, door-to-door salespeople, and people with "shifty" eyes. Some of us were also taught as children to be suspicious of people of other races or religions. Some people have always been suspicious, others always trusting. A dementing illness may exaggerate these personality traits.

> *Ms. Henderson returns to her office to find her purse missing. Two other purses have disappeared this week. She suspects that the new file clerk has stolen it.*

> *As Mr. Starr comes out of a restaurant at night, three teenagers approach him and ask for change for the telephone. His heart pounds. He suspects that they plan to mug him.*

> *Mrs. Bellotti called her friend three times to meet for lunch and each time the friend refused, giving the excuse that she had extra work. Mrs. Bellotti worries that her friend is avoiding her.*

Situations like these occur frequently. One difference between the response of a well person and that of a brain-impaired person is that the latter's ability to reason may become overwhelmed by the emotions the suspiciousness raises or her inability to make sense out of her world.

> *Ms. Henderson searched for her purse and eventually remembered that she had left it in the cafeteria, where she found it being held for her at the cash register.*

The confused person lacks the ability to remember. Therefore, she will never find her purse and will continue to suspect the file clerk, as Ms. Henderson would have if she had not been able to remember where it was.

Knowing that he is in a lighted, well-traveled area, Mr. Starr suppresses his panic and hands over twenty-five cents to the three teenagers. They thank him and run to the phone.

The confused person lacks the ability to assess her situation realistically and to control her panic. She often overreacts. Therefore, she might have screamed, the teenagers would have run, the police would have been called, etc.

Mrs. Bellotti discussed her concerns with a mutual friend and learned that her friend had been sick and had gotten behind in her work and was eating lunch at her desk.

The confused person lacks the ability to test out her suspicions against the opinions of others and then to evaluate them.

The person with the dementing illness who becomes “paranoid” has not gone crazy. She lives in a world in which each moment is starting over with no memory of the moments that went before, in which things disappear, explanations are forgotten, and conversations make no sense. In such a world it is easy to see how healthy suspiciousness can get out of hand. For example, the person with a dementing illness forgets that you carefully explained that you have hired a housekeeper. Lacking the information she needs to assess accurately what is going on, she makes exactly the same assumption we would if we found a strange person in the house—that the person is a thief.

The first step in coping with excessive suspiciousness is to understand that this is not behavior the person can control. Second, it only makes things worse to confront the person or to argue about the truthfulness of the complaint. Avoid saying, “I told you twenty times, I put your things in the attic. Nobody stole them.” Perhaps you can make a list of where things are: “Love seat given to cousin Mary. Cedar chest in Ann’s attic.”

When she says, “You stole my dentures,” don’t say, “Nobody stole your teeth, you lost them again.” Instead say, “I’ll help you find them.” Locating the lost article will often solve the problem. Articles that are mislaid seem stolen to the person who cannot remember where she put them and who cannot reason that nobody would want her dentures.

One son securely fastened a key to the bulletin board (so his mother could not remove and hide it). Every time she accused him of stealing her furniture, he replied gently, “All your things are locked in the attic. Here is your key to the attic where they all are.”

Sometimes you can distract a person from her focus on suspiciousness. Look for the lost articles; try going for a ride or getting her involved in a task. Sometimes you can look for the real cause of her complaints and respond with sympathy and reassurance to her feelings of loss and confusion.

When many of a person’s possessions must be disposed of so she can move into someone’s home or a nursing home, she may insist that they have been stolen. When you have assumed control over a person’s finances, she may accuse you of stealing from her. Repeated explanations or lists sometimes help. Often they do not, because the person cannot make sense of the explanation or will forget it. Such accusations can be discouraging when you are doing the best you can for someone. These accusations are often, at least in part, an expression of the person's overwhelming feelings of loss, confusion, and distress. They are not really harmful to anyone, except that they are distressing for you. When you understand that they occur because of the brain damage, you will be less upset by them.

Few things make us more angry than being falsely accused. Consequently, the impaired person's accusations can alienate sitters, other family members, neighbors, and friends, causing you to lose needed sources of friendship and help. Make it clear to people that you do not suspect them of anything and explain to them that accusatory behavior results from the confused person's inability to assess reality accurately. Your trust in them must be obvious and strong enough to override the accusations made by the impaired person. Sometimes it is helpful to share with others written materials such as this book, which explain how the brain impairment affects behavior. Part of the problem is that the confused person may look and sound reasonable. She may not look and sound as if this behavior were beyond her control, and, because dementing illnesses are often poorly understood, people may not realize what is happening.

Some suspiciousness goes beyond this explanation; it cannot be explained by the forgetfulness and loss of the ability to correctly assess reality. Such suspiciousness may be caused by the disease process itself. Low doses of medication may help. Treatment not only makes life easier for you but also relieves the ill person of the anxiety and fear that arise from her suspicions.

Hiding Things

In a world that is confusing and in which things inexplicably disappear, it is understandable that a person would put things of importance in a safe place. The difference between being well and being impaired is that the impaired person forgets where that safe place is more often than the well person. Hiding behaviors often accompany suspiciousness, but because they cause so many problems of their own, we have discussed them separately in Chapter 7.

Delusions and Hallucinations

Delusions are untrue ideas unshakably held by one person. They may be suspicious in nature ("The mafia are after me," or "You have stolen my money") or self-blaming ("I am a bad person," or "I am rotting inside and spreading a terrible disease"). The nature of the delusion can help doctors diagnose the person's problem. Self-blaming ideas, for example, are often seen in people who are severely depressed. However, when delusions occur in a person who is known to have a brain impairment from strokes, Alzheimer disease, or other conditions, the delusion is believed to arise out of the injury to brain tissue. It can be frustrating to have a person seem able to remember a false idea and unable to remember real information.

Sometimes delusions appear to come from misinterpreting reality. Sometimes they are tied to the person's past experiences. (A note of caution: not all odd things people say are delusions.)

Hallucinations are sensory experiences that are real to the person having them but that others do not experience. Hearing voices or seeing things are most common, although occasionally people feel, smell, or taste things also.

> *Mrs. Singer sometimes saw a dog asleep in her bed. She would call her daughter to "come and get the dog out of my bed."*
>
> *Mr. Davis saw tiny little men on the floor. They distracted him, and often he sat watching them instead of taking part in activities at the senior center.*
>
> *Mrs. Eckman heard burglars outside her window trying to break in and discussing how they would hurt her. She called the police several times and earned herself the reputation of a "nut."*
>
> *Mr. Vaughan tasted poison in all his food. He refused to eat and lost so much weight that he had to be hospitalized.*

Hallucinations are a symptom, like a fever or sore throat, which can arise from many causes. Certain drugs can induce hallucinations in otherwise well people. Several for you." This is not the same as agreeing with the person. Sometimes you can distract the person so that she forgets her hallucination. Say, "Let's go in the kitchen and have a cup of warm milk." When she returns to her bedroom, she may no longer see a dog in her bed and you will have avoided an upsetting confrontation.

It is often comforting to touch the person physically, as long as she does not misinterpret your touch as an effort to restrain her. Say, "I know you are so upset. Would it help if I held your hand (or gave you a hug)?"

Having Nothing to Do

As they progress, dementing illnesses greatly limit the things the confused person can do. It becomes impossible to remember the past or to anticipate the future. The confused person cannot plan ahead or organize a simple activity like taking a shower. Many impaired people cannot follow the action on television. While you or the nursing home staff are getting chores done, the ill person may have nothing to do but sit with vacant time and empty thoughts.

Restlessness, wandering, trying to go "home," repetitive motions, asking the same question over and over, scratching, masturbating, and many other behaviors begin as an effort to fill this emptiness. But for you the hours are full. We do not think that a family caregiver, with all the burdens he or she faces, should be expected to take on the additional responsibility of planning recreation. We do think activity is important and urge the use of a day center, other family, friends, or paid help, if possible.

Whenever you or someone else initiates an activity for a person with dementia, you must walk a fine line between providing meaningful activity and overstressing the person. Move at the confused person's pace. Never let an activity become a test of her abilities; arrange things so that she will succeed. Having fun should be more important than doing something correctly. Stop when the person becomes restless or irritable.

9

Special Arrangements If You Become Ill

Anyone can become ill or suffer an accident. If you are tired and under stress from caring for a chronically ill person, your risk of illness or accident *increases.* The spouse of a person with a dementing illness, herself no longer young, is at risk of developing other illnesses.

What happens to the confused, forgetful person if you, the caregiver, are injured or become ill? It is important that you have a plan ready. Perhaps you will never need to put your plan into effect, but because dementia disables a person in such a way that he cannot act in his best interests, you must make advance plans that protect you and the impaired person.

You need a physician who is familiar with your health to whom you can turn if you become ill, and who is available quickly in a crisis. In addition, you need to plan in advance for several kinds of possible problems: the sudden, severe problems that would arise if you had a heart attack or stroke or fell and broke a bone; the less sudden problems that would arise if you had a long illness, hospitalization, or surgery; and the problems that would arise if you got the flu or were at home, sick, for a few days.

> *Mrs. Brady suddenly began having chest pains and knew she should lie quietly. She told her confused husband to go get their neighbor but he kept pulling at her arm and shouting. When she finally was able to telephone for help, he refused to let the ambulance attendants in the house.*

Even an impaired person who appears to function well may, when he is upset, become unable to do things he usually can do. Should you suddenly become ill and unable to summon help yourself, the upset and confused person may not be able to summon help for you. He may misinterpret what is happening and impede efforts to get help.

There are several possible ways you can plan to summon help. If your area has an emergency telephone number (such as 911), try to teach the person to call for help. Post the number over the phone. Or post the number of a relative who lives nearby and who will respond to a confused telephone call. Some telephone companies offer an automatic dialing service. With this device the telephone will automatically dial a prerecorded number of your choice if you or the confused person is able to dial one or two digits. You can paint this digit red with fingernail polish so that it is easily identified.

At least one company manufactures a "panic button" that you can carry with you. It is about the size of a pocket calculator. If you press the button on it, it will activate the automatic dial described above and send a prerecorded message. Such equipment may seem expensive, but in some situations it could be life saving.

Many areas have programs for senior citizens in which someone will call once a day to see if you are all right. This may mean a long delay in getting help, but it is better than nothing.

Be sure that the person who would respond in a crisis has a key to your house. The upset, confused person may refuse to let anyone in.

If you must go into the hospital or if you are at home sick, you will want to plan carefully in advance for the care of the confused person. Changes are upsetting for people with a dementia, and it is helpful to minimize changes as much as possible. The substitute caregiver should be someone the person knows and someone who knows your routines for managing him. See Chapter 10 for possible sources of temporary help. Be sure that the names and phone numbers of your doctor, the patient's doctor, the pharmacist, your lawyer, and close family members are written down where the person helping out in an emergency can find them.

Some families have made up a "cope notebook" in which they have jotted down the things another person would need to know, for example, "Dr. Brown (555-8787). John gets a pink pill one hour before lunch.

He will take it best with orange juice. The stove won't work unless you turn on the switch that is hidden behind the toaster. John starts to wander around suppertime. You need to watch him then."

In the Event of Your Death

When someone close to you has a dementing illness, you have a special responsibility to provide for him if you should die. Probably your plans will never have to be put into action, but they must, for the sake of the sick person, be made.

When a family member is unable to take care of himself, it is important that you have a will that provides for his care. Find a lawyer whom you trust, and have him draw up a will and any other necessary legal papers. Every state has a law that determines how property will be divided among your heirs if you do not make a will or if your will is not valid. However, this may not be the way you wanted your estate to be distributed. In addition to the usual matters of disposing of property to one's heirs, the following questions must be addressed, and appropriate arrangements made. (See Chapter 15.)

What arrangements have been made for your funeral, and who will carry these out? You can select a funeral director in advance and specify, in writing, what kind of funeral you will have and how much it will cost. Far from being macabre, this is a considerate and responsible act that ensures that things will be done as you wish and that saves your distraught family from having to do this in the midst of their grief. Funerals can be expensive, and advance plans make it possible for you to see that your money is spent as you wish.

What immediate arrangements have been made for care of the person with a dementing illness, and who will be responsible for seeing that they are carried out? Someone must be available immediately who will be kind and caring.

Do the people who will be caring for the person with a dementing illness know his diagnosis and his doctor, and do they know as much as possible of what you know about how to make him comfortable?

What financial provisions have been made for the person with a dementing illness, and who will administer them? If he cannot manage his own affairs, someone must be available with the authority to care for him. You will want to select a person whom you trust to do this rather than leave such an important decision to a court or judge. When such decisions are made by a court, they involve long delays and considerable expense.

Sometimes a husband or wife cares for years for a spouse with a dementing illness and does not want to burden sons or daughters with the knowledge of this illness.

> *Said a daughter, "I had no idea anything was wrong with Mom because Dad covered for her so well. Then he had a heart attack and we found her like this. Now I have the shock of his death and her illness all at one time. It would have been so much easier if he had told*

> *us about it long ago. And we didn't know anything about dementia. We had to find out all the things he had already learned, and at such a difficult time for us."*

All members of the family need to know what is wrong with the impaired person and what plans have been made. An experience like this is one example of the disservice of "protecting" other members of the family.

You should have a succinct summary of your assets available for the person who will take over. This should include information on the location of wills, deeds, stocks, cemetery lot deeds, and information about the care of the confused person.

may be available. The second part of the chapter will discuss some of the problems you may encounter.

Help from Friends and Neighbors

Usually, caregivers who feel that they have the support of others manage the burdens of care more successfully. It is important that you not feel alone with your burden. Most people first turn to family members, friends, or neighbors for support and help. Often people will offer to help; at other times you may have to ask them for help.

Family members sometimes disagree or don't help out, or you may hesitate to ask others for the help you need. In Chapter 11 we discuss some ways to handle family disagreement and to ask for help.

Others are often willing to help. Sometimes a neighbor will look in on the confused person, the druggist will keep track of prescriptions for you, the minister, priest, or rabbi will listen when you are discouraged, a friend will sit with the person in an emergency, and so forth. As you plan, you should consider these resources, because they are important to you.

How much help should you accept or ask for from friends and neighbors? Most people like to help, yet making too many demands on them may eventually cause them to pull away.

When you turn to friends and neighbors for help, there are several things you can do to help them feel comfortable helping you. Some people are uncomfortable around those who are visibly upset. You may not want to express all of your distress to such people. Close friends may be more willing to share some of the emotional burden with you than people who do not know you well.

Although most people have heard of Alzheimer disease, many need more information to understand why the person acts as she does. Explain that the behaviors are the result of the damage to the brain, that they are not deliberate or dangerous.

People may be reluctant to “sit with” or visit with the person because they do not know what to do and feel uncomfortable. You can help by suggesting specific things that the visitor might do with the person. For example, mention that going for a walk might be more fun than a conversation or that reminiscing about old times will be fun for both of them. Tell the visitor what you do when the ill person gets irritable or restless.

Some chapters of the Alzheimer’s Association will train family members or friends to be special visitors. Such visitors bring pleasure to the confused person as well as giving you time away from caring.

When you ask people to help you, give them enough advance notice, if possible, so they can plan the time to help you. Remember to thank them and avoid criticizing what they have done.

Look for things others can do that they will not consider inconvenient. For example, neighbors may not

TABLE 1. DEFINITIONS OF CARE SERVICES FOR PERSONS WITH DEMENTIA

seling, social work help, referral services, and free tax assistance to people over 60, their spouses, and handicapped people. Some programs provide prescription medications or medical appliances at reduced cost. Some provide transportation.

There are a few programs that repair older people's homes at reduced rates. You may be able to use such a program to install wheelchair ramps, locks, grab bars, and other safety devices.

In some areas, programs such as Meals-on-Wheels will bring a daily hot meal to people who cannot get out. These meals are often delivered by friendly, dedicated volunteers who will also check to see how a person living alone is doing, but they provide limited help for a person who is becoming confused and are not a substitute for supervision.

Expanded nutrition programs offer a hot lunch and a recreation program in a sheltered group setting for several hours each weekday. They usually do not provide medical care, give medicines, or accept wandering, disruptive, or incontinent people. They are often staffed by lay or paraprofessional people. Mildly or moderately confused individuals may enjoy the group setting.

Nutrition programs are funded through the Older Americans Act and serve people over 60 and their spouses. You can find them by calling your local commission on aging. Some hot lunch programs are intended for well older people and an impaired person would not fit in. Other programs under the same or similar funding offer services to "frail" elderly people.

You may be able to attend with your spouse if you wish. *Such programs do not provide adequate supervision for a person living alone.*

> *Mr. Williams was confused and often became restless. His wife arranged for a senior volunteer to visit and play checkers with him. He loved checkers and the volunteer understood and did not mind that Mr. Williams often forgot the rules. The volunteer became his "checkers pal" and made it possible for Mr. Williams to have a friendship and an enjoyable activity at the same time that it gave Mrs. Williams a break.*

There are many other programs; we have referred to some of them in other parts of this book. You should find out what is available in your area even if you don't feel you need the service now. See Chapter 15 for a discussion of financial resources.

Having Someone Come into Your Home

Many families arrange for someone to come into their home to help with the ill person's care. A *homemaker* will help you with tasks such as housework, cooking, laundry, or shopping. A *home health aide* or a *personal care aide* will help the ill person dress, bathe, eat, and use the bathroom. Families of people with dementia most commonly turn to a *paid companion* or *sitter.* Sitters provide supervision and may help the person with meals. Some will give the person a bath. Some have had special training to provide the ill person with socialization and meaningful activities.

grams that mix persons with dementia and those with other conditions provide good care to both groups. The skill of the staff and the philosophy of the program are most important in determining its quality.

Adult day care is one of the most important resources for families. It provides urgently needed respite for the caregiver and *it often benefits the person with dementia.* For most of us, the pressures of family life can be relieved by getting away sometimes to be with friends or to be alone. The person with dementia does not have this opportunity. She must be with her caregiver day after day, but her impairment does not take away her need to have her own friends and time apart. The burden of this enforced togetherness may be difficult for the impaired person as well as for the caregiver.

People with dementia experience failures and reminders of their inadequacies at every turn. But even when they cannot feed or dress themselves, they often retain their ability to enjoy music, laughter, friends, and the pleasures of doing some simple activity. People with dementia may make friends with other impaired people at the center, even when they are so impaired that they may not be able to tell you about their friend. Day care staffs observe that participants regain a sense of humor, appear more relaxed, and enjoy the activities. Good day care programs find ways for people to succeed at little things and thereby feel better about themselves. Day care programs fill empty time with activities the person can do well. Some programs do not offer much stimulation is more effective when families use it *before* they reach the breaking point.

You may negotiate for this service yourself with a foster home or boarding home, or with an individual who will take in one or two clients. Since there is little governmental oversight of such care, you must make sure that the provider understands how to care for your family member and is a kind and gentle person. New surroundings may stress people with dementia, so short-stay respite programs will need enough skilled staff to give individual attention to their guests.

Planning in Advance for Home Care or Day Care

Once you have found a good respite program, there are a few things you must do to make visits go smoothly. Be sure that the provider understands the nature of the dementing illness and knows how to handle problem behaviors. Write out special information for the provider: how much help will the person need in the bathroom or with meals? What does she like for lunch? What cues does she give that she is getting irritable, and how do you respond? What special needs does she have?

Be sure the care provider knows how to reach you, another family member, or the doctor. Be sure that the provider knows from you that only you have the authority to hire and fire.

If the sick person has complicating health problems, such as a heart or respiratory condition, a tendency to

The person usually does not mean "husband." Perhaps she is trying to say "friend" but could not find the word. Perhaps "husband" is the closest word she can find to mean companion. It does not imply a romance and it should not affect the marital relationship.

Sometimes the confused person will say, "She hit me" or "They wouldn't give me anything to eat" or "The fat one took my purse." Avoid taking such remarks too seriously. People with dementia can misperceive, misremember, or express themselves inaccurately. Perhaps she can't remember having lunch. Ask the staff what took place.

You may ask the person, "What did you do today?" and she may reply, "Nothing." "Well, did you have a good time?" "No." Answers like this may indicate that she can't remember what went on. Don't embarrass her by continuing to ask. Ask a staff member what she enjoyed today.

If the person says she does not want to go to day care (or have the home care provider), you do not have to take this literally. She may mean that she does not understand what you are suggesting. She may not remember earlier visits at all. Avoid getting into arguments. Reassure her that this is something she can handle, that you will come back for her, and that the people there are nice and will help her.

A few people cannot adjust to home care or day care. Try several different providers. Some people have a way with people with dementia. Ask yourself whether your attitude is affecting her adjustment (see below). If you cannot use a respite program now, try again in a few weeks or months. Often changes in the person's condition will make it easier for her to accept someone later.

Your Own Feelings about Getting Respite for Yourself

It is not unusual for a family to be discouraged by their first visit to a day care center.

> *Mr. Wilson said, "I went to see the day care center. The hospital told me this was an excellent center. But I can't put Alice in there. Those people are old and sick. One of them was dragging a shopping bag around and mumbling. One was drooling. Some of them were sleeping in these chairs with a tray across them."*

The sight of other disabled or elderly people can be distressing. Our perception of the person we live with is colored by our memory of how she used to be. You may feel that such a program does not offer the individual care that you can give at home or you may feel that no one else can manage the person.

Some families are reluctant to bring a stranger into their home. You may not like strangers in your home or you may worry about whether they are honest. You may not want anyone to see your house in a mess. And many people feel, "My family and I are private people. We take care of our own. We just aren't the kind of people who use public help."

Like you, American families provide almost all of the care of frail elderly people. Seventy-five to 85 percent of all care comes from family members. Dementing illnesses cause particularly devastating burdens for family members. Because it is a disease of the mind, you are faced with the grief of losing companionship and communication, with the tasks of dressing, feeding, and toileting the person, and with difficult behavior. These diseases last many years, and caregivers usually cannot leave the ill person for even a few minutes. Many caregivers are doing little more than surviving—just barely hanging on.

If you become ill, as many caregivers do, others will have to assume responsibility for the person you care for. Good care means caring for yourself too. If you are tired and depressed, you may snap at the confused person. She will usually sense your distress and may respond (she can't help it) by whining or wandering or arguing even more. Many caregivers end up using medicine to control these behaviors. This may make the ill person more confused. Ask yourself: Am I rushing her? snapping at her? slapping her?

The best prescriptions we know are to talk with other families and to get some time away from the ill person. Arranging a little time for yourself and coming back a little rested and in better humor can allow you to continue caring.

If the people in day care seem more impaired than your family member, it is likely she will feel comfortable where her difficulties will not be noticed and where she can be the helper. If you have checked references, it is likely that the person coming into your home is honest.

Home care workers say they rarely notice how messy the house is. Talk with other families: often they too were reluctant but will tell you that the time apart helps the confused person as well as themselves. Caregivers have told us that knowing that a professional provider is also having difficulty with the person makes them feel better about their own efforts to manage.

Even if the respite situation is not perfect—if the home sitter watches soap operas or the participants in day care seem to just sit a lot of the time—you may want to continue with it. Your continued strength and your ability to keep providing care may depend on your getting regular breaks from caregiving.

Some in-home providers urge that you leave the house while they provide care. This is because they think carers need the time away. It is tempting to stay and talk with the respite worker or help with the confused person, but you may manage better in the long run if you get away, even if all you do is take a walk or visit with a neighbor. If you stay at home, go into another room, away from the patient.

Locating Resources

Most towns and cities have no central information source that can tell you what services are offered or how to get them. Even information and referral services often do not have a complete and current list of resources. Therefore, you will need to be persistent and may need to contact several individuals or agencies. The process of want adult day care. If there is a regional Alzheimer disease center or resource center near you, their staff members usually know what resources are available for people with dementia. Occasionally a community health center, a community mental health center, a geriatric assessment program, or a nursing home can refer you to resources. They often have information and referral services. Some will be helpful; others will not. Agencies may not know about local services. In a few places each of these agencies provides outstanding day care or in-home care to people with dementia, but in other areas, they do not serve people with dementia or their families.

You may not find what you need; unfortunately, the resources families of people with dementia need are often not available. Don't blame yourself if you can't find the resources you need. Some agencies have a waiting list, or they will take only certain kinds of people, while other agencies may be too expensive. Inadequate resources and services are major problems that can be changed only through public recognition of the dementing diseases and the needs of families.

Perhaps you will want to accept what resources are available, even if they are not ideal, since you may find that obtaining even some help is better than trying to cope alone.

Occasionally families are able to exchange services. Plans can be simple or elaborate; basically, two or three families agree to take turns sitting. You may sit with two confused people in your home for one afternoon a week. Then the next week someone else will sit, while you get an afternoon out. This works best when the impaired people are not agitated and do not wander. They will enjoy the contact with others. The "rules" of exchange services should be clearly spelled out.

An organization of families might want to train one or two people in the management of people with a dementing illness. Such a person would have a full-time job dividing her time among several families.

The person who helps you may be a family member, friend, neighbor, or church member. Alzheimer's Association chapters often provide training for such people so that they feel more secure in helping care for the confused person while you have some time away. Some families locate a respite care worker by advertising or through word of mouth. Older people who need work but lack formal skills are a good source of help. Also consider college students. Some students are gentle and kind and have had experience with their own grandparents.

Paying for Care

Fees for day care and in-home care vary, often depending on the sources of governmental or private funding the program has access to. There is no national resource for assisting middle-class families with the costs of day care or in-home care. Although home nursing is usually the most expensive kind of care, if the person needs nursing treatment for specific conditions (usually not associated with the dementia) or if periodic nursing reassessment is needed for an unstable condition, Medicare may pay for part of the cost of the nurse and may also pay for a home health aide. Medicaid may pay for day care it deems “medical day care,” but it will not pay for day care that provides only social enrichment. Find an experienced home health agency and discuss whether they will be able to help you get Medicaid coverage for their services.

Medicare regulations change with changes in federal policy and can be confusing to interpret. Ask the social worker or service agency to help you find out whether their services to you are reimbursable. It may be worthwhile to request that a decision be reviewed by Medicare. In general, except for a few demonstration projects, Medicare rarely pays for respite for people with dementia.

Home nursing and home health aides can also be hired from nursing agencies. If you use an agency, be sure you know whether they will replace a person if she does not show up and how much training or experience the person has had in caring for people with dementia.

Home health aides and companions that you locate and contract with yourself are usually less expensive than agency staff, but you can spend considerable time locating them and some are unpredictable. Some people advertise for help in local newspapers, where nurse aides advertise their availability. Families suggest you ask a home aide who is working with someone you know; she may have friends who are looking for work.

If you hire someone, recognize that it is unreasonable to ask a person to both clean the house and watch an ill person. Realistically, a domestic helper probably cannot look after a confused person and clean the house. It is challenging for *you* to do both and often impossible for someone unfamiliar with your house and with the impaired person. You may have to settle for a sitter and a house that is not very well kept. Discuss fees, hours, and exact responsibilities before you hire. Fees may be surprisingly high, particularly in metropolitan areas.

In some states Medicaid pays for home care and day care for a few low-income people, but eligibility is limited; and even this is not available in many areas. Some states have limited funds to pay for in-home or day care through the office on aging. Federal and state governments and some foundations are funding respite care demonstration programs, but these will serve only a few people for limited periods of time.

Some programs provide trained volunteers as in-home or day care workers. These programs work well, but there are costs: for supervisory and training personnel, transportation, and insurance. A fee may be charged to cover these costs.

A few Alzheimer's Association chapters have funds to assist families who need home care or day care. Some programs have sliding fee scales and some have financial aid available.

All these resources are extremely limited, however. Most families can expect to pay at least part of the cost of care. Many families fear the enormous costs of nursing home care. While they hope never to need such care, they feel they must conserve their resources rather than spend money on respite. For a full discussion of paying for nursing home care, see Chapter 16. However, since Medicaid pays for nursing home care only after the person has exhausted her own resources, the family may decide to expend part of the ill person's (*not the spouse's*) resources on respite care, keeping detailed records to prove that the money was spent on her care. Keep back sufficient funds to pay privately for the first few months of nursing home care (to ensure access to a nursing home). When this money is spent, you can apply for Medicaid funds. Because Medicaid rules change frequently, vary from state to state, and are extraordinarily complex, you must evaluate the ill person's resources carefully and consult someone knowledgeable about Medicaid law in your state before taking this step.

Should Respite Programs Mix People Who Have Different Problems?

You may have heard that respite programs that specialize in the care of people with dementia are supposed to be better than programs that mix people with different kinds of health problems. Families sometimes worry about what might happen if a frail, elderly person with Alzheimer disease is in the same program with a younger, strong person who has had a head injury or similar trauma.

Programs that serve a group of people whose needs and levels of functioning are similar can more easily provide specialized programming that meets their needs.

However, many programs have successfully mixed people who are confused with people who have head traumas or physical disabilities. In some areas there are not enough people with dementia who have similar needs to make a specialized program cost-effective. Also consider that diagnosis does not describe a person's needs and level of function well: the care of an active younger individual with Alzheimer disease may be more like that of a head trauma patient than like the care of a frail, anxious person with Alzheimer disease. Finally, staff skill is more important than diagnosis in most cases.

It is best to judge a program on how well it provides individual care and how well you think your family member will fit in with the group. A confused person can take great satisfaction from pushing a wheelchair or in handing a dish of cookies to a physically impaired person. On the other hand, a program that offers a lot of discussion groups, reading, and watching films is focusing on activities that will leave out most people with dementia. If you are concerned that your family member will not fit in or is too frail, discuss your concerns with the program director. Some programs are flexible and try to match activities to a person's current abilities. A trial period in the program is often the best idea. People with dementia often surprise us by how well they can fit in.

Determining the Quality of Services

Since the confused person may not be able to tell you about the care she receives, you must know about the quality of care the program provides. *Many of the agencies that refer you will not have reliable information about the quality of services they refer you to.* This is true even of governmental agencies, which may never have visited the program. To prevent discrimination, some referral programs are required to recommend all programs equally, without regard to the quality of the program. Hospital social workers are often under pressure from the hospital to place people quickly.

Many people assume that some governmental agency is responsible for safeguarding the quality of programs such as adult day care and in-home care. In fact, the federal government has almost no control over such programs. Some states have standards and enforce them; others have no standards, have minimal standards, or do not enforce the standards they have. Existing standards may not take into account the special limitations of people with dementia (for example, that they need more supervision or that they cannot respond to fire alarms).

Never assume that, because you were given the name of a service by an authority, it is a good-quality program, there are standards it must meet, or it has been recently inspected.

In most of the programs we have seen, providers work because they love the job, and they give good care. However, there is an occasional bad apple. Checking on the quality of a service is up to you. Always ask if the program is licensed and by what agency, and whether it meets existing voluntary or required standards. Ask when it was last inspected and ask to see the findings.

At a minimum, a day care center or a person coming into your home should be bonded. Workers should be supervised by a professional (usually a nurse or social worker) and should be trained in the safe care of elderly people and in the special care of people with dementia. Ask the providing agency whether your state certifies this level of worker and whether this person is certified. Ask questions, check references, and monitor the care given, particularly in the beginning. In a day center, ask about meal preparation, supervision of wandering, fire emergency plans, and the kinds of activities provided.

People with dementia often misunderstand or misinterpret things. As a result, they may report neglect or poor care that did not really happen. Carefully investigate complaints such as "They didn't give me any lunch" or "She is spying on us."

> *When her mother was sick, Mary had a woman stay with her in their home. On one occasion Mary's children accidentally left their tape recorder running and when Mary came home and replayed it, she realized the aide had watched soap operas all afternoon instead of spending time with her mother.*

It can be difficult to know how well another person is caring for your family member. Carers are almost always honest and caring, and it is important that you have some respite time. Do not avoid getting help because you worry about the quality of care. At the same time, be alert to potential problems.

11

You and the Impaired Person as Parts of a Family

Chapters 2–10 have discussed how to get help for the sick person and ways to care for him. However, you and the rest of your family are important also. A chronic dementing illness places a heavy burden on the whole family: it may mean a lot of work or financial sacrifices; it may mean accepting the reality that someone you love will never be the same again; it continues on and on; it may mean that responsibilities and relationships within the family will change; it may mean disagreements within the family; it may mean that you feel overwhelmed, discouraged, isolated, angry, or depressed. You and the person with a dementing illness, as well as the other people close to him, all interact as part of a family system. This system can be severely stressed by a dementing illness. It is helpful to consider the changes that may occur in families that are faced with a chronic illness and to identify the feelings you may experience. Sometimes just knowing that what is happening to you has

In addition, the burden of caring for a person with a dementing illness can be exhausting and distressing for you.

> *Mrs. Fried said, "I get so depressed. I cry. Then I lie awake at night and worry. I feel so helpless."*

Watching someone close to you decline can be a painful experience. This chapter discusses some of the problems that arise in families, and Chapter 12 will discuss some of the feelings you may have.

It is important to remember that not all of your experiences will be unhappy ones. Many people feel a sense of pride in learning to cope with difficult situations. Many family members rediscover one another as they work together to care for an ill person. As you help a forgetful person enjoy the world around him, you may experience a renewed delight in sharing little things—playing with a puppy or enjoying flowers. You may discover a new faith in yourself, in others, or in God. Most dementing illnesses progress slowly, so you and your family member can look forward to many good years.

> *Mrs. Morales said, "Although it has been hard, it's been good for me in a lot of ways. It's given me confidence to know that I can manage things my husband always took care of, and in some ways my children and I have grown closer as he has gotten sick."*

Since this book is designed to help you with problems when they do occur, most of what we discuss are unhappy feelings and problems. We know that this is a one-sided view that reflects only part of what life is like for you.

The feelings and problems you and your family experience interact and affect one another. However, for simplicity, we have organized them into separate topics: changes in roles within the family, finding ways to cope with changes in roles and the family conflict that can arise, your own feelings, and finding ways to care for yourself.

Changes in Roles

Roles, responsibilities, and expectations within the family change when one person becomes ill. For example,

> *A wife said, "The worst part is doing the checkbook. We have been married thirty-five years and now I have to learn to do the checkbook."*
>
> *A husband said, "I feel like a fool washing ladies' underwear in the laundromat."*
>
> *A son said, "My father has always been the head of the household. How can I tell him he can't drive?"*
>
> *A daughter said, "Why can't my brother help out and take his turn keeping Mother?"*

Roles are different from responsibilities, and it is helpful to recognize what roles mean to you and to others in the family. Responsibilities are the jobs each person has in the family. Roles include who you are, how you are seen, and what is expected of you. By “role” we mean a person’s place in his family (for example, head of the household, mother, or “the person everyone turns to”). Roles are established over many years and are not always easy to define. Tasks often symbolize our roles. In the examples above, family members describe both having to learn new tasks (doing the wash or balancing the checkbook) and changes in roles (money manager, homemaker, head of the household).

Learning a new responsibility, such as keeping the checkbook or washing clothes, can be difficult when you are also faced with the many day-to-day needs of the confused person, yourself, and your family. However, changes in roles are often more difficult to accept or adjust to. Understanding that each person’s responsibilities change and that roles and expectations of others change also will help you to understand the personal feelings and problems that may arise in families. It is helpful to remember that you have coped with changes in roles at other times in your life and that this experience will help you adjust to new responsibilities.

There are many relationships in which role changes occur as the person’s dementia worsens. Here are four examples.

1. *The relationships between a husband and wife change when one of them becomes ill.* Some of these changes may be sad and painful; others can be enriching experiences.

John and Mary Douglas had been married forty-one years when John got sick. John had always been the head of the household: he supported the family, paid the bills, made most of the big decisions. Mary saw herself as a person who always leaned on her husband. When he got sick, she realized that she did not know how much money they had, what insurance they had, or even how to balance a checkbook. Bills were going unpaid, yet when she asked John about it, he yelled at her.

For their anniversary Mary fixed a small turkey and planned a quiet time together when they could forget what was happening. When she put the electric carving knife in front of John he threw it down and shouted at her that the knife did not work and she had ruined the turkey. Trying to keep the peace, Mary took the knife, and then realized that she had no idea how to carve a turkey. Mary cried and John stormed. Neither of them felt like eating supper that night.

Having to carve a turkey seemed like the last straw for Mary. She realized that John could no longer do this, nor could he manage their finances, but she suddenly felt overwhelmed and lost. Throughout their marriage Mary had looked to John to solve problems. Now she had to learn to do the things he had always done at the same time that she had to face his illness.

Learning new skills and responsibilities involves energy and effort and means work added to what you already have to do. You may not want to take on new tasks. Few husbands want to learn to do the wash, and more than one has had a load of shrunken sweaters and pale pink jockey shorts before he finds out that he can't wash red sweaters with white underwear. A spouse who has never managed the checkbook may feel that he doesn't have the ability to manage money and may be afraid of making errors.

In addition to having to do the job itself, the realization that you must take this job away from your spouse may symbolize all of the sad changes that have taken place. For Mary, her carving the turkey symbolized John's loss of status as head of the family.

A spouse may gradually realize that she is alone with her problem—she has lost the partner with whom she shared things. Mary could no longer see herself as leaning on her husband. She suddenly found herself, at 60, on her own and forced to be independent with no one to help her. No wonder she felt overwhelmed by the task. But at the same time, learning new skills gradually gave Mary a sense of accomplishment. She said, "I was surprised at myself, really, that I could handle things. Even though I felt so upset, it was good for me to learn that I could manage so well."

Sometimes problems seem insurmountable because they involve both changes in roles and the need for you to learn new tasks. Having to learn new skills when you are upset and tired can be difficult. As well as recognizing the distress that may be caused by changing roles, you may need some practical suggestions for getting started with new responsibilities.

Chapter 15 lists some of the potential resources you should look for.

If you can't drive or do not like to drive and must take over the driving responsibilities, look for a driver education course designed for adults. Inquire through the police or the American Association of Retired Persons for driver's education courses and defensive driving programs for older adults. Life will be much easier if you are comfortable behind the wheel.

2. *The relationship of a parent with a dementing illness and his adult children often has to change.* The changes that occur when an adult child must assume the responsibility and care of a parent are sometimes called "role reversal." Perhaps this is better described as a shift in roles and responsibilities, in which the adult son or daughter gradually assumes increasing responsibility for a parent while the roles of the parent change accordingly. These changes can be difficult. You, the adult son or daughter, may feel sadness and grief at the losses you see in someone you love and look up to. You may feel guilty about "taking over."

> *"I can't tell my mother she shouldn't live alone any more," Mrs. Russo says. "I know I have to, but every time I try to talk to her she manages to make me feel like a small child who has been bad."*

To varying degrees many of us as adults still feel that our parents are parents and that we, the children, are less assured, capable, and "grown up." In some families the parents seem to maintain this kind of relationship with their adult children past the time when adult sons and daughters usually come to feel mature in their own right.

Not everyone has had a good relationship with his parents. If a parent has not been able to let his grown children feel grown up, a lot of unhappiness and conflict may develop. Then as the parent develops a dementing illness he can seem to be demanding and manipulative of you. You may find yourself feeling trapped. You may feel used, angry, and guilty at the same time.

What seems demanding to you may feel different to the impaired person. He may be feeling that with "just a little help" he can hold on to his independence, perhaps continue to live alone. As he senses his decline, this may seem the only way he can respond to his losses.

Adult children often feel embarrassed by the tasks of physically caring for a parent—for example, giving their mother a bath or changing their father's underwear. Look for ways to help your parent retain his dignity at the same time that you give needed care.

3. *The sick person must adjust to his changing roles in the family.* This often means giving up some of his independence, responsibility, or leadership, which can be difficult for anyone. (See Chapter 4.) He may become discouraged or depressed as he realizes his abilities are waning. He may be unable to change or to recognize his decline.

The roles a person has held within the family in the past, and the kind of person he is, will influence the new roles he assumes as he becomes ill. You can help him to maintain his position as an important member of the family even when he can no longer do the tasks he once did. Consult him, talk to him, listen to him (even if what he says seems confused). Let him know by these actions that he is still respected.

4. *As the roles of the sick person change, the expectations of each member of the family for the others change.* Your relationships and expectations of members of the family are based on family roles that have been established for years. Changes often lead to conflicts, misunderstandings, and times when people's expectations of each other do not agree. At the same time, adjusting to changes and facing problems can bring families closer together, even when they have not been close for years.

Understanding Family Conflicts

Mrs. Eaton says, "My brother doesn't have anything to do with Mom now—and he was always her favorite. He won't even come to see her. All the burden is on my sister and me. Because my sister's marriage is shaky, I hate to leave Mom with her for long. So I end up taking care of Mom pretty much alone."

Mr. Cooke says, "My son wants me to put my wife in a nursing home. He doesn't understand that, after thirty years of marriage, I can't just put her in a nursing home." His son says, "Dad isn't being realistic. He can't manage Mother in that big two-story house. She's going to fall one of these days. And Dad has a heart condition that he refuses to discuss."

Mr. Vane says, "My brother says if I kept her more active, she would get better. He says I should answer her back when she gets nasty, but that only makes things worse. He doesn't live with her. He just stays in his own apartment and criticizes."

Division of Responsibility

The responsibility of caring for an impaired person often is not evenly shared by the family. Like Mrs. Eaton, you may find that you are carrying most of the burden of taking care of the person who has a dementing illness. There are many reasons why it is difficult to divide responsibility evenly. Some members of the family may live far away, may be in poor health, may be financially unable to help, or may have problems with their children or marriage.

Sometimes families accept stereotypes about who should help without really considering what is best. One such stereotype is that daughters (and daughters-in-law) are "supposed" to take care of the sick. But the daughter or daughter-in-law may already be heavily burdened and not able to take on this task. Perhaps she has young children, or a full-time job. Perhaps she is a single parent.

Long-established roles, responsibilities, and mutual expectations within the family, even when we are unaware of them, can play an important part in determining who has what responsibility for the impaired person. For example,

"My mother raised me; now I must take care of her."

> *"She was a good wife, and she would have done the same for me."*

> *"I married him late in life. What responsibility is mine and what responsibility is his children's?"*

> *"He was always hard on me, deserted my mother when I was ten, and he's willed all his money to some organization. How much do I owe him?"*

Sometimes expectations are not logical and may not be based on the most practical or fair way to arrange things. Sometimes there have been long-established disagreements, resentments, or conflicts in the family which are aggravated by the crisis of an illness.

Sometimes family members fail to help as much as they might because it is difficult for them to accept the reality of the impaired person's illness. Sometimes a person just can't bear to face this illness. It is painful, as you know, to watch a loved one decline. Sometimes family members who do not have the burden of daily care stay away because seeing the decline makes them feel sad. However, others in the family may view this as deserting the declining person.

Sometimes one family member assumes most of the burden of care. He may not tell other members of the family how bad things are. He may not want to burden them or he may not really want their help.

> *Mr. Newman says, "I hesitate to call on my sons. They are willing to help, but they have their own careers and families."*

Mrs. King says, "I don't like to call on my daughter. She always tells me what she thinks I am doing wrong."

Often you and other members of the family have strong and differing ideas of how things should be done. Sometimes this happens because not all family members understand what is wrong with the person who has a dementing illness, or why he acts as he does, or what can be expected in the future.

Family members who do not share the day-to-day experience of living with a person suffering from a dementing illness may not know what it is really like, and may be critical or unsympathetic. It is hard for people on the outside to realize how wearing the daily burden of constant care can be. Often, too, people don't realize how you are feeling unless you tell them.

Occasionally a family member will oppose your efforts to get outside help. If this happens, insist that the family member help take care of the ill person so that you can get some rest. If the family member lives out of town, ask him to attend a support group in his community or to volunteer some time in a program for people with dementia so that he will better understand what you are facing. Ultimately, the family must accept that the person who provides most of the care should make the final decisions to use day care, in-home care, or a nursing home. Fewer misunderstandings develop when everyone is kept informed about what resources are available and what they will cost.

Your Marriage

When the ill person is your parent or in-law, it is important to consider the effect of his illness on your marriage. Maintaining a good marriage is often not easy, and caring for a person with a dementing illness can make it much more difficult. It may mean more financial burdens and less time to talk, to go out, and to make love. It may entail being involved with your in-laws, having more things to disagree over, often being tired, or short-changing the children. It can mean having to include a difficult, disagreeable, seemingly demanding, and sick person in your lives.

A dementing illness can be painful to watch. It is understandable that a person may look at his impaired in-law and wonder if his spouse will become like that, and if he will have to go through this again.

A son or daughter can easily find himself or herself torn between the needs of an impaired parent, the expectations of brothers and sisters (or the other parent), and the needs and demands of a spouse and children. It's easy to take out frustrations or fatigue on those we love and trust most—our spouse and our children.

The spouse of an ill parent may also add problems. He or she may be upset, critical, or ill, or he may even desert his ill partner. Such problems can add to the tension in your marriage, and, if at all possible, should be discussed with everyone involved. It is sometimes easier if a son initiates a solution with his own family or a daughter with her own relatives.

A good relationship can survive for a while in the face of stress and trouble, but we believe it is important that the husband and wife find time and energy for each other—to talk, to get away, and to enjoy their relationship in the ways that they always have.

Coping with Role Changes and Family Conflict

When the family does not agree, or when most of the burden is on one person, it adds to the problems you face. The burden of caring for a chronically ill person is often too much for one individual. It is important that you have others to help—to give you "time out" from constant care, to give you encouragement and support, to help with the work, and to share the financial responsibility.

If you are getting criticism or not enough help from your family, it is usually not a good idea to let your resentment smolder. It may be up to you to take the initiative to change things in your family. When families are in disagreement or when long-established conflicts get in the way, this may be difficult to do.

How do you handle the often complex, painful role changes that are set in motion by a chronic, dementing illness? First, recognize these as aspects of family relationships. Just knowing that roles in families are complex, often unrecognized or unacknowledged, and that changes can be painful will help you feel less panicked and overwhelmed. Recognize that certain tasks may be symbolic of important roles in the family and that it is the shift of role, rather than the specific issue, which may be painful.

Find out all you can about the disease. What family members believe to be true about this illness affects how much help they provide for a person and affects whether there will be disagreements about caring for the impaired person. Family members who live out of town can attend Alzheimer's Association meetings in their community.

Think about the differences between the responsibilities or tasks that an impaired person may have to give up and the roles that he may be able to retain. For example, although John's illness means he can no longer carve a turkey or make many decisions, his *role* as Mary's loved and respected husband can remain.

Know what the impaired person is still able to do and what is too difficult for him. Of course, one wants a person to remain as self-reliant as possible, but expectations that exceed his abilities can make him upset and miserable. (Sometimes such expectations of how well he can function come from others, sometimes they come from the impaired person himself.) If he cannot do a task independently, try to simplify the job so that he can still do part of it.

Recognize that role changes are not one-time things, but are ongoing processes. As the illness progresses, you may have to continue to take on new responsibilities. Each time, you will probably reexperience some of the feelings of sadness and of being overwhelmed by your job. This is a part of the grief process in a chronic disease.

you might suggest at the beginning: everyone comes (including children who will be affected by the decision), each person has his say uninterrupted, and everyone listens to what the others have to say (even if they don't agree).

If family members disagree about what is wrong with the confused, forgetful person or about how to manage his care, it may be helpful to give other members of the family this book and other written materials about the specific disease, or to ask the doctor to talk with them. It is surprising how often this reduces the tensions between family members.

Here are some questions to ask of each other when you get together. What are the problems? Who is doing what now? What needs to be done, and who can do it? How can you help each other? What will these changes mean for each of you? Some of the practical questions that may need to be discussed are: Who will be responsible for daily care? Does this mean giving up privacy? not having friends over? not being able to afford a vacation? Does this mean that parents will expect their children to act more grown up because the parents will be busy with the sick person? Who will make the decision to put a parent in a nursing home? Who will be responsible for the sick person's money?

If a well spouse of the impaired person is to move into a son or daughter's home with the impaired person, what will this person's roles in the family be? Will she have responsibility for the grandchildren? Will there be two people using the kitchen? An expanded family can and who is paying these bills? When a family cares for a person at home, there are many "hidden" costs to consider: special foods, medication, special door latches, a sitter, transportation, another bed and a dresser on the ground floor, grab bars for the bathroom, perhaps the cost of a spouse's not working in order to care for the confused person.

4. Does everyone know what it costs to care for a person with a dementing illness in a nursing home, and does everyone know who is legally responsible for those costs? (We discuss nursing home costs in Chapter 16.) Sometimes when a daughter says, "Mother must put Dad in a nursing home," she does not realize that doing so may have serious financial consequences.

5. Do some members of the family feel that money has been unequally distributed in the past? For example,

> *"Dad put my brother through college and gave him the down payment on his house. Yet now my brother won't take him, so I get the work—and the cost—of taking care of him."*

Families sometimes say, "There is no way you'll get my family together to talk about things like that. My brother won't even discuss it on the phone. And if we did get together it would just be a big fight." If you feel that your family is like this, you may be discouraged. Although you need your family's help, you may feel trapped because you feel that your family will not help. It is not unusual for families to need the help of an outside person—a counselor, minister, or social worker—to help work out their problems and to help them arrive at equitable arrangements. (See pp. 397–99.)

One of the advantages of seeking the assistance of a counselor is that he can listen objectively and help the family keep the discussion on the problems you face and not drift aside into old arguments. Your doctor, a social worker, or a counselor may be able to intervene on your behalf and convince everyone involved of the need for a family to discuss issues of concern to them all. Sometimes a family attorney can help. If you seek the help of an attorney, select one who is genuinely interested in helping resolve conflict rather than helping you get into litigation against your own family. If a family is having difficulty and you ask a third party to help you, the first topic of conversation may be to agree that the third party will not take sides with any one person.

You need your family. Now is an excellent time to put aside old conflicts for the sake of the impaired person. Perhaps if your family cannot resolve all your disagreements, you can, in a discussion, find one or two things upon which you agree. This will encourage everyone and the next discussion may be easier.

When You Live out of Town

> *"My father takes care of my mother. They live about a thousand miles from here and it's hard for me to get back home often. I don't think Dad tells me how bad things really are. It's just terribly hard to be so far away: You feel so guilty and helpless."*

> *"I'm just the daughter-in-law, so I can't say much. They haven't gotten a good diagnosis. They keep going to this old family doctor. I worry that there is something else wrong with her. But every time I make a suggestion, they pretend they didn't hear it."*

Not living in the same community as the confused person and the person who provides daily care creates special problems. Long-distance family members care just as much as those close to home and they often feel frustrated and helpless. They worry that they do not know what is really happening, that the caregiver has not gotten the best diagnosis, or that the caregiver should do things differently. They may feel guilty that they cannot be nearby at a time when their family needs them.

In the beginning it can be more difficult to accept the severity of a person's limitations if you see the person infrequently. Later, the shock of seeing how a person has declined can be heartbreaking.

Your support of the person who provides the daily care is probably the single most important contribution you can make to the ill family member. The dementing illnesses usually last for several years. You need to build family cooperation for the long haul. If the person who provides daily care rejects your suggestions at first, she may accept them later.

Consider having the ill person spend several weeks with you, or go stay with the ill person, to give the usual caregiver a break. Moving an ill person to another home can be upsetting, but, especially early in a dementing illness, it might serve as a "vacation" for the ill person as well as the caregiver.

When You Are Not the Primary Caregiver, What Can You Do to Help?

American families do not abandon their elderly members, nor do they abandon each other. Despite differences, families usually resolve their disagreements enough to pull together for the long haul.

There are many things family members can do. One caregiver may need a telephone call every day; another may need a sitter so he can go out one night a week; one may need someone who can run over on short notice when things get difficult; another may just need a shoulder to cry on.

Stay in close touch. Maintain open lines of communication with the caregiver. This will help you sense when the caregiver needs more help. Caregivers manage better and experience less stress when they feel well supported by their family. It is not solely how much help caregivers receive, but also how well supported they feel that helps them cope better.

Avoid criticizing. Criticism usually does not lead to constructive change. None of us likes to be criticized. Many of us tend to ignore criticism. If you must say something, be sure your criticism is valid. If you do not live close, are you sure you completely understand the problem?

Recognize that the primary caregiver must make the *final decisions.* Although you can offer help and advice, the person who provides care day in and day out must be the one to decide things like whether she can use outside help and whether she can continue to provide care.

Take on the job of finding help. Caregivers are often so overwhelmed that they cannot seek a sitter or day care program, better medical care, supportive equipment, or help for themselves. Just finding respite can require many telephone calls. Take on this job and be gentle and supportive as you persuade your relative to use respite.

Be informed. You can help most if you understand both the disease and what the caregiver in your family is going through. There are excellent books describing the dementing illnesses and books by caregivers. Attend family support group meetings in your community. You may meet other long-distance family members, and you can learn from primary caregivers what *their* long-distance relatives did that helped most. Avoid the temptation to ignore the problem. These diseases are so devastating that the whole family must pull together.

Call the ill person's physician and others who have evaluated him. If they are willing, ask direct questions (see Chapter 2). If you have concerns about the diagnosis, adequacy of the assessment, or likely course of the disease, ask the professionals who know the person.

Take on tasks the confused person used to do. Balance the checkbook, take the car to the mechanic, bring over a home-cooked meal.

Give the caregiver time off. Care for your relative for a weekend, a week, or a few days so that the primary caregiver can get away. Many Alzheimer's Association chapters will teach you the basics of caregiving before you undertake this. Not only will it be valuable for the caregiver to get away, but this will bring you and the caregiver closer together. Do things that are therapeutic and fun for the ill person: take walks, go out to dinner, play with the cat together, or go window shopping.

Obtain help if you cannot provide it yourself. In many communities you can obtain sitter care and adult day care. You can also pay someone to do the shopping, get the car fixed, or track down resources.

Caregiving and Your Job

Many caregivers are juggling the care of a person with dementia and a full- or part-time job. The double demands of caring and holding down a job can be overwhelming. Some caregivers must take time off from work each time there is a problem with the ill person. Sometimes, when there is no other choice, caregivers must leave the confused person alone even if this is really not safe. Even caregivers who use a good adult day care program or a reliable sitter face extra demands and problems. For example, when the person with dementia is awake and active at night, the caregiver loses sleep.

If you are thinking about leaving your job to provide full-time care, consider the options carefully. Many caregivers have found that they were more stressed and more depressed after giving up a job. Full-time caregiving may mean that you must put up with the person's annoying behavior all the time, and may mean that you will be more isolated and trapped than when you could get out of the house and go to work. Leaving your job usually means a significant loss of income. It may mean putting your career on hold and not staying current in your profession. Returning to work after several years of caregiving can be difficult. Will there be a vacancy? Will you have lost seniority or benefits?

Before you make a decision to leave, discuss your options with your employer. Can you arrange more flexible hours? Can you share the job? Is a paid or unpaid leave of absence possible? Some loving daughters and sons find that a good nursing home is a wiser choice for both themselves and their ill patient.

Your Children

Having children at home can create special problems. They, too, have a relationship with the sick person, and they have complex feelings—which they may not express—about his illness and roles in the family. Parents often worry about the effect that being around a person with a dementing illness will have on children. It is hard to know what to tell a child about a parent's or grandparent's "odd" behavior. Sometimes parents worry that children will learn undesirable behavior from people with dementing illnesses.

Children are usually aware of what is going on. They and loving relationships with them. Try to create an atmosphere in which the child can ask you questions and express his feelings openly. Remember that children also feel sadness and grief, but they may be able to enjoy the childlike ways of an impaired person without feeling at all sad. The more comfortable you feel in your understanding of this illness, the more easily you will be able to explain it to your child.

Children may need help knowing what to tell playmates who tease them about a “funny” parent or grandparent.

It is unlikely that children will mimic the undesirable behaviors of a person with a dementing illness for long if you don’t make a big deal out of this should it happen and if the child is getting enough love and attention. Clearly explain (probably several times) to the child that his parent or grandparent has a disease and cannot help what he does but that the child can, and is expected to, control his behavior.

Young people may be frightened by unexplained, strange behavior. Sometimes they worry that something they did or might do will make the person worse. It is important to talk about these concerns and to reassure the young person.

One family with children ranging from ages 10 to 16 shared with us the following thoughts based on their own experience:

- Don’t assume that you know what a youngster is thinking.

- Children, even small children, also feel pity, sadness, and sympathy.
- If we had it to do over again, we would talk more with the children.
- The effects of this illness linger long after the confused person has gone to a nursing home. Get together with the children afterward and continue to discuss things.
- Make an effort to involve all of the children equally in the person's care. Children can find it hard to be depended on or they can feel left out. Sharing in care gives them a sense of responsibility.
- The parent closest to the sick person needs to be aware of the children's feelings and of how her grief and distress may be affecting them. Sometimes parents can be so overwhelmed by their own troubles that they forget the children. Their behavior can be as hard on the children as the illness itself.

Perhaps the biggest problem when there are children at home is that the parent's time and energies are divided between the ill person and the children—with never enough for both. In order to cope with this double load you will need every bit of help available—the help of the rest of the family, the resources of the community, and time—for you to replenish your own emotional and physical energies. You may find yourself torn between neglecting the children and neglecting a "childish" or demanding person with a dementing illness.

As the person's condition worsens, so may your dilemma. The declining person may need more and more time that they may feel resentful or embarrassed. Mixed feelings lead to mixed actions that are often puzzling to other family members. Adolescent years can be hard for young people, whether there are problems at home or not. However, many adults, looking back, recognize that sharing in family problems helped them to become mature adults.

Be sure your adolescent understands the nature of the disease and what is happening. Be honest with him about what is going on. Explanations, given gently, help a lot. Children seldom benefit from attempts to shelter them. Involve the adolescent in the family discussions, groups, and conferences with health professionals, so that he, too, understands what is happening.

Take time away from the sick person, when you are not exhausted or cross, to maintain a good relationship with your adolescent and to listen to his interests. Remember that he has a life apart from this illness and this situation. Try to find space for his teenage friends apart from the impaired person.

Remember that you may be less patient or more emotional because of all you are dealing with. Again, breaks for you may help you be more patient with your children.

When a grandparent moves into your home, it is important that both he and your children know who sets the rules and who disciplines the children. When the grandparent is forgetful, it is important that your children know *from you* what is expected of them to avoid conflicts like, "Grandmother says I can't date" or "Granddad says I have to turn off the TV."

others do not. Sometimes people think that certain feelings are unacceptable—that they should not have certain feelings or that, if they do, no one could possibly understand them. Sometimes they feel alone with their feelings.

Sometimes people have mixed feelings. One might both love and dislike the same person, or want to keep a family member at home and put her in a nursing home, all at the same time. Having mixed feelings might not seem logical but it is common. Often people do not realize that they have mixed feelings.

Sometimes people are afraid of strong emotions, perhaps because such feelings are uncomfortable, perhaps because they are afraid they might do something rash, or perhaps because they are concerned about how others will view them. These and other responses to our feelings are not unusual. In fact, most of us will have similar responses at one time or another.

We do not believe there is a "right" way to handle emotions. We think that recognizing how you feel and having some understanding of why you feel the way you do are important, because your feelings affect your judgment. Unrecognized or unacknowledged feelings can influence the decisions a person makes in ways that he does not understand or recognize. You can acknowledge and recognize your feelings—to yourself and to others—but you have a choice of when, where, and whether to express your feelings or to act on them.

People sometimes worry that not expressing feelings causes "stress-related" diseases. Suppose you know that

> *talk to me?' Then I started yelling at him and I yelled and yelled."*

Episodes like this can wear out even the most patient person. It seems as if they always start when we are most tired.

The things that are most irritating sometimes seem like little things—but little things mount up, day after day.

> *Mrs. Jackson says, "I had never gotten along with my mother that well, and since she's come to live with us, it's been terrible. In the middle of the night she gets up and starts packing.*
>
> *"I get up and tell her, 'It's the middle of the night, Mother,' and I try to explain to her that she lives here now; but I'm thinking, if I don't get my sleep I won't be any good at work tomorrow.*
>
> *"She says she has to go home, and I say she lives here, and every night a fight starts at two o'clock in the morning."*

Sometimes a person with a dementing illness can do some things very well and appear unwilling to do other, seemingly identical tasks. When you feel that the sick person can do more or is just acting up to "get your goat," it can be infuriating. For example,

> *Mrs. Graham says, "She can load the dishwasher and set the table just fine at my sister's house but at my house she either refuses to do it or she makes a terrible mess. Now I know it's because I work and she knows I come home tired."*

It is often helpful to think about the difference between being angry with the person's *behavior* and being angry with the *person herself.* She is ill and often cannot stop her behavior. Certainly, the behavior can be infuriating, but it is not aimed at you personally. A dementing illness might make it impossible for a person to be deliberately offensive because she has lost the ability to take purposeful action. Mrs. Palombo's husband was not deliberately insulting his family. His behavior was the result of his illness.

It often helps to know that other families and professional caregivers have the same problems.

> *Says Mrs. Kurtz, "I didn't want to put my husband in day care, but I did it. It helped me so much to find out that his constant questions made trained professionals angry too. It wasn't just me."*

Many families find that discussing their experiences with other families helps them to feel less frustrated and upset.

Sometimes it is helpful to find other outlets for your frustrations: talking to someone, cleaning closets, or chopping wood—whatever ways you have used in the past to cope with your frustrations. A vigorous exercise program, a long walk, or taking a few minutes to relax totally may be helpful for you.

Embarrassment

Sometimes the behavior of a person with a dementing illness is embarrassing, and strangers often do not understand what is happening.

you going to say "What is done is done" and go on from there? There is no way to remedy the fact that you never liked your mother or that you slapped a sick person, for example. However, guilt feelings tend to keep us looking for ways to remedy the past instead of letting us accept it. Make decisions and plans based on what is best now. For example,

> *Mrs. Dempsey had never liked her mother. As soon as she could she had moved away from home and called her mother only on special occasions. When her mother developed a dementing illness, she brought her mother to live with her. The confused woman disrupted the family, kept everyone up at night, upset the children, and left Mrs. Dempsey exhausted. When the doctor recommended that her mother enter a nursing home, Mrs. Dempsey only became more upset. She could not bring herself to put her mother in a nursing home even though this clearly would be better for everyone.*

When the feelings of guilt in such a relationship are not acknowledged, they can destructively affect how you act. Perhaps being faced with a chronic illness is a good time to be honest with yourself about not liking someone. You can then choose whether to give a person care and respect without being influenced by not liking her. We have little control over whom we like or love; some people are not very likeable. But we do have control over how we act toward them. When Mrs. Dempsey was able to face the fact that she did not like her mother and that of Alzheimer disease does not help to slow or reverse its progression.

If you don't feel right about doing things for yourself and by yourself, remind yourself that it is important for the confused person's well-being that your life have meaning and fulfillment outside of caring for her. Rest and the companionship of friends will do much to keep you going.

When guilt feelings are keeping you from making clear-headed decisions, you may find it helpful to talk the whole thing out with an understanding counselor, a minister, or other families so that you can go on more easily. Learning that most people do similar things helps to put little nagging guilt feelings in their proper perspective. If, after doing the best you can, you still feel immobilized by guilt, this may be a symptom of depression. We discuss depression in caregivers and what to do about it later in this chapter.

Laughter, Love, and Joy

A dementing illness does not suddenly end a person's capacity to experience love or joy, nor does it end her ability to laugh. And, although your life may often seem filled with fatigue, frustration, or grief, your capacity for happier emotions is not gone either. Happiness may seem out of place in the face of trouble, but in fact it crops up unexpectedly. The words of a song written by Sister Miriam Therese Winter of the Medical Mission Sisters reflect this:

made decisions" or "She was always such a friendly person." When these things change, it may precipitate feelings of sadness, which are sometimes not understood by people less close to the situation. For example, when a person is unable to talk or understand clearly, her family may acutely feel the loss of her companionship.

A husband or wife has lost the spouse he or she used to have but is not a single person. This creates a special set of problems, which we will discuss below, in the section "You as a Spouse Alone."

Another problem is that the grief that follows a death is understood and accepted by society, while the grief that comes with a chronic illness is often misunderstood by friends and neighbors, especially when the ill person looks well. Your loss then is not as visible as it is in a death. "Be grateful you still have your husband," or "Keep a stiff upper lip," people may say.

There are no easy antidotes for grief. Perhaps you will find, as others have, that it is eased somewhat when it is shared with other people who are also living with the unique tragedy of a dementing illness. You may feel that you should keep feelings of sadness and grief to yourself and not burden others with your troubles. However, sharing these feelings can be comforting and can give you the strength you need to continue to care for a declining person.

Depression

Depression is a feeling of sadness and discouragement. It is often difficult to distinguish between depression and grief, or between depression and anger, or depression and worry. Families of the chronically ill often feel sad, depressed, discouraged, or low, day after day, week after week. Sometimes they feel apathetic or listless. Depressed people may also feel anxious, nervous, or irritable. Sometimes they don't have much appetite and have trouble sleeping at night. The experience of being depressed is painful; we feel miserable and wish for relief from our sad feelings.

A chronic dementing illness takes its toll on our emotions and provides a real reason for feeling low. Sometimes counseling helps reduce the depression you experience, but counseling cannot cure the situation that has made you depressed; it can only help you deal with it. Many families find that it helps to share experiences and emotions with other families in support groups. Others find that it helps to get away from the sick person and spend time with hobbies or people they enjoy. When you are unable to get enough rest, your fatigue may make your feelings of discouragement worse. Getting help so that you can rest may cheer you up. Still, the feelings of discouragement and depression may stick with you—understandably.

For a few people depression goes beyond—or is different from—the understandable feelings of discouragement caused by this illness. If any or several of the things listed on pages 394–97 are happening to you or someone else in the family, it is important to find a physician who can help you or can refer you to a counselor. They can help significantly.

with depression and fatigue and is a fact of life for families. Each person has his own way of coping with worries: some people seem to shrug off serious problems, others seem to fret interminably over trivia, most of us fall somewhere in between. Most of us have also discovered that the kind of worrying we do when we lie awake at night does not solve the problem, but it does make us tired. Some of this kind of worrying is often inevitable; but if you are doing a lot of it, you may want to take yourself in hand and look for other ways to manage your problems.

A woman who faces some real and terrible possibilities in her life has tried this approach to worry: "I ask myself what is the worst thing that could happen. We could run out of money and lose our home. But I know people wouldn't let us starve or go homeless. It seems like I don't worry as much once I've faced what the worst could be."

Being Hopeful and Being Realistic

As you struggle with the person's dementing disease, you may find yourself sometimes chasing down every possible hope for a cure and other times feeling discouraged and defeated. You may find yourself unable to accept bad news the doctors have given you. Instead, you may seek second, third, and even more medical opinions at great expense to yourself and the sick person. You may find yourself refusing to believe that anything is wrong. You may even find yourself giggling or acting silly when you really don't have anything to laugh about. Such feelings are normal and are usually a part of our mind's efforts to come to terms with something we don't want to have happen.

Sometimes, of course, ignoring the problem can endanger the sick person (for example, if she is driving or living alone when she cannot do so safely). Seeking many medical opinions can be futile, exhausting, and expensive, but sometimes seeking a second opinion may be wise.

This experience of a mixture of hope and discouragement is common to many families. The problem is complicated when professionals give conflicting information about dementing illnesses.

Most families find reasonable peace in a compromise between hope and realism. How do you know what to do?

Know that we may be a long way from a major research breakthrough or we may be close. Miracles do happen, and yet not often.

Ask yourself if you are going from doctor to doctor hoping to hear better news. If your reaction is making things more difficult or even risky for the confused person, you need to rethink what you are doing. If you are ignoring her impairments, is she endangering herself by driving, cooking, or continuing to live alone?

Put the sick person in the care of a physician whom you trust. Make sure that this physician is knowledgeable about dementing illnesses and keeps abreast of current research. Avoid quack "cures."

Keep yourself informed about the progress of legitimate research. Join the Alzheimer's Association and local groups to keep abreast of new knowledge.

someone else is dependent on you for care, your sickness can become a serious problem. Who takes care of the confused person when you have the flu? You, probably. You may feel that you have no choice but to keep on dragging yourself around and hope you don't wear out.

Our bodies and our minds are not separate entities; neither is one the slave of the other. They are both parts that make up a whole person, and that whole person can be made less vulnerable—but not invulnerable—to disease.

Do what you can to reduce fatigue and to get enough rest. Eat a well-balanced diet. Get enough exercise.

Arrange to take a vacation or to have some time away from your duties as caregiver.

Avoid abusing yourself with alcohol, drugs, or overeating. Get an expert—a good physician—to check you routinely for hidden problems, such as high blood pressure or anemia and chronic low-grade infections.

Few of us do all that we can to maintain good health even when we have no other serious problems. When you are caring for a chronically ill person, there is often not enough time, energy, or money to go around, and it is yourself that you most often cut short. However, for your sake, and, very importantly, for the sick person's sake, you must do what you can to maintain your health.

Sexuality

It can seem insensitive to think about your own sexuality when there are so many pressing worries—a chronic illness, financial concerns, and so forth. However, people have a lifelong need to be loved and touched, and sexuality is a part of our adulthood. It deserves to be considered. Sometimes sex becomes a problem in a dementing illness, but sometimes it remains one of the good things a couple still enjoys. This section is for those couples for whom it has become a problem. Do not read this *expecting* a problem to develop.

If Your Spouse Is Impaired

Despite the so-called sexual revolution, most people, including many physicians, are uncomfortable talking about sex, especially when it involves older people or handicapped people. This embarrassment, combined with misconceptions about human sexuality, can leave the spouse or companion of a person with a dementing illness alone in silence. Many articles on sex are no help; the subject often cannot be discussed with one's friends; and, if one gets up the courage to ask the doctor, he may quickly change the subject.

At the same time, sexual problems, like many other problems, are often easier to face when they can be acknowledged and talked over with an understanding person.

The spouse of a brain-impaired person may find it impossible to enjoy a sexual relationship when so many other aspects of the relationship have changed so drastically. For many people their sexual relationship can only be good when the whole relationship is good. You may be unable to make love with a person with whom you can no longer enjoy sharing conversation, for example. It may not seem "right" to enjoy sex with a person who has changed so much.

When you are feeling overwhelmed by the tasks of caring for a sick person, when you are tired and depressed, you may be totally uninterested in sex. Sometimes the person with the dementing illness is depressed or moody and loses interest in sex. If this happens early, before the correct diagnosis has been made, it can be misinterpreted as trouble in the relationship.

Sometimes the sexual behavior of a person with a brain disorder may change in ways that are hard for her partner to accept or manage. When the impaired person cannot remember things for more than a few minutes, she may still be able to make love, and want to make love, but will almost immediately forget when it is over, leaving her spouse or partner heartbroken and alone. A few such experiences can make you want to end this aspect of life forever.

Sometimes the person you have cared for all day may say "Who are you? What are you doing in my bed?" Such things can be heartbreaking.

Memory loss can sometimes cause a formerly gentle and considerate person to forget the happy preliminaries to sex. This, too, can be discouraging for the partner.

Occasionally a brain injury or brain disease will cause a person to become sexually demanding. It can be devastating to a spouse when a person who needs so much care in other ways makes frequent demands for sex. This problem is rare, but it is difficult to treat when it does occur. Medication is seldom helpful except to sedate the ill person. If the problem persists, you should think about placement out of the home. When the sexual behavior of a person with a dementing illness changes, this very likely relates to the brain injury or brain damage and is something the person cannot help; it is not a purposeful affront to your relationship.

Often what people miss most is not the act of sexual intercourse but the touching, holding, and affection that exist between two people. Sometimes, for practical reasons, the well spouse chooses to sleep in a separate room. Sometimes a formerly affectionate person will no longer accept affection when she becomes ill.

> *Mr. Bishop says, "We always used to touch each other in our sleep. Now if I put an arm across her she jerks away."*

What can you do about problems of sexuality? Like many of the other problems, there are no easy answers.

It is important that you understand from your spouse's physician the nature of her brain damage and how it affects this and all other aspects of behavior. If you seek help with this problem, be sure the counselor is qualified. Since sexuality is such a sensitive issue, some counselors are not comfortable discussing it or they give inappropriate advice. The counselor should have experience addressing the sexual concerns of handicapped people and should clearly understand the nature of a dementing illness. He should be aware of his own feelings about sexual activity in elderly or handicapped people. There are excellent counselors who have talked about sexuality with many families and who will not be shocked or surprised at what you say. There are also some insensitive people posing as sex counselors whom you will want to avoid.

If Your Impaired Parent Lives with You

So far we have discussed the problems of the spouse of a person with a dementing illness. However, if your ill parent has come to live with you, the sexual aspect of your marriage can be badly disrupted, and this can affect other areas of your relationship. You may be too tired to make love, or you may have stopped going out together in the evening and thus lost the romance that precedes love making. Your confused parent may wander around the house at night, banging things, knocking on your door, or shouting. The least little noise may rouse the parent you tried so hard to get to sleep. Love making can turn into hurried sex when you are too tired to care, or it can cease altogether.

Relationships are enriched by all of the parts of a relationship: talking together, working together, facing trouble together, making love together. A strong relationship can survive having things put aside for a while but not for a long time. It is important that you find the time and energy to sustain a good relationship. Carefully review the discussion in Chapter 13. Make yourself find ways to create the romance and privacy you need at times when neither of you is exhausted.

The Future

It is important that you plan for the future. The future will bring changes for the person with a dementing illness and many of these changes will be less painful if you are prepared for them.

Some husbands and wives discuss the future while both of them are well. If you can do this, you will feel more comfortable later, when you have to make decisions for your spouse. Helping the forgetful person talk about the future and how she would like her possessions disposed of can help her feel that this is her life and that she has some control over her final years. Other people will not want to think about these things and should not be pressured to do so.

Members of the family may also want to discuss what the future will bring, perhaps talking it over a little at a time. Sometimes, thinking about the future is too painful for some members of the family. If this happens, you may have to plan alone.

Here are some of the things you will want to consider. (We discuss each of these concerns elsewhere in this book.)

- What will the ill person be like as her illness progresses and as she becomes increasingly physically disabled?
- What kind of care will she need?
- How much will you honestly be able to continue to give to this person?

- At what point will your own emotional resources be exhausted?
- What other responsibilities do you have that must be considered?
- Do you have a spouse, children, or a job that also demands your time and energies?
- What effect will this added burden have on your marriage, on growing children, or on your career?
- Where can you turn for help?
- How much help will the rest of the family give you?
- What financial resources are available for this person's care?
- What will be left for you to live on after you have met the expenses of care? It is important to make financial plans for the future even if you and the ill person have only a limited income. The care of a severely ill person can be expensive. (See Chapter 15.)
- What legal provisions have been made for this person's care?
- Will the physical environment make it difficult for you to care for an invalid? (Do you live in a house with stairs that the person will eventually be unable to manage? Do you live in a big house that may be difficult to maintain? Do you live a long way from stores? Do you live in an area where crime is a problem?)

As time passes, you, the caretaker, may change. In some ways you may not be the same person you were before this illness. You may have given up friends and hobbies because of this illness, or you may have changed your philosophy or your ideas in the process of learning to accept this chronic illness. What will your future be like? What should you do to prepare for it?

You as a Spouse Alone

This was a difficult section of this book for us to write. We know that husbands and wives think about their futures but we have no "right" answers to give you. Each person is unique. What is right for one person is not right for another, and only you can make those decisions. However, as you think through these things, there are several factors you will want to consider.

Your status changes. Sometimes a spouse feels that he is neither part of a couple (because they can no longer do many things together, talk together, or rely on each other in the same ways) nor a widower.

Couples sometimes find that friends drift away from them. This is a particularly difficult problem for the well partner. "Couple" friends often drift away simply because the friendship was based on the relationship among four people, which has now changed. Establishing new friendships can be difficult when you can no longer include your spouse and yet you still have the responsibility for her care. You may not want to make new friends alone.

You may face a future without the ill person. Statistics indicate that dementing illnesses shorten the life of those who contract them. It is probable that she will die before you do or that she will become so ill that she needs nursing home care. It is important that, when the time comes that you are alone, you have friends and interests of your own.

A husband told of trying to write an account of what it is like to live with someone who has a dementing illness. He said, "I realized that I was telling the story of my own deterioration. I gave up my job to take care of her, then I had no time for my hobbies, and gradually we stopped seeing our friends."

As the illness progresses and the person needs more and more care, you may find yourself giving up more and more of your own life in order to care for her. Friends do drift away, there is no time for hobbies, and you can find yourself alone with an invalid.

What then happens to you after she has become so ill that she must be placed in a nursing home or after she dies? Will you have "deteriorated"—become isolated, without interests, lonely, used up? You need your friends and your hobbies through the long illness to give you support and a change of pace from the job of caregiver. You are going to need them very much after you are left alone.

Even though placing a person in a nursing home means that others will provide the day-to-day care and that you will have more free time, you may find that you feel as burdened and distressed after the person's placement as you did before. Place reasonable limits on the amount of time you spend at the nursing home. Be prepared for an adjustment period and make plans to resume interests and contacts with friends. (See Chapter 16.)

The problems of being alone but not single are real. Usually the relationship between husband and wife changes as the dementia progresses. For many caregivers, the relationship continues to have meaning. For some this means a continuing commitment to a changed relationship. For others it means establishing a new relationship with another person.

One husband said, "I will always take care of her but I've started dating again. She is no longer the person I married."

A wife says, "It was a terribly difficult decision. For me, the guilt was the hardest part."

Another husband said, "For me, caring for her, keeping my promise, is most important. It is true that she is not the same, but this too is a part of our marriage. I try to see it as a challenge."

Sometimes it happens that a person falls in love again while he is still caring for his ill spouse. If this happens to you, you face difficult decisions about your own beliefs and values. Perhaps you will want to talk this over with people close to you. Perhaps the "right" decision is the decision that is "right" for you. Family members often find that their children and in-laws are very supportive.

Not all marriages have been happy. When a marriage was so unhappy that a spouse was already considering divorce when the person became ill, the illness can make the decision more difficult. A good counselor can help you sort out your mixed feelings.

In any event, should you be faced with questions about new relationships, divorce, or remarriage, you are not alone. Many others have also faced—and resolved—these dilemmas.

When the Person You Have Cared for Dies

People often have mixed feelings when the person they've been caring for dies. You may feel glad in some ways that the ill person's suffering and your responsibilities are over, but sad at the same time. There is no "right" way to feel after the death of someone with a dementia. Some people have shed their tears long ago and feel mostly relief. Others are overwhelmed by grief.

Talking about your feelings with someone you trust can be helpful. Sometimes, saying things out loud helps clarify your feelings and thoughts. If you find your feelings changing over time, remember that this too is normal.

When much of your time and emotional energy were focused on the person's care, often for many years, you may find yourself at loose ends after the death. You may have lost touch with friends, given up your job or your hobbies. No longer carrying the responsibility you had for so long may bring feelings of both relief and sadness.

One wife said tearfully, "I don't have to tell anyone how they can reach me when I'm away."

responsibilities may be, you probably feel anxious, saddened, and frustrated.

Throughout this book we have offered suggestions for ways to modify annoying behaviors. While modifying the ill person's behavior will help considerably, it is often not possible to eliminate some behaviors and they may continue to get on your nerves. To continue to cope, you will need to get enough rest and sometimes to get away from the ill person.

This book has emphasized that behavior problems are caused by the brain damage: neither you nor the confused person can prevent problems. However, your *mood* can affect the ill person's behavior. When you are rushed, tense, or irritable, the confused person may sense your feelings. He may become more anxious or more irritable, move more slowly, or begin an annoying behavior. When you are rested and feel better, the person may manage better and feel better too.

It is not unusual for family members to feel alone in their struggle with a chronic illness. Friends may drift away and one doesn't know about other people with similar problems. It may seem impossible to get out of the house, and life narrows down to a tight circle of lonely misery. Feelings of sadness and grief seem more painful when you also feel alone with your problem.

For all of these reasons you need to take care of yourself. You need enough rest, time away from the sick person, and friends to enjoy, to share your problems with, and to laugh with. You may find that you need additional help to cope with your feelings of discouragement or to sort out the disagreements in the family. You may decide that it will help you to join other families to exchange concerns, to make new friends, and to advocate better resources for people with dementing illnesses.

Take Time Out

> *"If only I could get away from Alzheimer disease," Mrs. Murray said. "If only I could go someplace where I didn't have to think about Alzheimer disease for a little while."*

It is absolutely essential—both for you and for the person with a dementing illness—that you have regular times to get away from twenty-four-hour care of the chronically ill person. You must have some time to rest and to be able to do some things *just for yourself.* This might be sitting down uninterrupted to watch television or it might be sleeping through the night. It might mean going out once a week or taking a vacation. We cannot overemphasize the importance of this. The continued care of a person with a dementing illness can be an exhausting and emotionally draining job. It is quite possible to collapse under the load.

It is important that you have other people to help you, to talk with, and to share your problems. We know that it can be difficult to find ways to care for yourself. You may not have understanding friends, your family may not be willing to help, and it may seem impossible to get time away from the sick person. The confused person may refuse to stay with anyone else, or you may not be able to afford help. Finding ways to meet your own needs often takes effort and ingenuity. However, it is so important that it must be done.

If resources to give you time out are difficult to find, perhaps you can piece together a respite plan. For example,

> *Mr. Cooke persuaded the day care center to take his wife one day a week by agreeing to teach the staff how to manage her. His son, who lived out of state, agreed to pay for the day care. His neighbor agreed to come over and help get his wife dressed on those mornings.*

You may also have to compromise, and accept a plan that is not as good as you would like. The care others give may not be the same as the care you try to give. The confused person may be upset by the changes. Family members may complain about being asked to help. Paying for care may mean financial sacrifices. But be persistent in your search for help, and be willing to piece things together and to make compromises.

Taking time out, away from the care of the confused person, is one of the single most important things that you can do to make it possible for you to continue to care for someone with a dementing illness.

> *Mrs. Murray said, "We had planned for a long time to go to France when he retired. When I knew he would never be able to go, I went alone. I left him with my son. I was scared to go alone, so I went with a tour*

tion, he may still not be remembering names or really following conversations. It is important to explain to friends that forgetfulness is not bad manners but something the person cannot avoid.

It can be painful to tell old friends what is happening, especially those who do not live nearby and have not seen the gradual changes a dementing disease causes. Some families have solved this problem by composing a Christmas letter, lovingly and honestly sharing this illness with distant friends.

Avoid Isolation

What can you do if you find yourself becoming isolated? It takes energy and effort to make new friends at a time when you may be feeling tired and discouraged. But this is so important that you must make the necessary effort. Start by finding one small resource for yourself. Little things will give you the guidance and energy to find others. Call your nearest Alzheimer's Association chapter (see p. 401). Join a support group for families or get one going yourself. Maintain or renew ties with your church or synagogue. Your rabbi, priest, or minister can offer you comfort and support. Friendships within the church can develop, and many churches have some resources to provide practical help for you.

As you find time for yourself away from the person you are caring for, use that time to do things with other people: pursue a hobby or attend discussion groups. New friends are most easily made when you are involved in activities you have in common with other people.

We know that it is difficult to find the time or energy to do anything beyond the necessary care of the sick person. Some activities can be put on the "back burner" while you are burdened with care, but they must not be completely discontinued. This is important. When the time comes that you no longer have the care of this person, you will need friends and activities.

> *"I like to go to the Masonic lodge. I still go once a month. When Alice has to go to a nursing home, I'll probably get more involved—volunteer to run the Christmas drive or something. I still have my friends there."*

> *"I play the violin. I can't play with the quartet anymore, but I keep in touch with them and I still practice a little. When I have more time, there will be a place for me in the community symphony."*

You may also become involved in new activities, such as joining a local Alzheimer disease organization. Some spouses have deliberately sought out new activities.

> *"My wife got sick just about the same time I retired. All I was doing was taking care of her. I thought I should get some exercise, so I joined a senior citizens' exercise group. I take my wife to a day care center the day I go to that group."*

Find Additional Help If You Need It

> *Mrs. Scott says, "I worry that I am drinking too much. John and I used to have a cocktail when he got home in*

> *the evening. Now, of course, he doesn't drink, but I find I have to have that cocktail and another one at bedtime."*

Fatigue, discouragement, anger, grief, despair, guilt, and ambivalence are all normal feelings that may come with caring for a chronically ill person. Such feelings may seem overwhelming and almost constant. The burden you carry can be staggering. Sometimes one's coping skills are overwhelmed and things can drift out of control. You may want to seek professional help if this happens.

Recognize the Warning Signs

Each individual is different and each person has his own ways of responding to problems. A healthy response for one person may be unhealthy for another. Ask yourself the following questions: Do I feel so sad or depressed that I am not functioning as I should? Am I often lying awake at night worrying? Am I losing weight? Do I feel overwhelmed most of the time? Do I feel terribly isolated and alone with my problem? While depression and discouragement are common feelings for families of people with chronic diseases, if you are often lying awake at night worrying, if you are losing weight, or if you usually feel isolated, alone with your problem, or overwhelmed, perhaps you need some help to keep your feelings manageable.

Am I drinking too much? Definitions of alcohol abuse vary widely. The amount of alcohol that is too much for worth living, he may consider suicide. Suicide may be considered when someone feels that the situation he faces is hopeless, when he feels that there is nothing either he or anyone else can do. The present can seem intolerable, and the future appears bleak, dark, empty, and meaningless.

> *One family member who attempted suicide said, "Looking back, I don't know why I felt that way. Things have been hard, but I'm glad I didn't die. My perceptions must have been all mixed up."*

It is not uncommon for our *perception* of things to be more bleak than the reality. If you are feeling this way, it is important to find another person (a counselor, if possible) whose perception of the situation may be different and with whom you can talk.

Do I feel that I am out of control of my situation or at the end of my rope? Is my body telling me I am under too much stress? Do I often feel panicky, nervous, or frightened? Would it help just to talk the whole thing over with someone who understands? If the answer to some of these questions is yes, it may be that you are carrying too heavy a burden without enough help.

Counseling

It may be that all you need is more time away from a seemingly demanding, difficult person or more help in caring for him. But perhaps you see no way to find more help or more time for yourself. Perhaps you see yourself trapped by your situation. We feel that talking these problems over with a trained person is one good way to help you feel less pressured. You and he can sort out the problems you face a bit at a time. Since he is not as caught up in the problems as you are, he may be able to see workable alternatives you had not thought of. At the same time, you will know that you have a life line in this person that you can turn to if you begin to feel desperate. Family or friends can be of help as well, but if they are too close to the situation they may not be able to see things objectively.

Should you get counseling? Do you need "help"? Most people are not "sick," "crazy," or "neurotic." Most people are healthy individuals who sometimes have trouble coping with real problems. They may feel overwhelmed or discouraged, or find that they are thinking in circles. Such a person may find that talking over feelings and problems helps to clarify them.

We believe that most people most of the time do not need counseling. However, we know that counseling is sometimes a great help to families struggling with a dementing illness. Such help may come from discussion groups, clergy, an objective friend, or a social worker, nurse, psychologist, or physician.

The first step in seeking outside help is often the hardest. One's reasoning sometimes goes around and around in circles.

> *"I can't get out of the house because I can't get a sitter. He's terrible to anyone in the house but me. I can't afford counseling because I can't get a job because I*

can't leave the house, and a counselor couldn't help me with that anyway."

This kind of circular thinking is partly the product of your situation and partly the way you, in your discouragement, see the problem. A good counselor can help you objectively separate the problem into more manageable parts, and together you can begin to make changes a little at a time.

Sometimes people feel that it is a sign of their own weakness or inadequacy to go to a counselor. With the burden you carry in coping with a dementing illness, you can use all the help you can get, and this is not a reflection on your strength.

People sometimes avoid counseling because they think that the therapist will delve into their childhood and "analyze" them. Many therapists begin directly by helping you in a matter-of-fact way to cope with "here and now" concerns. Find out in advance what approach the therapist you select prefers. If you decide to seek counseling, the kind of counselor you choose may be influenced by what you can afford, who is available, and who is knowledgeable about dementing illnesses.

Psychiatrists are physicians and they are able to prescribe drugs to treat mental illness. They have a good understanding of physical problems that accompany psychological problems. Psychologists, social workers, psychiatric nurses, clergy, and some other professionals can have excellent therapeutic or counseling skills. If they do, they may be an excellent choice for counseling.

You will want to select a person whose services you can afford, who is knowledgeable about dementing illnesses, and with whom you feel comfortable.

You have a responsibility to discuss with the counselor your concerns about your relationship with him. If you are worried about your bill, if you don't like his approach, if you wonder if he is telling your family what you have said, *ask* him.

There are several ways to find a counselor. Ask the Alzheimer's Association chapter. If you have an established relationship with a clergyperson or a physician with whom you feel comfortable, ask if he can counsel you or can refer you to someone he feels is a good counselor. If you have friends who have had counseling, ask them if they liked the person they consulted. If there is an active family group in your area, ask if there is someone other members have consulted.

If you cannot find someone through such recommendations, counseling services or referrals are available from the community mental health clinic or from religious-affiliated service agencies like Jewish Family and Children's Society, Associated Catholic Charities, or Pastoral Counseling Services (these agencies usually serve people of all religions). The county medical society can give you the names of local psychiatrists.

Not all counselors are equally good, nor are they all knowledgeable about dementia. Select a counselor as carefully as you would any other service you seek and know what his credentials as a therapist are. If, after a period of time, you do not think the counselor is help-brochures about the dementing illnesses are available through the chapters. Chapters sponsor speakers and films on a wide range of topics related to dementia. They usually can refer families to physicians, respite services, attorneys, social workers, and nursing homes that other families have found to be knowledgeable about dementia. There is no charge for calling the help line or attending a support group.

Most chapters have someone who will listen supportively to your concerns and who has been a caregiver or has worked with caregivers. That person may be available over the telephone or in person. You usually do not need an appointment for a telephone conversation and there is no charge. You can usually reach someone quickly during regular business hours. These people offer understanding and suggestions on how to get help. They are usually not trained professionals; they cannot offer therapy or prescribe medications. However, if you need assistance beyond their expertise, they often can refer you to someone who has worked with other families of people with dementia.

Chapters publish newsletters, and many caregivers subscribe to several. The newsletters are full of information, letters from caregivers, and tips on how to manage. Chapters are a good source of information about current research.

Some support groups are not affiliated with the Alzheimer's Association. They may be sponsored by nursing homes, hospitals, state offices on aging, or family service agencies.

Support Groups

> *"I did not really want to go to a group, but my mother was driving me crazy and so finally I went. The speaker talked about power of attorney—until then I didn't realize I had to get one to take care of my mother's property. Then over coffee I was talking to three other women. One of them told how her mother was driving her crazy hiding the silverware in the dresser. She said one day she suddenly realized it didn't matter where they kept the silverware. Up until then I thought I was the only one dealing with things like that. I told them about my mother and these other women understood."*

> *"There are usually more women than men in groups, you know. I didn't want to go to a hen party, but there was this other fellow there whose mother-in-law lives with them, and he really understood what I am going through. Going to that support group saved my marriage."*

Thousands of family members have had the same experiences: people in support groups *understand.* Many support groups meet once a month, but schedules vary. They usually have a film or speaker, followed by coffee and a social period. They may be led by a professional or by family members.

You may find all sorts of people in support groups: bankers and construction workers, men and women, adult children, spouses, long-distance carers, and professionals who work with people with dementia. There are a few support groups for young children of people with dementia.

The dementing diseases strike people of all groups and all races, and their families are struggling with grief, exhaustion, behavior problems, and limited public services. Families of all races are doing all they can to care for their loved ones. African Americans, Hispanics, Asians, and other minorities who join a mostly white support group find that the problems they struggle with are universal, but many people feel more comfortable sharing with people from a similar background. The Alzheimer's Association or the local agency on aging will have the resources to help you get a group started. However, you must guide them in setting up a support group that meets the special needs of your community—when and where the group meets, how it is structured, the role of the group leader, etc.

Excuses

When we are overwhelmed and tired, we find excuses for not joining a support group. We don't have the energy and we don't feel up to facing a room full of strangers. Here are some answers to those excuses shared by families.

I'm not a group type of person. The families we know say "Go anyway," even if this is the only group you ever attend. These diseases are so terrible and last so long that our usual methods of coping are not sufficient. We all can use suggestions on how to cope. Just hearing that cern to caregivers and professionals (see Appendix 1), and enacted extensive nursing home reform. For the first time, nursing home residents with dementia were considered to be a separate group of patients with special needs (see Appendix 4). Private foundations initiated research and direct care programs for people with dementia. Many states have established task forces to study state needs for service and many have passed dementia-related legislation.

Perhaps the most meaningful advance is that Alzheimer disease and similar disorders are now widely recognized. Your friends and relatives have probably heard of them. Many professionals in various health-related fields have attended courses about the dementing illnesses.

However, much remains to be done. There is only enough money to fund about half of the good research projects that seek funding; diagnosis and follow-up care are not available everywhere; the federal- and state-funded respite programs are only a drop in the bucket—most families are still unable to obtain financial assistance for day care or help at home; and in many places the Alzheimer's Association chapters, help lines, and support groups are understaffed, with most of the work being provided by a few hard-working volunteers. Most nursing home care falls short of what people with dementia need. Although federal law now mandates that nursing aides have some training, most of them will learn little about the daily management of dementia.

Families often tell us that participating in advocacy efforts is a way to fight back against this terrible disease. Perhaps you will want to get involved, too. Here are some ways you might contribute.

- Participate in research projects. (See Chapter 18.)
- Answer telephones or assist with office work.
- Volunteer your skills. Can you balance the books for a small, volunteer-run day care program? Can you fix the plumbing for a struggling caregiver?
- Lead a support group. Often the best group leaders are those who have been caregivers.
- Locate and reach out to other caregivers who need support. If you have ties to minority groups, you might contact others and let them know that they are not alone.
- Participate in fund raising. Even small amounts of money make big differences. There are many skills needed in fund raising and good books on how to do it.
- Teach your local elected officials or agency leaders about dementia. Write your congressional representative or your newspaper.
- Spearhead a movement to establish a day care or home care program in your area. Many of the respite care programs for people with dementia have been created by the families who needed them.
- Work for a local political candidate who supports long-term care services.
- You may recognize a particular need in your community—help for people with dementia who are living alone or help for rural families.

14

For Children and Teenagers

This chapter is written especially for the young people who live with or know a person with a dementing illness. Most young people will be able to read and understand the rest of the book as well.

It is important that you understand what is wrong with the person and why he acts as he does. When you understand why the person does certain things, it is easier not to get mad at him. Also, it is important that you understand that he acts as he does because he is sick, not because he wants to or because of you. The person has a disease that destroys part of the brain. With a larger number of brain cells lost, the brain cannot work as it should. That is why the person forgets names, is clumsy, or can't talk properly. Parts of the brain that knew how to do these things have been damaged.

Sometimes these people get upset over little things. That is because the brain can no longer understand what is going on (even when you explain it to the person). The and you may need to get an adult to help you. Sometimes it is helpful to pick out the one thing that bothers you the most and ask your family to help you change that. Often, together you can come up with compromises that will help. For example, you might be able to put a lock on your door or get earphones for your stereo. If you have given up your room, perhaps you and your friends can fix up a place in the basement where you can get away from the sick person.

Some young people tell us that it is not the sick person's behavior that is the worst problem, but how their parents or the sick person's husband or wife acts.

> *"I don't mind Granddad, but Grandmother moved in too, and she wants me to do everything like she did when she was young."*
>
> *"It isn't Grandma, it's my mother always fighting with my grandfather."*

These may be real problems for you. The grandparent who isn't sick is probably upset about the one who is. Even when a person doesn't get upset he may be feeling sad or unhappy, and this may make that person cross or impatient or hard to live with. Probably the best you can do is to be understanding, since you know that grief and worry are the causes of the trouble. When a grandparent is setting strict standards for you or nagging you, ask your parents how they want you to handle this. If things get too difficult, find an adult who is not tired and upset—perhaps somebody outside your family—and talk it over.

a situation you cannot control, that you *do* have control over how you react to it. You decide how a bad situation affects your life.

If your grades at school drop or if you are fighting with your parents a lot or "tuning out" most of the time, you need to talk the problem over with someone. Often you can talk things over with your parents, other adult friends, or teachers. Some people are easy to talk to and some are not. Sometimes a counselor is a good person to talk with. If you cannot talk to your parents, your teachers can usually help you find a counselor. Some people feel funny about talking to a counselor. It isn't because there is something "wrong" with you that you get counseling. Here are some of the things that happen with a good counselor or someone else who is a good listener.

- You can find out what's going on.
- You can let off steam.
- You can talk with your parents with the counselor helping so that you don't fight with them.
- You can find out what your parents are thinking.
- You can say all you want about your side.
- You can ask about things that worry you—like whether the sick person will die—in private.

None of these things may solve the problem, but they will make living with the problem easier.

and plans you make now. Many factors must be considered in assessing your financial future, including the nature of the illness and your individual expectations.

Begin by assessing both the current costs of care and the potential costs as the person becomes more severely impaired and by assessing her available resources. Whether the ill person has little income or is affluent, *it is most important that you plan ahead for her financial future.*

The costs of nursing home care are discussed in Chapter 16. If there is any chance that your family member will need nursing home care, you must read this section and plan ahead. Planning can save you money and anguish.

Potential Expenses

Lost income:

Will the impaired person have to give up her job?

Will someone who would otherwise be employed have to stay at home to care for the person?

Will the impaired person lose retirement or disability benefits?

Will the real purchasing power of a fixed income decline as inflation rises?

Housing costs:

Will you or the impaired person have to move to a home that is without stairs, closer to services, or easier to maintain?

Will you move a parent into your home? This may mean expenses of renovating a room for her.

Will the person enter a life care facility, foster care, or sheltered housing?

Will you have to make modifications to your home (new locks, grab rails, safety devices, wheelchair ramps)?

Medical costs:

Will you need
  visiting nurses?
  doctors?
  medical insurance?
  evaluations?
  occupational therapists? physical therapists?
  medications?
  appliances (hospital bed, special chair, wheelchair)?
  disposable care supplies (adult diapers, moisture-proof pads, egg crate pads, petroleum jelly, tissues, cotton swabs, etc.)?

Costs of help or respite care:

Will you need
  someone to clean?
  someone to stay with the person?
  someone to help with care?
  day care?

Food costs:

Will there be costs of having meals prepared or of eating out?

Transportation costs:

someone to drive if you cannot; taxis

Taxes

Legal fees

Miscellaneous costs:
easy-to-use clothing, ID bracelets, various devices for safety or convenience
Nursing home costs:
In addition to basic costs, you may be charged for adult diapers, laundry, medications, disposable supplies, therapies, and hair care.

Potential Resources

The Impaired Person's Resources

You will want to look first at the sick person's own assets and financial resources. Consider pensions, Social Security, savings accounts, real estate, automobiles, and any other potential sources of income or capital.

Occasionally, an impaired person becomes secretive about her finances. At the end of this chapter we list some of the possible available resources she may have and where to look for the relevant documents.

Resources of the Impaired Person's Spouse, Children, and Other Relatives

Laws regarding the financial rights and responsibilities of family members, particularly when they apply to nursing home care, are complex. Not all social workers, tax accountants, or lawyers understand them. The Alzheimer's Association may be able to refer you to professionals with expertise in this area. In addition, families have feelings of obligation to each other. With obligation come dilemmas:

legal responsibility of the spouse is defined in two separate bodies of law: the laws governing Medicaid (which often pays for nursing home care) and the family responsibility laws of each state. Both federal and state laws shape Medicaid. Family responsibility law is completely under state control; thus the law is very different in different states. You will need legal advice before taking any steps to protect your financial assets.

Tax Breaks for the Elderly or for the Care of a Person with a Dementing Illness

The elderly are eligible for various tax breaks. General information about these is in the Internal Revenue Service publication "Tax Benefits for Older Americans."

Tax deductions for the care of a person with a dementing illness can make a significant difference to families. You are entitled to medical deductions for someone who is your dependent. The definition of whom you may claim as your dependent for medical deductions and the tax credit for disabled dependents allow you to claim some people who might not otherwise qualify as your dependents.

If you work and must hire someone to care for your disabled dependent, you may be entitled to a tax credit for part of the cost of the care.

Some nursing home costs that are not covered by Medicare or Medicaid may be deductible. The definitions of what part of nursing home care can be deducted and when it can be deducted are complex, and you may want to review carefully the IRS and tax court definitions of whom you can claim as your dependent and what deductions you can take.

The tax laws are being examined by family organizations and some legislators, who are urging tax relief for families who care for a disabled elderly person. You may want to look into the most recent legislation concerning your individual situation.

If you are uncertain about your rights, a tax consultant may be helpful to you. You do not have to accept as final the information given to you by the IRS staff.

State, Federal, and Private Resources

State, federal, and private funds support a range of resources, such as day care centers, Meals-on-Wheels, food stamps, sheltered housing, mental health clinics, social work services, and recreation centers. The funding source usually defines the population to be served in specific terms (such as only people over 65 or only people with income under a certain amount).

Pilot programs are programs funded for a brief period to determine their effectiveness.

Research programs are programs in which participants are studied in specific ways. Such programs sometimes offer excellent free or low-cost services. They usually have specific criteria for eligibility. Most research programs must meet exacting standards to assure that research does not harm the subjects. You will be asked to sign a consent form that explains exactly what research is being done, what risks, if any, are involved, and what benefits are to be expected. You also will be given the option of withdrawing from the study at any time.

Where to Look for the Forgetful Person's Resources

Sometimes an impaired person forgets what financial resources she has or what debts she owes. People may be private about their finances or disorganized in recording them. Sometimes suspiciousness is a part of the illness and the individual hides what she has. Families may not know what resources a person has that could be used to provide for her care.

> *A wife said, "I did not know the VA hospital would care for him. I was spending $1,500 a month for a nursing home I didn't like and I never even asked about VA."*

Finding out what resources a person has can be difficult, especially when things are in disarray or are hidden.

Debts usually turn up on their own, often in the mail. Most businesses will be understanding if a debt or bill is not paid on time. When you do find a bill, call the company, explain the circumstances, and arrange with them how and when the bill will be paid. If the confused person is losing her mail, you may be able to have it held for you at the post office.

Assets may be harder to find. Review recent mail. Look in the obvious places such as a desk, an office, clothing, and other places where papers are kept. Look under the bed, in shoe boxes, in pockets of clothes, in old purses, in teakettles or other kitchen items, under rugs, and in jewelry boxes. One wife asked the grandchildren to join her in a "treasure hunt." The children thought of obscure places to look. Look for: bank statements, canceled checks, bank books, savings books, passbooks, or checkbooks; keys; address books; insurance policies; receipts; business or legal correspondence; or income tax records for the past four to five years (a spouse filing a joint return or a person possessing a power of attorney or guardianship of property can obtain copies from the Internal Revenue Service. The power of attorney must meet IRS standards or be on their form). These items can be used to piece together a person's resources.

There are many kinds of assets.

Bank accounts. Look for bank books, bank statements, checkbooks, savings books, passbooks, statements of interest paid, joint accounts held with others. Most banks will not release information about accounts, loans, or investments to anyone whose name is not on the account. However, they may give limited information (such as whether there is an account in an individual's name) if you send a letter to the bank from your doctor or lawyer explaining the nature of the person's disability and the reason you need the information. Banks will release information about the amount in an account or about current transactions only to a court-appointed guardian or other properly authorized person. However, often you can piece together what you need to know from papers you can find.

Stock certificates, bonds, certificates of deposit, savings bonds, mutual funds. Look for the actual bonds, notices of payments due, notices of dividends paid, earnings claimed on income tax, regular amounts paid out from a bank account, receipts. Mutual funds are accounts held in the name of the broker; look for canceled checks, correspondence, or receipts from a broker. Look for records of purchase or sale.

Insurance policies (life insurance, disability insurance, health insurance). These are among the most frequently overlooked assets. Life insurance policies and health insurance policies may pay lump sum or other benefits. Look for premium notices, policies, or canceled checks that give you the name of the insurer. Contact them for full information about the policy. Some insurers will release this information upon receipt of a letter from a physician or attorney; others will need proof of your legal right to information.

Safe deposit boxes. Look for a key, bill, or receipt. You will need a court order to be permitted to open the box.

Military benefits. Look for discharge papers, dog tags, old uniforms. Contact the military to determine what benefits are available to the person. Dependents of veterans may be eligible for benefits.

Real estate property (houses, land, businesses, rental property, joint ownership or partial ownership of the above). Look for regular payments into or from a checking account, gains or losses declared on income tax, keys, fire insurance premiums (on houses, barns, businesses, or trailers). The insurance agent may be able to help you. Look for property tax assessments. Ownership of real estate property is a matter of public record; the tax assessor's office may be able to help you locate properties if you have some clues.

Retirement or disability benefits. These are also often overlooked. You must apply for Social Security, SSI (Supplemental Security Income), veterans benefits, or railroad retirement if you are eligible. Spouses and divorced spouses may also be eligible for benefits. Federal and state government employees, union members, clergy, and military personnel may have special benefits. Check into retirement or disability benefits from *all* past employers. Look for an old job résumé, which will list previous jobs. Look for benefit letters.

Collections, gold, jewelry, cash, loose gems, cars, antiques, art, boats, camera equipment, furniture, other negotiable property. In addition to looking for such items, look for valuable items listed on property insurance policies. Some of these items are small enough to be easily hidden. Others may be in plain sight and so familiar as to be overlooked.

Wills. If the individual has made a will, it should list her assets. Wills, if not hidden, are often kept in a safe deposit box, recorded by the court, or kept by one's attorney.

Trust accounts. Look for statements of interest paid.

Personal loans. Look for withdrawals, payments, correspondence, alimony payments (occasionally divorce settlements provide for payment of alimony should the wife become disabled).

manage her property, and the nature and extent of the property.

The most efficient way to prepare for an eventual disability (which could happen to any of us) is for the person to make plans for herself *before* she reaches the time when she cannot do so. Such plans usually include making a will and establishing a power of attorney (see below).

Families sometimes find it difficult to face these things when the person still seems quite able. Sometimes a confused person resists these steps. Unfortunately, waiting until the person cannot participate in decision making may cost the family thousands of dollars later or may result in decisions that no one would have wanted.

We believe that it is important to discuss with a lawyer what plans you should make. He can advise you on how best to protect the confused person and which powers should be transferred, and can see that whatever papers are drawn up are legally valid. However, these laws (particularly those governing the financial responsibility of families) are very complex. Lawyers who have not specialized in this area may not have the best information. Ask the Alzheimer's Association or a disability law center for a referral.

Lawyers specialize in different areas of law (criminal law, corporate law, divorce law, civil law). You have a right to know what you can expect from a lawyer and what his fees are. Misunderstandings can be avoided by discussing with him what he charges and what services you will get for that fee. Find out if he practices this sort of law and is knowledgeable about it.

In addition to making a will, a person who is still able to manage her own affairs (by the above definition) may sign a *power of attorney,* which gives a spouse, child, or other person who has reached legal age authority to manage her property. A power of attorney can give broad authority to the specified person or it can be limited. A limited power of attorney gives the person authority to do only specific things (sell a house or review income tax records, for example).

A power of attorney becomes void if the person who granted it becomes mentally incapacitated. This means that if you have a power of attorney to do your mother's banking, you no longer have that authority when she becomes confused. Thus, a power of attorney is of little use to the family of a person with dementia. Because of this, most states have passed laws creating a *durable power of attorney.* This authorizes someone to act in behalf of the person after she becomes unable to make her own decisions. You can tell which kind you have: a durable power of attorney must state that it can be exercised even if the person becomes disabled.

Since a power of attorney authorizes someone to act in another person's behalf, the person giving such power must be sure that the person selected will, in fact, act in her best interests. Someone who holds a power of attorney is legally responsible to act in the other person's best interests. Once in a while someone abuses this responsibility. The risk of abuse is small in a limited power of attorney but a durable power of attorney transfers greater responsibility and requires greater trust. A per-

2. Will moving mean less property for you to clean or maintain? Will help, such as meal preparation or house cleaning, be provided for you?
3. Will moving bring you close to doctors, hospitals, shopping centers, recreation areas?
4. What kind of transportation will you need?
5. Will moving put you closer to or farther from friends and family who can help you?
6. Will moving affect your eligibility for special programs or financial assistance? (You may not be eligible for some programs until you have lived in a state for a given period of time.) If you have sold your house, you may be required to spend most of your capital on nursing home care before you are eligible for Medicaid. You are not usually required to sell a house in which you are living to pay for care (see p. 454).
7. Will moving provide a safe environment for the person (call bells, a ground-floor bathroom, supervision, no stairs, lower crime rate)?
8. What will you do if your financial or physical circumstances change?

Types of Living Arrangements

Retirement communities and *senior citizens' apartments or condominiums* are planned for retired people who can live independently. In a condominium, the resident pays for a mortgage plus a monthly condominium fee for services such as the maintenance of buildings and grounds, recreation facilities, security systems, and transportation to shopping areas. In senior citizens' apartments, the resident pays rent. Retirement communities may be set up as rental units or as condominiums. These forms of housing may have emergency call services and easy access to medical facilities, but they generally do not offer special help for confused or ill people.

Assisted living facilities (also called *residential care programs*) often market specialized care for people with dementia. They may be more homelike and less like a hospital than a nursing home. Some of these facilities are an excellent option for people with dementia; others are not. Many states have regulations that govern the quality of assisted living facilities, but state standards (and inspection) vary. You have the primary responsibility to ensure that the person continues to get good care.

Use the "Family Guide" from the Alzheimer's Association to help you evaluate the facility. Ask yourself:

- What is really special about the care they provide?
- Is the care worth trade-offs such as cost or the distance you will have to travel to visit?

Find out exactly what services they provide. Many of the recently developed special dementia programs have a more social approach to care and are excellent alternatives for people with dementia.

Since assisted living facilities are not licensed to provide skilled nursing care, expect them to transfer the person to a nursing home at some point as the disease

4. What services and activities are included in the monthly fee? Is participation in community meals or activities required? What if a resident doesn't like the food or the activities?
5. Does the facility have a nursing unit? Do you like the nursing unit? Is there an extra charge for it? Does the nursing unit accept people with dementia? Is the staff trained to care for people with dementia? Is there an extra charge for people with dementia on the nursing unit? Are you satisfied with the quality of care offered? Review the guidelines on pages 463–64.
6. Can people with dementia be asked to leave? If a resident is later found to have had a pre-existing dementia, which you did not know about at the time of admission, can he be asked to leave? Under what other circumstances can a person or couple be asked to leave?
7. How are other medical, dental, and vision needs met? Does the facility have its own physician? Is transportation to medical providers available? How are medical needs met in the nursing unit? Do the physicians who work in the facility have expertise in geriatrics and do they understand the medical needs of people with dementia?

Your state may have regulations governing life-care fees, but you must carefully examine the policies and the quality of services before making an investment. Check with the state consumer protection office or the Office of the Attorney General.

In an *adult foster home* the confused person lives, for a fee, with an individual who provides a room and may provide care. Ideally, foster homes care for their guests as members of the family, and provide meals, a room, transportation to the doctor, access to social work assistance, and supervision. Many adult foster homes will not accept people with dementia; those that do may provide nothing more than food and a bed. A few adult foster homes specialize in the care of people with dementia and provide excellent care. There is little regulation of foster care in most states. If you use such a program, you generally assume full responsibility for monitoring the quality of care given. Quality can decline rapidly if the management or staff changes or if the impaired person's condition changes.

Boarding or domiciliary homes (also called homes for the aged or personal care homes) provide less care than nursing homes. They usually provide a room, meals, supervision, and some other assistance. A few specialize in dementia and offer excellent care. Some of the best special care programs in the United States are homes for the aged. Others, however, take advantage of the vulnerable person with dementia and of lax regulations. They call themselves "Alzheimer facilities," but they provide inadequate or dangerous care.

There are no federal quality-assurance standards for these facilities, and state oversight ranges from good to nonexistent. If you use such a program, you must assume full responsibility for ensuring that good care is provided. Facilities can change ownership and the quality of care can deteriorate abruptly.

Fees vary widely. Neither foster care nor domiciliary care is covered under Medical Assistance or Medicare. Many states supplement the federal Supplemental Security Income (SSI) pension to help pay for housing. Some homes accept Social Security as full or partial payment.

Social workers in hospitals may be under pressure to place patients quickly. You should not rely solely on the hospital social worker's word about the quality and reliability of a facility; she may never have visited the facility. Look carefully at any facility you are referred to.

If you are considering adult foster care or a domiciliary home, use the checklists in this book and those available from the Alzheimer's Association to guide you. If the program claims to provide specialized Alzheimer care, obtain the booklet "Selecting a Nursing Home with a Dedicated Dementia Care Unit," published by the Alzheimer's Association (see Appendix 2). Ask the Alzheimer's Association chapter near you what they know about the home. If your family member takes medication or has an unstable medical condition, be sure that the facility can care for him. Food quality and quantity, sanitation, fire safety, control of communicable diseases, and cleanliness may or may not be supervised by the state. You must check these things yourself. People with dementia usually cannot recognize a fire alarm or leave the building independently. Is there enough staff, particularly at night, to assist everyone in leaving the building in case of a fire? Ideally a facility should have smoke detectors, fire alarms, fire barrier walls and doors, and a sprinkler system. However, these can be expensive and are not required in many domiciliary and foster care settings. Programs that use such systems usually must charge more.

Nursing Homes and Assisted Living Facilities

As the disease progresses, it may become more difficult for you to care for a person at home. Taking care of a person with a dementing illness can be a twenty-four-hour-a-day job and may require the skills of a professionally trained individual. At some point the family may be unable to continue providing all the care that is needed.

Placing your family member in a nursing home or assisted living facility can be a difficult decision to make and it often takes time. Families usually try everything else first. However, a time may come in the process of caring for a person with dementia when nursing home placement is the most responsible decision the family can make.

Family members may feel great sadness and grief at having to accept the inevitable decline of their spouse, parent, or sibling. They frequently have mixed feelings about nursing home placement. They may experience a sense of relief that a decision has finally been made and that part of the care will be assumed by others yet feel guilty for wanting someone else to take over these real burdens. Family members may feel angry that there are no other choices available to them.

Many people don't want to place a family member in a nursing home or assisted living facility. They feel that they should care for their loved ones at home and many have heard that American families "dump" unwanted old people in institutions. Not all families care lovingly for their elderly members, but statistics clearly show that families are *not* dumping their elderly in nursing homes, that most families do all they can to postpone or prevent nursing home admission, and that they *do not* abandon their elderly members after placement. Instead, most families visit in the nursing home regularly.

We tend to think of the "good old days" as a time when families took care of their elderly at home. In fact, in the past not many people lived long enough for their families to be faced with the burden of caring for a person with a dementing illness. The people who did become old and sick were in their fifties and sixties and the sons and daughters who cared for them were considerably younger than you may be when your parent needs care in his seventies and eighties. Today many children of an ailing parent are themselves in their sixties or seventies.

The term *nursing home* brings negative images to many people's minds, but often nursing homes give good care and are the best alternative for an ill person. Some nursing homes do not give adequate care, and there has been much publicity about them. Not all homes, however, deserve a bad reputation, and this publicity has brought about needed changes that have improved the quality of nursing home care.

It is not unusual for family members to disagree about nursing home plans. Some members of the family may want the impaired person to remain at home while others feel the time has come for him to enter a nursing home. It is helpful if all involved family members discuss the problem together. Misunderstandings and disagreements are often worse when everyone does not have all the facts. Everyone in the family should discuss at least these three topics: the cost of nursing home care and where that money is to come from (see p. 445), the characteristics of the home you select (see "Finding a Home . . . ," beginning on p. 459), and the changes that placement will make in each person's life.

Going to live in a nursing home is a major change for the confused person. His ability to respond to this change will be influenced by how ill he is. You will want to help him participate in this move and adjust to this change as much as he is able.

Once you have decided to look for nursing home care for someone, you will need to begin a four-step process:

1. Investigate all funding resources.
2. Have the ill person see a physician if he has not seen one recently. (Most homes require a recent medical exam.)
3. Locate a suitable home.
4. Make the placement and adjust to the changes that the placement brings about for both you and the person who has moved to the nursing home.

There is no "right" time to place a family member in a nursing home. A time may come when the caregiver is just worn out. Other demands, children, spouse, or job may make it impossible for anyone in the family to be a full-time caregiver. A common reason for placement is that the patient needs more care than the family can provide. Older adult children and spouses are likely to have health problems of their own. In many households today, both husband and wife work outside the home; it is often financially impossible for a family member to stay at home and care for the confused person. Caregivers often wait too long to place a family member in a nursing home: both you and the ill person may find it easier if you plan for placement before you are exhausted and while he still has the ability to adjust to a new setting.

It is important that you plan ahead, even if you do not need a nursing home now. It takes time to select a good facility. There are serious shortages of nursing home beds for people with dementia. If you find a facility that you feel offers exceptional care, get on the waiting list well in advance. If you delay until you must place the person quickly (for example, following a hospitalization), you may have to take whatever is available, at least in the short term, even if it does not offer the quality of care you want.

Some families accept whatever is available but remain on the waiting list of the home they prefer. They can then decide whether to move the person when there is an opening in the preferred home.

Some people with dementia are depressed. Sometimes these individuals do not get good care for their depression in a nursing home. Keeping the person in a different setting or paying privately for psychiatric care may be your only option (see Chapter 8). Depression should not make a person with dementia ineligible for nursing home care. However, when a person has both a dementia and a mental illness, such as depression, you may need expert help to get the person admitted to a nursing home.

Paying for Care

Nursing home care is expensive. Before you can make a final decision, you need to know how much the care is going to cost, how this cost will be met, and whether meeting the cost will create a financial burden for members of the family.

Nursing home care in 1998 cost between $30,000 and $40,000 per year in most communities. The cost of assisted living varies but may be about the same. The person's own income and savings usually must be spent on long-term care. We will briefly explain the exceptions and alternatives to this. However, the laws governing payment for nursing home care are complicated and vary from state to state. If there is even a *possibility* that the person will need assisted living or nursing home care, even for a short period, you must look into payment well in advance. Doing so may make it possible for you to use the person's funds more wisely. This allows you not only to save money but also to purchase the best-quality care for as long as possible.

There are several resources that will help you get information. Keep in mind that the laws are complex and that not everyone you talk to will have accurate information. Talk to more than one person and read the available brochures. The national Alzheimer's Association publishes some brochures that explain the major sources of funding for nursing home care. The local chapters give talks on this subject and often have a staff person who is knowledgeable. Day care and in-home care programs may have a staff person who is well informed about payment options.

If the person is already in the hospital or in home care, a social worker or discharge planner can help you find a nursing home and determine how to pay for it. However, hospital social workers are under pressure to discharge patients and may not be able to help you determine the quality of the home or the wisest way to spend the person's funds. This is "last minute" planning and is not in your or the ill person's best interest.

Insurance companies can give you information about long-term care insurance. Your state office on aging or state insurance administration may be able to provide guidelines for choosing a long-term care policy.

Some attorneys specialize in financial planning for long-term care. Find a professional with experience in this area. For people with savings that they wish to protect or use wisely, an attorney may be able to show you how to transfer or invest money so that it does not have to be spent on care. However, the law requires that such transfers be made at least three years before the person applies for Medicaid, so this requires long-term planning.

Payment Sources

There is no national governmental program for funding long-term nursing home care. People often must bear the cost of their own care unless they are impoverished. However, nursing home care is so expensive that many patients exhaust their personal resources and become eligible for Medicaid (see below).

There are several ways in which families can pay for nursing home care. Some families, or the impaired person himself, may be able to pay for the full cost of care. The patient may have private long-term care insurance that will pay for a portion of the nursing home costs.

If the person is a veteran, find out from the Department of Veterans Affairs to what extent the VA will be a resource for you (see pp. 490, 544).

In some cases, Medicare pays for part of the cost of nursing home care for a limited time. However, in planning for nursing home placement, it is important that you not overestimate Medicare benefits. We recommend that you identify and check out all resources, because the patient's own funds and Medicaid are usually the only available sources of payment for nursing homes, and Medicaid has serious limitations.

Medicare

Medicare is designed to cover acute care, not chronic or long-term care. However, for people who are acutely and seriously ill and who need intensive rehabilitation or nursing care, Medicare may provide coverage for up

Federal law governing nursing home care and eligibility for Medicaid was extensively revised in the 1987 Omnibus Budget Reconciliation Act (OBRA). States are now revising their policies to conform to federal requirements. Some parts of the state and federal law may be tested in the courts. It is not possible to know at the time of this writing how these changes in law and regulation will actually affect you. This text provides the best available information, but we urge you to seek legal counsel and obtain information from the Alzheimer's Association, the National Citizens Coalition for Nursing Home Reform, or the state nursing home ombudsperson (often located within the state office on aging) (see Appendix 2).

care and should not be spent to allow individuals to save their own money. Thus, individuals are generally required to spend their own income and assets before Medicaid will pay for their nursing home care.

You may have strong feelings of discomfort about taking what some people call "welfare." In fact, Medicaid pays for at least part of the care for about two-thirds of nursing home residents. Nursing home care is so expensive ($30,000–40,000 a year) that many middle-class people use up their own resources quickly and then become eligible for Medicaid. It is important to remember that our taxes pay for these social programs and that when you are eligible for a program, you are entitled by law to receive its benefits. The government intends that this program help families manage the high costs of nursing home care.

If you apply for Medicaid, it is important that you receive fair and equitable consideration. Unfortunately, in the past, some families have been determined to be ineligible when, in fact, they were eligible. Some spouses and other family members have been impoverished by the cost of care because of incorrect interpretations of the law. There are both federal and state laws governing Medicaid, so the eligibility requirements vary from state to state. Medicaid law is complex, and state laws and interpretations of policy change frequently.

You may have considerable difficulty getting accurate information about your eligibility. Not all lawyers are knowledgeable about this complex law, and social workers and nursing homes may have erroneous or out-of-date information. It is in the best interest of the state to give you the most conservative interpretation of the law. It is in your best interest to know the most generous interpretation that is allowed. Information can be obtained from the Alzheimer's Association, the National Citizens Coalition for Nursing Home Reform, and other advocacy groups. If the ill person or his spouse has some income or assets, you should consider consulting a lawyer who is experienced in Medicaid law *as soon as you realize that the person has a dementia.* State laws differ and the language of the federal law provides for various exemptions, which are too complex to discuss here. New court decisions will also affect the way states interpret the new law.

Medicaid considers assets (resources such as stock, property, life insurance policies, etc.) separately from income. Certain assets are exempt.

Income: Most of the income of a person who enters a nursing home must be spent on his care. He is allowed to keep a small personal needs allowance. If his income is not sufficient to pay for care, Medicaid will make up the difference. Beginning with the first day of the first full month of institutionalization, Medicaid does not require that any income belonging solely to the spouse who remains in the community be paid to support the institutionalized spouse. A spouse remaining in the community may retain for her own use part of the couple's joint income.

Assets: Laws governing assets vary from one state to another. Usually the institutionalized person may retain only a small amount of assets. Assets (property) held solely by the spouse who remains in the community generally will not be considered available for the care of the institutionalized person. When assets are held jointly by a married couple, the spouse remaining in the community is entitled to retain part of the assets.

Families sometimes consider transferring assets out of the ill person's name and into that of another family member so that these assets will not be considered in determining eligibility for Medicaid. This must be done at least *30 months* before the person applies for Medic-nursing home will come from two sources. The first source is the individual patient's income from Social Security, pension plans, or insurance. The second is Medicaid, which pays the remainder of the cost.

Often the cost of nursing home care is borne first by one resource and then by another. For example,

> *Mrs. Campbell has Alzheimer disease. She was cared for at home by her husband until she had a series of falls and became unable to walk. Mr. Campbell took her to the hospital, where x-rays showed that she had broken her hip. The family decided that it was time for her to enter a nursing home. During the first 150 days, her care was paid for by Medicare because she needed skilled nursing to help her hip heal. Then Mr. Campbell divided the stock he and his wife jointly owned. He kept half of it and used the rest to pay for her care. When all but $2,000 of her half had been spent on her care, he applied for Medicaid, which paid for her care because she had no other source of income and had exhausted her assets. In addition to his half of the stock, Mr. Campbell retained the family home and car, all of his own pension, and a small inheritance from his father (which belonged solely to him).*

Here are some of the questions that families often ask about Medicaid:

1. *Are children or other relatives required to support their family member in a nursing home?* Under federal Medicaid law, spouses and adult children are not legally responsible to use their own income to support family

members in nursing homes. Under certain conditions in some states, relatives can be required to pay support for a person who is under 65 and living in a state mental hospital.

2. *If the spouse remaining in the community has no income, how will she manage?* If the income of the spouse remaining in the community is less than 122 percent of the poverty level, she is eligible to receive part of the institutionalized spouse's income as support. If the institutionalized spouse has no income, the spouse remaining in the community may be eligible for Supplemental Security Income (SSI). This is a federal program for people without Social Security or other retirement income. It will provide a very small monthly income (in 1996, approximately $470 a month). She may also qualify for food stamps and other social benefits.

3. *Will the ill person have to sell his house to be eligible for Medicaid?* The home is exempt as long as it is occupied by the spouse or a dependent child, even if ownership has not been transferred. The home can be transferred to the spouse living in the community at any time; the 30-month rule does not apply.

4. *Can a family member transfer the impaired person's assets (land, stocks, property) out of his name to make him eligible for Medicaid?* A person's assets must be spent on his care before he can be eligible for Medicaid, except: (1) a home shared by the impaired person and the spouse who remains in the community is exempt; (2) half of a couple's assets, up to certain limits, are considered to belong to the spouse who remains in the community;

the process, the establishment of the medical need for care. If the person has been receiving medical attention, this step will probably be quite simple. Nursing homes require basic medical information about the patient and his treatments; many require a recent physical examination by his physician. Homes also require positive proof that the patient does not have tuberculosis, so the patient may need to have a new chest x-ray. If the person or his family will be paying for his care, this may be all that is necessary.

If the person's care is to be covered by Medicare, he must meet Medicare criteria. These generally require that he need skilled nursing or rehabilitative services. The Medicare office will give you a list of approved treatments. If the person needs a treatment not on the list, you may want to appeal the denial.

If the person's care is to be covered under Medicaid, his need for medical care must be demonstrated. In general, Medicaid requires that the person need nursing care above the level of board and room. Medicaid is less restrictive than Medicare, but standards vary from state to state. After the doctor has examined the patient, he will fill out a form. This form will be sent to a review organization, who will decide whether nursing home care is needed.

The Mental Health Screening Requirement

Federal law (PASARR) requires that everyone (whether paying privately or through Medicaid) who is entering a nursing home that uses federal funds have a mental nursing home advocacy group (see Appendix 2) may have information about facilities that have not met state or federal standards. Federal law requires that this information be available to the public. However, this information is not always a good reflection of the home's current status. Your own eyes and ears over several visits will be your best guide. It is difficult to correctly interpret the official reports, and the quality of care can change rapidly—for better or worse—with a change of ownership.

Some Alzheimer's Association chapters or local offices on aging have social workers who can advise you on the application process. If the ill person is being discharged from a hospital, the hospital social worker can help you. Family service agencies have social workers and in larger cities there are private social workers listed in the yellow pages of the telephone directory.

A social worker can help you establish financial and medical eligibility, provide you with a list of nursing homes in your area, and help you through the eligibility process. A social worker may be able to help with other steps in the total process as well, and may also help you handle the painful feelings you may be having about the placement. Agencies and social workers are often prohibited from recommending some facilities over others. So their recommendations usually do *not* imply a judgment about the quality of a facility.

Hospital social workers are caught between their professional commitment to help you and the pressure on hospitals to discharge people as soon as possible. Be aware that if the person is to move from a hospital to a nursing home, you may be pressured to make decisions rapidly. *Planning ahead helps to protect you from serious problems.*

Nursing homes and assisted living facilities are listed in the yellow pages of the telephone directory. Good homes may be known to other families in your community, or your doctor may recommend a good home. Some physicians have financial interests in these homes, which may bias their recommendations. Always get more than one opinion.

When you have a list of possible homes, call to make an appointment to see the administrator and/or the director of nursing and to visit the home. There are some fundamental questions you might ask on the telephone before you visit. First, you will need to find out if the home has openings or a waiting list. You should go to see the home; if it is a good home, you may wish to place the patient on the waiting list. Second, you will need to find out if the home accepts the funding sources you are planning to use.

When you visit the home, you will need to observe and ask questions. Take a friend or family member or a member of the Alzheimer's Association with you. This person will be less emotionally involved and can help you observe the facility and think through your decision. We recommend visiting more than once if there is time: on the second visit you will notice things you missed on the first. Many families have told us that the things you notice when you first enter a home may not be the things that matter as time goes on. Allow plenty of time to visit, talk to alert residents and the staff, and try to picture how your relative will fit in.

> *When Art first visited Sunhaven Nursing Home he was favorably impressed. He was struck by the spacious lobby, the long clean corridors with the patients' names on their doors. He observed several staff members all in fresh uniforms and he liked the sunny rooms and well-equipped bathrooms. After visiting his father several times at Sunhaven, Art noticed that no residents used the lobby. He decided that what mattered most was whether the aides were friendly to his father and whether they came and helped him in the bathroom when he needed it. His father had always enjoyed meals and the bland, lukewarm food depressed him. He wished the home had spent more money on a cook and less on the lobby. His father had always liked to stay up late at night and to sleep late in the morning, but the facility required that everyone be in bed by 8:30 P.M. and up by 7:00 A.M.*

When meeting with the home's administrators, you should feel free to ask questions about the home's accreditation, about financial procedures, and whether they meet state standards for the quality of care. Discuss financial arrangements in detail. Do not take anything for granted. If there are things you do not understand,

1. Does the home have a current license from the state?
2. Does the administrator have a current license from the state?
3. Does the home meet or exceed state fire regulations? Because it is difficult to evacuate frail elderly people in case of fire, sprinkler systems and fire doors are important.

If the above questions cannot be answered yes, do not use the home.

If Medicare and/or Medicaid is needed, is the home certified to accept it? (If you will pay from another source initially and then switch to Medicaid, you need to know that the home is certified for it and will be able to keep the patient.)

A 1987 federal law spells out the rights of nursing home residents. These are listed in Appendix 4. If the home you are considering does not meet these criteria, discuss with staff members why it does not. Consider not using the home. People with dementia cannot exercise all of these rights, but you should be able to exercise them in the patient's behalf.

Visiting

Is the home close enough that you can visit frequently? Is there adequate parking and public transportation? Does the home have long and convenient visiting hours? (When a nursing home restricts visiting hours, one wonders what goes on when no family members are around.) May children visit? Can you spend extra time in the beginning to help the person adjust? (See p. 476.) Will you feel comfortable visiting here? Can you and the resident have privacy?

Meeting Regulations

Was the home cited by state inspectors in the last inspection for failure to meet federal or state standards? (See pp. 459–60 or ask the administrators.) If you are considering a home that has been cited, ask what the failure was and what has been done to correct it. Some violations are quickly remedied; others indicate serious problems. If the staff evades your question, you may not wish to use that facility.

Costs

Do you clearly understand what costs are included in the basic charge? Obtain a list of extra charges, such as laundry, television, radio, medications, hair cuts, incontinence pads, special nursing procedures, behavior management procedures. Ask how residents' personal funds are handled. If the resident enters the hospital or goes home for a few days, what charges are involved?

Cleanliness and Safety

Is the home clean? Look at bathrooms and the food-preparation area.

A facility can be clean and still have a warm, comfortable atmosphere. Highly waxed floors and shiny aluminum create glare, which can confuse people with dementia, and may not be the best indicators of cleanliness.

A strong smell of urine may indicate either poor patient care or poor housekeeping. Occasional odors are difficult to avoid.

Are bathrooms and other areas equipped with grab bars, hand rails, non-skid floors, and other devices for residents' safety?

What provisions are made for the safety of people who wander or become agitated? Can staff members spend individual time with someone who becomes upset? Are doors secure (either locked or equipped with a buzzer to alert the staff that someone has gone out)? Are physically frail residents protected from stronger, more mobile confused people? Is the facility well lit, the furniture sturdy, and the temperature comfortable? Is the home reasonably quiet?

It is difficult to balance independence and maximal function for people with dementia and to ensure their safety. Ask how the home has addressed this. Are their policies acceptable to you? What provisions have been made for fire safety? Will their procedures protect your family member in the event of a fire?

Staff

Ask whether there is enough staff to individually assist your family member or to wait while he slowly does some things for himself. The larger the staff, the higher the cost of care; but some individual assistance should be available. How many people must each aide take care of? Does this seem reasonable, given the severity of patients' impairment? How is the facility staffed on evenings and weekends? How well trained are supervisory nurses? Observe how residents are handled. Are they asking for help and not getting it? Do the nurses seem hurried?

Does the staff seem happy and friendly? Happy personnel indicate a well-run institution. Also, contented staff people are less likely to take out their personal frustrations on the residents. Ask staff members how staff turnover rates compare with those at other local homes. The staffs of good nursing homes recommend this as an excellent clue to the level of staff satisfaction.

Ask what training the nursing staff, including nursing aides, have received. Have nurses, aides, social workers, and activity directors had training in the care of people with dementia? Staff members need to know how to manage catastrophic reactions, suspiciousness, wandering, irritability, etc. If they have not had training, how willing are they to accept information from you on how to manage your family member?

Ask about the extent of professional training the social worker and activity director have had. These two people make a significant contribution to the quality of patient care. Ask to meet with them. Ask them how much of their time is spent with people with dementia. Ask to see some care plans. Do they seem to have been filled out by rote, or do they describe individual needs that the home is really addressing?

Care and Services

Federal law now mandates that homes have individual care plans for each patient. Ask to see what things are considered in the care plan. Are you welcome to participate in care planning? Do the activity director and the social worker participate?

What things will the home want to know from you about the patient? In addition to many questions about medical history, financial resources, etc., does the home want to know about the person's likes and dislikes, habits, how you manage behaviors, what abilities the person still has? These things are essential for good care.

How much of the time are people with dementia included in activities? Long hours of inactivity indicate poor dementia care. Do the activities offered seem dignified and adult? Will they interest your family member? Ask to observe activities. Do the residents appear to be interested and content, or are they dozing off or wandering away? Are programs available to keep residents alert and involved within the limits of their abilities?

Is supervised daily exercise provided? Even people who are confined to a wheelchair or bed need exercise, and those who can walk should be doing so. Exercise may reduce the restlessness of people with dementing illnesses.

Are there creative and effective planned social activities? A television room is not enough. Nursing home residents need structured programs, such as music programs, recreation groups, and outings, to keep them as involved in interpersonal activities as they are able to be.

Are physical therapy, speech therapy, and occupational or recreational therapy available to residents who need it?

quently will this person see the patient? Will this physician meet with you when you have concerns? Can you meet with him ahead of time? Does he have training in geriatric medicine? People with dementia need close, skilled medical supervision and their medical care requires special skills. In the absence of such a physician, does the home employ specially trained nurses or physician's assistants? How does the home provide ongoing good medical care?

If the person is bedbound or has serious health problems, has the staff had special training in these areas?

Does the home have a consulting psychiatrist who can see the person if he develops serious behavioral problems or becomes depressed? How will the home address these problems?

Does the facility have arrangements for the transfer of acutely ill people to a hospital? Is this hospital satisfactory to the family?

How is incontinence managed? Nursing management, such as individualized scheduled toileting, is preferred over catheters for ambulatory people with dementia. Look around. Do you see more than a very few people who have catheter bags hanging from their wheelchairs or beds?

Ask aides or the ombudsperson about reports of decubitus ulcers (pressure sores).

People with dementia are sensitive to the way they are treated. Observe how the staff treats residents. Do they address them as adults or as if they were children? Do they stop and pay attention to residents who approach them? Do they greet people before doing something to them? Do they seem sensitive to needs for privacy and dignity?

The Physical Plant

Is the home pleasant to be in and well lit? Is the staff cheerful, is the furniture comfortable, are residents' personal possessions in sight in their rooms? A nursing home that looks like a hospital is not necessarily a pleasant place in which to live. Pleasant surroundings and a kind, patient staff are important to a confused person. Also, you need to feel comfortable when you come to visit.

Do you think the patient will feel comfortable here? There are "homey" nursing homes that have worn furniture but seem more like home to some people. Other people will feel more comfortable in a newer facility. Is it too noisy and confusing for your family member, or too quiet and boring? Does it allow private time for those who seek it and provide social activities for outgoing people?

Glare, noise, and dim light all add to the difficulties a person with dementia experiences. If these things bother you, chances are they will also create unnecessary stress for a person with dementia.

Policies on Terminal Care

What is the home's policy regarding life-sustaining measures? Ask if state laws require that a statement recording the family's preference be placed in the chart.

Although this is a painful subject to think about at the time of the person's admission, it is important that you ask about this. Families, nursing homes, and the home's physician often have different opinions about how to respond at the end of a patient's life. Your wishes may not be carried out unless you state them at the beginning. (See pp. 197–98.)

Meals

Visit at mealtime and ask to eat a meal there. Does the food look appetizing? Are meals adequate? Are individual diets available? Are snacks available?

Is the food wholesome, attractive, and suitable for elderly people? Are people with dementia served in a small, quiet area or in a large, noisy dining room? Do you observe nurse aides helping people who cannot feed themselves? Volunteers may be used to help people at mealtimes.

Are people with swallowing problems closely supervised? Long-term use of nasogastric (NG) tubes or other devices that circumvent voluntary eating are not recommended if good nursing management will enable a person to eat.

Rights

The federal government has mandated a nursing home patients' bill of rights (see Appendix 4). Ask how it is carried out for people with dementia.

Is there a resident council that can take problems and complaints to the administrator? Where can you take complaints? Is the social worker readily available to discuss your concerns? Is there a family council?

Ideally you should be able to respond positively to many of these questions. In reality, high-quality care is hard to find. If the person is difficult to manage or if you must rely on Medicaid funding, you may not be able to find an ideal home. Use these questions as a guide to help you decide which things are most important and which ones you are willing to compromise on.

Nursing Home and Assisted Living Programs that Specialize in Dementia Care

Some nursing homes have opened special units for people with dementia (often called Alzheimer units). If you are considering such a unit, use the booklet "Selecting a Nursing Home with a Dedicated Dementia Unit," published by the Alzheimer's Association (see Appendix 2). The booklet describes those characteristics that we believe you should seek in specialized care.

Dementia care units range from those that offer no specialized care to those that provide excellent care that meets the unique needs of a confused person. Here are some of the questions to consider:

Does this program offer care that will be helpful to your family member? Do not assume that it will be better for your family member just because it is called special. Some people do not need special care, and some "special care" facilities are not offering care that really meets the needs of people with dementia.

Does this care cost more? If so, is the difference worth the price? Do they require that you pay privately? Can you afford it? If your family member will need to change to Medicaid after a few years, will the facility keep him? Increased fees do not necessarily mean better care.

Is the facility close enough that you and others can visit easily? Seeing you frequently may be better for the person than whatever special care is offered.

Are people moved off the unit if their condition declines? If so, is this satisfactory to you? Do you like the unit where they would be transferred? Will they be transferred within the same home?

Ask what changes being in the unit produces in most residents. The amount and type of positive change that excellent dementia care can produce in patients are controversial. No large studies have documented particular benefits, but many programs in the United States and abroad report positive changes in patients' social function and behavior, though not in the relentless progress of the disease itself, after the person has adjusted to the program. Some changes that occur in most but not all residents and indicate good care are: minimal use of behavior-controlling medication, evidence of increased enjoyment of activities, decreased agitation and wandering, weight gain, evidence of pleasure in daily life, better control of continence (through staff assistance), evidence that the person feels that he belongs, increased tendency to sleep through the night without sleeping medications, and little or no screaming. Good programs care for very difficult patients without using any physical restraints. Residents in these programs smile and person who is upset or severely impaired needs to feel that this is his life and he is still important.

You may have to close your ears to the person's accusations if he blames you for this move. If he repeatedly becomes upset when the home is mentioned, it is not helpful, we feel, to keep mentioning it. You may need to go on matter-of-factly with arrangements. Try to avoid dishonest explanations such as "we are going for a ride" or "you are going for a visit." This can make the person's subsequent adjustment in the nursing home more difficult.

In some states the family does not have the legal right to move a person against his will. If the hospital or nursing home raises this issue, consult an attorney. All states have legal provisions for allowing families to make decisions for someone who is not competent to do so.

Many people with dementia will make a better adjustment to the nursing home if the family visits frequently in the early weeks. People vary: some residents need some time on their own before they begin to join in facility activities. If the person continues to be uncomfortable in the home, ask yourself whether your own tension and anxiety are making it more difficult for the resident to relax in the new surroundings. Avoid a facility that asks you to stay away until the person gets used to his surroundings. This only increases his feeling of being lost. You may be exhausted at this point and the person may greet you with accusations or beg you to take him home with you. Remember that these may be

Family members find it painful to see a loved one so impaired. Because dementing illnesses interfere with communication and comprehension, families can have difficulty thinking of things to do when they visit. In the following section we describe things that families tell us make visiting easier.

You can help your relative orient himself in his new home. While you are visiting, explain again why he is there (for example, say, "You are too sick to stay at home"). Review what the daily routines of the home are; make a schedule for him if he can read it. Help him find the bathroom, dining room, television, and phone. Help him find his things in his closet. Think of a way to identify the door of his room as his. Decorate his room with things that are his.

Tell him exactly when you will visit next and write this down for him so he can use it to remind himself. Some families write a letter to the resident mentioning highlights of the most recent visit and the time of the next. The staff can read the letter with the resident between visits to reassure him that you do come frequently. Try to continue to involve him in family outings. If he is not acutely ill, take him for rides, shopping, home for dinner or overnight, or to church. Even if he resists going back he may eventually come to accept this routine, and he will benefit from the knowledge that he is still part of the family. Select activities that do not overly stress or tire him. Occasionally it continues to be difficult to get the person to return. In this instance it is better to visit him at the home.

Help him to remain a part of special family events such as birthdays and holidays. Even if he is depressed or confused, he usually should still be informed of sad events.

Telephone calls between visits help a forgetful person keep in touch and remind him that he is not forgotten. Don't expect him to be able to remember to call you.

Take an old photograph album, an old dress from the attic, or some other item that may trigger memories of the past and urge the person to talk about things he remembers from long ago. If he always tells you the same story, accept this. It is your listening to him and your presence that communicate that you still care about him.

Talk about the family, neighbors, gossip. Even if the person is not fully aware of the issues, he can enjoy the act of listening and talking. Being together is important to both of you. Confused people may not be interested in some topics, such as current events. If the person seems restless, do not insist on bringing him up to date on information.

Be sympathetic about his complaints. Listening to the things he complains about tells him that you care about him. He may make the same complaint over and over because he forgets that he told you. Listen anyway; it is your empathy he needs. Investigate his complaint thoughtfully, however, before you complain to the staff or act on it. Remember that his perception of things may not be accurate, although there may be an element of truth in his complaint.

Sing old, familiar songs. Don't be surprised if other residents drift by to listen or participate. Music is a wonderful way to share. Nobody will remember if your singing isn't very good. Take along tape recordings of the family or the children.

Make a personal history scrapbook telling the story of the person's life—where he grew up, when he married, his children, his job, hobbies, and so on. Write in large letters. Illustrate it with photographs, clippings, bits of fabric, medals, etc. Making the scrapbook can occupy both of you for several visits. Reviewing it may help him recall his past. Even if he does not remember, he may be reassured that he *has* a past.

Make a personal history box. Put in items that will trigger memories; treasured keepsakes, antique kitchen or farm tools that will be familiar to the person, assorted screws and bolts for a handyman or spools of thread for a seamstress. Look for items with interesting colors, weights, textures, and sizes. The person may enjoy sorting and touching the things in this box. You and the staff can use it to trigger memories. Include a card that gives information about the items: "This is an old-fashioned apple corer like the one Mother used when she made apple butter for her five children," "Dad wore these dancing shoes until he was seventy."

Avoid too much excitement. Your arrival, news, and conversation may overexcite the impaired person and could precipitate a catastrophic reaction.

Do things that show that you are interested in his new home. Walk around it together, read the bulletin board to him, talk to his roommate or other residents and

Sharing family life and loving a person who is in an institution and who is in the late stages of a dementing illness are not easy, but perhaps you will find your own meaning in doing so, as this man has.

Your Own Adjustment

You also will have changes in your life when a family member has moved to a nursing home. If the person lived with you, and especially if he is your spouse, the adjustment may be difficult. You may be tired from the efforts of arranging for the placement and, on top of your fatigue, you may feel sad at the changes that have happened. The move to a nursing home may intensify your feelings of grief and loss. At the same time you may wish that you could somehow have kept the person at home, and you may feel guilty that this was not possible. You may have mixed feelings of relief and sorrow, guilt and anger. It *is* a relief not to have to carry the burden of care, to be able to sleep or read uninterrupted. Still, you probably wish things were different and that you could have continued to care for this person yourself.

Families often tell us that in the first few days they feel lost. Without the usual demands of caring for a sick person, they cannot decide what to do with themselves. At first you may not be able to sleep through the night or relax enough to watch television.

The trips to the nursing home may be tiring, especially if the home is some distance from where you live. The visits may be depressing. Sometimes confused people are temporarily worse until they adjust to a new setting, and this can upset you. Sometimes, too, the other people in the home are depressing to see.

Nursing home staff members are geared to provide care for many people and you may not feel that your loved one is getting the individual care that you would like. Other things about the home or the staff may upset you. It's not unusual for family members to feel angry with the nursing home staff from time to time. If you are upset with the home or the staff you have a right to discuss your concerns with them, to be given answers, and not to jeopardize the patient's care or status in the home by doing this. It is against federal law for a facility to discharge a resident because his family raised questions about his care.

If there is a social worker in the home, she may help you work out your concerns. If there is not, discuss your concerns in a calm, matter-of-fact way with the administrator or the director of nursing.

Often things are better after placement, especially when they have been difficult at home. With other people responsible for daily care, you and the patient can relax and enjoy each other. Since you are not always tired, and can get away from the person's irritating behaviors, you may be able to relax and enjoy your relationship for the first time in a long while.

If other family members do not visit, it may be because they find it very hard to face visiting in a nursing home or don't know what to talk about. If someone in your family reacts this way, try to understand that this may be their way of grieving and you may not be able to change them.

Sometimes family members spend many hours at the nursing home, helping with the patient. Only you can decide how much time you should spend visiting. Ask yourself if part of your reason for being there has to do with your loneliness and grief, and might it be better if you spent less time there so the resident can make his adjustment to his new home.

Time does pass, and gradually the acute phase of adjustment also passes. As time goes on you will settle into a routine of visits. It is natural for you gradually to build a life apart from the person who has changed so much.

When Problems Occur in the Nursing Home

Sometimes serious problems about patient care do arise.

> *Mr. Rosen says, "My father has Alzheimer disease and we had to put him in a nursing home. He got terribly sick and was transferred to a hospital, where they said his condition was made worse because he was dehydrated. Apparently the home failed to give him enough fluid. I feel like I am guilty of not checking up on this and I feel like I can't send him back to a home that neglects him."*

As you know, people with dementing illnesses can be difficult to care for, especially in the late stages of the disease. If Mr. Rosen complains to the nursing home staff, one person that you could give at home. However, if there are not enough staff members to keep residents clean, comfortable, and fed, and their medical needs monitored, then something is wrong. The National Citizens Coalition for Nursing Home Reform publishes information about laws governing nursing home quality. Reading this material will help you judge what you can expect from a home.

Talk over your concerns honestly but calmly with the administrator, director of nursing, or social worker and offer her the information you have about the care of people with dementia. How do they respond? Do they thank you for talking to them and say they will take care of the problem or do they make excuses or brush you off? If a physician or other professional should be aware of the problem, ask for that person's support in correcting the situations.

> *Mr. Rosen said, "The doctor at the hospital was so helpful. He called the nursing home and talked to them, explained that people with dementia can easily become dehydrated and should be watched."*

If this does not solve the problem, contact the Alzheimer's Association chapter and the local nursing home ombudsperson (usually in the office on aging). Both have resources to help you. As a final resort, report the problem to the state nursing home inspector's office. However, problems are often most successfully solved by working informally with the administrator and staff of the home.

The problem may be that the staff needs more information about how to care for people with dementia. The Alzheimer's Association has information about training resources. Encourage all levels of staff, from the nurses and administrator to the aides, to get training.

It is against the law to discharge a person because the family has made a complaint. It is also against the law to mistreat a patient whose family has complained. You must closely monitor the care your family member receives.

Sexual Issues in Nursing Homes

Sometimes confused residents in nursing homes undress themselves in public, masturbate, or make advances to staff members or other residents. The sexual needs and behaviors of residents in nursing homes are a controversial issue. Sexual behavior in a nursing home differs in significant ways from such behavior at home: it no longer is a private matter, but in one way or another has an impact on the staff, other residents, and the families of residents; and it raises the ethical issue of whether a person who is impaired can or should retain the right to make sexual decisions for himself.

While our culture seems to be saturated with talk about sex, it is the sexuality of the young and beautiful that is being discussed. Most of us are uncomfortable considering the sexuality of the old, the unattractive, the handicapped, or those with dementia. Nursing home staff members also often feel uncomfortable.

If the nursing home staff reports inappropriate behavior to you, remember that much of the behavior that at first seems sexual is really behavior of disorientation and confusion. You and the nursing home staff can work together to help the person know where he is, when he can use the toilet, and where he can undress. Often all that is needed is to say, “It isn’t time to go to bed yet. We’ll put your pajamas on later.” Distractions, such as offering a glass of juice, are helpful.

Confused persons may become close friends with another resident, often without a sexual relationship. Friendship is a universal need that does not stop when one has a dementia. Occasionally one hears stories about people getting in bed with other residents in a nursing home. This is not hard to understand when we consider that most of us have shared a bed with someone for many years and have enjoyed the closeness this sharing brings. The confused person may not realize where he is or whom he is with. He may not realize that he is not in his own bed. He may think that he is with his spouse. Remember that nursing homes can be lonely places where there is not much opportunity for being held and loved. How you respond to such an incident depends on your attitudes and values and on the response of the nursing home.

Some nursing home residents masturbate. The staff usually ignores such behavior, which is usually done in the person’s room. If it occurs in public the person should be quietly returned to his room.

Flirting is a common and socially acceptable behavior for men and women. In a nursing home a person may flirt to reinforce old social roles. It makes a person feel younger and more attractive. Tragically, the dementia may cause the person to do this clumsily, making offensive remarks or inappropriate gestures.

When the staff are trained to remind the person matter-of-factly and kindly that this behavior is not acceptable, it seldom remains a problem. Residents can be provided with other opportunities to reexperience their social roles.

The Department of Veterans Affairs (VA)

The Department of Veterans Affairs is obligated to serve people with service-related illnesses first, and other veterans as the space and the availability of services permit. Occasionally a person with dementia will be admitted to a VA long-term care hospital but may be discharged later. A few VA facilities also offer respite or family support services. In some cases the VA will pay for six months of care in a community facility. Policies vary with each VA hospital. What is available in one area may not be available in another. Your congressional representative may be able to help you obtain services through the VA.

State Mental Hospitals

Occasionally a person with a dementing illness exhibits behaviors that are so difficult to manage that no nursing home will accept him. Perhaps the person has hit or harmed other residents. Such a patient may be referred to the geriatric unit of a state mental hospital.

You may have heard that care in state mental hospitals is poor. A few state hospitals deserve their bad reputation. However, some do provide good care, and most are doing the best they can within their limitations. Find out how your hospital is regarded by local psychiatrists, psychologists, and the Mental Health Association.

Most states have been mandated by the legislature to reduce their mental hospital populations. These hospitals have experienced drastic budget cuts. They may be reluctant to accept new patients. These factors may mean that there is no place for your family member to go. Fortunately, there are things you can do.

Often, severe behavior problems can be reduced with skilled psychiatric intervention. A combination of low doses of medication and a staff trained to work with these people can make a big difference.

Some states have programs designed to help impaired people avoid state hospital placement if possible, by mobilizing other resources to address these people's needs. Such programs may be staffed by psychiatrists, nurses, and social workers. Their staff may be able to evaluate the person's problem, prescribe medication, and train nursing home staff. If such a team is not available in your state, seek the help of your physician, social worker, clergyperson, and elected representatives to mobilize the resources needed to help your family member. The Alzheimer's Association may be able to recommend experts who can teach specialized patient care to the nurs-

17

Brain Disorders and the Causes of Dementia

Sometimes the brain does not work as it should. The problem may be called retardation, dyslexia, dementia, or psychosis. It may be caused by an injury to the brain, a genetic condition, chemicals in the environment that damage the brain, interruption of the supply of oxygen to the brain, or many other things. In this chapter we will explain how dementia differs from other problems of the brain and describe some of the most common causes of dementia.

Dementia

Doctors and scientists group the different things that can go wrong with the brain by their symptoms. Just as fever, coughing, vomiting, and dizziness are symptoms of several different diseases, memory loss, confusion, personality change, and problems with speaking are also symptoms of several diseases.

Dementia is the medical term for a group of symptoms. It indicates a decline in several areas of intellectual ability sufficiently severe to interfere with daily functioning in a person who is awake and alert (not drowsy, intoxicated, or unable to pay attention). This decline in intellectual functioning means a loss of several kinds of mental processes, which may include mathematical ability, vocabulary, abstract thinking, judgment, speaking, or physical coordination. It may include changes in personality. “Not feeling quite as sharp as you used to” does not mean that one is developing a dementia. The person’s ability must decline from what was normal for her. Dementia is different from mental retardation, in which a person has been impaired since infancy.

The symptoms of dementia can be caused by many diseases. Some of these diseases are treatable; some are not. In some, the dementia can be stopped; in some it can be reversed; in others it cannot be changed. Some of these diseases are rare; others are more common but do not usually cause dementia. Do not assume that a dementia is the inevitable result of having these diseases. A *partial* list of the conditions that can cause dementia follows:

Metabolic disorders
  Thyroid, parathyroid, or adrenal gland dysfunction
  Liver or kidney dysfunction
  Certain vitamin deficiencies, such as Vitamin B_{12} deficiency

- Structural problems of the brain
  - Normal pressure hydrocephalus (abnormal flow of spinal fluid)
  - Brain tumors
  - Subdural hematoma (bleeding beneath the skull, which results in collections of blood that press on the brain)
  - Trauma (injuries to the brain)
  - Hypoxia and anoxia (insufficient oxygen)
- Infections
  - Tuberculosis
  - Syphilis
  - Fungal, bacterial, and viral infections of the brain, such as meningitis or encephalitis
  - Acquired immune-deficiency syndrome (AIDS)
- Toxins (poisons)
  - Carbon monoxide
  - Drugs
  - Metal poisoning
  - Alcohol (Scientists disagree about whether alcohol can cause dementia.)
- Degenerative diseases (causes generally unknown)
  - Alzheimer disease
  - Huntington disease
  - Lewy body dementia
  - Parkinson disease
  - Frontotemporal dementia, including Pick disease
  - Progressive supranuclear palsy
  - Wilson disease

from those of Alzheimer disease. The person can express himself well (language is rarely affected), but personality change, irritability, and explosiveness are common. These symptoms can be difficult and frustrating for families. Therefore, it is important for caregivers to recognize these differences and try approaches directed toward this form of dementia. The first step is to ensure that the person no longer has access to alcohol, because he will not be able to control his drinking voluntarily. When there are questions about how disabled the person is or whether his behaviors are deliberate or manipulative, neuropsychological testing is helpful. If the family has painful memories of the person's alcohol abuse, counseling is helpful. The coping strategies that the family learned to use with the alcoholic person may no longer be appropriate when dementia enters the picture.

Alzheimer Disease

Alzheimer disease was first described by a German physician, Alois Alzheimer, in 1907 and the condition was named for him. The disease Alzheimer originally described occurred in a woman in her fifties and was called *presenile dementia.* Neurologists now agree that the dementia that occurs in the elderly is the same as or similar to the presenile condition. It is usually called dementia of the Alzheimer type (DAT) or Alzheimer disease (AD).

The symptoms of the disease usually are a gradual, though sometimes imperceptible, decline in many areas of intellectual ability and an accompanying physical decline. Early in the illness only the memory may be noticeably impaired. The person is more than a little forgetful. She may have difficulty learning new skills or difficulty with tasks that require abstract reasoning or calculation, such as math. She may have trouble on the job or may not enjoy reading as much as she used to. Her personality may change or she may become depressed.

Later, impairments in both language and motor abilities are seen. At first the person will be unable to find the right word for things or will use the wrong word, but she will gradually become unable to express herself. She will also have increasing trouble understanding explanations. She may give up reading or stop watching television. She may have increasing difficulty doing tasks that once were easy for her. Her handwriting may change or she may walk with a stoop or shuffle or become clumsy. She may get lost easily, forget that she has turned on the stove, misunderstand what is going on, show poor judgment. She may have changes in her personality or uncharacteristic outbursts of anger. She will be unable to plan responsibly for herself. Families often do not notice the beginnings of language and motor problems, but as the disease progresses all of these symptoms will become apparent.

Late in the illness the person becomes severely impaired, incontinent, and unable to walk or may fall frequently. She may be unable to say more than one or two words, and may recognize no one or only one or two people. She will need nursing care from you or from professionals. She will be physically disabled as well as intellectually impaired.

Alzheimer disease usually leads to death in about seven to ten years, but it can progress more quickly (three to four years) or more slowly (as much as fifteen years). Occasionally Alzheimer disease progresses slowly for years and then more rapidly. The relatively stable periods are sometimes called "plateaus." Typically the disease is slowly but relentlessly progressive.

Under a microscope, changes can be seen in the structure of the brain of a person who suffered from Alzheimer disease. These include abnormally large numbers of structures called neuritic plaques and neurofibrillary tangles (see Chapter 18). They may indicate direct damage to the brain itself. A diagnosis of Alzheimer disease can be made on the basis of the type of symptoms, the way the symptoms progress over time, the absence of any other cause for the condition, and a compatible CT or MRI scan. However, a final diagnosis of Alzheimer disease rests on the presence of these specific abnormal structures (neuritic plaques and neurofibrillary tangles) in the brain tissue. A brain biopsy is the only way of making this determination. The biopsy is done by removing a piece of skull bone and taking out a small piece of brain tissue. The removal of this small amount of tissue has no effect on mental function. Brain biopsies are not routinely done at present because no treatment for the disease is available even if a diagnosis is made.

This may change as research in dementia progresses. Several blood tests and spinal fluid tests have been developed, but at present they are only slightly more accurate than a diagnosis based on the person's symptoms.

Multi-Infarct or Vascular Dementia

In the past, dementing illnesses of old age were thought to be caused by *hardening of the arteries* of the brain. We now know that this is not the case. In multi-infarct dementia, repeated strokes destroy small areas of the brain. The cumulative effect of this damage leads to a dementia.

Multi-infarct dementias affect several functions, such as memory, coordination, or speech, but the symptoms differ somewhat depending on what areas of the brain are being damaged.

Multi-infarct dementias generally progress in a steplike way. You may be able to look back and recall that the person was worse after a specific time (instead of the gradual, imperceptible decline in Alzheimer disease). Then she may not seem to get worse for a period, or she may even appear to get a little better. Some multi-infarct dementias progress as time passes; others may not get any worse for years. Some multi-infarct dementias may be stopped by preventing further strokes; in others the progression cannot be stopped.

Sometimes the cause of the repeated strokes can be identified and treated, and further damage prevented. Recent evidence suggests that low doses of aspirin may slow the progression of the disease. Ask your doctor.

Some people may have both Alzheimer disease and multi-infarct disease.

Lewy Body Dementia

First identified in the 1980s, Lewy body dementia may account for 5–10 percent of cases of dementia. The Lewy body is a microscopic abnormality found in the brain at autopsy. Originally it was thought to be present only in Parkinson disease, but scientists now recognize that some individuals with dementia have Lewy bodies spread throughout their brain.

The symptoms of Lewy body dementia are similar to those of Alzheimer disease, but unlike Alzheimer disease, Lewy body dementia usually has mild symptoms of Parkinson disease (called "parkinsonism") early in the course of the illness. Stiffness, slowness, and poor balance are common. Because of this, people with Lewy body dementia usually fall several times during the illness. One reason to make the diagnosis of Lewy body dementia is that people with this illness often experience adverse side effects from neuroleptic medications. These medicines should be avoided if possible or used in the lowest possible dose if they are needed to treat delusions or hallucinations. Depression is common in Lewy body dementia.

The Frontotemporal Dementias, Including Pick Disease

Pick disease is a rare form of dementia first described at the beginning of the twentieth century by Ludwig

Other Brain Disorders

There are several other mental conditions that are not dementias.

Delirium

The term *delirium* describes another set of symptoms that can have various causes. Delirium is often confused with dementia. Like the person with dementia, the delirious patient may be forgetful or disoriented. Unlike a person with dementia, *the delirious person shows a changed level of consciousness.* She is less alert and more easily distracted than is usual for her. Other symptoms of delirium may include misinterpretation of reality, false ideas, or hallucinations; incoherent speech; sleepiness in the daytime or wakefulness at night; and increased or decreased physical (motor) activity. Symptoms of delirium often develop over a few hours or days. They tend to vary through the day.

Older people who do not have dementing illnesses may show symptoms—often intermittent—of impaired alertness, confusion, or memory problems. This may be a delirium caused by some other illness or by medication. Such a delirium should be regarded as a symptom, and the cause should be identified and treated, if possible.

People who have a dementia are more likely than other people to develop a delirium in addition to the dementia. You may observe a sudden worsening in a person who has other problems, such as constipation, the flu, an infection, or even a slight cold. The complications of conditions like prostate cancer, diabetes, heart failure, chronic lung disease, or other serious illnesses also often cause a delirium.

The person with a delirium may become more irritable, seem more confused and drowsy, and be less alert. She may become incontinent, agitated, or fearful. She may become apathetic. You may notice an increase or decrease in activity level, a decreased level of alertness, or an increase or decrease in the amount of movement or motor activity. Visual hallucinations are common in delirium. Such changes are sometimes assumed to be a worsening of the dementia, and the underlying problem then goes untreated. Always consider the possibility of an illness and delirium when you observe a sudden change in behavior. Too much medication, or medication interactions, can also cause a delirium, even weeks after the medication was begun.

Senility, Chronic Organic Brain Syndrome, Acute or Reversible Organic Brain Syndromes

The word *senile* merely means *old*. Thus, *senility* does not describe a disease, and the term is considered by many people to be derogatory or prejudicial.

Chronic organic brain syndrome and *acute or reversible organic brain syndromes* are obsolete terms used by some to refer to dementias and delirium. These terms are no longer used because they are not specific and because they imply that some conditions cannot be treated. As research advances, we hope that in time there will be no chronic brain syndromes.

TIA

TIA stands for *transient ischemic attack.* This is a temporary impairment of brain function that is due to an insufficient supply of blood to part of the brain. The person may be unable to speak or may have slurred speech. She may be weak or paralyzed, dizzy or nauseated. These symptoms usually last only a few minutes or hours, then the person recovers. This is in contrast to a stroke, which may have the same symptoms but after which some deficit remains. Very small deficits may not be noticeable. TIAs should be regarded as warnings of stroke and should be reported to your doctor. Your physician may take steps to reduce the risk of a future stroke.

Localized Brain Injuries

Damage can happen to the brain or head and temporarily or permanently affect either small or greater parts of the brain. This can be caused by brain tumors, strokes, or head injuries. Unlike dementia, such damage may not be generalized, although it may affect more than one mental function. The symptoms can tell a neurologist just where the damage is. This is called a *focal* (localized) *brain lesion* (injury). When the damage is widespread the symptoms may be those of dementia.

Major *stroke,* which causes such things as sudden paralysis of one side of the body, drooping of one side of the face, or speech problems, is an injury to part of the brain. Strokes can be caused by a blood clot blocking vessels in the brain or by a blood vessel bursting and causing bleeding in the brain. Often the brain cells are injured or impaired by swelling but can recover when the swelling goes down. It may be that other parts of the brain can gradually learn to do the jobs of damaged sections of the brain. People who have had a stroke may get better. Rehabilitation training is important for people who have had a stroke. The chance of having another stroke can be reduced by good medical management.

Head Injuries (Head Trauma)

Head injuries can destroy brain tissue directly or by causing bleeding within the brain. Head injuries may result in permanent brain damage and changes in behavior. Sometimes blood collects between the skull and the brain, forming a pool of blood. This puts pressure on the brain cells and damages them. It is called a *subdural hematoma.* Even mild falls can cause such bleeding.

People with dementing diseases are vulnerable to falls and may not be able to tell you about them. If you suspect that a person has banged her head, she should be seen promptly by a doctor, because treatment can prevent permanent damage. The bleeding beneath the skull may not occur in the same place as the head was hit. Bleeding may be slow, and symptoms may not appear until hours or days after the fall. Bleeding inside the skull may occur on the side opposite the injury.

Anoxia or Hypoxia

When a person suffers a heart attack, the heart may stop pumping blood for a period of time before the person is resuscitated. During that time the brain may not get enough oxygen. This can result in brain damage that looks similar to Alzheimer disease, except that it does not get progressively worse and usually does not affect language or the ability to carry out physical actions. People with hypoxic brain damage need much the same care as people with Alzheimer disease or multi-infarct dementia.

18

Research in Dementia

We have reached an exciting point in research into dementia. Not long ago, most people assumed that dementia was the natural result of aging, and only a few pioneers were interested in studying it. In the last thirty years that has changed. It is now known that:

1. dementia is not the natural result of aging;
2. dementia is caused by specific, identifiable diseases;
3. diagnosis is important to identify treatable conditions; and
4. a proper evaluation is important in the management of diseases that at present are not curable.

Today an increasing amount of research is focused on the dementing illnesses. With new tools for study we can get a much clearer look at what goes on in the brain. Because of better public understanding, there is a growing demand for solutions.

The federal budget for dementia research increased from $4 million in 1976 to $350 million in 1998. Most of the current research is supported by the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute of Mental Health (NIMH), the National Institute on Aging (NIA), and the Department of Veterans Affairs (VA). The NIA has funded Alzheimer's Disease Research Centers, which pull together talented researchers, and much exciting work is taking place in these centers. Some additional research funds are contributed by nongovernmental sources, such as foundations and drug companies. However, many potentially productive research projects go unfunded each year.

Understanding Research

The increased public awareness of Alzheimer disease has been accompanied by a number of announcements of "breakthroughs" and "cures." Some of these are important building blocks in the search for a cure, but each breakthrough, in itself, is but one small step in the direction of a cure.

Understanding the therapeutic implications of the research can challenge scientists and families alike. Here are some things you need to know about research to help you understand what you read.

- Research scientists need to make their findings public, and the public wants to know what researchers are finding. The enthusiasm of the press in publicizing these findings plays an important role in maintaining temporarily cheering up the patient or brightening his thinking. This is called the placebo effect and it is quite common. Good studies of drugs are carefully designed to eliminate the possibility that other factors cause improvement.

- Preliminary studies are often done on small groups of people. The small size of the sample increases the chances that extraneous factors confuse the outcome. If you hear of exciting results from a small-group study, remember that these results may or may not be confirmed by tests on a large group or tests done by another researcher.
- The presence of two factors together does not mean that one causes the other. Both A and B might be found in the brains of dementia patients, but this does not mean that A caused B; A and B might both have been caused by an unknown factor, C. It may be years before the relationships among these factors are understood.
- The drugs that may affect the brain of a person with Alzheimer disease are likely to cause serious side effects throughout the body. Sometimes research on such drugs must be stopped because their potential damage to other organs outweighs their therapeutic value.
- You may have heard of studies done with laboratory animals. Animal research allows scientists to learn more about how the brain works and to test drugs that cannot safely be tested on humans. The federal government has laws to assure that animals are treated

Research in Multi-Infarct Dementia and Stroke

Multiple strokes are the second most common cause of dementia. If ways can be found to prevent these strokes or to improve rehabilitation, many thousands of people would benefit.

Scientists are seeking to determine how hypertension, obesity, diet, smoking, heart disease, and other factors increase a person's vulnerability to stroke or multi-infarct dementia. They are studying the relationship between larger strokes and the multiple strokes that cause dementia. At present, the best way to prevent stroke is to eliminate the risk factors. A new treatment, given immediately after a stroke, can reduce the disability that remains.

Researchers are also studying which areas of the brain are most likely to be damaged and what changes in brain chemistry take place after a stroke. They are looking at how, when, and to what extent rehabilitative training helps a person. They are examining the effectiveness of drugs in preventing stroke, dilating blood vessels, increasing the oxygen supply to the brain, and preventing blood clotting. Some studies are evaluating the effects of surgery to remove atherosclerotic plaque from the arteries that deliver blood to the brain.

Scientists are examining the relationship of stroke, depression, and the dementia that accompanies depression. They have found that it is important to treat depression when it occurs following a stroke.

teins in the brains of people who die from Alzheimer disease.

Nerve Growth Factors

Cells within the brain and spinal cord (as well as nerve cells outside the central nervous system) develop in specific patterns that are directed by chemicals called nerve growth factors. Nerve cells outside the central nervous system (called peripheral nerves) can regrow or regenerate after an injury, but cells within the brain are thought not to have this ability. Scientists are studying whether nerve growth factors might be used to stimulate the replacement or regrowth of damaged nerves in the brains of people with Alzheimer disease.

Transplants of Brain Tissue

Much excitement has been generated in recent years about the possibility of replacing damaged brain cells by transplanting new cells. Work in animals has shown that certain cells from fetuses or laboratory-grown cell cultures will grow and manufacture neurotransmitters when they are transplanted into animals with brain damage. Cells have been transplanted into the brains of a few people with Parkinson disease. So far, this has had only limited success. It is not known whether this technique will be applicable for people with Alzheimer disease. Because some of the cells for tissue transplants are obtained from tissue taken from human fetuses, this has generated controversy. However, it is most important that research *on animals* be permitted to continue, to determine whether this procedure has any possibility of helping patients with Alzheimer disease. It may be possible to grow the needed cells in a laboratory.

Drug Studies

Hundreds of drugs are being studied for their effect on Alzheimer disease. Most of them will quickly be found to be ineffective or to have toxic side effects. A few will make the news because there is some preliminary evidence that they alleviate symptoms.

Several drugs have been developed that slow or prevent the breakdown of acetylcholine (one of the neurotransmitters that is deficient in the brain of people with Alzheimer disease). These drugs temporarily improve cognitive function, but the disease continues to progress at the same rate. One such drug, donepizel, was approved in 1996. Several others may be approved in 1999. They are equally effective but differ in their side effects. Many other compounds are being studied. With enough information, chemists may be able to tailor-make a drug that can alleviate specific symptoms.

Metals

Aluminum has been found in larger than expected amounts in the brains of some people with Alzheimer disease. Other metals, such as manganese, are known to be associated with other forms of dementia. It now seems most likely that the presence of aluminum is a result of whatever is causing the dementia rather than aluminum itself being a cause of dementia. People sometimes wonder if they should stop taking antacids or cooking with aluminum pans or using deodorant (all sources of aluminum). There is no evidence that their use is a cause of dementia. Studies of people who have been exposed to much larger amounts of aluminum indicate that exposure does not lead to dementia. Treatments that promote the elimination of aluminum from the body do not benefit people with Alzheimer disease, and some of these treatments have serious side effects.

Viruses

Some tentative research led scientists to suspect that a viral defect could be causing Alzheimer disease. You may read about Creutzfeld-Jacob disease or Kuru. Both of these rare diseases have been studied because they cause dementia and appear to be transmitted by a virus-like agent.

Prions are particles even smaller than viruses that can reproduce themselves. It has been suggested that these particles might be a cause of Alzheimer disease. While this has not been totally disproven, it now seems quite unlikely.

There have been many efforts to determine whether Alzheimer disease is infectious, that is, whether it can be transmitted. At present there is no evidence to support the hypothesis that Alzheimer disease is caused by a slow virus, prion, or other infectious organism.

injury theory. It seems unlikely that head trauma is the cause of Alzheimer disease in most people.

Epidemiology

Epidemiology is the study of the distribution of diseases in large groups of people. Studying the epidemiology of dementing illnesses may eventually show scientists a link between the disease and other factors. Many epidemiologic studies suggest that head trauma, low education, and a family history of dementia increase the likelihood that a person will develop Alzheimer disease. This does *not* mean that a person who has these risk factors *will* get the disease, only that he is more likely to get the disease than another person would be. These studies have found that people who use anti-inflammatory medications, take estrogen, and have a higher education are less likely to develop a dementia.

So far, Alzheimer disease has been found in all groups of people whose members tend to live long enough to reach late life. Epidemiologic research is expensive, difficult, and can take many years. However, studies now under way in the United States and other countries may yield valuable clues.

Down Syndrome

People with Down syndrome (a form of mental retardation) develop plaques and tangles similar to those in Alzheimer disease as they reach their forties. They do not all develop the symptoms of Alzheimer disease, although some do experience a further decline in intellectual function. Because Down syndrome is known to be caused by an extra chromosome 21 or an extra piece of this chromosome, many scientists have been studying the role this chromosome might play in Alzheimer disease.

Old Age

Living into very old age increases the risks of developing Alzheimer disease. While an adult's risk of developing Alzheimer disease is about 1–2 in 100 at age 65, at age 80 his risk is 1 in 5. But the statistics also mean that 4 out of 5 people at age 80 have normal or nearly normal intellectual function.

Heredity

Some of the most stunning advances in Alzheimer disease research have been in the area of genetics. Families often worry that this disease is inherited and that they or their children will develop it. As you learn about the genetics of Alzheimer disease, keep in mind that "at risk" does not mean "for sure." "At risk" means the person is more likely than other people to develop the disease, but it does not mean that a specific person will get the disease. Many people are at risk of having other diseases, like heart disease or prostate cancer or breast cancer. For many diseases, people who know they are at risk can take steps to reduce the likelihood of getting the disease. For example, if you take a blood cholesterol test and learn that you have high blood cholesterol, you are at risk of having a heart attack or stroke. Changing your diet and/or taking medication can lower your cholesterol and therefore lower your risk for heart attack or stroke. Researchers can now identify who is at risk of developing Alzheimer disease and are seeking to find a treatment that will lower the risk or prevent the illness.

Scientists are identifying the genes that are involved in Alzheimer disease. Two genes, one on chromosome 19 and one on chromosome 12, influence the likelihood that an individual will develop Alzheimer disease, but they do not cause the disease. The gene on chromosome 19, the APO E gene, is by far the best studied. This gene exists in three forms: epsilon 2, epsilon 3, and epsilon 4. These forms of the gene are normal, and all individuals inherit one of these genes from each parent. This means that each person has two copies of the gene and can have any combination of epsilon 2, epsilon 3, and epsilon 4. The evidence is strong that individuals who inherit the epsilon 4 form of the gene are at risk of developing Alzheimer disease. Some researchers believe that individuals who inherit the epsilon 2 form of the gene are protected against Alzheimer disease.

There is a test that can identify which form of the APO E gene a person has inherited. Right now, it is not very useful, because it only slightly improves the accuracy of the diagnosis. The test is not useful for nor-

Earlier in this chapter we discussed other possible factors that are not genetic but that increase the risk of developing Alzheimer disease. Ultimately, researchers will understand how these factors interact with the genetic factors. This may help them develop a treatment.

In chapter 17, we talked about other diseases that cause a dementia. Sometimes people with another dementia have been misdiagnosed as having Alzheimer disease, leading their families to worry unnecessarily about the risk of developing Alzheimer disease themselves. Be certain that you have obtained the best diagnosis possible.

We recommend that individuals with a strong family history of dementia or Alzheimer disease contact a research center if they are concerned about their own risk. People undergoing genetic testing should meet with a genetic counselor before the testing is done to make sure they understand the implications and limitations of the genetic tests.

Gender

Some investigators believe that women are more prone to Alzheimer disease than men but that men are more prone to multi-infarct dementia. This may be simply because men are more likely to develop vascular disease, while women tend to live longer and the incidence of Alzheimer disease increases with age. Researchers are looking for clues to whether this is so.

Promising Clinical and Research Tools

Neuropsychologists use a combination of questions, simple tasks, and observation to evaluate patients. They can identify the kinds of mental skills a person has lost and those he retains. With this knowledge, clinicians can devise individual plans that help a person use his remaining skills and that place minimal demands on his diminished abilities. Information from a neuropsychological examination helps a family understand why a person cannot do some things but can successfully do similar activities. Neuropsychology can also help to confirm a diagnosis and potentially could identify subtypes of Alzheimer disease.

The PET (positron emission tomography) scan provides a picture of the brain at work. That is, the image it produces shows which areas of the brain are working hardest during a particular kind of mental activity. Like the CT and MRI scan (p. 26), it requires that the patient lie on an x-ray table. The patient is given a radioactive material by injection or by inhalation. This material goes through the bloodstream into the brain. (This material is in a small dose and lasts in the body only a few minutes.) Special equipment measures the amount being used in each area of the brain.

The SPECT (single positron emission computerized tomography) scan is similar to the PET scan but is less expensive and may eventually be used in diagnosis.

Functional MRI (fMRI) uses multiple MRI scans to ing before the person retired and that this early, unidentified dementia may have been a factor in the person's decision to retire.

Many people wonder if continuing to exercise after Alzheimer disease develops will slow the progress of the disease or help people remain active longer. While we know of no good scientific evidence to support this, we believe that common sense supports keeping active within realistic limits (see p. 126).

The Effect of Acute Illness on Dementia

Sometimes people appear to develop a dementia after a serious illness, hospitalization, or surgery. Again, as far as is known, these things do not affect or alter the course of Alzheimer disease. Upon close examination it often is clear that the dementing illness had begun before the person had surgery or developed another disease. The stress of the acute illness and the tendency of people with a dementia to develop a delirium make the person's thinking worse, so his dementia is noticeable for the first time. Then his brain impairment will make it more difficult for him to adjust after the acute illness, making the dementia more apparent.

Research into the Delivery of Services

Scientists are now focusing on Alzheimer disease, multi-infarct disease, and stroke. In time we will learn to prevent or treat each disease. But research is not limited to the pursuit of treatments and cures. Also important are studies that tell us how to help the people who have these diseases live comfortable, satisfying lives despite their disease and studies that tell us how to assist the families who care for them. No one knows how long it will take to find a cure, but many experts suspect that it may take some time. Thus, this research is important, to help families and patients now.

We already know how to change the quality of life for some people with dementia: we can make changes that help them to function as well as possible, we can reduce their anxiety and fear, and we can make it possible for them to enjoy things sometimes. Researchers are studying the kinds of living arrangements that are best for those people with dementia who go into nursing homes and are seeking ways to help those who live at home function at their best. This is an exciting and rewarding field. Researchers have observed people who had previously paced, screamed, and struck out become relaxed and begin to participate in enjoyable activities. Even though we cannot cure these diseases, we can treat some symptoms and sometimes reduce suffering.

We know that families need help: day care, home respite, support groups, and other assistance. Researchers are studying how best to reach families, what things families need most, how to encourage families to use respite services, and the most cost-effective ways to provide respite. While it may seem that the answers to these questions are obvious, different kinds of families have different needs and people do not always do what re-

For Laypersons

Books

Personal Experience

There are many moving accounts of personal experience. Ask your local Alzheimer's Association chapter about others.

Doernberg, M. *Stolen Mind: The Slow Disappearance of Ray Doernberg.* Chapel Hill, N.C.: Algonquin Books, 1989. A wife's story.

Honel, R. W. *Journey with Grandpa: Our Family's Struggle with Alzheimer's Disease.* Baltimore: Johns Hopkins University Press, 1988. Told by a daughter-in-law; the household included children.

Zabbia, K. H. *Painted Diaries: A Mother and Daughter's Experience through Alzheimer's.* Minneapolis: Fairview Press, 1996.

For the person with dementia:

Davies, H. D., and M. P. Jensen. *Alzheimer's: The Answers You Need.* Forest Knolls, Calif.: Elder Books, 1998. A clear discussion of the issues that concern many people, based on the authors' experience with people with dementia.

Care

Alzheimer's Association. *Residential Care: A Guide for Choosing a New Home.* Chicago: Alzheimer's Association, 1998.

Gwyther, L. P. *Care of Alzheimer's Patients: A Manual for Nursing Home Staff.* Washington, D.C.: American Health Care Association; Chicago: Alzheimer's Disease and Related Disorders Association, 1985. Although written for nursing home staff members, this book, which explains common behaviors, is also useful to laypeople. Available through local Alzheimer's Association chapters.

Robinson, A., B. Spencer, and L. White. *Understanding Difficult Behaviors: Some Practical Suggestions for Coping with Alzheimer's Disease and Related Disorders.* Ypsilanti, Mich.: Geriatric Education Center of Michigan, Michigan State University, 1988. Available through local Alzheimer's Association chapters.

General

Aronson, M. K., ed. *Understanding Alzheimer's Disease: What It Is, How to Cope with It, Future Directions.* New York: Scribner's, 1988.

Cohen, D., and C. Eisdorfer. *The Loss of Self: A Family Resource for the Care of Alzheimer's Disease and Related Disorders.* New York: Norton, 1986.

Kushner, H. S. *When Bad Things Happen to Good People.* New York: Schocken, 1981.

Lewis, C. S. *A Grief Observed.* New York: Harper and Row, 1963.

(The books by Kushner and Lewis are drawn from the authors' personal losses and place those experiences in the perspectives of their religions.)

National Institute on Aging. *Alzheimer's Disease: Unraveling the Mystery.* Bethesda, Md.: National Institutes of Health, 1995. Call 800-438-4380 for a free copy.

Rogers, J. *Candle and Darkness: Current Research in Alzheimer's Disease.* Chicago: Bonus Books, 1998. A discussion of current research written for the layperson.

Warner, M. L. *The Complete Guide to Alzheimer's Proofing Your Home.* West Lafayette, Ind.: Purdue University Press, 1998.

For Children

Guthrie, D. *Grandpa Doesn't Know It's Me: A Family Adjusts to Alzheimer's Disease.* New York: Human Sciences Press, 1986.

In Foreign Languages

The 36-Hour Day has been translated into many languages. For more information, contact the Benjamin B. Green-Field National Alzheimer's Library and Resource Center of the Alzheimer's Association.

Magazine and News Articles

Many of the Alzheimer's Association chapters, as well as its national office, publish newsletters. These are valuable sources of information about current research and public policy, and they provide a network for the exchange of information among caregivers. Some chapters charge a small fee for their newsletter.

American Journal of Alzheimer's Disease. Prime National Publishing Corp., 470 Boston Post Road, Weston, Mass. 02193. This bimonthly journal is for both family members and professionals.

Videos

Caregiver Kit (5 videos). Chicago: Alzheimer's Association, 1990. Titles are "Safety First," "Communicating," "Caring for the Caregiver," "Meeting Daily Challenges," and "Managing Difficult Behaviors."

Helping People with Dementia in Activities of Daily Living. Chicago: Terra Nova Films, 1987.

Web Sites

There is a lot of information available through the Internet (see also Appendix 2). The Web sites listed below are reliable and useful.

Alzheimer's Association: http://www.alz.org.
Alzheimer's Disease Education and Referral Center: http://www.alzheimers. org.

For Professionals

There is an extensive literature on dementia in publications on medicine, psychiatry, neurology, geriatrics, gerontology, nursing, social work, public policy, long-term care, and other related subjects. The Alzheimer's Association publishes bibliographies by topic. Professionals will find the international literature helpful as well.

If you are a layperson exploring the professional literature, begin with the topical reading lists published by the Benjamin B. Green-Field National Alzheimer's Library and Resource Center. Many community libraries have a computer link to nearby university libraries and can obtain copies of articles from them for you. The literature on dementia has grown enormously; if you use a computer search, you will need to make your request narrow and specific.

Brawley, E. C. *Designing for Alzheimer's Disease: Strategies for Creating Better Care Environments.* New York: Wiley, 1997.

Coons, D. H., ed. *Specialized Dementia Care Units.* Baltimore: Johns Hopkins University Press, 1991.

Coons, D., and N. Mace. *Quality of Life in Long-Term Care.* New York: Haworth Press, 1996.

Cummings, J., and D. F. Benson. *Dementia: A Clinical Approach,* second edition. Boston: Butterworth-Heinemann, 1992.

Dowling, J. R. *Keeping Busy: A Handbook of Activities for Persons with Dementia.* Baltimore: Johns Hopkins University Press, 1995.

Hellen, C. R. *Alzheimer's Disease: Activity-Focused Care.* Boston: Andover Medical Publishers, 1992.

Lidz, C. W., L. Fisher, and R. M. Arnold. *The Erosion of Autonomy in Long-Term Care.* New York: Oxford University Press, 1992. An excellent perspective on care.

Lishman, W. A. *Organic Psychiatry: The Psychological Consequences of Cerebral Disorder,* third edition. Oxford: Blackwell Scientific Publications, 1998.

site address: http://www.aarp.org. A nonprofit, nonpartisan organization dedicated to helping older Americans achieve lives of independence, dignity, and purpose.

American Cancer Society, 1599 Clifton Rd. N.E., Atlanta, Ga. 30329; tel. 404-320-3333/toll-free 800-277-2345. Web site address: http://www.cancer.org.

American Diabetes Association, P.O. Box 25757, 1660 Duke St., Alexandria, Va. 22314; tel. 703-549-1500. Web site address: http://www.diabetes.org.

American Geriatrics Society, 770 Lexington Ave., Suite 300, New York, N.Y. 10021; tel. 212-308-1414/toll-free 800-247-4779. Web site address: http://www.americangeriatrics.org. A professional association of geriatric physicians.

American Health Care Association, 1201 L St. N.W., Washington, D.C. 20005; tel. 202-842-4444. Web site address: http://www.ahca.org. An association of for-profit and not-for-profit nursing homes; they have several publications.

American Heart Association, 7272 Greenville Ave., Dallas, Tex. 75231; tel. 214-373-6300. Web site address: http://www.americanheart.org.

American Society on Aging, 833 Market St., Suite 511, San Francisco, Calif. 94103; tel. 415-974-9600/toll-free 800-537-9728. Web site address: http://www.asaging.org. Publishes the journal *Generations* and the newsletter *Aging Today.*

Children of Aging Parents, 1609 Woodbourne Rd., Suite 302-A, Levittown, Pa. 19057; tel. 215-945-6900/toll-free 800-227-7294. Web site address: http://www.careguide.net. Provides information and referrals for caregivers of older people.

Family Caregiver Alliance, 425 Bush St., Suite 500, San Francisco, Calif. 94108; tel. 415-434-3388/toll-free 800-445-8106. Web site address: http://www.caregiver.org. A resource center serving the San Francisco Bay area, for families of adults with brain damage, including people with dementia. Their publications are available to caregivers and professionals. (Note: was previously called Family Survival Project.)

Family Service America, 11700 W. Lake Park Dr., Milwaukee, Wisc. 53224; tel. 414-359-1040. Web site address: http://www.fsanet.org. A network of member social service agencies.

Gerontological Society of America, 1275 K St. N.W., Suite 350, Washington, D.C. 20005-4006; tel. 202-842-1275. Web site address: http://www.geron.org. A professional organization; publishes *The Gerontologist* and *Journal of Gerontology.*

Gray Panthers, 733 15th St., Suite 437, Washington, D.C. 20005; tel. 202-466-3132/toll-free 800-280-5362. An advocacy organization for older people.

Huntington's Disease Society of America, 158 W. 29th St., 7th Floor, New York, N.Y. 10001; tel. 212-242-1968/toll-free 800-345-4372. Web site address: http://www.hdsa.mgh.harvard.edu.

National Adult Day Services Association, 409 3rd St. S.W., Suite 200, Washington, D.C. 20024; tel. 202-479-6682. Web site address: http://www.ncoa.org/nadsa/.

National Association for Continence, P.O. Box 8310, Spartanburg, S.C. 29305-8310; tel. 864-579-7900/toll-free 800-252-3337. Web site address: http://www.nafc.org. A patient-advocacy group that works to educate the public and health professionals about the prevalence, diagnosis, and treatment of urinary incontinence. Publishes a resource guide of products and services for incontinence. (Note: was previously called Help for Incontinent People.)

National Association for Homecare, 228 7th St. S.E., Washington, D.C. 20003; tel. 202-547-4724. Web site address: http://www.nahc.org. A trade association representing home care providers.

National Association of Professional Geriatric Care Managers, 1604 North Country Club Rd., Tucson, Ariz. 85716; tel. 520-

Safe Return, P.O. Box 9307, St. Louis, Mo. 63117-0307; toll-free tel. 888-572-8566. A joint program of the Alzheimer's Association and the National Center for Missing Persons. Caregivers fit a person who has dementia with a bracelet showing the person's name, the registered caregiver's name, and Safe Return's toll-free number (800-572-1122) to aid in that person's return should he or she become disoriented or lost.

U.S. Department of Veterans Affairs, 1120 Vermont Ave. N.W., Washington, D.C. 20421; toll-free tel. 800-827-1000.

Federal Institutes

National Institute of Mental Health, Adult and Geriatric Treatment and Preventive Interventions Research Branch, Room 10-75, 5600 Fishers Lane, Rockville, Md. 20857; tel. 301-443-1185.

National Institute of Neurological Disorders and Stroke, Office of Scientific and Health Reports, National Institutes of Health, Building 31, Room 8A-06, 31 Center Dr., MSC 2540, Bethesda, Md. 20892-2540; tel. 301-496-5751/toll-free 800-352-9424. Web site address: http://www.ninds.nih.gov.

National Institute on Aging, National Institutes of Health, 31 Center Dr., Building 31, Room 5C27, Bethesda, Md. 20892-2292; tel. 301-496-1752/toll-free 800-438-4380. Distributes brochures and information about the federally funded dementia centers and other federal initiatives; publishes a free directory of organizations that serve elderly people.

International Agencies

Alzheimer Europe, 145 Route de Thionville, L-2611 Luxembourg; tel. 352 29.79.70, fax 352 29.79.72. Web site address: http://www.alzheimer-europe.org. An organization dedicated to raising awareness about all forms of dementia through coordination and cooperation among Alzheimer organizations throughout

Europe. Also organizes support for people with Alzheimer disease and their caregivers.

Alzheimer's Disease International, 45/46 Lower Marsh, London SE1 7RG, United Kingdom; tel. 44 171 620-3011, fax 44 171 401-7351. Web site address: http://www.alzdisint.demon.co.uk. An international organization of associations dedicated to the dementias. It will provide the addresses of member organizations in other countries.

Also see http://www.thirdage.com/freestuff/yellow/i_chap19 .html for a listing of organizations that may be of interest.

Internet Sites

AgeNet. Web site address: http://www.agenet.com. An information and referral network designed to communicate information about products and services that are important to enhancing the quality of life of older adults and their families.

SeniorNet. Web site address: http://www.seniornet.org. A national nonprofit organization whose mission is to build a community of computer-using seniors.

Appendix 3

Locating Your State Office on Aging and State Nursing Home Ombudsperson

The state office on aging may have referral information, information about respite resources, and useful pamphlets. In some states the office will have extensive information and can be helpful.

The ombudsperson is an advocate for nursing home residents. This person will have information about whether a home is meeting licensure standards and what complaints, if any, have been made against it. The ombudsperson may also have literature on how to select a facility. If you have a complaint about a nursing home, start with the ombudsperson. In some states the ombudsperson's office is located in the state office on aging. The state office on aging is required by law to provide the address and telephone number of the nearest ombudsperson.

Below is a list of state offices on aging, their addresses, and their telephone numbers. This list is current as of September 1998. If you find that an address or telephone number has been changed, check with the reference department of your public library or consult the Administration on Aging's Web site (http://www.aoa.dhhs.gov) for the current address and telephone number.

Alabama
Commission on Aging, RSA Plaza, Suite 470, 770 Washington Ave., Montgomery 36130; tel. 334-242-5743

Alaska
Commission on Aging, Division of Senior Services, Department of Administration, P.O. Box 110209, Juneau 99811-0209; tel. 907-465-3250

Arizona
Aging and Adult Administration, Department of Economic Security, 1789 West Jefferson, #950A, Phoenix 85007; tel. 602-542-4446

Arkansas
Division of Aging and Adult Services, Department of Human Services, P.O. Box 1437, Slot 1412, 7th and Main Sts., Little Rock 72201-1437; tel. 501-682-2441

California
Department of Aging, 1600 K St., Sacramento 95814; tel. 916-322-5290

Colorado
Aging and Adult Services, Department of Social Services, 110 16th St., Suite 200, Denver 80202-5202; tel. 303-620-4147

Connecticut
Division of Elderly Services, Department of Social Services, 25 Sigourney St., 10th Floor, Hartford 06106-5033; tel. 860-424-5277/toll-free 800-443-9946

Delaware
Division of Services for Aging and Adults with Physical Dis-

abilities, Department of Health and Social Services, 1901 North DuPont Highway, New Castle 19720; tel. 302-577-4791/toll-free 800-223-9074

District of Columbia
Office on Aging, One Judiciary Square, 9th Floor, 441 Fourth St. N.W., Room 900-S, Washington, D.C. 20001; tel. 202-724-5622

Florida
Department of Elder Affairs, Building B, Suite 152, 4040 Esplanade Way, Tallahassee 32399-7000; tel. 904-414-2000

Georgia
Division of Aging Services, Department of Human Resources, 2 Peachtree St. N.E., 18th Floor, Atlanta 30303; tel. 404-657-5258

Guam
Division of Senior Citizens, Department of Public Health and Social Services, P.O. Box 2816, Agana 96932; tel. 011-671-475-0263

Hawaii
Executive Office on Aging, 250 South School St., Suite 107, Honolulu 96813; tel. 808-586-0100

Idaho
Commission on Aging, 3380 Americana Terrace, Suite 120, Boise 83706; tel. 208-334-3033

Illinois
Department on Aging, 421 East Capitol Ave., Suite 100, Springfield 62701-1789; tel. 217-785-2870, Chicago office: 312-814-2630

Indiana
Bureau of Aging and In-Home Services, Division of Disability, Aging and Rehabilitative Services, Family and Social Services Administration, 402 W. Washington St., #W454, P.O. Box 7083, Indianapolis 46207-7083; tel. 317-232-7020

Iowa
Department of Elder Affairs, Celemens Building, 3rd Floor, 200 Tenth St., Des Moines 50309-3609; tel. 515-281-5187

Kansas
Department on Aging, 503 S. Kansas Ave., Topeka 66603-3404; tel. 785-296-4986

Kentucky
Division of Aging Services, Cabinet for Human Resources, 275 East Main St., 6 West, Frankfort 40621; tel. 502-564-6930

Louisiana
Office of Elderly Affairs, P.O. Box 80374, 412 N. 4th St., 3rd Floor, Baton Rouge 70802; tel. 504-342-7100

Maine
Bureau of Elder and Adult Services, Department of Human Services, 35 Anthony Ave., State House, Station 11, Augusta 04333; tel. 207-624-5335

Maryland
Office on Aging, State Office Building, Room 1007, 301 West Preston St., Baltimore 21201-2374; tel. 410-767-1100

Massachusetts
Executive Office of Elder Affairs, One Ashburton Place, 5th Floor, Boston 02108; tel. 617-727-7750

Michigan
Office of Services to the Aging, P.O. Box 30026, Lansing 48909-8176; tel. 517-373-8230

Minnesota
Board on Aging, 444 Lafayette Rd., St. Paul 55155-3843; tel. 612-296-2770

Mississippi
Division of Aging and Adult Services, 750 State St., Jackson 39202; tel. 601-359-4925

Missouri
Division on Aging, Department of Social Services, P.O. Box 1337, 615 Howerton Court, Jefferson City 65102-1337; tel. 573-751-3082

Montana
Senior and Long Term Care Division, Department of Public Health and Human Services, P.O. Box 8005, 48 N. Last Chance Gulch, Helena 59604; tel. 406-444-7788

Nebraska
Division on Aging, Department of Health and Human Services, P.O. Box 95044, 301 Centennial Mall South, Lincoln 68509-5044; tel. 402-471-2307

Nevada
Division for Aging Services, Department of Human Resources,

State Mail Room Complex, 340 North 11th St., Suite 203, Las Vegas 89101; tel. 702-486-3545

New Hampshire
Division of Elderly and Adult Services, State Office Park South, 115 Pleasant St., Annex Building 1, Concord 03301-3843; tel. 603-271-4680

New Jersey
Division of Senior Affairs, Department of Health and Senior Services, P.O. Box 807, Trenton 08625-0807; tel. 609-588-3141/toll-free 800-792-8820

New Mexico
State Agency on Aging, La Villa Rivera Building, 4th Floor, 224 East Palace Ave., Santa Fe 87501; tel. 505-827-7640

New York
Office for the Aging, 2 Empire State Plaza, Albany 12223-1251; tel. 518-474-5731/toll-free 800-342-9871

North Carolina
Division of Aging, CB 29531, 693 Palmer Dr., Raleigh 27626-0531; tel. 919-733-3983

North Dakota
Aging Services Division, Department of Human Services, 600 South 2nd St., Suite 1C, Bismarck 58504; tel. 701-328-8910

Northern Mariana Islands
Office on Aging, P.O. Box 2178, Commonwealth of the Northern Mariana Islands, Saipan 96950; tel. 670-233-1320

Ohio
Department of Aging, 50 West Broad St., 9th Floor, Columbus 43215-5928; tel. 614-466-5500

Oklahoma
Services for the Aging, Department of Human Services, P.O. Box 25352, 312 N.E. 28th St., Oklahoma City 73125; tel. 405-521-2281 or 521-2327

Oregon
Senior and Disabled Services Division, 500 Summer St. N.E., 2nd Floor, Salem 97310-0105; tel. 503-945-5811/toll-free 800-232-3020

Palau
State Agency on Aging, Republic of Palau, Koror 96940; tel. 9-10-288-011-680-488-2736

Pennsylvania
Department of Aging, Commonwealth of Pennsylvania, 555 Walnut St., 5th Floor, Harrisburg 17101-1919; tel. 717-783-1550

Puerto Rico
Governor's Office of Elderly Affairs, Commonwealth of Puerto Rico, Call Box 50063, Old San Juan Station 00902; tel. 787-721-5710, 721-4560, or 721-6121

Rhode Island
Department of Elderly Affairs, 160 Pine St., Providence 02903-3708; tel. 401-277-2858

American Samoa
Territorial Administration on Aging, Government of American Samoa, Pago Pago 96799; tel. 011-684-633-2207

Washington
Aging and Adult Services Administration, Department of Social and Health Services, P.O. Box 45050, Olympia 98504-5050; tel. 306-493-2500

West Virginia
Bureau of Senior Services, Holly Grove, Building 10, 1900 Kanawha Boulevard East, Charleston 25305-0160; tel. 304-558-3317

Wisconsin
Bureau of Aging and Long Term Care Resources, Department of Health and Family Services, P.O. Box 7851, Madison 53707; tel. 608-266-2536

Wyoming
Office on Aging, Department of Health, 117 Hathaway Building, Room 139, Cheyenne 82002-0480; tel. 307-777-7986

with a written plan of care which . . . is initially prepared, with participation to the extent practicable of the resident or the resident's family or legal representative."

Participation in Facility Administration

The law emphasizes the importance of "resident and advocate participation" as criteria for good facility administration.

Specific Rights

Under the law, each nursing facility must "protect and promote the rights of each resident," including:

A. Rights to Self-determination

Nursing home residents have the right

- to choose their personal physician;
- to full information, in advance, and participation in planning and making any changes in their care and treatment;
- to reside and receive services with reasonable accommodation by the facility for individual needs and preferences;
- to voice grievances about care or treatment they do or do not receive without discrimination or reprisal, and to receive a prompt response from the facility;
- to organize and participate in resident groups (and their families have the right to organize family groups) in the facility.

B. Personal and Privacy Rights

Nursing home residents have the right

- to participate in social, religious, and community activities as they choose;
- to privacy in medical treatment, accommodations, personal visits, written and telephone communications, and meetings of resident and family groups; and

- prominently display and provide written and oral information for residents about how to apply for and use Medicaid benefits and how to receive a refund for previous private payments that Medicaid will pay for retroactively.

E. Rights to Visits

The nursing home must

- permit immediate visits by a resident's personal physician and by representatives from the health department and the ombudsman program;
- permit immediate visits by a resident's relatives, with the resident's consent;
- permit visits "subject to reasonable restriction" for others who visit with the resident's consent;
- permit reasonable visits by organizations or individuals providing health, social, legal, or other services, subject to the resident's consent; and
- permit ombudsmen to review the resident's clinical records if the resident grants permission.

F. Transfer and Discharge Rights

Reasons for transfer: Nursing homes "must permit each resident to remain in the facility and must not transfer or discharge the resident unless"

- the facility is unable to meet the resident's medical needs;
- the resident's health has improved to such a degree that he no longer needs nursing home care;
- the health or safety of other residents is endangered;
- the resident has failed, after reasonable notice, to pay an allowable facility charge for an item or service provided upon the resident's request.

Notice to residents and their representatives before transfer:

- Timing—at least 30 days in advance, or as soon as possible if more immediate changes in health require more immediate transfer
- Content—reasons for transfer; the resident's right to appeal the transfer; and the name, address, and phone number of the ombudsman program and protection and advocacy programs for the mentally ill and developmentally disabled
- Returning to the facility—the right to request that a resident's bed be held, including information about how many days Medicaid will pay for the bed to be held and the facility's bed-hold policies, and the right to return to the next available bed if Medicaid bed-holding coverage lapses
- Orientation—A facility must prepare and orient residents to ensure safe and orderly transfer from the facility.

G. Protection of Personal Funds

A nursing facility must

- not require residents to deposit their personal funds with the facility;
- if it accepts written responsibility for residents' funds
  - —keep funds over $50 in an interest-bearing account, separate from the facility account;
  - —keep other funds available in a separate account or petty cash fund;
  - —keep a complete and separate accounting of each resident's funds, with a written record of all transactions, available for review by residents and their representatives;
  - —notify Medicaid residents when their balance comes within $200 of the Medicaid limit and the effect of this on their eligibility;

- —upon a resident's death, turn funds over to the resident's trustee;
- —purchase a surety bond to secure residents' funds in its keeping; and
- —not charge a resident for any item or service covered by Medicaid, specifically including routine personal hygiene items and services.

H. Protection against Medicaid Discrimination

Nursing homes must

- establish and maintain identical policies and practices regarding transfer, discharge, and the provision of services for all individuals, regardless of source of payment;
- not require residents to waive their rights to Medicaid, and must provide information about how to apply for Medicaid;
- not require a third party to guarantee payment as a condition of admission or continued stay; and
- not "charge, solicit, accept or receive" gifts, money, donations, or "other consideration" as a precondition for continued stay for persons eligible for Medicaid.

Index

Library of Congress Cataloging-in-Publication Data

Mace, Nancy L.
The 36-hour day : a family guide to caring for persons with Alzheimer disease, related dementing illnesses, and memory loss in later life / Nancy L. Mace, Peter V. Rabins. — 3rd ed., large print.
p. cm. — (A Johns Hopkins Press health book)
Includes index.
ISBN 0-8018-6521-2 (large print : alk. paper).
1. Alzheimer's disease—Patients—Home care. 2. Senile dementia—Patients—Home care. I. Title: Thirty-six hour day. II. Rabins, Peter, III. Title IV. Series.
RC523 .M33 2000
362.1′98976831—dc21 00-042416