

# One Step at a Time

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*A Guide For Parents Navigating The Hospital  
Experience With Their Child*

*Authors: Jennifer Smith, RN and Bradie Kvinsland, CCLS*

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Trust  
Inspiration

This book belongs to: \_\_\_\_\_



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**Global-HELP Publication**

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**DISCLAIMER**

This book should not be used as an alternative for professional care. It is meant to be used for documenting care, exploring feelings, and informing parents of the routines of hospitals in a general sense. There is no guarantee that the information in this book will remain current over time. The appropriate professionals should be consulted with respect to the care of the hospitalized patient and those involved in their care.

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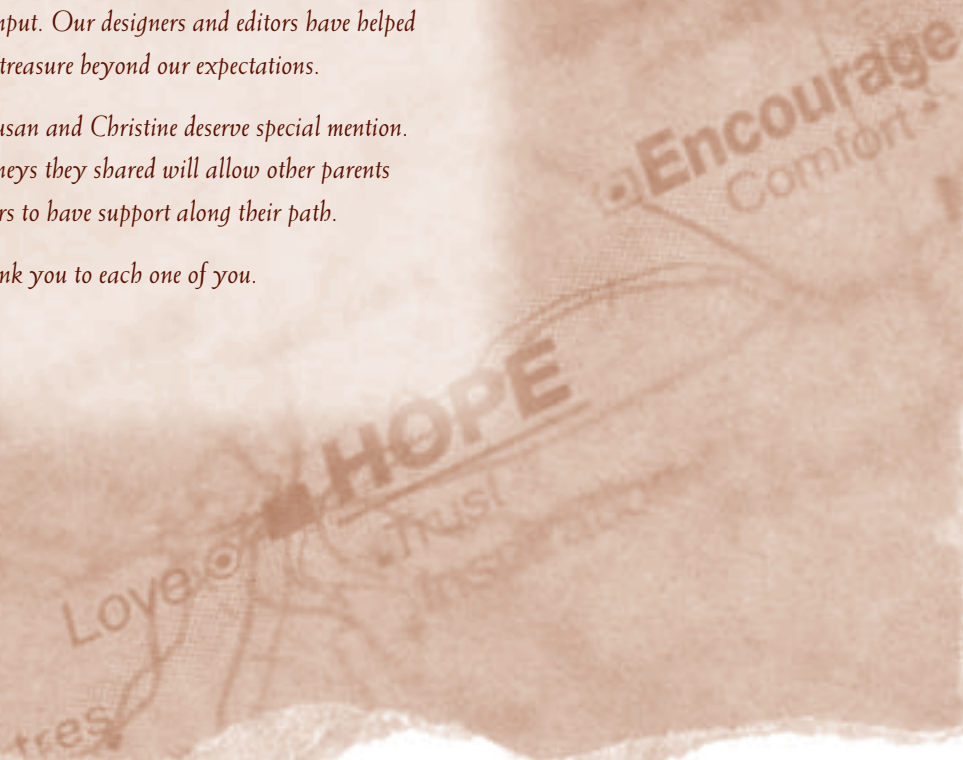


*Our dream of creating this book was made possible by  
the support and expertise of many people.*

*We are thankful to those who have embraced this book and given  
wonderful, creative input. Our designers and editors have helped  
to create a treasure beyond our expectations.*

*Robin and Brita, Susan and Christine deserve special mention.  
The personal journeys they shared will allow other parents  
and caregivers to have support along their path.*

*Thank you to each one of you.*



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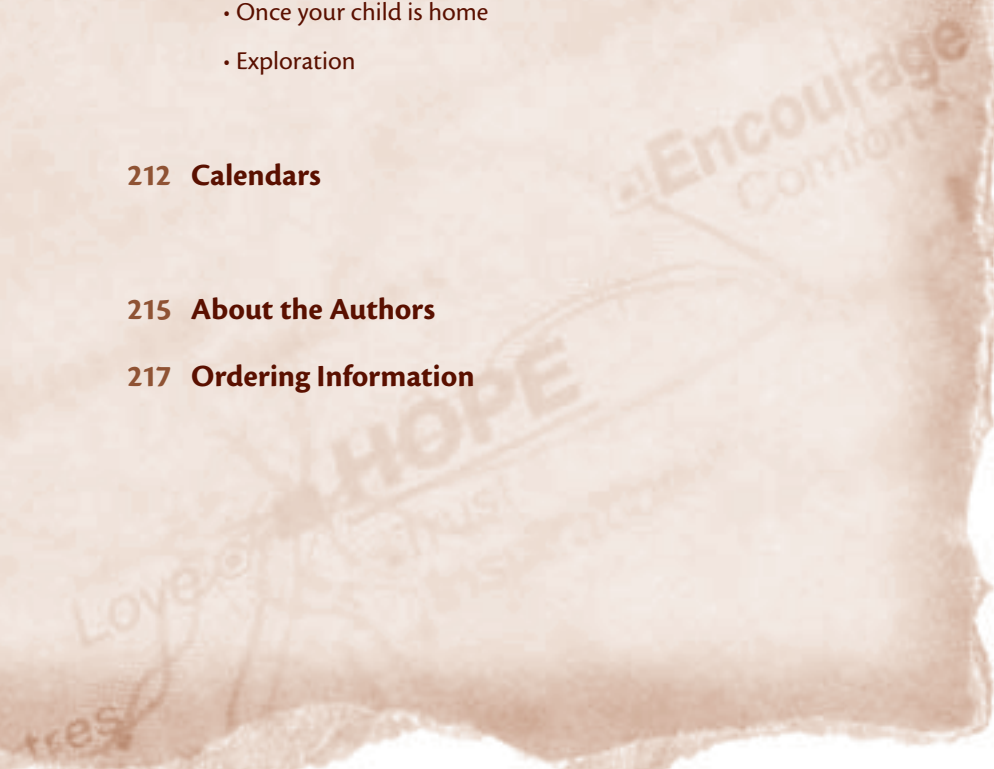
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*Something is drastically wrong with your child  
and you are expected to be a warrior. But you  
are losing control and beginning to crumble inside.  
Questions and concerns, duties and demands rage  
through your mind and you ask yourself...*

*How am I going to make it through this with my child?*

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## Preface

*A letter from the authors*

We are a child life specialist and an intensive care nurse who care for babies and children. Our satisfaction comes from helping sick children, as well as embracing and sustaining you, the family members and friends. We wrote *One Step at a Time* to offer you support during your child's hospitalization.

The effects of prolonged lack of sleep, food and spiritual support during a hospital stay are devastating. As a parent, you may have difficulty facing important decisions and coping when your sick child requires your attention. It may be almost impossible to handle the details of your home and work life. In addition, relationships with your spouse or partner may become distanced, strained and cold. Devotion to your sick child can sometimes mean excluding not only your spouse, but your healthy children as well. Your lives can become parallel and separate instead of together and synergistic. *One Step at a Time* can help.

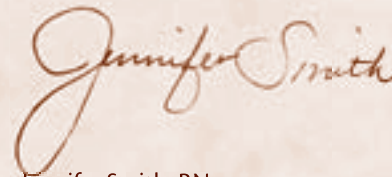
Our vision for *One Step at a Time* came from the realization that more can be done to support and help you during your child's hospitalization. Our goal is to help give you a voice and empower you with the tools you need so that you are able to be a vital part of the family-centered care which is available to you during your child's hospital stay.

In this book, you will find words of advice from other parents and health professionals. There are reminders and tips to help you deal with your new environment as well as spaces for you to track important information and events. Perhaps hardest of all, but so very important, there are many opportunities to record your feelings. Your ability to search

inward is a vital key to coping and taking care of yourself.

Maybe the book is more than you can handle right now. Maybe it feels overwhelming. That's okay. We hope you will give it time - because we believe working with this book can help penetrate your feelings of anger and fear, help you work through your roller-coaster emotions, and help you regain a sense of control.

We believe each and every one of the patients we work with is well cared for. Through this book, we hope to sustain and embrace you as well. Then we'll know our work has a larger purpose beyond medicine. And we'll be reminded-in a very real way-of why we do our jobs.



Jennifer Smith, RN



Bradie Kvinsland, CCLS

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## Using This Book

You don't know who to talk to or where to go for answers. In fact, you don't even know the questions yet.

You know that there are many people surrounding you with extensive knowledge and education. But when you do get answers, they're spoken in a language you don't understand. They talk of concepts and processes that are strange and confusing.

And it's your child they're talking about!

*One Step at a Time* is a guidebook that will give you a road map for dealing with your child's hospitalization. It will guide you through your new environment and help you explore your feelings throughout this experience.

Each section of this book is introduced with carefully selected words that float across the page. These words hint at what you'll find in the pages that follow. Each section is designed to be used for however you're feeling that day, that hour, that minute. Moving from one section to another—even randomly—is encouraged.

Throughout the book you will find tips that may or may not apply to your family's situation. The authors are reaching out to families with premature infants and those with older children who have varying diagnoses.

The first section begins with a general guide to hospital terminology, routines, and protocols. You'll also find guidance

for gathering information even when your coping skills are not at their best.

The next section begins with tips for interacting and advocating with your baby or older child, coping with siblings, and tips for giving medicine to your child. It also encourages you to explore your feelings with guided exploration pages that provide a safe place to release some of your emotions.

Next, the daily entry pages are introduced, where you can keep track of questions you want to ask and answers you receive. You'll soon learn that by asking the right questions for your child, you're also paying attention to your own needs. Scattered through these pages are tips from other parents, suggestions from health professionals, and inspirational quotes to help you get through each day.

The remainder of the book is a mix of daily entry pages and exploration pages with more tips, poems, and suggestions throughout.

Finally, your journey through the hospitalization will take you back home, regardless of the traveling it took to get there. Going home will require yet another adjustment as you leave the safety net of the hospital and the skilled people who have been caring for you and your child every day. This section will provide the new road map you'll need to find your way home and begin yet another step on your journey toward healing.

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Illness

Hospital Terminology

Support

Overload

# 1 Learning The Ropes

1

*This section will serve as your guide to getting to know the hospital staff, basic hospital terms, routines, resources and language. It will help you process the information given to you and guide you in developing a support system to help cope with all this new information.*

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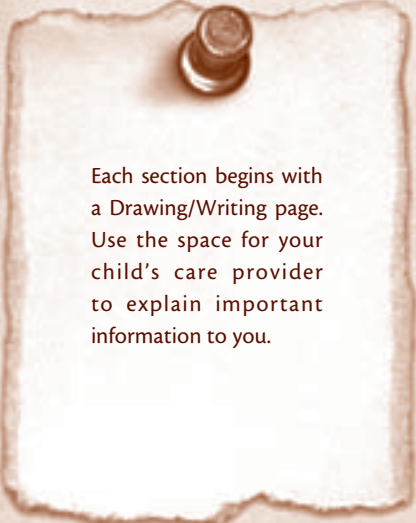
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## Drawing/Writing Page

*For your health care professional to explain procedures, your child's condition, tests and so on through drawings or written explanations.*



Each section begins with a Drawing/Writing page. Use the space for your child's care provider to explain important information to you.

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## Understanding Simple Changes

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Your child's heart rate may be high for many reasons. Here are some possible causes:

- 1) Fever
- 2) Low circulating blood volume, reflected with a lower blood pressure
- 3) Pain
- 4) Abnormal heart rhythm
- 5) Medicines
- 6) Infection

Ask your health care team what is happening with your child and have them continue explaining until you understand.

### Why do we get a fever with infection?

- The body raises its internal temperature to kill the harmful germs affecting your child.
- Your child's body is triggered to increase core body temperature by minimizing heat loss. Shivering causes the veins to constrict (make smaller) so heat won't be lost through skin surface. Your child will want to curl in a ball. Your natural response is to cover her with blankets. All this is done subconsciously to help the body conserve heat and to help destroy bad bacteria and viruses.

- Your child's hands and feet may feel cold during a fever. This is the body's natural response to constricted vessels, minimizing heat loss.

— From *Understanding Pathophysiology*,  
Sue E. Huether and Kathryn L. McCance.

### Why do your nurses worry if your child is too cold?

Especially in newborns, the nervous system is not as developed to have the shivering response that older children and adults have. Instead, a newborn's body turns to chemical means of increasing core body temperature which uses up their energy stores. If your child is already sick, using up precious oxygen and sugar to help the body run can be harmful.

Even with older children, being too hot or too cold causes the body to work extra hard to regulate itself to a normal temperature.

— From *Handbook of Neonatal Intensive Care*,  
Gerald B. Merenstein and Sandra L. Gardner,  
Mosby, 5th Ed. 2002.

## Your hospital may have the following staff ...

Most hospitals caring for children have **volunteers** who will stay with your child when you need a break. They can also help with your other children.

A **child life specialist** works with the developmental and emotional needs of children and families. This member of your health care team uses play and other forms of communication to help relieve some of the stress that comes from hospital experiences.

Hospital **social workers** are trained to help parents become familiar with the hospital routine and can connect you with other hospital and community resources. They often provide emotional support during your hospital experience and can ensure that your voice is heard among your health care team.

There is a team of doctors and nurses specifically trained to deal with pain. If you feel that your child's pain is not adequately controlled, ask for the **pain service**.

There are **financial counselors** and **case managers** available who can communicate with insurance companies on your behalf and set up options with local programs.

**Hospital chaplains** are available when you have difficult questions regarding faith and spirituality. They are also available for baptisms. Chaplains are usually non-denominational, but they'll locate a chaplain from your own religion if you prefer.

**Interpreters** are available for almost all languages. If English is your second language, it might help you to request an interpreter when the health care team talks to you about your child's condition and plan of care at length.

**Lactation consultants** are available to work with the mother and baby if there are breastfeeding difficulties. The consultant may also work with just the mother if you need to pump and store your milk when your baby is unable to breastfeed.

**Respiratory therapists** are responsible for the respiratory treatments and setting up and monitoring respiratory assistive devices. They work with the health care team to evaluate and treat your child's airway and lungs.

Please know that hospital staff other than your nurse cannot silence alarms or turn off beeping machines but can alert your child's nurse.



# Nursing Staff

**Nurse Practitioner** is a nurse with a master's degree who is able to assist the doctors in managing the care of your child. He or she may also be the person writing orders for your child.

## Your nursing staff's chain of command

The **bedside nurse** is the person with you most of the time, at your child's bedside. Initial concerns should be discussed with your bedside nurse.

If you would like to have specific nurses working with your child, ask if the unit has a system in place for primary nursing. This creates a consistent team of caregivers who really get to know your child. With this team approach, complete and accurate information is more likely to be passed from one regular nurse to the next.

Your nurse can act as your filter and spokesperson. If you and your child need breaks from visitors and medical staff, he or she can communicate that your child needs some quiet time and coordinate "appointments."

The **charge nurse** is the next in line for discussing issues that aren't resolved by talking with the doctors or your bedside nurse. The charge nurse also decides bedside nurse assignments and helps coordinate transfers, admissions and discharges.

If you still need more follow-up, discuss your concerns with the **nurse manager** or the **director of your unit**. Nurse managers can also address problems or concerns with your doctors if you are having trouble doing this yourself.

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## Doctor's chain of command

### *Teaching Hospital*

Hospitals are all organized differently, but they typically fall into one of two general categories: teaching hospitals and non-teaching hospitals. The doctor's chain of command is different for each.

**Interns** have completed medical school and are referred to as "first year residents."

**Residents** have decided to specialize in pediatrics. A residency in pediatrics is a three year program, so you may have a first year (intern/resident), second year or third year resident. Residents who have completed their three year program can practice as pediatricians in a clinic.

**Fellows** have completed three years of residency and have decided to further specialize in pediatric intensive care, neurology, pulmonology and so forth. For most specialties, a fellowship is also a three year program.

**Attending doctors** have completed their fellowship and can teach and guide other residents and fellows. They are ultimately responsible for your child's care.

Your **primary doctor (pediatrician)** has on-call doctors replacing them at night and on the weekends. This change-over occurs at about 4-5:00 p.m. on weekdays.

Your **consulting doctors** make recommendations to your primary team. Consulting doctors also have doctors on call for them.

Each of these services (primary and consulting) have residents, fellows and attendings. When you are introduced, clarify what service they are with, what level of training

they have and if they are your child's regular doctor or the on-call doctor.

When children are cared for by multiple specialties within a hospital, parents often get frustrated because they don't know who is in charge of the care.

An example is a brain tumor patient in the intensive care unit:

*Typically, the doctors and services involved would be the cancer team, the intensive care team, and the neuro-surgical team. Because this patient would normally spend a lot of time in the cancer unit, the family would be most familiar with the cancer doctors and the neuro-surgical team who has advised them on possible surgery. But once the child is moved to the intensive care unit, the primary team of doctors shifts to the intensive care doctors. The child's other services then become "consultants" to the intensivists, who then write the orders, arrange for tests and manage the entire care of the child. If the child becomes sick with an infection, the infectious disease team may recommend medicines to the intensive care doctors.*

As you can see, the number of doctors working with you and your child may quickly become overwhelming.

Write down to whom you are supposed to go for the treatment plan and answers. This may change as your child's condition changes so it is important to continue asking these questions. Only one service can write orders for your child at a time.



# Doctor's chain of command

*Non-Teaching Hospital*

## **Pediatric Hospitalist Program**

Patients have traditionally been cared for in the hospital by their primary care doctors (private practice pediatrician). In many hospitals, this system has been replaced by one in which primary care doctors relinquish or share care of their hospitalized patients to inpatient specialists called "hospitalists."

A **pediatric hospitalist** is a pediatrician that specializes in caring for hospitalized children. Pediatric hospitalists have completed a residency with emphasis on inpatient management of newborns and acutely ill infants and children. A hospitalist may treat medical problems like fever, infections, breathing difficulties (asthma, pneumonia), and dehydration.

Most hospitalists work in partnership with referring pediatricians during a child's hospitalization. These doctors, who are available in the pediatric units 24 hours a day, 7 days a week, coordinate and oversee all inpatient care including subspecialty appointments, procedures, tests and transport. Families often consider hospitalists their liaison to the hospital and an important resource regarding their child's health.

Hospitalists can be found in all areas of the hospital including the emergency department, the newborn nursery and in inpatient units. They perform daily examinations to keep parents updated on the child's condition and provide patient education material when necessary.

**Pediatric intensivists /neonatologists** are pediatricians with advanced training in managing complex medical conditions. A pediatric intensivist typically handles severe problems that require admission to a **Pediatric Intensive Care Unit (PICU)/Neonatal Intensive Care Unit (NICU)** such as trauma, critical heart or lung disease, car or near-drowning accidents, problems associated with prematurity or birth defects.

In some cases, pediatricians and hospitalists consult with pediatric and neonatal intensivists concerning metabolic abnormalities, infections, feeding difficulties, pain management and sedation and post-operative issues.

Pediatric and neonatal intensivists are generally available 24 hours a day in the PICU or NICU.

**The above models may not apply to your child's hospital. Ask questions and learn your hospital's process and chain of command to determine who assumes responsibility for your child.**

Write down your child's doctor chain of command here:

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## Understanding the medical language and terminology

**Report**—When your nurse updates an oncoming nurse, he or she gives a review of your child's history and progress. The nurse will have an established list of things to review. Common items include allergies, weight, and updates on the neurologic, respiratory and cardiovascular systems. The nurse also shares things like lab results, medicines and IV access, as well as social aspects that may affect how care is delivered to your child.

**Rounds**—This is the time when your health care team meets to discuss your child's events over the past 24 hours and plans for the upcoming day. This is also how knowledge about your child is passed on to health care professionals who are not familiar with your child. Ask to be included so you can be aware of what's being said.

**Care conference**—When your child is being followed by multiple specialists, sometimes it is necessary to gather your team to meet and discuss the plan for your child. You may make requests for whom you would like to attend. Sometimes your nurse, social worker and/or case manager may attend this meeting as well as your doctors.

**Oxygen saturations** or "sats" (not "stats")—Are measured by a probe with a laser attached to your child's finger or toe. This pain free laser can read how *saturated* the hemoglobin (blood) molecule is with oxygen; this saturation level is read as a percentage. The laser gets a better, more accurate reading on warm hands and feet that have a strong pulse. When your child is cold, the reading is not as accurate. Find out what the acceptable range is for your child and make note of it.

*My child's sats must be greater than \_\_\_\_\_*

**Heart rate**—Refers to the number of times the heart beats in a minute to pump blood and deliver oxygen to the rest of the body. Ask your nurses what the acceptable range is for your child. When there are significant variances, ask why this is happening and write it down.

*My child's heart rate range is \_\_\_\_\_*

**Intubate**—If your child is having a hard time breathing on his or her own, the doctors may intubate. This means placing a breathing tube down your child's throat attached to a ventilator to "breathe" for your child.

**Sepsis**—Refers to a type of infection that has spread from a local area into the blood stream. When this occurs, stronger medicines will be used to help your child's body fight the infection.

**Culture**—A *lab draw* that tests for bacteria, viral or fungal infections. Cultures may be obtained from any open wound or body fluid such as blood, secretions or cerebral spinal fluid.

**Arteries**—Take blood that carry oxygen from the heart to the organs.

**Veins**—Take blood from organs back to the heart/lungs to be replenished with oxygen.

**Blood Gas**—Your team is referring to a set of numbers that represents metabolic and respiratory functioning. It is obtained by getting blood from an artery, a vein or a capillary (from a heel stick).

Crit or **hematocrit**—Is a measure of red blood cells and is expressed as a percentage of your child's total blood volume.

**Bagging**—An inflatable bag, operated by hand, is used to give



**NG** = *Naso-Gastric*. A feeding tube may be placed into the nose, going into the stomach. This is called a “NG tube.”

**LP** = *Lumbar Puncture*. A test performed if an infection in the spinal fluid or central nervous system is suspected.

**ICP** = *Intracranial Pressure*. The amount of pressure on the brain. Excessive ICP is usually caused by extra fluid or blood within the skull.

**ETT** = *Endo-Tracheal Tube*. The tube that is used to help your child breathe.

**BID / TID / QID** = *Twice a day / Three times a day / Four times a day*

**Q8 / Q12 / QOD** = *Every 8 hours / Every 12 hours / Every other day*

**NPO** = *nothing by mouth*

**PRN** = *as needed*

**Renal/Nephrology** = relating to the kidney

**Hepatic** = relating to the liver

**Pulmonary** = relating to the lung

**Orthopedics** = relating to bones

**Here is space for you to write other terminology that is new to you:** \_\_\_\_\_

\_\_\_\_\_

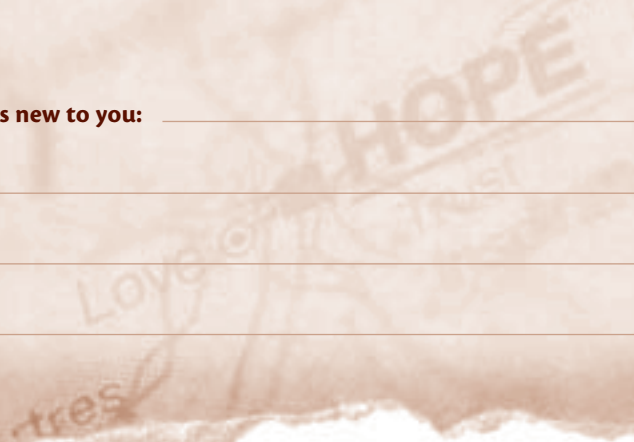
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### Confusing Words

Ask your staff and visitors to be mindful of words and phrases which can confuse your child.

words to avoid	use this instead
shot	medicine through a needle
table	bed
stretcher	bed with wheels
gas	medicine called anesthesia
floor	unit or ward
dressing	bandage
put you to sleep	give you medicine to help you sleep. When your test or procedure is finished, the doctor will stop giving you this medicine and you will wake up.



## Why is my child in the hospital?

*From an experienced parent: "Be prepared to have many of the same questions asked of you over and over."*

**What were the events leading up to the hospitalization?** \_\_\_\_\_

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**What do I know about my child's condition right now?** \_\_\_\_\_

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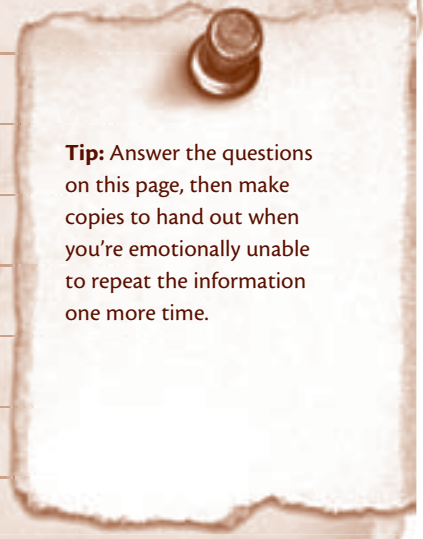
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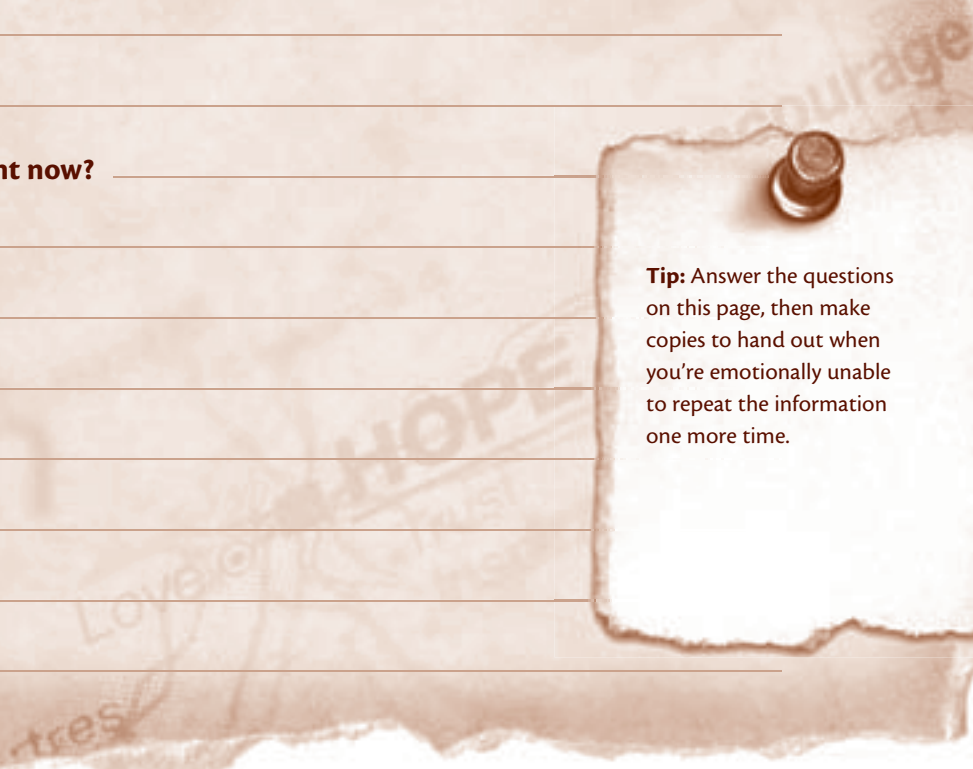
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**Tip:** Answer the questions on this page, then make copies to hand out when you're emotionally unable to repeat the information one more time.





## Tests and Procedures

*This page will arm you with the right questions when your health care team begins to discuss your child's treatment plan.*

11

**What is the purpose of this test or procedure?** \_\_\_\_\_

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**How will this enable you to help my child?** \_\_\_\_\_

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**Are there risks associated with this procedure?** \_\_\_\_\_

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**Will you please explain the procedure to me and to my child?** \_\_\_\_\_

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**Who will give me the results of the test and when can I expect them?** \_\_\_\_\_

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**Tip:** Copy this page to use it for each test or procedure your child may experience.

**Reminder:** If your hospital has a child life specialist, she can help prepare your child for all tests and procedures as well as be present to help support and advocate for your child's needs.

## Evaluating and managing pain

### Evaluating Pain

Children who can communicate may be asked to describe their pain so the medical staff can respond in the right way. If your child is in a great deal of pain, tell your health care team your concerns and strive to create a plan to control pain. It is important to remember that pain is interpreted individually. Take time to help your child learn age appropriate ways to express pain. Evaluating pain in children differs by age and communication ability.

#### For your infant

- Ask that your baby be given pain relief or sedation for medical procedures that could be difficult for him to handle.
- Sucrose solutions may be used alone or with pain medicines to help with painful procedures such as lab draws or IV pokes. The pain relief is achieved in about 2 minutes and lasts for about 5 minutes. It is not a medicine and does not require a doctor's order. Ask your nurse if this is something that your baby could benefit from. Noerr, B (2001), *Sucrose for neonatal procedural pain*, *Neonatal Network* (20) 7: 63-67.

**Children who are developmentally under 3 years** of age can often tell you they are hurting, but often cannot tell you how much. If they are not able to effectively communicate with words, look for other signs of pain, such as touching the area that hurts, crying and making a painful face.\*

For those children who cannot verbally communicate and are able, have a consistent method to ask about pain and discomfort.

Have your child blink twice if the answer is "yes" and blink once for "no" (hand squeezing is another method). Begin with her head and move down her body asking if there is pain or discomfort along the way.

The most important way to measure pain is to ask your child how much he or she hurts. Below are tools to help children of various developmental ages communicate pain they may be feeling.

**Children who are developmentally between the ages of 3-7** can effectively tell you how much pain they are in by using a pain rating scale. Here is an example of a pain scale:

#### Wong-Baker FACES Pain Rating Scale.



#### Instructions:

Explain to your child that each face is for a person who feels happy because he has no pain (hurt) or sad because he has some or a lot of pain. **Face 0** is very happy because he doesn't hurt at all. **Face 1** hurts just a little bit. **Face 2** hurts a little more. **Face 3** hurts even more. **Face 4** hurts a whole lot. **Face 5** hurts as much as you can imagine, although you don't have to be crying to feel this bad. Ask your child to choose the face that best describes how he is feeling.

The rating scale is recommended for a child with a developmental age of 3 years and older.

\* Reference: Association for the Care of Children's Health and Patrick McGrath, "Pain, Pain, Go Away: Helping Children with Pain" Patrick McGrath, Ph.D., G. Allen Finley, M.D., FRCPC, and Judith Ritchie, R.N., Ph.D. 1994



# Evaluating and managing pain

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## Wong-Baker FACES Pain Rating Scale continued

**Brief word instructions.** Point to each face using the words to describe the pain intensity. Ask the child to choose the face that best describes her own pain and record the appropriate number.

*From Wong D.L., Hockenberry-Eaton M., Wilson D., Winkelstein M.L., Schwartz P.: Wong's Essentials of Pediatric Nursing, ed. 6, St. Louis, 2001, p. 1301. Copyrighted by Mosby, Inc. Reprinted by permission.*

**Children who are developmentally over the age of 7** can use more descriptive words to describe their pain. They can rate their pain using a 0-10 scale. Zero being no pain and 10 being the worst possible pain.

Remember, pain evaluation can be tricky. Your child may think that if she tells you she's hurt, it will mean more tests or surgeries. Perhaps in the past, she was praised for being "tough" or "strong." Or when she sees you sad, she might not want to express her own hurts.

**For children with a strong vocabulary,** language is an effective way to communicate pain. Here are some questions to help organize your child's description of his or her pain:

*Where do you feel pain? Is it constant or does it come and go? How long does it last? What does it feel like: Dull? Sharp? Throbbing? Does it increase or decrease with activity? Does it hurt on the outside or inside of your body?*

*From Healing Images For Children, Nancy Klein, M.A., 1st Ed. Inner Coaching*

## Managing Pain

Children are comforted by hugging, kissing and holding from loved ones. It is important for children to know they have someone with them during painful and scary situations that may arise in a medical setting. If possible, be present during your child's painful procedures. This alone can be an effective pain management tool.

**Breathing techniques** are useful in managing pain. Encourage your child to breathe slowly and deeply (inhaling through the nose, exhaling through the mouth) as a way to cope. Some breathing tricks can be used with younger children, like blowing a pinwheel, blowing bubbles or blowing out a pretend candle.

**Guided imagery** can often effectively reduce pain. This visualizing technique uses all your child's senses and helps in relaxation. Ask your child where his or her favorite place is and help your child visualize that place. Ask a member of your health care team to assist you and your child in practicing this useful technique.

**Distraction** is an excellent way to help children cope with pain. Books, toys, games, video games, computer activities and television are common and effective distraction tools. Encourage your child to participate in picking an activity. And remember, laughter can be the best distraction and medicine.

## Handy Information

**EMLA cream** is a topical numbing ointment applied to the skin, which helps decrease the pain sensation of IV insertions, lab draws, lumbar punctures, etc. It must be placed on the skin for 60 minutes prior to the planned procedure and its effects last for four hours.

**PCA (Patient Controlled Analgesia)** is helpful for children who can push a button to obtain pain relief. PCA allows your child to have some control over his or her own pain relief. It works like this—your child may have a low dose of continuous medicine running through an IV and also have a dose of self-delivered on-demand medicine by pushing a button. This system has a pre-set amount of pain medicine "locked-in" so your child won't get too much.

*From Nursing Care of Infants and Children – Whaley and Wong, 5th Ed. Mosby*

## More Handy Tips

- Be prepared for “I don’t know” responses from your care providers. Even with modern technology, there are still many unknowns in medicine. And in spite of all their training and knowledge, they simply can’t predict every outcome.
- Ask questions about what all the tubes and wires and machines do.
- Children hear and understand more than we think. Misconceptions and fears can arise from information that’s heard but not explained, so don’t talk as if your child isn’t there.
- Empower your child by giving appropriate choices whenever possible. For instance, instead of saying “Are you ready to take your medicine?” offer a real choice like “Would you rather take your medicine now or in three minutes?”
- Take medical conversations away from the bedside.
- As a father of a pre-term infant you may be split between spending time with your recovering wife and your new baby. Use your support to stay with your partner to visit your baby. Take pictures that you can bring back to the new mom.
- Ask if you can give your child a massage with lotion.

### **When friends ask “How can I help?”**

Suggest that they bring:

- Tylenol and/or ibuprofen for those potential headaches parents get (note: your hospital staff cannot give you any medicines)
- phone cards, disposable camera
- hobby items like arts and crafts, scrap-booking supplies, knitting supplies, crossword puzzles and playing cards
- art supplies like drawing paper and colored pencils
- thank you cards, stationery and stamps
- gift certificates to local stores and restaurants
- meals or healthy snacks like fresh fruit or veggies, cheese, crackers, and bottled water

### **How friends can help with your other children:**

- Help with homework
- Take them to their activities
- Make their lunches for school
- Donate money for school lunches
- Read to them



# Who can I call on for emotional support?

## Suggestions from a social worker who works with families in Intensive Care:

As a parent of a sick child, you may well be in a state of shock. Look back on previous traumatic experiences (perhaps a car accident) and try to remember how you handled that crisis.

- Did you need people around you or were you better handling things on your own?
- Was your “auto pilot” on or were you unable to keep things under control?
- After several days did you remember events and things you said or were said to you?

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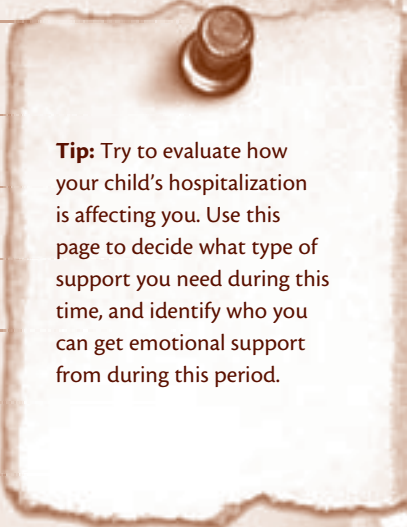
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**Tip:** Try to evaluate how your child’s hospitalization is affecting you. Use this page to decide what type of support you need during this time, and identify who you can get emotional support from during this period.

HOPE  
Love  
Trust  
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# Getting used to my new environment

*Answers to My Basic Questions*

Where can I sleep? \_\_\_\_\_

How do I make a long distance call? \_\_\_\_\_

Can I use my cell phone? Where? \_\_\_\_\_

Where is an ATM? \_\_\_\_\_

How many people can be in my child's room at one time? \_\_\_\_\_

Do I have to check in first before I come back to my child's room? \_\_\_\_\_

What are visitor's hours? \_\_\_\_\_

When is the cafeteria open? \_\_\_\_\_

Where can I do laundry? \_\_\_\_\_

Where can I access the internet? \_\_\_\_\_

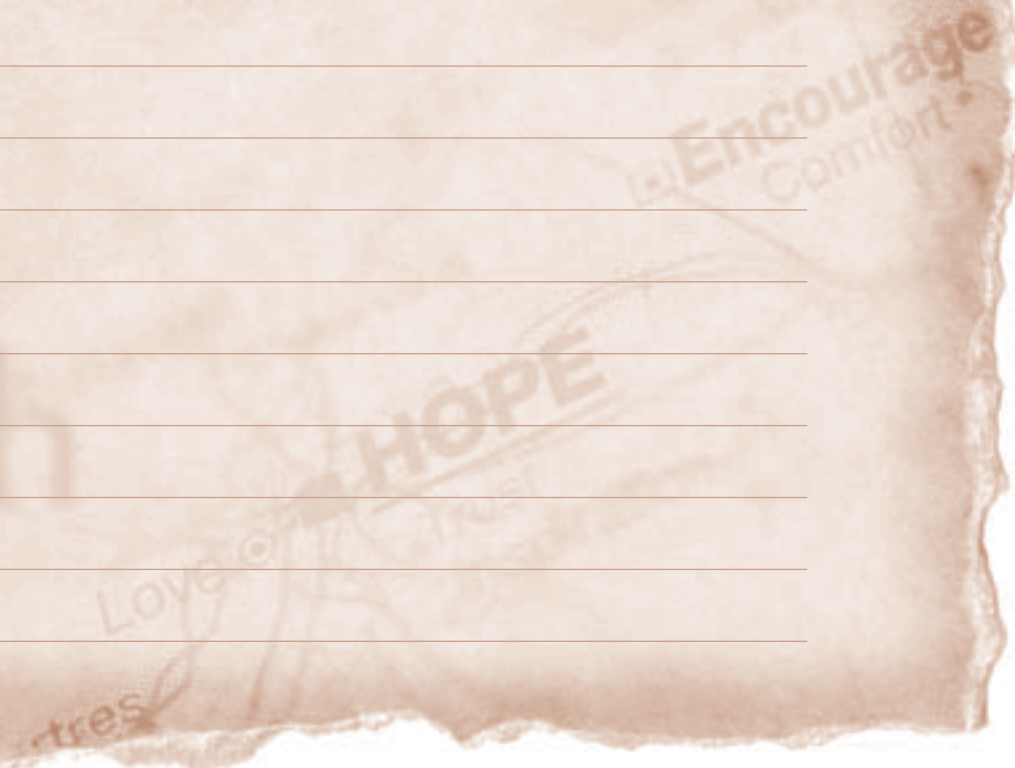
Is there a place to have quiet, spiritual time? \_\_\_\_\_

What long term parking options are available? \_\_\_\_\_

Where are the local grocery stores? \_\_\_\_\_

What good, inexpensive restaurants are nearby? \_\_\_\_\_

Hospital resource numbers: \_\_\_\_\_

















**My support team:**

Name \_\_\_\_\_

Phone \_\_\_\_\_ E-mail \_\_\_\_\_

Name \_\_\_\_\_

Phone \_\_\_\_\_ E-mail \_\_\_\_\_

Name \_\_\_\_\_

Phone \_\_\_\_\_ E-mail \_\_\_\_\_

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Name \_\_\_\_\_

Phone \_\_\_\_\_ E-mail \_\_\_\_\_

Name \_\_\_\_\_

Phone \_\_\_\_\_ E-mail \_\_\_\_\_

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Comfort

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# Receiving Information

## Thoughts from an intensive care nurse

Everyone processes information differently. Think about how you process information and ask yourself these questions:

- Do you need to know small bits at a time or the whole picture?
- Do you want the overview, or every small detail?
- Are you able to really hear what the doctors and nurses are saying?
- Are you remembering what is being said to you enough to repeat this information to your spouse and close friends and family?
- Would you like to have explanations of what is happening to your child drawn out? Use the back of the divider pages for doctors and other health care team members to explain visually.

## Tips from an intensive care nurse

- Have explanations repeated until you understand.
- Ask another family member or friend to be with you so they can also help absorb information.
- Write things down—it will be easier to handle all the information.

Know how you process information and decide what's best for you. It's okay for you to write down your questions and ask them later. Or, for you to ask the doctor or nurse to give you some time to digest what she just told you.

It's difficult to gauge your state of mind right now, but as a parent you want to remember all the details. These questions will help you focus on some of your needs. Use this space to make notes about what help you need in order to hear what's being said to you.

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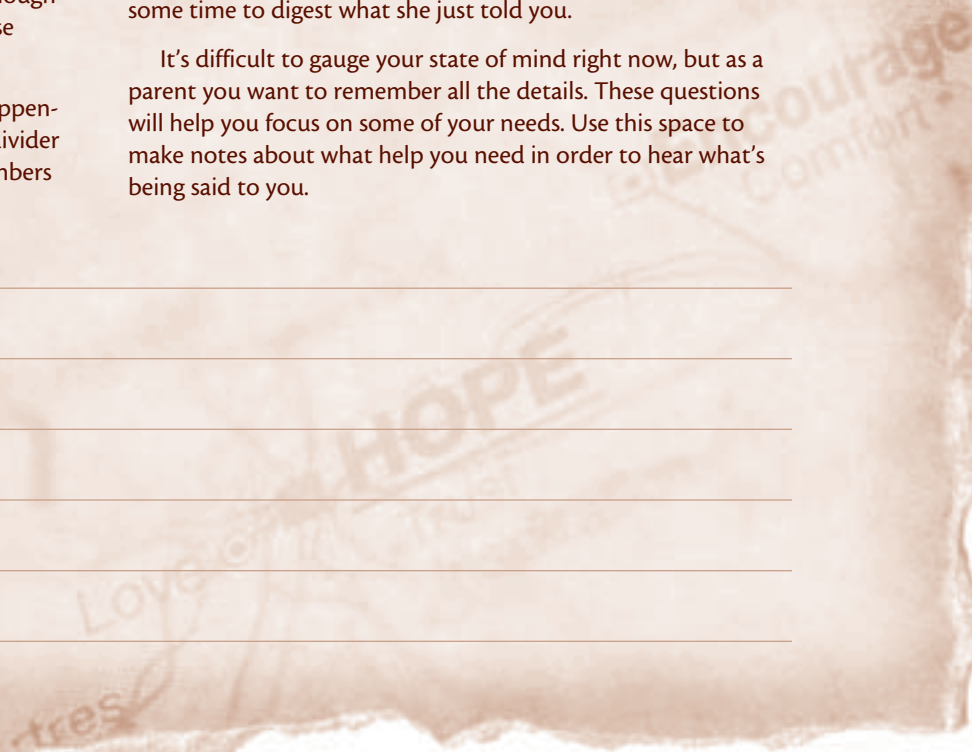
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*It's Not Fair!*

I've told her time and again... I don't want to hear her say, "It's not fair! It's not fair that I don't have anyone to play with; I want to go to Grandma's house; I don't have a toy like hers" ...and on and on. I patiently explain that some kids don't have enough food to eat or a warm house to sleep in or a family who loves them.

Now, I'm the one saying, "It's not fair!" My heart aches as I see my child and our new friend in the other bed crying from pain. I leave the room to cry for them, and I think, "It's not fair!" As they wheel my little one off to surgery, I think of the other children playing at recess and I sob, "It's not fair!" As I watch a mommy down the hall standing over her tiny infant in the metal hospital crib, I whisper again, "It's not fair!"

I know it's okay to feel this way and I lean over my sweet girl as she cries, and I say, "I know, Honey... It's NOT fair!"

— Kristina Bashor

Love  
HOPE  
Trust  
Inspiration

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Comfort



## Acknowledging My Feelings Helping My Child

*This section will help you sort through the feelings and emotions you're dealing with right now—from trying to understand how this could be happening to your child to trying to name your fears and make sense of things. It also provides helpful ways to advocate and interact with your child in the hospital.*

Guilt

Anger

Disbelief

Blame

HOPE  
Love  
Trust  
Encourage  
Comfort

## Drawing/Writing Page

*For your health care professional to explain procedures, your child's condition, tests and so on through drawings or written explanations.*

encourage

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Comfort

HOPE

Love


Trust



## Photo Page

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encourage



**Tip:** The camera that holds pictures of your child's experience does not have to be developed or printed... ever. Take the pictures to have if later you, your sick child or healthy siblings want to remember.

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Trust

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## Interacting with my new baby

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If your baby is born prematurely or is sick, you will likely be both amazed and perhaps a little shocked at that first close-up view of your baby in the Neonatal Intensive Care Unit (NICU). Parents are often amazed at the size of this tiny person and at the same time, overwhelmed by the tubes and electrical leads typically attached to their baby's body. When a baby is born sick, parents are often overwhelmed by hard-to-handle emotions. Feelings of fear, inadequacy, guilt, grief and isolation are all normal.

Think of your baby's life before birth, nestled in the uterus nice and warm and cozy. Even the gentlest of births can be a jolt for a newborn, and certainly so for a premature baby. That's why your baby is likely very sensitive and may show signs of activity intolerance by hiccupping, splaying her hands, and having her oxygen saturations or heart rate drop. Sometimes even a mere touch or a loud noise can cause these reactions. Encourage soft voices near her bed and take medical conversations away from the bedside. Minimizing light and noise is also very important for your baby.

Although it may seem difficult to help your baby, there are things parents can do to help and soothe a fragile baby. One way is to provide breast milk if possible. Breast milk has been shown to contribute to a baby's well-being, and is a great way for a new mother to help her infant. The nursing staff can provide you with a breast pump and help with collecting and storing your milk. If your breast milk is unavailable, your baby will receive a formula specially designed for premature infants.

Even if your baby is extremely fragile, you can learn how your baby likes to be touched, how to bathe and change her, and how to care for her dry skin.

### **Infant massage has many benefits to your baby:**

**Relaxes Infant** - Loving touch lessens tension, fussiness and irritability. Digestion is aided and this can provide relief of gas and colic. Massage is also a wonderful way to lessen your stress.

**Enhances Bonding** - Touch conveys nurturing and love, the essential ingredients for emotional and physical growth and well-being.

**Aids Growth and Development** - Studies have shown increased weight gain and immune function. Development of nerves is also increased. These things in turn are needed for brain and muscle development.

**Promotes Communication** - You become more aware of your baby's nonverbal cues. One-on-one communication instills a message of love and security.

**Improves Baby's Sleep** - As your infant learns to relax and release stress, sounder and longer sleep is often the end result.

You can work with your baby and her nurses to not over-stimulate, but give your nurturing touch.

*(Childbirth. "What is infant massage?" 1998. [www.childbirth.org/articles/baby/infantmassage.html](http://www.childbirth.org/articles/baby/infantmassage.html))*



### More tips for your infant:

- Pacifiers encourage the development of your baby's sucking and swallowing reflexes. They are also helpful in soothing your baby.
- Take regular photos of your baby (without that flash!) next to a constant toy, so you can measure her progress.
- Read and sing to your baby. She knows your voice is safe.
- Despite the medical knowledge and expertise, you have special qualities that no health care professional can match: strong love for your baby and a familiarity that your baby finds calming.
- You may leave a cloth with your scent on it in your baby's incubator.
- Provide one form of stimulation at a time if your baby shows signs of activity intolerance: if you rock her, don't talk; if you are feeding her, try not to look her in the eye; add more types of stimulation slowly, watching your baby for signs of stress. ([www.prematurity.org](http://www.prematurity.org))
- If your baby must be unwrapped from her blankets for a procedure, use your hands to keep her arms and legs tucked and to create a "nest" around her. This will comfort your baby and help her feel more secure.
- If your baby isn't able to have your breast milk, you may pump and store it in a freezer (if you are interested in this).
- Your baby will love "Kangaroo care!" Obtain some privacy and have your baby up against your bare chest with a blanket covering you. Ask your nurse to help you with this.

## Advocating and interacting with my child

*Tips from a Child Life Specialist:*

### Advocating for my child

- When possible, encourage staff to administer all painful procedures in the treatment room. Playrooms and patient rooms should be safe places for children.
- Ask staff to introduce themselves to you as well as to your child.
- Do not hide the truth from your child and be careful to not withhold medical information from your child. Honesty and your willingness to working out feelings sets a good example and fosters trusting relationships.
- Respect your child's need for privacy. Everyone needs their own time away from family and medical staff.
- Encourage others to speak to your child at eye level. It is scary for children to have others speak down to them or over them.
- When possible, stay with your child during a procedure or test. Children have an intense need for you to be present.
- Encourage medical staff to perform distressing components of an exam last.
- You and your child have limits. If a procedure is not going well for your child, ask to have another staff member try, or give your child a break altogether.
- Older children have more grown-up needs. Encourage your child to participate as much as they can in their care.
- Ask that daily plans and procedures also be explained to them, with time allowed for questions.
- Encourage care providers to gather information from your older child also, not just you.
- Comfort holding eliminates certain stresses around procedures. For example, infants feel more secure when they are sitting up, or children of all ages benefit from sitting in their parents lap. Encourage staff to place your child in a safe, secure position during a procedure.



### Interacting with my child

- Children need sensory explanation. Remember to use the following senses when explaining potential hospital experiences: see, hear, feel, smell, taste.
- Play is a child's work. It is the process by which children grow and develop. Children need the opportunity to play while in the hospital. Try medical play by allowing your child to touch medical equipment. Consult with a Child Life Specialist, if your hospital has them available, for more ideas on fostering a playful environment.
- Acknowledge positive behavior and praise your child after any procedure. Examples include watching a favorite movie or giving tangible rewards, such as stickers or a small prize.
- Medical language is a foreign, scary language. Tune in to your child and give information in an age appropriate way. Help translate for your child and encourage your health care team to use simple language. For example: "IVs are like straws that help give water and medicine to your blue lines (veins) to help your body get medicine and water."

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Comfort

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## Helping your child take medicine

Children often refuse to swallow pills or to taste that “yucky” medicine. Taking medicine can be a very stressful event. It is very important to be honest with your child about taking medicine, talking in a simple, age appropriate manner. Prepare them ahead of time and give appropriate choices when possible. Most importantly, be creative! Use play and a lot of imagination when encouraging your child to take medicine.

Make taking medicine part of a daily schedule. Provide your child with a visual chart using stickers; this will allow her to visualize her progress throughout the day.

**Important:** Check with your doctor or pharmacist before your child takes medicine. Some medicines can't be mixed or taken with specific food or liquids. Be aware of any diet restrictions your child may have.

### Tips for taking liquid medicine

- For younger children and babies, a syringe (without the needle) is a favorable choice.
- If your baby tries to spit out the medicine, gently squeeze her cheeks so you can put the medicine in the back pocket of her mouth and leave your finger in her mouth until she swallows it.
- Mix a small amount of formula with the medicine and give

your baby the nipple from a bottle. With a syringe, drop the formula/medicine into the nipple.

- For older children, prior to giving medicine, numb the taste buds first with a Popsicle or crushed ice.
- Mix the medicine with a syrup flavor or ask your pharmacist about FLAVORx®.
- Just after your child takes medicine, “chase” it with a drink of choice, such as Coca Cola®, grape juice or Gatorade®.
- Before giving your child medicine, coat her tongue with peanut butter or chocolate syrup.

### Tips for learning how to swallow pills

- Practice first by using small pieces of candy such as Red Hots®, Tic Tacs®, or Nerds®. Eventually work your way up to pill size.
- Cut pills into smaller pieces. Give one at a time and try to work up to larger sizes as your child gains confidence.
- Place pills (either whole or crushed) in gel tablets. This will help remove the awful tastes some pills have. This may also be an easier way to swallow the medicine. Gel tablets are available at pharmacies and come in different sizes.



## Helping your child take medicine

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- Put the pill in food. This can help disguise the pill and help it be swallowed more easily. Here are some suggestions of types of foods to use:

- Ice cream
- Applesauce
- Jell-O®
- Pudding
- Fruit Roll-Ups®
- Place smaller pill inside candy (such as Junior Mints)

### Tips for taking crushed medicine

Try mixing with the following liquids:

- Sweet fruit drink
- Orange juice
- Coca Cola®
- Water and latte syrup of choice
- White grape juice
- Frozen raspberry juice concentrate

Try mixing with the following foods:

- Yogurt
- Applesauce
- Sherbert
- Pudding

- Milkshake
- Chocolate milk

FLAVORx® is a product available at most pharmacies and some pediatric hospitals. It works by making medicine into a suspension and adding a flavor of choice such as strawberry, chocolate, piña colada, watermelon, etc. Most liquid medicines, as well as pills and powders, can also be used with FLAVORx®. You can visit the website [www.Flavorx.com](http://www.Flavorx.com) for more information and to find a pharmacy near you.

Be careful to not mix the medicine in an entire bottle or a large portion of applesauce, jell-o, etc. If your child decides to not take the entire portion, he will not receive the entire dose of the medicine.

**And remember... once the medicine is taken, praise and hug your child for his efforts.**

### References:

*Children's Hospital and Regional Medical Center Home Page. Patient and Family Education, Child Life Department "Helping Children take Medicine" April 2003. ([www.seattlechildrens.org/child\\_health\\_safety/pdf/flyers/PE398.pdf](http://www.seattlechildrens.org/child_health_safety/pdf/flyers/PE398.pdf))*

*Pediatric Oncology Resource Center. "How to Get Kids to Take...Pills!" 2001. ([www.acor.org/diseases/ped-onc/treatment/Pills/pills.html](http://www.acor.org/diseases/ped-onc/treatment/Pills/pills.html))*

## Helping Siblings Cope

Children often feel guilt, jealousy, resentment, anger, neglect and regression surrounding their sibling's illness or hospitalization. Their lives are disrupted and routines are likely to be altered to accommodate the sick child. It is normal if your healthy child experiences some behavioral problems and regression as a result. Below are tips for helping siblings cope during and after their sibling's hospitalization.

### Tips for helping siblings cope

- **Speak honestly.** Children respond better when given honest, age appropriate information. It is far worse to protect siblings by not giving them information. When left to their own imagination, they may create a far more frightening situation than what is actually occurring.
- **Maintain routine.** It is important to provide siblings with as close to a normal routine as possible. Allow family and friends to assist you in maintaining a daily routine at home. Also, create a schedule with siblings for doing chores, spending time together (such as a consistent dinner time), a regular bedtime and possibly visiting the hospital.
- **Encourage open communication**  
*Talk* - Children need to know it's okay to ask questions and express feelings. By creating a tone of open communication, you are giving your child permission to freely convey feelings and ask questions.  
*Play* - Children learn and discover their world through play. It is also a way for children to express feelings when they are unable to express with words. Use props such as dolls, puppets, medical equipment, or art supplies to allow a child freedom of expression.

### • Helping siblings handle common reactions

*Jealousy* - Children may feel it's unfair that they are getting less attention. Here are some ways to help. Make special time for your well child. Provide special gifts or appreciation for helping. Assign a "special friend" (relative or close family friend) to help provide love and give the child a feeling of being cared for during the times you cannot be present. Let them know how much you miss spending time with them. This allows the sibling to express her feelings.

*Fear* - Due to the nature and development of children, they may begin to feel that something may happen to them or that they can catch the illness. Assure them honestly and allow them to express feelings.

*Guilt* - Children may feel that something they said or did caused their brother or sister to be in the hospital. Be sure that they clearly understand that they are not responsible and assure them that their feelings are normal.

*Sadness* - It is normal to feel an overwhelming sadness. During the time you spend away from home, provide siblings with photos, comfort items, and a special reminder of you, such as a watch, shirt, or voice recording.

### Tips for supporting and involving siblings

- **Invite and encourage the sibling to visit the hospitalized child (if possible).** This allows the sibling to be involved and avoid misconceptions. Provide siblings with age appropriate information about their brother or sister's illness using photos or a sensory explanation, allowing your child to understand at his or her level.



# Helping Siblings Cope

- **Tips on preparing a sibling for a hospital visit:**

Ask a Child Life Specialist to assist you in supporting your healthy children through this difficult time. They can provide resources such as books, videos, and play materials that will help in explaining and helping siblings cope.

*Show* the sibling a photo of his sister or brother in the hospital before visiting so he can ask questions and become more familiar with the surroundings.

*Explain* how the hospitalized child may look different from usual. Spend time explaining bandages, tubes, bruises, etc., and allow your child to ask questions.

*Describe* and allow the sibling to see the medical equipment being used to care for his sister or brother.

*Allow* the sibling to ask questions and encourage open dialogue by giving his permission to ask or say anything.

*Read* stories about hospitals or encourage the sibling to make his own story about what it's like to have a brother or sister spend time in the hospital.

*Give* the sibling permission to touch his brother or sister, even if the sick child is unable to respond. It is also okay if the sibling does not want to touch and he should be supported in his decision.

If possible, allow the sibling to decide the length of the visit. If there is a time limit, inform the sibling prior to the visit.

*Encourage* the sibling to express feelings after the visit. Playing, drawing, and talking are all great ways to help children cope and process stressful situations.

*Tips referenced from Penn State Children's Hospital web site. Child Life Program. "Support for Siblings of Hospitalized Children" 30 July 2004. (<http://www.hmc.psu.edu/childrens/childlife/siblings.htm>)*


- **It is OK for a sibling not to visit the hospitalized child.**

If the sibling chooses not to visit the hospital, the decision should be supported and the child should not be made to feel guilty. Offer the sibling other ways to communicate with the hospitalized child. For example: drawings, letters, recording a message or sending an e-mail. You may want to reintroduce the idea of visiting at a later date.

- **Give affection.** Give the healthy sibling plenty of verbal and physical affection. Hugs, kisses and praise are all important ways to show you care.

- **Alert teachers, coaches, and leaders of siblings about the changes and stresses at home.** This will foster support for the sibling academically as well as emotionally.

- **Enroll the sibling** in support groups. It is important to get siblings involved in sibling workshops, support groups, or camps. This allows him to identify with others and create friendships with those going through similar stresses.



**Tip:** The blank calendars at the back of this book can help you get organized and keep track of things.













## Where is the meaning in this?

When people experience difficulties in life, they frequently are expected to take it as a time of growth and inward searching. If you are angry and fearful, this is especially challenging.

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Hope

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Love

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Remember, it's OK to cry in front of your child. Your child needs to know that you love him so much and that you feel his pain.

Has anyone brought you a care package recently? Ask for some good music, a magazine, nutritious snacks.





## The anger I'm feeling

Use this page to try to write about some of the anger you're feeling. It's easier to let it go if you can name it. Use the following pages to write down more about your feelings and situation.

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Comfort

Hope

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Loyalty

trust



Anger is ... a demand for change, a passionate wish for things to be different.

— Rachel Remen











*Starting the Race*

That ache had been there all day—again. My chest felt like it could explode. I could feel the weight pressing down on me and it seemed my body would give away.

I felt that I needed to know exactly what to expect for my daughter's treatment. I needed to see the whole picture. My husband felt that it would be too much to bear all at one time. I could only think of one way to explain:

I felt as if I was a runner. At the beginning of my race, I was told that I had five miles to run. But then I had a blindfold tied around my head. I was not told what to expect as I started out, except that the beginning would be a steep climb up. Now as my chest ached to the verge of bursting I needed to know. Did I have the whole five miles uphill? Would it level out soon? Were there rocks in the path? Would I run downhill? I needed to know so that I could pace myself and not collapse from sheer exhaustion before the course was completed.

When I did receive her treatment plan it was frightening, complex and painful to anticipate—but now I knew. Now I could have a “map” to plan my course. I knew there were possible detours or delays along the way, but that there were definite uphills, plateaus, and times of “coasting” downhill. And finally I found my chest didn't always ache with the exhaustion of apprehension. I could run this race.

— Kristina Bashor





Feel Empowered

Ask Questions

Advocate

Knowledge

# 3 Learning to Cope

51

*This section introduces the daily entry pages and offers additional helpful tips from parents and health care providers.*

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## Drawing/Writing Page

*For your health care professional to explain procedures, your child's condition, tests and so on through drawings or written explanations.*

strength

Love

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Comfort

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# Photo Page









## Introduction to the Daily Entry Pages

**Using this book:** You'll have greater success with this book if you tell your family and medical staff what you're doing so they can encourage and prompt you.

**Keep track of important information:** As you gather information it can quickly become overwhelming. Use these pages as a reference when you're having trouble remembering things or become confused.

Filling in the blanks on the daily entry pages will give you courage and strength in knowledge. Here are some thoughts for each entry:

### My Child's Page

#### What events occurred today that were meaningful in my child's care?

As you go through each day, week or month, it's important to note improvements or setbacks. Keeping track of daily events also provides valuable information for future health care providers who may need dates and names.

#### Changes in the care today

It's also important to note why changes are made. Asking "why" is important and necessary in the health care industry. Knowing answers to the many confusing and unfamiliar questions will help you make decisions and communicate with your support team, family and friends. Ask questions like: Why is a particular medicine being used? What does the medicine do? What changes are being made and why are tests done? What are the results of these tests and how does the care change as a result?

### Asking questions

Questions will come up frequently. Keep a list of your questions and write them down so you will not forget to ask. You have a right—indeed a responsibility—to ask them and receive answers you can understand.

### Medical information

Be sure you understand your child's illness and how all the technology, medicines and tests help your child. As you gather information from the medical staff and through your own research, write it down.

#### Health care providers: Who they are, how they help and what they have to say

Each health care provider has a unique way of delivering information to you. Don't let the doctors and nurses leave until you can repeat what they've said. Understanding and recording this information serves as a great reference. What's the bottom line being communicated?

Write down the names of your nurses, respiratory therapists, physical and occupational therapists, social workers, child life specialists, and so forth. You'll want to refer to the names in the future. Suggest that those friends and family who give you bedside breaks also take notes on the visits and comments.

For parents with twins or triplets in the hospital, use one line for each baby under the entries.



## **My Page**

### **Today I feel**

Here's an opportunity to express your feelings and emotions for the day. Take a moment to reflect on your own mind-set and recognize daily changes. What makes you feel better? Worse?

### **What happened with my child today that was encouraging?**

There may be a few days, or a lot of days, that are disappointing. But there's always something positive and it's important to search for those events or bits of information to keep yourself looking toward healing.

### **What can someone do to help me today?**

This someone can be a friend, family member or a care provider. What help do you need? What resources are available?

### **I'm thankful for...**

Illness can put perspective in our lives. It's important to recognize that life gives us many gifts along our journey.

### **Decisions to be made today**

This section can be for your child or for things in your life outside the hospital.

### **Goals**

Goals can be big or small. Set some goals for yourself, your family, or your ill child. Writing them down helps ensure they'll be met.

### **How I took time for myself today**

Taking time for yourself is very important. Your child and family need you to be physically and mentally sound. Try to have some private time for yourself every day. Eat healthy foods. Go for walks or get some other exercise. Meditate or just sit quietly and breathe deeply. Use this section to create ways to make time for you!

### **Something I ate and drank that was healthy**

It is important to eat healthy foods and to care for your own body.

\_\_\_\_\_ date

# My Child's Page

**What events occurred today that were meaningful in my child's care?** \_\_\_\_\_

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**Changes in the care today:** \_\_\_\_\_

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**Medical information:** \_\_\_\_\_

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**Health care providers—who they are, how they help, and what they have to say:** \_\_\_\_\_

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**Questions I have for the care providers:** \_\_\_\_\_

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encourage

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Comfort

HOPE

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# My Page

Daily Entry Page

\_\_\_\_\_ date

59

Today I feel: \_\_\_\_\_

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What happened with my child today that was encouraging? \_\_\_\_\_

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What can someone do to help me today? \_\_\_\_\_

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I am thankful for: \_\_\_\_\_

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Decisions to be made today: \_\_\_\_\_

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Goals: \_\_\_\_\_

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How I took time for myself today: \_\_\_\_\_

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Something that I ate and drank that was healthy: \_\_\_\_\_

Are your plants and animals being cared for? Your mail being collected? Delegate these tasks to a dependable friend.

**Advice from a new mom:**  
If you need help getting to and from the hospital, ask for it!

\_\_\_\_\_ date

# My Child's Page

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# My Page

Daily Entry Page

\_\_\_\_\_ date

61

Today I feel: \_\_\_\_\_

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Decisions to be made today: \_\_\_\_\_

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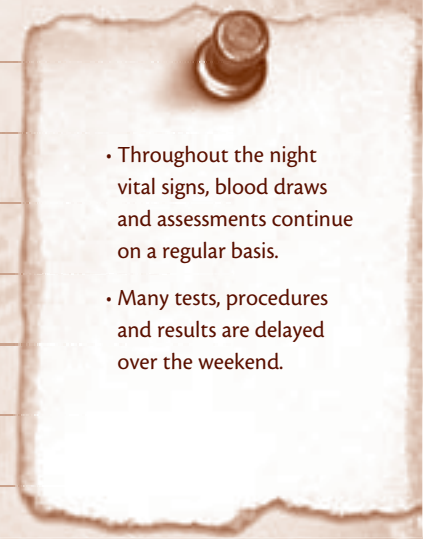
Goals: \_\_\_\_\_

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How I took time for myself today: \_\_\_\_\_

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Something that I ate and drank that was healthy: \_\_\_\_\_



- Throughout the night vital signs, blood draws and assessments continue on a regular basis.
- Many tests, procedures and results are delayed over the weekend.

\_\_\_\_\_ date

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Something that I ate and drank that was healthy: \_\_\_\_\_

**Tip from the sister of a teenager who was in a car crash:**

Pay attention to the small things. Have cozy slippers and have a stash of herbal teas and a special mug—those styrofoam ones don't do a soothing job!

\_\_\_\_\_ date

## My Child's Page

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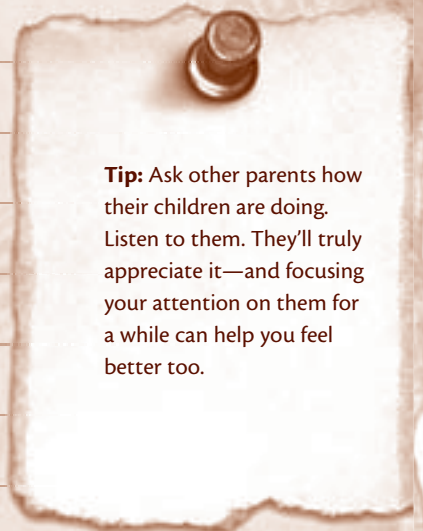
**Goals:** \_\_\_\_\_

\_\_\_\_\_

**How I took time for myself today:** \_\_\_\_\_

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**Something that I ate and drank that was healthy:** \_\_\_\_\_



**Tip:** Ask other parents how their children are doing. Listen to them. They'll truly appreciate it—and focusing your attention on them for a while can help you feel better too.

\_\_\_\_\_ date

# My Child's Page

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# My Page

Daily Entry Page

\_\_\_\_\_ date

67

Today I feel: \_\_\_\_\_

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What happened with my child today that was encouraging? \_\_\_\_\_

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Goals: \_\_\_\_\_

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How I took time for myself today: \_\_\_\_\_

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Something that I ate and drank that was healthy: \_\_\_\_\_

**Tip:** What are the top five things that drive you crazy when you run home to grab something?

- The dirty bathroom?
- The cluttered kitchen?
- The "lived in" car?
- The unmowed lawn?

Ask for help! You deserve to have other parts of your life in order!

\_\_\_\_\_ date

# My Child's Page

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# My Page

Daily Entry Page

\_\_\_\_\_ date

69

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How I took time for myself today: \_\_\_\_\_

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Something that I ate and drank that was healthy: \_\_\_\_\_

**Tip:** Have your friends bring treats for the medical staff caring for your child.

Keep a supply of special self-care things, like non-scented lotions, fingernail polish, makeup, a good toothbrush and toothpaste.

\_\_\_\_\_ date

# My Child's Page

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Something that I ate and drank that was healthy: \_\_\_\_\_

**Tip:** Identify who the one specialty or person is that you can go to for answers about your child. *(Advice from a parent whose child was being covered by multiple specialties.)*

Ask to speak with your doctor when you're awaiting test results. By law, nurses, respiratory therapists and technicians are not allowed to give you test results.

\_\_\_\_\_ date

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Encourage  
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# My Page

Daily Entry Page

\_\_\_\_\_ date

73

Today I feel: \_\_\_\_\_

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What happened with my child today that was encouraging? \_\_\_\_\_

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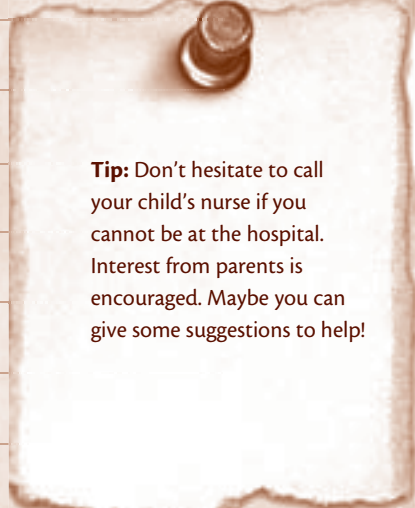
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How I took time for myself today: \_\_\_\_\_

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Something that I ate and drank that was healthy: \_\_\_\_\_

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**Tip:** Don't hesitate to call your child's nurse if you cannot be at the hospital. Interest from parents is encouraged. Maybe you can give some suggestions to help!

encourage

HOPE  
Love  
Trust

\_\_\_\_\_ date

## My Child's Page

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How I took time for myself today: \_\_\_\_\_

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Something that I ate and drank that was healthy: \_\_\_\_\_

It's not stress that's the issue; it's insufficient intermittent recovery.

— James E. Loehr

**Reminder:** Often, when cultures are drawn from your child, you will learn preliminary results within 24 hours. But final results aren't usually available for at least 72 hours.

\_\_\_\_\_ date

## My Child's Page

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# My Page

Daily Entry Page

\_\_\_\_\_ date

77

Today I feel: \_\_\_\_\_

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What happened with my child today that was encouraging? \_\_\_\_\_

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What can someone do to help me today? \_\_\_\_\_

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I am thankful for: \_\_\_\_\_

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Decisions to be made today: \_\_\_\_\_

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Goals: \_\_\_\_\_

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How I took time for myself today: \_\_\_\_\_

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Something that I ate and drank that was healthy: \_\_\_\_\_

**Tip:** Don't be afraid to tell the hospital staff about your child—no matter how busy they look!

Remember to also bring in pictures of your child when she was healthy.

*We Will Fight*

I wish it was a real monster... one with ferocious teeth, raging eyes—a monster, huge and dark. Then, without hesitation, I would gladly stand in my child's place. I would send her off to a safe haven to be held in loving arms. I would then take on this great terror. I may not be a hero with superhuman strength, but I have faith in God, a mother's fierce love and the burning passion of a million tears to carry me forward. I would hit and kick and fight with all my might. I would not give up until one of us was finished... and in the end my child would be safe.

But it's a different fierce creature that we face. This one has hold of my precious child. I cannot see its horrid face, only the face of my child in pain, tears running down her cheeks and neck. I cannot see this monster's ferocious teeth and appetite, only the evidence of it in my child's very pale skin. This monster can't be seen towering above us, but it is huge and dark.

Now we will fight! With God as our strength, this mother and father will join with doctors and nurses! Behind us we are carried forward by an army of family, friends, and others who have fought similar monsters! We will fight! Our weapons are great: prayers, technology, faith, love, and also... tears! We will not give up! And we believe whatever battles lie ahead, our child will be safe again... in the haven of loving arms.

— Kristina Bashor





Stress Relief

Receiving Help

Finding Strength

Trust

# 4 Settling In

79

*Your hospital room and surroundings have become familiar. You're allowing yourself to be helped so you can focus on your child. You have good and bad days, but your goal is clear: to see your child healed.*

*Throughout this book you'll find many exploration pages to encourage reflection and growth.*

*Use these pages anytime you feel a need to download.*

*It may take a long time before you feel you can use these pages.*

*That's OK.*

## Drawing/Writing Page

*For your health care professional to explain procedures, your child's condition, tests and so on through drawings or written explanations.*

strength

Love

HOPE

Encourage  
Comfort

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# Photo Page



\_\_\_\_\_ date

# My Child's Page

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**Changes in the care today:** \_\_\_\_\_

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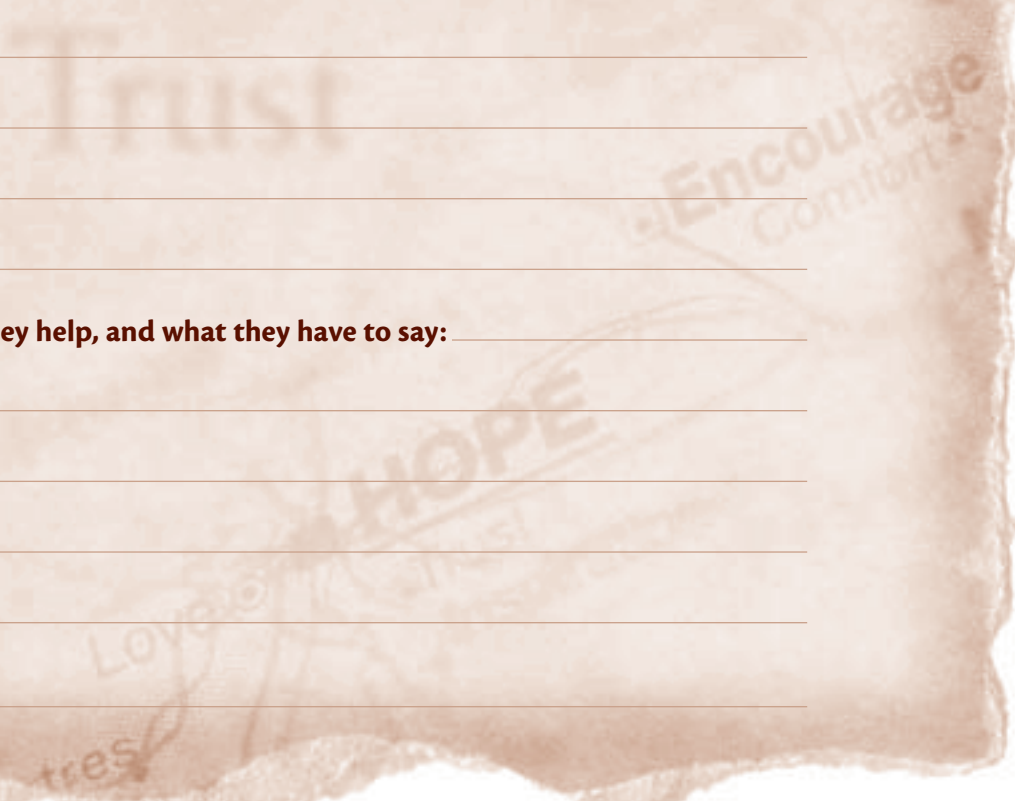
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**Questions I have for the care providers:** \_\_\_\_\_

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# My Page

Daily Entry Page

\_\_\_\_\_ date

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Today I feel: \_\_\_\_\_

What happened with my child today that was encouraging? \_\_\_\_\_

What can someone do to help me today? \_\_\_\_\_


I am thankful for: \_\_\_\_\_

Decisions to be made today: \_\_\_\_\_

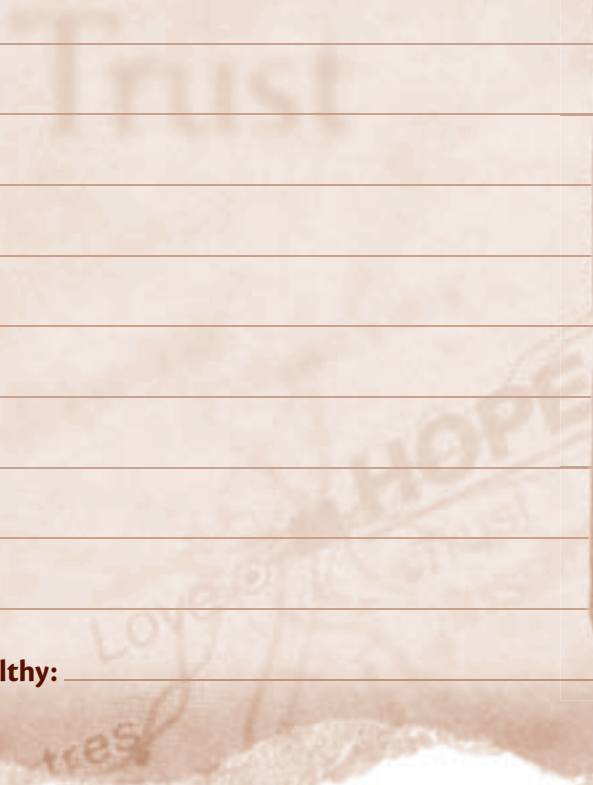
Goals: \_\_\_\_\_

How I took time for myself today: \_\_\_\_\_

Something that I ate and drank that was healthy: \_\_\_\_\_



**Note from a nurse:** Each child has different needs for interaction when they are sick. Some children seem to prefer being soothed by solid hands holding steady on body parts. Others prefer holding your hand. Still others do not like being touched at all and your presence is what's important. When children are very sick, it is often difficult for them to handle being stroked or patted because there is already a lot of stimulation in the hospital setting.







From *Kitchen Table Wisdom*

Each person is born with an unencumbered spot, free of expectation and regret, free of ambition and embarrassment, free of fear and worry, an umbilical spot of grace where we were each first touched by God. It is this spot of Grace that issues peace. Psychologists call this spot the Psyche, theologians call it the Soul. Jung calls it The Seat of the Unconscious, Hindu masters call it the Atman, Buddhists call it the Dharma, Rilke calls it Inwardness, Sufis call it Qualb, and Jesus calls it The Center of Our Love.

To know this spot of inwardness is to know who we are, not by surface markers of identity, not by where we work or what we wear or how we like to be addressed but by feeling our place in relation to the Infinite and by inhabiting it. This is a lifelong task, for the nature of becoming is a constant filming over of where we begin while the nature of being is a constant erosion of what is not essential. We each love in the midst of this ongoing tension, growing tarnished or covered over only to be brought back to that incorruptible spot of grace of our core.

— Mark Nepo

*Tap into yourself and find the strength within.*

\_\_\_\_\_ date

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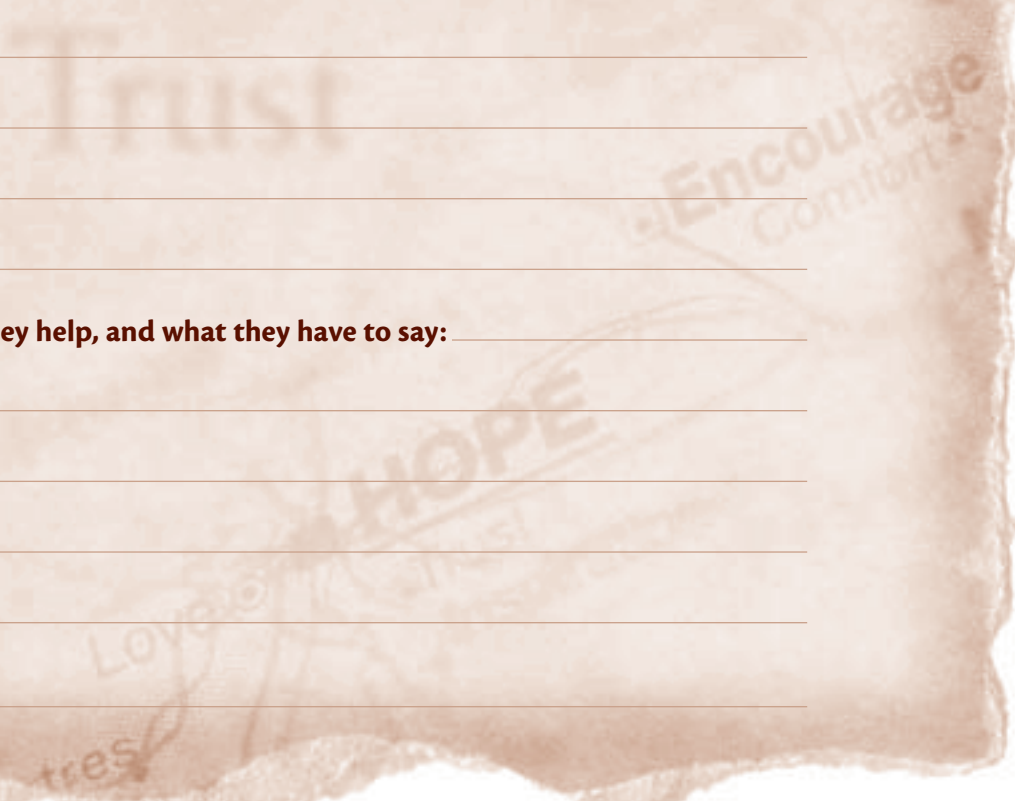
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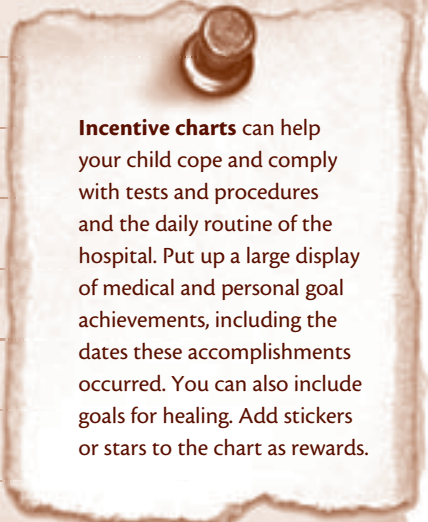
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**How I took time for myself today:** \_\_\_\_\_

\_\_\_\_\_

**Something that I ate and drank that was healthy:** \_\_\_\_\_



**Incentive charts** can help your child cope and comply with tests and procedures and the daily routine of the hospital. Put up a large display of medical and personal goal achievements, including the dates these accomplishments occurred. You can also include goals for healing. Add stickers or stars to the chart as rewards.







\_\_\_\_\_ date

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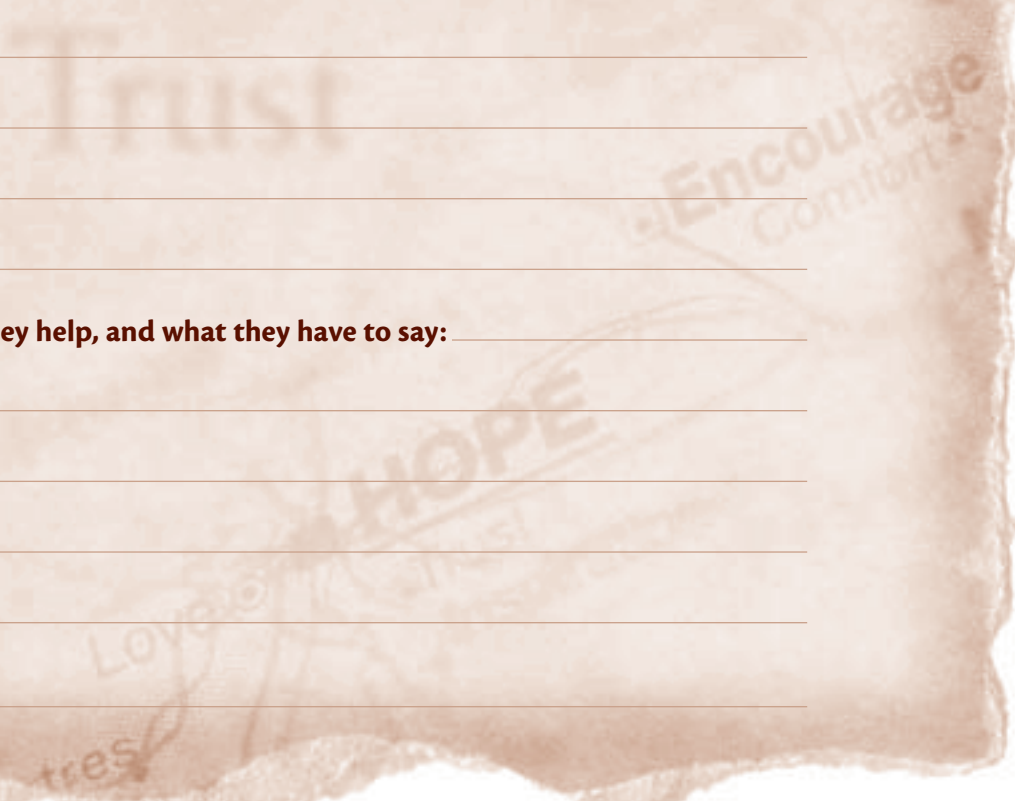
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# My Page

Daily Entry Page

\_\_\_\_\_ date

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Goals: \_\_\_\_\_

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How I took time for myself today: \_\_\_\_\_

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Something that I ate and drank that was healthy: \_\_\_\_\_

Let your mistakes fine-tune the compass deep inside your heart so that you will have splendid travels worthy of a kind and wise, soulful self!

—Nancy Swan Drew







\_\_\_\_\_ date

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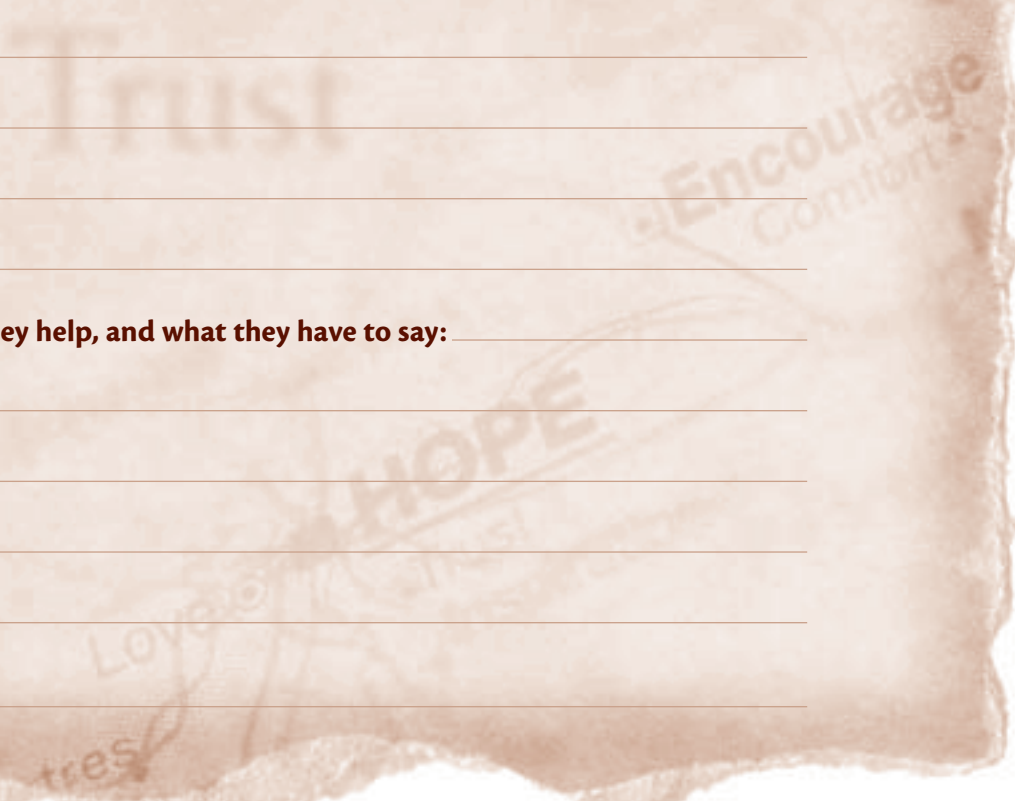
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# My Page

Daily Entry Page

\_\_\_\_\_ date

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I am thankful for: \_\_\_\_\_

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Goals: \_\_\_\_\_

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How I took time for myself today: \_\_\_\_\_

\_\_\_\_\_

Something that I ate and drank that was healthy: \_\_\_\_\_

**Tip from a parent whose child spent more than two months in intensive care:**

If you're having trouble keeping track of what's going on, keep a record called "Today's plan for my child is..." Ask your health team to fill it in for you. This is especially helpful when your child is being followed by multiple services.





Even the best relationships will be challenged at times. An easy or contented relationship isn't always a good one—the couple may be avoiding the lessons and the opportunity for growth, change and expansion. After all, the purpose of relationship is to love and believe in oneself and each other, to help and support each other, to open to and receive your partner's love and grow together.

When challenges or suffering arise in your relationship, remember that help is available within the same loving guidance that brought you together. Willingness to ask for that help is the first step in receiving it. Challenges don't mean you have a bad relationship. They mean you have a growing relationship. Let the loving hand of guidance bring healing and spiritual closeness.

— From *Love and Fate* compiled by  
Joyce and Barry Vissell

Encourage  
Comfort

HOPE

Love of Trust

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\_\_\_\_\_ date

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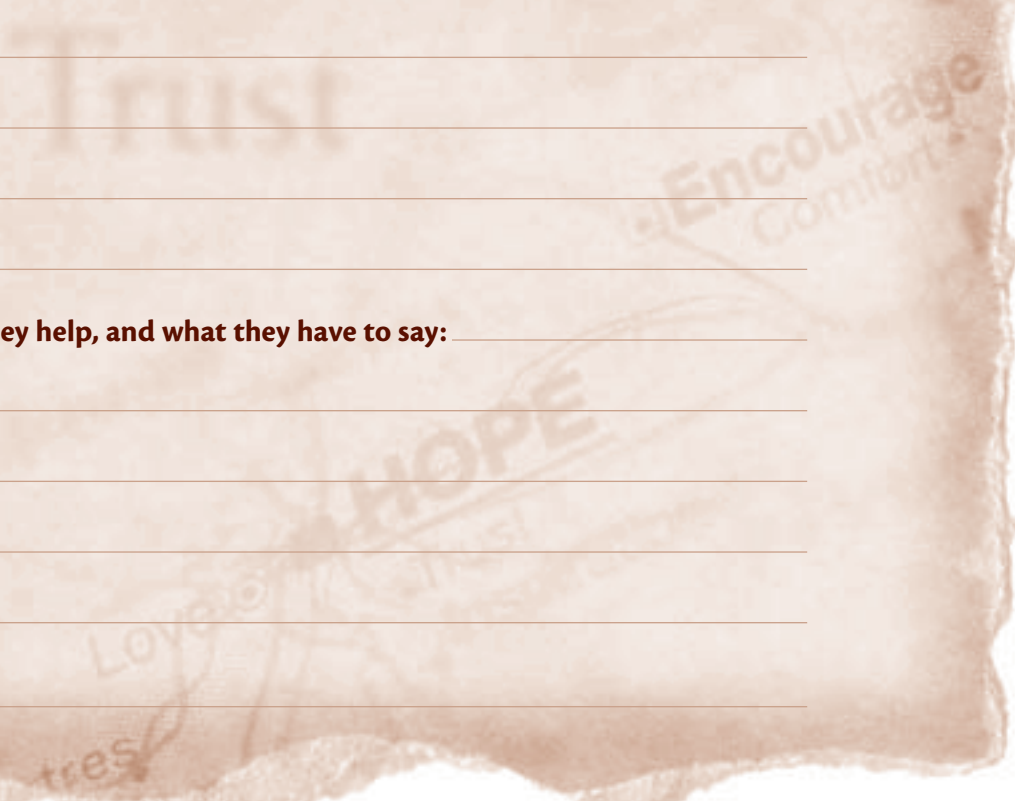
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# My Page

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99

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I am thankful for: \_\_\_\_\_

\_\_\_\_\_

Decisions to be made today: \_\_\_\_\_

\_\_\_\_\_

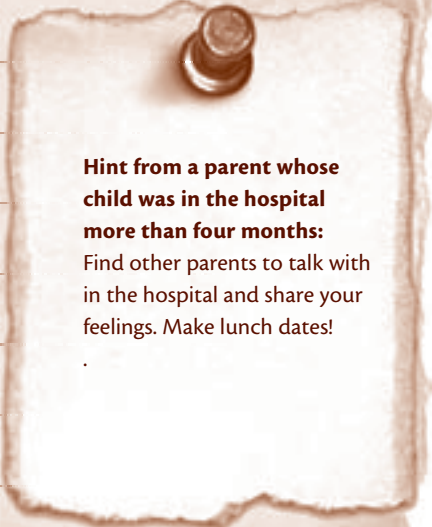
Goals: \_\_\_\_\_

\_\_\_\_\_

How I took time for myself today: \_\_\_\_\_

\_\_\_\_\_

Something that I ate and drank that was healthy: \_\_\_\_\_



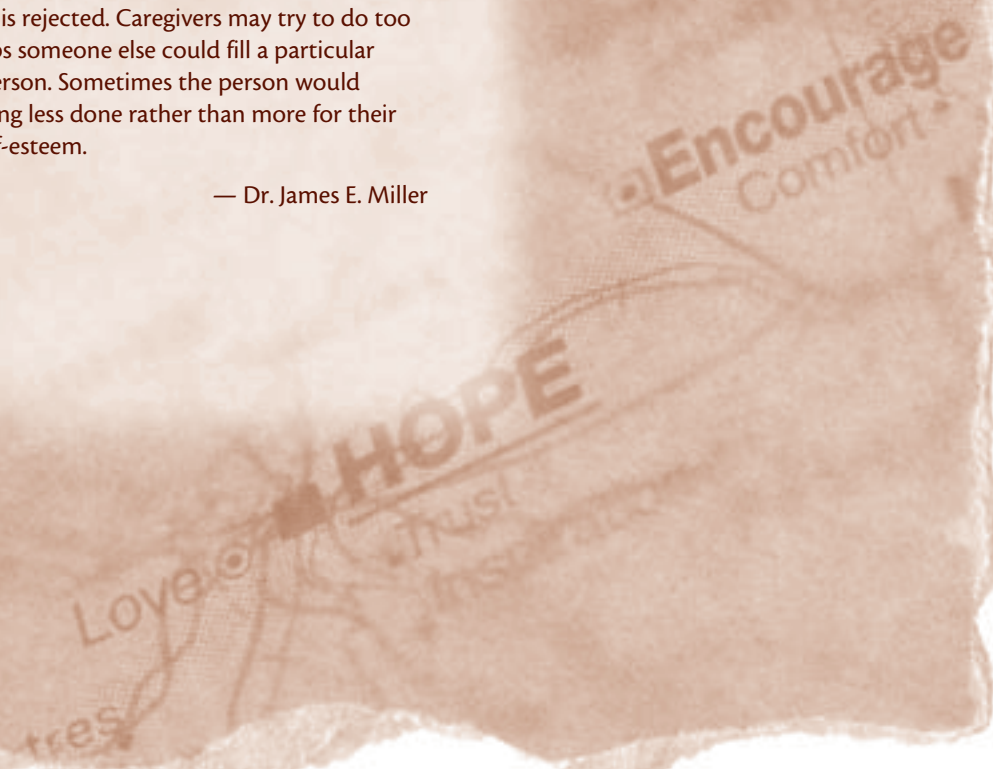
**Hint from a parent whose child was in the hospital more than four months:**  
Find other parents to talk with in the hospital and share your feelings. Make lunch dates!





In accepting the helplessness of your helping, you become a better helper. No matter how much you do, you can't do it all and you may find at times that what you offer is rejected. Caregivers may try to do too much—perhaps someone else could fill a particular need for the person. Sometimes the person would benefit by having less done rather than more for their dignity and self-esteem.

— Dr. James E. Miller



\_\_\_\_\_ date

# My Child's Page

**What events occurred today that were meaningful in my child's care?** \_\_\_\_\_

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**Changes in the care today:** \_\_\_\_\_

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**Medical information:** \_\_\_\_\_

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**Health care providers—who they are, how they help, and what they have to say:** \_\_\_\_\_

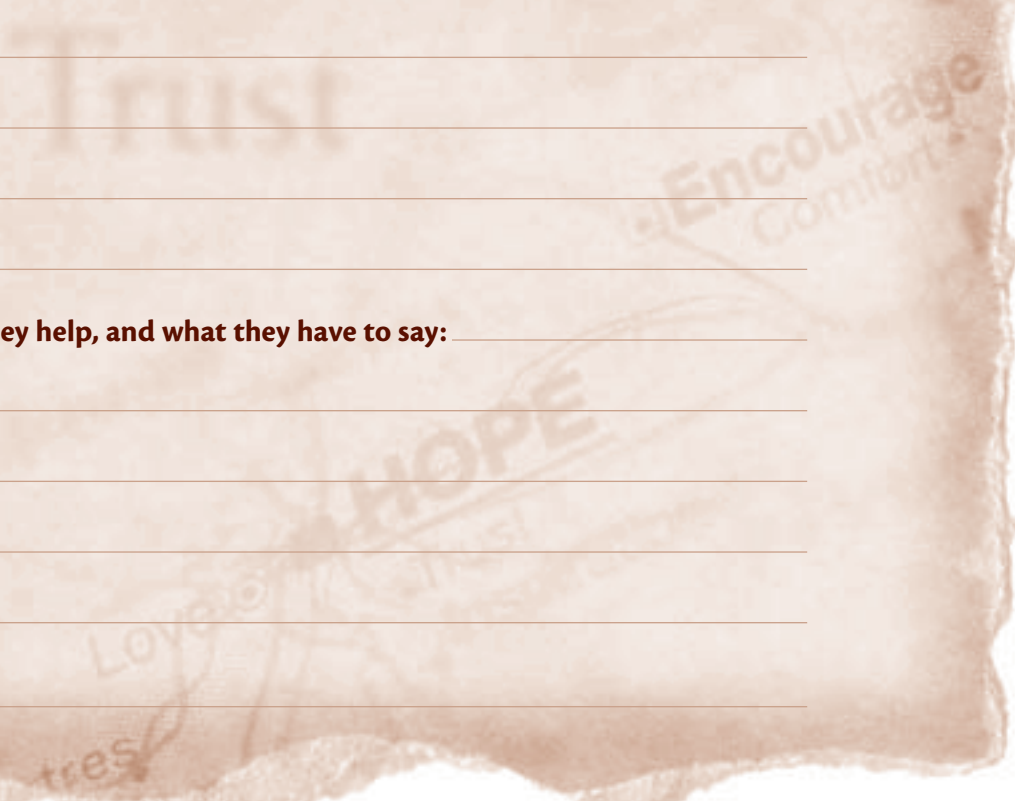
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**Questions I have for the care providers:** \_\_\_\_\_

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# My Page

Daily Entry Page

\_\_\_\_\_ date

103

Today I feel: \_\_\_\_\_

\_\_\_\_\_

What happened with my child today that was encouraging? \_\_\_\_\_

\_\_\_\_\_

What can someone do to help me today? \_\_\_\_\_

\_\_\_\_\_

I am thankful for: \_\_\_\_\_

\_\_\_\_\_

Decisions to be made today: \_\_\_\_\_

\_\_\_\_\_

Goals: \_\_\_\_\_

\_\_\_\_\_

How I took time for myself today: \_\_\_\_\_

\_\_\_\_\_

Something that I ate and drank that was healthy: \_\_\_\_\_

Treat yourself to a massage.  
Let someone else take care of  
*your* body!

**Advice from a parent whose  
son was born premature:**  
Record your voice talking or  
reading stories for when you  
are not at the bedside. Also  
bring favorite music.







\_\_\_\_\_ date

# My Child's Page

**What events occurred today that were meaningful in my child's care?** \_\_\_\_\_

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**Changes in the care today:** \_\_\_\_\_

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**Medical information:** \_\_\_\_\_

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**Health care providers—who they are, how they help, and what they have to say:** \_\_\_\_\_

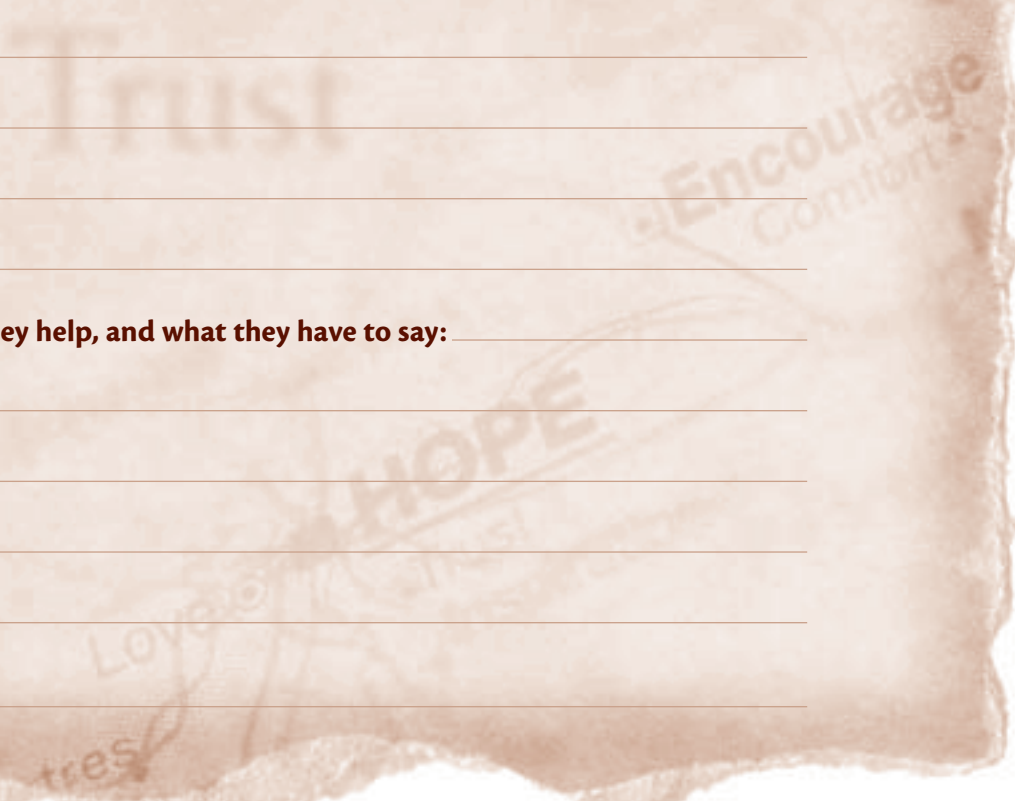
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**Questions I have for the care providers:** \_\_\_\_\_

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# My Page

Daily Entry Page

\_\_\_\_\_ date

107

Today I feel: \_\_\_\_\_

\_\_\_\_\_

What happened with my child today that was encouraging? \_\_\_\_\_

\_\_\_\_\_

What can someone do to help me today? \_\_\_\_\_

\_\_\_\_\_

I am thankful for: \_\_\_\_\_

\_\_\_\_\_

Decisions to be made today: \_\_\_\_\_

\_\_\_\_\_

Goals: \_\_\_\_\_

\_\_\_\_\_

How I took time for myself today: \_\_\_\_\_

\_\_\_\_\_

Something that I ate and drank that was healthy: \_\_\_\_\_

I needed to know I was  
cared about too.

— From a parent whose  
home and family were in  
another state.

**Reminder:** Hugs heal.  
Give and receive hugs.

## Drawing out your feelings

108

*Life will bring you pain all by itself. Your responsibility is to create joy. — Milton Erickson, MD*

Colored pencils and crayons can help you and your child draw out your feelings. Use this page for drawing or just doodling.

Trust

Encourage  
Comfort

HOPE

Love

tres





*Acceptance*

Acceptance is the word of this decade—acceptance of social status, economic status, race and so much more. I've never had a problem with acceptance... not until NOW. Now I am struggling with myself... striving to learn acceptance. This time, however, I am trying to learn to accept something so painful that it causes me to be repulsed at the word... acceptance.

I don't want to accept this diagnosis my child has been given. I don't want to accept the pain in her face or the fear in her voice. I don't want to accept the many days and weeks (I won't say years) ahead of medical procedures. I don't want to accept the many bottles and syringes of medicine that we will go through. I don't want to accept the many changes that are necessary for our family life! But these changes are an important part of my child's life now, and so is acceptance.

Now... knowing that God will be my strength, realizing that life has changed, learning as much as possible about these changes and accepting a little at a time is what I've got to do. This will all help me to stay sane. It's going to help me help our little girl. It's going to help me to care for our other children. Best of all, acceptance is going to help us all take a big step toward a better tomorrow. Thank God for acceptance!

— Kristina Bashor

*This does not mean liking one's disability, but rather it means learning to live with it rather than suffering from it.*

— A Healing Ministry, Rev. Nancy Lane, Ph.D.





# 5 Acceptance

*This section alternates between daily entry pages and exploration pages. This will help you focus on your changing life, come to terms with your current circumstances and begin thinking about the future.*

Future

Self-reflection

Healing

Survival

Encourage  
Comfort

HOPE

Love

Trust

tres

## Drawing/Writing Page

*For your health care professional to explain procedures, your child's condition, tests and so on through drawings or written explanations.*

strength

Love

HOPE

Trust

Encourage  
Comfort

tres



# Photo Page



\_\_\_\_\_ date

# My Child's Page

**What events occurred today that were meaningful in my child's care?** \_\_\_\_\_

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**Changes in the care today:** \_\_\_\_\_

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**Medical information:** \_\_\_\_\_

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**Health care providers—who they are, how they help, and what they have to say:** \_\_\_\_\_

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**Questions I have for the care providers:** \_\_\_\_\_

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Encourage  
Comfort

HOPE

Love

tres



# My Page

\_\_\_\_\_ date

**Today I feel:** \_\_\_\_\_

\_\_\_\_\_

**What happened with my child today that was encouraging?** \_\_\_\_\_

\_\_\_\_\_

**What can someone do to help me today?** \_\_\_\_\_

\_\_\_\_\_

**I am thankful for:** \_\_\_\_\_

\_\_\_\_\_

**Decisions to be made today:** \_\_\_\_\_

\_\_\_\_\_

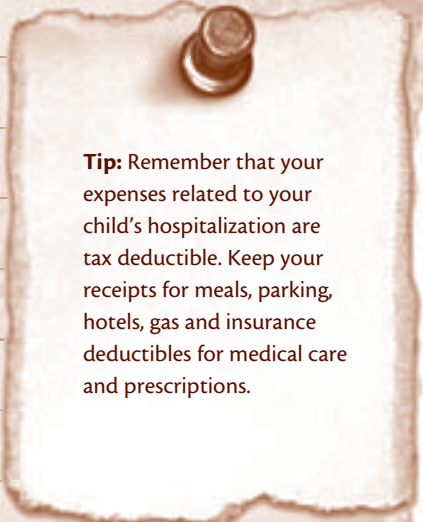
**Goals:** \_\_\_\_\_

\_\_\_\_\_

**How I took time for myself today:** \_\_\_\_\_

\_\_\_\_\_

**Something that I ate and drank that was healthy:** \_\_\_\_\_



**Tip:** Remember that your expenses related to your child's hospitalization are tax deductible. Keep your receipts for meals, parking, hotels, gas and insurance deductibles for medical care and prescriptions.

## Exploration

**In general, how do you feel about the care your child is receiving?** \_\_\_\_\_

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**If you could, how would you change it?** \_\_\_\_\_

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Encourage  
Comfort

HOPE

Love

Trust



## Significant Others

117

I'm thinking about someone significant who's entered my life through this experience... \_\_\_\_\_

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Are you sharing the medical decisions with your spouse or partner? \_\_\_\_\_

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Encourage  
Comfort

HOPE

Love

Trust

\_\_\_\_\_ date

# My Child's Page

**What events occurred today that were meaningful in my child's care?** \_\_\_\_\_

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**Changes in the care today:** \_\_\_\_\_

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**Medical information:** \_\_\_\_\_

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**Health care providers—who they are, how they help, and what they have to say:** \_\_\_\_\_

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**Questions I have for the care providers:** \_\_\_\_\_

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Encourage  
Comfort

HOPE

Love

tres



# My Page

\_\_\_\_\_ date

**Today I feel:** \_\_\_\_\_

\_\_\_\_\_

**What happened with my child today that was encouraging?** \_\_\_\_\_

\_\_\_\_\_

**What can someone do to help me today?** \_\_\_\_\_

\_\_\_\_\_

**I am thankful for:** \_\_\_\_\_

\_\_\_\_\_

**Decisions to be made today:** \_\_\_\_\_

\_\_\_\_\_

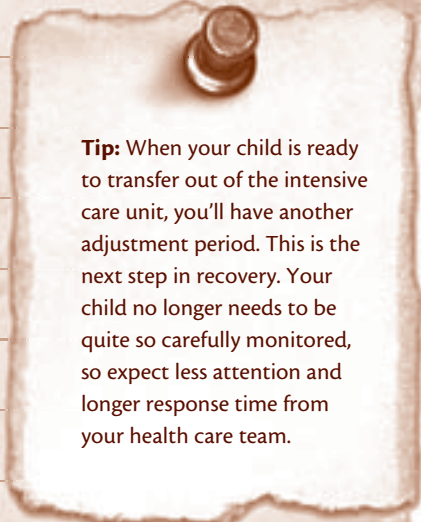
**Goals:** \_\_\_\_\_

\_\_\_\_\_

**How I took time for myself today:** \_\_\_\_\_

\_\_\_\_\_

**Something that I ate and drank that was healthy:** \_\_\_\_\_



**Tip:** When your child is ready to transfer out of the intensive care unit, you'll have another adjustment period. This is the next step in recovery. Your child no longer needs to be quite so carefully monitored, so expect less attention and longer response time from your health care team.





Our deepest fear is not that we are inadequate. Our deepest fear is that we are powerful beyond measure. It is our light, not our darkness, that most frightens us. We ask ourselves, who am I to be brilliant, gorgeous, talented and fabulous? Actually, who are you not to be? You are a child of God. Your playing small doesn't serve the world. There's nothing enlightened about shrinking so that other people won't feel insecure around you. You were born to make manifest the glory of God that is within us. It's not just in some of us; it's in everyone. And as we let our own light shine, we unconsciously give other people permission to do the same. As we are liberated from our own fear, our presence automatically liberates others.

—Marianne Williamson

Love • HOPE  
Trust

Encourage  
Comfort

\_\_\_\_\_ date

## My Child's Page

**What events occurred today that were meaningful in my child's care?** \_\_\_\_\_

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**Changes in the care today:** \_\_\_\_\_

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**Medical information:** \_\_\_\_\_

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**Health care providers—who they are, how they help, and what they have to say:** \_\_\_\_\_

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**Questions I have for the care providers:** \_\_\_\_\_

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Encourage  
Comfort

HOPE

Love

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# My Page

Daily Entry Page

\_\_\_\_\_ date

123

Today I feel: \_\_\_\_\_

\_\_\_\_\_

What happened with my child today that was encouraging? \_\_\_\_\_

\_\_\_\_\_

What can someone do to help me today? \_\_\_\_\_

\_\_\_\_\_

I am thankful for: \_\_\_\_\_

\_\_\_\_\_

Decisions to be made today: \_\_\_\_\_

\_\_\_\_\_

Goals: \_\_\_\_\_

\_\_\_\_\_

How I took time for myself today: \_\_\_\_\_

\_\_\_\_\_

Something that I ate and drank that was healthy: \_\_\_\_\_

**Tip:** If your infant falls asleep during feeding time, unwrap him so he is not so cozy! This will help him stay awake.

**Remember:** It is natural for there to be stress between spouses during times like these. This is normal.







\_\_\_\_\_ date

## My Child's Page

**What events occurred today that were meaningful in my child's care?** \_\_\_\_\_

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**Changes in the care today:** \_\_\_\_\_

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**Medical information:** \_\_\_\_\_

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**Health care providers—who they are, how they help, and what they have to say:** \_\_\_\_\_

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**Questions I have for the care providers:** \_\_\_\_\_

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Encourage  
Comfort

HOPE

Love

tres



# My Page

Daily Entry Page

\_\_\_\_\_ date

127

Today I feel: \_\_\_\_\_

\_\_\_\_\_

What happened with my child today that was encouraging? \_\_\_\_\_

\_\_\_\_\_

What can someone do to help me today? \_\_\_\_\_

\_\_\_\_\_

I am thankful for: \_\_\_\_\_

\_\_\_\_\_

Decisions to be made today: \_\_\_\_\_

\_\_\_\_\_

Goals: \_\_\_\_\_

\_\_\_\_\_

How I took time for myself today: \_\_\_\_\_

\_\_\_\_\_

Something that I ate and drank that was healthy: \_\_\_\_\_

There are only two ways to live your life. One is as though nothing is a miracle. The other is as though everything is a miracle.

— Albert Einstein







\_\_\_\_\_ date

## My Child's Page

**What events occurred today that were meaningful in my child's care?** \_\_\_\_\_

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**Changes in the care today:** \_\_\_\_\_

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**Medical information:** \_\_\_\_\_

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**Health care providers—who they are, how they help, and what they have to say:** \_\_\_\_\_

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**Questions I have for the care providers:** \_\_\_\_\_

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Encourage  
Comfort

HOPE

Love

tres



# My Page

Daily Entry Page

\_\_\_\_\_ date

131

Today I feel: \_\_\_\_\_

\_\_\_\_\_

What happened with my child today that was encouraging? \_\_\_\_\_

\_\_\_\_\_

What can someone do to help me today? \_\_\_\_\_

\_\_\_\_\_

I am thankful for: \_\_\_\_\_

\_\_\_\_\_

Decisions to be made today: \_\_\_\_\_

\_\_\_\_\_

Goals: \_\_\_\_\_

\_\_\_\_\_

How I took time for myself today: \_\_\_\_\_

\_\_\_\_\_

Something that I ate and drank that was healthy: \_\_\_\_\_



The greatest accomplishment  
is not in never falling, but in  
rising again after you fall.

— Vince Lombardi







\_\_\_\_\_ date

# My Child's Page

**What events occurred today that were meaningful in my child's care?** \_\_\_\_\_

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**Changes in the care today:** \_\_\_\_\_

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**Medical information:** \_\_\_\_\_

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**Health care providers—who they are, how they help, and what they have to say:** \_\_\_\_\_

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**Questions I have for the care providers:** \_\_\_\_\_

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Encourage  
Comfort

HOPE

Love

tres



# My Page

Daily Entry Page

\_\_\_\_\_ date

135

Today I feel: \_\_\_\_\_

\_\_\_\_\_

What happened with my child today that was encouraging? \_\_\_\_\_

\_\_\_\_\_

What can someone do to help me today? \_\_\_\_\_

\_\_\_\_\_

I am thankful for: \_\_\_\_\_

\_\_\_\_\_

Decisions to be made today: \_\_\_\_\_

\_\_\_\_\_

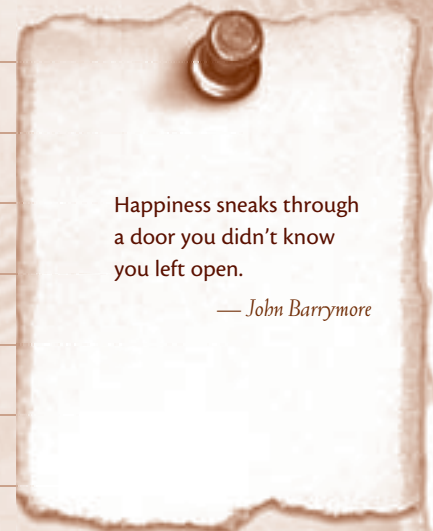
Goals: \_\_\_\_\_

\_\_\_\_\_

How I took time for myself today: \_\_\_\_\_

\_\_\_\_\_

Something that I ate and drank that was healthy: \_\_\_\_\_



Happiness sneaks through  
a door you didn't know  
you left open.

— John Barrymore

## Things I'd really like to do

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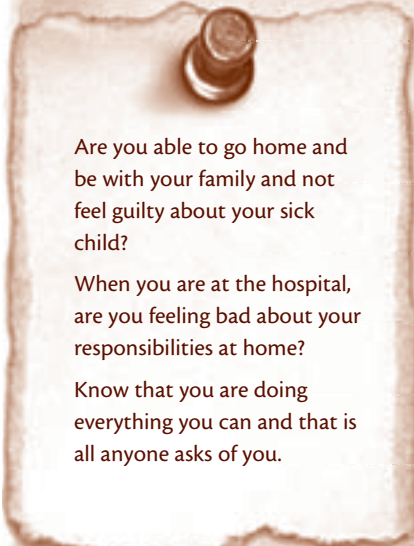
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Are you able to go home and be with your family and not feel guilty about your sick child?

When you are at the hospital, are you feeling bad about your responsibilities at home?

Know that you are doing everything you can and that is all anyone asks of you.

Encourage  
Comfort

LOVE

HOPE

Love

tres





\_\_\_\_\_ date

## My Child's Page

**What events occurred today that were meaningful in my child's care?** \_\_\_\_\_

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**Changes in the care today:** \_\_\_\_\_

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**Medical information:** \_\_\_\_\_

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**Health care providers—who they are, how they help, and what they have to say:** \_\_\_\_\_

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**Questions I have for the care providers:** \_\_\_\_\_

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Encourage  
Comfort

HOPE

Love

tres



# My Page

\_\_\_\_\_ date

Today I feel: \_\_\_\_\_

\_\_\_\_\_

What happened with my child today that was encouraging? \_\_\_\_\_

\_\_\_\_\_

What can someone do to help me today? \_\_\_\_\_

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I am thankful for: \_\_\_\_\_

\_\_\_\_\_

Decisions to be made today: \_\_\_\_\_

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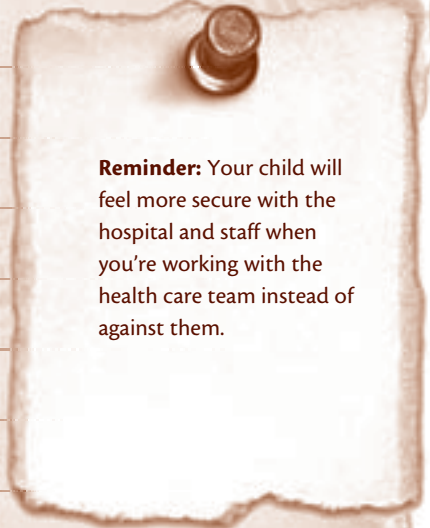
Goals: \_\_\_\_\_

\_\_\_\_\_

How I took time for myself today: \_\_\_\_\_

\_\_\_\_\_

Something that I ate and drank that was healthy: \_\_\_\_\_



**Reminder:** Your child will feel more secure with the hospital and staff when you're working with the health care team instead of against them.







\_\_\_\_\_ date

# My Child's Page

**What events occurred today that were meaningful in my child's care?** \_\_\_\_\_

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**Changes in the care today:** \_\_\_\_\_

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**Medical information:** \_\_\_\_\_

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**Health care providers—who they are, how they help, and what they have to say:** \_\_\_\_\_

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**Questions I have for the care providers:** \_\_\_\_\_

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Encourage  
Comfort

HOPE

Love

tres



# My Page

Daily Entry Page

\_\_\_\_\_ date

143

Today I feel: \_\_\_\_\_

\_\_\_\_\_

What happened with my child today that was encouraging? \_\_\_\_\_

\_\_\_\_\_

What can someone do to help me today? \_\_\_\_\_

\_\_\_\_\_

I am thankful for: \_\_\_\_\_

\_\_\_\_\_

Decisions to be made today: \_\_\_\_\_

\_\_\_\_\_

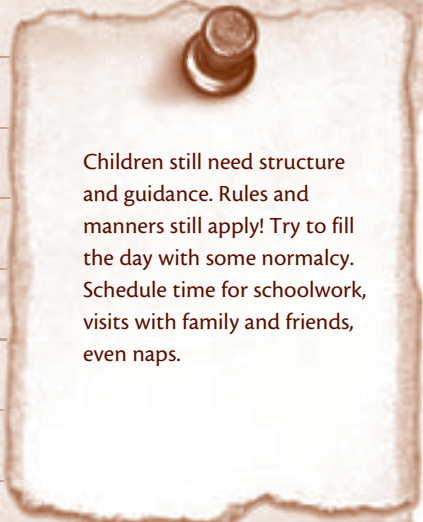
Goals: \_\_\_\_\_

\_\_\_\_\_

How I took time for myself today: \_\_\_\_\_

\_\_\_\_\_

Something that I ate and drank that was healthy: \_\_\_\_\_



Children still need structure and guidance. Rules and manners still apply! Try to fill the day with some normalcy. Schedule time for schoolwork, visits with family and friends, even naps.





## There is no cure for healing!

*Healing vs. Curing*

### **Healing**

- Is done by you
- Happens from the inside out
- Is active
- Addresses the cause
- Encompasses all of you
- Is gradual but long-lasting
- Leaves you better than you were before
- Focuses on you

### **Curing**

- Is done to you
- Happens from the outside in
- Is passive
- Addresses the symptom
- Singles out one part of you
- Is quick but short-lived
- Restores you to where you were before
- Focuses on the ailment

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Love • HOPE  
Trust  
Inspiration

Encourage  
Comfort

\_\_\_\_\_ date

# My Child's Page

**What events occurred today that were meaningful in my child's care?** \_\_\_\_\_

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**Changes in the care today:** \_\_\_\_\_

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**Medical information:** \_\_\_\_\_

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**Health care providers—who they are, how they help, and what they have to say:** \_\_\_\_\_

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**Questions I have for the care providers:** \_\_\_\_\_

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Encourage  
Comfort

HOPE

Love

tres



# My Page

\_\_\_\_\_ date

**Today I feel:** \_\_\_\_\_

\_\_\_\_\_

**What happened with my child today that was encouraging?** \_\_\_\_\_

\_\_\_\_\_

**What can someone do to help me today?** \_\_\_\_\_

\_\_\_\_\_

**I am thankful for:** \_\_\_\_\_

\_\_\_\_\_

**Decisions to be made today:** \_\_\_\_\_

\_\_\_\_\_

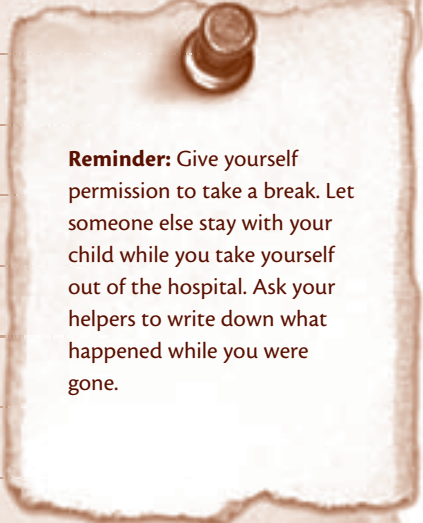
**Goals:** \_\_\_\_\_

\_\_\_\_\_

**How I took time for myself today:** \_\_\_\_\_

\_\_\_\_\_

**Something that I ate and drank that was healthy:** \_\_\_\_\_



**Reminder:** Give yourself permission to take a break. Let someone else stay with your child while you take yourself out of the hospital. Ask your helpers to write down what happened while you were gone.





Remember that people with disabilities, parents, other family members, and caregivers, are each in a different stage of the grief cycle and may not be able to communicate where they are. They may not even know where they are, much less why.

Being courageous in the face of adversity does not serve anyone well. When we postpone grief it will erupt in other ways, perhaps as a global anger and bitterness. It will affect our mind, thus causing biological changes in our bodies until we are physically ill. If we avoid dealing with grief, we succeed only in drawing our emotional energy away from our family and friends. We become distant and detached, further isolating ourselves, thus further contributing to grief and anger.

The grief cycle is part of our growth. It is part of the journey to God. It is not to be avoided, nor is it to merely be endured. It is to be entered into; we have to walk through it in order to move beyond it.

— *A Healing Ministry*, The Rev. Nancy Lane, Ph. D.

\_\_\_\_\_ date

# My Child's Page

**What events occurred today that were meaningful in my child's care?** \_\_\_\_\_

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**Changes in the care today:** \_\_\_\_\_

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**Medical information:** \_\_\_\_\_

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**Health care providers—who they are, how they help, and what they have to say:** \_\_\_\_\_

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**Questions I have for the care providers:** \_\_\_\_\_

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Encourage  
Comfort

HOPE

Love

tres



# My Page

Daily Entry Page

\_\_\_\_\_ date

151

Today I feel: \_\_\_\_\_

\_\_\_\_\_

What happened with my child today that was encouraging? \_\_\_\_\_

\_\_\_\_\_

What can someone do to help me today? \_\_\_\_\_

\_\_\_\_\_

I am thankful for: \_\_\_\_\_

\_\_\_\_\_

Decisions to be made today: \_\_\_\_\_

\_\_\_\_\_

Goals: \_\_\_\_\_

\_\_\_\_\_

How I took time for myself today: \_\_\_\_\_

\_\_\_\_\_

Something that I ate and drank that was healthy: \_\_\_\_\_

Remember to laugh!

— From "Laughter,  
The Best Medicine,"  
a section in Readers'  
Digest featuring  
humorous anecdotes







*Some Days*

Some days I'm exhausted before I even wake. I'm exhausted as I stagger to the shower in an attempt to revive myself, and I'm exhausted through every tedious moment of the day.

Some days I just know that I can conquer! I can conquer my daily tasks. I can conquer caring for my sick child along with caring for my busy toddlers, and I can even conquer my fear!

Some days I am so unstable that the slightest friction, the smallest complaint from my sick "baby" or the most subtle tender look from a caring soul will send me into tears.

Some days I can't stop looking back over my shoulder into the past—remembering those "other" days. Those days were so carefree and simple... before.

Some days I want someone or something to lash out at. I want someplace to put all the anger I feel because my child has to go through this horrible ordeal.

Some days I look around me at the hardships others are enduring and it shakes me up. I say a prayer for them, and I begin to count my blessings and the days I have to enjoy them. These are the days we are in, and these are the days that make some days more bearable!

— Kristina Bashor





Dreams

Triumphs

Coping

Fear

# 6 Moving Forward

*This section reflects on you and your child's experiences in the hospital and how you've dealt with them. Daily entry pages continue to alternate with exploration pages.*

Encourage  
Comfort

HOPE

Love

Trust

tres

## Drawing/Writing Page

*For your health care professional to explain procedures, your child's condition, tests and so on through drawings or written explanations.*

strength

Love

HOPE

Trust

Encourage  
Comfort

tres



# Photo Page



\_\_\_\_\_ date

# My Child's Page

**What events occurred today that were meaningful in my child's care?** \_\_\_\_\_

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**Changes in the care today:** \_\_\_\_\_

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**Medical information:** \_\_\_\_\_

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**Health care providers—who they are, how they help, and what they have to say:** \_\_\_\_\_

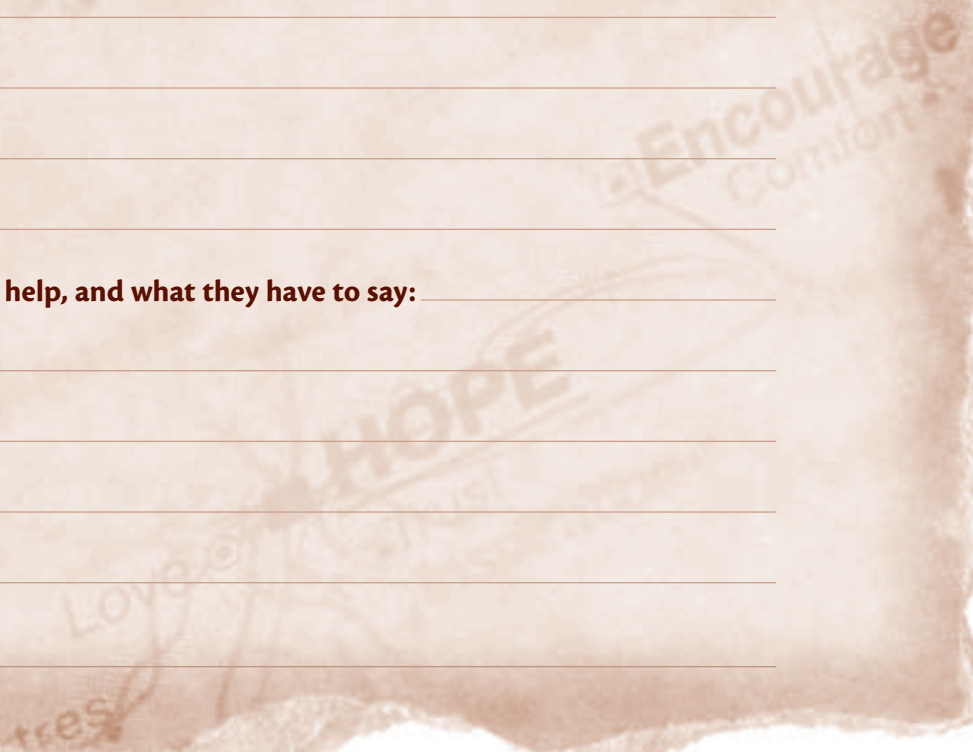
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**Goals:** \_\_\_\_\_

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**How I took time for myself today:** \_\_\_\_\_

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**Something that I ate and drank that was healthy:** \_\_\_\_\_

Scars tell a story of the battles endured and are a reflection of the warrior inside.

— Bradie Kvinsland





## Doodle Away!

161

forgiveness

Every day, and the living  
of it, has to be a conscious  
creation in which discipline  
and order are relieved  
with some play and pure  
foolishness.

— *May Sarton*

\_\_\_\_\_ date

# My Child's Page

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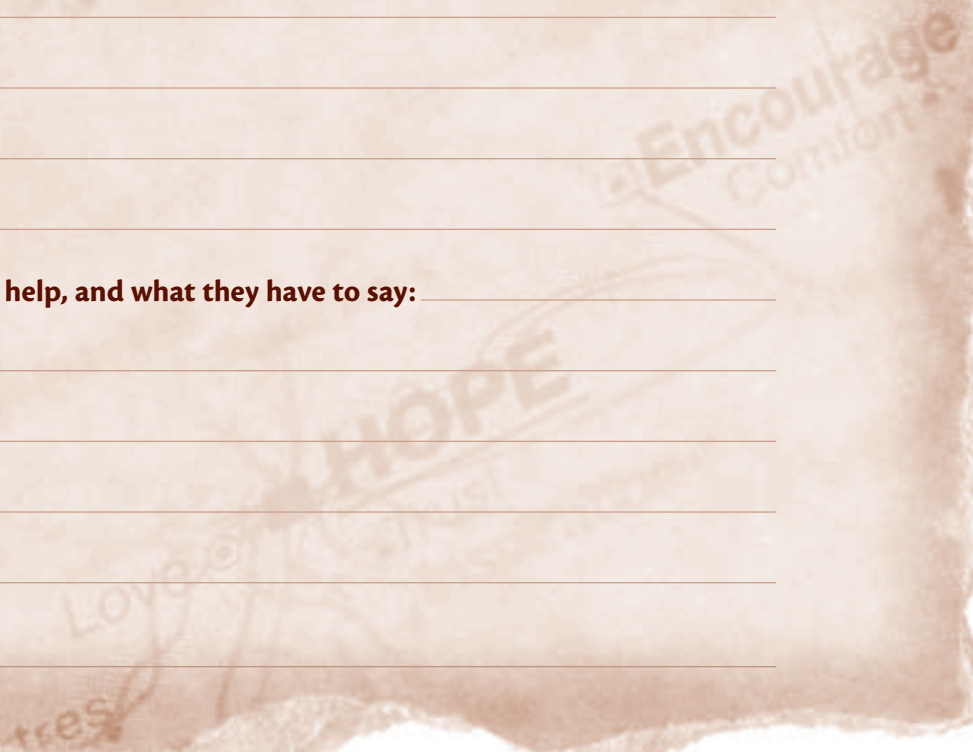
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Be the change you wish to see  
in the world.

—Ghandi

## Dream Catcher

Write about dreams you've had and what they mean to you. Or write about your dreams for your future, your family's future and your hospitalized child's future.

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A miracle cannot prove what is impossible; it is useful only to confirm what is possible.  
— Maimonides

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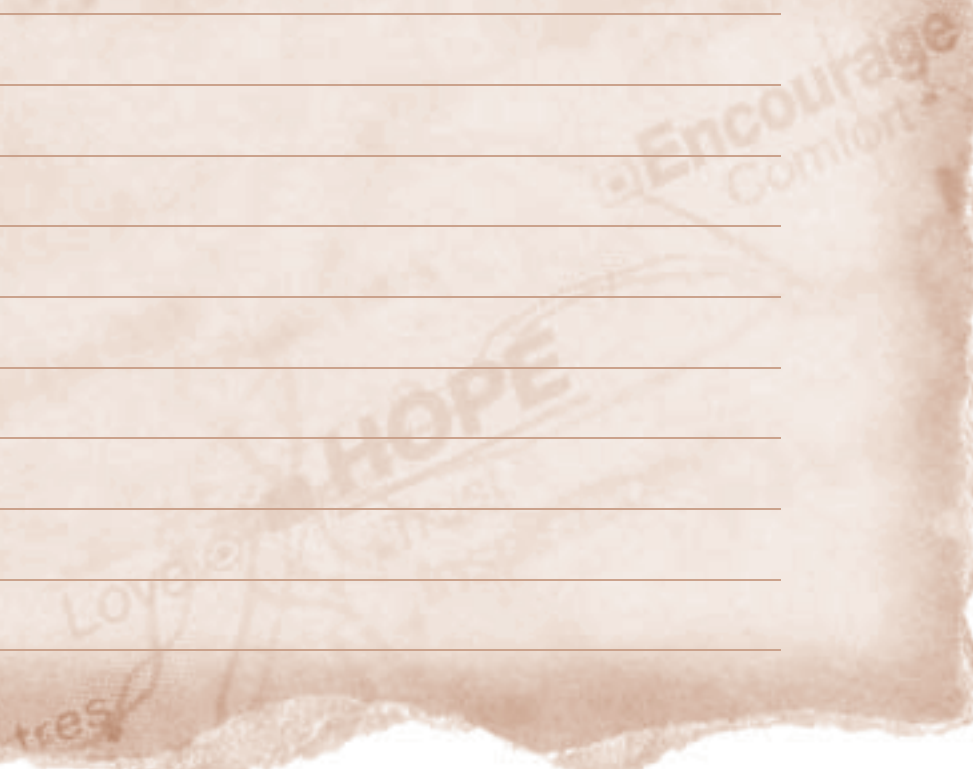
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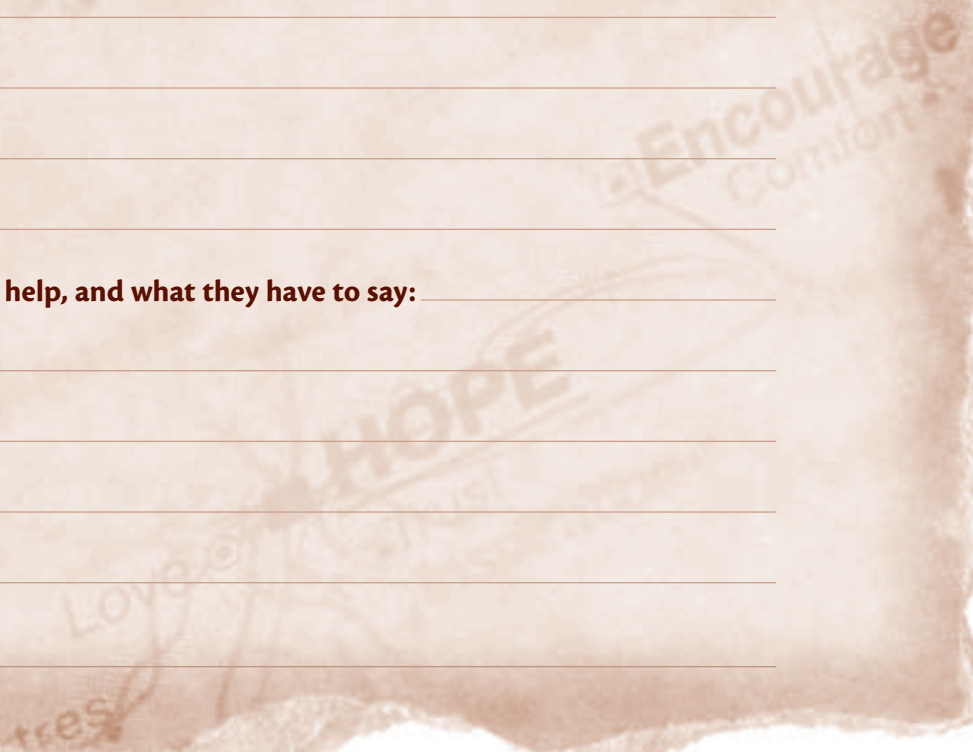
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**Tip from a parent of a child with cerebral palsy:** Find a support group online if you do not have time in your busy schedule to attend meetings. You can compare treatment options, trade equipment, exchange secrets, use your experiences to help others and draw on them when you need help.







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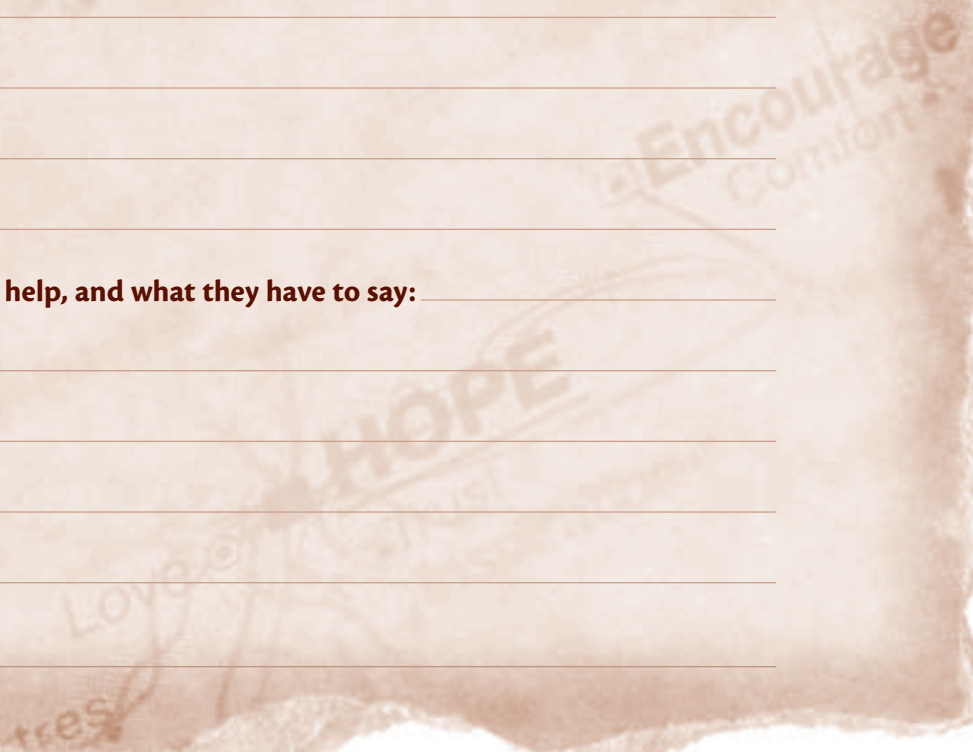
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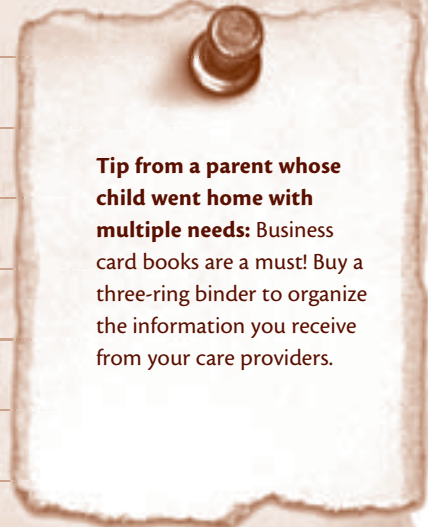
Goals: \_\_\_\_\_

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How I took time for myself today: \_\_\_\_\_

\_\_\_\_\_

Something that I ate and drank that was healthy: \_\_\_\_\_



**Tip from a parent whose child went home with multiple needs:** Business card books are a must! Buy a three-ring binder to organize the information you receive from your care providers.







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Forgiveness

Encourage  
Comfort

HOPE

Love

tres



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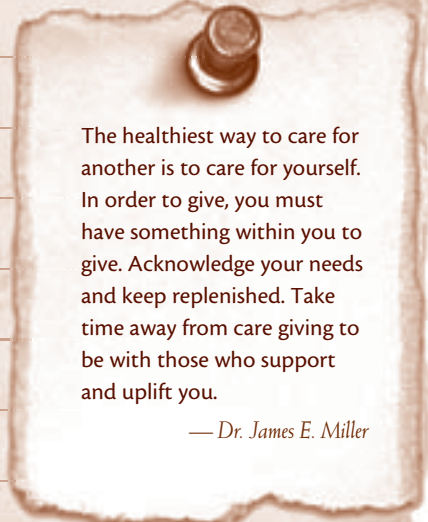
**Goals:** \_\_\_\_\_

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**How I took time for myself today:** \_\_\_\_\_

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**Something that I ate and drank that was healthy:** \_\_\_\_\_



The healthiest way to care for another is to care for yourself. In order to give, you must have something within you to give. Acknowledge your needs and keep replenished. Take time away from care giving to be with those who support and uplift you.

— Dr. James E. Miller







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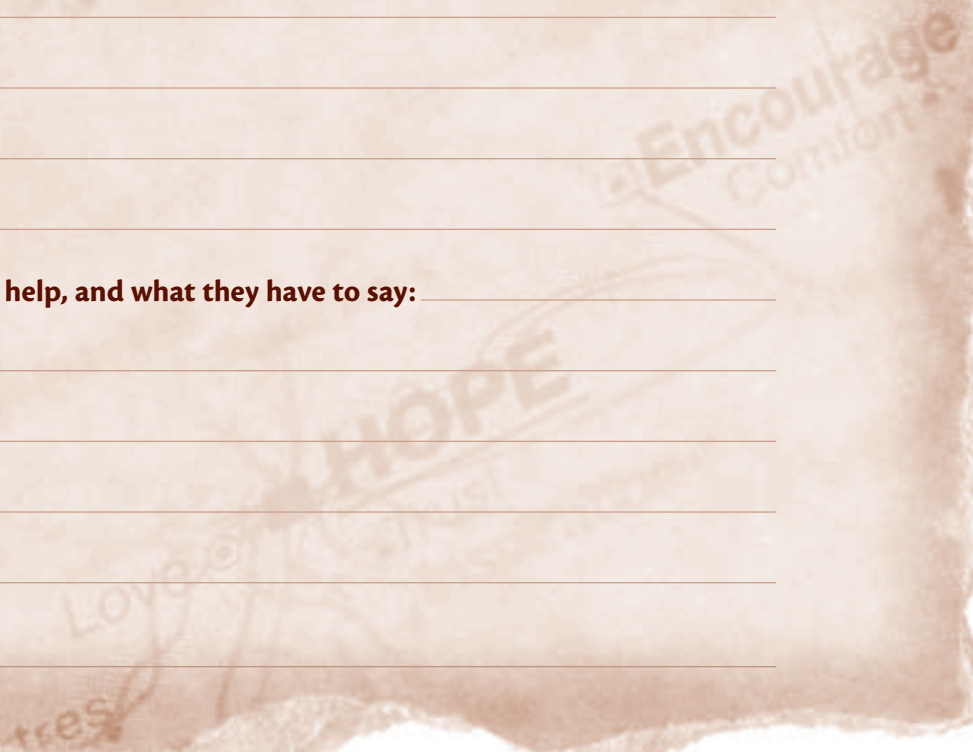
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**Something that I ate and drank that was healthy:** \_\_\_\_\_

In the everydayness of your care-giving lies sacredness. You may witness signs that the divine is in your midst. You may see it in the person's face and feel it in their touch. You may discover what it means to truly love. In the act of accepting, you will be accepted. In the act of comforting, you will be comforted. In being a blessing for another, you are blessed.

— Dr. James E. Miller

## Things I've said and done that I wish I could take back

This is your garbage page. Once you have written these out, let them go. You don't need to hold onto them any longer.

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forgiveness

Encourage  
Comfort



There is no one, no matter how wise he is, who has not in his youth said things or done things that are so unpleasant to recall in later life that he would expunge them entirely from his memory if that were possible.

— Marcel Proust

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HOPE  
Loyalty

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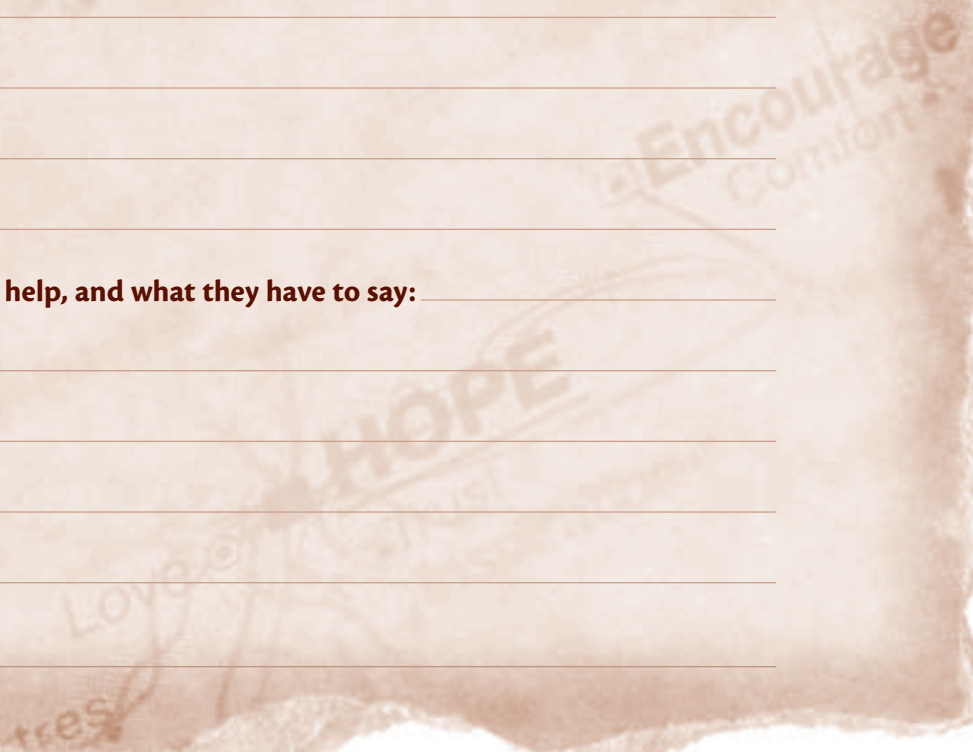
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\_\_\_\_\_

TOGETHERNESS

Encourage  
Comfort

HOPE

Love

tres





*Dance*

*As if no one is watching*

*Love*

*Like you've never been hurt*

*Sing*

*As though no one can hear you*

*Live*

*As though heaven's on earth.*

— Souza

Encourage  
Comfort

HOPE  
Trust  
Inspiration

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tres

\_\_\_\_\_ date

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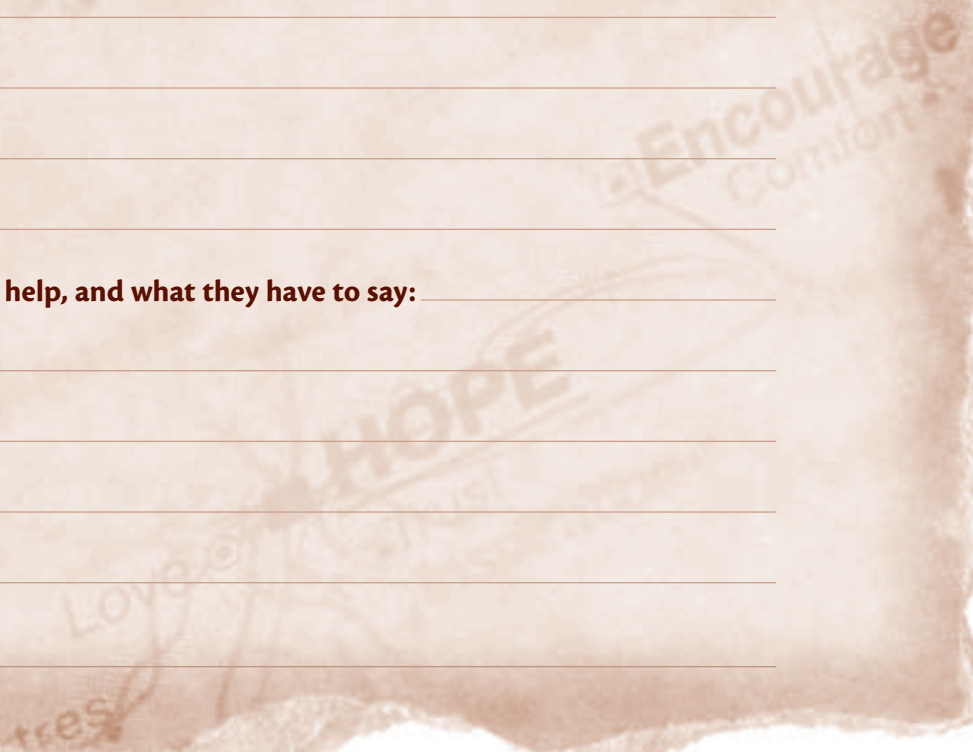
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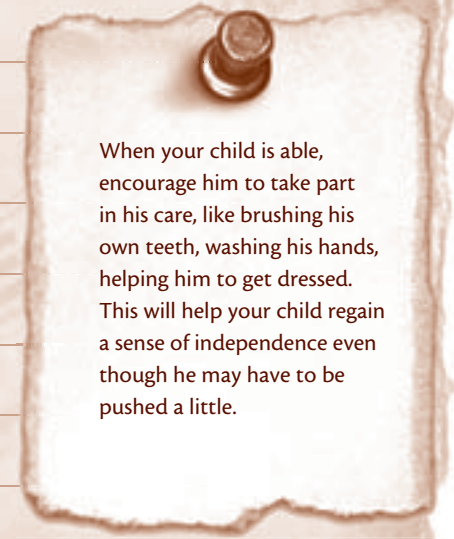
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\_\_\_\_\_

**How I took time for myself today:** \_\_\_\_\_

\_\_\_\_\_

**Something that I ate and drank that was healthy:** \_\_\_\_\_



When your child is able, encourage him to take part in his care, like brushing his own teeth, washing his hands, helping him to get dressed. This will help your child regain a sense of independence even though he may have to be pushed a little.







\_\_\_\_\_ date

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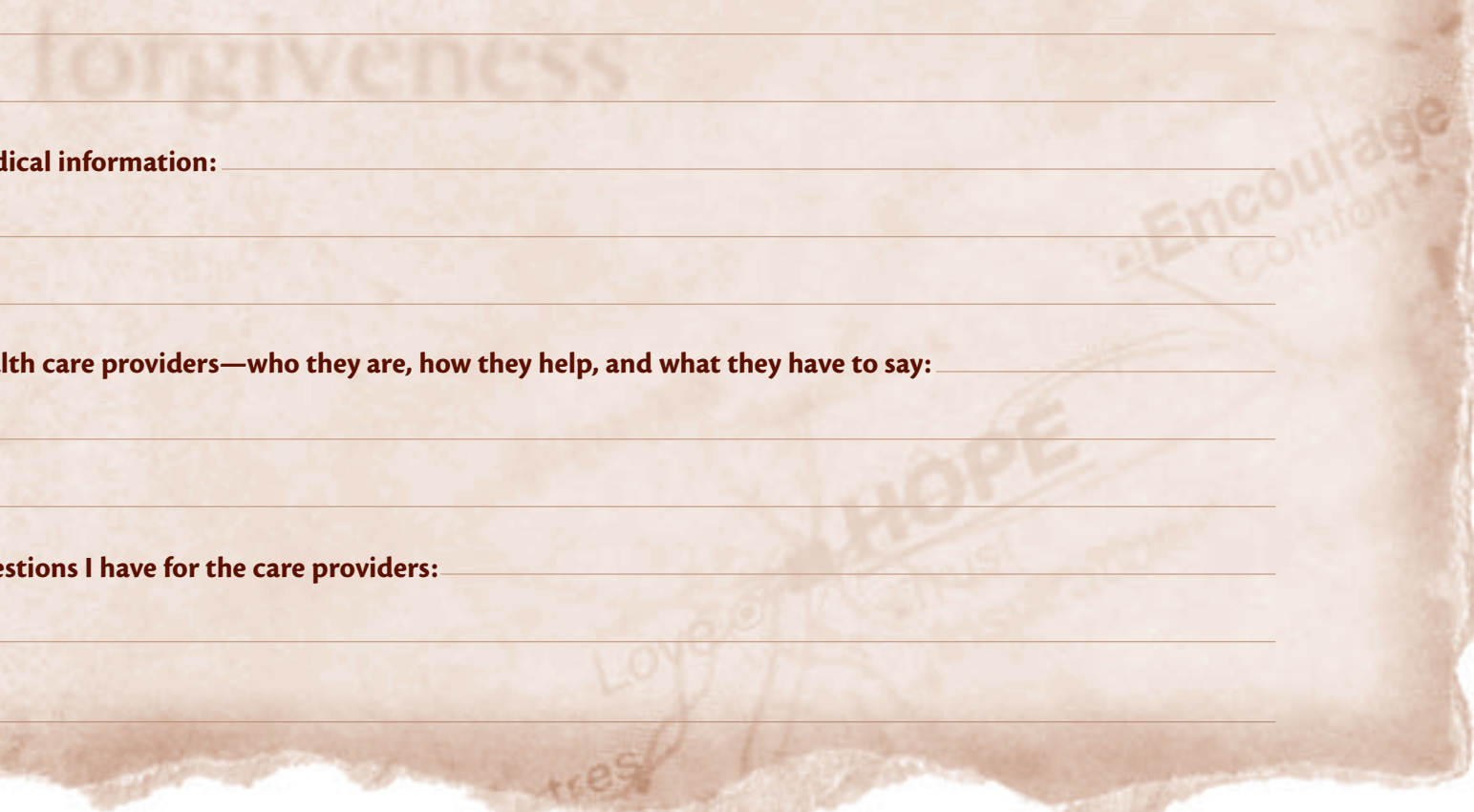
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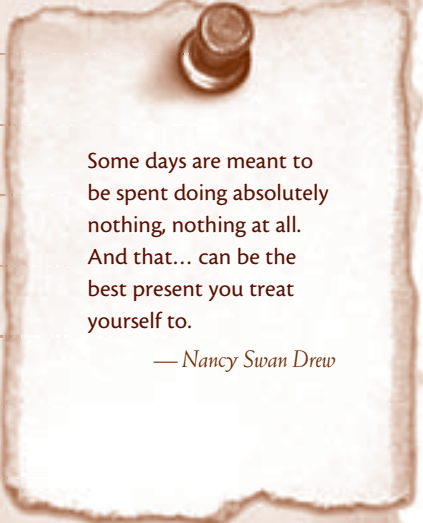
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Some days are meant to be spent doing absolutely nothing, nothing at all. And that... can be the best present you treat yourself to.

— Nancy Swan Drew







\_\_\_\_\_ date

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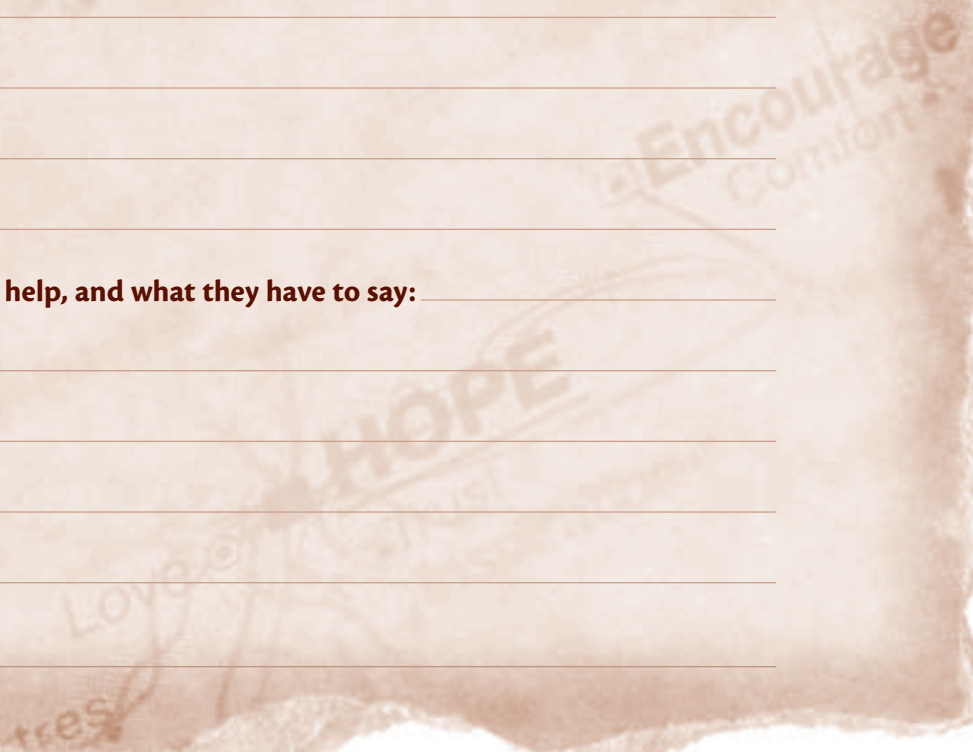
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\_\_\_\_\_

**Tip:** This is the last daily entry page in this book. Copy these pages off if you need more days to write.

## Welcome to Holland

By Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability— to try to help people who have not shared the unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip— to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum. Michelangelo's *David*. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The flight attendant comes and says, "Welcome to Holland."

"Holland?!" you say. "What do you mean, Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guidebooks. You must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for awhile and you catch your breath, you look around, and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever go away, because the loss of that dream is a very significant loss.

But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.



# 7

## Learning to Walk Again

*Leaving the hospital can be just as scary as entering. You've come so far in your journey and now you're faced with re-entering "real life." You'll leave the security of your medical support system, and will be making many decisions on your own. You may be feeling worried, helpless, disappointed, angry or even guilty. These are typical feelings. That's OK. It's normal—indeed, appropriate—for you and your child to feel insecure and to question your physical and emotional readiness.*

*Being prepared will help alleviate some of these feelings.*

Anticipation

Worries

Going Home

On My Own

Love

HOPE

Trust

tres

## Drawing/Writing Page

*For your health care professional to explain procedures, your child's condition, tests and so on through drawings or written explanations.*

strength

Love

HOPE

Trust

Encourage  
Comfort

tres



# Photo Page



## Check-out Lists

200

### Hospital check-out list

Meet with your child's medical team to discuss details about medical and social needs outside the hospital. Include these team members in your discussions if they are available at your hospital: discharge facilitator or case manager, physical therapist, occupational therapist, dietitian, teachers, home health nurses, social worker, child life specialist and, of course, your hospital nurses, doctors and community doctors.

- Most hospitals offer CPR and first aid classes. Take advantage of these if you are able and bring along a close friend and family members to learn with you.
- Make a "home care" schedule that will fit your life at home.
- Understand treatments that may need to be done at home.
- Be comfortable and informed about medicines.
- Stock up with the basics: acetaminophen, pedialyte, ibuprofen, and for infants (even if you are breast feeding) keep a can of powdered formula in case of emergencies.
- Ask all the questions you and your child have.
- Get verbal and written directions for schedules, medicines, procedures and any machines you are taking home.
- If your child is going home with monitors that have alarms. You will need to remember that you cannot be more than 20 seconds (or so) away. Breaks are a must—having extra hands that know how to work the machines and do CPR is invaluable.
- If your baby or small child is going home on oxygen, get a double stroller to hold the tank.
- Get your prescriptions filled ahead of time so they are ready before you are to leave the hospital.
- Ask about your baby or older child's immunizations prior to being discharged (can numbing cream be placed ahead of time?).
- Arrange for transportation home for you and your child and all your belongings.
- If you live a distance from the hospital, try to feed your child before you leave the hospital. If you have frozen breast milk, bring a cooler to transport your milk home with you.
- If you are breast feeding, rent or buy a good breast pump—the manual ones are more difficult to use and may cause undue stress for milk collection.
- Have fresh, clean clothes for your child to go home in. For an infant bring a sleeper, a onesie or a pants outfit. The hospital nightgowns do not allow for car seat straps.
- For your newborn or preemie, make sure to practice putting the car seat in and out of the car. If your baby is small, make sure the car seat has straps that will adjust to your baby's size. Once your baby is secure, you can use receiving blankets around her for comfort. Often, a member of the health care team is assigned or is willing to give instruction and assistance in installing your baby's car seat.
- Have a trial day in which you're the only person caring for your child in the hospital. You'll come up with questions you hadn't thought of and—most important—you'll gain confidence to go home.



# Check-out Lists

## Home check list

Going home takes on a whole new meaning. Yes, your child is well enough to leave the close eyes of the health care team and that is a celebration. However, the ultimate care and responsibility of the child lies with you, which can increase stress. The support usually tapers as friends and family assume that now that your child is home, your family is returning to normal. The reality is that you may be up at all hours of the night, not sleeping well because you are on alert, and then you are expected to carry out all of the household tasks, resume your job, etc. The care of your family should continue until you are getting adequate sleep and have had follow-up visits with your primary care doctors to ensure that your child is stable.

- Understand your own feelings. Knowing how you feel and exploring your concerns can help both you and your child. Talk about how you feel with someone you trust.
- For your toddler or older child, understand his feelings. Children's emotional responses differ by age and development. It's important to talk to your child honestly about his feelings about leaving the hospital.
- Support your child. It's common for children to have behavioral regression from the stress of hospitalization. Be sensitive and reassuring.
- Support your siblings. Siblings have different feelings and concerns about the hospitalization and their sister or brother coming home. Listen to their feelings and validate them.
- Make a visitation schedule for friends and family if you have a lot of support nearby. It can be overwhelming

when you first get home so give yourself a week or so before too many people come to visit. You need time to rest and get a routine with your child at home. A schedule will ensure that you have help even a couple of weeks after you get home: meals, helping with laundry, bringing over crafts to play with your children. Each of these will allow you to take a nap, have quiet time, work out or do something that eases your mind.

- It is always best to avoid large crowds for the first few weeks. You may feel that you have a neon sign flashing everything you and your child have been through but, unfortunately, people can't see that sign. They will admire and touch your child without thinking twice, possibly sharing germs.
- Know that you may feel like a prisoner in your own home until you feel comfortable venturing out. Allow your support team to help care for your child at home while you leave to run errands or get a haircut!
- Anti-bacterial gel is great to have around the house and while you are out with your child. It is an easy way for people to have clean hands before touching your newly discharged child.
- Put an index card with your pediatrician's name and phone number in your wallet, tape one by each phone in the home, and give one to a neighbor and nearby family members.

## Facing the outside world

**Questions.** Be prepared for questions from people in the community. If possible, rely on your support team to relay information ahead of time. Sometimes even strangers will ask questions. Empower yourself and your child to deal with these. Explore how the questions make you feel and talk with your child about potential responses.

**Stares.** Even at a very young age, children are aware of being “different.” If your child has special equipment or physical changes, people may stare—which can be devastating to you both. Develop coping strategies like talking, holding a positive focus, maintaining hospital relationships, and enlisting support from friends in the community.

**Limitations.** Your child may have to adjust to new limitations. This can be frustrating, embarrassing and defeating. Whether these limitations are temporary or permanent, it’s important to allow your child to participate as much as possible in normal activities. Explore ways to resume familiar activities and also find new things to do.

**Maintain hospital friendships.** It’s important to maintain the friendships you made during the hospitalization. These relationships can provide tremendous support while you’re adjusting to life outside the hospital. Join support groups and encourage your child to keep relationships with other children their age who’ve had similar experiences. Stay connected and gain additional support through e-mail, phone calls, personal visits, hospital support groups and websites.

### Once your baby is home

- Be aware that your baby needs to adjust to new sounds and smells in her new environment. You may notice a change in her sleeping pattern or she may be extra fussy.
- Give your baby a tour of her new environment by walking room to room and verbally tell her about her new environment.
- To help ease the transition from hospital to home, use a hospital blanket with all the smells she is familiar with.
- Make sure your home is a comfortable and familiar temperature for the baby. Somewhere around 72 degrees Fahrenheit. As your baby transitions, you can begin to turn the temperature down to what your household normally maintains.
- Avoid comparing your premature baby’s development with those who were born near their due dates. Your doctor will even apply a correction factor to your baby that will base her developmental exam on your due date.

### Once your older child is home

- Your child may be fearful and overly concerned about her health.
- Sleeping and eating habits may be different.
- You may notice a change in your child’s relationship with her siblings.
- It is not uncommon for siblings to feel neglected and resentful of the extra attention given to your hospitalized child.

Whatever the case, your child will need reassurance. Creating a regular routine and a sense of normalcy will help. Use the support team you’ve been establishing since the beginning of this journey. It will take time—and patience—for life to return to normal. And remember to take care of yourself!





# Outpatient Office Visit

*Copy this page to help when you leave the hospital*

**Date and time:** \_\_\_\_\_

\_\_\_\_\_

**Provider:** \_\_\_\_\_

\_\_\_\_\_

**Service:** \_\_\_\_\_

\_\_\_\_\_

**Directions to the office:** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Other Notes:** \_\_\_\_\_

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\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Encourage  
Comfort

HOPE

Love

tres



# Outpatient Office Visit

*Copy this page to help when you leave the hospital*

**Date and time:** \_\_\_\_\_

\_\_\_\_\_

**Provider:** \_\_\_\_\_

\_\_\_\_\_

**Service:** \_\_\_\_\_

\_\_\_\_\_

**Directions to the office:** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Other Notes:** \_\_\_\_\_

\_\_\_\_\_

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\_\_\_\_\_

Encourage  
Comfort

HOPE

Love

tres



















*A story from a nurse*

I was working with a family that was preparing to go home. Their child's condition had become very complicated within a matter of months, and she was going home with a tracheotomy, ventilator, feeding tube and pump. The parents felt overwhelmed and very nervous about being responsible for her care, and decided to have as much home nursing as their insurance would allow. A year or so later, this same family returned to our unit for a course of IV antibiotics—and no longer were we doing the teaching. The parents had become experts and were educating us on how to care for their child!

Love

HOPE

Trust

Respiration

Encourage  
Comfort



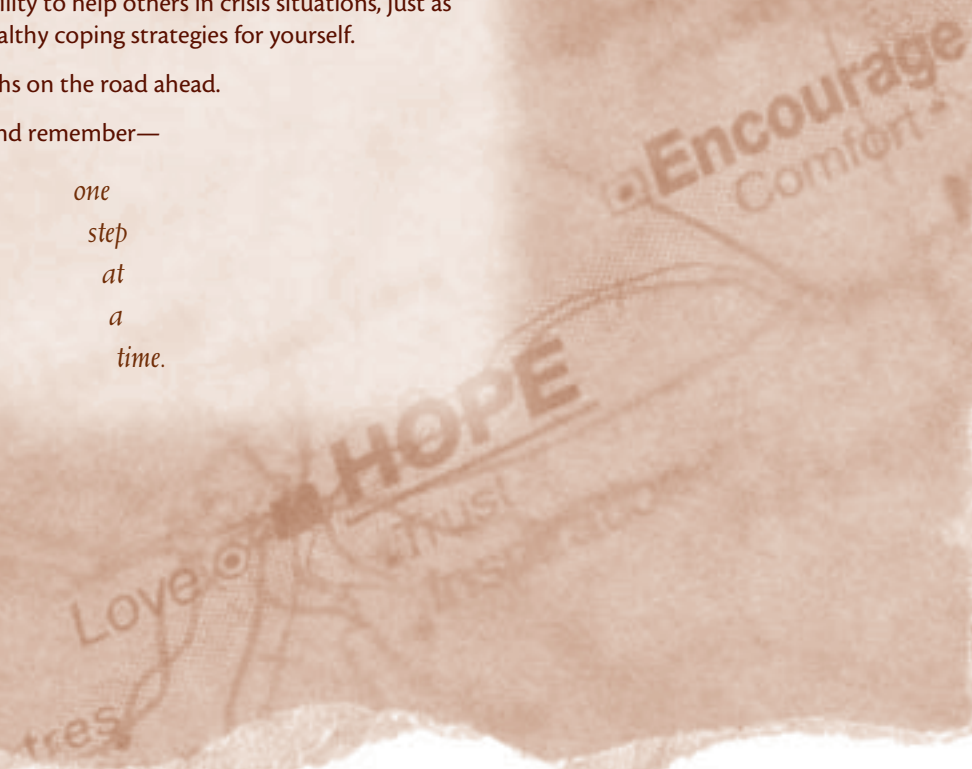
**As one journey ends, another begins....**

You now have the experience of “been there, done that.” You’re no longer intimidated by the hospital and the health care staff. Now you can be an incredible advocate for your child’s health. You also have the ability to help others in crisis situations, just as you’ve developed healthy coping strategies for yourself.

Use those strengths on the road ahead.

And remember—

*one  
step  
at  
a  
time.*



# Calendars

Month \_\_\_\_\_

<i>Sunday</i>	<i>Monday</i>	<i>Tuesday</i>	<i>Wednesday</i>	<i>Thursday</i>	<i>Friday</i>	<i>Saturday</i>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Include outside events and things to remember: birthdays (spouse, other children and family members), bills due, school events, appointments, etc.



Month \_\_\_\_\_

<i>Sunday</i>	<i>Monday</i>	<i>Tuesday</i>	<i>Wednesday</i>	<i>Thursday</i>	<i>Friday</i>	<i>Saturday</i>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Copy this page off if you are in the hospital longer than two months.

**Kristina Bashor** is the mother of Holly, a child who was hospitalized with cancer and spent months in the intensive care unit. Holly was in remission after her initial round of chemotherapy and then her cancer resurfaced. The family summoned their strength and inner resources a second time. Holly pulled through yet again. Kristina's poems were written during Holly's hospitalizations and at the time, didn't have a purpose—now, Kristina's poems serve to reach out to you to tell you that another parent has suffered, another parent has come through the experiences and can offer her experiences to help others.

Love  
HOPE  
Trust  
Inspiration

Encourage  
Comfort



## About the Authors

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*One Step at a Time* was co-written by **Jennifer Smith** and **Bradie Kvinsland**, health care professionals who work with critically ill children and their families. Their first-hand knowledge of parents' experiences led them to create this inspirational and informative book. Jennifer, a pediatric intensive care nurse and Bradie, a child life specialist, have a passion for helping patients and their families through their hospital experiences. Both are from the Pacific Northwest and currently work in hospitals in the Seattle area.



**Jennifer Smith** is a registered nurse specializing in pediatric intensive care with babies and children. Since the beginning of her career, she has advocated strongly for her patients and worked to empower their parents through education and support.

After working at Texas Children's Hospital for three years, she returned to the Pacific Northwest where she continues her nursing career in the

pediatric intensive care unit of Seattle's Children's Hospital and Regional Medical Center.

Jennifer lives in Gig Harbor, Washington, and enjoys skiing, running and spending time with friends and family, including her husband, Matt, and their dog, Blaize.



**Bradie Kvinsland** is a Certified Child Life Specialist, working with the emotional and developmental needs of acute and chronically ill children and their families.

Bradie has spent her career working at Swedish Medical Center in Seattle, Washington, with pediatric patients in oncology, intensive care, and surgical services. She has created programs to enhance family-centered care and

advocates for the needs of children and families through hands-on clinical work.

Bradie received her bachelor's degree in Family Studies from Washington State University. She resides in Gig Harbor, Washington, with her husband, Eric, and their son, Ryker.

Please visit our website at:

**[www.journeytowardhealing.com](http://www.journeytowardhealing.com)**.

**[www.journeytowardhealing.com](http://www.journeytowardhealing.com)** contains a link to the second book written by Jennifer Smith & Bradie Kvinsland titled *"Life's Toughest Moments: A Guide For Parents Facing End Of Life Decisions With Their Child"*.

The website allows you to download *"Life's Toughest Moments"* at no cost if your child is not getting better and may not be able to go home with you.

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Trust  
Inspiration

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## Order Page

**Fax orders:** 253-858-1752

**Telephone orders:** 1-888-858-3752 (toll free)

**On-line orders:** [www.journeytowardhealing.com](http://www.journeytowardhealing.com)

**Postal orders:** One Step at a Time, PO Box 2584, Gig Harbor, WA 98335

### Pricing:

1-4 books: \$23.95/ea.

5 or more books: \$21.95/ea.

100 or more books: \$18.95/ea.

500 or more books: \$18.95/ea. *includes a complimentary, personalized 2-color sticker*  1000 or more books: \$15.95/ea. *includes a complimentary, personalized, pre-printed front cover*

### Mailing Information & Contact Information

Company Name: \_\_\_\_\_ Customer Name: \_\_\_\_\_ Email: \_\_\_\_\_ Tel: \_\_\_\_\_

Street Address: \_\_\_\_\_ City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

### Preferred Method of Payment:

Check or Credit Card:  VISA  MasterCard  Discover Card  American Express

Card Number \_\_\_\_\_ Name on Card: \_\_\_\_\_ Exp. Date: \_\_\_\_/\_\_\_\_

Is your Billing Address different from mailing address? If so, please indicate your credit card billing address:

Street Address: \_\_\_\_\_ City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

### Total Amount of Order:

Number of books \_\_\_\_\_ @ \$\_\_\_\_\_ per book = \_\_\_\_\_

Sales tax for WA state residents @ 8.4% of sales = \_\_\_\_\_

Shipping and handling (\$4.95 for first book, \$1.50 for each additional book) = \_\_\_\_\_

(For orders larger than 100 books, s/h will be charged at actual cost)

**Total Due:** = \_\_\_\_\_

Please make checks payable to "One Step at a Time"







## Contact Us

### We would love to hear from you!

Do you want instructions for filling out here?

Where did you obtain *One Step at a Time*?

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Why was your child hospitalized?

---

---

What hospital was/is your child in?

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How was One Step at a Time helpful to you?

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What is the best advice you could give to another parent?

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What suggestions do you have for future publications and/or website content?

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May we use your comments as a testimonial? If so, do you want to include your name?

Use my comments  (yes)

Use my name  (yes)

Encourage  
Comfort

Love  
trees



**One Step at a Time**  
**P.O. Box 2584**  
**Gig Harbor, WA 98335**

Fold Here





## Testimonials

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“... For parents and families of hospitalized children, *One Step at a Time*, is a handbook and historical record, an inspirational warehouse, and a guide for personal crisis/stress management and resolution. Every family of a hospitalized child should have a copy of this outstanding book.”

—Jerry J. Zimmerman, PhD, MD/Director, Pediatric Critical Care Medicine,  
Children's Hospital and Regional Medical Center, Seattle, WA

“I never knew any of the big words used and was intimidated to ask. They all just assumed we knew their language. I needed this book when my baby was in the hospital—this is great!”

—Dara Feltus, mother of Parker, who was born with a  
single ventricle heart

“Thank you for creating such an excellent resource for parents of children with a serious illness! I often see loving parents put themselves last during this stressful time. Your book reminds parents that to be there for their young loved ones, they must first take care of themselves. *One Step at a Time* provides an amazing amount of encouragement and support, as well as concrete tips on how to survive as a caregiver. It's invaluable!”

—Joanne Patten, CCLS  
Certified Child Life Specialist  
Children's Hospital and Regional Medical Center, Seattle, WA

“I wish I had kept a journal during the times of Michaela's hospitalizations. It is amazing how much you forget. I wish all parents with kids in long term care could have a book like this.”

—Lucinda King, mother of Michaela, a child with  
cerebral palsy who has been hospitalized many times.



**\$23.95 U.S.**  
**\$33.95 Canadian**

**Health/Family/Inspirational**

Is there a child in your life who's been severely injured or is facing a serious illness?

*One Step at a Time* is a book, keepsake and guide for coping with a child's hospitalization. It offers a unique way for a parent to ask the right questions, record important medical information, and express joy, fear and hope during a very difficult time. And most important, it encourages parents to take care of themselves physically, emotionally and spiritually.

*One Step at a Time* includes:

- Messages and helpful hints from parents who have been through similar experiences
- Tips from nurses and other health care professionals
- Inspirational poems, quotes and meditations
- Information on hospital terminology, chains of command and protocols
- Guidance on navigating the ups and downs of the hospital experience—from admission and handling visitors, to adjusting to a new environment and advocating for your child's needs
- Journal pages for parents to document day-to-day events during their child's hospitalization and to express their emotions
- Tips on leaving the hospital and going home

*One Step at a Time* offers valuable hospital information and serves as a type of "user's guide." But it's also much more. It's a road map to courage, strength and honest self-exploration—a beacon of light for surviving one of the most difficult experiences a parent will ever face.

