

## YOU'RE NOT ALONE

No discussion about children with special health care needs would be complete without some discussion of the emotional and spiritual needs/concerns of the child's parents and family members or care givers.

There are some 300,000 infants born each year with some type of birth defect. There are approximately 12.6 million children in the United States who are living with disabilities and who have chronic health conditions. In addition, there are many children who are the victims of trauma: accident or injury. So, you should know...

...that you are not alone!

Reactions of fear, anger, guilt, denial, grief, frustration, sorrow, confusion and "overload" in addition to many other feelings are all very normal, very expected and very acceptable at this time...or, at any other time in the course of caring for your special needs child.

A parent of a special needs child noted the following poem, as helpful to her in coping with the overwhelming sorrow that she was feeling:

"the deeper that sorrow carves in your being,  
the more **joy** you can contain"

- Kahlil Gibran

We want to be very clear about the fact that there are many joyful moments to be had when you are the parent of a special needs child.

Please feel free to take a few moments, from time to time to write down your feelings. On the next few pages you may want to include pictures of your child:

- coming home from the hospital
- in the hospital
- at home
- or of any of the times that you remember as special.

This is a great opportunity to focus on your child what he or she **has accomplished** and what you are **working on together**.

**PICTURE PAGE**

**PICTURE PAGE**

## COPING WITH LOSS

It is important to look at the shape and form that grief and grieving takes on for the families of children with special health care needs. Without doing this at some point, it is difficult to move through the stages of grieving. It is felt that grieving is necessary to each and every person who has faced a loss of some type. There are no "time lines" for completing the process of grieving. We can't say this enough! However, if you feel "stuck" in a certain phase of working through your grief, we encourage you to seek help from a health care professional or organization that is an expert in the field of grief.

There are many types of loss, and people mourn their losses in a wide variety of ways. **Losses do not only happen when a death occurs.** Loss can be symbolic.\*

...loss of a role (wife, husband, parent, sibling, child)

...loss of family structure (through illness, financial stress, hard times)

...loss of a future (for example; what you had hoped and dreamed for your child)

...loss of status, loss of identity, etc.

There are many well meaning people, who in an attempt to bring comfort to you in your time of stress, will tell you that "what you really need is a positive attitude". Well, great! But how to do that when your world has been turned upside down and there are many unknowns to deal with? One of the most inspirational, uplifting and encouraging pieces is "Welcome to Holland" Emily Perl Kingsley on the next page, we hope you enjoy it.

\*adapted from Iowa City Hospice in services

# WELCOME TO HOLLAND

*I am often asked to describe the experience of raising a child with a disability—to try to help people who have not shared that 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---trip to Italy. You buy a bunch of guide books 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 stewardess come in 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 guide books. And 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 a while 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 planned."*

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

*-Emily Pear Kingsley*

**TIP SHEET #2**  
**HOW TO MANAGE ONE OR MORE APPOINTMENTS IN THE SAME DAY**

Things to take to an appointment including this notebook:

1. Birth/Development and Family history especially if your child is seeing a doctor or provider for the first time.
2. A list of all medicines with dosages your child is currently taking. Don't forget to list allergies, sensitivities or negative reactions your child has experienced when taking certain medications.
3. A list of questions/concerns for your child's health care provider.
4. Don't forget to write down their answers!
5. A list of general questions/concerns that your child voices.
6. Bring information on insurance coverage and other payment sources.
7. Toys, books, snacks and loose change for vending machines to entertain your child. Books or other things to keep your hands/mind busy during wait periods (crocheting, needle point, cross word puzzles). Credit cards (you never know when a visit is going to turn into an admission).
8. Bring diapers, pull ups, etc. along with wipes and soap-less hand cleanser. You may also want to bring a change of clothing for your child in case of accidents or spills.
9. Consider taking a neighbor, friend or babysitter to watch your child so you can speak privately or at length with the doctor after your child has been examined.
10. A clear mind and an open mind – Be prepared for the doctor to say something negative or something you don't agree with.

**TIP SHEET #3**  
**WHAT TO DO IF YOUR CHILD IS HOSPITALIZED**

1. In advance (see page 42), prepare an information sheet on your child to give to the hospital where your child will be admitted if possible.
2. Be sure you understand what requirements your insurance requires of you before your child is admitted. Do you need to notify them? Do you need to have pre-authorization? (Some one from the insurance company to ok your child's admission).
3. Do you need to notify the Department of Human Services if your child is in the hospital for a prolonged period of time as well as the Social Security administration office if you receive benefits.
4. Staying with your child is a great idea. Most hospitals will allow you to stay 24 hours a day, if your child's condition allows. You may, however, be responsible for your own needs while you are at the hospital.
5. If your infant or toddler is breastfed, and you need breastfeeding help or support, the Lactation Consultant at UI Children's Hospital can be reached.
6. If you can't stay with your child, you may want to visit regularly or just as often as you can.
7. At the end of the visit, be sure your child is aware that you are leaving. Leaving without saying goodbye can cause anxiety for your child.
8. Talk to the staff! Share your observations, thoughts and concerns about your child and the care that they are receiving. This will help increase the sensitivity of the health care team toward you as a parent.
9. Prepare your child as much as possible (especially if they are older) for the hospital experience. Let your child know:
  - That you will be with them or how often you will visit.
  - What his/her room will be like
  - To the best of your ability: what kind of treatments/exams your child will be receiving
  - What kind of food they will be eating
  - When their anticipated return home will be
10. Give this information (#9) in small doses. Repeat this information as often as it seems necessary over the course of several days.
11. Be ready to answer your child's questions, and explore your child's fears.
12. Ask for help from staff in explaining procedures, test, etc. that you can't or don't feel comfortable in explaining to your child.

13. Bring your child's favorite toy, such as a stuffed animal or blanket.
14. Bring a tape or CD of your child's favorite music or a recording from a relative at home.
15. Before you go home, be sure to get a copy of the written "discharge" instructions for your child. Keep them in this book for easy reference at home.