FAMILIES CONFRONTED WITH CHRONIC ILLNESSES NEED SURVIVAL SKILLS.

Become Informed

• Ask questions! Write them down before going to the doctor.
• Gather all of the information that you need to make informed decisions and minimize needless worry.
• Don't be afraid to ask for a second professional opinion if appropriate, or even a third or fourth.

Become Aware of Feelings

Take the time to notice your own feelings; observe how other members of the family are behaving; learn how different and unique each family member is; learn how to meet each other's needs within your family unit; recognize that medical staff and other helping members of the community have feelings and struggle also.

Become Aware of the Grief Process

Shock—Denial—Anger—Bargaining—Depression—Acceptance

Each person experiences grief in his/her own way. The stages may be in this order or all mixed up. We tend to experience each stage numerous times. As we heal, we are better able to acknowledge the feelings.

Experiences we may have during the grief process include: Feeling like you're going crazy / Lashing out irrationally at unrelated people and circumstances / Feeling exhausted / Unable to concentrate on the simplest of tasks / Unable to make the simplest of decisions / Wanting someone to take care of YOU / Feeling major irritation at spouse, parents, children or siblings because they just don't understand your perspective / Crying at the drop of a hat, or the loss of the car keys / Never crying / Going full blast ahead on some project totally forgetting an important appointment / Feeling guilty...for everything / Feeling unloved / Feeling alone / Feeling isolated / Thinking others are making too much of their situation / Thinking others can't control their feelings / Wanting to know more than the doctors / Raging at God / Giving up in disgust on God / Feeling like you're going in circles / Not wanting to eat / Eating all the time / Not being able to sleep / Sleeping all the time / Not wanting to socialize / Wanting to party all the time.
Find or Create the Support and Resources You Need

Regional Centers - Home Care Services - Creative Living Programs - Respite Services - Family Service Agencies - Catholic Social Services - County Mental Health Agencies - Hospital Support Groups - Hospice Services - Counseling Group Practices - Groups for Codependents - Groups for Dysfunctional Families - Church, Synagogue or other religious support groups - Individual Counseling - Art Therapy - Sandtray Therapy - Movement Therapy - Writing Groups - Dream Groups - Journaling Groups

Reach Out

Often when traumatic illness occurs, we tend to isolate ourselves. We are not alone! Reach out. Make a date at least once a week to have lunch with someone outside your immediate family unit. Walk through a nearby park. Say hello to people you see. Recognize the pain you’re feeling.

Help out in your child’s class at regular intervals. Join a garden club, a book club, a walking group. Take an art class. Ask a friend to help you start a group around a special interest you have.

Reach Inside Yourself

Start a journal. In it keep track of your feelings. Put color and shape on the page to express your feelings. Write down questions, both detailed and cosmic in size. Write down ponderings. Look at something beautiful in nature and write about it. Consider a seed and how it grows into what it’s meant to be. Write about the incredible complexity of the human body and the pain you feel in your family’s current situation. Look more closely and write about the small wonders that still occur in spite of the illness. Write about how the illness relates to the rest of your life. Write about your dreams, both nocturnal and day.

Listen

Listen carefully to others. Ask questions to be sure you understand. Repeat in different words to be sure you understand. Let the other person know you hear them. Be there to hear. Ask to be heard yourself. Ask again, if they don’t hear the first time. Ask a third time. Ask someone else.

We all need to be heard. All of our feelings are valid and need to be expressed. We all need help sorting through the maze of our emotions when confronted with an illness.

Take Time to be Still

Close your eyes and take several deep slow breaths. There are things in life other than the illness. Sit comfortably for five minutes and let your mind wander through a favorite relaxing spot (the beach, a forest, the mountains). While doing routine chores listen to some soft, gentle, soothing music. Place your feel firmly on the floor and realize that you are firmly supported by the earth. Sit on the lawn and feel the grass. Touch a lovely blossom or leaf and feel the softness. Reflect on the good things that have happened. Reflect on your happy memories.
Take care of Yourself Physically

Eat nourishing well balanced meals. Exercise. Choose the exercise that suits you. Take care of your appearance. Have some body work done. There are both gentle and painful massage type therapies, all of which help reduce stress. Choose what suits your needs. Touch is important. Check with other family members. Find out how many hugs they need. Tell them how many you need. Say you need a hug when you need a hug.

Get Help Negotiating the Bureaucratic Maze

Hospital social work staff can often answer questions regarding paperwork about the illness. They should also be able to direct you to services which can assist your family's situation in a number of ways. If it feels too overwhelming for your family to deal with all of the paperwork, ask a friend or a pastor or other community helper to assist. Don’t be afraid to ask. Later on there will probably be others whom you can help in similar situations.

Communicate Clearly

If you find yourselves having to communicate with a number of specialists over a period of time, it helps to have a clear concise dated record of what has happened so far.

Create a simple diary of symptoms. Keep a calendar chart. Note days and times when various symptoms occur. Make copies so that the health professionals can keep one for their records and you can have a full record yourself at home. Mail this record to the health professional before your visit.

Know Your Rights

As a patient, or the family of the patient, you have the right to full information concerning your family member's illness. Consult your patient advocate in the medical system.

If you have needs, state them. Recognize the enormous number of requests medical professionals and office staff process each day...and gently restate your needs until they are met, if it is possible to meet them. Sometimes it’s not possible, but more often it is, and YOU deserve the full cooperation of the medical team working with your family.

This Information Sheet was produced by the Hydrocephalus Association, copyright © 1997. It was adapted from a presentation given by Carolyn C. Shultz, M.S., M.F.C.C., Sonoma, California. It may be reproduced provided a full citation of source is given. For additional resources about hydrocephalus and information about the services of the Hydrocephalus Association, please contact:

Hydrocephalus Association
870 Market Street #705
San Francisco, California 94102
Telephone: (415) 732-7040 Fax: (415) 732-7044