
Other

Introduction

This section contains additional useful information that does not fit within any of the other sections. There is a bibliography which lists books and other reading material that other parents in similar circumstances have found to be valuable. A glossary of common medical terms is included, along with a list of resource agencies that can be contacted for further information, services or just for support.

As with the other sections, portions of this section can be removed if you wish to take them with you for reference during an appointment. Also, you can add pages with additional information that you have found useful. The pocket on the section divider at the beginning of this section can be used to hold booklets, pamphlets or other material.

Tips

How to leave instructions for caretakers:

Parents need to occasionally leave their children in the care of a babysitter or other adult caretaker. This can be a stressful experience, particularly if the child requires specialized care. The following are some tips that may make leaving your child with another caretaker easier for everyone involved.

1. Meet with the caretaker ahead of time to teach him or her about the care of your child.
2. Prepare a list of instructions for the caretaker, including a phone number at which you can be reached, your destination, route to the destination, emergency phone numbers, name and phone number of physician(s), and the hospital to which you would prefer your child to be taken if an emergency necessitates such action. Also indicate your expected time of return and other people you would like to have contacted, in case of an emergency, if you cannot be reached. Leave this by the phone.
3. Leave with the caretaker a written description of your child's current medical condition, medical history, treatment plan, medications currently being received, etc. (You may find it useful to leave all or portions of your child's Coordinated Care Record.
4. Discuss with the caretaker, beforehand, your wishes regarding feeding, naps, discipline, play activities, snacks, television viewing, and so forth. Special precautions related to your child's medical condition should be put in writing and discussed person-to-person to be sure that they are clearly understood by the caretaker.
5. If your child is not able to communicate his or her needs and wishes verbally, discuss with the caretaker the nonverbal cues that you have learned to recognize (such as how your child shows that he or she is hungry or tired). The approach to comforting which works best for your child is useful information for the caretaker. If possible, also put this information in writing.
6. Put together an easily transported bag of supplies and medications required by your child. This can be left with the caretaker, who will then be able to quickly locate it and take it along in case an emergency requires a hasty departure.
7. If your child requires a car seat, leave the car seat with the caretaker during your absence in case the child must be transported by car. Discuss with the caretaker any plans for recreational or other outings that may be planned during your absence.

Responding to Questions

Most parents of children having special health care needs must at times deal with questions from friends, relatives, neighbors, and even to total strangers regarding their children and their medical conditions. Sometimes the questions are asked directly; at other times the questions are inferred from a remark or a stare, even by teasing initiated by neighborhood children. Your response may depend on how you feel at the time or how you interpret the intent of the questioner. You may wonder if you responded appropriately or you may feel that you said too much or too little. You may feel anger or frustration.

A question (or a comment or a stare) may represent genuine curiosity about your child and his or her condition. If so, a factual, straight forward response can do much to promote understanding, compassion and tolerance.

Questions, whispers, and stares can be upsetting at times, even if they are not meant to be negative. You may have become quite accustomed to your child's appearance, but a question from a stranger can remind you anew that your child is different, thus reviving the feelings of hurt, anger and grief that you may have been able to suppress or adjust to over the course of time. Your reaction to the question may then be one of anger based on your own inner feelings, regardless of the intentions of the questioner.

Your response to a question may need to vary according to the situation. A brief explanation to a stranger on the street may be all that's needed. More detailed information might be appropriate, however, for people who see your child on a regular basis, such as school classmates or neighborhood children. Supplying information can resolve curiosity. Not supplying it can lead to continued questioning, staring, and misunderstanding.

But, you should also keep in mind that you don't owe an answer to anyone, especially if the questioner is clearly rude or does not intend to use the information in a positive manner. To a certain extent, you must also respect your own feelings; if you don't feel like answering, you have a right not to respond.

In general, however, an honest explanation, whether brief or detailed, will promote understanding. The questioner may even have personal experiences similar to yours that he or she wishes to share with you.

Vacation Planning

The following are things to consider before you go on vacation with your child with special health care needs:

1. Plan ahead. The safety of your child is very important.
2. Your child with special health care needs may require unexpected medical care while you are on vacation.
3. Be sure that care is readily available before you go.
4. Ask your medical specialist to refer you to a physician located nearest to your vacation site.
5. Talk to your insurance company, DSCC consultant, Public Aid caseworker, etc., before you go. Be sure arrangements are made to pay for medical care you may need while away. Do not assume you will be covered.
6. Ask your doctor for a letter about your child and what he would like done should an emergency occur. Note: DSCC requires that the child's specialist in Illinois be contacted about emergencies related to the care of a medically eligible condition.
7. Be sure your travel plans are safe for your child. Discuss this with your doctor. Is it

safe for your child to fly or to go on a long train, bus, or automobile trips?

8. Think of things that could go possibly wrong and plan for a way to handle them.

Grief

SHOCK is what parents say they first feel when they realize their child has a special health care need, a handicap, or a disability. The doctor may be the first to tell them, but many times parents say "I knew something was wrong even before I saw the doctor." No matter how you learn about your child's problem, IT HURTS. The initial shock and pain - maybe a sense of numbness - soon changes into other feelings that have been described in a process called "grief" or "coping."

There have been many articles written about the grief process and several stages have been described. If you like, your DSCC Consultant can share more information with you. It is important for you to realize that feelings like anger, guilt, depression, or isolation may occur and are normal. Many parents have said "I thought I was crazy, I felt so upset all the time." It helped when they learned this was a normal part of adjusting to and coping with the changes in their life as a result of their child's special health care needs.

Many parents find help and support from their families and the professionals working with their child. But most find talking to other parents of children with similar health care needs especially helpful; other parents understand what you are going through and feeling. There are many parent support groups in Illinois. Some of them are listed in this section. Your DSCC Consultant can help you identify groups in your area if you would like to meet other parents of children with special health care needs.

Most parents are able to adjust and cope and, although the feelings of grief will come back from time to time, they are able to live

normally. Some parents have needed professional counseling to be able to work through their feelings. If you are worried about how you are feeling, talk to your doctor or your DSCC Consultant.

Local Parent Support Groups

These are a wide variety of small local support groups who meet to share information, provide practical help and emotional support to you and your family.

The following suggestions should help you find a group in your area which is best suited to your needs.

1. Hospital where your child receives treatment (the Social Service Department often keeps listings of local self-help groups).
2. Doctor - (your child's doctor or his nurse or receptionist can often direct you to local groups).
3. Service Providers, such as DSCC, ARC, UCP and/or national organizations which have local chapters, mental health clinics, etc.
4. Pediatric Medical Centers, Social Service Departments and Public Service Departments.
5. Special Education Centers, and special education teachers in your school district.
6. Newspaper, community calendar/events section will often list notices for upcoming meetings held by parent support groups.
7. The Self-Help Center (1600 Dodge Ave., Evanston, IL 60201, 708-328-0471) keeps an extensive listing of local, county and regional groups who provide parent support.

Telephone Directory

One of your greatest assets for finding help in your area is your telephone directory. Below are some examples of headings to look under to aid you in finding the help you need in your area:

Yellow Pages

Social Services - Local social service providers, specific disability organizations, mental health clinics

Fraternal Organizations - Local civic groups who help with funding or equipment needs specific services (such as Home Health Care, Medical Supplies and Equipment, In-home Nursing Services)

White Pages

Illinois State of, then specific department such as Public Health, Rehabilitation Services, Mental Health, Public Aid, etc.

United States, then specific office, such as Social Security Administration.

Schools - Public, then Special Education Department or Centers

Recommended Reading

- A Child Goes to The Hospital*, available from the Association for the Care of Children's Health
- A Difference in the Family - Living with a Disabled Child*, Helen Featherstone
- A Doctor's Tools*, Kenny DeSantis
- A Glossary of Heart Terms*, Upbeat
- A Guide for Teachers; Children and Hospitals*, available from the Association for the Care of Children's Health
- A Handbook of Heart Terms*, prepared by the National Heart, Lung, and Blood Institute
- A Handicapped Child in the Family*, Verda Heisler
- A Hospital Story: An Open Family Book for Parents and Children Together*, Sara B. Stein
- A Parent's Guide to Learning Disabilities*, Alice C. D'Antoni
- A Practical Dictionary of Medical Terms for Parents of Children with Heart Disease*, Mid-Michigan Parent Group
- A Visit to the Hospital on Sesame Street*, Deborah Houtzig
- About Dying*, published, New York Walker & Company
- After the Tears*, Robin Simons
- Alternatives: A Family Guide to Legal and Financial Planning for the Disabled*, L. Mark Russell
- Anna Joins In*, Katrin Arnold
- Becky's Story*, Donna Bazik
- Betsy and the Chicken Pox*, Gunilla Wolde
- Betsy and the Doctor*, Gunilla Wolde
- Bibliotherapy With Children Experiencing Loss*, Evelyn and Duff Berg
- Books for Children about Death*, Carolyn R. Haridean
- Cancer: The Whispered Word*, Judy Swenson and Roxane Kunz
- Children Die Too*, Joy Johnson and Dr. S.M. Johnson
- Dare to Discipline*, James Alabson
- Directory of Self Help Mutual Aids Groups*, published, The Self Help Center
- Disabled? Yes, Defeated? No*, Kathleen Cruzic
- Emergency Room*, Bob and Diane Wolfe
- Eric Needs Stitches*, Barbara Marino
- Explaining Death to Children*, Earl A. Grollman
- Feeling Down: The Way Back Up*, Roxane B. Kunz and Judy H. Swenson
- For Those Who Live*, Kathy LaTour
- Going to the Doctor*, Fred Rogers
- Good Grief*, G. E. Westberg
- Growing Pains: Helping Children Deal with Everyday Problems through Reading*, Maureen Cuddigan and Mary Beth Hanson
- Handbook for Parents of Children with Learning Disabilities*, R. J. Schoonover
- Harry's Dog*, Barbara Porte
- Help for Your Child: A Parent's Guide to Mental Health Services*, S. Brehm
- Helping Children with Learning Disabilities:*

In the Home, Church and Community, Ruth Dinkins Rowan

Helping Your Exceptional Baby: A Practical and Honest Approach to Raising a Mentally Handicapped Child, C. Cunningham and P. Sloper

Home Care for the Chronically Ill or Disabled Child, Monica Jones

Hospital Roadmap: A Book to Help Explain the Hospital Experience to Young Children, Ingrid Elliot

How to Build Special Furniture and Equipment for Handicapped Children, Ruth Hofmann

How to Discipline Without Feeling Guilty, Melvin Silberman and Susan Wheelan

I Am, I Will, I Can, F. Rogers

I Wish I Was Sick Too!, Franz Brandenburg

Is Human Life Precious?, A. E. Dudale

It's Easy to Make Aides for Your Handicapped Child, Al Gaston

I'll Never Love Anything Ever Again, Judy Delton

Jeff's Hospital Book, Harriet Sobol

Jeff's New Pacemaker, Medtronic, Inc. (Available through Medtronic salesman)

Living When a Loved One Has Died, E. A. Goldman

Living with the Handicapped Child, Evelyn Ayauet

Meeting the Challenge of Disability or Chronic Illness, L. A. Goldfarb, M. J. Brotherson, J. A. Sanmenrs and A. Turnbull

Mentally Retarded Children: What Parents and Others Should Know, H. E. Blodgett
Michael and the Dentist, Bernard Wolf

Miffy in the Hospital, Dick Bruna

Mr. Rogers Talking with Young Children about Death, available through Family Communications, Inc.

My Book for Kids with Cansur, Jason Gaes

My Dentist, Harlow Rockwell

My Doctor, Harlow Rockwell

My Hospital Book, William L. Coleman

No Easy Answers - The Learning Disabled Child, S. Smith

No Measles, No Mumps for Me, Paul Showers

No One to Play With: The Social Side of Learning Disabilities, Betty B. Osman with Henriette Blinder

Nobody Cares About Me, Sarah Roberts

On Becoming a Special Parent; A Mini Support Group in a Book, Marcia Routberg

On Death and Dying, Elizabeth Kubler-Ross

One Miracle At A Time: How to Get Help For Your Disabled Child - From the Experiences of Other Parents, Irving R. Dickman and Sal Gordon

Our Special Child, Bette M. Ress

Parent Effectiveness Training, Thomas Gordon

Patty Gets Well, Patricia Frevert

Pop-Up Going to the Hospital, Bettina Clark and Lester L. Coleman

Preparing Your Child for Repeated and Extended Hospitalizations, available from the Association for the Care of Children's Health

Promises to Keep: A Handbook for Parents of Learning Disabled, Handicapped and Brain-Injured Children, David Melton

Raising A Handicapped Child, Charlotte Thompson, M.D.

Retarded Isn't Stupid Mom!, Sandra Z. Kaufman

Sesame Street Hospital Kit, Available from local parents' groups in the Chicago area

Sick in Bed, Anne and Harlow Rockwell

Something's Wrong With My Child, M. Brutton

Sorrow into Joy, Hugh Salisbury

Spots are Special!, Kathryn O. Galbraith

Support Groups for Parents Whose Children Die, Compassionate Friends

Talking About Death, A Dialogue Between Parents and Child, published, Boston Beacon Press

Taryn Goes to the Dentist, Jill Kremenz

Teaching Individuals with Physical and Multiple Disabilities, June Bigge

Teddy Bears Cure a Cold, Susanna Gretz and Alison Sage

Tell Me Papa, Joy and Marve Johnson

Telling a Child About Death, published, New York Hawthorne Books, Inc.

The American Heart Association Cookbook, published, the American Heart Association

The Bereaved Parent, Harriet Sarnoff Schiff

The Checkup, Harold Roth

The Child with the Disabling Illness, John Downey and Neils Law

The Chronically Ill Child and Family in the Community, available from the Association for the Care of Children's Health

The Chronically Ill Child: A Guide Book for Parents and Professionals, Audrey F. McCollin

The Dentist and Me, Joy Schaleben-Lewis

The Emergency Room, Anne and Harlow Rockwell

The Exceptional Parent Magazine, published, Exceptional Parent

The Grief of Parents When a Child Dies, Mary Shandial Miles

The Heart of a Child, William J. Potts

The Hospital Book, James Howe

The Hospital Scares Me, Paula and Kirk Hogan

The Inner World of Childhood, Francis Wickes

The New American Pocket Medical Dictionary, published, C. Scriber Publishers

The New Diary, Tristine Rainer

The Single Parent Experience, Carole Klein

The Special Child Handbook, John McNamara and B. McNamara

The Special Child: A Source Book for Parents of Children with Developmental Disabilities, Siegfried Pueschel, James Bernier and Leslie Weidenman

The Tenth Good Thing About Barney, J. Viorst

The Ultimate Loss: Coping with the Death of a Child, Joan Bordow

The Wheelchair Child, Philippa Russell

Understanding Your Cardiac Catheterization,
Gayle Lacita and Suzanne Burae

Ways for the Disabled Magazine, published,
First Publications, Inc.

We Remember Phillip, Norma Simon

Wendy Well and Billy Better Ask a "Mill-Yun"
Hospital Questions, John Welzenbach

Wendy Well and Billy Better Meet the Hospital
Sandman, John F. Welzenbach

Wendy Well and Billy Better Say "Hello
Hospital", John F. Welzenbach and Nancy Cline

Wendy Well and Billy Better Visit the Hospital
See-Through Machine, John F. Welzenbach

When Bad Things Happen to Good People,
Harold S. Kushner

When You Visit the ICU, the Association for
the Care of Children's Health

Where's Jess, Joy and Marve Johnson

Whoever Said Life is Fair?, Sara Kay Cohen

You and Your Grief, E. Jackson

Your Child's Heart Catheterization, Variety
Club

Your Heart Test, Candice Superira

Your Hospital: Meeting the Special Needs of
Children, available from the Association for
the Care of Children's Health

Your Turn Doctor, Carla Perez and Deborah
Robison

Resources

Academy of Dentistry for Persons with Disabilities
211 E. Chicago Avenue
Suite 948
Chicago, IL 60611
312-440-2660

Professional Organization

American Foundation for the Blind
Illinois Chapter
401 N. Michigan Avenue
Chicago, IL 60601
312-245-9961

Provides information on conditions that lead to vision loss and blindness, as well as information on services available to the blind.

American Heart Association - Illinois Chapter
P. O. Box 2666
1181 North Dirksen Parkway
Springfield, IL 62708
800-252-8511 or 217-525-1350

Mission is to reduce premature disability and death due to heart and vascular diseases through research, education and community programs.

Arthritis Foundation - Illinois Chapter
111 E. Wacker Drive
Chicago, IL 60603
312-616-3470

Provides educational programs and peer support to patients and families with arthritis. Group meets monthly. Membership is open to persons with arthritis and family members.

Association for Retarded Citizens of the U.S. - Illinois Chapter
925 W. 175th Street
Homewood, IL 60430
708-206-1930

Goal: to advance through all resources, the total well being, dignity and rights of all citizens who are mentally retarded and to foster the prevention of mental retardation. Program includes: early infant intervention, adult vocational program, adult residential

services, family support, respite care, foster care and recreational assistance.

Association for the Care of Children's Health
3615 Wisconsin Avenue N. W.
Washington, DC 20016
202-244-1801

Professional Organization

Children's Defense Fund
122 C. Street, N.W.
Suite 400
Washington, DC 20001
202-628-8787

Provides information and/or advocacy for individuals with disabilities and their families.

Compassionate Friends, Inc.
P.O. Box 3696
Oak Brook, IL 60522
708-990-0010

National organization offering support for families of children who have died.

Coordinating Council for Handicapped Children
20 East Jackson, Room 900
Chicago, IL 60604
312-939-3513 (Voice) 312-939-3519 (TDD)

Provides parent information, advocacy and training with regard to special education, including information and written material related to Public Law 94-142 and Public Law 99-457. Provides information on parent/child rights and responsibilities.

Cystic Fibrosis Foundation - Illinois Chapter
150 North Michigan Ave., Suite 400
Chicago, IL 60601
800-824-5064 312-236-4491

Provides information on support groups for parents of children with cystic fibrosis. Also, may coordinate telephone network in some groups. Meetings are for patients, parents and siblings.

Epilepsy Foundation - Illinois Chapter
20 E. Jackson Blvd., Suite1300
Chicago, IL 60604
312-939-8622

Informs and shares experiences in coping with the various aspects of epilepsy. Topics of discussion include family and psychological problems, the treatment of epilepsy, vocational problems, insurance and social security problems. Meetings are twice monthly for families and friends.

Families of Spinal Muscular Atrophy
P.O. Box1 465
Highland Park, IL 60035
312-432-5551

Offers families support and up-to-date information; sets up library of protocol for different stages of management; raises money for research to reach goals of treatment, prevention and cure; forms national registry and clearinghouse.

Family Resource Coalition
200 S. Michigan Avenue, 16th Floor
Chicago, IL 60604
312-341-0900

Information and resources, including updated research regarding "family centered care" of children with disabilities. Newsletter.

Illinois Association of Community Mental
Health Agencies
110 W. Lawrence Avenue
Springfield, IL 62704
217-789-1380

Provides referrals to local mental health offices for child, family and individual counseling on a sliding fee scale based on ability to pay.

Illinois Early Childhood Intervention
Clearinghouse
830 S. Spring Street
Springfield, IL 62706
800-852-4302

Operates resource library of books and videotapes, printed material, bibliographies and copies of medical/social/educational articles. All information services and publications are

provided free of charge, with the exception of some film rentals. A rich source of information regarding all aspects of caring for a "special needs" child. Newsletter.

Illinois Department of Mental Health and
Developmental Disabilities
401 S. Spring Street
Springfield, IL 62765
217-782-2753

Assists with referrals to local offices for family and/or child counseling and developmental testing. Information regarding current programs which serve individuals with developmental disabilities in Illinois. Coordinates information regarding respite services. Operates regional institutions for mentally ill/developmentally disabled persons. Operates Home Individual Program (HIP) Homes, "foster" placements for developmentally disabled individuals who cannot live in their own homes and who require extensive rehabilitation services, but who do not require institutional placement.

Illinois Department of Rehabilitation Services
625 East Adams
P.O. Box 19429
Springfield, IL 62794-9429
217-782-2093 or 1-800-275-3677

Responsible for vocational training services for older teenagers and adults. Offers limited home health care and respite services to families who are income eligible. Provides human rights and disability rights advocacy services. Administers Illinois School for the Deaf, Illinois School for the Visually Impaired and Illinois Children's School and Rehabilitation Center. Provides information and assistance.

Illinois State Board of Education
100 N. First Street
Springfield, IL 62777
217-782-6601

Administers and oversees implementation of Illinois Special Education Rules and Regulations. Supports parent advocacy efforts.

Lekotek
National Center
2100 Ridge Avenue
Evanston, IL 60201-2796
708-328-0001

Provides resources for parents of children (0-8 years old) who have special needs, whether permanent or temporary: 1) toy lending library; 2) parent support group (monthly); 3) preschool project; 4) computer project. Provides parents with a resource center.

National Down Syndrome Congress
1605 Chantilly Drive, Suite 250
Atlanta, GA 30324
800-232-6372

National Easter Seal Society
230 W. Monroe
Chicago, IL 60606-4802
312-726-6200 (Voice) 312-726-4258 (TDD)
Has a wide range of services and therapies for people with congenital or acquired disabilities. Operates information and referral services, parent education classes and self-help groups and equipment lending "libraries." Not all services are available at every center.

National Hydrocephalus Foundation
Route 1 River Road
Box 210A
Joliet, IL 60436

Not-for-profit organization for parents of children or adults with hydrocephalus, mainly offering educational and referral services. People with similar concerns are linked; symposiums held and new groups formed. Parents and adults with hydrocephalus have formed their own subgroup and support system.

Neurofibromatosis Incorporated
407 Indianapolis Avenue
Downers Grove, IL 60515
800-322-6363 or 708-963-6040

Provides information to people with neurofibromatosis (NF), the medical community and the public. Offers support to people and families affected by NF and seeks to end the isolation felt by those with rare disorders.

Parents of Chronically Ill Children
1527 Maryland Avenue
Springfield, IL 62702
217-522-6810

Parent Coalition Group

Equip for Equality
11 East Adam, Suite 1200
Chicago, IL 60603
800-537-2632 or 312-341-0022

Advocates legal and human rights of persons with disabilities. Specific services includes information and referral, legal advice and representation in negotiations, assistance with administrative hearings in court, if necessary. P&A also provides training and education sessions on legal rights and self advocacy techniques and information regarding guardianship.

United Cerebral Palsy
1-800-872-5827

Provides a variety of supportive services, including assessment, equipment loan and early intervention. Services vary somewhat among the seven affiliate offices.