



# Caring for Children with *special needs*

## CHRONIC ILLNESSES

*Chronic illness is an “umbrella” term. It is not equivalent to a physical disability because, for example, children with cerebral palsy can be ill or well, independent of their disability. While it is likely that children will have a variety of health problems during infancy and childhood, these problems for most children are relatively mild and intermittent, and do not interfere with their development. For some children, however, chronic health conditions affect their everyday lives throughout their childhood. These children’s parents and child care providers must also deal with the child’s ongoing health problems on a daily basis.*

Chronic illness may limit a child’s activities a lot or a little, and the limitations may come and go. It is impossible to determine a child’s special care needs just from the name of an illness or diagnosis.

Some factors perhaps are more important for children with chronic illnesses than for others because illness can interfere with their developmental needs. As one example, chronic illness can affect preschoolers as they become more aware of their bodies and mastery of the environment. A medical condition may necessitate parental control beyond the time when “typical” preschoolers are assuming part of the control.

Here are several situations where conflict may be created as the youngster tries to assert independence:

- following a special diet for a child with Celiac Syndrome (and cannot eat wheat),
- remembering insulin shots for a child with diabetes, and
- frequent postural drainage for a

child with cystic fibrosis (which also can be embarrassing because he is now conscious of what other children think of him), and

- lack of stamina for a child with a congenital heart condition (who must watch other children in active play).

However, parents and caregivers know that these limitations or restrictions are not negotiable. As preschoolers test adults’ limits, there is natural conflict with adults’ demands. Children with chronic illness, more than other children, need opportunities to make choices—to have control over whatever part of their lives they can have control over. They must be able to say (in safe situations) the emphatic “No!” for which preschoolers are famous.

### Strategies for inclusion

Build your relationship with the child in ways other than rules regarding the child’s chronic illness. Use language about the child’s

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illness that the child can understand. Use the same terms and phrases that the child's parents use to avoid confusion. Ask the child if she wants privacy when you are doing some illness-related procedure that might be embarrassing. Of utmost importance are the possible medical needs of a child with a chronic illness.

Here are other things you'll need to keep in mind when caring for a child with a chronic illness:

- Update medical records frequently.
- Post telephone numbers where you can reach parents (and alternate emergency contacts) at all times.
- Keep records of the results of special testing that has been done.
- Keep dated reports of all injuries or health-related incidents that occur while the child is in your care.
- Document your health-related communications with the child's parents and health care providers.
- Keep careful, ongoing records of the child's medications.
- Make sure your staff know routine medical needs for this child.
- Frequently check supplies needed for routine care of the child and that everyone knows where they are stored.
- Be vigilant about following the child's dietary or activity limitations.
- Discuss daily activities with the child's parents and ask them to tell you activities that should be avoided or modified.
- Check with the child's parents before any field trips, special events, or activities that are out of the ordinary for your program.

All programs that serve young children are required to have careful plans for handling emergency situations. When a child with a chronic health problem comes into your program, make sure you have a specific plan for this child. You should:

- Talk to the child's parents (or child's health care provider) to plan in advance for an emergency health crisis.
- Understand what might cause a crisis and how often a crisis might occur.
- Learn how the child might behave before, as well as during and after a crisis (sometimes there are

changes in behavior, level of activity, or other warning signals).

- Know when you need to call for additional help.

As a caregiver, you will need to remember that parents who have children with chronic illnesses are often afraid to leave them. Here's a common response: "I was scared stiff the first time I left Stacey with somebody else. I don't think I left her until she was two years old, not to go to a movie or anything. Other people convinced me that she'd be safe with a trained respite person, which gave me confidence. And now I can leave her for a little while at least."

Children with chronic illnesses are more likely than other children to experience frequent doctor and hospital visits. Some of the medical procedures they undergo are, in fact, frightening or painful. Hospital stays can also be frightening and lonely. Because of young children's limited ability to understand their illnesses, they sometimes believe that they are being punished.

As a person experienced in soothing children in ways suited to their developmental level, you are in a position to help parents calm a chronically ill child's fears and confusion about "punishment." Don't be surprised if a child regresses after a hospital stay. If you have any questions or doubts, ask the child's parents or ask your county public health nurses for suggestions.

## Resources for caregivers

If you want more information about a child's chronic illness or health condition, ask the child's parents, your county public health nurses, or the child's health care provider. There are many national organizations for specific health conditions.

Association for the Care of Children's Health  
3615 Wisconsin Avenue NW  
Washington, DC 20016  
(202) 244-1801

Cystic Fibrosis Foundation  
6931 Arlington Road  
Bethesda, MD 20814  
(301) 951-4422

Juvenile Diabetes Foundation International  
432 Park Avenue South  
New York, NY 10016

(212) 889-7575  
National Easter Seal Society  
2023 West Ogden Avenue  
Chicago, IL 60612  
(312) 243-8400

Sickle Cell Disease Association of America  
200 Corporate Pointe/Suite 495  
Culver City, CA 90230  
(800)-421-8453 or (310) 216-6363

## Technical references

Allen, K.E. (1991). *The Exceptional Child: Mainstreaming in Early Childhood Education*. Delmar Publishers, Albany, N.Y.

Chandler, P.A. (1993). *A Place for Me: Including Children with Special Needs in Early Care and Educational Settings*. National Association for the

## More information

This publication is part of a series, *Caring for Children with Special Needs*. You may find other fact sheets in this series with helpful information. For the most current update of these fact sheets, check the National Network for Child Care website

at: <http://www.nncc.org>

- *Caring for Children with Special Needs: Feeling Comfortable (overview)*-NNCC-98-06
- *Caring for Children with Special Needs: The Americans with Disabilities Act*-NNCC-98-07
- *Caring for Children with Special Needs: Allergies and Asthma*-NNCC-98-08
- *Caring for Children with Special Needs: Attention Deficit Disorder*-NNCC-98-09
- *Caring for Children with Special Needs: Challenging Behaviors*-NNCC-98-10
- *Caring for Children with Special Needs: Chronic Illnesses*-NNCC-98-11
- *Caring for Children with Special Needs: Developmental Delays*-NNCC-98-12
- *Caring for Children with Special Needs: Hearing Impairments*-NNCC-98-13
- *Caring for Children with Special Needs: HIV or AIDS*-NNCC-98-14
- *Caring for Children with Special Needs: Physical Differences and Impairments*-NNCC-98-15
- *Caring for Children with Special Needs: Seizure Disorders*-NNCC-98-16
- *Caring for Children with Special Needs: Speech and Language Problems*-NNCC-98-17
- *Caring for Children with Special Needs: Visual Impairments*-NNCC-98-18



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Also see the National Network for Child Care web site:

<http://www.nncc.org>

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