

PATHWAYS CENTER *for* GRIEF & LOSS

HELPING CHILDREN COPE WHEN A LOVED ONE HAS A CHRONIC ILLNESS

Chronic illness has an impact on all family members. It creates changes in many aspects of the family's functioning. All family members – including children – are affected by these changes. Children who are excluded from what is occurring can feel abandoned, lonely, angry, confused, scared. Children who are included feel more secure and supported by those around them. As difficult as it is, going through this time together can strengthen relationship. The key is to keep your approach very simple.

QUESTIONS COMMONLY ASKED BY PARENTS AND CAREGIVERS

- **How much do I tell my child? Isn't it better to just say he's sick?**

Sickness is one thing; a chronic illness is another. Since our goal in raising children is to prepare them to live independently of us, our role in this case is to help the child to adjust and cope with life's changes. Give your child a brief honest explanation of the illness changes as they occur and what you think could happen. The more he or she understands, the less fear and anxiety there will be. Your child will know to come to you with the questions rather than let them turn inward.

- **What if I'm so upset I don't want to talk about it? I might cry.**

Your child may see you tearful and sad at one point, then cooking a meal later on. This helps show that the range of feeling you all are experiencing is normal. By crying in front of or with your child, you are saying that it is okay to express feelings. This is important and positive. Your child will have permission to do the same. During such a stressful time for all family members, you may want to take "time-outs." You might ask a trusted family friend or relative to help

- **What are some ways to help my child feel included?**

Talk openly about the changes that are taking place in the family. Talk about how routines are different, and about who will be doing what. Encourage a younger child to draw pictures that can be hung at the bedside, to pick flowers for the loved one or carry a mealtime tray. Try to provide a few suggestions so the child can make the choice about how they want to help. Know that there may be times he or she may not want to be a part of any loved one's care. Let the child know that it's okay to feel this way too sometimes. Find time to check in with your child, perhaps when arriving home from school, traveling in the car, or at bedtime each night. Let him or her know you want and are available to listen to their perspective on all that is happening. Books can provide a helpful way to "bridge the gap" between adult and child.

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It has been found that families who found a way to simply be together were the families who coped best. Being together and comfortable with each other is the first step towards talking about feelings. Playing games as a family or working on a puzzle together can provide a feeling of control at a time when other parts of life may feel out of control. Don't ask children if they want to participate. Instead, set up the game or puzzle and invite them to do it with you.

Whatever the feelings that are expressed, your child needs to be reassured that it is okay to feel that way. Emphasize you are there for support through this time. Look for all the many ways you can do this and do it often. If your child is older, treat him or her in an adult-like manner. Include your child in some of the decision making that is taking place. Encourage your teen to take on any roles that feel comfortable such as light meal preparation or in-house upkeep. At the same time encourage some previously "normal" activities such as sports, hobbies, or lessons.

For additional information for children about specific illnesses, you can contact the following national organizations. If the disease you are dealing with is not listed, ask your physician for the address.

American Heart Association Inc.
205 East 42nd Street
New York, NY 10017
(212) 661-5335

American Diabetes Association
1600 Duke Street
Alexandria, VA 222314
1-800-232-3472

Alzheimer's Disease & Related Disorders Assoc, Inc.
360 North Michigan Avenue
Chicago, IL 60601

American Cancer Society
777 Third Avenue
New York, NY 10036

American Lung Association
1740 Broadway
New York, NY 10019
(212) 477-8700

The Arthritis Foundation
115 East 18th Street
New York, NY 10003
(212) 477-8700

Assoc. For Care For Children's Health
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814

The National Cancer Foundation, Inc.
One Park Avenue
New York, NY 10016
(212) 221-3300

Lupus Foundation of America, Inc.
4 Research Place, Suite 180
Rockville, MD 20785

Multiple Sclerosis National Society
205 East 42nd Street
New York, NY 10018
(212) 986-3240

National Hospice Organization
1901 North Fort Myer Drive, Suite 902
Arlington, VA 22209
(703) 243-5900

National Kidney Organization
2 Park Avenue
New York, NY 10016
(212) 889-2210

Stroke Foundation, Inc.
898 Park Avenue
New York, NY 10021
(212) 734-3461

