"Having a child with a serious illness can be extremely stressful for a family. As caregivers, one important lesson we learn is that it is OK to ‘take care of you.’ Making time for yourself strengthens your ability to care for your family during this stressful time. You are not alone in this journey; there are many people who are able to support you and your family every step of the way."

— Mother of a child treated at CHOP

Introduction
When your child receives a serious medical diagnosis, it can be overwhelming. There is so much to learn about the disease or condition and treatment options. At first the focus is — necessarily — on helping your child. Over the course of inpatient stays at The Children's Hospital of Philadelphia and rounds of outpatient treatments, many parents and caregivers have found they can better help and support their children if they give themselves permission to take care of themselves, too.

Research has shown there is a close relationship between caregiver distress and how a child adjusts to the diagnosis and the child’s quality of life after treatment ends. That means if you aren’t doing well, your child may have more trouble. While finding time to take care of yourself is not always easy, the following pages offer ideas and resources that can help.
A Caregiver’s Bill of Rights

I have the right:

- To take care of myself. This is not an act of selfishness. It will give me the capability to take better care of my loved ones.
- To seek help from others, even though some may disagree. I recognize the limits of my own endurance and strength.
- To maintain parts of my own life that do not include the person I am caring for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for my child, and I have the right to do some things just for myself.
- To be angry, to be depressed and to express other difficult feelings in an appropriate manner.
- To set limits and expectations for my loved ones.
- To receive consideration, affection, forgiveness and acceptance for what I do.
- To take pride in what I am accomplishing and to applaud the strength it sometimes takes to meet the needs of my loved ones.
- To protect my individuality and my right to make a life for myself that will sustain me.
- To expect and demand that as new strides are made in finding resources to aid medically, physically and mentally impaired persons, similar strides will be made toward aiding and supporting caregivers.

By Jo Horne
Adapted by the CHOP oncology psychosocial team

Things YOU Can Do

- **Take care of yourself.** We know it is hard to think about yourself when your child is sick, but it really is OK to take care of you. Try to maintain regular sleep habits and stay physically active. Eating balanced meals can help you feel better and will allow you to provide better care to your child. Even short breaks during the day to laugh or take a breath can help you be more present for your child.

- **Get out of the hospital room!** Work with your child’s nurse and child life specialist to find a time when you can take a break. Great times to get away are while your child is at school, in a child life group or during physical/occupational therapy. You can even arrange to have one of CHOP’s volunteers stay with your child so you can take a break. Many families appreciate time to:

  - **Get coffee.** There is a coffee stand adjacent to the Main Food Court on the first floor of the Main Building. Starbucks and Dunkin’ Donuts are a five-minute walk from CHOP’s Main Campus. Go out the front doors of the Main Building, turn left and walk north on 34th Street to Walnut Street. Both are on the left on Walnut Street.

  - **Take a nap.** The Connelly Resource Center for Families (eighth floor, Main Building) has quiet rooms with beds and phones for families to use between 10 a.m. and 3 p.m. daily (times may vary on holidays). Feel free to stop by to use a sleep room. The center also has brochures and information on local attractions, some of which are within walking distance of CHOP.

  Connelly Resource Center for Families

Promise of Partnership: Best Practices for Family-Centered Care

CH The Children’s Hospital of Philadelphia* | Hope lives here.*
• Visit the Schlimm Center for Prayer and Reflection. Located on the first floor of the Main Hospital just off the Rotunda (near the Food Court entrance), the Schlimm Center is a place of peace where families of all faiths can pray, reflect, meditate, and find comfort.

• Sit outside in the sunshine. Kaskey Park at the University of Pennsylvania has a beautiful pond with trees and is a quick walk from the Wood Center. Exit the Wood Center onto Osler Circle and turn right. Take a left on Curie Boulevard and walk west to University Avenue. Turn right and walk north one block. Take a right onto Guardian Avenue. Kaskey Park is on the left.

• Visit food trucks or local restaurants for something different to eat. Trucks offer fresh fruit, breakfast sandwiches, tacos, vegetarian fare and a lot more. For a list of eating options in the area and reviews, visit [bit.ly/fodersphillyfood](http://bit.ly/fodersphillyfood) or [roaminghunger.com/phl](http://roaminghunger.com/phl).

• Run errands. The University of Pennsylvania Book Store (36th and Walnut) and the Drexel University Book Store (33rd and Chestnut) are Barnes & Noble stores. A large CVS is located on Walnut between 34th and 36th streets.

• Work out. Ask your social worker about a nearby gym available to inpatient CHOP families.

Connect with your friends and family members outside the Hospital. Stay in touch with those who give you support. If you don’t have time to get away from your home or the Hospital, ask if they can visit you, even for a short time. Sometimes you need to talk about things other than illness, or you might need someone from outside CHOP to listen. You can meet friends for a meal in the Food Court or a nearby restaurant to have a few minutes away with someone with whom you can laugh, cry or talk. Take advantage of video chatting to help stay connected with friends and family while you are at the Hospital.

Seek support from other caregivers. Great places to connect are:

• The Ronald McDonald Family Room (3 South, Main Building)

• The Connelly Resource Center for Families (eighth floor, Main Building). Coffee hours and continental breakfasts (on weekdays) are open to both inpatient and outpatient caregivers. Ask your nurse for the schedule.

• Inpatient Parent Support Groups. Ask your social worker about group schedules. Groups typically focus on adjusting to hospitalization, coping with the diagnosis, supporting your child, etc.

• Ask your social worker for other ideas about how to find and connect with other families that are going through similar challenges.

Let others help you. When friends and family members ask if they can help, take them up on the offer! Help cleaning your house, making dinner, grocery shopping, driving siblings to after-school activities, or picking up prescriptions can save you a lot of time and also allows those who care about you and your child to do something useful. Some families have friends bring over frozen dinners that can be eaten at home or taken to the Hospital, or give snacks for the Hospital stay. Keep a cooler outside your front door so friends can leave a meal for you even if you aren’t home at the time. Every little bit helps.

Use caution when searching the Internet. Medical information found online can be overwhelming and is not always accurate or up to date. Please share any concerning information with your child’s healthcare team to make sure what you find is accurate and applicable to your child.

Use your Care Binder. This will help you keep important information — such as test results, insurance information and contact information — organized and available when you need it.
Resources at CHOP

Schlimm Center for Prayer and Reflection
The Schlimm Center for Prayer and Reflection is located on the first floor of the Main Hospital just off the Rotunda (near the Main Food Court). Families of all faiths and denominations are welcome to visit this serene place to pray, reflect, meditate and find comfort. If you would like a visit from a member of our Spiritual Care staff, ask a staff person to page #10743.

Connelly Resource Center for Families
The Connelly Center is located on the eighth floor of the Main Building. Opened in 1997, the center was designed by families and professionals to provide support to parents, caretakers, siblings and other relatives of our patients. Inside, families will find a family and children’s library, a game and DVD lending library, a learning center, and a comfortable place to take a break.

Internet Resources

Lotsa Helping Hands: www.lotsahelpinghands.com
Lotsa Helping Hands is a volunteer coordination service for friends, family, colleagues and neighbors to assist loved ones in need. It’s a free and easy-to-use private group calendar, specifically designed for organizing helpers. Everyone can pitch in with meal delivery, rides and other tasks necessary for life to run smoothly during a crisis.

CaringBridge: www.caringbridge.org
A user-friendly site that allows parents to create a free Web page about their child and to keep a virtual diary of how they are doing. It can be updated at any time, and friends and family can access it from any Web browser.

CarePages: www.carepages.com/chop
This simple-to-use, online service helps family and friends stay in touch during a child’s hospitalization and recovery. With a CarePage, you can share news and updates about your child and also receive messages of support from friends and family on your own message board.

Today’s Caregiver: www.caregiver.com
A Web page for, about and by caregivers.

Caregiver Action Network: www.caregiveraction.org
The Caregiver Action Network serves a broad spectrum of family caregivers ranging from parents of children with special needs to families and friends of wounded soldiers; from a young couple dealing with a diagnosis of multiple sclerosis to adult children caring for parents with Alzheimer’s disease. The network can connect people to valuable resources, advice from caregiver voices, peer support and advocacy information for caregivers.

Family-centered Care at CHOP: www.chop.edu/fcc
This link takes you to CHOP’s family-centered care Web page. Under Resources for Families, you will find communication tools and tip sheets to help you communicate with your child’s healthcare providers.

“There are only four kinds of people in the world — those who have been caregivers, those who are currently caregivers, those who will be caregivers and those who will need caregivers.”

— Former First Lady Rosalynn Carter