Mended Hearts

Mended Little Hearts
A program of The Mended Hearts, Inc.

TIPS FOR CAREGIVERS

When you are caring for a loved one, whether in the hospital or at home, caring for yourself is often your last priority. However, it is important to create a balance between caring for others and yourself. You may not feel that caring for yourself is a priority, but it is imperative that you try. The best gift you can give your loved one is to also care for yourself. Below are some tips on how to deal with the stress and anxiety that accompanies caring for a patient with heart disease or a child with congenital heart disease.

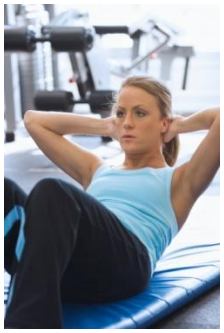
- **Ask for and accept help**
  - Acknowledging that you need help can be just as difficult as accepting it. However, helping you in both big and small ways is a great opportunity for your family and friends to feel like they are supporting you during this stressful time. Make a list of things that need to be done to keep your life running and be realistic about what you have the time and energy to accomplish. Keep the list handy and next time a friend or family member asks and let them know what they could do to help. Family and friends are often happy to help with child care, collecting your mail, mowing your grass, grocery shopping, meal planning or taking you out for a meal for a break.

- **Give yourself a break, literally and figuratively**
  - No one expects you to have all the answers or solve all of the challenges currently facing your family. Please give yourself a break! Accept that being a child, spouse, parent, sibling or family member of someone with heart disease means sometimes you will have to rely on others for information and assistance while you focus on being the patient's or your child's best advocate and caregiver. While you are at it, take a break from care giving once in a while too! It is essential to schedule time away (for parents, from the dual responsibilities of parenting and care giving) for your own mental health. Make plans for a friend, family member or health care provider to spend time with your loved one while you spend time away. Read a book, go shopping, nap – choose something that allows you to relax.

- **Connect – with your care team, your support network and other families**
  - Being the caregiver of a loved one with medical needs can be an isolating experience. It is important that you reach out and connect with people who can help you navigate the patient's or your child's health care needs and help you feel less alone on the journey. Ask your medical provider or social worker for referrals to community support groups and to put you in touch with another person or family who has experienced a similar situation. Use the internet to keep your distant family and friends updated on your loved one's condition and plan of care. Utilize the support services that your hospital offers such as social work services, child life, pastoral care or parent navigators.

- **Eat and drink regularly**
  - Living on coffee and food from a hospital cafeteria is no way to treat your body and it won't give you the energy you need to continue to be your loved one's advocate. It is important that you eat nutritiously and drink plenty of water during hospitalization. Although it is easy to lose track of time and miss important meals when you are on "hospital time," combat this by keeping snacks such as granola bars, fruit or nuts with you.

- **Exercise**
  - Whether your loved one is in the hospital or at home, regular exercise is important to both your physical and emotional well being. Try to schedule at least twenty minutes of exercise a day – even a brisk walk around the hospital counts! Studies have shown that regular exercise clears the mind, encourages better sleep and is a great stress reducer.



- **Distraction, Distraction, Distraction**
  - Keeping up with favorite hobbies, or developing a new one, is a good way to take a mental vacation. Knitting, reading, drawing, blogging are easy ways to busy your hands and quiet your mind.

- **Take care of your own health**
  - When you are caring for a loved one, your health becomes secondary. However, if you aren't healthy, meeting your loved one's needs will be more difficult. Get a yearly flu shot and make the time to see your physician regularly. If you are a parent of a child with a congenital heart defect and have recently given birth, it is important to follow your physician's recommendations regarding activity restrictions and keep your follow up appointments. Pay attention to your emotional state as well, and contact your physician or social worker if you are concerned about depression.

- **Get organized**
  - Keep all of the information you've received regarding your loved one's diagnosis safely in one place. If your hospital doesn't provide a notebook to organize medical information, purchase one yourself. A binder makes it possible to keep medication schedules, discharge instructions, clinic letters, important phone numbers and insurance information organized and portable.

- **Educate yourself**
  - Knowledge is power, so arm yourself with appropriate information about your loved one's diagnosis, medication and treatment plan. If your hospital allows, participate in medical rounds. Request family meetings for updates or to discuss care plan changes. Keep a notebook nearby and write down questions as you think of them. Ask your physician, social worker or child life specialist for referrals to trusted websites and other resources. Avoid "internet overload" by sticking to reputable websites.

- **Take back your family**
  - Don't let your loved one's diagnosis define your family. Recognize that a severe illness in the family places all members of the family under increased stress and makes it more difficult for you to support each other. This is especially true for children in the family who may have fears and anxiety that they aren't voicing. It is important that your family spend time together that is not focused on your loved one's diagnosis. Plan family game nights, special meals or attend a sporting event as a family or as a special treat for siblings of a child with heart disease.

- **Don't beat yourself up for negative feelings, but recognize when you need medical help**
  - Taking care of a loved one with heart disease and/or having a child with a congenital heart defect may cause negative feelings. At times you may feel sad, angry, scared, confused, lonely, etc. For parents of a child with a heart defect, you may even mourn the loss of the healthy child you did not have. These feelings can be completely normal, so give yourself permission to feel them and let them go. However, if you notice that any of these feelings are taking over your life—you don't want to get out of bed, you are sleeping all of the time, you want to be alone constantly, you can't stop crying, your are always angry or you feel like you just can't function, give yourself permission to get medical help as soon as possible.

Take care of the care giver!