All parents are caregivers, but parents of children with congenital heart defects have extra challenges. Mended Little Hearts (MLH) parents not only deal with the “normal” parenting issues, but they must also care for a child with life-long health issues. Many MLH children not only undergo multiple open-heart surgeries and other heart procedures, but they also can have problems with learning, motor skills development and feeding, and face physical activity restrictions. To learn more about issues unique to caring for children with congenital heart defects, we asked three parents of “heart children” to share their experiences.

Caregiving for Children with CHD: Three Parents’ Perspectives
Jennifer Kowal

Jennifer Kowal of Rochester, N.Y., had two children — Simon, age 2 ½, and Oliver, age 1 ½ — when her third child, Claire Elizabeth, was diagnosed with a congenital heart defect. “We gave Claire Elizabeth two saint names,” Jennifer said, “to give her more power to make it through everything.”

Claire Elizabeth, now 2 ½, was followed by Bridget, who’s now six months old. With four kids, all age five or under, and a husband who travels for work, Jennifer might need a few saint names and some care herself!

Claire Elizabeth has hypoplastic right heart syndrome. (Her right ventricle is only one-third the size it should be and doesn’t contribute.) She also has pulmonary and tricuspid atresia. Claire Elizabeth has had two surgeries, one at three days and another when she was 15-months old.

Cheyenne Gibbs

Cheyenne Gibbs of St. Charles, Minn., has a daughter, MaKennah, who turns 4 in May. MaKennah has DiGeorge syndrome, which includes heart defects as well as other conditions. Her defects include an interrupted aortic arch, VSD, ASD, PDA and aortic valve stenosis. MaKennah had heart surgery when she was 26 days old.

Terry and Dixie Varns

Terry Varns of Spearfish, S.D., and his wife Dixie have two boys: Steven, 17, and Tucker, 13. Tucker was diagnosed with hypoplastic left heart syndrome — his left ventricle didn’t develop — and he had other heart defects, too. He was diagnosed when he was three days old and had his first heart surgery at eight days later. He’s had four open-heart surgeries and four pacemaker surgeries.
Reaching Out

When Claire Elizabeth was diagnosed, Jennifer had countless questions, but her hospital didn’t have a support group for parents of children with heart defects. With encouragement from the chief of cardiology and other surgeons, Jennifer founded Mended Little Hearts of Rochester, N.Y. The chapter was chartered in February 2010 and, because it enjoys such strong hospital support, it already has 150 members and about 300 supporters on its email list.

The Varns family helped start a support group for children with heart defects in 2000. In 2004, they joined Mended Little Hearts. Their chapter, Mended Little Hearts–Thumpers in Rapid City, S.D., serves people within a 250-mile range.

Cheyenne learned about Mended Little Hearts through the Mayo Clinic, where MaKennah had her surgery. Cheyenne says that joining Mended Little Hearts of Southeast Minnesota in July 2008 was “the best thing I ever did.”

Feeding Issues

Every parent wants their child to eat and be healthy, but feeding a child with CHD can be stressful. A majority of children with CHD have problems with feeding, growing or both.

When babies have open-heart surgeries, their ability to learn to eat can be compromised. Some babies have to be fed through a feeding tube. Others have to see specialists for help with feeding. Cheyenne’s daughter, MaKennah, had to be fed with a tube. “Instead of feeding and bonding with my child, I had to manage a pump and watch tubes. I had to learn to put the tube in and scoop her up instead of lifting her. MaKennah didn’t just have an incision in her heart — she had one in her tummy, too.” The tube feeding went on for nearly four years; it didn’t end until just before April of this year.

In addition to feeding issues, many CHD children have trouble gaining weight and must go on special high-calorie diets.

Physical Activity

Some children with congenital heart defects tire easily and have issues with physical activity. This may limit the activities they can participate in and make them feel “different.” Claire Elizabeth tires more easily so Jennifer seeks a healthy balance for her and her siblings. “Our family works like a team, so when Claire Elizabeth needs a break, all the kids take a break.”

continued on page 18
A Little Girl’s Bag Dreams

It all started with a birthday party. Four-year-old Katie Shadoan’s dad teased her about getting more toys when she had so many, planting the seed for her to think about others. And that’s just what the little girl from Toledo, Ohio, did.

Because her mom, Shawna, had had a triple bypass at age 33 and was a Mended Hearts member, Katie thought about collecting items for kids in Mended Little Hearts. After attending a meeting and learning about a boy named Alex who’d had multiple surgeries, her heart was touched – and her mind was made up.

“I want to help,” Katie, now 9, told Shawna.

The 23 kids who were invited to her birthday party were asked to bring specific items to include in the care bags. Some brought crayons, others had coloring books, games or puzzles, popcorn, candy — and the bags were a big success.

Over the years, there were more birthday parties and more invitations about care bag items. But collecting for care bags grew beyond birthdays. As Katie’s reputation grew, church members began collecting items, assembling bags became a year-round endeavor and friends helped.

Katie used to make about 80 to 100 bags a year to help kids with heart defects in three area hospitals. Now 225 bags have been ordered.

The Mended Hearts and Mended Little Hearts chapters in Toledo have closed but Katie is undaunted. Kids with heart defects need her, so her work continues.
When you are caring for your child, 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 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, 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 or 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 your child’s parent means sometimes you will have to rely on others for information and assistance while you focus on being your child’s best advocate and caregiver. While you are at it, take a break from caregiving once in a while, too! It is essential to schedule time away from the dual responsibilities of parenting and caregiving for your own mental health. Make plans for a friend, family member or health care provider to spend time with your child 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 child with medical needs can be an isolating experience. It is important that you reach out and connect with people who can help you navigate 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 family who has experienced a similar situation. Use the internet to keep your distant family and friends updated on your child’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 child’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 child 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 and blogging are easy ways to busy your hands and quiet your mind.

Take care of your own health
When you are caring for your child, your health becomes secondary. However, if you aren’t healthy, meeting your child’s needs will be more difficult. Get a yearly flu shot and make the time to see your physician regularly. If you have recently given birth, it is important to follow your physician’s recommendations regarding activity restrictions and to 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 child’s diagnosis safely in one place. If your hospital doesn’t provide a notebook to organize your child’s 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 child’s diagnosis, medication and treatment plan. If your hospital allows, participate in medical rounds on your child. 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 child’s diagnosis define your family. Recognize that your child’s illness 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 other children in the family who may have fears and anxieties that they aren’t voicing. It is important that your family spends time together that is not focused on your child’s diagnosis. Plan family game nights, special meals or attend a sporting event as a family or as a special treat for siblings.

Thanks to Heather Langlois and the MLH Medical Advisory Board for their excellent work on these tips.
Monitoring has become easier as Claire Elizabeth has grown older, because she self-regulates and goes to bed when she gets tired.

Fatigue can still be an issue for Tucker, too. His hometown of Spearfish is about 3600 feet above sea level but his grandparents lived at a much higher elevation. Because of that, the Varns always held family gatherings at their house.

As Tucker grew older and stronger, he could go to higher elevations, but his parents monitored his oxygen levels and kept oxygen on hand. In recent years the family has enjoyed skiing at 7000 feet at two nearby resorts and visiting his grandparents. Tucker tires after about two hours but regular checkups have not shown any effect on his heart.

Many children with CHD aren’t allowed by their doctors to play contact sports. That’s true for Tucker, so he’s an assistant manager for the football, basketball and baseball teams. Some children just won’t have the energy to play sports like soccer and basketball that require a lot of running. Not allowing a child to play some sports can be difficult for their parents.

School

Often, sending a child with CHD to preschool or school, or even having siblings in school, can pose challenges for parents. Again, avoiding major illnesses is a concern. Educating school personnel about CHD and a child’s limitations can also be difficult.

In the fall, Claire Elizabeth will go to preschool. She has trouble with “anything respiratory,” so Jennifer has asked teachers and others to tell her whenever a child is seriously ill. If someone (even a child in one of Claire Elizabeth’s sibling’s classes) has a serious respiratory disease (flu, pneumonia, croup, severe cough), she’s told, and Jennifer keeps her kids home to protect Claire Elizabeth. Jennifer also put up flyers at school and encourages extra hand washing.

Calling a meeting to get everyone together who will be working with a CHD child is helpful, so that they all understand the condition or defect. The Varns created a list of limitations and special needs and took it to Tucker’s schools and discussed them with staff; written materials about a child’s condition can be good. (Jennifer did the same.) Sometimes educators can worry about teaching a child with CHD, so letting them know what is or isn’t normal for a child can help. For example, when some CHD children are running or cold, they will turn blue. This doesn’t necessarily mean the child needs medical attention unless other signs of distress exist. Educators need enough information to understand what’s happening and make good decisions.

Siblings and Other Family Members

Caregiving for a child with CHD often means helping family members and others see and understand the child’s needs.

After Claire Elizabeth had her first surgery, Jennifer wanted her oldest son to see his new sister. Claire Elizabeth’s chest was open; she had tubes and a nasal breathing tube bandaged to her nose. “Boo boo on her nose,” was all he saw or said. That’s when Jennifer realized how much different a child’s perception can be from an adult’s.

Today Simon knows his sister has a heart problem and must take meds. “Simon’s growth in understanding has been amazing,” Jennifer says. “Sometimes he asks, ‘Will she die?’” and she answers truthfully, “Possibly, but today is a good day.”

The Varns were less able to prepare Steven for Tucker’s trials because twice Tucker had heart failure and was rushed to Rapid City and then life-flighted to Omaha, Neb., more than 500 miles away. Steven stayed with his grandparents for two weeks at a time during Tucker’s hospital stays, which averaged 30 days. (His mom would stay with him the rest of the time so he
was never alone.) Steven was always “an easy child,” Terry said, and took it in stride. “We tried to keep his life as normal as we could,” Terry said. “We’d call him at night and tell him about his brother. He knew Tucker was sick.”

For Cheyenne, a single mom with one child, teaching other children wasn’t an issue. But she had a large network of brothers, sisters and friends who helped her. “Everything I learned, I had to teach others,” she said.

Financial and Emotional Toll

For a child with CHD, surgical costs can be astronomical, even with health insurance. The costs of meds and appointments add up in a hurry, too. And caregiving has an emotional cost as well.

Many children with CHD are on multiple medications, some taken several times a day. It’s not unusual for children who’ve had open-heart surgery to come home on six or more different medications. Besides being expensive, this can be confusing for parents and raise concerns about side-effects and long-term health risks.

Many CHD children, like MaKennah and Claire Elizabeth, have other health issues, too. Jennifer takes Claire Elizabeth to see five specialists.

All parents have hopes, fears and yearnings for their children, but these desires can come into greater focus for parents of a child with CHD. Tucker had development delays and didn’t walk until he was two. He also had delayed speech and today is a grade behind others his age. MaKennah also has developmental delays. In fact, she’s considered disabled by Social Security.

Claire Elizabeth will need more surgeries, the next when she’s five years old. Finding the best time for surgery can take patience, which is another aspect of care. Claire Elizabeth’s second surgery was delayed so she could get stronger, but then it was postponed five times. It was almost too long; Jennifer kept wondering, “Is my daughter going to die in my arms?”

Summering Up

Ultimately, caregiving for a child with CHD takes flexibility. It means constantly learning, solving problems and tuning in to another person without losing yourself. Cheyenne stayed home with MaKennah for 1½ years before returning to work as a part-time hairstylist. “If you never get out of the house, you can forget who you are,” she says. Taking care of yourself is also important.

There are unmistakable rewards, too. “We take every day as it comes and try to make the best of it,” Jennifer says. “Claire Elizabeth has taught us so much about courage, strength, patience and resilience. Sometimes just watching her brings tears of joy. I am so blessed to have been given a heart child.”