



Part 3: In the Hospital



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Part 3: In the Hospital

Packing List for the Hospital Stay

As a parent or primary caregiver, you'll want to be as comfortable as possible during your baby's hospital stay. Having some of the comforts of home can make a big difference for both you and your son or daughter. Be sure to check with your hospital to learn what you can and cannot bring. Here are some hospital packing suggestions from other Mended *Little* Hearts families:

For parents and primary caregivers:

- Books, magazines, crossword puzzles, Sudoku
- Electronics: laptop, phone, camera, iPad, etc.
- Charging cords for your electronics
- Medications and vitamins, especially prescription medications
- Tissues
- Eye drops (hospital rooms can get dry)
- Lip balm
- Hand lotion
- Re-usable water bottle
- Snacks (with protein, if possible)
- Sweatshirt/sweater (for chilly hospital rooms)
- Slippers/flip-flops
- Comfortable clothes
- Your own pillow
- Toiletries
- Quarters for vending and laundry machines
- Pad of paper for taking notes

For your baby:

- Accessories: socks, hats, hair bows
- Snap-up onesies or sleepers for when you can dress your child
- Large swaddle blanket
- Photos from home (to personalize the room)
- A special stuffed animal or blanket
- Sound machine for soothing noise/music
- Infant car seat for the trip home
- Collapsible stroller



Things You May Be Feeling in the Hospital

You'll experience many emotions while your child is in the hospital, and those may change many times a day, depending upon how your son or daughter is doing. Here are some of the emotions you may experience:

(See the [Things You May Be Feeling](#) section of the Mended *Little HeartGuide* for more information on things you may feel after a CHD diagnosis.)

Uncertainty

Parents and caregivers have to constantly adjust to news delivered by medical professionals, so your feelings may go from devastation to hope to intense gratitude (or vice versa) in a short amount of time. Your child may recover in a different pattern than expected. They may, for example, do really well for one or two days then worsen on the third day and then start doing well again.. It can seem like taking two steps forward and one step back. Some parents compare the experience of having a child in the hospital to a roller coaster ride — but without the fun.

Disconnectedness

If you are in the hospital for a few weeks or longer, you may feel very disconnected from events outside of the hospital. You may find it hard to believe that life is going on as usual for many people. This creates feelings of disconnection and sometimes anger. You may feel discouraged, as though you'll never get to leave the hospital. You will.

Confusion

For many reasons, you may also feel confused. You may Google unfamiliar medical jargon, only to end up more perplexed by what you find. Consent forms for procedures are long and scary and may make you feel as if you are always signing something that agrees to the



risk of death or severe disability in order for your child to get the care that he or she needs. When shifts change, well-meaning nurses may give information in a different way than the previous nurse, which can add to your confusion and make it hard for you to understand what is actually happening with your child. Reports may even seem to conflict with one another. Finding your way around the hospital and locating resources can also be challenging.

(See [Tips for Managing a Hospital Stay](#) in this Guide.)

Surprise

Some parents and caregivers put themselves into automatic pilot mode during a hospital stay, not allowing themselves to feel anything during that stressful time. The problem is that these suppressed feelings catch up with them once they have returned home, which can be unexpected and alarming.

Fear

Bringing a child home from the hospital is a relief, but is also a frightening experience because you are no longer surrounded by doctors and nurses who can support you in caring for your child. You may feel discouraged when you continue to feel sad and angry, or just sad, instead of happy that you made it through the hospital stay.

Tips for Emotional Wellness During a Hospital Stay

Your child's stay in the hospital will not be an easy experience, but there are things you can do to minimize the inevitable stress. Here are a few important things to remember:

Take care of yourself.

If you are going to be the best possible caregiver for your child during a hospital stay, you will need to take care of yourself. Your child needs you to be able to make the best decisions about his or her care and you can't do that if you are neglecting your own health and well-being. When you feel overwhelmed, sad or angry, find ways to take care of yourself and get a break if you need one. The [Taking Care of Yourself](#) section of this Mended *Little Heart*Guide will give you tips on how to do this.

Take care of your other children.

The hospital stay can be a frightening time for your sick child's siblings as well. Let them know when hospitalizations are coming up and help them prepare. Here are a few tips:

- Let them know who will care for them and when they will see you.
- Get help from social workers and child life specialists to give them age-appropriate information about their brother or sister's surgeries and/or procedures.
- Read them books to help explain what will happen in the hospital. There are some good children's books about hospital visits that you might find helpful.

Do Something Special



PLAY VIDEO

Supporting Siblings While Your Child Is in the Hospital

- Make sure that their caregivers and teachers know what is going on and that they might need to expect unusual emotions and behaviors.
- Try to keep some aspects of siblings' lives routine to reduce their anxiety.
- Involve brothers and sisters in the sick child's care by encouraging them to do things such as making homemade cards to hang in the hospital room. Honor their important role in helping the family get through this hard time.
- Do something special with your other children. Even a few minutes of your time will go a long way. If you will be away from them for a long period, schedule some special time when you return.

Talk to the hospital's social worker about your feelings.

He or she may have information and resources that can help you manage the emotions that come with being in the hospital.



Connect with others who have been in the hospital with a child.

Talk with people who have been through similar experiences. This will help you express your feelings and concerns, ask questions and better understand some of the emotions you are experiencing. Ask the social worker or your child's medical team what support resources are available at your hospital or in your area.

Ask questions until you understand.

Don't ever think that a question is stupid. Keep asking until you truly understand the answer. Doctors and nurses would rather have you ask questions than not understand what is happening. Record questions and answers using the **Question and Answer** form in this Mended *Little Heart* Guide.

Ask for a conference if you feel very confused about your child's status.

If you believe you are getting conflicting opinions and reports, you can ask for a conference of the medical professionals who are treating your child to get information from all of them at once. This will help you get a unified opinion about how your child is doing and what the plan is for him or her.

Don't be afraid to ask for a hospital tour, even if you have already had one.

Understanding where everything is in the hospital can help you feel much less lost and confused. There may be facilities for you to do laundry, get a snack, use the computer and even just relax.

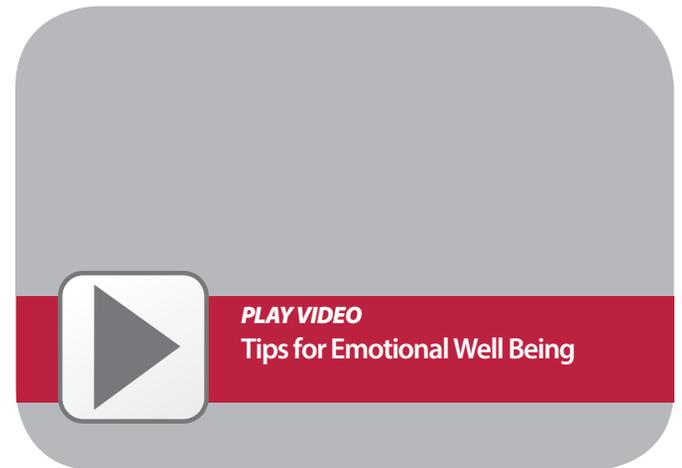
Tips from Parents for Managing a Hospital Stay

Parents who've been through the experience of having a baby or child who needed heart surgery answered this question: **"What is the one thing you wish you had known when you were in the hospital with your child that would have made your stay easier?"** Here is their advice to you:

Take Care of Yourself

In addition to the information on [Taking Care of Yourself](#) in this Mended *Little Heart* Guide, there are things you need to know specific to a hospital stay. It can be difficult to take care of yourself while your child is in the hospital, but it's important for your well-being. You will be a better caregiver for your child if you take care of yourself.

- **Take a break.** You need to get out of the hospital room, even for five or ten minutes at a time to give yourself a little time away from all of the stress. Go outside if you can and just breathe. If someone comes into the room and asks what they can do, have them stay and/or play with your child so you can get out for a little while. Don't spend your break time getting things done or working — really take a break. Get a snack and just sit and enjoy it.
- **Get sleep.** Being in the hospital, especially if you've just had a baby, is exhausting. Find a place where you can get some sleep. Hospitals sometimes have parent sleeping rooms where you can rest. You may have to sign up for the room, so be sure to find out.
- **It's okay to cry.** Sometimes parents and caregivers feel embarrassed about crying in front of medical professionals or others. It's okay to cry and release some emotions. It's normal to be sad and scared, and crying is a normal response to these feelings. In



fact, caregivers expect parents to feel and respond in this way. Be sure to keep tissues with you.

- **Stay warm.** It's often cold and dry in the hospital, so bring a sweater and slippers to keep warm. You may want to bring hand lotion and lip balm as well to prevent dry skin.
- **Eat regular meals with fruits and vegetables.** Healthy meals are especially important if you just gave birth. Breastfeeding moms are often able to get a meal from the hospital, so be sure to ask. Eating a well-balanced diet will make you feel better and less exhausted. Ask your hospital's social worker if they offer any discounts for patient families.
- **Connect with other parents or find a support group.** Most parents wish they had had someone to talk to who had been through heart surgery with a child. There is truly nothing like it, and connecting with other parents or caregivers can help ease the fear. Again, a social worker at your hospital should be able to help connect you with these types of resources both inside and outside the hospital.
- **Remember: This, too, shall pass.** It will not seem like it at times, but you will make it through this. Don't be afraid to ask for counseling or help. Hospital life is very challenging, but you won't be there forever.

Get Involved with Your Child

Be hands-on with your baby or child and his or her care as much as possible. Don't be afraid to ask nurses to teach you to take care of your child. It can be difficult to bond with a new baby who has just had heart surgery or is sick, but being hands-on in his or her care can help. Here are a few ways to do this:

- If you'd like to breastfeed your child, ask if the hospital has a lactation consultant. Also, find out what the arrangements the hospital can make to store breast milk. If your baby is bottle fed, ask if you can feed your baby.
- Get involved in your newborn's care. Ask to help change your baby's diapers and to bathe and dress him or her. The more comfortable you get with caring for your child in the hospital, the more in control and confident you will feel when you get home.
- Ask to hold your baby. Many parents and caregivers are afraid to ask to hold their baby, but it's important that you do so when you can. Nurses can often come up with creative ways for you to hold your baby, even with tubes and wires attached.
- Bring clothes for your baby or child and dress him or her once it's okay to do so, but be sure it is clothing you don't mind getting stains on. Try to avoid clothing with zippers or Velcro. Clothes with snaps or buttons are better because wires and tubes can go through the holes.



Tips for Improving Life in the Hospital

- Ask one of the nurses or doctors treating your child to take you on a tour of the unit where your child is staying.

- Ask if alarms can be silenced in your hospital room. Sometimes, especially with babies who are **cyanotic**, alarms will go off frequently. Some of these alarms can be silenced in the room but will continue to alert staff at the nursing station.
- Unless your baby or child needs certain procedures or medications at set times, you can ask that no one wake up your child. Sleep is important for your child's recovery.
- Many parents and caregivers are concerned about their child getting IVs. It's very hard for parents to watch their child get stuck with a needle over and over again for an IV. Ask the staff to send someone who has a lot of experience drawing blood or starting IVs in children. You can also ask that IVs or blood draws not be done in your child's bed. The bed should feel like a safe place for your child as much as possible.
- Be prepared for differences between the amount of care your child receives in the ICU/NICU/PICU/CICU versus the step-down unit. Many medical professionals are present in the ICU around the clock. In comparison, you may feel abandoned when your child is moved to the step-down unit because, suddenly, your baby or child is alone much of the time, and nursing care is less frequent. This is a good sign because it means your child is well enough to be in the step-down unit, but many parents and caregivers report feeling terrified about this. Before moving to the step-down unit, ask a nurse to describe the differences in the level of care so you are well prepared.
- Use websites or blogs to keep family and friends informed about your child. There are several ways to do this. Some people use [Care Pages](#) or [CaringBridge](#) sites.



PLAY VIDEO

Tips for Managing Hospital Life

Others like to create closed, or private, pages or groups on Facebook and invite family and friends to view their status updates. These are all good options to update many people at once and avoid the hassle of making multiple phone calls or sending separate emails. If you have a close friend or relative with you, that person can post for you when you're unable to.

Plans for Your Child's Feeding, Clinginess, Pain Management and Emotions

Each baby or child will have a different experience in the hospital, but there are some things to know that can help parents or caregivers manage a hospital stay.

- Feeding your baby or child in the hospital can be challenging. For breastfeeding or bottle feeding, see the sections on [Nutrition](#) in this Mended *Little Heart* Guide. Some babies or children will not be able to eat for a period of time and will get nutrients through an IV. This can be scary for parents and caregivers, but know that your child is getting nutrition. Other children will need a feeding tube so they can get the nutrition they need. Babies with a feeding tube can still be breastfed and/or bottle fed, but sometimes they need extra calories they can get through a feeding tube.

Older children may refuse to eat or change their food preferences during a hospital stay. This is normal behavior. Don't force your child to eat while in the hospital. Most children will eat when they get hungry enough.

- Some children get clingy in the hospital and want you to stay at their bedside around the clock. Find ways to entertain your child without having to be bedside 24/7, and make a plan so you can take a break. Child Life Specialists and volunteers can play with your sick child and his or her siblings while you step away. Many pediatric hospitals also have playrooms with age-appropriate activities, games and toys for patients and their siblings. Ask if your hospital has a Child Life department or volunteer group.
- Bring familiar toys or stuffed animals that your child loves, but keep close track of them so they don't get lost or dirty. Also, you may want to bring items to entertain older children, including a few surprises that are just for the hospital.
- Have a plan for managing your child's pain. Make sure you understand what can be done to keep your child more comfortable. It's very hard for parents and caregivers to see their child suffering, and understanding pain management will help you feel like things are more in control.
- Parents and caregivers worry that their children will have emotional distress from their hospital stay. Keep in mind that although parents and caregivers may remember every detail of the hospital stay, babies and very young children do not. You may see your child's behavior change for a little while after their hospital stay, but this often doesn't last. In fact, some kids even remember positive things about their stay — like riding in the wagon or playing in the playroom — and they may want to go back. However, older children are likely to remember more details about the hospital stay. Find

resources to help them deal with the emotions they are feeling, such as being scared. Often these emotions will improve with time.

- Don't forget about your own emotional health. Your social worker should be able to put you in touch with a counselor if you need one.



Advocating for Your Child

Most parents or caregivers who've a child in the hospital will tell you to remember that YOU are the best advocate for your child. Don't be afraid to speak up if you feel something is not right or if you have ANY questions. You will not offend your child's medical caregivers. You can also ask for a child/patient advocate if you need help.

Parents and caregivers should trust their instincts when they feel like something is wrong and should not be afraid to speak up. Most of the time, things are under control and will go as planned, even if it may not seem that way to parents and caregivers. Most of the care our children receive while in the hospital is very good, but medical professionals are human and mistakes can occasionally happen. Also, each child is different and will react differently to medications and procedures. Unexpected complications can arise. If you see something that concerns you, talk about it with a nurse or doctor so that they can address it.

Hospital Services

Ask the hospital social worker to see if your hospital has these services for you and your child:

- Someone to call about any concerns:

Contact Info _____

- Lactation consultant:

Contact Info _____

- Counseling services:

Contact Info _____

- Chaplain or Rabbi:

Contact Info _____

- Food discounts

- Snacks for parents and families

- Meals for breastfeeding mothers

- Showers

- Laundry facilities

- Sleeping rooms for parents

- Parking discounts

- Computers for parents and families

- Rooms for pumping breast milk

- Music therapy

- Playroom/toys

- Activities for siblings

- Katie Beckett and/or supplemental insurance

- Nearby grocery stores



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Financial Considerations During the Hospital Stay

You may be wondering, "Why would I want to think about financial considerations now? I am focused on my child in the hospital. I'll worry about that later. Financial information will just give me more stress than I already have." That is a valid point, and you do need to focus on your son or daughter, but many of us who have been through a hospitalization with our child wish that we had known some of this information earlier. It could have actually reduced stress and saved us some money too.

Regardless of their socio-economic status, families of children with CHD are financially impacted when their child requires surgeries or other medical interventions. They are not only faced with medical costs but also normal financial obligations, such as mortgage payments, household expenses and childcare for their other children. Many have to make lifestyle changes such as changing or quitting a job and reducing expenses. This impacts the entire family.

Although costs involved in having a child with CHD are often unpredictable, planning for these expenses as early as possible can help your family stay financially healthy throughout your child's hospital stay and CHD treatment.

Obviously, having a child in the hospital incurs medical costs, but many people don't realize that there are other costs involved as well. Understanding what these additional expenses are and becoming familiar with the resources available to you can help. Here are some tips for reducing and managing the cost of a hospital stay:

Gas and Parking

Gas and parking costs can add up if you are driving to and from the hospital regularly. If your child will be in the hospital for an extended period, you may want to consider public transit or carpool options. Your hospital may also have rooms where you can stay from time to time to reduce the amount of driving you'll need to do. If you travel to another city or state for your child's hospital stay and are staying near the hospital, there may be shuttles or other forms of transportation that are free or less expensive than gas and parking. There is often a parking discount available for parents and family members of hospitalized children. Ask your hospital social worker about this as soon as possible.

Lodging

If you are traveling to another city or state for your child's surgery, you'll likely need to pay for accommodation. Extended family members who are traveling to be with you during this time might also need a place to stay. Here are a few options that can save you money:

- **Ronald McDonald Houses:** In many cities, Ronald McDonald Houses, hospitality houses or other facilities are available for the immediate family of children in the hospital if the family lives more than a certain distance away (typically 30 to 50 miles). Ask your hospital social worker about this as soon as you find out that you will be in another city for your child's hospital stay. In many cases, you will need to let them know that you are coming ahead of time to get your name on a list for a room. The cost

of this lodging, if any, is usually low (around \$15 a night) and many Ronald McDonald Houses offer a shuttle to the hospital to save you from paying for gas and parking.

- **Hospital sleeping rooms:** Some hospitals have sleeping rooms for parents, but they are often on a first-come, first-serve basis and not ideal for long stays. They may, however, be a good short-term solution for parents who need a place to sleep immediately after their child's surgery or procedure. Siblings of a child in the hospital usually cannot use the hospital sleeping rooms and will need another place to stay.
- **Nearby hotels:** Sometimes nearby hotels offer discounts to families of children in the hospital. Ask hotels to see if they offer any type of discount for families and if they need any documentation showing that your child is in the hospital. If you have friends or family members with hotel rewards points, consider asking them if they would donate them to you to help you reduce lodging costs. Many people are very willing to share these reward points.

Food

Until you stay in the hospital for a while, you don't realize how expensive hospital food can get — especially during long stays. There are some ways to save money on food though. Many hospitals give discounts (usually 10 percent) to parents of children who are in the hospital for treatment. Some hospitals also have hospitality rooms or other areas where there may be food for families. Find out if there are days and times when food is available at your hospital. Ronald McDonald Houses and hospitality houses often prepare dinners for families staying there and put leftovers in the refrigerator for families to eat when they get back from visiting at the hospital. Occasionally,

hospitals have funds to help families with food costs while their child is hospitalized. Your hospital social worker will know if there are any programs like that available to you. Breastfeeding moms are eligible for a meal in some hospitals; ask whether this is an option in your hospital (even if you are pumping).



Medical Bills and Insurance Benefits

Families incur many medical costs when their child is in the hospital. Start talking to your insurance company as soon as possible. (See the [Navigating Insurance](#) section of this Guide to learn more.) We know how hard it is to think about insurance while your child is sick and in need of surgery or other procedures, but a call to your insurance company can help save money and reduce stress later.

Bills will begin to show up very quickly after your child receives services, sometimes even arriving before you get home from the hospital. Always review these bills carefully. Sometimes, there are mistakes that you can have corrected to reduce your costs. For example, if insurance companies see that a child has had a procedure (such as an x-ray) twice in one day, they may deny coverage of the second procedure because they think that it is a duplicate charge from the hospital when it is not.



Read the Explanation of Benefits information you received from your insurance company to make sure that your coverage is correct and that valid procedures are not being denied. Sometimes, procedures and treatments get coded wrong and they are either denied or end up costing you much more than they should. If you have ANY questions, ask your insurance company. These real-life scenarios have saved families thousands of dollars.

Knowing your insurance deductible (the limit on your out-of-pocket costs) will help you feel less stressed when bills start coming in because you will know that you can only owe up to that amount — even if it is a high amount. Your insurance company can assign you a case manager to help you manage your coverage. Often, you will get bills from different practices (cardiology, radiology, anesthesiology, etc.) within one hospital, which can be very confusing. Get help with this right away so that you understand all of the charges.

If possible, make sure everyone treating your child is an in-network provider. If your child needs to be seen by an out-of-network provider, ask your insurance company what you need to do. Talk to the hospital staff and your insurance company to be sure you understand your financial responsibilities.

Prescriptions

Another medical expense is the cost of prescriptions for your child. Make sure you know which medications are covered and what your costs are. Some medications are very expensive, and you need to know this up front. Most pharmaceutical companies offer assistance to people who can't afford medications, so ask your pharmacist or go online to see if help is available to you.

Other Medical Costs

Formula costs, monitor costs and other products your child may need are not covered by insurance. Ask your

hospital social worker to recommend resources that can help you reduce or cover these costs. Some formula companies, for example, may have programs to help you pay for special formulas for your child. Your state's Department of Health may also have information about options to help cover these costs. You may qualify for the Women, Infant and Children (WIC) program that will help cover infant formula cost. For more information, go to www.fns.usda.gov/wic/women-infants-and-children-wic.

Waivers

Waiver programs may be available to you, even if you are above the income level required to receive Social Security benefits. Some programs are provided for medically fragile children, regardless of income level. Contact your Department of Social Services or Department of Health and Human Services to find out which waivers are available for your family.

Expenses at Home

While you are at the hospital with your child, it feels like your whole world has changed. It's hard to think about life as usual continuing outside the hospital walls, but it does. Unfortunately, your mortgage company, credit card companies and utility providers do not stop billing during this difficult time. Here are a few things that may help:

- Make a list of bills that need to be paid and when they are due. If possible, set up automatic bill pay.
- If you traveled unexpectedly for your child's surgery, you probably did not arrange to have your mail checked. Ask a neighbor, friend or someone from your church to check your mail for you and to forward anything you may need during your family's hospital stay.



- If you explain your situation, some companies, such as mortgage companies, will allow you to delay payment for one month as long as you pay it the following month. It may be worth making a call to find out. If you do get late charges, call the company and explain why payment was late. Sometimes these charges will be removed.
- Your yard and house may need care if you are away for an extended period of time. Rather than paying landscapers or a housesitter, ask a friend, neighbor or family member if they would be willing to cut the grass and check on your house.
- Don't forget your pets! Ask a trusted friend or family member if they can keep and care for your companion animals while you are away.
- Be sure to keep up with childcare payments for your other children. Talk to your childcare provider if you will be unable to make payments on time, or make arrangements if they will be with your family at the hospital.

Transitioning From Hospital to Home

After the much-anticipated birth of a child with CHD, the reality of bringing him or her home can be both exciting and terrifying. While your child was in the hospital, doctors and nurses were his or her primary caregivers. Once you've returned home, you are faced with taking over care, which can be very scary. Here are some things you can do to help you feel more at ease:

Educate yourself on your child's heart defect.

A diagnosis of CHD should come with an honorary diploma for parents who, in a matter of days, go from blissfully expecting to incredibly well-informed about an unfamiliar medical condition. If your child was diagnosed before birth, you may have had some time to prepare yourself and absorb the information you were given. This is both a blessing and a curse. On one hand, knowing about a child's CHD before birth allows you to educate yourself and make more informed decisions about care. On the other hand, the knowledge can create a very stressful pregnancy. If your child was diagnosed after he or she was born, you may be caught in a whirlwind of information that is difficult to manage.

Before being discharged from the hospital, ask as many questions as necessary to get a solid understanding of your child's heart defect and any surgeries or procedures your son or daughter had. Research his or her heart defect using **ONLY** reliable resources. (Your child's doctor may provide you with some and Mended *Little* Hearts website at MendedLittleHearts.org has a list under the heading "[CHD Resources.](#)")



Learn everything you can from the nurses.

Nurses are the closest thing hospitals have to parents. They are at the bedside doing everything from changing diapers to providing life-saving surveillance and care. When you get home, you'll take over their role, so don't be afraid to ask them to teach you how to do something that you have seen them do. Keep in mind that nurses are people, and not all people are good teachers. You will quickly learn which nurses provide the best information and will benefit from working with them and asking questions.

Know emergency techniques.

Plan for the worst but expect the best. Start with cardio pulmonary resuscitation (CPR) training. As the parent or caregiver of a child with CHD, you'll probably be taught how to do CPR at the hospital. If you have not been taught before discharge, ask. Also, learn when you should call 911 or your child's doctor, and make an emergency plan. (You can use the [Emergency Plan](#) form in this Mended *Little* HeartGuide.)

Some areas have advance 911 systems that allow you to pre-register your child's medical conditions, preferences and needs with your area's emergency services. Call your local fire/rescue department to find out what you can do before an emergency. You may also want your child to wear medical identification with basic information about his or her condition. Many companies make medical ID products. Talk to your cardiology team about what information should be included.

Understand your equipment.

You may be discharged with no equipment other than a pacifier, or you may be sent home with an order for home health to provide you with a pulse oximeter, monitor, feeding pump or even oxygen tank. Sometimes, there is equipment or other things your child used in the hospital that will be discarded because they are opened or used, and the nurse may be willing to give them to you to take home, so be sure to ask before you leave the hospital. When home health arrives, have them teach you how to use and troubleshoot your equipment. Home health companies often provide 24-hour coverage; ask how to get in touch with them after hours.

Learn about medications.

When your child is put on medication, find out what it does, how it works, what side effects may occur, how much he or she needs and when it should be given. (You can record this information using the **Medication** form in this Mended *Little HeartGuide*.) Plan ahead and ask for prescriptions to be arranged and possibly filled before your child is discharged. Some prescriptions need to be compounded (made into liquid), and not every pharmacy is able to do this. Get help to find out which pharmacies can manage your child's medications. The pharmacist will explain how to store the medications properly; some need to be refrigerated. Pharmacists can help you double check

the instructions you received from the discharging nurse and physician.

Reach out to your primary cardiologist before discharge.

Many families who have a child with CHD will need to travel to another city for their son or daughter's surgery or procedure. If possible, before discharge, find a cardiologist close to home who can follow up with your child. If your family did not have to travel for surgery, you will still need to choose a primary cardiologist. Make sure you are comfortable with your choice and don't be afraid to try someone different. You need to feel good about the care your child is receiving.

Find a pediatrician/primary care doctor who knows how to care for children with CHD.

Your child will need a primary pediatrician to manage routine care and non-cardiac issues. In most cases, you will be required to designate a pediatrician for your child after he or she is born. When selecting, ask about their experience with children who have CHD. Use a pediatrician who understands that people living with CHD need lifelong specialized care.

Know who your contact person is.

There is often a contact person, such as a nurse practitioner, for the cardiology practice where your child had surgery. This person can help you coordinate anything from appointments to medication refills. Be sure to find out who this person is before you leave the hospital.



Understand your monitoring responsibilities.

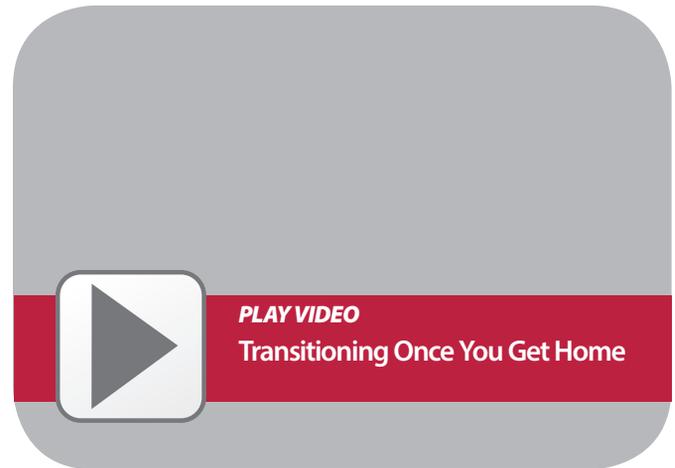
You may be asked to do monitoring at home for infants with single ventricles. A nurse or other medical professional may call your home to help you keep track of pulse oximeter and weight readings, for example. Be sure you understand your responsibilities; know what you need to monitor and how.

Don't feel trapped in your home.

Many parents and caregivers are afraid to take a baby or child with CHD outside of the house for fear that they will be exposed to germs. During cold and flu season, it might be a good idea to limit outings with your child, but in general, getting outside and interacting with others is helpful for your mental state and your child's. Use common sense: Keep hands washed, avoid people who are sick, drink plenty of fluids, eat a balanced diet and get enough sleep. These things will help your whole family stay healthy. Talk to your doctor about immunization options that may minimize risks during cold and flu season.

Get support.

It is also natural for parents and caregivers of children with CHD to feel like they can't leave their son or daughter in anyone else's care, but you need to find ways to take brief breaks and stay healthy. (See the **Taking Care of Yourself** section of this Guide.) Find someone you trust to babysit and take a 15-minute walk around your neighborhood once a day. Remember, your child would not have been discharged from the hospital if he or she was not well enough to be at home. Reach out to your family, local support group, church and your state's Department of Health and get support! There are resources available for you. Depression is not uncommon in caregivers. It needs to be addressed and treated. You are not alone.



Don't feel guilty when things don't go perfectly.

Sometimes you can do everything right and something will still go wrong. Your child may fail to grow or gain weight. He or she may have symptoms that need to be addressed. There is enough guilt involved in having a child with CHD; the last thing you need is to blame yourself for setbacks that may occur. You are doing the best that you can. If you feel like you can't manage, get help. Caring for a child with CHD right after surgery is scary. You may be afraid that your child will get seriously ill or even die. It's normal to feel that way.

Trust your instincts.

If you feel like there is something wrong with your child, don't doubt yourself. It is far better to check it out and find out that there is nothing wrong (even if you feel a little embarrassed) than to have something wrong with your child that isn't addressed. As a parent, you know your child best, so trust your instincts. Never feel bad about being persistent. No one advocates for a child as well as a parent.



Write it out.

Keeping a journal is a great way to work through the stress and emotional ups and down of having a child with CHD. It is also a great place for making notes about questions you'd like to ask your doctors and information that you learn at your appointments.

Prepare for your child's first appointments.

If you didn't do it while your son or daughter was in the hospital, make an appointment with your child's primary pediatrician and local cardiologists when you get home from the hospital. Again, be sure you have selected a pediatrician who has experience in caring for children with CHD, who understands the need for

lifelong specialized care and who is willing to work with your cardiologist. Before your child's first appointment, send any necessary medical records to the pediatrician so that he or she can better understand your child's condition and procedures. You can ask the pediatrician's office staff if they are able to get the records for you or ask the hospital to send them.

Remember, your child has CHD but will also need routine care. Go to all well-baby and well-child visits recommended by your child's doctors. Write down any questions that you have before your appointments and don't be afraid to ask for clarification. You can track your **child's appointments, medications** and **growth** using the **forms** in this Mended *Little Heart* Guide.