



# Part 4: Living With CHD



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- ▶ What About Siblings?
- ▶ Your Child's Nutritional Needs
  - ◇ Nutrition During Infancy
  - ◇ Nutrition During Childhood
  - ◇ Heart-Healthy Nutrition for Life
- ▶ Exercise for Patients With Congenital Heart Disease
- ▶ Neurodevelopmental Issues in Children With CHD
- ▶ Congenital Heart Disease: A Lifelong Journey
  - ◇ Empowering Your Child to Become a Healthy Adult
  - ◇ Transition Checklist for Parents and Primary Caregivers
- ▶ The Financial Impact of CHD on Families
- ▶ Building Positive Self Esteem in Children With CHD
- ▶ Frequently Asked Questions

# What About Siblings?

If you have other children besides your child with CHD, you may worry about how their sibling's heart condition will affect them. If their brother or sister's heart defect is severe and requires surgeries, hospitalizations or special services, they will feel an impact. The good news is that most of these kids do just as well — sometimes even better — than their peers. They may show more independence, maturity, understanding, compassion and tolerance than other children their age. Further, studies have shown that the siblings' relationships with each other tends to be more nurturing and positive than that of typical siblings.

Even though they will likely adjust well, you might still see some changes in behavior, particularly during times of stress. They need your ongoing support. Here are a few ways to provide that:

- Keep them informed with truthful, age-appropriate information about their brother or sister's health. (For age-appropriate information, please talk to a social worker or child life specialist.) Kids know when you are hiding something, which can make them even more scared. Ask if they have questions and check for misunderstandings.
- Involve siblings in their brother or sister's care. They will feel more in control if they can help in some way.
- Provide them with opportunities to talk about their worries, feelings, questions and themselves. If needed, get help from a counselor or someone who can help them open up about their concerns. Sometimes, smaller children can express feelings through art or play.
- Form connections with other families so that your children can meet other kids with CHD and their siblings.



**PLAY VIDEO**  
**What About Siblings?**

- Try to treat your children fairly and equally. Sometimes we have very high expectations of our healthier children and don't have the same expectations of our child with CHD. Rewards, punishments and expectations should be as equal as possible.
- When you can, give your healthy children some solo time and your undivided attention. Schedule one-on-one time on your calendar — even if it is just playing a game for 10 minutes.
- If you see signs of serious depression, violent behavior or excessive anger in your child, seek help immediately.

## The Toughest Question

Sometimes, particularly when a surgery is coming up, a sibling will ask if their brother or sister is going to die. This is a devastatingly painful question for a parent or caregiver to answer, particularly when the same question is going through our own minds. Answer as honestly as possible, but focus on positive aspects. You might, for example, say, "The truth is, we really don't know the answer to that. We certainly hope not. What we do know is that the doctors and nurses are going to do everything they can to make your brother or sister's heart work the best it can. They are very good at what they do and are going to do their best."

# Your Child's Nutritional Needs

Good nutrition is extremely important for growth and development, especially for babies and children with CHD. It can be tricky because a child with CHD may have trouble gaining enough weight, but you want to instill healthy eating habits to help them avoid acquired heart disease later in life. You may notice that it is hard for your child to gain weight because babies born with critical CHDs (those that require surgery or other procedures) usually need more calories to grow than other babies. This section contains information that will make it easier for you to provide your child with the nutrition he or she needs.

Your child's medical team — including cardiologist, primary care doctor and any nutritional specialists — should be your first source for information about your son or daughter's nutritional needs. Ask questions and express any concerns you have. If something isn't working, be sure to communicate that so that they can help you adjust the plan. Feeding a young child can be frustrating at the best of times, but feeding a child with CHD can be even more challenging.

## Nutrition During Infancy

Your baby's nutritional needs are highest during their first year of life. This time period is also most critical for growth and development.

### *Breastfeeding*

Breast milk is almost always the number one recommended source of nutrition, but for many reasons, you may choose not to breastfeed or may not be able to breastfeed. If your child has a CHD that requires



intervention or surgery soon after birth, for example, you may not be able to breastfeed for a period of time. It is important to follow orders about feeding so that your child can have surgery as scheduled. If you cannot breastfeed before surgery, be sure to pump your breast milk every two to three hours to develop a good milk supply. If you are in the hospital with your baby, ask a nurse or doctor if there are special rooms where you can pump. You can store this pumped milk to feed your baby later. Follow guidelines for proper breast milk storage. The [CDC's website](#) has more information. If you are in the hospital, they may have procedures for storing breast milk. Just ask.

Breastfeeding can feel frustrating or scary at first (that's normal), but with patience and persistence, many mothers have been able to breastfeed babies with CHD. If you have trouble pumping or breastfeeding your baby, or just want someone to work with you when you're getting started, find a lactation consultant to help. Most children's hospitals have one. If you are not at the hospital, your pediatrician can recommend one.

Although it may not seem like it, breastfeeding is actually less work for your baby than bottle feeding. Breast milk is easier to digest and also contains antibodies that help fight infection. If your child is having trouble gaining weight, you may need to fortify your breast milk with formula. This may be frustrating if you want to exclusively breastfeed your child, but it is important for your baby to get enough calories to grow. He or she will still get all of the benefits of breast milk, even if it is fortified.

### ***Bottle Feeding***

For some babies, it may not be possible to breastfeed exclusively or, in some cases, at all. Sometimes breastfeeding creates more stress and anxiety than mothers of babies with CHD feel they can handle. Do what works best for you and your family without feeling guilty. You will not harm your baby by giving him or her formula. Work with your child's medical team to find the right formula. Some babies need special, easier-to-digest formulas; these can be expensive, so ask about discounts or places where you can save money. In the beginning, babies usually take two to four ounces of formula at every feeding and need to be fed every two to four hours. Work with your child's medical team to set up a schedule, but understand that adjustments might be needed.

### ***Feeding Tubes***

Because of certain medical issues or because they are unable to drink enough formula or breast milk, some babies will need to be fed through a feeding tube. These are used for a short period until your child is able to feed and gain weight on his or her own. Most babies with CHD can begin eating infant cereal and puréed baby foods at the usual age of five to six months. Your child's medical team, and sometimes a home health team, will help you use a feeding tube if necessary.

## **Nutrition During Childhood**

As they grow, children with CHD may have greater nutritional needs than other children. Like any other child, it is also typical for them to become picky eaters and to experience food jags (when they like one food for a period of time then don't want it anymore). Feeding a child may be frustrating and emotional if he or she refuses to eat or becomes excessively picky. Remember that most children will eat when they are hungry. Here are a few tips to make feeding your child less of a battle:

- Offer your child three balanced meals (items from multiple food groups) and two snacks daily.
- Avoid forcing or bribing your child to finish a meal or snack.
- Always offer one food item per meal that you know your child will eat.
- Experiment with different textures and consistencies.
- Know that when your child is hungry enough, he or she will eat. Avoid becoming a short-order cook in your home.

Be sure to ask your child's cardiologist, pediatrician or nutritionist to help you create a plan for your son or daughter. If you or your child's medical team notices that your child is not gaining enough weight, that doesn't mean you are doing anything wrong. You will likely need to increase the number of calories he or she is taking in each day. Here are a few tips on how to do that:

- Add a teaspoon of canola oil when preparing your child's food.
- Add a tablespoon of dry milk powder to puréed foods or liquids.

- Avoid low-fat and fat-free items.
- In addition to fruits and vegetables, offer foods that are naturally high in calories: peanut butter, avocados, cheese, nuts/seeds, beans, meats, etc.

For more helpful information on increasing calories, see this [list of high-calorie foods](#) from Cincinnati Children's Hospital.



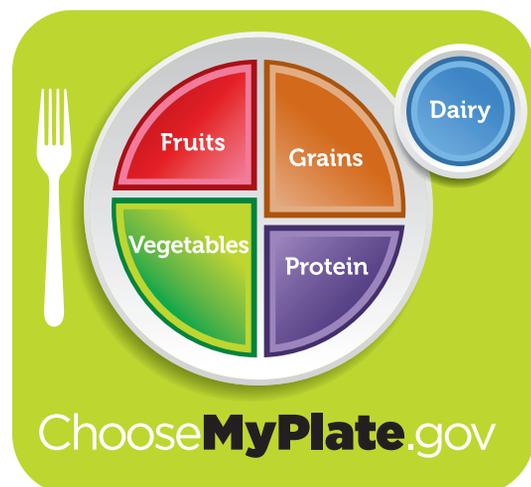
## Heart-Healthy Nutrition for Life

At the beginning of your child's life, you may have needed to increase calories so that your son or daughter would gain weight, but as he or she grows older, it is important to encourage a heart-healthy diet. A balanced diet will not only help your child avoid acquired heart disease and other conditions, it will also keep their weight at a healthy level. Pairing a nutritious diet with exercise where possible (see the section in this Mended *Little HeartGuide* on [Exercise and CHD](#)) will help children stay healthy into adulthood.

It may be necessary for your child to follow a low-sodium or fat-restricted diet at some point. It is also possible that his or her energy needs will always be higher than someone without CHD. Here are some general guidelines to follow. For more information, consult a dietitian:

- Eat foods from all food groups (vegetables, fruits, meat/protein, dairy, grains).
- Choose whole grains when possible (whole wheat bread, whole wheat pasta, brown rice, oatmeal, whole grain cereal, etc.). Avoid foods made with white flour.
- Choose lean meats (turkey, chicken, lean beef, fish).
- Use low-fat methods to cook foods (baking, broiling or grilling instead of frying).
- Limit the use of a salt shaker and limit frozen, canned and boxed foods, which are generally higher in sodium/salt.
- Choose fresh fruits over fruit juice.
- Eat a variety of non-starchy vegetables daily.

For more information about healthy eating for the whole family, visit [ChooseMyPlate.gov](#).

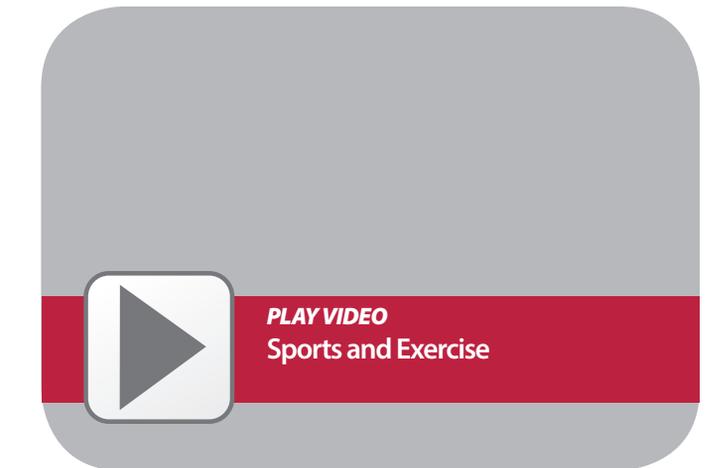


# Exercise for Patients With Congenital Heart Disease

In the past, children with CHD were often advised not to exercise to “be on the safe side,” but as more children with CHDs started surviving into adulthood, this approach changed. Preventing them from getting the health benefits of exercise, such as weight and blood pressure control, may end up doing more harm than good. Because we now expect most people with CHD to live into adulthood, we also have to consider how lack of exercise could negatively impact their cholesterol levels. In addition to its well-known cardiovascular benefits, exercise can also significantly improve a person’s sense of well-being. Preventing a child from participating in physical education classes, recreational sports or even competitive sports can have negative social and emotional effects.

Many parents wonder whether it is safe to let a child with CHD exercise. They fear that their son or daughter will push his or her heart too hard or make it beat too fast. Children also tend to get out of breath during exercise, and it can be frightening to see your child panting or trying to catch his or her breath. Despite these worries, exercise can help children with CHD stay healthy. Your child’s cardiologist will be able to advise you on your child’s needs and limitations. Although you may not want a teenager with certain heart problems to play high school football, it might be okay to let them play some other competitive sport that does not involve bodily collisions. It’s unlikely that turning your teenager into a couch potato will be good for him or her in the long run.

For certain people with CHD, the risk of some forms of exercise does outweigh the benefits. These individuals include, but are not limited to, those at high risk for dangerous heart rhythms (long QT syndrome,



hypertrophic cardiomyopathy, etc.); those at risk for tearing an enlarged or weakened blood vessel (Marfan’s syndrome, aortic aneurysms, etc.) or for bleeding (anticoagulation treatments); those with severe aortic stenosis, certain coronary artery problems, uncontrolled high blood pressure or vital medical hardware that might be damaged (pacemaker, defibrillator, etc.). Additionally, most children will need fairly significant exercise restrictions for several weeks after heart surgery but can eventually return to full activity. Anyone with CHD who has had symptoms associated with exercise should talk to their cardiologist.

Overall, there are many more questions than answers when it comes to this topic, and the risk of exercise is different for every patient. That’s why it is important to have a discussion with your child’s cardiology team to determine what kinds of exercise are appropriate. Make sure the discussion focuses on what your child can and should do to stay healthy rather than what he or she cannot do. Focusing on the risks of exercise while ignoring the benefits may shortchange your child in the long run.

For more information on exercise for CHD patients visit [CardioSmart.org](http://CardioSmart.org) and [Heart.org](http://Heart.org)’s online resources.

# Neurodevelopmental Issues in Children With CHD

The American Heart Association recently published a **statement** indicating that children with more severe congenital heart defects are at higher risk for neurodevelopmental issues. In simple terms, this means that kids with some forms of CHD (usually those that require surgery and regular follow-ups) will not meet developmental milestones at the same time or perform at the same level academically as their healthy peers. (The CDC has information about **normal developmental milestones**.) These children may also have behavioral issues such as attention deficit disorder (ADD) more often than other children their age.

Parents and caregivers of these children should be aware of potential neurodevelopmental issues so that their child can get early treatment for any problems that may arise. Addressing these issues early will help your son or daughter feel more confident and give him or her a better chance for developing life skills and attaining educational success. Not all children with CHD will have neurodevelopmental issues, and those who do often adjust very well and do not appear any different from their peers. Still, it is important to get screenings to avoid any learning problems your child may have.

## What is a neurodevelopmental issue?

There are two types of neurodevelopmental issues:

- **Developmental disability:** A limitation or disability of the cognitive function of the brain or the way the brain handles emotion, behavior and learning. It may also be a physical limitation.
- **Developmental delay:** Developmental, physical and/or mental skills that are not at the same level as other children of the same age.

In addition to social and psychological issues, children with complex CHD have a significantly higher risk of disability in the following areas:

- Intelligence
- Academic achievement
- Language (development, expressive and receptive)
- Visual construction and perception
- Attention
- Executive functioning
- Fine and gross motor skills
- Psychosocial maladjustment (internalizing and externalizing problems)

## Who is at risk?

Children with milder forms of CHD, such as atrial septal defects (ASDs), do not seem to have a higher incidence of developmental disabilities than their peers. Children who were on cardiopulmonary bypass during surgery or children who were born cyanotic (decreased blood oxygen) seem to be at the highest risk. Some types of CHD that increase the risk of neurodevelopmental issues include:

- Coarctation of the Aorta (Coarc)
- Tetralogy of Fallot (TOF)
- Ventricular septal defect (VSD) with **comorbidities**
- Total anomalous pulmonary venous return (TAPVR)
- Single ventricle defects
  - Hypoplastic left heart syndrome (HLHS)
  - Hypoplastic right heart syndrome (HRHS)
  - Tricuspid atresia

- Double outlet right ventricle (DORV)
- Double outlet left ventricle (DOLV)
- Transposition of the great arteries (TGA)
- Truncus arteriosus
- Interrupted aortic arch
- Children with syndromes associated with CHD
  - Down Syndrome
  - 22q 11 Deletion
  - Noonan Syndrome
  - Williams Syndrome

## How do I find out if my child has a neurodevelopmental issue?

If you notice problems with your child's development at any point, contact their primary care doctor or cardiologist right away. Early detection and treatment of issues is important. All children in the high-risk category should be screened for developmental disabilities at 12 to 24 months, again at three to five years and again at 11 to 12 years of age. Your child's primary care doctor or pediatrician may be able to conduct this screening during a normal wellness visit. Neurodevelopmental pediatricians are also able to perform these screenings, and some children's hospitals have specialized clinics for screening and treating neurodevelopmental issues in children with CHD. The **Development and Education** form in this HeartGuide can help you keep track of your child's progress and screenings.

## What resources can help me get the best care for my child?

Most cities, counties and states have resources to help children with developmental delays and disabilities. Before you even leave the hospital, your hospital's social worker may be able to recommend resources such as physical therapy, occupational therapy and early intervention services if needed. Record these on the **Development and Education** form in this Mended *Little HeartGuide*. If you are connected with a local support group, other parents and caregivers in that group can also guide you to resources and programs in your area.

Many school systems have a process to help detect delays and disabilities in school-aged children. If you have concerns about your child's academic performance, ask for a meeting to discuss any problems you are seeing. Your state's Department of Education website will help you find educational resources and provide you with information that can help guide you through the process of handling any special educational needs your child may have. There are also probably educational consultants in your area who can work with your child and help you coordinate the services that he or she needs. Finally, there are helpful resources for parents with disabilities at the **Center for Parent Information and Resources website** and on the **Special Education Advisor website**.

## Don't be discouraged.

Parents and caregivers often find it hard to come to terms with the fact that their child may have neurodevelopmental issues, but please don't feel discouraged. Most children with CHD — even those with the most severe forms — appear no different than other kids their age. They are usually happy, well-adjusted children. Being aware of the risk of neurodevelopmental issues will help your child get the services he or she needs to have the highest chance of success.

# Congenital Heart Disease: A Lifelong Journey

The good news is that most children born with CHD will survive into adulthood. In fact, today there are more adults than children living with CHD. However, people living with CHD will require specialized care throughout their lives. Living with CHD is a lifelong journey, but it can be a happy and healthy one with appropriate care.

Often, parents believe (and some are even told) that their child is “fixed” after their surgery or heart procedure. While your child may appear normal and may have absolutely no restrictions, he or she still needs specialized lifelong care. Even people who have technically minor congenital heart defects that were repaired during childhood should visit a cardiologist who specializes in CHD at least once as an adult. Children with more complex defects should receive regular cardiac care throughout their lives, even if everything seems fine. CHD patients who don't receive regular treatment could end up in an emergency situation that could have been avoided with regular care. Always follow your child's cardiologist's recommendations for check-ups.

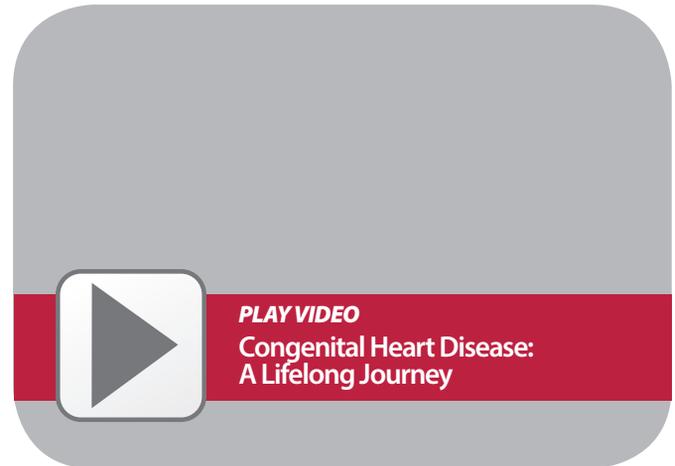
The American College of Cardiology and the American Heart Association have published a guide, [“Management of Adults With Congenital Heart Disease,”](#) on this topic.

## Empowering Your Child to Become a Healthy Adult

A big fear of many parents and caregivers is that their child with CHD will not take proper care of themselves and their heart during adulthood. There are some things you can do to facilitate the transition from pediatric to adult CHD care:

### **Talk to your child, in age-appropriate ways, about his or her heart defect.**

Don't hide information. As soon as your son or



daughter is old enough, discuss and provide information about his or her heart defect. Share the name of the defect. Some CHD names are tough, even for adults, but helping your child learn about their CHD will help with proper lifelong care.

There is some helpful information written for Teens with CHD on the [Pediatric Heart Network Web site.](#)

### **Help your child learn which medications he or she takes and why.**

Sometimes, when children with CHD are on their own, they stop taking some medications because they don't like the side effects or don't want to pay the high price to get refills. If your son or daughter understands the reason for each medication, he or she is more likely to keep taking it as an adult.

### **Involve your child in medical care.**

Encourage your child from an early age to ask the cardiologist and other doctors questions. This will help him or her feel more empowered and in control, and that feeling will continue into adulthood. Get your child in the practice of writing down questions before appointments. By the age of eight, your child should be able to answer some of the doctor's questions. Parents and caregivers often answer out of habit, but

stop and let your child answer questions such as, “How are you feeling?”; “Is anything new happening?”; or “What medications are you taking?” (Children may not know the dosages or spelling of medications, but they may know the names.)

### Let your teen talk to the cardiologist and other doctors alone.

Yes, we know how uncomfortable this makes you feel. Parents and caregivers can talk to the doctors after the appointment. Get teenagers used to managing their own health by allowing them to practice before they are out on their own. We know this is very difficult and that you will worry, but the goal is to raise adults with CHD who can care for themselves.

### Help your teen find an adult congenital heart disease (ACHD) specialist.

Help your teen find an ACHD specialist and make an appointment with that specialist before your child reaches the age of 18. Better yet, have your son or daughter make the appointment. The Adult Congenital Heart Association has a listing of ACHD specialists on their website at [ACHAheart.org](http://ACHAheart.org).

### Teach your child how to keep and organize medical records.

You may use a binder, keep scanned copies on the computer or flash drive, or use another method that works well for you. Keeping organized medical records in one place is an important part of managing care and extremely helpful when changing medical providers. It will also help your child relay the proper information to his or her adult CHD cardiologist.

## Transition Checklist for Parents and Primary Caregivers

Check all that apply. My child...

- Knows the name of his or her heart defect/disease
- Knows the name of any surgeries he or she had and what happened during that surgery
- Knows the names of any medications he or she takes
- Knows what his or her medications are for and when to take them
- Knows how and where to get prescriptions filled
- Understands his or her health coverage
- Knows how to contact his or her insurance company
- Has the name and contact information for his or her pediatric cardiologist
- Understands the potential impact of risky behaviors like drinking alcoholic beverages, smoking cigarettes or marijuana, and using other recreational drugs
- If female, understands the risks associated with pregnancy
- Has the name and contact information for his or her adult CHD cardiologist
- Has made an appointment with his or her adult CHD cardiologist
- Has had a solo cardiology appointment with his or her pediatric cardiologist
- Understands any physical limitations he or she may have and why



Print a PDF of this list

# The Financial Impact of CHD on Families

The financial impact on your family is probably the second-most stressful part of having a child with CHD. We make health care decisions based on what is best for our children, not what is best for our wallets, so we are often faced with intimidating medical bills after a hospital stay. This can cause a huge strain on young families. Being aware of financial considerations early in your child's life can help you plan (as much as possible).

## Living With Uncertainty

Having a child with CHD means living with a lot of uncertainty when it comes to expenses. Obviously, this can lead to stress. Talking with other parents of children with CHD about how they managed may be very helpful. They may also be able to point you toward some useful resources in your city, county or state that can help ease the financial burden on your family. Your hospital social worker may also be able to recommend options to help during and after your child's hospital stay. While life has definitely become less certain for you and your family, remember that you will get through this and that help is available.

## Managing Your Expenses

While you may have a lot of financial uncertainty now, there are things you can do to help keep your finances manageable. Many people want to avoid even thinking about or looking at their financial situation, but that uncertainty just leads to more stress. Facing it head-on will help you manage it and feel more in control. Here are a few tips:

- Create a new budget that includes any medical payments you may have. Schedule a day of the week to look at your bank account and pay your bills. If possible, pay off or at least reduce



the balance of credit cards to minimize the interest you'll pay on your debt.

- If you have to give up something to save money, find out if there is a less expensive alternative.
- Talk to a financial consultant. Sometimes there are ways to save money that you may not have considered. There are resources available to help families like yours manage their finances.

- Create a payment plan with your hospital or doctors. Many parents and caregivers take one look at medical bills and panic. The bills may be too big for you to handle at this time. Call the billing department and set up a payment plan you can manage. Even paying a little each month is better than avoiding bills altogether.

## Lifestyle Changes

While this Mended *Little* HeartGuide is designed to be a useful resource that helps to reduce stress, parents and caregivers do need to be aware of lifestyle changes that families experience. The truth is, understanding and mentally starting to accept that these changes might be necessary can reduce stress down the road by helping you avoid surprises. Lifestyle changes experienced by many families who have children with CHD include:

- **A parent changing or leaving a job:** Sometimes, a parent will need to change employers or quit his or her job to stay home with a child who has CHD. Changes in employment can happen for a variety of reasons — a need for better insurance coverage, more flexible hours, more time off or a shorter commute. These choices can cause significant stress on the family, both in terms of reduced income and reduced satisfaction for the unemployed parent, but they can also help both parents feel more secure and in control of their child's care.
- **Changes in spending:** Some families who have children with CHD need to reduce spending because of medical bills or changes in employment. This can cause anger and resentment, both of which are completely normal. The best way to reduce negative feelings is to find fun things you can do as a family that are low-cost or free. Focus on the

many things you have rather than the things you have to give up. This is hard to do, and there may be days when you still experience negative feelings, but focusing on the positive creates a better atmosphere for your whole family.

- **Day care/childcare arrangements:** Childcare may be a little trickier for the parent or caregiver of a child with CHD. Some choose to avoid day care/childcare entirely because they are concerned about exposure to illnesses. Others have to change childcare because their former provider is not willing or equipped to care for a child with CHD (CPR training, AEDs, emergency plans, etc.). Still others avoid day care around the time of surgeries but use it at other times. Ask your child's cardiologist about day care if you are a single parent or if your family needs both parents' incomes to pay the bills. Many children with CHD do fine in childcare situations, but others may not.
- **Relying more on extended family and others.** While having help from friends and extended family is a blessing, it can also cause stress for everyone involved. Parents and caregivers may feel guilty and uncomfortable about needing help, and friends and extended family often don't know what to do to help. Remember that your friends and family want to help you, so let go of the guilt. 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 how they can help, pick something from the list.



# Building Positive Self Esteem in Children With CHD

Many parents and caregivers of children with CHD worry that their kids will lack self-esteem because of their illness and/or scars. All children have phases where they feel better or worse about themselves. Your child will experience the same thing. These phases are normal, but your child may associate negative feelings with his or her CHD. While kids, especially teens, do struggle with feeling “different” from their peers, there are things you can do to help your child build a positive self-image:

## Check your own attitude first.

The attitudes of parents and primary caregivers have the greatest impact on a child's attitude and beliefs about him- or herself. If parents believe their children are fragile, sickly, weak or helpless, that is exactly what their kids will believe. Parents who are angry about their child's CHD or feel sorry for their child make their sons and daughters feel like victims and teach them that their CHD is something shameful that should be hidden. If you put yourself down or are angry, over-tired or always stressed, children are more likely to go down the same path. Avoid negative statements about yourself, too, so your child will be less likely to copy that behavior.

It is understandable and normal to have negative feelings about CHD. It isn't fair that your child has to have surgeries, medical procedures, medications, many appointments, etc., but most children are a lot stronger and more resilient than we think they are ... if we allow them to be. Stay positive. That doesn't mean denying your child's CHD, but it does mean thinking of your child as your son or daughter first rather than as a CHD patient.

One trick parents can use is what we call “pattern



interrupt.” When you find yourself feeling sorry for your child or thinking of your child as sick and fragile, notice those thoughts and think, “Pattern interrupt!” Then, quickly replace these feelings with something positive about your child so that the vacuum you have created will be not fill with more negativity. Think something like, “Wow! My child made it through open-heart surgery! That shows how strong she is!” or “My son is such a happy child even though he has been through so much. That shows his resilience and courage.” The more you can do this, the more positive your attitude will be about your child — and yes, even about CHD.

## Talk openly about your child's CHD.

Of course you would eliminate your child's CHD if you could, but it is here, so you need to accept it. Some parents try to avoid any mention of their child's condition in an attempt to live a “normal” life. That's understandable, but what happens when your son or daughter needs a procedure or surgery? They will be caught completely off guard and may feel angry or



betrayed. Children would rather understand what is going on than know that they have a problem no one will talk about. Kids know when something is different about them, and they know when parents are trying to hide something. Avoiding the topic of CHD will make your child feel that there is something wrong with him or her. Learn to talk about it early in an age-appropriate way. Talk to a social worker or counselor if you need help with this. Being open and honest about your child's health problems will make it seem like he or she has nothing to hide or be ashamed of. It will help your whole family accept the situation and live a more "normal" life — just a different kind of normal.

### **Focus on your child's abilities, not limitations.**

Parents and caregivers may believe that their child has the same limitations as another child with the same

CHD. Don't make those assumptions. Finding out what your child can do and what his or her limitations are will require an honest talk with your child's cardiologist and pediatrician. Things change as your child grows, so you may need to have the conversation several times. Sometimes, for example, children with CHD can play a rigorous sport when they are younger but have to stop as that sport becomes more physically taxing and competitive. When your child wants to do something that he or she can't do because of CHD, offer other options. If your child really wants to play football but can't, suggest baseball, golf or another sport recommended by his or her doctor. When your child is old enough (usually around eight years old), allow him or her to talk to the doctor about limitations and activities. Having someone other than a parent explain the reasons for limitations can help.



## Allow your child to have privacy.

As soon as your child is old enough to understand what is happening, avoid showing off scars and making your child the center of attention if it makes him or her uncomfortable. Many times, parents and caregivers are so busy trying to support other parents or raise awareness about CHD that they don't notice how uncomfortable their child is about being showcased. Children's scars are part of their bodies and should be kept private if that's what they want. Some kids like to show off their scars and talk about CHD; it makes them feel brave and strong. Other kids do not. Respect your child's wishes and allow for privacy. That doesn't mean you can't tell their story to others or raise awareness, but do so without involving your child.

Some kids are very uncomfortable with their CHD for a year or two but then come out of that phase if they are given space. Always make it okay for your child to refuse to talk about their heart defect, no matter who asks — even teachers or other adults. Teach your son or daughter to politely answer: "I would rather not talk about that right now. It's private." This will help your child feel secure and in control.

## Admit that CHD isn't fair, but don't encourage wallowing.

Let's face it, CHD is not fun or fair, but the fact is, your child has to live with it. If they feel angry or sad about it, don't minimize those feelings with platitudes like "It could be worse," and "You should be grateful you are alive," but don't participate in complaining, self-pity or anger, either. Sometimes, your child just needs a listening ear or someone to say, "Yes, this does stink." Sometimes a hug, a smile or a fun outing together can make a big difference. If your child goes through an angry or depressed phase, don't try to fix it (yes, you'll have a hard time with this), just keep giving them love — even if they won't let you close — until the phase passes. Seek counseling if you feel it would help or if

they become depressed or experience extreme emotions.

## Understand that adversity isn't always bad.

Many times, parents assume CHD is bad and that their child's struggle will cause harm, but many people who travel through adversity are kinder, stronger and more self-confident because of the experience. Living with a chronic illness can also make kids more compassionate toward others. Recognizing your child's strength and resilience will help build confidence. Tell your child how courageous he or she is. Parents and caregivers would take away their child's CHD in an instant if they could, but most acknowledge that the experience of dealing with it has somehow made them a better person. It is the same for your child.

## Find other families with children who have CHD.

Often, meeting other kids with the same or similar CHD can make your child feel more "normal" and confident. This is true for the siblings of children with CHD too; talking to other siblings makes their experience seem less scary. Even meeting adults with the same CHD can be inspiring to children, especially teens, and make them feel more hopeful.

# Frequently Asked Questions

Many families have questions about how various activities will affect children with CHD. The biggest worries are about exercise, but other activities such as air travel and even rollercoaster rides raise concern. The truth is, there are no clear answers to some of these questions, but experts agree on some things, and those are the answers we are presenting here. These recommendations do not come with any guarantees, and following these guidelines does not eliminate the possibility that something could go wrong. These are, however, the best answers we have to some common questions.

## Is it safe for children with CHD to travel by plane?

Many parents worry that commercial air travel might be dangerous for children with CHD. There are a few important things to know: Commercial airplanes are usually pressurized to the equivalent of an altitude of 5,000 feet (about the same as Denver, Colorado) to 8,000 feet (a little higher than Mexico City). Private aircraft may not be pressurized to the same degree.

Higher altitudes can make it just a little harder to get blood to move through the lungs, but that doesn't mean your child can't travel by plane. Although they tend to have lower oxygen saturations at higher altitudes, many children with CHD do surprisingly well with commercial air travel. Some people with CHD, particularly those with cyanotic conditions (where the blood oxygen is lower than normal) or single ventricle heart disease, may be affected, but most who are not cyanotic and do not have lung disease will not experience problems during commercial air travel. Always ask your child's doctor, but most children with CHD can travel safely by commercial airline.

## What if my child needs oxygen on a flight?

Unless they are on home oxygen, very few, if any, patients with heart problems will need in-flight oxygen. If your child is on home oxygen, check with your airline to learn about their policy on in-flight supplemental oxygen. Most airlines need advance notice about a patient's need for in-flight oxygen. Don't assume that you will be able to bring your home oxygen tanks on the flight!

## Is there anything else I should watch out for while flying with a child with CHD?

There are a few issues that might come up during air travel that are frequently overlooked but probably more important than the effects of altitude:

- It is easier to get dehydrated at higher altitudes, so make sure you and your child are getting enough to drink.
- Sitting for long periods of time can increase the chance of a venous blood clot, so make sure that you get up and move around now and then.
- Make sure you have access to your child's medications. Don't put them in your checked baggage. You might need access to them during a long flight or while at the airport, and if your luggage is lost, getting refills will certainly be a hassle.
- If your child has liquid medications, learn about the airline's policies and procedures for those before arriving at the airport.

- Take pictures of all medications or keep a record with you. Get refills before traveling so you don't run out.
- If your child needs special foods or formula, be sure to bring it with you on the plane.
- Make a list of doctors at your destination who could treat your child, if needed. Keep this list handy. Ask your child's cardiologist for recommendations if you can't find the information yourself.

Again, it is always best to talk to your doctor before air travel to make sure your child is okay to travel via plane. If your child has both lung disease and heart disease, you should speak with both your cardiology and pulmonary teams.

## Can my child play football or other contact sports?

Many parents of children diagnosed with a critical CHD are told that their child will never play contact sports or be a marathon runner. Parents have different reactions to this based on their hopes and dreams for their child. The fact is that some kids with CHD can play football and run marathons. One young man with CHD biked all the way across the nation. Other kids with CHD cannot do these things because their heart disease creates more limitations on what they can do. Kids with arrhythmias, for example, may have more medical restrictions than kids without them. Also, kids on blood thinners may be at greater risk for bleeding. Sometimes, children with CHD can play a sport like football when they are young (before it gets too competitive) but will not be able to keep up with their peers as they get older. Some kids will try a sport, like soccer, and find that they get out of breath too easily to enjoy the game. Each child is different.

The first step is to talk to your child's doctors to find out what his or her true limitations are and, more

importantly, what he or she is able to do. If your child is old enough, let your child ask the doctor directly. Some activities, like martial arts, might seem off limits but can be done in the right environment with the right precautions. When your child shows an interest in a sport you know they cannot play, you may feel sad, guilty or angry, but try to think in terms of what your child CAN do. If he or she loves football and baseball, focus more on baseball.

Don't set limits because of your fears; only limit your child if a doctor has set restrictions. Many kids with CHD are able to play sports and stay active, and we need to let them be kids.

## Can we live at high altitudes?

Many parents who have children with complex CHD are concerned about visiting or living in a place at high altitude. While babies with complex CHD in Denver do have lower blood oxygen saturations than babies living at sea level, that does not mean that those families can't live in Colorado. Ask your child's cardiologist about the considerations involved in living at higher altitudes.

## Can my child ride rollercoasters and other thrill rides?

This topic causes a lot of controversy. Unfortunately, there is no clear answer. It is something to discuss with your child's cardiologist. On one hand, parents and caregivers want kids to be kids and to have fun. On the other hand, we don't want our kids taking potentially life-threatening risks. Many thrill rides have signs warning people not to ride if they have a heart condition because there is a risk involved for heart patients, and that risk includes the possibility of death. Some kids with heart conditions have died on thrill rides. Most parents of children with CHD want their son or daughter to have a "normal" life with "normal experiences," but some risks may be too high. That is a decision to make with your child's doctors.

## Does my child need antibiotics for dental treatment?

Some children with certain congenital heart defects need antibiotics, like amoxicillin, one hour before dental treatments or procedures throughout their life to prevent endocarditis. Endocarditis is a condition where bacteria takes up residence in the heart and begins to grow. As the bacteria grows, it damages the heart. The best way to prevent endocarditis is to practice good dental care. People with CHD should see a dentist every six months. Parents should begin familiarizing their child with the dentist at age two. If your child has teeth, brush them twice daily.

The practice of providing antibiotics prior to procedures is called antibiotic prophylaxis. It should also be used for dental treatments that take place during the first six months after a surgery or heart catheterization where a device was used. The list of conditions requiring antibiotic prophylaxis is frequently revised, so ask your cardiologist if your child's condition warrants antibiotics before dental treatments.

## Should my child with CHD get immunizations?

This is another issue that needs to be discussed with your child's cardiologist and pediatrician. They may decide to wait on certain immunizations or to give immunizations (such as those for RSV and pneumonia) that other kids without CHD do not get. They may also encourage you to give your child an influenza (flu) vaccination every year because children with severe heart defects are at higher risk of death and serious illness from the flu.

It is important for parents and caregivers to understand what immunizations are for and why their child needs them. Don't hesitate to ask your child's doctors questions until you understand immunizations, and ask for a schedule for your child's immunizations. If you

want to have your child immunized on a different schedule than the one suggested, let doctors know. Often there is flexibility in the schedule. If you are strongly opposed to an immunization, discuss it with your child's doctor to find out whether there are any alternatives and to understand the true risks if your child does not receive that particular immunization.