

A Parent's Guide to HLHS:

Raising a Toddler

Parenting a toddler with HLHS can come with unique challenges. This bulletin was created by parents of children with HLHS, in collaboration with mental health and healthcare professionals, to provide information and resources that may be helpful for your family during your child's toddler years.

Maintaining a Healthy Family Life

We know your journey with HLHS has been stressful and exhausting. Early on, you may have needed to protect your baby from germs and limit family activities. Now that you have a toddler, this is the time to let your child be a child. Let your child explore, play, get dirty and be around other kids, with the same developmental opportunities as any other child. This is also a great time to start good self-care habits. **A healthy parent = a thriving child.**

- **Let your child learn to set limits.** Try not to limit your child's physical activity (unless specifically told to do so by your child's cardiologist). Your child will naturally know when limits are reached and will act accordingly.
- **Include your child in family and social activities** and outings such as parties, holidays, sibling activities, concerts. The more your child is included, the better the entire family will feel.
- **Carve out time for you alone and for your relationships.** Although it can be difficult to take time away from your HLHS child, it is important to care for yourself and your relationships. Brief periods of separation can also be helpful for toddlers, as they begin to develop independence and learn that they are okay with other trusted caregivers. Commit specific time to your partner and friends. Care for yourself by returning to activities you enjoy and by exploring new things, such as yoga, mindfulness, walking/jogging, or reading. Start small and build your self-care practice over time.
- **Connect with other HLHS parents.** Research and experienced parents tell us that connecting with others in similar situations builds our resilience and can make us happier.

Resources

Connect with other parents of children with HLHS or congenital heart disease:

- Sisters By Heart/Linked By Heart
- Mended *Little* Hearts
- Conquering CHD

Mindfulness/Self-Care: There are many mindfulness apps that can help people manage stress and anxiety. Several members of our community have found the *Calm*, *Smiling Mind*, and *Relax Lite: Stress and Anxiety Relief* apps to be helpful (available for free).



Never a dull moment!

“Early on, we limited outings with our son to ensure he wouldn't pick up germs or illnesses. As he grew older, we began allowing him to play and socialize like any other kid his age. He knows his limits and we let him lead. This has helped us finally take a deep breath and enjoy the fun of parenting a toddler.”

Taylor, Heart Dad



National Pediatric Cardiology
Quality Improvement Collaborative



Balancing Developmental and Medical Needs

Setting limits for your toddler is an important but often difficult part of parenting. Having limits helps toddlers feel safe and learn self-control. However, HLHS parents can sometimes feel stressed when trying to separate normal toddler behavior from a potential medical concern. HLHS parents may also have questions related to nutrition, daycare, sleep and other typical toddler concerns. Here are some common challenges that parents report when trying to balance their HLHS child's developmental and medical needs:

- **Should my HLHS child attend preschool or daycare?** Many toddlers with HLHS benefit from preschool or daycare, as the socialization and structure can help enhance development and independence. However, every child is different, so check with your child's cardiologist before enrolling them.
- **Can I let my child cry it out?** Toddlers often benefit from learning how to fall asleep on their own and to sleep through the night. This also helps parents get a better night sleep! The "cry it out" method can be safe and effective for many toddlers with HLHS—check with your child's cardiologist if you are interested in trying the "cry it out" sleep method or other strategies to encourage independent sleep.
- **Who to call with a concern, and when.** Your child's pediatrician is typically the first person to contact when your child seems to be sick with a virus or fever. Concerns with a change in coloring or base saturation levels should be directed to your child's cardiologist.
- **What if my child is a picky eater?** It's normal for toddlers to go through phases of picky eating. Provide healthy options at each meal and eat together as a family. Be your child's role model for healthy eating. If your child is having difficulty gaining weight or is still eating pureed/baby foods, talk to your child's pediatrician about whether seeing a feeding specialist and/or dietitian may be helpful.

Resources

Books/Websites

- **Setting limits and discipline:** *1-2-3 Magic: Effective Discipline for Children 2-12* by Thomas Phelan, PhD; Triple P Positive Parenting Program (*online*)
- **Promoting independent sleep:** *The Good Sleeper* by Janet Krone Kennedy, PhD or *Sleeping Through the Night: How Infants, Toddlers, and Their Parents Can Get a Good Night's Sleep* by Jodi Mindell, PhD

Hospital/Clinic Resources

- Pediatric psychologists help parents learn to manage difficult behaviors, such as tantrums, defiance, aggression, sleep problems, and behavioral feeding issues. Many children's hospitals/clinics have pediatric psychologists on staff.
- Many children's hospitals have specialized programs for feeding and sleep problems. Ask your child's cardiologist about those types of programs.



It's a balancing act!

"Sometimes I think about how many doctors were treating my daughter during interstage versus today. I am finally starting to appreciate the space we have right now to treat her like a regular kid who needs to sleep and eat her veggies, but know that there is a team of people who will always help when I am a concerned mama."

Samantha, Heart Mom



National Pediatric Cardiology
Quality Improvement Collaborative



Educating Others About Your Child's Heart Condition

There are often new challenges that come up when it is time to educate your toddler with HLHS about their health. Some things to focus on with your toddler can be:

- Explaining to your child how their heart is different
- Teaching your child to feel proud of their scars
- Preparing your child for additional hospitalizations and surgeries

Many parents also find as their toddler gets to know more people, whether it be family or others in the community, it can be a struggle to educate them about HLHS. Here are some common challenges:

- Teaching siblings about HLHS in a developmentally appropriate way
- Explaining the severity of your toddler's condition to extended family and friends. It can be useful to have a one-liner to explain the diagnosis, such as, "She is doing well now but her condition is a lifelong challenge that won't ever be healed"
- Preparing other people for the future – there will be more surgeries, hospitalizations and interventions in the future
- Helping others understand how they can assist your family during hospital stays and other times of need

You should always feel empowered as your toddler's parent to reach out for help to educate your child, their family and the community about HLHS.

Resources

- Child Life Specialists at your hospital
- Books (*My Brother Needs an Operation*, *Riley's Heart Machine*, *Zipline*, *Charlie the Courageous*, *Jeremiah the CHD Aware Bear*, *Exclamation Point*)
- CHD Apps (*Heartpedia*) and websites (many children's hospitals have information about different heart conditions on their website)
- Connecting with other families who can share their experience and provide support
- Websites that provide information to extended family/friends on how to help during hospital stays and other times of need (Search online for "how family and friends can help when a child is in hospital" and you'll find several articles on this topic)

Trusting Your Parental Instincts When Something Doesn't Feel Right

It can be hard not to compare the development and behavior of your HLHS toddler to other children. Although each child is unique, if you have noticed that your child seems further behind in their development than peers, or is having challenging behavioral or emotional difficulties, talk to your child's cardiologist and pediatrician. Children with HLHS are at increased risk for developmental and behavioral challenges, and early intervention therapies can help reduce these challenges and set your child up for success in school.



Sliding into toddlerhood.



Making a mess is so much fun!



National Pediatric Cardiology
Quality Improvement Collaborative



Many babies with HLHS receive early intervention services, but some of them “graduate” before toddlerhood. A re-evaluation during the toddler/preschool years can help to ensure that your child remains developmentally on-track.

- If your child has received early intervention in the past, try contacting the team who worked with your family to discuss your concerns and observations.
- If your child has never received early intervention, speak with their pediatrician to get the number for early intervention in your area. Each state has a program provided at no-cost to families for children who need extra help in meeting milestones.
- State provided services alone may not be enough for your child. Speak with your child’s pediatrician about the benefits of a referral for outpatient rehab services.
- At age three, children transition from early intervention into their local preschool program. Contact your school district and request an IEP (individualized education plan) meeting for your child if continued developmental services are needed. Starting this process a few months before your child turns three will ensure that there are no gaps in services.

Noticing that something does not feel right about your child’s development can be scary. However, just like noticing medical symptoms, taking quick action is best. Getting your child into services when they are first learning skills can often reduce/prevent problems down the road.

Resources

- Supporting Development in Children with Congenital Heart Disease (available online through the journal *Circulation*)
- Find a Cardiac Neurodevelopmental Follow-Up Program: cardiacneuro.org
- US Government information on early childhood education: On the internet, search for “Birth to Five: Watch Me Thrive” and click on the “Families” link
- Information about laws to help you advocate for your child: wrightslaw.com
- For local resources, speak with your child’s medical providers and/or cardiac social worker

While parenting a toddler with HLHS has many challenges, it also comes with many rewards. As your child grows, each new experience is appreciated and every milestone met is celebrated. Your child is an example of resilience and determination to every person they meet. Take time to enjoy the present moment with your child and family, and take comfort in knowing there are many people encouraging you along the journey.



Growing and developing!

“Being the parent of a child with special needs means never taking a milestone for granted. Every skill that is mastered is not only celebrated with my daughter, but deep down it’s a victory for me when I can say ‘We did it!’”

Randy, Heart Dad



National Pediatric Cardiology
Quality Improvement Collaborative

