

A Parent's Guide to HLHS: Confronting Postnatal Diagnosis

Learning soon after birth that your baby has hypoplastic left heart syndrome (HLHS) or another single ventricle heart condition can be shocking and overwhelming. This bulletin was designed 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 as you prepare for your baby's HLHS journey.

Feelings

Parents who learn of their child's diagnosis of HLHS after birth have many feelings. You are not alone. Parents of children with HLHS have shared many of the same feelings. Some of these might include:

- Anger
- Sadness
- Fear
- Helplessness
- Nothing will be okay
- Everything is out of control

Stress

You should expect to be stressed as you prepare for your baby's HLHS journey. Many families say the most stressful parts of finding out their baby has HLHS were:

- Seeing their baby sick and worrying what was going to happen.
- How their baby looked after the first operation—the incision, the medications, and tubes are frightening.
- Not being able to be feed or take care of their baby.
- Worrying that their baby would not know them.
- Being away from other family members and children.

Coping

Parents cope in different ways. Many parents put themselves second to their baby at this time. You need to take care of yourself to be in the best shape to make decisions and to support your child. Some helpful hints include:

- Eating and taking care of your own health and hygiene needs.
- Getting a good amount of rest and sleep.
- Eating meals away from the hospital and exercising.
- Asking for help is okay—lean on friends and family members to help you.
- Talking with family, friends, ministers or people taking care of your baby.
- Asking for help with household tasks, child care, or other daily activities.

Finding Answers

Many parents find that asking a lot of questions helps them learn about their baby's condition.

- Write down questions as you think of them. That way you have them when a nurse or doctor is available.
- Don't be afraid to ask care providers to go over things more than once.
- Ask nurses and doctors to use different words if they don't explain things in a way you understand.



Catching some much needed ZZZ's.

“Learning of her heart condition was devastating. I just wanted to take my baby home and do regular parenting tasks like change her diaper and feed her. I had to learn how to care for her in a completely different way. I cherished the moments to hold her hand and sing to her when she was in her hospital bed.”

Heart Mom



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- You know your child best. Partner with the medical team to understand all treatment options and participate in decision making.
- It is your right to know what is happening, and the more you know, the more you can help.

Development

You can develop a connection with your baby and help to promote your baby's development while in the intensive care unit. Some things you can do might seem small but can make a big difference:

- Ask for ways to hold, touch, and take care of your baby.
- Softly talk, sing, or read to your baby.
- Hold their hand, or put a hand around their head and feet.
- Leave a cloth in your baby's bed that you have worn so it smells like you.
- Bring in photos for around your baby's bed.
- Provide breastmilk for your baby.



Ask for ways to hold, touch, and take care of your baby.

Support

There are many supports available for families dealing with HLHS.

Community Support

- Support is available online through Sisters by Heart/Linked by Heart, MLH CHD Chat, Postpartum Support International and others.
- Local and national groups (for example, Mended Little Hearts and Conquering CHD) may meet in your community to support and inform parents about congenital heart disease.
- Professional Mental Health Counseling for individuals, couples, and/or siblings. (Speak to your insurance company to find a provider.)
- Sibshop: offers support groups and resources for siblings.

Hospital Support

In the hospital and after discharge there are people who can help you with lodging, finances, feeding, reaching milestones, and wellness. Connect with a cardiac social worker for guidance about available supports.

Books/Apps

- Books for Adults: *HLHS Book of Hope*, *Single Ventricle Q&A Book*
- Talking about congenital heart disease with young children can be difficult. These children's books might help: *My Brother Needs an Operation*, *Hayden's Heart*, *Riley's Heart Machine*, *Zipline*, *Charlie the Courageous*, *Jeremiah the CHD Aware Bear*.
- There are numerous mindfulness apps (via the Android or Apple app stores) that can help with stress and anxiety. Several members of our community have found the "Calm" app to be helpful (available for free).

We encourage you to lean on available supports as you adjust to this new diagnosis. Try to take care of yourself so that you can be in the best shape to care for and support your child.



Celebrating and enjoying life!

"We went from having a healthy baby at home to a critically ill one on life support and readied for emergency surgery in the space of a few hours. We didn't know what decisions were important and despite our educations, knew nothing about Lucy's disease or its treatment. The experience was traumatic, terrifying, and overwhelming."

Richard, Heart Dad of Lucy, HLHS, pictured above



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