

A Parent's Guide to HLHS: Coping During Interstage

The "interstage" period (the months between stage 1 and stage 2 heart surgeries) can be an emotionally challenging time for families. This bulletin was designed by parents of children with hypoplastic left heart syndrome (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 the months ahead.

Feelings

Many parents feel alone during interstage. Opportunities to connect with family/friends is limited by hospitalization or concern for germs. Parents also feel emotionally alone, when others can't relate to what they are going through.

These feelings are normal. There is a community of parents with HLHS children who have walked a mile in your shoes and want to provide you with support and connection.

- Connect with other HLHS parents, through your hospital, a local support group or online.
- Identify a trusted caregiver for your child so you can find a few hours to connect with friends or have dinner with your partner. Getting out of the house can provide a much needed break and is refreshing!

Stress

Caring for a baby during interstage involves tracking weight/oxygen saturation, operating medical equipment, and navigating the healthcare system. These tasks are important, but not what most parents expect after bringing their baby home. Adjusting to being both a parent and a care provider is stressful and overwhelming. It is also common to feel sadness or grief about the loss of "typical" parenting experiences, such as breast/bottle feeding.

Don't let stress take away from these enjoyable, day to day parenting times with your baby:

- Bath time and dressing your baby
- "Wearing" your baby
- Reading & singing songs
- Playing peek-a-boo

Also take time to care for yourself. It is important that you stay healthy and strong to provide the best care for your baby. Share responsibilities with other family members when possible.

Bonding

Bonding with your baby can be difficult during interstage. So much attention is placed on the medical needs of babies with HLHS that sometimes parents feel like their baby's nurse rather than their parent/nurturer. The fear of losing your baby can also make it difficult to bond.



Comfy and cozy at home

"We canceled most of our plans during interstage because of my son's tube feeding schedule or fear of illness. Connecting with other heart families, both locally and online, really helped improve my feelings of loneliness and seclusion."

Lacie, Heart Mom

"Having so many responsibilities during interstage was difficult and sometimes interfered with the joy of becoming a parent. But we had all these tasks and responsibilities for a good reason: to see her survive and thrive through this fragile period."

Arman, Heart Dad



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Find someone you can talk to about your feelings, hopes and fears (social worker, therapist, friend, or fellow HLHS parent). This person should help you feel both safe and supported. Difficulty bonding is common. Try not to judge yourself or your relationship with your baby. Many HLHS parents have felt this way and go on to have strong bonds with their baby.

Self-Doubt

Doubting yourself is common during interstage. Even after training at the hospital, caring for an HLHS baby at home without the security of nurses and monitoring is challenging. The stakes are high and parents often fear they will miss something or make a mistake. Parents may also be intimidated by medical providers and hesitant to ask questions or raise concerns.

- Please know that you are enough and you can do this. Of all the people involved in your baby's care, you have the special job of being their parent. You are the expert on your baby!
- Trust your gut instinct, be a strong advocate for your baby. Don't hesitate to speak up or ask questions.
- Rely on your training and if you have questions, call your care team and ask for help.
- Give yourself credit for all that you've already learned. Take comfort knowing you will continue to learn and your confidence will increase.

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 Pediatric Congenital Heart Association) 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.
- Tube Feeding: Tube Feeding Awareness Foundation

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).

Although the interstage period can be a challenging time, there are many available supports to help your family. We encourage you to lean on these supports for healthy coping during interstage.



Happy and smiling, oxygen and all!

"I wanted to enjoy being a mom and embrace everything that comes with it, but then I would stop myself. What if I lose her? ... I've realized there are so many things we can learn from these heart kids, and the first one is: Never give up!

Pinar, Heart Mom

Even though you may not always feel like it, you are strong, capable, brave, and more than qualified to take care of your heart warrior. Always trust your gut and know that just by being their parent, you are more than enough. You are their everything.

Christina, Heart Mom



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