

A Parent's Guide to HLHS: Adjusting Post-Glenn

For parents of children with hypoplastic left heart syndrome (HLHS) or another single ventricle heart condition, the time after Glenn completion can be exciting, yet scary at the same time. 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 adjust to life post-Glenn and beyond.

Feelings

Many parents express feeling a “rollercoaster” of emotions after the Glenn surgery. You are not alone. These, and other emotions you may experience, are completely normal:

- Relief
- Self-blame or guilt
- Hopeful but still anxious
- Overwhelmed by responsibility
- Proud
- Lonely and unprepared

It is often hard to know when you need more support. Try doing “emotional check-ins” on yourself. At least once a day, stop and think what emotion(s) you are feeling and how strong the emotion is. If your emotions are negative, try using a coping strategy. If you notice your emotions are usually or strongly negative or are impacting your sleep, work, relationships, or parenting, it may be time to get more support.

Stress

Stress is a natural reaction after the Glenn. Knowing what to expect can often help. Parents often report these new stressors as they move beyond the interstage period:

- A change in care providers
- Cold/flu season and illness
- Feeding issues
- Developmental milestones and delays
- Child and family limitations

It is common to feel stress, even if your child is doing well. This stress often goes down over time, but if it does not, seeking additional support is recommended.

Coping

People cope in many ways. One of the best ways to take care of your family is to take good care of yourself. After the Glenn, you have the chance to find your family’s “new normal,” as well as recharge and refocus on yourself and relationships. Take at least five minutes a day to do something for you.



Post Glenn and feeling great!

“The post Glenn period was filled with highs, lows, and mixed emotions. Ultimately, at discharge, I felt a sense of pride and relief. We’d made it to safer ground.”

Alexis, Heart Mom

“Not having interstage monitoring when we returned home after the Glenn was stressful. It took several weeks to feel at ease and adjust to this new normal.”

Caleb, Heart Dad



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- Pay attention to the basics: diet, sleep, physical activity, and support
- Spend time with positive people; discuss your worries and your wishes for your baby
- Practice relaxation to release tension in your body and calm your mind, including yoga, meditation, deep breathing, and imagery
- Journal, color, or use other forms of expression
- Connect with your spirituality or faith
- Control what you can, accept what you cannot
- Laugh! Find reasons to celebrate or even create new family traditions

There are many different ways of coping, including unhealthy ways. Ask for help if you are struggling.

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).

As this bulletin mentions, there are many trials and tribulations in the care of a child with HLHS. Always remember, you have done a great job in the care of your child in so many ways. Life is like a maze, some days the path is clear, and other days a wall is present. In moving forward, take time for yourself so you can enjoy this new adventure with your child, for this time only comes once.



Roommates: Post-Glenn and Going Home!



Snuggling at home.

“For our family, we coped by staying organized, continuing to advocate for our child, and doing our very best to take care of ourselves.”

Kevin, Heart Dad

“For me, the biggest source of support was talking with other HLHS parents – at the same stage as us or those further along in their journey.”

Stacey, Heart Mom



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