

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.



Post Glenn and feeling great!

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 decreases 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.

- 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

"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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- 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 coping with HLHS.

Hospital Support

In the hospital and after discharge our Thrive Team can help you with lodging, finances, early intervention (PT, OT & Speech Therapy referrals), reaching milestones and counseling services.

Thrive Team contact: Email: thrive@cmh.edu Phone: 816-302-8064	Thrive Team:	
	Social Worker	Child Life Specialist
	Psychologist	Chaplain
	Financial Counselor	Palliative Care Team
	Music Therapist	

POPS (Parents Offering Parent Support) - connect with another parent who has a child with HLHS. Email: pops@cmh.edu or call: 816-302-8229

Community Support

- Congenital Heart Defects Families Association (local and regional) www.chdfamilies.org
- Sisters by Heart (national support specifically for HLHS) www.sistersbyheart.org
- Pediatric Congenital Heart Association (national): www.conqueringchd.org
- HopeKids KC: www.hopekids.org
- Sibshop: offers support groups and resources for siblings
- Tube Feeding: Tube Feeding Awareness Foundation
- Imagination Library- Free Book Program

Books/Apps

- Books for Adults: HLHS Book of Hope, Single Ventricle Q&A Book
- Children's Books: My Brother Needs an Operation, Hayden's Heart, Riley's Heart Machine, Zipline, Charlie the Courageous, Jeremiah the CHD Aware Bear
- Mindfulness apps that can help with stress and anxiety: Calm, Headspace, Insight Timer, 10% Happier. *Apps for kids:* Stop Breathe Think and Settle Your Glitter



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

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.



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