

Preparing for Fontan

The Pre-Fontan stage can be both exciting and scary for patients and families. This bulletin was designed by parents of children with single ventricle diagnosis, in collaboration with mental health and healthcare professionals, to provide information and useful resources for your family as you prepare for the Fontan surgery. Consider the following ideas in conjunction with your child's likes, dislikes, coping style, age and preferences.

Preparing Your Child

- Encourage familiarity with the medical experience through medical play, books, tv shows and apps to increase your child's and family's comfort level.
- Utilize mindfulness apps to help your child identify emotions and learn coping strategies.
- Discuss the surgery with your child no more than 1 week before; recommended 1 day per year of age (ex: 3 days before if child is 3 years old).
- Consult with your hospital's child life specialist, psychologist, or social worker on specific language to use with your child.
 - » Emphasize surgery is not punishment because your child did anything wrong. Avoid words such as "sick" or "broken," instead, use words like "help" or "make stronger."
 - » Reinforce that the Fontan is part of growing up with single ventricle and means he/she is getting stronger and may allow increased activity (ex: run without getting winded, take swim lessons).
 - » Remember it's okay to not have all the answers, "I'm not sure, but I can find out for you" or "let's ask the doctor together" are good responses.
- Ask, non-judgmentally listen and support how your child is feeling about the upcoming surgery.
 - » Children often express emotions through their play so watch for this in various ways.
 - » Reach out to your child's care team if you have any questions or concerns.
- Feeling a loss of control is common. Try to give your child a sense of control. Ideas include: packing a bag and choosing books/ activities for the hospital stay, choosing comfort items like a blanket or stuffed animal.
- Pre-surgery hospital consultation is recommended and often available including a hospital tour, room pictures and information on hospital resources.



"I was anxious and nervous about my son's Fontan now that he was three years old and able to voice fear, pain, and other emotions. The last time he was hospitalized he was five months old and obviously didn't remember it."

Kristen, Heart Mom

Child-Focused Resources

Free Fontan Superhero Package: After you receive your child's surgery date, you can order a free Fontan Superhero package here: <https://www.sistersbyheart.org/request-a-care-package>.

Book of Hope – HLHS Stories of Hope and Inspiration from Parents and Patients: To order a free copy: empoweredbykids.com/books-hope/hlhs-book-of-hope/.

For printable PDF version: [empoweredbykids.com/wpcontent/uploads/2015/04/HLHS Book Of Hope.pdf](http://empoweredbykids.com/wpcontent/uploads/2015/04/HLHS_Book_Of_Hope.pdf)

Books: *At the Hospital* by Carron Brown (A Shine-A-Light book), *My Brother Needs an Operation* by Anna Marie Jaworski, *Super Heart Hero* by Samantha Kelly.

Preparing Yourself and Your Family

- Bring a journal or notebook to write down specific questions.
- Ask your child's cardiologist and surgical team about pre- and post-op testing, expectations for surgery, expected length of stay, review of current medication and anticipated medications post-Fontan.
- Ask for illustrations of what your child may look like after surgery.
- Contact Ronald McDonald House (or other housing) as soon as you have a surgery date.
- Connect with other families with a child who is post-Fontan; consider establishing a relationship pre-operation.
- Parents/caregivers may have strong emotions triggered when returning to the hospital. Know this is normal. Anticipate it may happen. Consider your resources and helpful ways you have coped in the past.
- Establish good self-care habits before surgery. Suggested coping and self-care include: walking outside, time with supportive friends, healthy sleeping and eating habits, mindfulness practice. Ask about hospital self-care resources (parent groups, massage, etc.)
- Siblings also often have varied emotions. Ask, non-judgmentally listen and support how the sibling is feeling. A hospital child life specialist can also help prepare a sibling.
- Keep siblings connected during hospitalization. Ideas include:
 - » Sibling helps pack bag, or makes decorations for room.
 - » Ask about hospital visitation policy and volunteers for sibling support.



“Preparing for my son’s Fontan was a family event. We made it as optimistic for him as possible. We answered questions that he had in the most simple ways possible and checked in with his level of understanding.”

Jennie, Heart Mom

Parent/Family Resources & Support

Children's Mercy Support

Thrive Team – support and resources for Heart Center patients and families from: Social work, Psychology, Child Life, Music Therapy, Financial Counseling, Spiritual Services and Palliative care.

Phone: (816) 302-8064

Email: thrive@cmh.edu
childrensmercy.org/thrive

Community Support

- Sisters by Heart (Specifically for HLHS, national): sistersbyheart.org
- Conquering CHD (national): conqueringchd.org
- Congenital Heart Defects Families Association (local): chdfamilies.org
- HopeKids KC: free events/activities for patients & families: hopekids.com

Mindfulness Apps

Mindfulness apps can help with stress and anxiety.

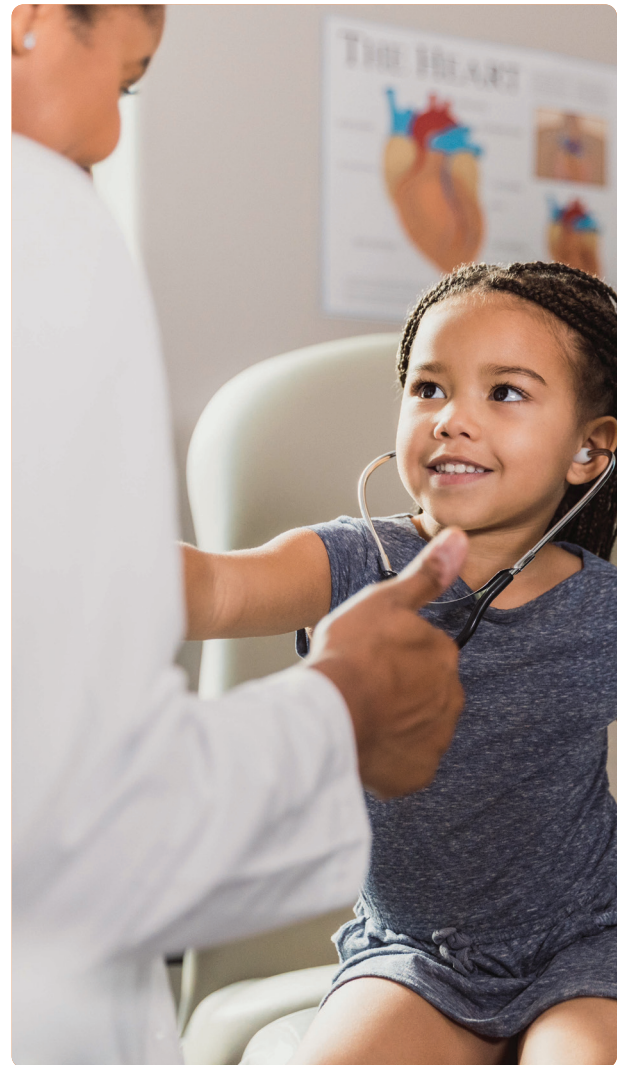
- *For parents:* Insight Timer, Calm, 10% Happier and Stop, Breathe & Think
- *For older children:* Stop, Breathe and Think Kids
- *For younger children:* Breath, Think, Do with Sesame Street

Music

Calming sounds & music: Relax Melodies app

Suggested Books For Parents

- *Heart Warriors: A Family Faces Congenital Heart Disease*
- *It's My Heart* by The Children's Heart Foundation
- *The Parent's Guide to Children's Congenital Heart Defects: What They Are, How to Treat Them, How to Cope with Them.*



Children's Mercy POPS (Parents Offering Parent Support)

Connect with another parent who has a child with HLHS.

Email: pops@cmh.edu

Phone: (816) 302-8229



National Pediatric Cardiology
Quality Improvement Collaborative



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Ward Family Heart Center
CHILDREN'S MERCY KANSAS CITY