

## A Parent's Guide to HLHS:

# 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. (See resources below.)
- Utilize mindfulness apps to help your child identify emotions and learn coping strategies. (See resources below.)
- Discuss the surgery with your child no more than one week before; recommended 1 day per year of age (ex: 3 days before if 3 years old).
- Consult with your hospital's child life specialist 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 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

## Child-Focused Resources

**Websites:** *Anesthesia:* Visit [kidshealth.org/en/parents](http://kidshealth.org/en/parents), search for "Preparing your child for anesthesia" *Surgery:* Visit [kidshealth.org/en/parents](http://kidshealth.org/en/parents), search for "Preparing your child for surgery"

**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

**TV:** Doc McStuffins, popular children's show about medical care

**Mindfulness Apps:** *For younger children:* Breathe, Think, Do with Sesame Street  
*For older children:* Stop, Breathe & Think Kids



*"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**



**National Pediatric Cardiology**  
Quality Improvement Collaborative



## Preparing Yourself and Your Family

- Bring a journal or notebook to appointments; write down specific questions for providers before appointments.
- Ask your child's cardiologist and surgical team about pre & 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 (*see resources below*); consider establishing a relationship pre-operation; check with your hospital as many have peer mentor programs (parents, patients, and siblings).
- 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 (*see resources below*). Ask about hospital self-care resources (parent groups, massage, etc.)
- To prepare siblings see the "Preparing your child" section above for tips. A hospital Child Life specialist can also help prepare a sibling.
- Siblings also often have varied emotions. Ask, non-judgmentally listen and support how the sibling is feeling.
- 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.

## Parent/Family Resources

**Support for Parents/Caregivers:** Visit [kidshealth.org/en/parents](http://kidshealth.org/en/parents) and search for "Taking Care of You: Support for Caregivers"

### Connect with Post-Fontan families:

- Sisters by Heart – [sistersbyheart.org](http://sistersbyheart.org) – support community and provides Fontan care packages for children
- [linked-by-heart.org/chd-resources](http://linked-by-heart.org/chd-resources) – A list of ways to connect with other parents of children with congenital heart disease.

### Mindfulness Apps:

- Headspace – Guided Meditation and Mindfulness
- Mindfulness Daily

**Other Apps:** Baby Connect – Tracks children's medications

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The Fontan operation is the next milestone to aid in your child's development with continued focus on health and quality of life.



*"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**



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