

A Parent's Guide to HLHS:

Fontan Hospitalization

Congratulations! You have made it to the Fontan surgery. Below are some tips to assist your child, your family, and yourself through the hospital stay. This bulletin was designed by parents of children with single ventricle diagnosis, in collaboration with mental health and healthcare providers, to provide information and resources that may be helpful for your family.

Pain Management & Coping

- Create a healing environment (dim lights, comfort items from home)
- Create a sense of normalcy – decorate hospital room with items from home, window markers / wall stickers with favorite characters, etc. Maintain parental or adult presence in room whenever possible.
- Age appropriate explanations of environment & equipment are helpful. Most hospitals have a Child Life specialist who can explain post-op lines & tubes.
- Remind your child this is not a punishment, they are not staying “forever”
- Encourage healthy coping habits during times of stress or discomfort, such as deep breathing and listening to music.
- Distractions can be helpful (busy activities, toys, I Spy books, sensory activities)
 - Listening to music
 - Walking around outside of room
 - Consider a “Bravery Box” of surprises or little wrapped goods. Keep across the room as incentive for child to also get moving!
 - Provide multi-day art projects such as creating, building and painting
 - Try to remain positive; encourage laughter; praise your child; model resilience and healthy coping.

Play Needs in the Hospital

- Ask your hospital for Child Life Services – specialists who engage your child in play in ways that reduces fear, anxiety, and pain.
- If your hospital has a playroom, introduce your child pre-surgery as it may be a motivator to get out of bed.
- Play in the hospital is fun! It promotes normalization, a positive hospital experience and allows kids to be kids.
- Children can still take part in some of their favorite activities – some may just need to be adapted.
 - Consult with Child Life or Physical or Occupational Therapy for adaptive play help. Examples include: card holders for playing card games, washcloths around markers or paint brushes for easier gripping, lap desks if unable to get out of bed
- Medical play uses realistic and pretend medical equipment to offer some control and understanding to the child. Consider “playing hospital” with your child.



“The Fontan hospitalization was hard but also the most rewarding experience of my life. To see my daughter walk after surgery and get stronger day by day left me awestruck. Not many people get to see that side of their child and it is a special gift I will always cherish.”

Samantha, Heart Mom



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- Children express themselves through play; watch for misconceptions about the hospital or other themes (separation, blame, fear of staff)
 - Ask about hospital resources – music therapy or Beads of Courage – play with a therapeutic component
 - Play can also be a great motivator! Use it to encourage getting out of bed, walking, expanding the lungs, etc.

Behavior

- Many children will show regression (more clingy, anger, temper tantrums, thumb sucking, etc.)
 - Know this is normal – be patient – this is temporary
 - Your child may need more positive attention; praise & affection are helpful!
 - Create a sense of safety with comfort items from home, nightlights, modeling trust in the medical team, extra cuddles and reassuring words
- This is a good time to “choose your battles.” Consider which behavior challenges are most important to you and which you can just “let go” during this time.
- Make commands rather than requests (“It’s time to take your vitals” not “can the nurse take your vitals now?”)
- Offering choices when possible (ex: “Would you like to take your medicine with water or juice?” “Would you like your blood pressure taken on the right or left arm?”)
- Ask care providers about visual tools to create incentive or indicate progress (sticker charts, “map toward home”)

Caring for Yourself

- Taking time to care for yourself ensures you are best able to care for your child. Model a positive attitude and healthy coping.
- A lot of parents experience distress returning to the hospital. This is expected and normal. Be patient with yourself and care for yourself.
- Consider what coping skills have worked best for you in the past; consider trying a new one. Suggestions: journaling, walking outside, time with supportive friends, healthy sleeping and eating habits, mindfulness practice (*see resources section*). Ask about hospital self-care resources (parent groups, massages, etc.)
- Know the visitation schedule – encourage other adults to visit so you can take breaks from the room and hospital.
- Take advantage of others’ help, both emotionally and logistically (e.g. sibling school pick-up, meals).
- Try to get adequate sleep.
- Connect with other parents who have been through similar situations (*See resources section*.)
- Try to find your balance of participating in rounds and advocating for your child, while also letting staff manage daily medical aspects.
- Take advantage of this special 1:1 time with your hospitalized child to strengthen your bond and simply have fun! (play special games, special reading time, celebrate accomplishments.)



Child and Parent Resources

Mindfulness apps:

- **For young children:** Breathe, Think, Do with Sesame Street
- **For older children:** Stop, Breathe & Think Kids
- **For caregivers:** Headspace, Mindfulness Daily, Calm

Taking Care of You:

- Visit kidshealth.org/en/parents search for “Taking Care of You: Support for Caregivers”

Connect with other Congenital Heart Disease parents

- **Sisters by Heart** sistersbyheart.org
For moms of children with single ventricle
- **Brothers by Heart** sistersbyheart.org/content/brothers-heart
(off-shoot of Sisters by Heart) for dads of children with single ventricle
- **Linked by Heart** linked-by-heart.org
Password protected nationwide database of HLHS families for networking as well as a Facebook group for parents
- **Mended Little Hearts** connect.mendedhearts.org
Scroll to bottom left to connect with Mended Little Hearts on Twitter and Facebook
- **Conquering CHD** conqueringchd.org
to connect with a chapter in your state, scroll down and click on “State Chapters—Get Connected”



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- Remember this can be a stressful time with your partner. Check in with social workers or psychologists for recommendations and additional resources.
- Set limits with extended family when needed in order to prioritize your child, your family, and yourself!

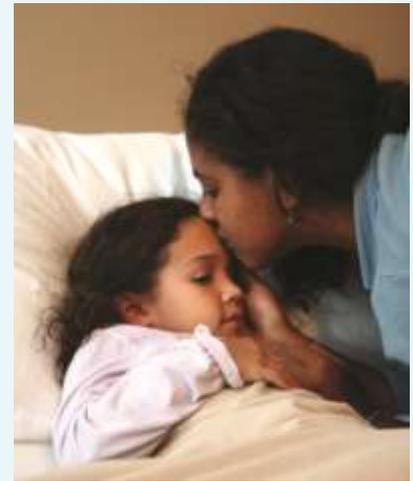
Caring for Siblings

- Since sibling routine is disrupted during hospitalization, it is normal for siblings to demonstrate attention-seeking behaviors and worry about their sibling.
- Research indicates that sibling visitation helps coping for both children. Utilize Child Life and Social Work to support both patient and siblings prior to and during visitation.
- Consider the sibling's age and developmental level when planning length of visit. Quick visits to see their sibling is okay and otherwise take advantage of sibling time with other significant people.
- Prepare the sibling for visit including what child may physically look like and expectations for lower energy.
- Find out about sibling visitation limits especially during flu season.
- Consider other ways to connect if in person visitation is not possible (FaceTime, Skype, phone calls, making or sending cards/decorations).
- It is common for siblings to have a range of emotions, including worry, sadness and perhaps resentment. Know this is normal. Be patient, this is temporary.
- Provide individualized attention to siblings when able. Utilize extended family when possible.
- Maintain home routine as much as able.
- Inform teacher and guidance counselor so they can be aware of potential change in behavior and provide additional support if needed.

The Fontan hospital experience can be one of challenges, fear and yet also excitement. Use the resources included in this bulletin and draw upon the supports and coping skills that have helped during prior hospitalizations. You and your family are already models of resilience!

“Siblings can often feel overlooked when the focus is on surgery and recovery. It is important to help them feel as involved as possible. We found that sharing age-appropriate details helped our daughter to understand what was happening and limited negative feelings.”

Trent, Heart Dad



Sibling Resources

- **Child Life Specialists and Social Worker**
Ask for these specialists at your care center to see if they can help discuss ways to support siblings before and during visits to the hospital
- **Play Spaces and Programs**
Ask about your care centers options and activities for children, including siblings
- **Beads of Courage**
Siblings can help participate together with the patient. Older children can help keep track of beads earned, while younger can help string them. Some hospitals even have bead programs for siblings too.
- **SibShop**
siblingsupport.org/about-sibshops/find-a-sibshop-near-you
A support workshop for brothers and sister of children with chronic illness. Visit the website to see if there is one in your area.

Books

- *My Brother Needs an Operation* by Anna Marie Jaworski
- *What About Me? When Brothers and Sisters Get Sick* by Allan Peterkin
- *When Molly Was in the Hospital: A Book for Brothers and Sisters of Hospitalized Children* by Debbie Duncan



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