



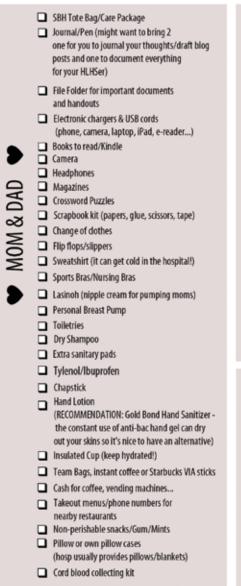
A guide to communicating with your child's care team



www.jcchdqi.org/parents



Suggested Hospital Pack List





■ Sweatshirt



The National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC) is a group of parents, physicians, nurses, nurse practitioners, surgeons, and dietitians working to improve care for children needing a three-staged open heart repair (i.e. HLHS).

This booklet was prepared by NPC-QIC and Sisters by Heart, a parent non-profit organization, as a guide for questions to ask the cardiac team and surgeon regarding your child's care.

We hope these questions prepare you for the medical journey ahead and help foster a good, working relationship with your child's medical team.



Discovering your child has a heart defect is shocking... **Words of Wisdom we'd like to share.**

SUGGESTED QUESTIONS TO ASK THE CARDIAC TEAM **About Your Hospital/Cardiac Center**



- Sometimes you have time to research, sometimes you don't. Remember, not everything you read on the internet is accurate. Discuss findings and concerns with medical professionals.
- Each child is different, each family is different; only you can decide what is best for you and your baby.
- The suggested questions in this booklet may be overwhelming

 don't feel pressured to ask them all at once and don't feel you
 need to ask them all.
- Information regarding your child's care can be confusing, especially numbers and data. Ask your center to explain their numbers and data in a way that you can understand.
- Communication with your child's care team is important. Be open and honest about your feelings and expectations for your child.
- Remember that your child's medical team is there to help you and your child; they care about your family's well-being.
- If you're concerned about the care your child is receiving, you
 may get a second opinion from another doctor or cardiac center.
 Ask your child's medical team or Sisters by Heart for guidance on
 how to obtain a second opinion.

 Can you tell me more about your center? Why is your center the best option for the care of my child? How many Norwoods/Hybrids has your program done in the last year? Over the last 5 years? 	
2. What are your surgeon's expected survival rates from birth through the sequence your center's overall survival rates from birth through Glenn? How do you other centers' survival rates?	ır survival rates compare with
3. What are the most common complications following a Norwood/Hybrid? of babies need re-intervention (cardiac catheterization or surgery) in the 1.	
Do your surgeons hold sub-specialty certification in congenital cardiac sur surgeon who will perform my child's surgeries?	rgery? When can I meet with the
 Does your program participate in the National Pediatric Cardiology Quality (NPCQIC), Society of Thoracic Surgeons (STS) Database, and/or Impact Reg 	
6. How am I included in decision-making regarding my child? How can I combefore, during, and after surgery? Who is on my child's care team and what cardiologist, surgeon, ICU team, outpatient team, etc.)?	
7. How do you decide when my child will have each surgery - Norwood, Glei certain criteria (weight, age, etc.) my child must meet prior to each surgery	

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SUGGESTED QUESTIONS TO ASK THE CARDIAC TEAM About Your Hospital Stay

SUGGESTED QUESTIONS TO ASK THE CARDIAC TEAM **Looking Ahead**



8. How long can I expect my child to be in the hospital after the Norwood? Glenn? May I participate in daily clinical "rounds" when my child's health is discussed with the care team?	17. What can I expect for the next few years as my child develops and grows? Can he or she play sports? Are there potential life-long complications my child may experience?
9. What are your visiting policies? Am I allowed to stay with my baby overnight? Can you help prepare siblings for hospital visits?	18. Developmentally and socially, what can I expect for my child as a preschooler, school-age child, a teenager, and as an adult? Do you have a neuro-developmental program my child can participate in?
10. What are my options for when, where and how to deliver my baby? When and how do you communicate with my OB/GYN regarding delivery and perinatal care?	19. Do you have a plan for transitioning my child from pediatric to adult care?
11. When and how do you communicate with my child's pediatrician following birth, procedures, and surgeries? When do I need to identify a pediatrician for my child and can you provide guidance in my search?	Additional Notes:
12. Who will care for my baby between birth and his/her first procedure? After the procedure? Do you have a dedicated Cardiac Intensive Care Unit (CICU)? Can I tour your heart center? Are physicians in the CICU board certified in both cardiology and critical care?	
13. Will I be able to hold my baby before and after his/her Norwood? If so, when and how?	
14. How will I feed my baby before and after their first surgery? Can I breastfeed? If so, what supports do you have for breastfeeding? What percentage of babies eat by mouth when they are released from the hospital after the Norwood?	
15. Will my baby be sent home after his/her Norwood recovery? How will you prepare me to care for my baby at home? Does your center require interstage monitoring? If so, who is responsible for my baby's care during the interstage period?	
16. What support is available for me and my family? Do you provide any professional or peer support? Do you provide financial, nutritional, mental health, and developmental guidance?	