

Questions for Parents to Ask About Hypoplastic Left Heart Syndrome (HLHS)

Finding out your child has hypoplastic left heart syndrome (HLHS), and learning how to manage it, can be overwhelming. It's important to understand the condition, communicate your concerns, recognize your options and know what questions to ask your doctor.

Karla's list of questions to ask your cardiac surgeon

Karla, a mom whose 3-year-old son has HLHS, knew how important it was to keep a running list of questions for each appointment so she would remember what to ask. She shares her list of HLHS questions that parents of newly-diagnosed children might forget - or not even know - to ask.

Questions to ask when your child is diagnosed with HLHS

1. Now that I know my child has a heart defect, what are the next steps?
2. What are the treatment options for HLHS?
3. Why is your center the best option for my child?
4. How many surgeries do you perform each year for the Norwood, Glenn and Fontan?
5. How often will I need an ultrasound or echocardiogram during my pregnancy?
6. Can you explain the surgical procedures my child will need?
7. How am I included in the decision making for my child?
8. What are your outcomes and survival rates for the Norwood, Glenn and Fontan procedures?
9. Do you have resources to help families cope with a diagnosis like HLHS?
10. Are there support groups for parents?
11. Can you connect me with other HLHS families?
12. What kind of support and resources do you have for siblings?

Questions to ask your cardiac surgeon before your child's HLHS surgery

1. How long is a typical hospital stay after each surgery?
2. What is the difference between pediatric anesthesia, cardiac anesthesia and general anesthesia?
3. Do oxygen saturation levels improve after each surgery?
4. How long will my child need to be on oxygen after each procedure?
5. What kind of monitoring and support do you offer between the Norwood and the Glenn?

Questions to ask after all HLHS surgical procedures

1. How often do we need to schedule follow-up visits?
2. How long do you follow and support my child?
3. What will life look like for my child a year or two from now?
4. Is it safe for my child to run and play after they recover from each surgery?
5. Will my child have psychological delays or other problems we should be aware of as they get older?
6. What kind of feeding and nursing support do you offer?
7. What can I do to help my child have a successful recovery?

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