

## **Discharge: The Top Ten Things You (*hospitals*) Can Do to Best Prepare a Parent for Interstage**

1. All parents should be armed with an interstage monitoring program and the necessary supplies for interstage care and monitoring: Pulse ox machine, infant scale, care binder or dedicated pages to record specific information (BP/Sats/Weight/intake, meds given, etc.). Most interstage parents feel that all of these supplies are necessary tools that help parents track changes and concerns during the interstage period. “Interstage monitoring” training should begin in the step-down unit so parents can get the hang of it for a few days prior to discharge.
2. Provide the parent a medication chart with dosage/administration directions, a proposed medication schedule and medication precautions list. The provided chart and schedule helps to eliminate parental anxiety regarding medication administration. Be certain parents know where they can obtain compounded medications before leaving the hospital. If the hospital pharmacy can provide a supply of oral syringes and caps, parents would be very appreciative.
3. Provide a nutrition and feeding schedule and contact information for a nutritionist/dietician when questions regarding feeding arise. Feeding issues occur over and over for interstage parents and we feel that a dedicated nutritionist/provider would greatly benefit our infants.
4. Recommended guidelines regarding exposure to outside risks (hand washing, sanitizing, visitors, etc.)
5. One-page handout delineating signs/symptoms of known complications along with contact information for a cardiologist or cardiac nurse practitioner which may be used at any time (24/7) for emergent situations. Additionally, provide an email address for this same provider for non-urgent questions and concerns. Parents feel like they are on a deserted island once home with their fragile HLH Ser. Knowing that you have a trained professional to contact 24/7 is a must for interstage parents.
6. Infant CPR education and training along with infant CPR instructions to post on the refrigerator at home.
7. Handouts regarding sternal care, scar and infant massage and physical therapy that can be done in-home by the parent during the interstage period. These modalities provide a way in which parents feel they can take control over their uncontrollable situation. Giving parents something they can “do” to help their infant is a simple and easy gift that cardiac centers can give a parent.

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8. Talk to your parents! Be certain they realize what being an interstage parent means – they will essentially be a nurse/doctor without a degree during those interstage months. Interstage is very much an isolating 4-plus months, which is “normal” for interstage families. There are tools provided by non-profits to find other interstage families – [www.linked-by-heart.org](http://www.linked-by-heart.org). Encourage them to reach out to others in similar situations to help ease the burden, gain a sense of community and diminish the sense of isolation.
9. Advise parents about REFLUX and that it is extremely common. What are the signs of reflux? Can dosages be increased? Can you order a change in reflux medications if one reflux med is not effective after a month or two? Provide tips on how to counter act reflux or avoid flare-ups.
10. Allow parents to TRUST THEIR OWN INSTINCTS. No question or concern is too small at this critical time. We’ve been given the task to keep an extremely fragile infant alive for several months and we want to be empowered with our “gut instincts.” Many times, the parent’s gut is accurate and we want to know you are listening to our thoughts and concerns.

Other areas of importance to an interstage parent:

11. Is there a communication plan between the treating cardiologist and pediatrician?
12. Social work can play a larger role in most centers to help parents prepare for interstage. Is insurance coordinated with supply companies, are parents set up with a compounding pharmacy, are there programs (WIC, Medicaid, Early Intervention) that can be applied for/set up prior to discharge, etc.? All of these things are horribly burdensome for a parent to figure out while they’re extremely anxious and doing all they can to keep their child alive.
13. Advise parents not to compare their child to another HLHS infant. All of these children come with their own complications and set of circumstances. This is often easier said than done, but a reminder prior to discharge is extremely helpful, especially when coming from a medical professional.
14. A pre-discharge meeting with child’s surgeon or cardiologist to explain the Norwood/hybrid, draw diagrams of their child’s heart post-op and explain what took place during surgery. Often, we are in such shock pre-operatively that we only retain half of what is stated. Each parent should have a good understanding of their child’s cardiac anatomy and their child’s baseline saturations and heart rate. This is particularly helpful if the infant was not prenatally diagnosed.