An Open Letter to New Heart Moms

Dear New Heart Mom,

We know the fear, the sadness, the devastation, and the anger you are feeling since your precious child has been diagnosed with a congenital heart defect (CHD). We know you are looking for answers, for information, for anything that will help you understand this and get through what is ahead for you. How do we know this? Because we have been there too. Here are some thoughts we put together to give you support and let you know you are not alone on this journey:

- You will feel tremendous guilt. It’s not your fault.
- Don’t compare your child to “heart-healthy” children. If you want to see if your child is meeting milestones, you need to ask your child’s medical professionals about what is normal for a child with his or her heart defect, not what is normal for a heart-healthy child your child’s age. And never, ever, ever read What to Expect when You’re Expecting!
- You choose who to listen to, take advice from, and rely on during your journey. Not everyone will understand what you are going through... but the ones who do, and who want to understand to help you, will be integral parts of your support system.
- It isn’t easy, but it will always be worth it. There will be a lot of tears, but also a lot of joy. Enjoy the small things, celebrate the milestones, even if they seem minor.
- Don’t be afraid to ask questions. If you feel like something is wrong, trust yourself and don’t be afraid to ask your child’s healthcare team. If you don’t like something, don’t agree or don’t understand, speak up. Ask them to explain it again, and again until you understand. Also, don’t be afraid to get a second opinion. Good and humble doctors will welcome a second opinion.
- You are your child’s best advocate. Often, mothers will notice or sense things that others cannot—maternal instinct is usually right.
- Educate yourself on your child’s diagnosis and any medical procedures your child may need, but use reliable sites from trusted sources. Don’t believe everything you read online. Sometimes even well-meaning people can give inaccurate information.
- Reach out to others (when you’re ready)—know there are others facing the same battles who are there for you when you need someone to talk to.
- Don’t be afraid to ask for help if you need it. It’s often hard for moms to feel like they can’t do it all, but you don’t need to be superwoman. Make a list of things people could help you with, and the next time someone asks, let them do one of the things on the list.
- Take some time for yourself. You are still a person and need time to recharge. It’s okay, and normal, to need a break. Even five minutes a day can do wonders.
• Stay positive and don’t let other’s opinions of the situation dictate your emotional well-being. Your child will pick up on stress and a negative environment. People will say things that may be offensive. Learn to let them roll; they just don’t know any better and most of the time it’s innocent ignorance.

• Take care of yourself when you are in the hospital. Don’t be afraid to leave your child’s side—you have the most expensive babysitters your child will ever have. Get rest when you can, drink lots of water and go for a walk once a day. Getting outside of those hospital walls, even once a day for a couple of minutes, will help make you feel better.

And last, but not least,

• YOU CAN DO THIS! You are stronger than you think!

Happy Mother’s Day!

Love, Your Fellow Heart Mom