

Dear Fellow Parent,

At this moment you may be feeling overwhelmed. Hearing the diagnosis that your precious child has a heart condition can stop you in your tracks. Your emotions might be all over the place. You may be scared. You may be sad. You may feel a sense of grief. Please know whatever you are feeling right now is OK and normal. Some days you may feel confident and hopeful and other days you may feel discouraged and confused. It can feel like an emotional rollercoaster. You do not have to figure it all out right now. It's OK to pace yourself on this journey. Take time to sit and process what this may mean for your child and family.

You are not alone. Although no one's journey is the same, many of us have had the rush of emotions run over us as we were faced with an unknown future. We want to stand beside you, to comfort and assist you with sources of support, care, knowledge and encouragement to help you rise to the challenge and embrace your family's new normal. There are many heart kiddos who are functioning well and thriving.

This is hard. You are doing everything you can. Your child will find comfort through your support in this journey. You know your child best and are their best advocate. Believe in yourself and in your child. Have grace with yourself on the bad days and take breaks when necessary. Allow your family and friends to help. Use the tools that are available to you. Talk to your doctor and other members of the health care team about your needs and your child's needs. You may have concerns about feeding tubes, surgeries, medications, cognitive effects and what the future holds for your child and family. Fortunately, Children's Mercy provides the best heart team who will help you understand your child's diagnosis and suggest treatment options for your child. We are hopeful that through inpatient stays, clinic appointments and programs available to you at Children's Mercy, you will find peace and understanding.

Every parent copes differently. Know there are numerous resources available—parent support groups, nutrition resources, counseling referrals and emotional and medical guidance. The Heart Center Thrive Team can help you better understand what resources and supports are available to your family.

Remember we walk with you. Be patient, take it one day at a time and enjoy the happy moments.

With hope for the journey,
Fellow Parents of Heart Warriors

