

## This is Heart Month ? A mother explains what being a Heart Mom has meant

By Melissa Kottelenberg

In November 2008, when our son Tyson was born, our world changed forever and we became a Heart Family.

I already had seven years' experience being a Mom, but being a Heart Mom is different. It's not better, it's not worse; it's not inferior or superior. It's just different.

What does it mean to be a Heart Mom? Being a Heart Mom means never looking too far ahead in the future, but trying to live each day in thankfulness and praying you get to enjoy many more. It means taking things one day at a time, and some days it means taking things one hour at a time. It means preparing for the worst, and hoping for the best.

Being Heart Parents means we had to brush up on our knowledge of the heart anatomy and how it works, because in three short days our newborn son was having his first of three palliative open-heart surgeries. We had three days to try and understand what the cardiologists meant when they told us "your son has very serious, complex congenital heart defects."

We had to try to understand the complexity of his heart and what the surgeons planned to do to help, and then try to mentally prepare ourselves to lay our newborn son on the operating table so that the surgeon can stop his heart, open his sternum, and re-knit his tiny, strawberry-sized heart.

Being Heart Parents means nervously waiting hours in the surgical waiting room, hoping and praying that the surgeon's hands are steady, praying that the heart and lung machine will keep our son alive so that he will be given back to us again when it's over. It means spending hours by our son's bedside, watching him fight for his life on life-support, with so many tubes and wires you can't even count them, with monitors and machines beeping constantly.

Being a Heart Family means learning and developing a new kind of "normal" when we finally get home from the hospital. It means learning and administering several different medications. It means low-fat feeds, pumps, NG tubes and reflux. It means needles, X-rays, ECHOS, ECGS, antibiotics and IVs. Blood thinners, sedation, MRIs, heart cath, stickers and bravery beads. It means that hospital visits aren't scary at all, because in a sad sort of way, it kinda feels like home.

When he sleeps too long or he doesn't answer immediately when we call his name, we worry about cardiac arrest or stroke. If he drinks too many fluids, it could put undue stress on his heart. If he doesn't drink enough, he could dehydrate and be at risk for a stroke.

Being a heart family means monitoring daily fluid intake, and always watching and monitoring sleep patterns, behaviour, colour and activity levels; checking respiratory rate, heart rate and oxygen levels. Does his cough sound wetter today than yesterday? Is he coughing because he has a cold or is it the start of heart failure? Is he looking bluer today? Does he look puffy? When was the last time he went pee ? is he retaining fluids? Did he meet his required daily fluid intake? It means analyzing every little cough or sneeze. And trying not to worry, trying not to expect the other shoe to drop. It means owning medical equipment you never knew existed, like pulse oximeter monitors and CoaguChek machines. It means owning an AED and praying you never have to use it.

Being a Heart Family means sometimes spending Christmas, New Year's or long weekends in the hospital.

Being the sibling of a heart child means learning to roll with the punches, knowing that we can never etch our plans in stone because they are bound to change in a heartbeat. They develop an early understanding of life and death, heaven and Jesus, and have experienced the truth that God always carries us through.

Being a Heart Family also means never taking a single day for granted and counting each and every little blessing. We make the best of our quality time, because we never know when our time will run out. It means rejoicing over all the little milestones that maybe we'd otherwise take for granted. And thanking God every day for His grace and mercy, acknowledging that it's all because of Him that we have the blessed opportunity to know and love: a living, breathing miracle.