

HEART MATTERS



Alice's Heart Journey

By Jessica Dalton

My journey as a parent to a complex heart kid began at my 20 week ultrasound. I was pregnant with twins when we learned that Twin B was heart healthy, but our Twin A had a long list of heart defects, as well as her organs being positioned differently than expected. After meeting with the cardiologist, we learned that our baby had heterotaxy, specifically right atrial isomerism, along with a very complex single-ventricle heart. There were also things we simply couldn't know while she was still in utero. We didn't know whether she would have Primary Ciliary Dyskinesia, whether she had a functioning spleen, or whether she had intestinal malrotation.

Because of all those unknowns, we really didn't know what to expect after birth or what her life would look like. We were simply preparing ourselves for our heart baby to be born struggling. The twins were born full term, and both Alice, our heart baby, and Emily were pink, thriving, and healthy. Alice surprised everyone. She didn't need any support or intervention after birth. There was no immediate crisis, no rush to the NICU, and no intervention needed. Instead, we got to spend those precious first moments doing exactly what every new parent hopes to do, cuddling our babies, soaking them in, and simply being together. For a little while, we could just be a family of five.

Because of the complexities of Alice's diagnosis and all the uncertainty surrounding what the future might hold, we had Canuck Place alongside BC Children's Hospital to support us, no matter what happened. At the time, we didn't know just how important that support would become.

As the weeks went by, Alice continued to grow and thrive. She was doing so well that we were able to complete some of the additional testing we had been waiting for. Thankfully, we learned that she did not have many of the additional challenges that can come with heterotaxy. But after two months of life, we started to see signs that Alice's heart was struggling to keep up with her growth. Plans were made for her first open-heart surgery. For most children with single ventricle heart defects, the surgical journey typically happens in three stages: first a shunt, followed by the Glenn surgery, and eventually the Fontan surgery. But Alice had already surprised us by making it two months without a shunt and was doing remarkably well. Because of that, her surgeon suggested taking a different approach and we skipped the shunt altogether, going straight to the Glenn surgery.

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WHAT'S HAPPENING

Coffee Groups Near You

If you would like to organize a coffee group for heart parents in your community, please contact Sam Aitken at saitken@childrensheartnetwork.org and we can get you set up with a coffee card for drinks and treats!

ABBOTSFORD - Rupe Brah - rupe3395@gmail.com
CHILLIWACK - Jenna Winterhoff - jennawinterhoff@gmail.com
SURREY/LANGLEY - Ashlee Forero - ashlee.gugins@hotmail.com
MAPLE RIDGE - Meghan Fabbi - safabbi@gmail.com
NANAIMO - Sandy Barlow - sandygbarlow@gmail.com
SUNSHINE COAST - Courtney Carolei - courtneycarolei@gmail.com
VANCOUVER - Samantha Aitken - saitken@childrensheartnetwork.org

Hearts of Gold – Lower Mainland and Victoria

Hearts of Gold is a community for teens aged 13–18 who have congenital heart conditions. The group meets monthly for fun and engaging activities, including hockey games, ceramic painting, dinner and a movie, skating, bowling, Playland visits, and an annual trip to Camp Zajac.

If you are a heart teen or a parent of one and would like more information about joining a Hearts of Gold group, please contact the appropriate coordinator:

- Lower Mainland: Emily Deimling - chnheartsofgold@gmail.com
- Victoria/Island: Kirsten Stratton - viheartsofgold@gmail.com



Heart & Soul: An Introductory Guide for Families Living with Congenital Heart Disease

This guide was developed by heart families and heart professionals for new heart families. [Read more here](#), or check it out on our website: childrensheartnetwork.org.

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ABOUT

Heart Matters is the newsletter of the Children's Heart Network, which works to educate, support, and enhance the lives of children, youth, and families living with congenital heart disease.

The views expressed in this newsletter are those of the authors, and not necessarily those of the board of the Children's Heart Network. The best sources of medical information are your child's physician and the health care professionals who provide care for your child.

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Hearts of Gold Reunion



Recently, one of our Hearts of Gold (HOG) grads, Jillian Wiebe, hosted a reunion, and there was a wonderful turnout! These young adults first met through monthly HOG events and camp over the years, forming friendships that have truly stood the test of time. Growing up with heart disease gave them a shared understanding and a unique connection that helped create lifelong bonds.

It's so exciting to hear about what they're up to today and to celebrate their incredible accomplishments! Seeing these friendships continue into adulthood is a beautiful reminder of the lasting impact of community and connection. Thank you, Jillian, for bringing everyone together and for helping inspire the next generation of young heart families.

My name is **Callaghan**, I am 30 years old. I am a homeowner with a dog and a cat. I have Hypoplastic Left Heart syndrome. I am married, my wife is named Fara. I love driving fast, raves, food, cooking and animals. And, I have 27 tattoos! My best friend is Zuleika! Yay!

My name is **Zuleika Boya**. I am 27 years old and I am a high school teacher. I have an Aussie Doodle named Benedict and he is a cutie pie! My heart condition is Tricuspid Regurgitation. I now have an aluminum ring in my heart. I love to read, hike and spend time with my friends!

Hi, my name is **Joey Dachwitz**. I am a Biomedical Engineering Technician from Kelowna, BC. I was born in 1996 with a heart condition called Aortic Stenosis. I had the Ross Procedure in 2007 to replace my aortic valve with a pulmonary valve. I stay involved in healthcare through my work at GE Healthcare. My job is repairing and maintaining CT, MRI and Ultrasound equipment. Thanks to my procedure I get to live an active lifestyle doing tons of hobbies like long distance running, kayaking, mountain biking, X-country skiing and curling.

My name is **Sydney Walker**. I am 31 years old. I was born with Hypoplastic Right Heart syndrome. I have had three open heart surgeries (the Norwood, the Glenn and the Fontan). I had a pacemaker when I was a baby, but had it removed when I was 4 years old. I am a preschool teacher, and I like to read, go for walks, bake and spend time with friends and family!

My name is **Daniela Lester**. I am 27 years old and work for the BC government in Pharmacare. My heart condition is Truncus Arteriosus Type 2 and I have a mechanical valve. I am living in Victoria and I am engaged. I love reading, spending time outdoors, exploring new coffee shops and spending time with my friends.

My name is **Sophia Draper**. I am 27 and I am a Speech language Pathologist. I work at the BC Centre for Ability with children aged 0-5 years old. I have a mechanical mitral valve, and I have had a COA and ASD repair. I have had two open heart surgeries. I live in Vancouver with my fiancé and I love being outside, hiking, going to new cafes and breweries and reading.

My name is **Danielle Karlsson**. I am 36 years old and I own food trucks with my family. I am married with 2 beautiful boys. I have Mitral Valve prolapse. I love musicals, dogs and spending time with my family.

My name is **Jillian Wiebe**. I am 32 years old and was born with Hypoplastic Left Heart syndrome. I have had three open heart surgeries, the first when I was 36 hours old, the second when I was 5 months old and the third when I was 3 years old. I am a full-time nanny for 3 families. In my free time I enjoy knitting, going to the gym (at 5:30am) and spending time with family and friends.

My name is **Eric Dickie**. I am 30 years old and I have a condition called Aortic Stenosis. To date I have had four surgeries. Two years ago, I got married to my wife. We enjoy hiking, paddle boarding and cycling. Currently we are training for the 2026 Vancouver Sun Run.

Hello, I am **Samantha Armstrong**. I was diagnosed with Epstein's Anomaly and an Atrial Septal defect when I was born. I am now working as a Social Worker for Correctional Services. I am getting married in May 2026 to my fiancé Derek. We bought our home last year in Langley where we live with our two cats and a bearded dragon. I love to read, travel and hike.

Alice's Story (cont'd from page one)



It was a big risk. Alice was only two months old, and doing a Glenn at that age was not without its challenges. But Alice absolutely amazed us. She did incredibly well. She spent just one day in the Cardiac ICU, followed by two days in cardiac stepdown, and then, unbelievably, she was home on day three. It was surreal.

After that, life was pretty good and normal for a few months but then we started slowly seeing some changes. She stopped sleeping well, her fingernails began to club (widen and bulge) and she became obsessed with eating dirt and sand. It wasn't easy to figure out what was normal development and what was a sign that something was wrong. Then she started having fragility fractures and her blood work results were trending in the wrong direction. At that point we knew there was something going on.

Just before Alice turned two, she was admitted to the hospital for a week of investigations. During that admission, she underwent a heart catheterization, and we finally got an answer. Alice had developed a massive veno-venous collateral vessel. This abnormal vessel was essentially creating a pathway that allowed blood to bypass where it needed to go. As a result, Alice's body had to work much harder to receive the oxygenated blood it needed.

Once the collateral vessel was closed, Alice was instantly like a brand new kid. That procedure bought us another two and a half years before it was time to take the next step in her heart journey. At 4½ years old, Alice was ready for her Fontan surgery.

Because of Alice's unique heart anatomy, her Fontan was a little more complicated than usual. Her Fontan pathway had to be placed on the lower left side of her heart and then connected up to the upper right side. She also needed a repair of her unbalanced common atrioventricular valve. We were prepared for a longer hospital stay while her body adjusted to its new circulation. But, once again, Alice had other plans. She was home in just six days. Yet again, we were completely amazed by her recovery.

Once Alice was fully healed from her Fontan, we were, and still are, in total awe of how much more energy she has. We have watched her thrive in kindergarten and now in Grade 1. She is funny, determined, energetic, and completely herself.

We know that life with a complex heart is not linear, and we have certainly experienced some bumps along the way. But one of the biggest things we have learned through our journey is that heterotaxy kids are notorious for marching to the beat of their own drum.

We have learned to pay attention to every little detail, to notice the subtle changes, trust our instincts, and listen when something just doesn't seem right. We have also learned that we don't have to navigate this journey alone. We have leaned heavily into the **Heterotaxy Connection** community, which has provided us with opportunities, knowledge, encouragement, and support as we navigate our own journey. Last year, our family even flew to Boston to attend a scientific and family conference hosted by Heterotaxy Connection.

It was an incredible experience to meet, in person, so many of the people who helped us along the way. We were able to connect with other families who truly understood what this journey is like, while also learning from doctors and experts who understand heterotaxy.

For anyone else living life with a child with heterotaxy, I cannot recommend connecting with Heterotaxy Connection enough. And if you are brand new to this journey, I hope Alice's story can offer you a little bit of hope. Trust your gut. Pay attention to the little things. Ask the questions. Find your people. And most importantly, know that these kids are so incredibly resilient.

Alice's Story (cont'd from page five)



The community that the **Children's Heart Network** has built has also brought so much support, connection, and so many amazing experiences and memories to our family. The parent evenings offer a chance to connect with other parents who truly understand what it is like to navigate life with a heart kid.

The family experiences are something our kids look forward to as well. From the Easter and Christmas events, to the Critter Cove fishing trip and trips to the pumpkin patch, these experiences are amazing. Alice loves connecting with her "heart friends," and it has been wonderful for her siblings to connect with other siblings who understand each other in a way that is sometimes difficult to explain to anyone else.

In addition, the resource parent connections are invaluable, I cherish those conversations deeply. There is something special about being able to talk with another parent who has walked a similar path.

In between all of Alice's medical challenges, she's just a regular kid, living life on a farm. She gets dirty, she rides her pony, plays with her twin sister and older brother, goes to school, goes camping and loves going on adventures. This journey is not easy, but it is worth it.

RESOURCES TO EXPLORE



WEBSITE SPOTLIGHT

 **mindyourmind**
<https://mindyourmind.ca>

Mind your mind is a youth-focused website with practical tools, information, and resources to help youth and young adults manage stress, build coping skills, understand their mental health, and find support.

It's a safe place for youth to start when they're feeling overwhelmed or looking for ways to support their mental well-being.

PODCAST SPOTLIGHT



Episode 32: Caregiver burnout in Medical parents - How to recognize it before you crash

- What caregiver burnout looks like—and why it can be hard to recognize.
- Why the transition from hospital to home can be especially overwhelming.
- What self-care really looks like, including the idea of "mothering yourself."
- Why "you're so strong" can feel isolating for medical parents—and how this changes over time.

ARTICLE SPOTLIGHT

What Educators should know about CHDs
<https://cnd.bostonchildrens.org/resources/what-educators-should-know-about-learners-with-congenital-heart-disease>

About 1 in 100 students has a congenital heart defect (CHD), and for many, CHD can affect learning. Yet teacher training programs rarely prepare educators to support students with CHD. While every student is different, many share common learning needs. Knowing what to look for can help educators recognize these needs and provide support early.

Community Resource Spotlight: Langley Community Services Society (LCSS)

Looking for family counselling support? LCSS offers counselling for families in the Langleys parenting children 14 and under, along with parent education and referrals - services many of our CHN families have told us they need. LCSS was also recently awarded funding through the 100 Women Who Care program. Learn more at lcss.ca.

Meet our new Island Hearts of Gold Coordinator!



Kirsten Stratton

I am a Certified Child Life Specialist, currently practicing at Victoria General Hospital.

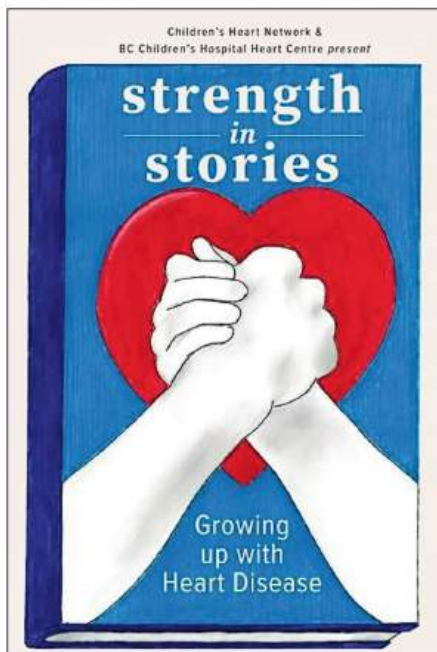
I spent most of my career working at BC Children's Hospital but relocated to the island last year.

During my career I have worked with a number of patients and families impacted by heart disease and also have a nephew who had open heart surgery at a two days old.

I am a mom of two littles ones so am currently spending my free time exploring all the new playgrounds in Victoria.

I am very excited to get to explore Victoria during the fun monthly events and getting to know the teens in the group.

Growing Up With Heart Disease - Strength in Stories November 14, 2026



Every heart journey is unique. Behind every diagnosis, surgery, milestone, challenge, and success is a story with the power to inspire, connect, and teach.

This year's theme, *Strength in Stories*, celebrates the experiences of children, youth, young adults, families, and professionals who are part of the heart disease community. Stories help us make sense of difficult experiences, find hope in uncertain times, and remind us we're not alone - creating connections between families facing similar challenges, empowering young people to share their voices, and offering insight for the healthcare professionals who support them.

Throughout the conference, we'll explore how lived experience builds resilience, strengthens community, and deepens partnership between families and care teams. Whether you're a parent, youth, caregiver, or healthcare professional - your story matters. Join us in discovering the strength of our collective experiences, together.

[Register today.](#)



Preparing Your Child for Open-Heart Surgery: A Child life Perspective

By Dawn McKellar, BA, CCLS - Education Coordinator

Learning that your child needs open-heart surgery can feel overwhelming. As parents, our instinct is often to protect our children from worry and fear. However, research consistently shows that children cope better, experience less anxiety, and often have a more positive recovery experience when they receive honest, developmentally appropriate preparation before surgery. While every child is unique, there are many ways parents can help their child feel more informed, confident, and supported as they prepare for surgery. Taking time to prepare your child can help reduce uncertainty, build trust, and provide them with coping tools for the hospital experience ahead.

Why Preparation Matters

Fear and anxiety are common for children and teens facing heart surgery and a hospital stay. Some of the most common worries include pain after surgery, separation from parents, fear of the unknown, uncertainty about hospital routines and expectations, and a loss of control. Preparing for surgery gives children and youth an opportunity to learn about what will happen, ask questions, express their concerns, and develop coping strategies before they arrive at the hospital. This can help reduce anxiety and support a smoother adjustment during recovery.

Parents experience their own fears and stress leading up to their child's surgery. Common concerns include the risks of the procedure, uncertainty about what to expect, navigating the hospital environment, spending time in the intensive care unit, and seeing changes in their child's appearance, behaviour, or emotions after surgery. Parents may also wonder how to maintain their parenting role while their child is receiving care from a large medical team.

The goal of preparation is not to eliminate fear completely. Feeling nervous about surgery is normal. Instead, preparation helps children, youth, and families understand what to expect, build trust in the healthcare team, and develop coping strategies to manage difficult thoughts and feelings throughout the surgical journey.

Developmental guidelines for supporting your child/youth

One of the most important principles in preparing children and youth for surgery is honesty. Children often sense when something significant is happening. Providing truthful information helps build trust and prevents children from imagining scenarios that may be even scarier than reality.

Infants

Because infants have a limited understanding of illness, surgery, and hospitalization, preparation at this stage focuses primarily on supporting parents and caregivers. The most significant stressors for infants are physical discomforts, such as pain or fasting before surgery, and separation from their primary caregivers. Whenever possible, maintaining familiar routines and providing comfort through touch, holding, and soothing interactions can help reduce distress. Bringing a favorite blanket, stuffed animal, pacifier, or other familiar comfort item can also provide reassurance and help infants feel more secure during times when parents may not be able to be present.

Preschool Children (Ages 2–6 Years)

Children at this age are still developing their understanding of how their bodies work and may not fully understand why they need surgery. They often think in simple terms, such as "good" and "bad," and may create their own explanations for what is happening around them. Because of this, some children may worry that they did something wrong to cause their heart condition or the need for surgery. Separation from parents can also be particularly stressful during this stage of development, making familiar routines, comfort, and reassurance especially important.

One of the best ways to help preschool-aged children prepare for surgery is through play. Using a toy doctor's kit, stuffed animals, dolls, or books about hospital visits can help children explore their feelings, ask questions, and become more familiar with what to expect. Children often return to this type of play repeatedly as they work through their worries and gain a sense of mastery over the experience.

Many children in this age group benefit from meeting with a Child Life Specialist before surgery. Through play-based preparation and hands-on activities, Child Life Specialists can provide simple, honest explanations about what will happen, introduce some of the medical equipment they may see, and help make the hospital environment feel less frightening. Ask your healthcare team about Child Life services available at your hospital.

Simple Phrases to Use with Preschool Children

- "The doctors are going to fix a part of your heart that needs some help."
- "You will get special sleep medicine so you won't feel the surgery."
- "When you wake up, your body will be healing."
- "We will be with you as much as possible while you are in the hospital."
- "It's okay to feel scared, worried, or have questions."
- "The doctors and nurses will help keep you safe."

School-Age Children (Ages 7–12 Years)

Children between the ages of 7 and 12 are developing a greater ability to think logically and understand how their bodies work. They can often see situations from more than one perspective, connect past experiences to future events, and are naturally curious about how things happen and what to expect next. When preparing for open-heart surgery, children in this age group benefit from honest, concrete information provided several days before their procedure. Common worries include pain, loss of control, changes to their body, and missing school, sports, or other important activities.

At this age, most children understand that the heart is a muscle that pumps blood throughout the body. They can begin to grasp that their heart works differently than it should and that surgery is needed to help it function better. Simple explanations such as, "Your heart is a muscle that pumps blood around your body. One part of your heart was built a little differently when you were born. The doctors know how to repair that part so your heart can do its job better," can help children understand their surgery in a way that is both reassuring and age-appropriate.

At this stage a Child Life Specialists can provide age-appropriate education and support to help children understand what to expect and feel more prepared for their hospital experience. Together, they may review a preparation booklet that introduces different areas of the hospital, such as the operating room, pediatric intensive care unit (PICU), and inpatient unit. Children can learn about the healthcare team members they will meet and the important role each person plays in their care.

Preparation may also include discussing what will happen on the day of surgery, including changing into hospital clothing, having vital signs and measurements taken, meeting with the anesthesiologist, and waiting before the procedure. Children are given realistic information about recovery, including what they may look and feel like after surgery, the purpose of medical equipment such as IVs, monitors, and drains, strategies for managing pain and discomfort, the importance of movement and deep breathing, and what to expect as their incision heals.

By providing honest information, addressing misconceptions, and teaching coping strategies, children will build confidence to help reduce anxiety, and develop a greater sense of control during what can be an unfamiliar and challenging experience.

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Simple Phrases to Use with School-Age Children

- "The doctors are going to repair the part of your heart that needs help so it can work better."
- "You will receive medicine that helps you sleep during the surgery, and you won't feel it happening."
- "When you wake up, you may notice tubes, bandages, and monitors that are helping your body heal."
- "You can ask questions anytime, and we'll answer them honestly."
- "It's okay to feel nervous, scared, angry, or worried."
- "There are things you can do to help your body heal, like taking deep breaths, moving when it's safe, and telling us when something hurts."

Teenagers (Ages 13–18 Years)

Adolescence is a time of increasing independence, identity development, and growing responsibility for one's own healthcare. Teens are capable of abstract thinking and often want detailed, honest information about their heart condition, the surgery itself, and what recovery will mean for their daily lives. While they may appear mature and self-sufficient, many adolescents will still experience anxiety before surgery.

Common concerns include pain, loss of independence, changes in body image, scarring, privacy, missing school or extracurricular activities, falling behind their peers, and uncertainty about the future. Some teens may openly express their worries, while others may cope by withdrawing, minimizing their concerns, or avoiding conversations about surgery altogether.

Preparation for surgery should respect a teen's growing need for autonomy while ensuring they have accurate information and opportunities to ask questions. Whenever possible, teens should be encouraged to take an active role in their healthcare and participate in discussions with their cardiology and surgical teams. Involvement in decision-making not only helps with surgical preparation but also supports the development of skills that will be important as they transition to adult healthcare. Being honest, respecting their independence, and creating opportunities for meaningful conversations can help teens approach surgery with greater confidence, resilience, and a sense of control.

At this stage a Child Life Specialist can help teens understand the surgical process, what to expect before and after surgery, and how recovery may temporarily affect school, sports, work, social activities, and family life. Discussions may include pain management, medical equipment they may see after surgery, activity restrictions, the healing process, and realistic expectations regarding scars and recovery timelines.

Because peer relationships are often central during adolescence, conversations may also focus on maintaining connections with friends, staying engaged with school, and managing questions from others about their surgery. Child Life Specialists can further support adolescents by helping them identify coping strategies that fit their personality and preferences, such as music, mindfulness, journaling, creative expression, technology, or connecting with peers who have had similar experiences. Learning and practicing these coping skills before surgery can help teens navigate the postoperative period and continue to draw on these strategies long after they leave the hospital.

Simple Phrases to Use with Teenagers

- "You deserve honest information and answers to your questions."
- "It's normal to have concerns about surgery, recovery, and what comes next."
- "Let's talk about what you're most worried about and what might help."
- "You can be an active member of your healthcare team."
- "Recovery can be challenging, but we'll help you develop strategies to manage it."
- "You're not alone."

Children with additional support needs

Children with developmental differences, neurodivergence, sensory sensitivities, or communication challenges may benefit from additional preparation and support to help them feel safe, understood, and confident throughout their hospital experience. While every child is unique, thoughtful preparation can reduce anxiety, strengthen coping, and help the entire family feel more prepared for the journey ahead.

Your knowledge of your child's personality, preferences, and needs is one of the most valuable tools in helping the healthcare team provide individualized care. Before surgery, consider:

- What helps your child feel calm, comfortable, and secure?
- How do they communicate fear, pain, stress, or discomfort?
- Are there sensory sensitivities, such as loud noises, bright lights, certain textures, or unexpected touch?
- What coping strategies have been helpful during previous medical appointments or challenging situations?
- Are there special interests, comfort items, routines, or activities that provide reassurance?

Sharing this information with your child's healthcare team can help them tailor their approach and create a more positive hospital experience.

Recovery after open-heart surgery can be challenging for any child, particularly those who rely on routine, predictability, and familiarity. Preparing your child for what to expect after surgery can help reduce uncertainty and build confidence. Before surgery, talk with your child using a method that works best for them, whether that is a visual schedule, social story, countdown calendar, pictures, or simple explanations. Help your child understand that recovery happens in stages and that each day brings them one step closer to healing and returning home. It may be helpful to review:

- Medical equipment they may wake up with after surgery
- Changes in activity levels during recovery
- How pain and discomfort will be managed
- How parents and caregivers will continue to provide comfort and support
- Ways familiar routines can be maintained whenever possible

There is no single "right" way to prepare a child for open-heart surgery. Speaking with a child life specialist before surgery can help your child and family feel more prepared throughout the surgical journey. Child life specialists tailor preparation to a child's developmental level, learning style, communication needs, and individual strengths rather than focusing solely on age. They can create visual supports and social stories, use medical play and rehearsal to familiarize children with upcoming procedures, identify sensory accommodations that may increase comfort, and teach coping strategies for procedures and hospitalization.

A Final Thought

Children do not need perfect preparation—they need honest information, opportunities to ask questions, and caring adults who will support them every step of the way. Open-heart surgery is a significant experience for the entire family, but preparation can help transform fear of the unknown into confidence, trust, and resilience.

By combining information, play, emotional support, and family-centred care, parents can help their child face surgery feeling informed, supported, and ready for the journey ahead.

This article was informed by the following resources: American Academy of Pediatrics. (2021). Preparing Children for Surgery and Procedures. | Association of Child Life Professionals. (2024). Child Life Services. | Autism Speaks. Hospital Preparation Toolkit and Healthcare Resources for Children with Autism. | Campbell, L. A., et al. Preparing Children with Congenital Heart Disease for Cardiac Surgery. *Journal of Pediatric Psychology*. | Centers for Disease Control and Prevention. (2024). Developmental Milestones and Information on Neurodevelopmental Conditions. | Family Support Institute of BC. Children with Disabilities Toolkit for Healthcare Settings. <https://familysupportbc.com/toolkits/children-with-disabilities-toolkit-for-healthcare-settings/> | Koller, D., & Goldman, R. D. (2012). Distraction techniques for children undergoing procedures: A critical review of pediatric research. *Journal of Pediatric Nursing*, 27(6), 652–681. | Li, H. C. W., Lopez, V., & Lee, T. L. I. (2007). Psychoeducational preparation of children for surgery: The importance of parental involvement. *Patient Education and Counseling*, 65(1), 34–41. | Melnyk, B. M., & Fineout-Overholt, E. (2019). Evidence-Based Practice in Nursing & Healthcare (4th ed.). Wolters Kluwer. | Society of Pediatric Psychology. Evidence-Based Resources for Preparing Children for Medical Procedures and Hospitalization. | Sorensen, H. L., et al. Using a Collaborative Child Life Approach for Continuous Surgical Preparation. *AORN Journal*. | The Arc. Resources for Supporting Children and Youth with Intellectual and Developmental Disabilities in Healthcare Settings. | Thompson, R. H. (2018). *The Handbook of Child Life: A Guide to Pediatric Psychosocial Care* (2nd ed.). Charles C Thomas Publisher.

Heart Heroes!

“Volunteers do not necessarily have the time; they have the heart.” — Elizabeth Andrew



Adrie Ip

Adrie is a 10-year-old girl who loves sewing and helping others. Her inspiration and motivation to create a project this summer came from her experiences at BC Children's Hospital, where she has seen many children recovering from open-heart surgery using beautiful heart-shaped pillows. After open-heart surgery, children can hold or hug these pillows against their chests when coughing, sneezing, or taking deep breaths to help minimize pain and provide support and stability to the sternum. Knowing that children of different ages and sizes undergo heart surgery, Adrie thoughtfully made 25 heart pillows in a variety of sizes. Through this project, she hopes to bring comfort to children during their recovery and let them know that someone in their community is thinking of them.

Thank you, Adrie, for being so thoughtful! ❤️



Dee de los Santos

Dee is mom to heart warrior Winston and has been involved with the Children's Heart Network (CHN) for more than six years. Currently, Dee manages our website and social media, produces our newsletter, and is one of this year's Gala Coordinators. But her contributions to CHN go far beyond these roles.

Five years ago, inspired by her son Winston's experiences spending several summers in the Cardiac Intensive Care Unit, Dee created our **Heart Box Project**, a program that brings sunshine, smiles, and comfort to children in the Cardiac Intensive Care Unit (CICU) and Cardiology ward at BC Children's Hospital.

Every summer, dozens of children, from newborns to teens, spend their days at BCCH recovering from heart surgery. For many, it's their first summer, or their first extended time away from home, and instead of enjoying the season with family and friends, they find themselves under the bright lights of hospital care.

The Heart Box Project is our way of reminding these children: *You are not alone.*

Each lovingly assembled box is filled with thoughtful items designed to bring a little joy, comfort, and distraction during a difficult time. Whether a child is recovering from surgery or preparing for one in the days ahead, these small gestures can make a big difference, lifting spirits and reminding both children and their families that someone is thinking of them, cheering them on, and holding their hearts close.

For the past two years, Dee has created our **“1 in 100” T-shirts** (included in the Heart Boxes) featuring each heart warrior's name on the back. Through her dedication and countless volunteer hours, Dee has helped assemble and deliver nearly **200 Heart Boxes** to BC Children's Hospital.

The CHN Board of Directors would like to recognize Dee for her incredible generosity, creativity, compassion, and never-ending support of our heart families.

Thank you, Dee, for putting so much heart into everything you do! ❤️