

# Cancer Care Journey

Better journeys, better outcomes

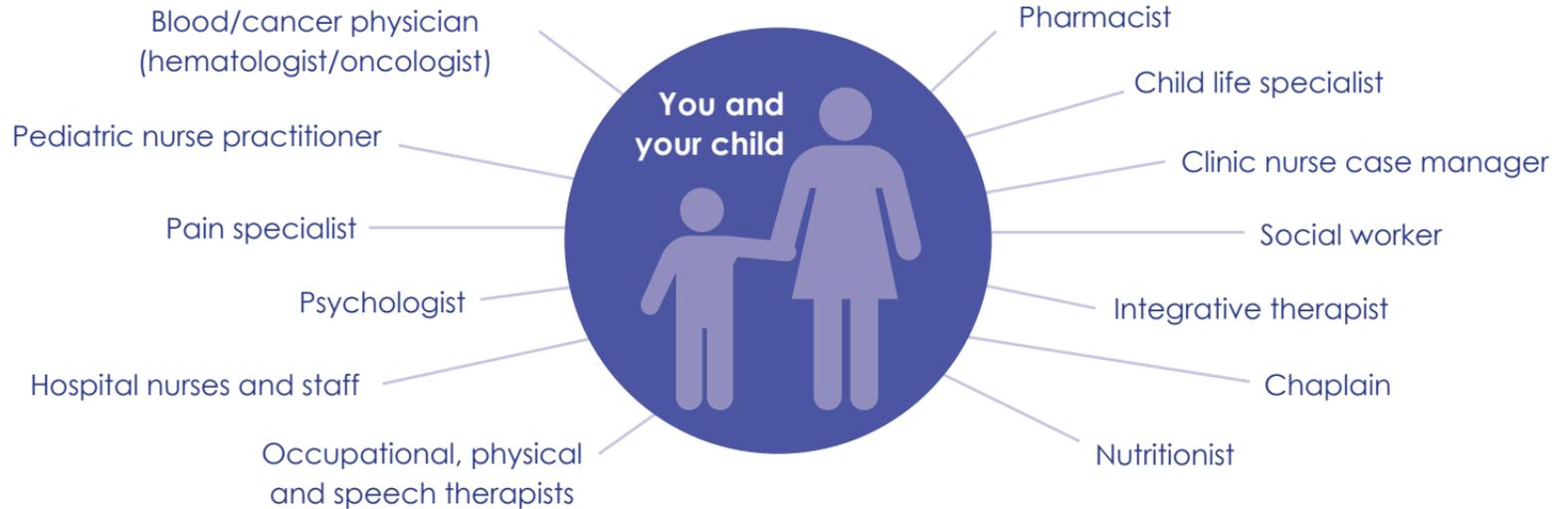
If your child is diagnosed with cancer, know that Children's Hospitals and Clinics of Minnesota will be with you every step of the way.



[childrensMN.org](http://childrensMN.org)

# Know you're on the right path

*Comprehensive care* is an approach that cares for the whole patient and all needs, not just the medical and physical ones. This starts by assembling the best team to treat and manage the needs of your child. At Children's we have had the privilege to treat and manage thousands of patients, which has provided a great opportunity to develop the best care journey for you and your child.



## What to expect

Cancer treatment journeys are broken into three phases:



There are many stages on the journey through cancer diagnosis and treatment, recovery and wellness and ongoing surveillance. We recognize that your family will have unique needs and we will focus on those unique needs, while supporting you with common themes of **your team**, **your care** and **your life** within each phase.



**Your team:** The whole team has experience and training in caring for kids. That's all we do.



**Your care:** Comprehensive care is an approach that cares for the whole patient and all his or her needs, not just the medical and physical ones.



**Your life:** We'll give you the tools and support you need every step of the way, and at any point if you have a question, simply ask.

# Phase 1: Diagnosis and treatment



## Your team

- Personalized treatment planning with your cancer (oncology) team and primary care provider and clinic
- Consultation with other pediatric specialists, as needed



## Your care

- Clinic and hospital visits scheduled with your cancer team
- Scheduled lab, x-ray, organ function and other tests, as needed.
- Planned and unplanned clinic and hospital visits
- Continued well care evaluations through your primary care provider and clinic
- Care Closer To Home for in-between labs and checkups
- Completion of treatment, recovery planning, central line removal



## Your life

- Coordination of school/ work life, home life, friends, wellness
- End of Therapy Celebration



## Meet Jaela O'Brien

On the ice, 13-year-old powerhouse Jaela O'Brien was unstoppable. An elite athlete and top-ranking goalie, she consistently gave 100% to protect the net and support her team.

But, she would face her biggest competitor off the ice: an unexpected and

unimaginable diagnosis, acute lymphoblastic leukemia.

The very same day she was faced with this devastating news, she also started her 158-week treatment plan: an obstacle she's confident she'll overcome.

Even though Jaela was temporarily benched, she was still surrounded by teammates. They just looked a little different. Instead of jerseys, they wore scrubs. And instead

of her defense to protect her on the ice, she had Deb, a nurse who would work doubles when Jaela was inpatient, just so she could be by her side. That's just how Children's nurses are.

After weeks of hospital stays, dozens of daily medications and waves of depression, Jaela didn't want to fight anymore. That's when her mom suggested an idea. One of the doctors got behind it, too. For the first time in nearly three months, Jaela was back on the ice. If only for a few moments, she felt like herself again. A month after she returned to hockey, Jaela dropped 17 as-needed medications.

Though she still remains in treatment for another year, Jaela is playing hockey at full-strength six days a week. Now, she not only has her teammates protecting her, she also has her care team at Children's walking with her. Every step of the way.

## Phase 2: Recovery and wellness



### Your team

- Visits with your primary oncology team members, which become less frequent with time from end of therapy
- Specialized evaluations of side effects from treatment with recovery and wellness team



### Your care

- Continued well care through your primary care provider and clinic, resuming/catch-up vaccines
- Evaluations of heart and lung function, nutrition, learning assessment, growth and development testing
- Consultation with other pediatric specialists, as needed
- Coordinated visits with physical, occupational and speech therapists, as needed
- Scheduled lab, x-ray, organ function and other tests, as needed and dependent on treatment plan



### Your life

- Access to periodic group gatherings for wellness education, yoga and exercise
- Assistance with transition to life after cancer therapy



## Meet Shepard Kelly

A month after his second birthday, Shepard Kelly ended up in the emergency department for what seemed like a pretty common circumstance for a toddler; he wasn't feeling well. Doctors didn't find anything wrong and sent him home. The very next

day, he was back in the ED with similar symptoms — except now, his breathing was erratic. This time, he didn't go home. He went to Children's Hospitals and Clinics of Minnesota in Minneapolis.

The next nine hours were full of tests, with a bit of waiting and a lot of anxiety. By 5 p.m., Shepard, along with his doctor and parents, took a walk they'll never forget. It was then they learned their toddler had acute lymphoblastic leukemia.

Within 24 hours of hearing the news, the Kellys were admitted and the two-year-old got his first dose of chemo. He would be in and out of the hospital over the next three years, fighting and overcoming each obstacle that came his way. One of his biggest challenges came when he was faced with a life-threatening infection that required hospitalization for 23 days.

Chemo caused some weakening of Shepard's muscles. Luckily two of his cancer care team members, Lynn and Katherine (physical therapists extraordinaire) came to the rescue. Through ongoing exercises like obstacle courses and hallway races, Shepard was able to strengthen his muscles and have a little fun.

In December 2014, more than three years after his life-threatening diagnosis, Shepard's treatment was completed and he is officially cancer-free. Now, he can focus all his energy on just being a kid.

## Phase 3: STAR Clinic (Surveillance and testing after recovery)



### Your team

- Scheduled annual visits with your STAR Clinic cancer team
- Consultation with other pediatric specialists, as needed



### Your care

- Evaluations of heart and lung function, learning assessment, growth and development testing
- Continued well care evaluations through your primary care provider and clinic
- Scheduled lab, x-ray, organ function and other tests, as needed and dependent on treatment plan



### Your life

- Access to periodic group gatherings for wellness education, yoga and exercise
- Assistance with transition to life after cancer therapy



## Meet Isabel Leininger

Ask Isabel Leininger where she started running and the answer might surprise you... while she was inpatient at Children's Hospitals and Clinics of Minnesota, battling leukemia.

A typically energetic and bubbly five-year-old preschooler, she often

became fatigued and out of breath. Isabel's mom Gretchen knew in her gut that something was wrong. A visit to the clinic confirmed that hunch, and within two hours the pair was sitting at Children's.

While she should have been at preschool munching on apple slices and reading about Curious George's latest adventure, Isabel sat quietly listening to the doctor tell her that she wouldn't be going back to school for awhile. She was sick.

Diagnosed with acute myeloid leukemia, she was given a 60% survival rate. The eighth floor of Children's would become her home for the next six months. Nurses took the place of friends. And instead of learning her ABCs, she was memorizing her daily medications.

"I knew I was sick, but I wasn't worried about dying. I didn't know how serious it was," Isabel — now 16 years old — says. "I do remember naming all the fish in the tank on the eighth floor, riding the trike down the hallway and making my mom time me as I ran laps around the floor."

Her mom laughs, "I swear she was always under a minute." She adds, "The freedom the staff gives the kids when they are feeling well was great; it allows them to feel and act like kids when they need it the most."

Now a high school sophomore, Isabel is cancer-free. She's also on the varsity track team. Rumor has it, she started running at a young age.

## Cancer Kids Fund helps kids be kids

Beyond providing the very best medical care, there are many services and amenities at Children's that provide extra care and comfort to kids and families in the midst of a cancer or blood disorders journey. These special services are made possible in large part through the Cancer Kids Fund. This fund is generously supported by community members, local businesses and benefit events hosted by or on behalf of Children's. Here are some of the special ways that the Cancer Kids Fund may help make your family's journey at Children's a little easier.

### The Cancer Kids Fund supports *patients* by:

- Arranging visits from special guests like the Zoomobile and the Science Museum of Minnesota and special celebrations like end-of-therapy parties
- Ensuring specialists like nutritionists, psychologists and care coordinators are part of each child's medical team
- Supporting complementary medical services like aromatherapy and massage therapy
- Offering a variety of art supplies, toys and games for patients of all ages

### The Cancer Kids Fund supports *families* by:

- Ensuring the services of chaplains, child life specialists, interpreters and social workers are readily available to all families
- Providing parking vouchers to help ease stress during visits
- Offering complimentary support services like our sibling play area and family resource center
- Supplying families with comforting in-room amenities during overnight stays

For more information on the types of financial assistance that may be available to you, please talk to your child's social worker.



## Never alone

Cancer or a blood disorder can be a difficult diagnosis to process. If your child has one of these conditions, you, your child and Children's will be on the journey together. We are always available to answer questions or address concerns — any time, day or night. Just pick up the phone and call us.

**Main:** 612-813-5940

**Toll-Free:** 888-811-5940

[www.childrensMN.org/cancerandblood](http://www.childrensMN.org/cancerandblood)



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