

Coping with cancer

RN helps families deal with the reality of life beyond chemotherapy.

BY JILL-MARIE BURKE

Is it okay to hug Joshua?" "Can we catch cancer from him?" "Is he going to die?" These are just some of the questions Vicky Wilton fields from elementary school students when the RN visits classrooms to explain that a fellow student has been diagnosed with cancer and has just started chemotherapy treatments.

Wilton assures the anxious children that it will be okay to touch their friend; cancer isn't contagious. She also prepares them for the day Joshua will return to school. She explains he won't have any hair, but he'll still be the same boy inside. Then she tells them there is always a possibility that he could die, but the doctors and nurses are very hopeful he won't.

Today, 90 per cent of children survive leukemia, compared to 60 per cent just 15 years ago. But living with the disease is still an emotional roller coaster for the families who are touched by it. As one of 10 Interlink nurses with the Pediatric Oncology Group of Ontario, it's Wilton's job to accompany them on the journey to health and help them make sense of the twists, turns and dips along the way.

Wilton's relationship with a family begins when a fellow Interlink nurse or social worker at the Hospital for Sick Children in Toronto or the Children's Hospital of Eastern Ontario (CHEO) in Ottawa calls to say a child from northern Ontario is receiving chemotherapy at their hospital. Wilton says it's common for families to make the trip south because Sudbury doesn't have a pediatric oncologist. Wilton phones the parents to introduce herself, describe the help she can provide, and make arrangements to meet them when they return home from having treatments in southern Ontario.

Her first face-to-face meeting with families, who live anywhere between Thunder Bay and Parry Sound, normally takes place in the family's home. Since their child has just completed the intensive, initial round of chemotherapy called induction, Wilton says parents usually have a



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good understanding of their child's cancer and the maintenance treatments he will soon begin receiving at the regional cancer program in Sudbury. However, they're overwhelmed at the thought of coping without the team of health-care providers who were just a short walk away when they were in Toronto or Ottawa. "They need to be acquainted with what's available in their communities," she says.

As a former home care nurse, Wilton says she jumped at the chance to become an Interlink nurse in 2007, because it allowed her to combine her experience in the community with the 12 years she spent working in adult medical oncology, palliative care and pediatrics at Sudbury Regional Hospital. Today, her role encompasses everything from finding the nearest lab where kids can go for tests, to helping families cope with the day-to-day realities of having a sick child at home.

Wilton says most parents need to figure out how they can afford to stay home with their child. She helps them access compassionate care benefits or arrange a short-term leave of absence from work. If school age children feel well enough to start learning again, she'll contact the school board to

arrange for a teacher to come to their house. She also links them with child life specialists who can help children who've had an arm or leg amputated learn to live and play again.

Sometimes, Wilton is also a travel agent. If families need to go back to Toronto or Ottawa for appointments, she will help them access grants to offset travel costs, arrange accommodation, and link them with a support group that provides grocery coupons, long distance telephone cards and parking vouchers.

Wilton has also been involved in projects that would be more common for a general contractor than an RN. When one young boy couldn't be exposed to dust because he'd just had a bone marrow transplant, she called a local service club and arranged to have all the carpets removed from the family's home.

No matter what she does for them, Wilton says it's a privilege to help families get their lives back on track. "One of the biggest rewards is sharing this experience with families," she says. "Being able to go into their homes, being part of the school, being privy to their financial information – and knowing that they trust you."

Because Wilton knows the families she works with so well, she says it's hard to watch them struggle financially, mentally and physically and to know that she can only help them so much. "Cancer is like a big cloud hanging over their heads all the time. Even when the child seems better, you never know what's going to happen tomorrow. So it's always in the back of parents' minds."

Still, watching families tap into courage and resilience that some didn't realize they had fills Wilton the memories about her job that will always stick with her. "It's rewarding to see families overcome their struggles and their battles and be successful. A lot of families shine and really rise up to the challenge," she says. **RN**

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