

IN GOOD HANDS

Care for paediatric diabetes at MSH comes of age

Type I diabetes is a lifelong condition that's challenging even at the best of times — and even more so for parents with a newly diagnosed toddler or a child heading into their rebellious teenage years.

More than 200,000 children and adolescents across Canada have been diagnosed with Type I diabetes, which occurs when the pancreas no longer produces insulin.

That's why Markham Stouffville Hospital (MSH) started up the MSH Paediatric Diabetes Program in 1996.

"Our families and their needs are the driving force for everything we do," said Alanna Landry, a diabetes nurse educator for the program.

As the program evolved, the team wanted input into their delivery of services and programming, so they created an advisory committee.

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The new committee consists of the diabetes clinic staff, and the manager and director of the program along with three parents and a former patient, who meet quarterly.

"They give us valuable feedback — there's nothing we do not talk about at these advisory meetings that they're not part of," said Landry.

The advisory committee has been working with the team to create an orientation video for newly diagnosed families, providing feedback on making the hospital rooms feel less sterile and reinstating the department's annual diabetes day, among other initiatives.

More children under the age of six are being diagnosed with Type I diabetes, and that means parents need additional support. "Toddlers can't tell you that their blood sugar is low," said Landry. This can cause increased anxiety for the parents of these toddlers. So MSH started a support group, where parents can meet, have coffee, share stories and listen to guest speakers on topics ranging from carb counting to dealing with picky eaters.

But those needs change as toddlers turn into teenagers. "We're really here as a team to support the child and the parents through all the different changes ... such as the transition of responsibility to the child as they grow up," said Landry.

At some point, teenagers become "carriers of all that information that makes parents feel safe and comfortable," said Landry. "There's so much happening — they want to be independent, they don't want to be different from their friends — so how can we help using new technologies to decrease conflict?"

Landry is working on a research proposal for new blood glucose meters with share technology to facilitate better communication between parents and teens.

"My hypothesis is it would help decrease daily conflict and improve quality of life of the teen if there wasn't constant conflict around the actions and results of doing blood glucose testing," she said.

Landry is also working with a patient to develop an app that will act as a tool to provide transition education. "It's going to track all of the education and information the teens need to take with them to adult care, along with insulin doses," she said. "Transition is a really huge topic in paediatric diabetes and everybody is looking at ways to improve this process. Our kids don't carry pieces of paper anymore, but if we make it available on their phones they're going to use it."

This summer, MSH also piloted a 'transition' field trip where they took 12 teens that were ready for transition on a canoe trip in the wilderness, giving them a chance to test their knowledge of carb counting and insulin adjustments, while being active and away from their parents.

Marilyn Fry, a clinical dietician for the program, helps educate families on managing their nutritional needs through various stages of life — from the time they're diagnosed until they reach 18 years of age.

Typically, parents' first instinct is to take things away, and that causes anxiety. "They can still go out for Halloween, they can still have birthday cake," she said. But it's about balance. "If you're standing in line at Harvey's, you know what you're going to order, so here's what you do. We're trying to support what they're doing instead of saying, 'no you can never go to Harvey's.'"

Patients — and their families — need to be empowered to manage diabetes, said Cheryl Osborne, director of Childbirth and Children's Services at MSH.

"This is something they live with — they travel with it, play sports with it, sleep with it," she said. "We need to train families to troubleshoot, to celebrate their successes, to forgive themselves if something doesn't go as planned. It's not just a matter of [educating] them, but helping them to manage it from an emotional perspective as well."

During the adolescent years, these services are particularly vital.

MSH PAEDIATRIC DIABETES PROGRAM AT A GLANCE

- Developed in 1996: now the longest-running diabetes program in York Region
- Currently cares for 450 children and adolescents with Type I diabetes
- Supported by a multidisciplinary team that includes two paediatric endocrinologists, three diabetes nurse educators, two registered dietitians, a pediatrician and a social worker
- Provides initial education to newly diagnosed families, as well as ongoing care every three months until the child turns 18



"They feel different, so it becomes very important to address body image, how they relate to their peers, the things that teenagers go through — do I smoke or don't I smoke," she said. "Those can severely impact a child with diabetes."

This also challenges parenting. "It's so much harder to step away and let them make their own decisions," said Osborne. "The parent advisory committee is really critical because we need to know firsthand what parents need and how we can develop our programs to help them."

They do know, however, that paediatric diabetes-related emergency room visits have decreased since they started providing a 24-hour support line. And, based on feedback, parents feel a greater sense of community and support — not just from MSH, but also from their peers.

It's critical to be able to self-manage, said Fry, which is what the program teaches patients — and their families. "We are here to support and give advice, but they're in the trenches every single day and they have to be able to make decisions for the rest of their life."

For more information about the paediatric diabetes program at MSH visit msh.on.ca/paediatric_diabetes

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