

Caregiver Recognition Awards Honour Unsung Heroes

Emily Yeskoo's life changed when she was eight years old. Once an active, outgoing child, she began to lose control of her physical movements, and her behaviour became erratic. Living overseas at the time, the family was at a loss to understand.

"It was tremendously difficult to watch this beautiful girl experiencing inexplicable things happening to her. We had no way of knowing what was wrong, and none of the professionals we consulted had any answers," says her mother Lindsey. "By the time she turned 10, she was no longer functioning and her spirit was broken."

Many specialists and tests later, Emily was diagnosed with a rare and fatal disease called Metachromatic Leukodystrophy - or MLD. The illness affects the brain cells and the layer that protects the nerve cells, blocking messages from the brain to the rest of the body. The diagnosis launched the family on a long journey, bringing them halfway around the world, to Lindsey's hometown of Toronto, to be closer to the care Emily needs.

Now 22 years old, Emily requires total care. Although she has good days, when she can sit in a wheelchair briefly or take in some food by mouth, she is bed-bound most of the day and cannot eat on her own or speak. Despite these physical limitations, Emily is a smart and engaged young woman. She has a big smile, a good sense of humour and many unique ways of expressing herself, and she knows she is loved.

Lindsey is Emily's primary caregiver, along with raising two other children. Her husband is a diplomat whose work keeps him away most of the year. Although Emily receives nursing services from the Central CCAC, there are many things that Lindsey does daily for her daughter. First and foremost, she helps Emily acknowledge what she has lost in her life due to this disease, and work through the resulting emotions, so that she can move forward in a positive way.

She sleeps in Emily's room, feeds, bathes and dresses Emily, and reads to her. When Lindsey is caring for Emily alone, she has the total responsibility of maintaining the integrity and sterility of the tubes that provide Emily with the necessary food and medicine. In order to provide this level of clinical care, Lindsey had to receive medical training.

Dedicated and loving caregivers like Lindsey Yeskoo are the reason that Central Community Care Access Centre (CCAC) launched its Heroes in the Home Caregiver Recognition Awards. The awards acknowledge caregivers who step in to provide support to their family members, friends and neighbours, or even to strangers in the community. These selfless people make it possible for people who are ill or elderly to stay healthier and able to manage living in their own homes.

Caregivers like Lindsey play an important role in caring for their loved ones each and every day. "Lindsey is both caregiver and advocate for her daughter," says Sandy Hustler, Care Coordinator at the Central CCAC. "It's a tough road she has to travel and she is an inspiration to all of us."

Lindsey was nominated by Sandy, who admires Lindsey's unwavering support of her daughter, her commitment to ensuring Emily receives the best care possible, and the way she treats everyone on Emily's care team with such respect.

"I am not sure how Lindsey accomplishes all that she does, but I know she counts every day with her daughter as a blessing," says Sandy. "She is one of the kindest and most genuine women I have ever met."

Each year, the number of people needing care in the community increases. Last year, Central CCAC delivered care to over 85,000 people in the communities of the Central region. The organization also works with its many care partners to help people and their families connect with care and services in the community. Informal caregivers are an important thread in the fabric of the health system.

According to Statistics Canada, between 1997 and 2012, the number of family caregivers across Canada increased by about 64 percent – to more than 8 million people. In fact, family caregivers provide about 80 percent of the care required by those in our communities who are aging, seriously ill and who are in the final stages of their life.

Central CCAC's Heroes in the Home Awards was embraced by patients and others who were delighted to have the opportunity to say thank you to these special caregivers who make such a huge difference in their lives.

Active in her community, Lindsey is a member of the Advisory Council for Emily's House, Toronto's first paediatric hospice, which was named after her daughter. She also finds time to write about her experiences as a way to process the complex emotions that come with a mother and a caregiver's territory and to give a voice to Emily in the absence of her having her own.

According to Lindsey, Central CCAC is an indispensable part of her support system, and is one of the few places she can go to get the tangible help she and Emily need. Just as important to Lindsey, when she calls the CCAC, she knows that she will be listened to and heard, almost always resulting in helpful action.

While honoured by the nomination, Lindsey is not entirely comfortable being called a "Hero" for her part in Emily's journey.

"We are ordinary people in the middle of something extraordinary and our lives are richer and more fruitful for it," says Lindsey. "When you live with someone, for whom nothing happens unless somebody else does it for them, it will tax you in every way possible. But it also hands a baton to each of us to be the best person we can be for our loved one. Emily is truly the most incredible gift. She is the real Hero."