Ontario
Palliative Care
Network

Caregivers' Perspectives

From Valerie M.

When my nine-year-old daughter, Natalie, was dying of leukemia, a pieced-together network of people cared for her. Her care was very much enabled by the goodwill of those individuals, as there was no systematic referral to reliable, coordinated and integrated palliative care services.

My hope is that the Ontario Palliative Care Network (OPCN) will ensure a systematic approach to the delivery of palliative care services so that whenever anyone in Ontario is nearing the end of curative treatments, they will have a clear and easy pathway to the palliative supports they need.

Real change will require education and a shift in attitude. There is a perception that palliative care means giving up. Even among the hospital staff, when we decided not to continue curative treatment for Natalie, some doctors and nurses would literally pretend they didn't see us in the hallway because they were so uncomfortable and didn't know what to say. But we never gave up hope that our daughter might live, that some new clinical trial would come through. Palliative care was about making her comfortable and giving her the best quality of life possible. Both the public and healthcare providers need to see palliative care as another important treatment option for people with life-threatening conditions.

Conversations about end of life are really hard to initiate, but not talking about it leaves patients and families frightened and frustrated. Sometimes patients continue with unnecessary, unpleasant treatments that diminish their quality of life. My 91-year-old father-in-law, for example, has multiple serious health issues, but no one has talked to him about what his last months or years of life might look like. It is important to engage patients and families as true partners in care planning. Don't make assumptions about what we need or want. Ask us about our circumstances, tell us what services are available, suggest options and help us choose what might work for us.

From Denis C.

My partner, Dave, died from AIDS. One day, I came home to find him on the floor where he had fallen three hours earlier. From then on, I knew he couldn't be left alone in the house. For a year and a half, a team of friends, colleagues, members of Dave's church, family and personal support workers were able to provide 24/7 care at home. But when he started experiencing dementia and posing a potential threat to himself and others, I couldn't risk leaving him with volunteers. He received wonderful care at Casey House for the last three weeks of his life.

Caring for Dave was a very difficult but also positive experience. It was such an honour to do this for him. Caring for people has become my calling, and working with the OPCN's Partnership Advisory Council is an extension of that journey. My hope is that the OPCN will help improve Ontarians' understanding, knowledge, accessibility, availability and utilization of palliative care services.

Service providers need to start talking to patients about palliative care as soon as a life-limiting illness is diagnosed, and those services should be available much earlier, not just in the last months and weeks of life. We also need to put more emphasis on offering bereavement services, helping survivors learn to live the rest of their lives without their loved one.

It is important that we raise awareness about what services are available and how to access them. I am amazed that in 2017 people still have no idea where to start when they need palliative care services. That's unfortunate because, at some point, we will all be touched by end-of-life issues.

Acknowledgement: Valerie and Denis are Patient and Family Advisors who are members of the OPCN's Partnership Advisory Council. We thank them for sharing their stories.

From Denise R.

My mother, Marjorie, was diagnosed with Stage 4 lung cancer with metastasis to the brain on June 12, 2015. She died two months later.

I wanted to ensure that Mom's last days and weeks rolled out the way she wanted them to. The people who cared for her were wonderful, but we struggled to understand the system and processes to get her the care she needed. It was confusing to say the least.

There were so many care providers – her family physician, oncologist, palliative care doctors, nurses, caseworkers, technicians, therapists and supervisors – but no one to take control or tell us what the next step could or should be. Mom did not want to die at home, but there were no hospice facilities available at the time. We were fortunate to find a nursing home with palliative care beds, although an administrative glitch delayed her admission by more than a week. Once she was admitted, the staff provided excellent care for Mom and helped our family deal with her final days.

Overall I feel a sadness that so much of my mother's last weeks was spent navigating the system. It seemed that the focus was on making us fit into the system, not on what my mother needed at her end of life or about supporting her family. That time should have been for our family to spend together in calm.

Before she died, my mother asked me, "What if a person does not have someone like you to help them through this?" She wanted me to raise awareness of the challenges facing people like her and to advocate for those who need palliative care services.

My hope is that, going forward, patients and their caregivers will be asked, "What do you need to know?" and be answered with concrete and directional information. I think significant improvements can be made by remembering to put the needs of patients and families at the centre of the system.