



PALLIATIVE CARE IN CANADA

Caregivers' perspectives on home-based palliative care

Involving caregivers in home-based palliative care is essential. Engaging their expertise and knowledge in advance care planning, early assessment and service delivery, managing equipment, supplies and medication and supporting communication among the health care team is vital.

Values & Wishes



“

My sister's advance care plan was simple – she wanted to be at home with her family around her. That was it. Not in hospital, not in a swirl of chaos in an emergency department ... we worked with her team to make it happen that way.

–

We knew what we wanted, but we didn't know how to make everyone else know.

”

Access to Care



“

If a person can die at home in one province, shouldn't they be able to just the same somewhere else?

–

It's crazy, my Mom and Dad lived and died less than a hundred and fifty kilometers apart and it was all completely different.

–

As a same sex couple, I can say I felt respected and the relationship was valued for what it was. Just like every other couple in home care.

”

Medications & Supplies



“

After my husband's death, no one seemed the least bit interested in the fact that I still had some very dangerous prescription medications in my home.

–

[We] did not know what to have, where to get it, when. Or even who was responsible for the purchases or from where.

–

Six weeks after my sister died, my brother-in-law still couldn't get into his garage. It was full of equipment he moved out of the house, so he didn't have to face it every day.

”

Communication



“

It is very difficult when a loved one is in and out of lucidity. I represented his wishes most often and felt that my voice was not being listened to by the frontline team. The caregivers voice should be a primary concern of the palliative team in situations such as this.

–

They listened to me. They understood—I knew what my husband wanted. If they didn't understand, they asked. We all agreed.

”

64% of caregivers believed their loved-one's wishes influenced the care they received*

The plan was well thought out and in theory was a good plan. The execution and delivery on the plan was what fell short.

21% of caregivers felt care delivery did not reflect their loved one's end of life wishes*

Night time was always when I needed the help. I felt like I was alone in a life raft with the sharks circling at night

Only 29% of caregivers said the care team was often available to them*

I couldn't help my husband because I didn't know how to even help myself.

*Results of an on-line survey and caregiver interviews conducted by the CHCA in July - August 2018. (15 caregivers interviews and 61 on-line responses representing 7 provinces)

A Caregiver (also referred to as carer or family caregiver) is a person who takes on an unpaid caring role for someone who needs help because of a physical or cognitive condition, an injury or a chronic life-limiting illness.

[Learn more](#) information about Operational Excellence in Home-Based Palliative Care

