

# Community Support Service Agencies – Part of the Palliative Care team

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**DO** you know that over 90% of Canadians wish to die at home? But most of them die without having their last wish fulfilled!

What prevents people in the end stages of life from dying at home? Too often, arrangements are made for end-of-life care when someone is dying, rather than just after their diagnosis. Those who wish to die at home - as well as their informal caregivers - should be knowledgeable about the services they need before they become too ill and are admitted to the hospital.

Having a plan in place for end-of-life care improves the quality of life for people with a terminal diagnosis, as they can access services they need during the entire progression of their disease, rather than just at the end. Early on, they should consider making a living will and assign a Power of Attorney for personal care and to look after their finances. They should make their wishes known to their family and have appropriate documentation in place so their wishes are carried out.

End-of-life care includes the physical and psychological aspects of the end of life, pain management and support for both the patient and the caregiver. A team of professionals, made up of a family or palliative care doctor, as well as nursing and community support services which are usually arranged through the local Community Care Access Centre (CCAC), works together to provide end-of-life care.

When palliative clients or their families first contact the local community support services

agency, they are usually referred to a social worker who works with them and becomes part of their palliative care team. The social worker provides counselling, emotional support and information and arranges for other services needed, including assistance with getting affairs in order. Social workers become an emotional sounding board and help palliative clients through the dying process by listening to their feelings concerning their death, helping them sort out family problems and keeping in contact with other members of their palliative care team.

Palliative care clients and their families can have access to many community support services to help them live more comfortably. Services used vary from client to client and depend on the level of personal support they have to help them with the tasks of everyday living and what type of limitations they may have, whether physical, cognitive or dietary.

Community support service agencies that have a contract with their local CCAC can provide in-home care, mainly to help with personal care, such as bathing, dressing or meals. If a client needs more hours than they receive from the CCAC, they can get extra help from their community support service agency for a small fee. Families that provide 24-hour care can arrange for a personal support worker to provide respite care and provide them with a much-needed break to recharge and do things for themselves.

"Palliative care clients who don't have family or friends nearby to help out rely more on community support services to help them than those with close supports," said Social Worker Anne Bail-

largeon. "Because they don't have anyone to prepare meals for them, they often rely on Meals on Wheels. If they have dietary restrictions or can't eat regular meals, Meals on Wheels also provides meals for special diets and pureed or minced meals."

Palliative care clients can also get rides to medical appointments from their local agency. Their driver can escort them to an appointment if they are too weak to walk without help. This can be a great help to family caregivers who work, as they don't need to leave work to take their family member to medical appointments.

As the disease progresses, most palliative care clients need medical and nursing services that are usually delivered at a hospital. Instead of having treatment at the hospital, a palliative care team can bring the hospital to the patient. Many medical and nursing services including dialysis, intravenous pain medication, and feeding tubes can now be administered at home and a hospital bed can be arranged when needed.

At this time, palliative care clients need more help with personal care and don't have the strength to undertake day-to-day tasks, such as doing laundry, preparing meals and going to the store. They can arrange for as much help as they need, including round-the-clock care. If needed, their local agency can provide a team of personal support workers to work regular shifts, making sure that each worker waits until the next worker arrives before leaving their shift. Personal support workers who provide palliative care are trained to understand and look after both the physical and emotional needs of people with a terminal illness.



Palliative care clients can get rides to medical appointments from their local agency, such as SPRINT.

Their job can be very emotionally demanding, but also very satisfying because they know they helped their clients be as comfortable as possible during the last few months of their lives.

The husband of a deceased palliative care client who relied heavily on community support services wrote: "My wife died at home, as she wished, with grace and dignity. I appreciate the caring attention she needed to obtain her last wish." For palliative care team members, a thank you from a family reinforces their pride in helping people live at home and die with dignity in the comfort of

their own home.

*\*SPRINT (Senior Peoples' Resources in North Toronto) is a non-profit United Way member and representative Community Support Service agency that provides a wide range of effective community and home support services in North Toronto to help seniors and persons with cognitive and physical disabilities live independently in their own homes. Services are provided by professional staff and dedicated volunteers.*