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## Dying Cancer Patients Need More Support

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TORONTO -

The type and quality of care and services to ensure a cancer patient dies with dignity in the setting of their choice depends on where the person lives in Canada, according to a special report about end-of-life care in *Canadian Cancer Statistics 2010*, released today by the Canadian Cancer Society.



"Right now, in Canada we have a patchwork approach to providing care at the end of life. This means that some cancer patients and their families are not getting the support they need during a very difficult time,"; says Heather Chappell, Director, Cancer Control Policy, Canadian Cancer Society. "Uniform, high-quality support for any person dying of cancer should be available no matter where they live."



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Cancer is the leading cause of death in Canada – in 2005 (the most recent data available), 29% of all deaths in Canada were from cancer. Due to our aging and growing population, the number of deaths from cancer and other chronic diseases will increase.

"Action is needed to ensure palliative care services are in place to meet the needs of patients now and in the future," says Chappell.

Caring for a dying cancer patient is part of a palliative approach that is provided when a patient's healthcare team determines that a cancer is unlikely to be cured. The goal of this type of palliative care is to improve quality of life. This includes:

- managing physical symptoms such as pain, nausea and shortness of breath
- meeting emotional needs such as anxiety and depression
- addressing spiritual needs
- support for caregivers

The special report is a compilation and comparison of data from end-of-life research in three provinces – British Columbia, Ontario and Nova Scotia. Findings show:

- There are inadequate services to allow people to die at home when this is their preference.
- Survey data show that most terminally ill people would prefer to die at home, but more than 55% of deaths occur in hospitals. One reason for this is because community-based services are not available for dying people in some jurisdictions.
- Palliative care services exist, but they are often not used.
- Patients and their families sometimes are not aware of available services.
- Because it is often difficult to anticipate death, healthcare providers may not be able to judge when people with cancer should begin receiving care that is focused on palliative needs rather than disease treatment. Late enrolment to palliative care can mean a patient will not receive the benefits from care specifically focused on the needs of the dying.
- Families caring for dying people experience significant psychological and financial burdens.



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- The family of a person with cancer assumes most of the costs and other burdens of home care. A caregiver's financial burden is about \$36 a day, or over \$1,000 a month, according to a 2005/06 estimate by Statistics Canada. This does not include lost income due to time off work to provide care for the terminally ill loved one.

Dr. Prithwish De, co-author of the special report and an epidemiologist with the Canadian Cancer Society, acknowledges that dying from cancer or any terminal illness is a difficult topic, but it's crucial to continue examining this issue.

"We must gain more knowledge and insights about this important group of people with cancer so we can determine what care and services will ensure they have a good quality of life until their death," says De.

Currently, data about quality of care for people with cancer at the end of their life are sparse and inconsistently collected across Canada. Knowledge about this subject is limited because:

- there is variation in the type of data collected across jurisdictions (without common data it is difficult to compare information so that gaps in care can be identified)
- there are, in many instances, no formal monitoring systems in place to consistently collect and report on end-of-life care across provinces
- there are no standard timeframes for the end-of-life period (studies have looked at one month, six months or nine months prior to death)

"Doing more research and better surveillance on care at the end of life is vital to our future efforts in this area," says Dr. Eva Grunfeld, co-author of the special report and researcher at the Ontario Institute for Cancer Research.

## **Recommendations**

To help ensure uniform, high quality support is available for people dying of cancer, it is recommended that:

- surveillance about end-of-life care be improved to help define the needs of people dying from cancer and to allow better planning
- definitions and methods of reporting end-of-life care be standardized so that surveillance data are more comparable across jurisdictions – this would allow researchers, policy makers and healthcare planners to more easily identify gaps in care



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"The Canadian Cancer Society supports these recommendations," says Paul Lapierre, Vice President, Public Affairs and Cancer Control, Canadian Cancer Society. "Each and every person who is dying from cancer deserves the best of care no matter where they live."

### **A caregiver's perspective**

Joanne Morrison calls the four and a half years she looked after her husband Guy, "a rollercoaster ride."

"He was certainly very ill sometimes and a lot better other times," says Joanne.

Diagnosed in 1997 with glioblastoma multiforme, an aggressive brain cancer, Guy was given 12 to 18 months to live but survived until March 2002, when he died at age 52.

Guy suffered seizures, so Joanne took over the driving. As well, confusion resulting from Guy's cancer meant he needed frequent monitoring, leaving her with little time to herself. Joanne's employer was close to home and flexible, which helped. So did family members and a hospice volunteer who spent one afternoon a week with Guy. But in the last weeks of Guy's life, Joanne realized she could no longer do it alone and her two grown children and daughter-in-law moved in.

"It took four of us to look after him," Joanne says, adding that Guy was able to die at home.

Joanne wishes more information on patient and caregiver support could be made available right in medical offices. It's that need for information that inspires her to serve as a Canadian Cancer Society CancerConnection volunteer for other caregivers.

Caregivers should not try to be a "super person," she stresses. "Make a list of everything that needs to be done. If anyone asks, 'What can I do?' give them the list and ask them to pick something."

### **Highlights: *Canadian Cancer Statistics 2010***

- An estimated 173,800 new cases of cancer (excluding 75,500 cases of non-melanoma skin cancer) and 76,200 deaths from cancer are expected to occur in Canada in 2010.
- More than one-quarter of all cancer deaths – 27 per cent – are due to lung cancer.
- More men than women are diagnosed with cancer, but the gap between the two sexes has narrowed in recent years (51.7 per cent of cases are in men vs. 48.3 per cent of women).



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- The death rate for all cancers combined is declining for males in most age groups and for females under 70.

*Canadian Cancer Statistics 2010* is prepared, printed and distributed through a collaboration of the Canadian Cancer Society, the Public Health Agency of Canada, Statistics Canada, provincial and territorial cancer registries, as well as researchers based in universities and provincial or territorial cancer agencies.

For more information about *Canadian Cancer Statistics 2010*, visit the Society's website at

### **About the Canadian Cancer Society**

The Canadian Cancer Society (CCS) is the only national charity that supports Canadians with all cancers in communities across the country. No other organization does what we do; we are the voice for **Canadians** who care about cancer. We fund groundbreaking research, provide a support system for all those affected by cancer and advocate to governments for important social change.

Help us make a difference. Call 1-888-939-3333 or visit [cancer.ca](http://cancer.ca) today.