

## Overview

The Canadian Cancer Society (CCS) is a national health charity providing services and supports to people living with cancer and their families across the entire country, particularly in Ontario at our 25 local community offices. We are well-positioned to play a key role in delivering a person-centered approach to cancer care, focused on seeing all Canadians living with cancer realize a positive patient experience.

We offer a range of services available to Ontarians that address the emotional, physical and practical needs of all those touched by cancer, from the date of diagnosis through to survivorship or end of life. On any given day, 34,200 Canadians will reach out to CCS for trusted information and caring support. The information provided is fully bilingual and available in 150 languages, including 14 Indigenous languages through an interpreter service.

In the *Living with Cancer*<sup>1</sup> report launched in 2018, the message from Canadians was clear. They told us it is essential to treat them as individuals, not just a diagnosis, with a reality that extends beyond being a person living with cancer. Fundamentally, we heard that people living with cancer need to be supported with accurate information and peer support services to help with the physical, emotional and practical concerns after diagnosis. The report exposed the raw edges of the cancer experience, including the fact that 69% of patients have to travel for tests or treatment and how financial and logistical concerns are impacting families and creating a call for better access to services and programs to manage distress.

For seniors, the need for cancer supports and services is particularly acute. Almost 60% of all new cancer diagnoses and 75% of all cancer deaths occur in seniors (age 65+). 1 in 4 caregivers report providing care related to aging and for 1 in 10 caregivers the care provided is cancer-related. At CCS, we see firsthand the burden this places on seniors and those who care for them and we are perfectly placed to support the Government's efforts to develop and implement the Ontario Seniors Strategy.

In order to be successful, we believe that the strategy should include a focus on:

- Closing gaps in palliative care, including education, access and funding;
- Eliminating financial and logistical barriers for seniors living with cancer; and
- Bolstering caregiver and bereavement support.

## Closing Gaps in Palliative Care

Palliative care focuses on quality of life of people with cancer and their families. In Ontario, indicators such as location of death, use of acute care before death and referrals to formal palliative care show that there is significant room for improvement. Many Canadians who require palliative care only receive it in acute and emergency care settings, if they receive it at all. About 45% of patients die in acute care hospitals even though most Canadians prefer to die at home.<sup>2</sup>

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<sup>1</sup> The Canadian Partnership Against Cancer (2018), *Living with Cancer: A Report on the Patient Experience*, Toronto, ON

<sup>2</sup> Canadian Cancer Society. (2016). "Right to Care: Palliative care for all Canadians."

To improve palliative care for seniors, the Ontario Seniors' Strategy needs to address:

- A lack of standards, insufficient data collection and lack of consensus on what indicators should be used to evaluate palliative care;
- Insufficient training for healthcare providers;
- Misunderstanding among people with cancer, families and healthcare providers of palliative care;
- Inadequate funding for palliative care; and
- Insufficient support for people with cancer and family caregivers.

In 2016, the Canadian Cancer Society published *Right to Care: Palliative care for all Canadians*. This report highlights the major gaps in care and existing barriers to ensuring all Canadians have access to quality palliative care, when they need it. It outlines the importance of palliative care in healthcare delivery, in particular for Canadians dealing with cancer. By doing so, we strive to inform our advocacy and information delivery activities as well as those of our partners, such as governments and other organizations, so that we can improve accessibility, affordability and quality of palliative care for all Canadians affected by a life-altering illness.

Several experts consulted on the Canadian Cancer Society's report stressed that palliative care education for healthcare providers is insufficient for specialists and non-specialists. These experts emphasized that not nearly enough palliative care specialists are being trained to cover the anticipated level of attrition in the field due to retirement expected over the next 10 years or to meet the increasing needs of our aging and growing population.

Course curricula have been developed for palliative care by organizations such as Pallium Canada and the Canadian Society of Palliative Care Physicians. Leadership and funding are needed from universities and governments to ensure curricula are implemented across all medical, nursing, pharmacy and allied health schools in Ontario. Furthermore, this education should be inter-professional (i.e. physicians, social workers, bereavement counsellors, etc.) due to the team-based nature of effective quality palliative care delivery.

Along with education and training for healthcare providers, the strategy should focus on empowering seniors and their caregivers with tailored, understandable information not only about their cancer and treatment options, but also about emotional changes, treatment of side effects and how to best manage them. As the only nationwide charity that focuses on all types of cancers, we are uniquely placed to contribute and work alongside the Government in the weeks and months ahead to ensure that the strategy guarantees seniors have the information that they need throughout every stage of their cancer journey.

## **Eliminating financial and logistical challenges**

Once empowered with information about their diagnosis, it is vital that seniors have the financial resources available to access their treatment options. While seniors automatically qualify for the Ontario Drug Benefit at 65 years of age, they are still required to pay an annual deductible as well as dispensing

fees for medications, including take-home cancer drugs. Over the last decade, take-home cancer drugs have become a standard treatment for many cancers. Nearly half of drugs used to treat all types of cancer are taken at home instead of in the hospital.<sup>3</sup> The seniors strategy should remove any cost related barriers for seniors accessing cancer medications, including take-home cancer drugs. The strategy should also ensure that Ontario's drug formulary remains up to date with the latest innovations in take-home cancer medications.

Many seniors also face logistical barriers, such as travelling to and from cancer appointments. In the 2018 *Living with Cancer* report, participants noted that traveling to and from treatment can be very difficult. These logistical issues disrupt family lives and everyday routines, resulting in further strain on families coping with the cancer diagnosis of a loved one. The Ontario Seniors Strategy should support existing programs that assist seniors in traveling to cancer-specific medical appointments or supportive care services. Our Wheel's of Hope service is a leader in this area and one of the largest volunteer programs in North America. We invest in recruiting, training and maintaining 2,100 volunteer drivers to support the program across Ontario. The program is largely delivered by seniors for seniors, with seniors accounting for 75% of people accessing the service and 80% of the volunteer drivers.

### **Bolstering caregiver and bereavement support**

In order to be complete, the Ontario Seniors Strategy must bolster family caregiver and bereavement supports. Family caregivers play an integral role in the care of people with advanced cancer and their needs must be addressed. While at-home palliative care increases the efficient use of hospital resources, moving care outside of the hospital setting often places a significant financial burden on family caregivers.<sup>4</sup> In a recent study, the timing of when information was provided to caregivers during their loved one's cancer journey was identified as a challenge.<sup>5</sup> Timing, guaranteed access to information and delivery of information provided to caregivers needs to be improved through the seniors strategy. For example, an additional investment could be made to guarantee access to resources for third-party organizations to provide psycho-social supports to families. Early integration of bereavement contact into routine support for caregivers should also be included in the strategy as its effectiveness is supported throughout the literature.<sup>6</sup>

### **Appendix: Canadian Cancer Society (CCS) Information and Support Programs – Seniors**

The following is an overview of how the Canadian Cancer Society's information and support programs provide support to Ontario's seniors population.

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<sup>3</sup> Cancer Care Ontario. (2019). Summary: Quality & Safety recommendations for enhancing the delivery of take-home cancer drugs in Ontario

<sup>4</sup> Nissim, R. et. al. (December 2017) "Supporting Family Caregivers of Advanced Cancer Patients: A Focus Group Study." *Family Relations: Interdisciplinary Journal of Applied Family Science*, 66:5. DOI: <https://doi.org/10.1111/fare.12291>

<sup>5</sup> Nissim, R. et. al. (December 2017) "Supporting Family Caregivers of Advanced Cancer Patients: A Focus Group Study." *Family Relations: Interdisciplinary Journal of Applied Family Science*, 66:5. DOI: <https://doi.org/10.1111/fare.12291>

<sup>6</sup> Makarem, M. et. al. (May 2018). "Experiences and Expectations of Bereavement Contact among Caregivers of Patients with Advanced Cancer." *Journal of Palliative Medicine*. DOI: <https://doi.org/10.1089/jpm.2017.0530>

### Cancer Control Context

- Seniors are Canada’s fastest growing demographic — the proportion of seniors is expected to reach up to 25% of the population by 2036.<sup>7</sup> It is projected that between 2015 and 2021, seniors will outnumber children under 14 for the first time.<sup>8</sup>
- Almost 60% of all new cancer diagnoses and 75% of all cancer deaths occur in seniors (aged 65+)
- In 2017, 150,500 Canadians aged 60+ were diagnosed with cancer and 69,000 died of the disease.
- In 2017, 73% of all cancer diagnoses and 85% of cancer deaths occurred in Canadians aged 60+.
- In 2009, almost 600,000 Canadians aged 60+ were living with or beyond cancer. Because of the growing and aging population, this number is expected to be much higher today.

*Note: 2017 statistics are based on seniors aged 60+, not 65+.*

### Proportion of Seniors served by various Support Program

- Cancer Information and Support (CIS)/ Service d’information sur le cancer (SIC) (National):
  - Provides answers to questions about all types of cancer, diagnostic tests, treatments, side effects, clinical trials and many other cancer-related topic.
  - Consistently, almost 50% of clients receiving services are seniors (60+ years).
  - The greatest concern of all callers relates to practical issues such as transportation needs and financial assistance, with more seniors (60+ years) contacting the service for this purpose. Seniors more frequently contact the service to address needs directly related to their own cancer experience (please refer to table below).

<b>Clients Aged 60+</b>	<b>All Clients</b>
1. Practical Issues (55%)	1. Practical Issues (37%)
2. Treatment and Disease Management (18%)	2. General Information (18%)
3. Psychological/Emotional Support (8%)	3. Treatment and Disease Management (14%)
4. General Information (6%)	4. Other/non-CIS (10%)
5. Diagnosis (3%)	5. Psychological/Emotional Support (7%)

- Wheels of Hope transportation program (ON):
  - Provides transportation to and from cancer specific medical appointments or supportive care services.
  - More than 75% of clients receiving rides to treatment related appointments are seniors (60+ years).
  - In Ontario, 1 in 5 cancer patients have trouble getting to their life-saving treatment appointments.
- Cancerconnection.ca:
  - Helps people who have cancer, cancer survivors and caregivers share their experiences and build supportive relationships.

<sup>7</sup> Statistics Canada. Canada year book 2012, seniors. Available: [www.statcan.gc.ca/pub/11-402-x/2012000/chap/seniors-aines/seniors-aines-eng.htm](http://www.statcan.gc.ca/pub/11-402-x/2012000/chap/seniors-aines/seniors-aines-eng.htm)

<sup>8</sup> IBID



- A growing number of seniors (65+ years) access our online support; currently 12%.
- Peer Match (National):
  - Connects people living with cancer and caregivers with trained volunteers who offer encouragement and share ideas for coping – all from their unique perspective as someone who’s been there.
  - Almost 40% of clients matched with peer volunteers are seniors (60+ years).
- Smokers’ Helpline (ON):
  - Offers proven tips and tools to help people quit smoking.
  - Nearly 20% of clients served by phone are seniors (65+ years).
  - However, less than 5% of our online clients are seniors (65+ years).

Additionally, CCS has engaged Seniors as volunteers to support our Support Programs

- Peer Match Volunteers (National):
  - More than 50% of our volunteers are seniors (60+ years).
  - Over 80% of senior volunteers share their experience as patients/survivors (almost 20% caregivers).
- Transportation (ON):
  - Nearly 85% of active Ontario drivers are seniors (60+ years).