



THE WAY FORWARD

AN INTEGRATED PALLIATIVE
APPROACH TO CARE



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FORWARD**

IMPACT AND LESSONS LEARNED



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The Way Forward: Impact and Lessons Learned

Across Canada, we are seeing a sea change in care for people faced with frailty and/or chronic life-threatening illnesses. Palliative care services – once only offered in the last days or weeks of life to people designated as dying – are now being integrated with treatment services to enhance people’s quality of life throughout the course of their illness or the process of aging.

On April 1, 2014, Alberta Health Services launched the province-wide adoption of an ambitious Palliative and End-of-Life Care framework that will improve choice and equity for all Albertans faced with life-limiting illnesses. Over the first year, the province will actively promote advance care planning, create a one-stop website with resources for health care providers, patients and families, train health care providers to provide high quality palliative care wherever people are (“treat in place”), add new services such as 24/7 on-call palliative physician support and increase palliative and hospice spaces in rural and urban settings.

Around the time that Alberta embarked on its innovative Palliative and End-of-Life Care framework, the Canadian Home Care Association began spearheading a two-year project – Mobilizing Action: Family Caregivers in Canada – designed to spark action to improve support for family caregivers. The project is actively promoting an integrated palliative approach to care, which focuses on meeting a person’s and family’s full range of needs – physical, psychosocial and spiritual – at all stages of frailty or chronic illness, not just at the end of life.

On the east coast of Canada, Health PEI and the PEI Provincial Integrated Palliative Care Team (P-IPCT) used the National Framework as a roadmap for the further development of a fully integrated palliative care service for all Islanders. The P-IPC Team will continue to focus their efforts on the priorities as outlined in the Framework to ensure that all Islanders have access to high quality hospice palliative and end-of-life care.

What do these and other innovations across Canada have in common? They were influenced by *The Way Forward*, a three-year (2012-2015) collaborative initiative of the Quality End-of-Life Care Coalition of Canada (QELCCC) and the Canadian Hospice Palliative Care Association (CHPCA), supported by one-time funding from the Government of Canada. Building on innovative programs already underway across Canada and the globe, *The Way Forward* helped identify and share best practices in integrating the palliative approach to care into all care settings.

The Grassroots Genesis for *The Way Forward*

The idea for *The Way Forward* came from the community. Five years ago, the QELCCC and the CHPCA approached Health Canada with a novel idea. To ensure equitable access to palliative care services, it was time for a more consistent federal, provincial, territorial and community response. Between 2001-2007, the federal government supported a Secretariat on Palliative and End-of-Life Care that developed the Canadian Strategy on Palliative and End-of-Life Care (2002-2007). With the Secretariat no longer active, there was still a need to see the national work continue.

To address this gap, the QELCCC and CHPCA pitched a community-led process, where they would take the lead, consulting with the provincial and territorial governments and using their established networks of agencies and organizations to develop a national framework. The theory was that the process itself would create a groundswell that would result in programs and settings across the country adopting an integrated approach to palliative care. The federal government was supportive of innovative national initiatives, and provided \$3 million from a 2011 budget commitment to fund *The Way Forward* between 2012-2015.

At the Tipping Point for Change

The Way Forward did not invent the concept of an integrated palliative approach to care. The sense that we need to think differently about care as people near the end of life has been growing for some time – driven by some key trends:

1. Significant changes in illness trajectories. Advances in treatment are changing the way we die. Canadians are now more likely to survive a heart attack or a cancer diagnosis, and to live for several years with chronic illnesses or increasing frailty. Although *when* people will die is less predictable, they will still experience the same losses throughout their illness trajectory (e.g. pain, loss of mobility and other functions, physical and mental limitations, loss of roles and relationships). They – and their families - would benefit from palliative care services – such as psychosocial support and pain and symptom management – that can enhance quality of life. Being diagnosed as “close to death” should no longer be the trigger for Canadians to receive these services.

2. The cost of “futile” treatments at end of life. Growing data on the cost of health care services show that our health systems spend a significant amount on procedures in the last days or weeks of a person’s life that offer little benefit and sometimes increase the person’s discomfort. A closer look at these interventions showed that many occurred simply because many people did not have advance care plans and health care providers were hesitant to have open transparent conversations with individuals and families about the prognosis or the benefits and risks of those interventions.

3. Increasing health care costs and pressure to manage them. Faced with rising health care costs and pressure to manage and control budget increases, health care systems are making concerted efforts to reduce the use of costly hospital services and provide more care in the community. Despite the fact that most Canadians would prefer to die at home and that only a small proportion need intense tertiary care in the last days or weeks of life, most (67%) still die in hospital. This disconnect between the care that people want and need and the care they receive is due, in large part, to a shortage of community providers who skilled in the palliative approach to care and the lack of supports for family caregivers who – given changing illness trajectories – are often providing care for a loved one for years.

4. Consumer advocacy. As our population ages, more people are speaking out about the kind of care they want as they near end of life. They are advocating for services that focus on quality of life as well as options that allow them to die “at home” wherever home may be. The success of the recent book, *Being Mortal*, by Atul Gawande is a sign of how pervasive and mainstream the conversation about how we die has become.

5. A growing focus on advance care planning. Over the past few years, a number of Canadian jurisdictions have actively promoted advance care planning – encouraging primary care providers to talk to their patients about the kind of care they want. However, the process itself raises expectations that the home-based and community-based care people want will be available as they age – which is currently not the case in many parts of Canada. Those expectations are another pressure for change.

Tools to Spark and Accelerate Change

By 2010, we had reached a tipping point in the thinking about care at the end of life. The health policy world had acknowledged that the approach to care needed to change, but wanting change and making change happen are two different things.

The Way Forward worked because it provided practical tangible tools and resources to help policy makers, health planners and service providers make changes and make them more quickly, including:

- a clear definition of an integrated palliative approach to care;
- a policy paper that explained the concept and the rationale for an integrated palliative approach;
- a summary of the literature;
- descriptions of innovative models of an integrated palliative approach to care already in place and working around the world;
- analyses demonstrating the cost-effectiveness of the palliative approach to care;

- surveys of Canadians, family physicians and nurses working in primary care to understand their attitudes and perspectives;
- a framework or roadmap to implementing an integrated palliative approach to care with clear action steps for sectors, health care settings and providers.

The Way Forward is a national initiative in a country where provinces make health care policy and decisions. Recognizing that tension, *The Way Forward* focused on providing research and information that would be useful to all jurisdictions and would save them the time and expense of doing their own technical reviews. Its background documents and papers answered key questions, such as: Who has already done this and does it work? Is it cost effective? What do you need to think about when shifting to an integrated palliative approach to care? Who needs to be involved? How do you measure quality?

The national framework or roadmap was structured in a way that had three key strengths.

1. The framework was developed as a draft and then used as the basis for consultation with people at all levels in the health care system – provincial/territorial ministries, regional health planners, health professional associations, local service providers and consumer groups. Not only did it provide a roadmap for implementing an integrated palliative approach to care, it became the way to engage people in the conversation.
2. The framework included sector specific actions. It laid out the steps that each sector could take to shift the system to an integrated palliative care approach. We were able to check with people working in all sectors and ask key questions such as: does this make sense to you? Does this reflect your reality? Will this work in your sector? Is anything missing?
3. The framework reinforced that change is organic and can start anywhere. It doesn't need to wait for provincial policy or the kind of province-wide initiative launched by Alberta. It can begin in a primary care practice, a home care service or a long-term care home. The goal of the framework was to empower people throughout the health care system and give them the tools to be able to start where they are and act now.

And this strategy worked. As Max Jajszczok from Alberta Health Services said, “We were able to fast track everything because we had all the information – evidence and data – at hand. We followed the framework and now we have a provincial plan.”

Through the QELCCC, different sectors were intensely involved in reviewing and providing advice on the national framework. As a result, they developed a greater sense of ownership. Speaking for the Canadian Home Care Association, Executive Director Nadine Henningsen acknowledged that “the palliative approach to care is

now one of our key priorities.” The Association has taken the issue to its family caregiver community and is helping to shape how services will roll out across the country.

The Way Forward documents are practical “how-to” tools, so they are less likely to be documents that sit on shelves. They are more likely to be used as a starting point or guidelines, providing the kind of detailed information that programs can use to develop their own plans.

Lessons Learned

Lessons learned from *The Way Forward* may also help shape national opportunities for other health system transformations. Here are four key lessons:

- 1. Build relationships.** Having the initiative led and championed by a network of organizations like the QELCCC means that you already have buy-in and influence across the system. The initiative can leverage these organizations’ networks and have more impact.
- 2. Provide the evidence.** A strong focus on acquiring, assessing and summarizing research – and a willingness to develop additional documents and discussion papers based on stakeholders needs – helps to build the evidence base for the change. This kind of research saves jurisdictions and organizations the work of having to do the reviews themselves. Instead, they can focus on the local/regional information they need to build their case.
- 3. Be responsive.** A genuine commitment to engagement – supported by a comprehensive engagement and consultation plan – and the willingness to listen to feedback and revise the national framework accordingly helps to make the process collegial and transparent. It builds commitment and keeps people engaged.
- 4. Be pragmatic.** A practical understanding of the challenges of implementing change within health care systems and the development of practical tools as well as the conceptual theory makes it easier for organizations to take action and move from theory to practice.

What’s Next?

Although the formal funded part of *The Way Forward* initiative is ending, the concept of an integrated palliative approach is taking flight. Other people and organizations are stepping up to the challenge. The name of the initiative may become history, but its impact will continue as people across the country work to integrate a palliative approach into different care settings.

CHPCA and the QELCCC will continue to be a catalyst for change. Until all Canadians have access to an integrated palliative approach to care across settings and people are comfortable having conversations about the kind of care they want towards the end of life, these organizations will keep pushing. One of the challenges they will face is keeping the policy briefs, research summaries and framework – the toolkit supporting the change – evergreen and current once *The Way Forward* funding ends. It also remains to be seen what is lost from no longer having an active, central nexus or voice for the issue.

In the view of those who have shepherded *The Way Forward* initiative, the best next step – and the way to have the greatest ongoing impact – would be a much closer integration between two inter-related initiatives: an integrated palliative approach to care and advance care planning. Each needs the other to actually meet Canadians' expectations that they will have the kind of care they want and need when faced with a life-threatening chronic disease or frailty.

While the recent Supreme Court decision on the issue of physician-assisted suicide has captured most of the media attention over the past few months, a relatively small number of Canadians are likely to meet the criteria for those services. But everyone has the potential to benefit from the growing willingness to acknowledge that dying is part of living, and that people deserve and should receive an integrated palliative approach to care when they need – at all stages along their illness trajectory and in all settings of care.

For more information:

The Way Forward integration initiative: www.hpcintegration.ca

Quality End-of-Life Care Coalition of Canada: www.qelccc.ca

Canadian Hospice Palliative Care Association: www.chpca.ca