

**Speaking Notes for the Honourable Sharon Carstairs, P.C.
Leader of the Government in the Senate and
Minister with Special Responsibility for Palliative Care**

**at the International Association of Gerontology 17th World Congress of Gerontology
Symposium on End of Life Care**

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Good afternoon. I am very pleased to be part of this symposium to speak about an essential value, and indeed, a fundamental right in our society - access for all to quality end-of-life care.

It has been just over a year since a Subcommittee of Canada's Senate released its report, Quality End-of-Life Care: The Right of All Canadians. I was honoured to chair that Subcommittee. I had also participated in 1995, in the Special Senate Committee on Euthanasia and Assisted Suicide. Essentially, the task of the Senate Subcommittee was to develop a five-year report card on the Special Committee's recommendations.

We heard from numerous witnesses, many of whom repeatedly called for more and better quality end-of-life care for all Canadians. What the Senate Subcommittee's examination revealed was that the principles, expertise and medical infrastructure for the care of the dying were evolving far too slowly.

The Subcommittee's final report included 14 recommendations aimed at the federal government. These recommendations dealt with the following five areas:

- the need for a national strategy on end-of-life care;
- the need for income and job protection for caregivers;
- the need for increased education and training for health care providers;
- the need for home care and pharmacare programs; and,
- the need for increased research and dissemination of findings.

To summarize the report's overall vision, I would like to quote this passage which eloquently defines our goal:

Quality end-of-life care must become an entrenched core value of Canada's health care system. Each person is entitled to die in relative comfort, as free as possible from physical, emotional, psychosocial and spiritual distress. The subcommittee sees care for the dying as an entitlement for all.

To my mind, this is a supremely worthy goal to which all of us can aspire.

The need for a compassionate, comprehensive approach to the end of life is becoming more pressing when we look at the increasing number of deaths and the changing demographics of our society. Our strategy on palliative care must take into account the growth of an ageing population with long-term chronic illnesses, as well as rising rates of disease such as cancer, AIDS and cardiovascular impairment in the general population.

Those factors that have given many of us longer life spans and helped seniors become a larger proportion of our population are the same factors that are transforming how we die, and what our care needs are as we approach death. For more and more people in our society, death comes not only at a more advanced age, but also at the end of a long course of chronic illness or increasing frailty. The vast majority of deaths in Canada, as in most of the industrialized world, are now in the population over age 65. These deaths result from conditions associated with aging -- cardiovascular disease, cancers, diabetes and its complications, and dementia. Older people are also more likely to approach death with combinations of conditions which complicate their care (for example: Alzheimer disease and congestive heart failure, osteoporosis and cancer, diabetes and Parkinson's disease). Patients who are cognitively impaired, as are ___% of individuals over the age of 85, may present communications challenges that make the assessment of pain and other symptoms difficult for care providers. These kinds of factors make the provisions of quality care to older people who are nearing death a particular challenge.

We must consider too, the changing situation today of the family members most closely affected by the death. These family members are also most likely to be the care providers, and these days, they are often themselves older people. It is no easier to lose a spouse of half a century to death than to lose any other loved one. Yet many older people face the double challenge of anticipating the loss of their spouse and, at the same time, taking on the strenuous task of providing round-the-clock care to meet that spouse's ever-increasing physical and emotional needs.

Our thinking about end-of-life care has to take these kinds of changing patterns into account. More to the point, we must make sure that these changes are reflected in the services available, and in the way we organize and deliver care to people who are nearing death.

Death at some point late in life is inevitable and natural. Older people who are dying, and their families, may need different services and approaches to care than those appropriate to younger people. However, and I do want to emphasize this point strongly, it is simply untrue and unconscionable that older people at the end of life require *less* care, or that nothing useful or meaningful can be done for them.

As they near the end of life, all Canadians, regardless of their age, need access to high-quality, integrated care that takes into account their needs as a whole person, physical, emotional, psychosocial and spiritual. This concept is central to the thinking behind the Senate Subcommittee report that we released last June. We advocated that all Canadians nearing the end of life receive the kind of whole-person, individualized and integrated care of which good palliative care consists.

That leads me to a very essential point, and that is the fact that individuals should convey their own personal preferences and values to their health care providers and family members *in advance*. In 1995 and again in 2000, the Senate Subcommittees made recommendations encouraging the expanded use of advance care directives in Canada. As we noted in last year's Senate Subcommittee report, eight provinces and one territory have passed and proclaimed advance care legislation.

While there are still difficulties to resolve in this area, the progress is tangible. There are now some good educational packages available to help people reflect about advance care directives, and how they can best convey their wishes to family members and to their health care providers. We are going to hear more about two excellent approaches today. Concentrated educational efforts in this area, aimed at both the general public and health care professionals, will continue to be a priority.

I would like to describe now some developments I regard as the basis for optimism. Increasingly, I believe we are seeing evidence that quality end-of-life is an idea whose time has come.

We see that evidence in the recent Speech from the Throne when the Government of Canada committed to a new policy in support of palliative care in relation to families. I would like to quote this passage for you. It reads: No Canadian should have to choose between keeping their job and providing hospice palliative care to a child. The Government will take steps to enable parents to provide care to a gravely ill child without fear of sudden income or job loss.

The Prime Minister's appointment of me as Minister with Special Responsibility for Palliative Care earlier this year underlines the federal government's commitment to progress on this issue. And on June 5 C the eve of the first anniversary of the Senate Subcommittee report C the federal government announced the creation of the Secretariat on Palliative Care within Health Canada. One of the Secretariat's roles will be to share information about the many excellent palliative care initiatives in place or under way throughout the country_ and help develop a strategy to ensure all Canadians have access to quality care at the end of their lives.

The Secretariat has numerous positive developments on which to draw, and to build. Across this country, in every province and territory, dedicated people and

organizations are developing new ideas and initiatives to improve the care they deliver to individuals who are dying.

There is a growing awareness among the public and health professionals of patients' rights to have good pain and symptom management, and of the fact that this management is just as important as treatments aimed at cure.

The whole idea of what palliative care means has evolved quite dramatically over the past two decades. Our models for palliative care are now far more flexible and broad-based than the traditional end-stage, pain-management care that cancer patients received in a hospital setting as they neared death.

We now recognize far more clearly that people with diseases other than cancer, also need the holistic, integrated approach that palliative care offers. The federal AIDS strategy led by Health Canada, for example, helped broaden our thinking about end-of-life care. People with AIDS do not necessarily suffer a steady decline. They may suddenly get better. The very nature of their illness requires a much more flexible approach to palliative care.

This broad-based palliative care model can accommodate active treatment, as well as pain and symptom management and emotional support. By way of illustration, in the context of the new palliative care models, a patient could have surgery to reduce the size of a tumor that was causing discomfort.

The availability of community and home-based care adds a very important dimension to the new flexible models of palliative care. As I said, our traditional idea of palliative care was of a special ward in a hospital where one went to die. The relatively new development of care in one's own home or community means an institutionalized setting is no longer a necessity. And for most people, the possibility of care in one's own home brings a tremendous added comfort

I hardly need tell you that the new palliative care models, with their flexible, broad-based character, are very well suited to older people nearing the end of life. Older patients do not inevitably undergo a steady decline. Their wellness ebbs and flows. So our new palliative care models are extremely compatible with the broad range of conditions and requirements of older people at the end of their lives.

There is a second major trend revolutionizing how we think about and deliver palliative care. This is the impact of the new cutting-edge communications technologies. The benefits offered by telehealth and tele-home care are enormous, particularly for older people near the end of life who want to stay in their own homes. Telehealth enables palliative care patients in rural and remote communities to receive consultative services and the benefits of specialist care, from literally thousands of miles away. Telecommunications also enables better continuity of care.

Major initiatives such as Health Canada's Health Transition Fund, the Health Infostructure Support Program and the Canada Health Infostructure Partnerships Program are also furthering the goal of quality end-of-life care for all Canadians. Specifically, the Health Transition Fund and HISP and CHIPP programs have provided funding for projects that will help us develop models for making palliative care available to a greater proportion of Canada's population.

With the help of the new technologies, projects under the Health Infostructure Support Program and the Canada Health Infostructure Partnerships Program have shown us how much telehealth can contribute. This care over great distances is made possible either through a direct link to a palliative care service in a larger centre, or by giving family practitioners and other health care workers access to consultative services that enable them to provide health care locally.

As you know, some of Canada's most remote communities are in our newest territory of Nunavut. In partnership with the Nunavut Department of Health and Social Services, the Government of Canada is contributing \$3.7 million under the Canada Infostructure Partnership Program to help the territory expand telehealth services to all communities. The IIU Network will establish links with the Northwest Territories, Alberta, Manitoba and Ontario. It will support the delivery of health and related social services to Nunavut residents, including diagnosis and care, telepsychiatry and mental health counselling and education.

In Prince Edward Island and Nova Scotia, the Health Transition Fund Rural Palliative Home Care Project demonstrated ways to meet some of the formidable challenges in providing effective palliative care in rural areas of the country. And telecommunications played an important part.

Before this project got under way, the palliative care services in the three selected rural communities were terribly wanting. They were fragmented and lacked continuity, and there was no common set of operational and evaluation standards.

I'm delighted to tell you that this demonstration project cleared the way to resolving these difficulties. Its success was due in large part to the project's education strategy for front-line and resource/consult teams. This comprehensive strategy also addressed the learning needs of the family physician, volunteers and members of the public. I think it's indicative of this project's success that all those who participated in it were overwhelmingly positive about what they got out of it.

Many valuable insights emerged from the integrated care program developed for this Rural Palliative Home Care Project. The starting point of selecting a centre in the region through which all access and referrals were processed, for example, is an

idea as effective as it is straightforward. When people are confronted with a crisis in their lives, having a central location for information is a must if they are to manage the situation successfully.

Perhaps above all, it was this project's high degree of integration and coordination, aided by excellent communications technology, that make it such a useful model with great potential for application in other rural and remote communities, and indeed, elsewhere.

A third and extremely gratifying developing trend is our society's growing awareness of the importance of palliative care for every Canadian nearing the end of life.

The Senate Subcommittee last June noted this very promising development in its five-year report card on progress since the Special Senate Committee completed its work in 1995. As that report noted, there is now a much greater awareness among physicians, and a growing sensitivity in society generally, about the role of palliative care for all those nearing the end of life. There is a much more extensive public awareness as well, about the development and application of advance care directives.

Over the next few minutes, I would like to highlight for you some of the ways this awareness is making itself felt in our society.

One very positive sign I welcome is the provinces' increasing recognition of the need for supports for palliative care in home and community settings.

Then too, over the past few years, Health Canada has supported initiatives and research projects that have had an impact on how we care for individuals at the end of life. These projects include a symposium that brought together geriatrics and palliative care specialists.

You may also be familiar with PALLIUM, a continuing professional development initiative in hospice palliative care. PALLIUM is a research partnership led by the University of Alberta, in conjunction with the University of Manitoba, the University of Calgary and the Regional Health Authorities of Yellowknife and Inuvik. The Government of Canada has contributed \$250,000 to this successful regional collaborative effort to improve hospice palliative care.

I also want to mention Health Canada's support which was instrumental in helping the Canadian Palliative Care Association get established. I work very closely indeed with this dedicated national organization, which has done, and continues to do, so much tremendous work on forwarding an agenda on palliative care for all Canadians.

One of the CPCA's many far-reaching projects is the development of national standards for palliative care. Once the CPCA completes its work on these standards, Canada will become the first country in the world to have developed a national consensus on standards of practice for hospice palliative care. Health Canada was also involved in supporting this ground-breaking initiative.

Another development with tremendous potential are the multidisciplinary partnerships we see at work in Canadian research conducted on palliative care.

In addition to supporting specific research projects on various aspects of palliative care over the past several years, the federal government has assisted the development of a research agenda bringing together the expertise of palliative care researchers from many disciplines.

The Canadian Palliative Care Association's Blueprint for Action is a very recent outstanding initiative that clearly sets out the work we need to accomplish in the field of palliative care. This Blueprint addresses the five priority areas specified in the Senate Subcommittee report. In essence, this Blueprint will help us formulate a strategy for the kind of quality end-of-life care for Canadians envisioned by the Subcommittee.

Out of the process of developing this Blueprint for Action, the Canadian Palliative Care Association has led the way in establishing a Coalition of over 20 non-governmental organizations, such as the Canadian Cancer Society, the Heart and Stroke Foundation of Canada, the Canadian Breast Cancer Network and the National Advisory Council on Aging. These more than 20 organizations have joined together to advance the cause of quality end-of-life care. They have much to contribute on behalf of the millions of Canadians they represent.

I would be remiss if I did not mention the many projects and initiatives relating specifically to seniors that Health Canada has supported over the years. Later in this symposium, for example, we will hear about one such project when Dr. Rory Fisher describes the guidelines for end-of-life care for seniors. I know this project will do a great deal toward improving the quality of care that older Canadians receive over the coming years.

Let me emphasize that all these extremely positive developments I've described occurred prior to the formation of a Secretariat within Health Canada with end-of-life care as its focus. Now that we have this focus, I am confident that we will see more such promising developments, reinforced by the means to share best practices and findings throughout the country.

Since assuming my position as Minister with Special Responsibility for Palliative care, I have been greatly encouraged by the public awareness I've seen and

people's readiness to talk about end of life. Everywhere I go, I find the message of quality end-of-life care is well received.

To sum up then, I see three trends converging in a juncture of great promise. The conditions are more than favourable for concerted work on realizing our goal of quality palliative care for every Canadian nearing the end of life C the emergence of new, flexible models of care, the technological power to deliver this care to all Canadians at end of life no matter where they live, and the growing awareness that this care is every Canadian's right. These are the three converging trends, and to my mind, they could not have come together at a more propitious time.

We have the right social, perceptual climate and technological climate. We have the focus afforded by the new Secretariat on Palliative Care. And we most assuredly have the will to realize our goal.

And we do have to talk about this goal, both at the policy and the public level, and at the research and professional level. We have to talk about it on an individual level C with each other and with our families. Health care providers and their patients have to talk openly and honestly about end-of-life care, and so too do friends, confiding sensitively in one another.

I am absolutely convinced that this is the only way we can effect the kind of progress that ensures our own care at the end of life is all that we would like it to be. I am speaking here about our goal for our society as a whole, and about the individual, highly personal perspective that each one of us has on this issue. This is our goal and nothing less C that our end-of-life care will be as we wish it to be.

Of course, I realize we have a long way yet to go to achieve this vision. But as I've highlighted this afternoon, there are abundant promising signs that we are making real progress. Working together with numerous dedicated organizations across Canada, we are determined to see that progress continue.

As I said, the conditions for making progress are most auspicious. Quality end-of-life palliative care is indeed an idea whose time has come.

Thank you.

