Five Years Later, Where is the Care in Dying?

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Care-in-Dying Coalition Presentation to the Senate Subcommittee to Update "Of Life and Death"

March 20, 2000

Introduction

The Care-in-Dying Coalition / Canadian Coalition Against Euthanasia is a coalition of over thirty organizations from across Canada which advocates compassionate, just, and respectful care for people who are dying. We represent a wide variety of religious denominations, community groups and health care related organizations. The coalition believes that every person has an intrinsic dignity and worth, and advocates compassionate, just and respectful care for persons who are dying. These convictions lead us both to oppose efforts to legalize euthanasia and assisted suicide, but also to strongly advocate increased access to palliative care and respectful end-of-life treatment for all persons.

Five Year Review of "Of Life and Death"

The Care-in-Dying Coalition was formed in 1994, before the Senate's "Of Life and Death" report, and we have followed the report and the reception it has received since then closely. In our view, while there were some problematic aspects to the 1995 report, it contains many excellent recommendations in the area of end-of-life care and is in many ways a landmark document. We think that it is appropriate to follow up on the report and see how governments and others have responded to its unanimous recommendations, but we are concerned that advocates of euthanasia and assisted suicide may attempt to use these hearings as a way to put these causes back on to the political agenda. That is why we strongly feel that the emphasis of your report should be to follow up on the unanimous recommendations of the report in the area of palliative care.

The Need for Focus on Palliative Care

Why is it that in discussions of end-of-life issues, the euthanasia and assisted suicide tail seems to wag the palliative care dog? Put another way, why is Dr. Jack Kevorkian a household name, while Dame Cicely Saunders, the founder of the modern hospice and palliative care movement, is virtually unknown outside of professional circles?

Dr. Kevorkian is far better known than Dr. Saunders, yet when it comes to facing the inevitable end of our own lives, far more people would want to benefit from the treatment of a palliative care provider like Dr. Saunders than would ever dream of putting themselves into the hands of an assisted suicide practitioner like Dr. Kevorkian. At the most, only a tiny minority of people would ever want measures to be taken to actually end their own life or that of a loved one. But everybody wants to be treated with respect, dignity, and relieved of pain when faced with the inevitability of death. Yet too often this debate becomes polarized around the euthanasia issue and the much more important priority of providing quality care for all dying persons is ignored.

The Senate's 1995 report, which some of the Senators here contributed to, contained many excellent recommendations in the area of palliative care and end-of-life treatment. But unfortunately, these recommendations seem to have been ignored not only by the media, focused on a small number of dramatic "who's life is it anyway?" stories, but by governments and Departments of Health which seem to have relegated palliative care to near the back of a long queue of demands for health care funding.

The Care-in-Dying Coalition is glad that in its update that the Senate has decided to concentrate on the unanimous recommendations of the "Of Life and Death" Report, which contain many positive recommendations in the area of palliative care, and avoid reopening the debate on the contested recommendations which primarily involve the arguments for and against euthanasia and assisted suicide. We hope that in writing its report that the committee will maintain that balance, and devote far more attention to palliative care issues than to reopening possible changes to the *Criminal Code*.

A Review of the Report's Recommendations

The "Of Life and Death" Report made unanimous recommendations in several important areas; palliative care, pain control and sedation, withholding and withdrawing of life-sustaining treatment, advance directives. The Care-in-Dying Coalition supports the vast majority of the report's recommendations in these areas, but we note that there has been little progress in implementing them, especially when it comes to providing palliative care and proper pain control and sedation techniques.

The committee called for governments to make palliative care "*a top priority in the restructuring of the health care system*." In fact, the opposite seems to have happened. Due to the health care cuts of recent years in many provinces, palliative care seems to have been a victim of disproportionate cutting. The Canadian Palliative Care Association testified before this committee that only the four Western provinces consider palliative care to be a core health care program with its own budgetary envelope, and that the total number of palliative care beds have been cut across the country. In some places the lack of trained staff has put the existence of palliative care programs in jeopardy. Health Canada officials testifying before your committee acknowledged that only slightly more than 5% of dying patients are able to access professional palliative care.

The committee called for "*the training of health care professional in all aspects of palliative care to be increased*," yet we note that the majority of medical schools in Canada still do not offer the certificate in palliative medicine created by the Royal College of Physicians and Surgeons and the College of Family Physicians of Canada, primarily due to a lack of funding. The University of Ottawa, with its specialized Institute of Palliative Care, graduates only between one and three palliative care specialists per year - accurately characterized before this committee as "a drop in the bucket" compared with the need for these services.

The committee called for "*an integrated approach to palliative care*" yet the evidence is that, outside of a few urban centres like Calgary, Edmonton, Ottawa, Winnipeg, and Montreal, there is little coordination between palliative care centres and other parts of the health care system. In other cities, or in rural areas, there is little or no coordination of services, and no funding for coordination projects. Perhaps more crucially, there has been little progress in the whole area of home care, where it is vitally important that patients be enabled to die in a home setting if they want to and it is possible for them to remain in the home.

The committee recommended that "*research into palliative care, especially pain control and symptom control, be expanded and improved*." Again, the response to this recommendation has been underwhelming. The major funding bodies such as the Medical Research Council and the National Cancer Institute of Canada have provided only a tiny amount of funding for palliative care research, and the new Canadian Institutes of Health Research have no programs in the area of end-of-life and palliative care. The testimony before this committee of Dr. Harvey Chochinov of the University of Manitoba, a renowned researcher who's *Lancet* article on the will to live in dying patients stirred international comment last year, was extremely troubling, especially his statement that a colleague considered to be one of Canada's top end-of-life researchers was unsure whether he could continue to stay in the field for another year.

Only in one area, the creation of national standards, has there been significant progress. But the credit here must go to the professional bodies like the Canadian Palliative Care Association that have worked to develop such standards with little government funding. Similarly, in the area of withholding and withdrawing treatment, it was the Canadian Healthcare Association, the Canadian Medical Association, and the Catholic Health Association, the Canadian Bar Association produced the1995 Joint Statement on Resuscitative Interventions, and not federal or provincial health ministries.

This overall lack of progress in the area of palliative care is unacceptable, and we believe contributes to the dangerous false dichotomy where many people feel that assisted suicide or euthanasia is the only alternative to dying a painful, miserable death.

In the areas of pain control and Sedation and withholding and withdrawal of life-sustaining treatment, the "Of Life and Death" report recommended that the *Criminal Code of Canada* be changed to clarify the legitimacy of providing pain relief even where this may have the unintended effect of hastening death, and the circumstances under which treatment may be withheld or withdrawn. Three Senate private members bills to this end have been introduced, one of which, Bill S-2, is still before the Senate. The Care-in-Dying Coalition made its views known on the previous Bill S-13, and we have also prepared a study on Bill S-2, which we will provide to this committee and to all Senators.

We acknowledge that there may be ambiguities in the existing *Criminal Code* that could use clarification, although it must be kept in mind that not a single doctor or medical professional has been charged under the sections of the *Criminal Code*

concerned for following a request to withhold or withdraw treatment or for administering painkillers - only clear cut cases of nonvoluntary euthanasia or assisted suicide have ever been prosecuted. In the public mind, unfortunately, respecting a patient's wishes to refuse treatment, or giving drugs to relieve pain which may have the unintended consequence of shortening life, are often confused with euthanasia. Thus, the Coalition supports the intent of these bills, including Bill S-2, to clarify that withholding and withdrawing of treatment in certain circumstances and the proper use of medication to alleviate pain are distinct from euthanasia or assisted suicide.

However, we have serious concerns with the wording of these bills, which we feel may in certain circumstances be interpreted as permitting euthanasia. With regards to the current Bill S-2, we must caution that there are several aspects of the current bill which we find highly problematic as they could potentially lead to allowing intentional killing either by action or omission. In its current form, we do not find this bill acceptable.

On another legal recommendation of the Senate report, the Committee unanimously recommended that "*the Criminal Code be amended to provide for a less severe penalty in cases where there is the essential element of compassion or mercy*." The Care-in-Dying Coalition opposed, and continues to oppose, this Senate recommendation. In our view, creating a less severe penalty for certain types of murder would lead to the implication that the lives of the elderly, the sick, and the disabled are some how less valuable and less worthy of the protection of the law than the lives of the non-handicapped. While there may be valid reasons for reviewing mandatory sentencing provisions, it is extremnely important to make sure that changes apply to all cases of second-degree murder and not only those where the motive is alleged to be compassionate. We feel that the case of Tracy Latimer has given ample evidence that a lesser sentence for crimes of this kind would undoubtedly send a negative signal about the relative worth of the lives of the disabled and handicapped. On January 30, 1998, in light of the *Latimer* case, the Care-in-Dying Coalition sent a letter to the Hon. Anne McLellan urging that the law not be changed in this respect. Seven member organizations of the Care-in-Dying Coalition are currently intervenors in the appeal of the *Latimer* sentence to the Supreme Court of Canada.

Care-in-Dying's Recommendations

While our Coalition has concerns about some of the legal issues raised by the "Of Life and Death" report which we have mentioned above, and which we are addressing in other fora such as the S-2 debate and the *Latimer* appeal, our greater concern is that the debate over these contentious, divisive legal issues should not overshadow the imperative for action in the area of palliative care.

We think that the recommendations of Dr. Chochinov of the Department of Psychiatry at the University of Manitoba on this point were excellent, and with slight modifications, we would like to reiterate them.

> First, the Senate should support designated funding, through MRC, the CIHR, or other bodies to support palliative care training, service delivery, and end-of-life care research.
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> Second, all medical training facilities and licensing agencies should be required to provide training and assessment in the area of end-of-life care. Specifically, all 16 Canadian medical schools should include palliative care education, and should be provided the funds to do so.
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> Third, all health care facilities, including hospitals and long-term care facilities, should be required to demonstrate appropriate standards and competence in end-of-life care.
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> Fourth, Health Canada should produce an annual report on the status of and progress made in end-of-life care nationally.
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> Fifth, the title of the update report should reflect a focus on end-of-life care such as "The Senate Report on End-of-Life Care in Canada."or "End-of-Life Care: A Crisis in Canadian Health Care."

We also think that many of the more detailed recommendations of the Catholic Health Association of Canada, who you will also hear from tomorrow, are also excellent and complement these basic recommendations.

We believe that there is a significant crisis in the lack of access to palliative care in this country, and it is this crisis, along with media sensationalism, which is fueling the calls for euthanasia and assisted suicide. We oppose euthanasia and assisted suicide as incompatible with human dignity and respect for human life. We are concerned to affirm the worth of the human life of the most vulnerable members of our society, such as the sick, the disabled and the elderly, and to ensure that there are effective advocates for the rights of those who cannot speak for themselves. We call for the Senate to deal with the problems of end-of-life care at their root by coming forward with a strong report urging that their excellent, unanimous recommendations in the area of palliative care and pain control be acted upon by governments as an urgent priority.