Healing the Body Enriching the Mind Nurturing the Soul

Covenant Health
Compassionate care led by Catholic values

September 1, 2010

George Paul Dienesch
Research Secretary
Parliamentary Committee on Palliative and Compassionate Care
Room 402, Justice Building
Ottawa, ON K1A 0A6

Re: Covenant Health Submission to the Parliamentary Committee

Dear Mr. Dienesch:

Thank you for this opportunity to provide feedback to the Parliamentary Committee on Palliative and Compassionate Care, and to add Covenant Health's own perspectives on end-of-life care which we believe are aligned with the Committee recommendations and goals.

We have provided some introductory comments, followed by background information on Covenant Health and our End-of-Life Strategy which focuses on education, research, clinical standards and best practice, serving planning, and access.

We conclude with our feedback on the Committee's recommendations to revise the *Canada Health Act*, implementing a national palliative care strategy, re-establishing a Federal Secretariat, and ensuring a sustainable funding strategy to meet the end-of-life needs of Canadians.

Given our experience and leadership as an institutional provider of palliative and end-of-life care, and the particular ethical and moral framework that informs our work, we believe we can help support and contribute to the Committee's work.

We look forward to meeting with the Committee in Ottawa to discuss our submission whenever this may be scheduled. Please do not hesitate to contact us if you need any further information.

In kind regards,

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Introduction

We commend the Members of Parliament for leading this non-partisan, national discussion on palliative and compassionate care, and especially in framing the debate within the broader context of care for vulnerable Canadians.

Along with soliciting input on certain health programs and services, including the most effective means to fund, deliver and evaluate end-of-life care, the Committee is wise to invite participants to step back and reflect on the kind of just and compassionate society we desire for Canadians. Covenant Health is pleased to provide some concrete feedback regarding a number of the Committee's recommendations that will follow in this submission, but first wish to acknowledge the significance of the Committee's work in helping shape public policy regarding care of the vulnerable in general.

As one of the largest faith based providers in Canada, informed by a Catholic moral and social justice tradition, we routinely challenge ourselves in reflecting on a number of fundamental questions about the ends or goals of our work. For example: Who are the most vulnerable of society today, and how are we called to serve these individuals? What do we mean by vulnerability, or for that matter, respect for the human person? What is our vision for end-of-life care? Our perspective to these and other related questions must form the basis of the kinds of programs and services we provide, and the lens to evaluate how successful we are in fulfilling our mission.

Although we have chosen to limit our comments in this submission to the area of palliative and end-of-life care, and from our context as an institutional provider, we believe Covenant Health's approach regarding the fundamental social and moral questions about what it means to be vulnerable, to be respected, and to be cared for will serve as an overarching framework to support the Committee's mandate. The vulnerable of society have many faces – be it the dying, the mentally ill, or those living with disability, and the Committee is commended in examining the needs of all vulnerable Canadians, and where opportunities exist for improving access to care.

Yet, even the broad scope of the Committee's mandate does not address all vulnerable Canadians. Those who are homeless, addicted, sexually exploited, and abandoned are equally vulnerable members of society deserving of respect, raising other questions that exceeds the Parliamentary Committee's mandate. Covenant Health has also wrestled with how much and how far a reach we can extend our services, recognizing the importance of owning our context, and setting strategic priorities as to where we believe we are called to serve and can be most effective.

Such limitations underscore the need for effective partnerships between organizations, developing comprehensive strategies and setting realistic goals and outcomes in support of the common good. Our value of *collaboration* reminds us we cannot do it all; nevertheless, we are called to provide leadership where we have expertise as an institutional provider.

To this end, Covenant Health has identified End-of-Life Care, Senior's Health and Mental Health as strategic organizational priorities. While the needs of the dying certainly require compassionate support, we also recognize that an aging society that persistently stigmatizes mental illness (not to mention death), requires equally effective leadership to address. It is not uncommon that all three strategies are operative when coordinating services in response to the needs of a single patient. Caring for an elderly patient can require tremendous coordination of services, especially when the person has compromised mobility, mild cognitive impairment, episodic psychosocial and spiritual anguish, ongoing pain management needs, and advanced planning requirements around the goals of care. Unfortunately, even within our own organization, lack of coordination and poor communication between disciplines, exacerbated by geography and different site cultures can result in service gaps. This is only magnified at the broader system level, *reinforcing the need for a coordinated national strategy as recommended by the Parliamentary Committee.*

We are proud of our Mental Health and Senior's Strategies, and pleased to discuss these priorities further with the Committee. However, we believe our comments regarding Covenant Health's End-of-Life Strategy are informed by a consistent ethical tradition and moral vision, and therefore reflective of our organization's approach to other vulnerable persons, be they the elderly, the mentally ill, or the dying.

Care of Vulnerable Persons

In response to the first question posed at the outset, we must acknowledge that there are many people who are vulnerable in society. Even the person entering our facilities for the most routine and benign procedure may be vulnerable. As a board and senior executive team, we have long debated what we mean by vulnerability, concluding that the human condition itself is a vulnerable state of being given our mortality and morbidity. We may or may not in our lifetime be accidentally hurt, develop a pathological tumor, or experience cognitive loss, but we will most certainly die. Despite technological advances in health care, we are, by virtue of the human condition, *all* vulnerable.

Thus, we have even questioned if use of the word, "vulnerable" itself can be a stigmatizing label, and inadvertently demeaning in talking about whole populations, i.e., "vulnerable immigrants." [i] A new Canadian may resent being described as vulnerable, especially if the label may gloss over this person's unique circumstances. Similarly, our vantage point may be a limiting factor. Perceptions regarding the quality of life of those living with disability have been reported far lower among the general population compared to scores of those actually living with a disability.

Therefore it is very important, when envisioning a national strategy for palliative and end-of-life care, that it begins with engaging the stakeholder views of those who have, or currently are, utilizing such services. Far from an ego-centric attitude of what "we" can do for "them," that can perpetuate dependency and further experiences of vulnerability, we are called to participate *with* serving the dying and their families. *A national end-of-life strategy must promote patient and family centered care.*

To ensure that even our language is consistent with our vision of health care, we have typically focused on messaging on what it simply means to be human and part of the human community, and in turn, how we in Covenant Health are called to serve our fellow human beings with justice and compassion.

The Call to Compassion

From a Catholic theological perspective, all persons, irrespective of age, physical infirmity, cognitive impairment, or failure to thrive, nevertheless possess an intrinsic dignity and incalculable worth. Human life is an immeasurable treasure that must be celebrated and nurtured. Our tradition has consistently upheld the dignity of human life, from conception to natural death. While there are undeniable burdens and losses associated with the dying process, including the demands caring for the dying, no person *is* a burden. Promoting and defending this vision of the human person defines the ultimate measure of success for every strategic initiative of Covenant Health. This lens extends to all we serve, in keeping with the nonjudgmental and universal regard demonstrated by the religious congregations who founded our institutions.

It is because of this bedrock ethical and moral lens that we have been extremely troubled by certain societal forces that have eroded the dignity of human life, exposing new vulnerabilities for Canadians. Recent efforts to legalize euthanasia and physician assisted suicide in this country has elevated the urgency in *advocating for a national and sustainable end-of-life strategy.*

Indeed, we see attempts to hasten the death of others as an abject failure of what it means to be a compassionate society. The etymological root of “compassion” comes from the Latin *cum* (with or together), and *passiō* (suffering, submission) a derivative of *passus* (to suffer, submit). At its root, compassion means to be “together in suffering.” Compassion calls us to stay *with* one another, and to be present despite our helplessness in altering the disease trajectory. Palliative and end-of-life care is the epitome of this compassionate presence, in providing quality pain and symptom relief, attending to complex psychological and spiritual needs, and ultimately, being truly with a patient and their family even when cure is not possible.

With these introductory comments we wish to emphasize the foundational ethical and moral lens by which Covenant Health evaluates its programs and services. Ultimately, we seek to contribute to the *flourishing* of human life, by promoting and defending human dignity at all stages of life. This is not an easy task, especially given the busyness of our broader culture that values expediency and materialism, often leaving individuals who struggle with disability, chronic health concerns, old age, and infirmity, as burdens onto society.

The so-called “warehousing” of the aged with substandard and unimaginative housing, under-resourced programming, and institutional practices which perpetuate conditions of isolation, indignity and dependency constitutes a grave injustice. Such models breed fear around the aged and dying as an unsightly affront to public sensibility that must be kept apart, or worse, disposed of entirely. Allowing this fear to go unchecked only fuels ongoing interest in euthanasia and assisted suicide as a viable addition to seniors care, or hospice and palliative care in a society that is increasingly scandalized by any human condition that is not powerful, beautiful and ruggedly independent.

We believe the notion of burden continues to fuel interest in euthanasia and why, therefore, it is critically important that the Parliamentary Committee on Palliative and Compassionate Care keep in its view *the fundamental moral questions proposed here about what kind of society in which we wish to live, grow old in, and eventually die.* How do we truly care for one another at the end of life? This is not the same meaning as how do we treat, or even cure others. Care speaks to relationship and a shared sense of vulnerability. How then are we vulnerable with one another, and stand with one another in times of need? These are some of the most important social justice issues of our time. The future of palliative and end-of-life care in this country will play an important part in helping shape our answers to these questions.

Background on Covenant Health and History with Palliative and End-of-Life Care

Covenant Health is Canada’s largest Catholic provider of health care, building on a 146-year history of service in Alberta.

Our organization draws on the rich legacy of eight communities of Roman and Ukrainian Catholic sisters who founded our health care ministries across Alberta and effectively laid the groundwork for Alberta’s health care system beginning in 1863. Covenant Health was formed on October 7, 2008 with the merger of 16 Catholic facilities in 11 communities across Alberta under a single board and administration. The goals of the consolidation were:

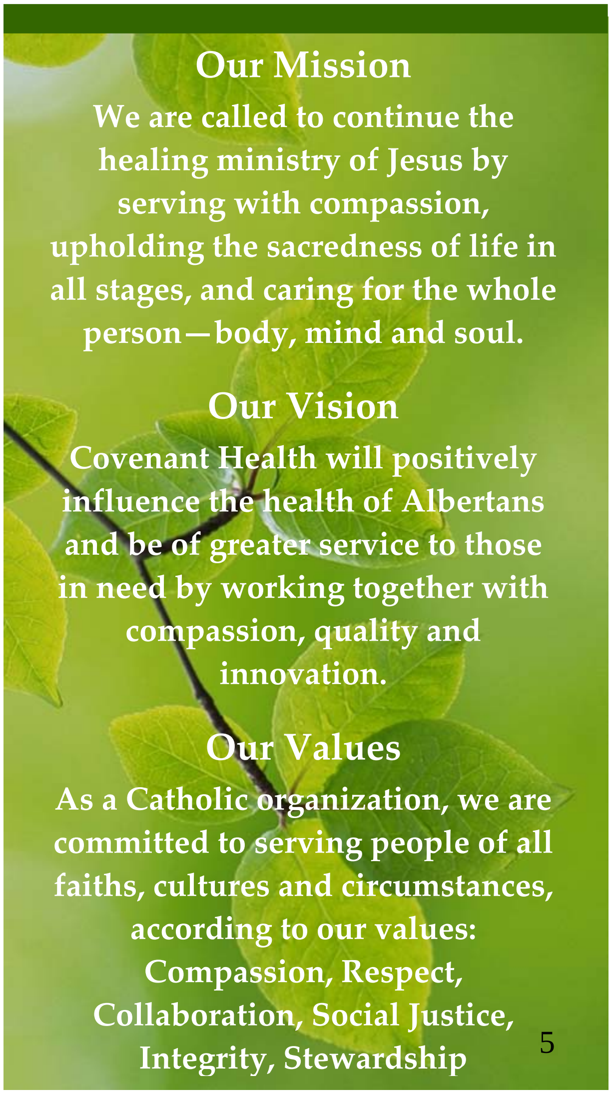
- to establish a bold new direction for Catholic health care in Alberta;
- maximize the strengths and contributions of each facility;
- improve operational effectiveness, and;
- ensure a coordinated approach to working within an integrated provincial health care system.

Covenant Health has a budget of over $600 million and a team of approximately 14,000 staff, physicians and volunteers.

We serve as a significant partner in Alberta’s integrated health system. Funded by Government through Alberta Health Services, Covenant Health provides a range of services—including acute care, continuing care, assisted living, palliative care, hospice, rehabilitation, respite care, and seniors' housing in urban and rural settings.

We provide quality end-of-life care in all of our facilities across Alberta. Covenant Health has 73 designated palliative care beds, including a 20-bed Tertiary Palliative Care unit for Albertans with high symptom needs. The majority of admissions to the Tertiary Palliative Care unit are for suffering related to severe psycho-social and spiritual distress.

Although we are a newly consolidated organization, together we have a long history in providing quality palliative care and hospice services. The Sisters who founded our institutions were widely known for the compassionate and holistic care in which they ministered to the dying. In fact, it was due in part to the leadership of the Grey Nuns congregation in responding to an unmet need that contributed to the establishment of palliative care services at the Edmonton General in 1983 which continues to this day as the Mel Miller Hospice.



Our Mission

We are called to continue the healing ministry of Jesus by serving with compassion, upholding the sacredness of life in all stages, and caring for the whole person—body, mind and soul.

Our Vision

Covenant Health will positively influence the health of Albertans and be of greater service to those in need by working together with compassion, quality and innovation.

Our Values

As a Catholic organization, we are committed to serving people of all faiths, cultures and circumstances, according to our values: Compassion, Respect, Collaboration, Social Justice, Integrity, Stewardship

In 1995, the Tertiary Palliative Care Unit at the Grey Nuns Community Hospital in Edmonton opened. Today, this is a world renowned teaching centre in palliative medicine, pain and symptom management, and research. These units form part of an innovative integrated regional palliative care service within the Edmonton Zone, which was the first in Canada and the best evaluated and published example of its kind.[ii]

Given our historical commitments to end-of-life care, and the ethos of our organization, we have signaled through Covenant Health's End-of-Life Strategy the enduring importance of this work. This strategic priority endeavours to meet the needs of dying Albertans through 4 pillars or objectives:

- *Educating health care professionals, volunteers and the general public;*
- *Conducting research;*
- *Clinical services, including implementation of end-of-life clinical pathways;*
- *Service Planning, including access to consultation services for frontline providers*

These strategic initiatives are reflective of the priorities identified by other national associations and coalitions. For example, the Quality End-of-Life Care Coalition of Canada (QELCCC) has advanced in its *Blueprint for Action 2010 to 2020* a number of recommendations, including: professional caregiver and family education and support, research and integration of findings into policy and practice, and timely access to services.[iii] Covenant Health is a participant in the *Catholic Health Alliance of Canada,* one of the coalition members of the QLECCC endorsing the blueprint for action priorities, which in turn are supported by our organization.

Covenant Health also participated in one-on-one interviews with Senator Sharon Carstairs and supports the findings and recommendations identified in the recent Senate report on the roadmap for palliative care in Canada.[iv] Finally, Covenant Health supports the standards of practice and benchmarks established by the Canadian Hospice Palliative Care Association, and are working in our early consolidation period to ensure they are consistently followed at all our sites, wherever end-of-life care is delivered.

Threats to Palliative and End-of-Life Care in Canada

As we face an aging population presenting with ever more complex end-of-life needs, we are well positioned to provide comprehensive palliative and end-of-life services and be of greater service to vulnerable populations. Covenant Health advocates for comprehensive care and end-of-life resources to meet the myriad needs of Canadians. However, we are vehemently opposed to the legalization of euthanasia and physician assisted suicide as care options.

Despite the recent defeat in the House of Commons of *Bill C-384 - An act to amend the Criminal Code (right to die with dignity)*, this issue is not far from public consciousness. We believe the lingering interest in euthanasia requires ongoing vigilance and examination of societal attitudes and values. Covenant Health wrote to the Federal Government, advocating why we did not support this or any future proposed legislation to legalize euthanasia and assisted death, but also what we do support as far as advancing palliative care and end-of-life resources in this country.

Arguments for euthanasia and assisted suicide are often advanced based on individual rights, and specifically, an individual's autonomous right to have suffering relieved. Proponents argue that we have a moral right to exercise our autonomy, including the means and timing of our own death in order to relieve suffering. Yet it remains that the strongest voices against legalizing euthanasia and physician-assisted suicide in our organization are the palliative care practitioners themselves who work with the dying. They believe society has not adequately addressed the needs of the dying and their families, and that the public is largely misinformed about appropriate pain management and comfort measures. Euthanasia is viewed as a means to an end, but as remarked at the outset of this submission, we must continually reflect on the end or goals of our clinical services. We are called to alleviate the pain and suffering of the person in our care, and not the person. *This again points to the need for public education that must be addressed in any comprehensive national strategy.*

In the Roman Catholic tradition, euthanasia and assisted suicide represents the ultimate failure of compassion and expression of solidarity, revealing the seeming incapacity of being truly present to one another's suffering. It has been said that if anyone in the community hurts, then the entire community hurts along with them. For the person confronting their mortality and the spiritual, psychological and existential questions often triggered during this process, having someone to accompany them and to listen to their experience is as important as the appropriate pain and symptom management that is provided.

It seems that whenever physical or psycho-spiritual needs are not appropriately attended together in a comprehensive and holistic manner that interest in euthanasia and assisted suicide grows. This is unfortunate, and we believe the lack of public education that seeks to dispel fears of people dying in abject pain or spiritual distress no doubt contributes to this misperception, which Bill C-384 and previous private member bill attempts appeared to capitalize on.

Suffering requires the mobilization of a community of interdisciplinary health care professionals trained in the skills to support those who suffer deeply. These skills include an ability to help the person explore the depths of their being and the source of the existential suffering. Legalization of euthanasia is not a substitute for such support. A society that permits euthanasia will not remain committed to such high standards of palliative care. There can be meaning in suffering but only if there is a support for those who suffer. *This requires comprehensive family and volunteer supports, including enhancements to the Compassionate Care Benefit program.*

The enduring taboo to talk openly about death and loss in our death-denying society cannot be underestimated. When broached, some Canadians will admit to their fears: of the loss of dignity or independence, of being a burden, of uncontrolled pain. Advocates for legalizing euthanasia and assisted death may misrepresent the ethical obligations of some religious groups, purporting a doctrine of vitalism that insists at life at all cost. In the absence of public education to the contrary, many Canadian's fears of being subjected to unnecessary and unwanted treatments will be reinforced, understandably leaving the door open for those advocating death on demand.

We believe the Federal Government has a responsibility to advance informed debate, as modeled by this Committee, *to ensure Canadians truly understand what palliation means, and the well established ethical framework for withdrawing and withholding treatment.*

A recent *Globe and Mail* article inadvertently added to this confusion in stating "we have to move beyond the religious sentiment that holds life is sacrosanct." [v] From a Roman Catholic perspective, life is indeed sacrosanct, but as attested by our long tradition in providing quality, world renowned palliative and end-of-life care within our Catholic institutions, there is always a need to weigh proportionate benefit and burden with any treatment decision. Prolonging dying is morally wrong, but so is intending and hastening death.

The availability of euthanasia as a legal right would redirect resources and energies away from understanding why someone may request euthanasia, and ultimately the relief of their suffering. We may too quickly capitulate to requests, perhaps driven by our own vulnerability and helplessness of being able to stay present to someone. Proponents of euthanasia assert that it would only be given to those patients who ask for it with clear, lucid, free, un-coerced consent. How would it be possible to eliminate coercion from the equation? The prevailing research shows that psychological and spiritual distress, suffering and burden are the reasons people request euthanasia, which speaks to the broader societal issues of a death-denying culture where loss, dependency and vulnerability are taboo. *It is for this reason that funding for qualified spiritual care providers be part of a national end-of-life strategy, to help patients and their families name and attend to their deeper issues of meaning, and to accompany them in their suffering.*

Moreover, we need to understand that no autonomous decision is ever a solely, private act. A decision made by one individual to terminate their life has implications for others, and for the entire community. Legalizing euthanasia threatens other Canadians who may feel pressured to do the same.

A Duty to Die?

The concept of burden has been well articulated as why some individuals request euthanasia. Thus we are deeply troubled that Bill C-384 risked the lives of people with disabilities, people with chronic physical or mental conditions and other vulnerable persons who already feel stigmatized as a perceived burden upon society, despite the questionable safeguards the bill promised. Making euthanasia an option may deny some the option of choosing life, especially the most vulnerable. If euthanasia is an autonomous choice, then continued existence must also be a choice. Either way, an individual is held responsible for the choice they make and will need to justify that choice.

This is especially challenging if others do not see value in your life and it becomes increasingly difficult as emotional demands, care-giving requirements, and financial burdens come to bear. Therefore, even those who feel their life is worth living may choose euthanasia if it is the opinion of others around them that it is not. The fact that there is a choice may lend itself to pressure to request euthanasia.

We are especially concerned that those who experience burden and anguish without any prospect of relief would view any legalization of euthanasia as reflective of their “duty to die.” We call upon provincial and national governments to support those who are arguably the most vulnerable citizens in our country with the appropriate community, mental health, and palliative care resources to mitigate even one person resorting to taking their own life, or asking another person to assist them to do so. *The voice of a national Secretariat could help ensure appropriate end-of-life care is available to all citizens, including safeguards to protect the most vulnerable.*

Bill C-384 raised some vital issues that still must be addressed. Euthanasia is not an end in itself with intrinsic value, but it is a means to realize a perceived quality of the dying experience as described by supporters. The argument against legalization is not necessarily about the care of an individual but is about the ethics of publicly sanctioning a social policy and practice regarding care of the vulnerable in society. It is important to explore the context of social issues related to euthanasia including burden, meaning in suffering and value of personhood. We believe it is insufficient to simply vote against a bill without, at the same time, bringing proportionate effort in advocating for quality palliative and end-of-life care. *This underscores the role of a national end-of-life strategy to support public education and promotion of palliative care.*

As the baby boomer generation begins to retire and our society ages, the demand for quality palliative and end-of-life care will undoubtedly increase. We believe Covenant Health can positively influence the health of Albertans by providing compassionate support to an aging population. Without such positive efforts, we believe some will turn to euthanasia and assisted suicide as a way of addressing a deeper social issue. We need to promote a just society that values the intrinsic dignity of all Canadians, as well as ensure appropriate seniors housing to allow the elderly to age in place and to flourish. Otherwise, we will continue to grapple with proposed solutions like Bill C-384.

The Urgent Need for a National Strategy

Given the pervasive cultural issues in our country that devalue human life, we believe a stronger national strategy must be advanced, and that such strategy be supported by the appropriate resources.

Covenant Health will continue to advocate with our provincial funder to strengthen palliative and end-of-life care in Alberta, and to ensure clinical leadership and best-practices, access to consultation, education, and research, however we also recognize the limited resources available to any one program. Moreover, despite the leadership of world renowned palliative clinicians and researchers in Alberta and elsewhere in Canada, these leaders will only continue to meet enduring resistance if a broader national vision for palliative care is not established.

The recent report from the *Economist Intelligence Unit* ranked Canada 9th in quality of palliative care services internationally.[vi] This is unacceptable and should serve as a rallying call to all Canadians. But without a national, by-partisan vision that clearly advances end-of-life as a moral imperative, enshrined in both public consciousness and in the *Canada Health Act,* with appropriate funding to ensure equal access to all Canadians, palliative care will risk becoming merely *optional.*

Inequitable access to palliative care and home care supports across the country as noted in the *Commission on the Future of Health Care in Canada* [vii] and the recent *Canadian Medical Association* report card [viii] reveals that it does make a difference where one dies, and the kinds of services that will be available. This too is unacceptable if quality palliative and end-of-life care is identified as a Canadian essential health care service. Even one person being underserved represents an affront to all those committed to end-of-life care in this country.

We also recognize that for the large majority of time, palliation is provided in the community, in the comfort of the patient's own home. A sustainable and well resourced strategy must also include adequate home care and primary care supports, including pharmaceutical care. *It is incumbent upon health policy makers that proportionate funding is dedicated to augment these essential elements of the health care system that has historically been under resourced.*

Yet, it is important that we allocate funding appropriately to place of care. It is not uncommon that patients, earlier on in the disease trajectory when they are feeling relatively well, will say they wish to stay at home until the end. However, as their disease progresses and their care needs increase so do their wishes (and those of their caregivers), change. Without giving people options for location of care and location of death as their circumstances change, we may risk *over-emphasizing* home care, which is counter productive and potentially harmful.

Home care rather needs to be situated as part of an integrated regional service delivery model. Until we are able to promote and develop integrated regional palliative care services in urban and rural areas across Canada we will continue to offer poor national palliative and end-of-life care with isolated areas of excellence.

In Alberta, for example we have excellent models in Edmonton, Calgary and the south zone, while the centre and north zones suffer from poor funding and lack of zone leadership. A national strategy and funding model that mandates this kind of service as a core expectation would go a long way to decrease clinical situations of poor end-of-life care that drive much of the enthusiasm for euthanasia or physician assisted suicide.

We maintain that funding should be allocated proportionately where patients choose to live and eventually die – be at home, in hospice settings, shelters, continuing care, acute care, or specialized tertiary settings.

Parliamentary Committee Recommendations

We have identified the strategic initiatives that comprise Covenant Health’s End-of-Life Strategy, and throughout the document noted in italics where alignment and broad support of recommendations advanced by other national associations or coalitions. The Parliamentary Committee on Palliative and Compassionate Care has proposed 4 specific recommendations of their own, inviting stakeholder feedback. We support all 4 Committee recommendations as they relate to our role as an institutional provider of palliative and end-of-life care.

Recommendation #1

That the government of Canada make palliative care a necessary service with revision to the Canada Health Act.

Covenant Health has historically viewed palliative and end-of-life care as a core service, and has identified it among its three organizational strategic priorities. Our commitment to end-of-life care epitomizes our mission and values to provide compassionate care to all, especially the most vulnerable. As much as dying is a universal human reality, so too should palliative and end-of-life care be afforded the appropriate funding and resources so it can be universally provided in this country. Funding of services that benefit all should be weighted above funding strategies requiring expensive, high-end technological interventions that may serve fewer. Revising the *Canada Health Act* can provide the elevated profile and demonstration of political will that palliative and end-of-life care are indeed a priority to Canadians.

Recommendation #2

That the government of Canada re-establish the Federal Secretariat on Palliative Care, and implement a National Palliative and End-of-Life Strategy

Covenant Health has identified end-of-life care as a key strategic priority, in response to the needs of an aging society, and what is demanded of us by virtue of our mission, vision and values. We believe our End-of-Life Strategy provides a compelling and positive alterative to counter enduring societal attitudes that view those who are old, infirm, or dying as burdens to be disposed of.

While Covenant Health will continue to advocate and advance this strategy within our own provincial jurisdiction, our organization will benefit in aligning our work within a broader national agenda. This will support inter-provincial cooperation, and leveraging of resources, research, and clinical best practices. Ultimately this will help minimize service gaps.

Moreover, such a Federal leadership role will communicate to Canadians that quality end-of-life care is an integral part of our national consciousness, helping reinforce the work of partner associations and coalitions. The Federal Secretariat can serve as the highest voice and champion of palliative and end-of-life care in Canada.

Recommendation #3

That the government of Canada establish a transfer of funding to the provinces and territories specifically tied to building and maintaining a Palliative Care infrastructure.

Covenant Health supports funding transfer agreements to support a palliative care infrastructure insofar clear accountabilities are identified, and the infrastructure adds value to the current provincial system and Covenant Health's own End-of-Life Strategy. The *Quality End-of-Life Care Coalition of Canada* has proposed a similar multi-sectoral task force or working group that intersects health and social services, drawing on the resources on many allied partner organizations.[ix] Covenant Health endorses such a proposed infrastructure. Whatever the model, it is important the structure works primarily to leverage resources to better meet Canadian's end-of-life needs, versus adding another layer of bureaucracy to the system.

We are concerned that unless a clear vision is articulated for a Palliative Care infrastructure through a national strategy and clearly defined Secretariat role, the infrastructure may result in duplication or even become a barrier to provision of quality palliative care in Canada. In turn this could undermine efforts to enhance the profile of palliative and end-of-life care. Sustaining such an infrastructure will also require a clear business plan and demonstration of need, especially in view of the necessary resources that may be diverted from front-line clinical care, education, and research to sustain it.

Recommendation #4

That the government of Canada reallocate 5% of the present funding for medical and particularly pharmaceutical research, utilizing the money saved to fund the building of a national Palliative Care and Home Care infrastructure.

Covenant Health recognizes that a funding strategy is required to support a national infrastructure. This is underscored by what government spends in comparison with other voluntary organizations and countries. For example, the UK spends 0.18% of its total government and charitable funding for cancer research on palliative and end-of-life care; the US does somewhat better at 0.9%; most other countries report an average of 0.5%. [x]

Although the Canadian Institute of Health Research identified palliative and end-of-life care as a priority, allocating targeted funds and establishing a separate peer review, of the $105,244,227 spent on cancer research in 2004-05, only $893,701 was allocated to palliative and end-of-life care. When considering CIHR's total expenditures for that year was $688 million, investment in palliative and end-of-life care only amounted to 0.13%. Moreover, a recent survey of cancer funding in Canada [xi] shows that CIHR's contribution to cancer research is 28.7%, with the balance provided by other levels of government, provincial cancer agencies (6%), voluntary organizations (20%) and multi-partnered initiatives (3%). In view of this, any creative funding strategy to build a national infrastructure, either by increasing or reallocating dollars, would demonstrate a real commitment to palliative and end-of-life care.

However, as in Recommendation #3 above, the expectation first is such an infrastructure adds value to the current provincial model. If this is established, with clear accountabilities and deliverables, then regardless how such infrastructure is funded it must ensure it does not detract from the value-add of other areas of the health care system.

Reallocating dollars currently assigned for medical and pharmaceutical research could potentially undermine advances in end-of-life care if directly related research funding is impacted. The interdependence of the health care system does not easily lend itself to isolate elimination of funding so as not to impact other areas of the system, either now, or at a later time. Clear parameters will be required and perhaps a sunset strategy to ensure research currently underway is not adversely impacted.

Covenant Health is also concerned that the loss of funding to industry may be transferred back onto the public through cost increase in supplies and medications. To truly ensure a sustainable funding strategy, new dollars may be required. One recommendation is to *increase* funding to support clinical practices or education that enhance efficiencies in the system and result in *decreased* costs. This requires collaborating with provincial and federal governments to enact a funding agreement. Such an accord would create shared ownership regarding the proposed national Palliative Care infrastructure.

Conclusion

In the absence of public education and strengthened commitment by Federal government to promote palliative and end-of-life care in this country, we believe there will only continue to be one private members bill after another purporting death with dignity, offering false hope and perpetuating unnecessary public fear and anxiety. We believe these are not viable options, nor do they represent what compassionate care, solidarity, and respect for the intrinsic dignity for persons is all about.

Moreover, society’s enamor with technological fixes, coupled by a pervasive death-denying cultural attitude undeniably influencing health care policy, has channeled a greater proportion of public funding to resources and services that often only extend life by a few days or weeks, with questionable outcomes. We believe the Federal government has a leadership role to educate Canadians about the benefit of palliative and end-of-life care, and to support more proportionate funding for these essential services.

The Federal Minister of Health responded positively to a letter from Covenant Health earlier this year regarding the Government of Canada’s efforts to ensure Canadians have access to quality palliative and end-of-life care in our country. We support this approach, which is in complete alignment with our organization’s mission, values and strategic priorities. We are committed to partnering with clinicians, funders, researchers, policy makers and all those who share this vision of quality palliative and end-of-life care.

However, our ability to positively influence is limited primarily by jurisdiction. We need to work together with others to support a national approach to palliative and end-of-life care, especially when some of the barriers to this goal lay within our broader cultural values. To this end, we are grateful for the Parliamentary Committee on Palliative and Compassionate Care for their leadership in promoting public debate, and wish to work closely with Members of Parliament serving on the Committee to ensure Canada’s future as a compassionate and just society.

Covenant Health is committed to support the Committee to help shape public health policy that aims to relieve suffering of Canadians, enhance the quality of living and dying, and respond compassionately to the physical, psychological, social, spiritual and practical needs of vulnerable persons. We applaud the Members of Parliament leading the Committee to engage necessary public debate that will promote shared learning, and to help spur on new clinical research, professional development and innovative practices. We see the role of a national strategy to also ensure Canadians are thoroughly informed of the realities of end-of-life care, to help dispel enduring myths, and to promote access to caregiver education and compassionate funding.

As we develop our organization’s End-of-Life Strategy, we will actively seek out opportunities to collaborate with others. This is in keeping with the history of our founders. These audacious women responded to the needs of the most vulnerable by working with all those who shared an unwavering commitment to serve those in need, with compassion, dignity and respect.

We respond today with the same audacity.

References

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