

Parliamentary Committee on Palliative and Compassionate Care

Not to be Forgotten

Care of Vulnerable Canadians



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Parliamentary Committee on Palliative and Compassionate Care



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Executive Summary

The Committee:

- The Parliamentary Committee on Palliative and Compassionate Care (PCPCC) is an ad hoc, all party group of MPs, dedicated to improving care for elderly, dying and vulnerable Canadians. It is unique in the history of the Canadian Parliament as it was formed by the MPs on their personal initiative and funded out of their member office budgets.
- The committee is an example of what is possible when MPs work closely across party lines on issues of profound concern to everyone. The spirit of non partisan collaboration exhibited by the members of the committee is a great example of what parliament is at its best.
- Receiving testimony from hundreds of people at twenty four hearings, and local round tables, MPs were profoundly impressed by the dedication and depth of concern expressed by Canadians for issues surrounding the way palliative and compassionate care is practiced in our country.

The committee grew out of our MPs' personal concern for compassionate care for vulnerable people. The issues primarily dealt with were: 1) Palliative and end-of-life care, 2) Suicide Prevention, 3) Elder Abuse, 4) A disability perspective on health care and inclusive community living.

As our testimony came in, the palliative care section of the report expanded to include an integrated community care model best able to address the care needs of persons with chronic conditions, a framework which is important to all our issues. A section on the urgent need for better pain treatment, including chronic pain, was also included; as was material on homecare and long term care. It also became clear that the issue of family caregiver support needs to be addressed, as family caregivers really are the unsung heroes of compassionate care in Canada.

Part –1. Palliative and end-of-life care:

- While progress has been made, Canada still falls far short of quality end-of-life care for all, with only 16-30% of those who need it receiving palliative care.
- Even where palliative care is available quality and accessibility will vary based on place of residence. In Toronto for example some parts of the GTA have palliative care services and some do not. The same is true of Montreal. This patchwork of services becomes still more pronounced in less populated regions. Many parts of Canada have no palliative care services at all.
- As our population ages, health services directed towards seniors will become a much greater need, and at present our health care system seems ill prepared for this shift.
- Our health care system is good at short term acute care but less so at dealing with people with chronic conditions, with serious pain, with mental health concerns, or with the psycho-social and spiritual needs of patients and their families surrounding the dying process.
- People with chronic conditions need holistic care that looks at them as a whole person. They require patient centered care that recognizes their individual needs and not those of the bureaucratic system, as most important. They require integrated continual care that does not allow them to become lost in a fragmented and confusing world of multiple siloed health systems with less than satisfactory inter-communication between them.

- The **palliative care philosophy** is person-centered, family-focused and community-based. It moves us from disease or condition-specific care to person-centered care. It recognizes that the psycho-social and spiritual dimensions have profound impact upon health and well being, and that a variety of specific conditions may be operating on different levels in the chronically ill or dying person's life. The philosophy of palliative care permeating medical culture is more important than the simple delivery of "services". As family physicians and local nurses come to accept a palliative care philosophy, palliative care services can begin to develop organically in communities.
- Palliative care is best delivered within a home and community-based integrated care system, which is generally more cost effective and care effective.
- Palliative care should be delivered in an integrated fashion, including: home care, small community hospices, and palliative care in nursing and LTC homes.
- While fully recognizing the importance of this range of palliative care options, the committee wishes to emphasize the **ideal** of caring for a person as close to their home and community as possible. Care in the home, surrounded by family and friends, with little institutional and bureaucratic overlay, is practiced successfully throughout the world and in parts of Canada. These successes need to be replicated nationwide.
- Capacity building is required to meet the needs of Canadians for palliative and chronic care. Building up home care capacity is extremely important.
- A national Palliative Care Strategy is desperately needed. Even Georgia, in the former Soviet Union, and Poland have national strategies.
- Research, knowledge translation and training are foundational to community capacity building.

Palliative Care delivery for First Nations peoples:

- Palliative care capacity for First Nation people needs to be built on existing local resources.
- A strengthened home care program for First Nation Communities is essential both for building palliative care capacity, and for addressing chronic care needs.
- At the present time far too many elders die in facilities far from their families and home communities.
- Community based models need to be developed, respectful of First Nation cultural beliefs, traditions, practices and preferred language.

Rural Palliative Care delivery:

- Rural people prefer to receive healthcare in their home communities, and especially don't want to travel to urban centres in their final days of life.
- Community based palliative care resources need to be developed utilizing home care services and local long term care homes.
- Hospice volunteers are a vital part of building rural capacity, supporting people receiving palliative care and their families.

- The whole community takes part in the dying process and supports the dying person and their family by meeting their physical, emotional, spiritual and psychological needs.
- Small local long term care homes can be an important resource for palliative care in rural and First Nations settings.

Pain Management:

- Adequate pain management should be regarded as a basic human right.
- Millions of Canadians suffer from unmanaged and undermanaged pain both chronic and acute. This has severe impact in terms of health and wellbeing, and significant costs in terms of the health care system and work place lost time/productivity expenses.
- Pain management training is inadequate for most medical professionals and must be given a higher priority in the health care curriculum.
- Capacity building is essential to develop centres of excellence in pain control across the country.
- Canada needs to develop and implement a National Pain control strategy.

Legal and Human Rights Perspectives on Palliative Care:

- Palliative care is part of a movement toward fundamental justice and basic human rights for citizens facing the last fragile stage of life.
- A growing body of human rights declarations is recognizing the importance of palliative care and pain management.
- Charter law in Canada specifically section 15 (the equality section) may provide a basis for palliative care services being “insured services” under the Canada Health Act. The CHA seems to assume an implicit distinction between cure-focused care i.e. hospital acute care (funded) and care without cure i.e. palliative care (not funded). Chronic conditions and dying persons are palliated but not ultimately cured. This distinction (cure/care) is based on the nature of the disability giving rise to the need, and is arguably discriminatory under section 15 as discrimination based on disability. If caring for a patient is as important as curing the patient (and it should be); palliative care should be included as part of “insured services” under the CHA.

Home and Long term care:

- Adequate Home care is foundational to transforming Canada’s health care system.
- Home care delivery within a continuing care system relieves burdens on the acute care system.
- An adequate home care system is an effective way to care for people with chronic conditions in a way that is good for patients and families, as well as being cost effective.
- At present home care systems are often fractured and services inadequate to meet patient needs. In the absence of national standards and adequate funding; seniors, persons with disabilities and chronic disease, as well as those in need of post acute care, are falling through the cracks, ultimately costing the system more money as people who could live at home with adequate support are forced into institutional care.

- Local long term care residences are needed as part of the continuum of care to provide care for people with complex health needs close to their own community.
- Long term care facilities would ease the burden on the acute care system which is presently housing people who would be better cared for in LTC, however the shortage of LTC beds makes this impossible.
- Additional LTC facility infrastructure is badly needed in the face of an aging population and increasing chronic conditions including significant growth in the number of people with dementia. Government and local communities need to plan ahead to meet future demand.
- The different levels of government need to collaborate on developing national standards for home and long term care.

Family Caregiver Support:

- Family care givers provide a substantial amount of care, some 70% - 80% of care given in Canadian homes and communities, worth an estimated \$25 billion per year. Family and friends have been described as the invisible backbone of the Canadian healthcare system. Canada like so many other nations must undertake the task of surveying and tackling caregiver issues. Family caregivers are essential to sustaining our health and social care system.
- It is necessary to find ways to support caregivers and conserve this important social resource. Care giving can often place people in grave financial hardship, especially when forced to quit their job while caring for a loved one.
- Family caregivers face significant physical, emotional and financial stresses in carrying out their tasks. Caregivers need recognition and support (financial, informational, emotional, respite, legal, etc.) in carrying out their care giving role.

Part 2 -- Suicide Prevention:

- At least ten Canadians die by suicide every day, almost 4000 every year.
- Suicide is the second leading cause of death among Canadian young people aged 10-24.
- Suicide rates among aboriginal young people are five to seven times higher than among non-aboriginal youth.
- Suicide has devastating impact taking its toll in shortened lives, grieving families, friends and communities.
- **Suicide can be prevented.** Suicide intervention does save lives. Yet suicide prevention and intervention is a patchwork in Canada mostly depending on the generosity of volunteers.

A Public Health Approach to Suicide Prevention:

- Suicide is a complex phenomenon with multiple intertwined causes, resulting in the need for a multi faceted approach to finding effective solutions.
- A **public health approach** emphasizes **primary prevention** reducing risk factors and increasing protective factors, **surveillance and evidence based response** – careful **research** on causes, risk and protective factors, and on interventions that work, **multidisciplinary perspectives** to complex

problems, and a **community health approach** which focuses on problems from the perspective of the whole community and not only of individuals.

- Suicide is not reducible to a mental health problem, though mental health problems can be a significant factor.
- Significant reductions in suicide rates have been effected in various countries by such public health approaches as a) **toning down media reports** -- the way suicide is reported in the media b) **controlling facilitating factors** – i.e. substance availability and addiction treatment (drugs and alcohol) c) **Means restriction** i.e. various forms of gun control, detoxification of cooking gases, restricting access to poison substances, environmental controls such as barriers on bridges.
- Efforts to support the person at risk, to alleviate isolation and loneliness, to build a community ethos of social inclusion, are highly effective ways of reducing suicide risk in vulnerable persons.
- Suicide risk detection and intervention is also a vital aspect of effective suicide prevention.

The need for a National Suicide Prevention Strategy:

- A National strategy and coordinating body are essential in order to mobilize resources in an effective way.
- Despite the centrality of Canadian expertise in developing UN guidelines for implementing National Suicide Prevention Strategies, suicide prevention in Canada remains fragmented, disconnected and lacking in an overall vision. In Canada we start from the disparate local parts without any idea where they fit into the big picture.
- Research is lacking as to causes, risk factors, protective factors, effective interventions, and evaluation of existing programs, resulting in suicide intervention that is done in an impromptu manner.
- Resources remain inadequate with no clear planning as to what is needed and how to implement needed infrastructure in an efficient manner.
- The Canadian Association for Suicide Prevention (CASP) developed The **CASP Blueprint for a Canadian National Suicide Prevention Strategy** in 2004. This document has helped many nations in developing their own national strategies, and would be an important starting point in developing our Canadian Strategy.
- The development of a national strategy is a collaborative process uniting communities, governments, and organizations in pooling resources and in coming to understand and respond to suicide in a unified and effective way. It is a catalyst to research and action.
- A National Suicide Prevention Strategy encompasses a wide range of issues with a few mentioned below:
 - 1) Suicide Prevention requires a **public awareness campaign** to teach that suicide is a significant problem that is preventable. Awareness is a key to suicide prevention, and a social marketing campaign needs to be carefully planned for maximum effectiveness.

- 2) Broad based support for suicide prevention needs to be developed among organizations and groups across the social spectrum. These groups provide the back bone of suicide prevention efforts.
 - 3) Stigma about suicide intervention and mental health issues needs to be overcome.
 - 4) The media needs to be educated on the most effective ways to deal with suicide.
 - 5) Sustainable community-based suicide prevention programs need to be developed across the country.
 - 6) Suicide intervention infrastructure is desperately needed, as well as long term social support infrastructure for isolated, depressed, and suicidal persons. Funding is virtually nonexistent at present with what intervention there is, being largely the result of volunteer efforts.
 - 7) Training is needed for risk recognition and effective intervention by gatekeepers, volunteers and professionals.
 - 8) Bereavement support is needed for families, friends and communities affected by suicide.
 - 9) Surveillance systems and research are desperately needed to deepen our understanding of suicide and of how to effectively intervene.
 - 10) Knowledge translation is vital to bring important research to the attention of front line suicide interveners, who need effective ongoing training and support.
 - 11) Strategies to reduce the availability and lethality of suicide methods are essential, as is work to strengthen protective factors (personal/social/cultural factors making it less likely a person will attempt suicide)
- The **federal government** has a key role to play in suicide prevention and intervention efforts: providing national health surveillance/statistics, health research funding, having an important role in public health awareness campaigns, facilitating collaboration between the various levels of government and the wider society, as well as having primary health care responsibility for several sectors of society particularly vulnerable to suicide including aboriginal people, those in the military, and inmates of federal prisons. Federal leadership and coordination is vitally needed if we are to succeed.
 - Working together in a coordinated manner many lives can be saved. Suicide prevention has been successful in many nations, and the time has come for Canada to seriously address this problem. A national strategy for the prevention of suicide is long past due.

Part 3 – Elder Abuse

- Between four and ten percent of seniors will experience some form of abuse during their lifetime and this may underestimate the extent of the problem as most abuse is never reported.
- Any senior can become the victim of abuse. Abuse is often committed by someone known to the victims including family members, friends, caregivers, neighbors, landlords, or persons paid to carry out work for them.
- There is a lack of accurate statistics in Canada. A large population based survey of elder mistreatment is badly needed. The only detailed survey on elder abuse is from 1989; hence prevalence statistics are extremely outdated. The *National Initiative for the Care of the Elderly* (NICE) has just **done the preparatory work** for a national prevalence study, work commissioned by *Human Resources and Skills Development Canada* (HRSDC), and could do a prevalence study if given the necessary funding.

- Much of what we know of elder abuse comes from anecdotal evidence. The report recounts some representative stories from across the country, putting a human face to the numbers.
- Abuse takes many forms ranging from physical violence, sexual abuse, psychological abuse, financial abuse, neglect, and various forms of institutional abuse. Some cases are remarkably tragic, but even lesser forms of abuse leave wounded, frightened people.

Causes of Abuse:

- The **ecological approach** is a powerful paradigm recognizing the complex interplay of **individual factors, relationship factors, community factors, and societal factors** in elder abuse. Violence is a multifaceted problem with biological, social and environmental roots, which all need to be considered in effective intervention.

Canada's agenda against elder abuse:

An adequate response to elder abuse requires a number of things, to occur simultaneously.

- A **public awareness campaign** would be needed to continue the important work of the Federal Elder Abuse initiative. It would need to speak with one voice, with Federal, Provincial and Territorial governments collaborating in delivering a common message that abuse of older persons will not be tolerated anywhere in the country.
- **Primary prevention programs** based on research into risk and protective factors would work to develop support networks countering isolation among seniors and caregivers, provide needed information about abuse and also about care giving issues, and finally engage seniors in the wider community, promote volunteering etc.
- **Intervention and Advocacy** is the area of greatest need, with the demand far outstripping the infrastructure available to help abused seniors. With a lack of dedicated services available abused seniors are falling between the cracks. Needs include legal services for low income seniors, emergency safe shelters for short term protection of abused seniors, as well decent long term housing, and adult protection services properly resourced to make effective protective interventions. Also needed are multi disciplinary teams to deal with the complexity of cases. Training of first detectors/responders, as well as ongoing training for adult protective services is a tremendous need.
- **Strengthening the legal response to abuse** is essential if the public is to be aware of the true seriousness of elder abuse. Seldom are abuse cases successfully prosecuted, and when they are, sentences are often a token 'slap on the wrist'. In order to improve prosecution of abuse cases, designated police units are needed, forensic expertise needs to be developed (medical, psychological and financial) to support police in preparing cases, and ongoing training of frontline officers in elder abuse detection and intervention must become standard. Judges, Crown prosecutors, and the wider legal system also need to be educated about elder abuse, and the legal system needs to be more sensitive to the needs of vulnerable victims (seniors, those with cognitive impairments etc.) throughout criminal proceedings.
- The **Restorative Justice** approach can provide an important tool in dealing with less serious abuse cases, in a way that works to repair harm -- with a focus on forgiveness, healing and restoration of relationships, while recognizing the need for true accountability for wrongs done. Restorative justice to be effective requires proper program resourcing, and is not always suitable due to power imbalances between the victim and the abuser.

Financial Abuse:

- A vigorous response to **financial abuse** of seniors is needed, as the asset rich older baby boomers reach retirement age in significant numbers. Their children with some of the highest debt loads in history, and a generalized sense of entitlement, can be tempted to look at their parents' nest egg as a potential source of capital.
- Financial abuse by way of manipulation and undue influence in relation to wills and bequests, fraud or forgery of documents, power of attorney abuse, abuse of joint bank accounts, misuse of funds or property, theft, exploitation, scams, and credit card or debit card theft, (seniors entrusting their pin number to another who does their banking) are becoming very common. Often the perpetrator is a relative or acquaintance.
- Financial abuse is extremely harmful to seniors, with many who are at the end of their earning life being left destitute and dependent on the generosity of friends, family and state support, to survive. Research shows that financial abuse can have far reaching psychological and health effects on seniors, being a significant source of stress for the elderly victim.
- Public Guardian and Trustee offices around the country need sufficient resources to deal with the rising flood of financial abuse cases. The federal government can play a key role in working with the provinces and territories to develop inter-jurisdictional unity across Canada in regards to financial planning and protection laws.
- Financial abuse is difficult to identify and prosecute and will necessitate close working relationships between police, public guardian and trustees, and the financial sector.

Elder abuse is a serious, all too often hidden crime, which affects large numbers of Canadians. Its existence challenges our self understanding as a society of inclusion and respect for all, and requires collaborative work by all sectors of society. A cultural transformation is needed, in which abuse comes to be regarded as absolutely unacceptable. The complexity of elder abuse necessitates action on a variety of fronts, with careful coordination and collaborative effort. It is essential that we as a society take steps to protect and support those who are abused.

Part -- IV. A Disability Perspective on Health Care and Inclusive Community Living:

Due to limited Committee resources the Disability Perspective report is still in progress and will be released on completion, later in the parliamentary session.

Committee Recommendations

Palliative Care recommendations

Recommendation # 1: We strongly urge that the federal government re-establish a **Palliative Care Secretariat**, provided with adequate funding to conduct and support research, and to facilitate communication and collaboration between the various levels of government, and community stakeholders, for the sake of:

- a) Developing and implementing a **National Palliative and End-of-Life Care Strategy**.
- b) Collaborative development and implementation of national standards as a benchmark of quality palliative care.
- c) Coordination and dissemination of palliative and end-of-life research and information resources.
- d) Ongoing coordination and support as the Strategy is implemented in jurisdictions across Canada. (p.31)

Recommendation # 2: We recommend the development of a flexible integrated model of palliative health care delivery, able to take into account the geographic, regional and cultural diversity of Canada; while providing a funding mechanism to help the provinces and territories with implementation. (p.32)

Recommendation # 3: We recommend that the federal government provide stable funding to the **Pallium Project** and the **Canadian Virtual hospice**, two important examples of innovation; while developing an easily accessible venue for funding other innovative programs. (p.36)

Recommendation # 4: We recommend that the federal government either through Health Canada or the recommended Palliative Care Secretariat fund a national public awareness campaign on palliative and end-of-life care. An aspect of this campaign should be to encourage Canadians both to talk about end-of-life care, and go through the process of advance care planning. The Canadian Hospice Palliative Care Association (CHPCA) Advanced Care Planning program is an existing resource which could be utilized in educating the public about advanced care planning. (p.37)

Recommendation # 5: We call upon the federal government to strengthen the home care delivery program for First Nations, Métis and Inuit communities, developing home delivered palliative care resources, sensitive to community, cultural, familial and spiritual needs. Research, training and capacity building, are required for First Nations, Métis and Inuit peoples to receive the high quality palliative and end-of-life care they deserve. (p.39)

Recommendation # 6: We recommend the development of rural palliative care delivery within the primary health care system, utilizing home care services, and local long term care homes; allowing care to be delivered in or close to a person's home community. (p.40)

Pain Control Recommendation

Recommendation # 7: We recommend that the federal, provincial and territorial governments along with the various NGO stakeholders (i.e. The Canadian Pain Society) develop and implement a National Pain Strategy, to provide a unified approach in the delivery of pain control methods. (p.45)

Funding for Home and LTC Services Recommendation

Recommendation # 8: We recommend that the federal government in collaboration with the provinces and territories implement a right to home care, long term care and palliative care, for all residents of Canada, equal to the current rights in the Canada Health Act, to those services defined as “insured health services”, including hospital services, physician services and surgical dental services. (p.51)

Caregiver Support Recommendations

Recommendation #9: We recommend that the federal government expand the provisions of the E.I. based compassionate care benefit to a minimum of 26 weeks coverage. We further recommend that the benefit be given flexibility to allow partial weeks to be covered, allowing caregiver leave for episodic care giving needs i.e. 5 or 6 days a month to allow a parent to stay in hospital with a child as they undergo chemotherapy. We recommend that the qualifying criteria be changed from “significant risk of death” to “gravely ill” so as to allow the hope of caregivers to be kept alive when applying for the caregiver benefit. Finally the government should look at raising the maximum payment cap to a higher amount, more in line with the costs of living and care giving. (p.64)

Recommendation # 10: We recommend that the federal government establish a refundable tax credit for family caregivers, to help families, with the high costs of care giving. The Caregiver credit and the infirm dependent credit could be made refundable for caregivers below a certain income level. (p.64)

Recommendation # 11: We recommend that the federal government set up a Canada Pension credit for family caregivers, so that those who are long term unpaid caregivers receive annual pension credit worth half their average annual salary from the years leading up to full time unpaid care giving. The annual credit could have a maximum capped amount, and a minimum amount for those who had small incomes leading up to the care giving years. (p.64)

Suicide Prevention Recommendations

Recommendation # 1: We urge that the federal government establish a **Suicide Prevention Secretariat**, provided with adequate funding to conduct and support research, and to facilitate communication and collaboration between the various levels of government, and community stakeholders, for the sake of:

- a) Developing and implementing a **National Suicide Prevention Strategy**.
- b) Collaborative development and implementation of a training program with established national standards, for the training of suicide intervention personnel.
- c) Coordination and dissemination of suicide prevention research and information resources.
- d) Development of a national public awareness program on suicide and suicide prevention, including a social media campaign on reducing stigma towards suicide and mental health issues.
- e) Ongoing coordination and support as the Strategy is implemented in jurisdictions across Canada. (p.82)

Elder Abuse Recommendations

Recommendation # 1: We recommend that the federal government establish an **Elder Abuse Awareness and Prevention Office** with a general directive mandate, under the **Minister of State for Seniors**, in conjunction with HRSDC, Public Health Agency of Canada, Justice and the RCMP, for the purpose of facilitating communication and collaboration between the various levels of government, and community stakeholders, with a view to:

- a) Developing and implementing a **National Elder Abuse Prevention Strategy**.
- b) Promoting and funding research on the incidence, and prevalence of elder abuse as well as effective tools and responses.
- c) Coordination and dissemination of elder abuse information resources.

- d) Development of a national public awareness program on elder abuse and elder neglect including elder abuse prevention, detection and response.
- e) Ongoing coordination and support for groups working to prevent elder abuse across Canada.
- f) Working with the Ministry of Justice, Health Canada, Public Safety, the RCMP, and other federal departments, to coordinate an integrated federal response to elder abuse, including the development of a **National Forensic Centre on Elder Abuse**, needed changes to the criminal code, and improved data collection by Statistics Canada. (p.124)

Recommendation # 2: We recommend that the federal government provide core funding to:

- a) The Canadian Network for the Prevention of Elder Abuse (CNPEA), so as to enable CNPEA to promote and coordinate networks for the prevention and detection of and response to elder abuse across Canada.
- b) The National Initiative for the Care of the Elderly (NICE) to continue work of the *Elder Abuse Theme Team* to identify, pilot, and train diverse responders across Canada on evidence based tools for preventing, detecting and intervening in situations of abuse of older adults.

The Committee believes that Core funding for the non-governmental sector is a cost effective way of building needed infrastructure for the reduction of elder abuse. (p.124)

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Introduction:

About a year ago the MPs of the Parliamentary Committee on Palliative and Compassionate care began a journey, seeking ways to improve the care given to vulnerable and dying Canadians. Twenty four hearings, and hundreds of witnesses later, the Committee is ready to release a report of its findings. This was a daunting task. The numerous submissions presented to the committee, exemplify the profound concern Canadians have for compassionate care. The Committee is not a standing committee; but rather an all party group of MPs who conducted these hearings as a response to the deeply felt concerns expressed by Canadians for issues surrounding the way palliative and compassionate care is practiced. No budget was made available to bring people to testify. Despite this, large numbers of Canadians came at their own expense, to provide expertise and share their stories. These are the people who are directly affected by the practice of palliative and compassionate care; either as front line caregivers and the remarkable people for whom they provide care, or as people who already experience the vulnerability of various disabilities. End of life issues can involve suffering, and great hope, discouragement and resilience, creativity and compassion. Everyone will ultimately face their own mortality as we encounter our own fragility, and that of our loved ones. In that way, the issues involved in providing compassionate care are important to every Canadian.

Canadians need to decide together, how we as a nation will care for our citizens facing end of life. The members of the committee were humbled by the calibre of those committed to influencing the practice of care for vulnerable Canadians. We thank each one of you for your commitment to caring, and for sharing your stories with us as we seek to do our part on the federal level to move these vital issues forward.

The Committee dealt with four areas surrounding compassionate care: palliative care, suicide prevention, elder abuse and rights of persons with disabilities.

1) Palliative Care:

The first area is **palliative and end-of-life care**. We have included in this section of the report some reflection on how we as a nation care for persons experiencing aging and chronic illness. The best possible care for those who are dying must flow seamlessly from the best possible care of all Canadians, including persons experiencing aging, mental illnesses, disabilities, chronic illness, and acute and chronic pain. The dignity which must be accorded to a person as they approach death is a dignity which must be accorded at each stage of a person's life. There is an opportunity to offer much better ways of providing this care in the future. Although Canada can be proud of the achievements and efforts made, the task of providing quality end of life care for all Canadians has not yet been achieved.

2) Suicide Prevention:

The second area we dealt with is that of **suicide prevention**. Nearly 4000 Canadians end their lives by suicide each year. Suicide is the second largest cause of death for young men. Many tragic deaths may be prevented, if a national strategy for suicide prevention is developed and implemented that seriously addresses the social and mental health concerns that contribute to this tragedy. Suicide is a major public health concern. Sadly, Canada lags behind much of the developed world in terms of responding to suicide. While most western nations have or are developing national suicide prevention strategies, Canadians have not politically addressed this issue in a comprehensive and systematic way. It should be mentioned that the Canadian Association for Suicide Prevention (CASP) strategy, developed independently of any federal or provincial funding, has been used as a model for developing other national strategies worldwide. The time has come for Canadians to take an effective public health approach that addresses the tragedy of suicide. Proposals for dealing with the prevention of suicide are dealt with in the second part of this report.

3) Elder Abuse:

The third area addressed by the Committee concerned elder abuse. Elder abuse has been described as a silent epidemic in Canada, and although strides to prevent and stop elder abuse have begun, political will is required to consolidate these first steps, and eradicate all forms of abuse against elderly Canadians. Within this report, are guidelines to assist those working on the front lines to get the resources required for intervention, and research. Best practices need to be identified that can assist those who advocate for people experiencing abuse.

4) Rights of Persons with Disabilities:

The fourth area discussed by the Committee concerned the rights of persons with disabilities, particularly in the areas of health care and personal support. As more Canadians age and experience the onset of disability, this topic will have increasing implications for Canada's health and social care systems. We received some very important testimony, but have determined that we require more information before we can write this section of the report. While we will make remarks relating to the disability perspective, it is the hope of the Committee to issue a supplementary report pertaining to disability, in the next session of Parliament.

The Role of the federal Government:

The Committee acknowledges that health care falls under provincial and territorial jurisdiction. At the same time, the federal government has a number of significant roles to play around end-of-life and palliative care.

First, the federal government can offer vital *leadership* in the country by raising awareness of compassionate, end-of-life and palliative care issues and by drawing attention to the needs of both care receivers and caregivers. End-of-life realities represent a complex mix of health, social, emotional, legal and financial pressures. Care receivers and caregivers currently have only a faint voice on the public radar screen. With an aging population, we recognize the need to give voice – to their voice.

Second, while provinces and territories are responsible for the day-to-day delivery of health services, the federal government has a *standard-setting* capacity to ensure comparable access to a continuum of high-quality care for all Canadians. This function involves setting benchmarks for the provision of health services, ensuring accountability and enforcing existing legislation.

Third, the federal government is a significant delivery agent. As the fifth largest provider of health care in the country, it directly serves a substantial segment of the Canadian population including veterans, First Nations and Inuit people, the military, the RCMP and inmates of federal prisons. Like other Canadians, these groups deserve high-quality, community-based compassionate care, palliative and end-of-life care.

Fourth the federal government plays an important role in terms of the *financing* of compassionate, end-of-life and palliative care. There are two dimensions to this financing role. The first involves the direct support of health care services through general taxation and health-related transfer arrangements. The second financing component takes the form of indirect support by helping offset the extended health care and drug costs paid by individual Canadians. Tax measures such as the medical expense tax credit and attendant care credit are examples of this indirect financial support.

Finally, the federal government can play a crucial role in *knowledge brokerage*. This task involves support for research and the collection of relevant data. It also entails the identification and exchange of information around effective compassionate, end-of-life and palliative care interventions. There are many exemplary models throughout the country with neither the means nor methods to scale up their interventions. Canada can save significant time and resources if we build on good practice already tested. We need not start from scratch in every community to develop a robust compassionate care infrastructure.

Compassionate, end-of-life and palliative care affects every citizen in this nation. Both leadership and collaboration are required to advance the practice and delivery of compassionate care. The Committee believes that a coordinated national effort among many key players is essential if we are to attain our goal of quality end-of-life care for all Canadians.

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“We may or may not in our lifetime be accidentally hurt, develop a pathological tumour, 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. In a society that is increasingly scandalized by any human condition that is not powerful, beautiful and ruggedly independent... it is critically important that the Parliamentary Committee on Palliative and Compassionate Care keep in its view the fundamental moral questions about what kind of society do we wish to live, grow old, and eventually die in. 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 in 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.” Covenant Health – Edmonton Alberta¹

Part 1

Palliative and End-of-Life care

“Each of us is fragile, with deep needs for both love and a sense of belonging. We begin and end our lives vulnerable and dependent, requiring others to care for us. ...In our states of dependence, our need cries out for attention and care. If this need is well received, it calls forth the powers of love in others, and creates unity around us, the gifts of the vulnerable to our world. If our cry and our need are unmet, we remain alone and in anguish. ...The danger in our culture of productivity and achievement is that we easily dismiss and ignore as unproductive the gifts and the beauty of our most vulnerable members, and we do so at our own peril, dehumanizing ourselves.” Jean Vanier – Founder of L’Arche²

Palliative and End-of-life Care:

Adequate palliative and end-of-life care becomes more essential as the numbers of Canadians requiring these services grows. Canada is not providing adequate palliative and end-of-life care for all who need it. Depending on where you live, only 16-30% of those who need it receive palliative care.³ 16-30% is a failing grade in any ordinary exam, how much more so in the context of our dying fellow citizens, friends and relatives.

Despite efforts made by palliative care providers, Canadians have a long way to go to meet our goal of quality end-of-life care. Canadians in all parts of our country should be able to get effective palliation of their pain and symptoms, and have their psycho-social and spiritual needs addressed.

“We may have forgotten in our evolution as societies, what communities can provide.” Catherine Yuill -- Colchester East Hants Hospice Society⁴

Palliative care requires the mobilization of persons and communities from coast to coast. Compassion has long been the hallmark of what it is to be Canadian.

“The essence of our caring society is to integrate all programs and services into one seamless system, to meet the health care needs of all citizens, using Health Canada’s social determinants of health as our foundation, and patient-centred care as our model. We need to ensure that the right person is receiving the right care, from the right caregiver, in the right way, at the right time, in the right place, for the right cost and for the right reasons for all Canadians.” Harry van Bommel – Toronto Ontario

The Section of the report concerning palliative and end-of-life care is set within the wider context of a description of the kind of health care system required to provide adequate care for the elderly, those with chronic conditions, those suffering with acute or chronic pain, mental illness, or a disabling condition. We deal first then with:

- 1) The question of patient centred care as a paradigm for all health care. Palliative care is the best existing example of truly patient centred care.
- 2) Health care integration, the development of a system of integrated continual care as a model of health care delivery in Canada, a model best suited for caring for people with long term chronic conditions.
- 3) Palliative care delivered from the perspective of an integrated continual care system.

including the United States, the United Kingdom, Ireland, New Zealand, and Australia.” Dr. Bernard Lapointe, Eric M. Flanders Chair of Palliative Medicine, McGill University³⁷

Innovative program trains medical students as hospice Volunteers

Dr. Valerie Schulz of the Schulich School of Medicine in London Ontario has developed a simple and effective way to get medical students interested in palliative care. Each year 12 students from the undergraduate program become hospice volunteers. Undergoing 30 hours of training, each being mentored by an experienced hospice volunteer; they visit clients in their homes. The experience is priceless for the future doctors, as it gives them a chance to meet and converse with people outside the clinical environment, and without the need to bring a clinical perspective to the relationship. They relate to the hospice clients as persons, learning how they feel and react to the prospect of dying. Friendships are formed, and lessons learned, which will be of lifelong value to the future doctors in terms of person centred care. The clients also are transformed, touched that a future doctor would care enough to spend time with them in a companion role. This program is worth emulation, and broader application. If larger numbers of medical and other healthcare students across Canada were able to experience one on one relationships, as hospice volunteers, the positive effects on our medical culture would be immense.

Knowledge Translation and Capacity Building

“Knowledge transfer is moving knowledge into practice. Evidence informed decision making, sounds reasonable and simple enough, yet policies and practices in the health system often lag well behind discovery, or do not take evidence into account in decision making.”³⁸

Knowledge gained through research needs to be translated into the practice of palliative care professionals; as well as into information for patients, families and volunteers. Knowledge translation is focused education. To this end we salute exemplary programs such as the Pallium project and the Canadian Virtual Hospice, as providing knowledge translation, education, and vital information, in a way that is both innovative, and cost effective.

The Pallium project:³⁹

The Pallium project began in 2001 creating innovative educational resources on Palliative care delivery, for remote and rural health care professionals. One of the earliest inter-professional educational initiatives in the country, Pallium sought to build capacity, by providing rural health providers with the tools they needed to build up community palliative care programs. The Pallium project utilizes the most advanced forms of communication technology, doing pioneering work with e-learning, utilizing pod-cast technology, as well as the tried and true hands on approach, through training seminars in remote and rural communities. Materials were developed through extensive collaboration with a wide ranging and interdisciplinary group of palliative care experts.

Between 2004 and 2006 phase II of the project received government funding of \$4.3 million and evolved into a “community of practice” working collaboratively with people across Canada, with the common goal to advance skills and knowledge in hospice/palliative care. Phase II continued to emphasize building up long term system capacity, through a range of local projects advancing outreach, education and professional development; focusing on knowledge management, work place learning, service development and innovative modes of collaboration. Emphasis was placed on improving supports to regional health authorities and community-based voluntary sector partners. 71 projects were implemented between 2004 and 2006. These were strategic investments to boost local capacity, with projects being implemented across the country.

In addition Pallium continued to do innovative research and to develop learning tools for physicians. **The Pallium Palliative Pocketbook** was released in September 2008 as a peer-reviewed, comprehensively-referenced handbook for health care professionals. It has been rapidly adopted as an authoritative

Canadian resource to assist in inter-professional education as well as daily, bedside decision-making about a range of palliative clinical issues. Ten thousand copies of the 2008 first printing are in circulation throughout Canada, with many being used by community practitioners who have limited palliative care resources or back-up. It is also widely-used in Canadian health care education. In late 2010, a second printing was commissioned with 7,000 copies being pre-purchased by institutions in the provinces of British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec, Nova Scotia, Prince Edward Island and Newfoundland & Labrador.⁴⁰

The Canadian Virtual Hospice:

Going on line in 2004, the Canadian Virtual Hospice provides support and personalized information about palliative and end-of-life care to patients, family members, health care providers, researchers, and educators. It uses a web-based platform to address information needs, in terms of palliative and end-of-life care. The Canadian Virtual Hospice gives people access to articles such as managing symptoms, accessing financial benefits, health system navigation and communication with health providers. The Virtual hospice pioneered an online exchange where both ordinary people and medical professionals can communicate with interdisciplinary palliative care professionals, expert in pain and symptom management, psycho/social/spiritual care, grief and bereavement issues, even a bioethicist, to address moral quandaries. Some 40% of the users of the Virtual hospice are medical professionals, who are seeking advice on complex cases; with the Virtual hospice being the largest repository of clinical tools in the world. One thousand people visit the web site every day, while to date the clinical team has answered more than 1200 questions, 40% from medical professionals, and 60% from patients and families. The Canadian Virtual hospice answers questions from all over Canada and around the world, having become a destination of choice for palliative care information. Ontario, Quebec, B.C. and Alberta are the largest users of the service.⁴¹ This cost effective venue for needed information on Palliative and end-of-life care, is an exemplary model of health care innovation.

Our third recommendation is addressed to the federal government, asking that two highly effective, innovative national projects be given the stable funding they need to continue their work. These two exemplary projects supply vitally needed information to people across Canada and around the world. Their irreplaceable work needs to be expanded, and their services advertised widely, so that countless Canadians and health professionals who don't yet know about them, can benefit from their resources.

Recommendation # 3: We recommend that the Federal government provide stable funding to the **Pallium Project** and the **Canadian Virtual hospice**, two important examples of innovation; while developing an easily accessible venue for funding other innovative programs.

National Public Awareness campaign:

Many Canadians think that palliative care is simply for cancer patients, and fear that palliative care is equivalent to giving up on life. **The benefits of palliative care** for any one with chronic, life limiting and terminal conditions need to be emphasized, along with the understanding that palliative care is not so much about dying, as about living the days one has to the maximum, free from pain and symptoms, in an affirming environment, surrounded by family and friends.

Canadians need to be educated about dying, **grief and bereavement**. These are universal human experiences that touch individuals, families and communities. They are primarily human not medical events.

Planning and communicating with one's family about medical and end-of-life decisions is a process that every Canadian should engage in. A public awareness campaign could place special emphasis on the informational needs of patients and families as they engage in care planning, and as they attempt to make informed decisions about care.⁴² Advance care planning must not become a process of bullying families

into the decisions their health care providers, and health care institutions desire, but rather a genuine dialogue on what is best for the patient. At the same time advance care planning requires information to be delivered in a way that is understandable to patients, families and caregivers. Low levels of health literacy means that information needs to be communicated to people in a more accessible manner, avoiding technical jargon, utilizing pictures and diagrams, and asking patients to explain what they have understood, to insure comprehension.⁴³

Supports for caregivers, including information resources, respite care, the EI caregiver benefit, and various tax benefits need to be widely known. Informal caregivers are the backbone of the health care system, and a public awareness campaign needs to make them aware that help is available in carrying out their vital role.

Recommendation # 4: We recommend that the federal government either through Health Canada or the recommended Palliative Care Secretariat fund a national public awareness campaign on palliative and end-of-life care. An aspect of this campaign should be to encourage Canadians both to talk about end-of-life care, and go through the process of advance care planning. The Canadian Hospice Palliative Care Association (CHPCA) Advanced Care Planning program is an existing resource which could be utilized in educating the public about advanced care planning.

VII – Thoughts and recommendations for Palliative care providers:

The following are not formal recommendations, but a list of ideas articulated during the hearings, that are worth reflecting on in the ongoing dialogue for developing palliative care in Canada.

- 1) Palliative care providers should reflect a family, not a disease model, an inter-professional team rather than a medical model.⁴⁴
- 2) Palliative care should not be regarded as an end stage crisis model of care; health professionals should strive to begin introducing palliative care from the point of diagnosis.
- 3) We must identify, establish, educate, and support social networks to help people who are chronically or seriously ill, disabled, dying and or bereaved. Social networks begin with family and friends, supporting this group with neighbours, occupational and community contacts.
- 4) **Health care system navigators** are needed, to guide individuals and families through the intricacies of the health care system. Navigators help with solution identification, decision making in crisis situations, consensus building between the family and care providers, the brokerage, implementation and review of care plans. Navigation is different than case management. It is driven by the family and patient's needs, not the health care system. It is knowledge transfer and translation. It is a family/person not a disease model.⁴⁵
- 5) **Health Literacy of patients and health communication by professionals** must be improved, with health care providers presenting health care information in an accessible manner, sensitive to cultural, social, and educational background. The elderly, minorities, persons with disabilities, persons with little formal education etc. often have a difficulty understanding complex jargon laden explanations of their health and treatment needs. Health communication ordered to communicating information at the level of understanding of the care recipient must become the best practice standard. This standard could perhaps be embodied in a standard protocol through Accreditation Canada.⁴⁶
- 6) We recommend building a national consensus on clear, unchanging terminology pertaining to end of life care. Confusion as to the meaning of terms, and even deliberate obfuscation of end-of-life terminology for political reasons, causes much unnecessary tension in end-of-life discussions.
- 7) We must fund and build capacity in those areas of palliative care that help individuals and families improve their quality of life in the non disease aspects of the dying process. Patients and families need help and encouragement, through the support of occupational and physiotherapists,

homemakers, volunteers, social workers, chaplains etc. These non medical supports help maintain the hope of both client and family during the care giving process.

- 8) It is important to respect the spiritual aspects of Palliative care and the role of spiritual caregivers, in a holistic approach to palliative care. The following thoughts on spirituality and chaplaincy are worth noting.

VIII - On Spiritual Care of the vulnerable:

“The experience of vulnerability at the end-of-life has many faces. Certainly, pain management issues and the myriad other manifestations triggered by the evolving disease pathology can make a person extremely vulnerable. But associated with these physical changes may come emotional and psychological stress in trying to cope with loss. A person may experience or anticipate the loss of dignity, self-esteem, or control. Many persons report a fear of being a burden, and becoming dependent on others. For some, the diagnosis of a terminal illness may be the first time one's sense of immortality may be shattered, representing yet another loss. It is not uncommon that these losses evoke deeper level questioning about meaning, spiritual beliefs, one's legacy in life, and the need for closure. While Canadians have a right to quality palliative care services to attend to their physical, emotional and psychological needs, ensuring this right is grossly incomplete unless hospice and palliative care programs also include access to spiritual care resources. One such resource is chaplaincy. Chaplains are invaluable members of the interdisciplinary health care team, ensuring we are able to provide for the person's total needs at the end-of-life. Together, chaplains, other spiritual care providers and volunteers are able to provide supportive presence and pastoral counselling, to listen to, and validate, the deeper level questions raised.” Dr. Gordon Self – VP Mission, Ethics and Spirituality -Covenant Health Edmonton, Alberta

The end of a person's life often raises profound questions as to the meaning of life, of the place each one of the myriad experiences that make up that life, had within the greater whole. There are questions from the past that were never addressed, relational issues requiring resolution, or perhaps just the respectful openness of a sympathetic ear. For those of religious faith, there are questions of moral fault and forgiveness, brokenness and redemption, hope and its consummation in a coming new life. These are realities that many people have a profound need to broach, particularly as their earthly life reaches its close. While not to be imposed, the right to spiritual support must necessarily be easily accessible for those who desire it.

“One essential support we can always bring to patients when there may no longer be aggressive treatment options available is simple presence, when questions of meaning, existential suffering, and loss may be raised. Doing this may challenge the health care providers own sense of helplessness and requires maturity and self-discipline to be able to enter a person's life at a time of great vulnerability, without proselytizing or imposing one's agenda. Chaplains bring a repertoire of evocative listening skills, non-judgmental, unconditional regard, and clinical experience, to effectively establish trusting relationships with persons, to attend to their deeper spiritual questions and to truly be present.”⁴⁷

In addition to support for the dying person, chaplains support family members through the day to day struggles of the dying process, and the bereavement period following a loved one's death.

“The ongoing presence of the faith community can bring tremendous consolation to persons at the end-of-life, perhaps even for some, giving them a sense of "permission" or freedom to let go. For those who belong to religious communities, chaplains can help connect or reconnect families to those communities, facilitate rituals and sacraments, lead prayers, and help plan funeral services. Many chaplains provide short-term grief counselling and bereavement supports, including memorial services to assist with the bereavement journey.” Dr. Gordon Self – Edmonton

IX - Palliative care delivery for First Nations peoples:⁴⁸

The Committee received several important submissions on First Nations Palliative Care. While enough to give us a sense of some of the problems, we did not receive enough testimony to get a clear picture across all regions of the country. We also did not receive testimony from Inuit or Métis groups. More work is needed on this important topic. We recommend that the re-established Secretariat spend time studying First Nations palliative care delivery in greater depth. Cultural diversity must be carefully taken into account, with a strategy flexible enough to respect cultural and spiritual needs, in the context of family and community.

All peoples in Canada want the choice to be able to die in their home communities. Due to lack of services in their local communities, however, most First Nations people end up being transferred to regional and urban hospitals, dying isolated from family, friends and community; in an environment which conflicts with deeply held cultural, familial and spiritual values.

“Given existing barriers and the lack of targeted funding, access to home and community based palliative care will remain limited for people living in First Nation communities unless palliative care programs are developed and integrated into existing local resources.” Holly Prince MSW. & Mary Lou Kelly PhD. – Lakehead University Thunder Bay, Ontario⁴⁹

By improving home care for First Nations communities, and by instituting first rate palliative care, Canada has an opportunity to become a leader on the world stage, an example to the world, of the kind of treatment that should be accorded to all Aboriginal peoples.

Recommendation # 5: We call upon the federal government to strengthen the home care delivery program for First Nations, Métis and Inuit communities, developing home delivered palliative care resources, sensitive to community, cultural, familial and spiritual needs. Research, training and capacity building, are required for First Nations, Métis and Inuit peoples to receive the high quality palliative and end-of-life care they deserve.

“Inconsistencies exist in how home care services are provided and delivered to First Nation communities across Canada. In addition, significant gaps also exist in the continuum of care when addressing the higher levels of needs, including palliative care, due to jurisdictional issues and lack of funding for these services.” Holly Prince MSW. & Mary Lou Kelly PhD. – Lakehead University Thunder Bay, Ontario⁵⁰

To build capacity for the delivery of adequate palliative care to First Nation people, research and education are required that is sensitive to the cultural uniqueness and resource deficits of these remote and rural communities. It is imperative that Canada dramatically improve health care delivery and chronic and end-of-life care for the elderly members of our rural and remote First Nation communities. We call upon the federal government to give special priority to the various recommendations that were given to the committee in this section:

- The need to fund ongoing research to develop a model of palliative care for First Nations communities that would be applicable across Canada.
- Implement a program of culturally appropriate palliative care education for First Nation community health and service providers.
- Develop a community based training program for local health care providers and community volunteers in First Nation communities for delivering palliative and end of life care. Such a training program would encompass e- learning, written resources, audio learning, and weekend training seminars. Home care professionals would work collaboratively in training volunteers.
- Assist local palliative care providers to develop supportive linkages to regional palliative care experts.

- Facilitate communication between local First Nations health care providers and outside palliative care experts via provision of needed communication technology and infrastructure in remote communities (high speed internet, video conferencing, virtual meeting technology).

“First Nations have grave concerns over the increasing number of Elders who are being placed in facilities outside their communities. First Nations feel isolated in provincial facilities and are often situated long distances from their families. This has a detrimental effect on their health and quality of life. ... First Nations have continually emphasized the importance of culture and tradition in the care of the elderly and disabled. This aspect has not been readily recognized or considered in many of the programs implemented by the various federal government departments. To ensure optimal health, the continuing care program and policies must ensure that clients receive effective, understandable and respectful care provided in a manner compatible with their cultural beliefs, traditions, practices and preferred language.”⁵¹ Assembly of First Nations

X – Rural Palliative Care delivery:

A significant number of Canadians, close to seven million people, live in rural areas and communities of only a few thousand people. If there is a form of “two tiered” health care in Canada it would be the distinction between urban and rural areas in terms of health care delivery. Canada’s health policy has emphasized urban centres, attempting to adopt urban models of health care to rural health care delivery. Certainly as vast an area as Canada, with a widely dispersed population, makes it extremely challenging to deliver health care to rural and remote areas. Creativity is required as we begin to address health care transformation from the rural perspective. Small communities have significant resources to bring about health care transformation. They come together more easily in times of crisis, cooperating together for the common goal. Faith communities, sporting groups, schools, and service clubs, provide powerful venues for action. People know each other and can get organized more quickly than in urban centres. We need to acknowledge this expertise and learn from it, supporting home grown initiatives for rural palliative and health care delivery.

“Rural health services often suffer from a lack of resources, including health care providers. Notwithstanding this lack of resources, rural people have expressed a preference to receive healthcare in their home communities; they do not want to travel to urban centres for care when they are dying.”⁵² Dr. Mary Lou Kelly – Lakehead University

Transportation is a significant factor in rural communities, and not only in remote communities. Consider a typical small town or village in Southern Ontario. If you are young, healthy and drive, a twenty five minute drive to the nearest city doesn’t seem far. Consider though an eighty year old woman, who never had or perhaps lost her driver’s license. If she has to go to a city 20 or 30 minutes drive away, for a medical appointment, or a test, this is a significant challenge. There is almost certainly no public transit, and a taxi, if available, is very expensive. If she has to enter a hospice or LTC home, in that neighbouring city, she is separated from her friends and family, many of whom would also not drive, or do so with difficulty. She may have lived her whole life in that small community, and to uproot her is no small thing. Health care delivery needs to take this into account.

Recommendation # 6: We recommend the development of rural palliative care delivery within the primary health care system, utilizing home care services, and local long term care homes; allowing care to be delivered in or close to a person’s home community.

Creative capacity building utilizing existing resources and health care professionals is important if we are to meet the needs of rural Canadians to good end-of-life care. A capacity building model of palliative care depicts “the process of developing palliative care as building up from the roots. It begins by assessing and strengthening available infrastructure, staff empowerment, the vision for change and collaborative

practice. Health care professionals use localised knowledge and skills to develop integrated palliative care programs that meet the unique needs of their community or long term care home.”⁵³

The stakeholders recommended to the Committee that governments and rural communities collaborate to develop a capacity building model for palliative care delivery. Such a model to be successful requires:

- Ongoing research into rural health care delivery from a systems perspective.
- Research on best practices as applicable to rural and remote palliative care delivery
- Development of hospice volunteer programs which both encourages volunteering in rural and remote areas, and supplies training needed so volunteers can be effective members of the rural palliative care team.
- Development of communication, networking, and information resources so rural health professionals can both link with specialists in urban centres for support on complex cases, and have access to up to date medical, and psycho/social/spiritual resources.
- Communications infrastructure to facilitate remote communication with palliative care specialists.

“Hospice volunteers have a vital role to play in supporting persons receiving palliative care and their families. Palliative care is not primarily a medical event. Volunteers can create a “culture of caring” that ensures that the social, emotional, and psychological aspects of dying are addressed which has an impact on the quality of life for those individuals who are impacted by death or dying. Hospice volunteers are valuable members of the palliative care team whether it is in a rural community or in long-term-care homes because they have time to talk and most importantly to listen.”⁵⁴ Dr. Mary Lou Kelly & Alesha Gaudet – Thunder Bay

- The Committee was told that the government should look at health care funding and revise the process to take account of the fact that dying is not just a medical event but requires enhancing and supporting community capacity.

“The whole community takes part in the dying process and supports the dying person and their family by meeting their social, emotional, spiritual and psychological needs. The need to build rural community capacity to support health services was a key finding of the federal Ministerial Advisory Council on Rural Health (2002)”⁵⁵ Dr. Mary Lou Kelly & Alesha Gaudet – Thunder Bay

This aspect of community development through palliative care and appropriate supports from governments can be a stepping stone to addressing other community needs like the minimizing of elder abuse, suicide prevention, poverty etc. Once one model of mutual support is supported, it is easier to expand to other social determinant needs.

XI – Long term care facility Palliative care Delivery:

“Residents of LTC homes represent one of society’s most frail and marginalized populations who often struggle with managing multiple chronic conditions and social isolation. Within LTC, over 75% of residents have cognitive impairment, which creates additional challenges for providing care due to the related communication, functional, and behavioural problems that arise. Thus, people who are dying in LTC homes form a growing population that consists of some of society’s most vulnerable citizens who would benefit by access to palliative care programs that encompass disease management, address the physical, psychological, social and spiritual issues at end of life, issues of loss and grief, and practical end of life/ death management concerns of residents and their families.”⁵⁶ Dr Mary Lou Kelly & Alesha Gaudet – Thunder Bay

Long term care homes form an important part of the health care infrastructure enabling palliative care delivery in rural areas. LTC also plays an important role in caring for persons with dementia. It is necessary to develop high quality palliative care delivery for all persons residing in LTC facilities. It was recommended that:

- The provincial governments develop implementation models, a funding envelope, and capacity building support for palliative care delivery in Long term care homes. The same applies to the federal government in terms of veteran homes, First Nation facilities etc.
- The provincial governments in conjunction with the stake holders develop inter-professional pain management protocols for long term care homes, which address systemic barriers to pain management, educate the staff on pain control issues, and improve pain care communication between staff, families and residents.

Given that long term care facilities provide an important component of palliative care delivery in rural communities, it is necessary to facilitate the development of high quality small LTC facilities in rural areas.

“Small Seniors residences provide an important service, to many who want to live in a smaller homelike environment close to their community. Rural communities need smaller residential care facilities by the nature of their demographics. Yet the Canadian Mortgage and Housing Corporation (CMHC) won’t give loan guarantees for homes of less than 50 people. Without CMHC loan guarantees, banks require a larger down payment and much larger (sometimes double) the interest rate. This makes it difficult to finance small senior residences. CMHC policy is biasing the system against the rural elderly.” David Morris – Montreal Round table Dec. 17, 2010

- A recommendation was made to the Committee that the government of Canada change CMHC policy so as to give mortgage guarantees for senior’s residences of less than 50 persons. Such policy change would correct the systemic bias against the rural elderly, allowing small seniors residences to be more easily built in smaller communities. This would allow elderly people to remain in their home community, rather than being forced to leave to large regional facilities. Such a policy can only be regarded as facilitating legitimate choice for those who prefer to live in smaller residential homes.
- Another interesting recommendation presented to the Committee was that the government fund options for providing in-home services to home owners who will accept one to three seniors to come live with them, whether these are family members, neighbours or strangers who want to remain in an actual house rather than a facility, but can’t live in their own homes anymore. For these home owners there would be costs of renovating their homes to accommodate mobility and health care needs.

XII - Palliative care and the ICU:

“On the surface, Palliative care and Critical care would seem to be polar opposites- one discipline focused on fighting illness and saving lives with aggressive treatments, the other focused on providing comfort to a dying patient as they navigate through the terminal phase of their disease. Yet palliative care is playing an increasingly important role in the care of ICU patients. While we may be able to bridge the gaps in care that patients receive before they become seriously ill, some dying patients will always end up coming to the ICU. For this reason, Palliative Care in ICU must be a part of the continuum of end-of-life care linking community, Long Term Care, and acute care hospitals.” Canadian Critical Care Society⁵⁷

Clearly we must minimize **inappropriate** admissions to ICU. Admitting incurably ill patients to ICU is harmful both for patients and for the healthcare system.

- It is harmful to patients, who prefer to avoid ICU care at the end of life, and who, as a result, experience a lower quality of life when they die in the ICU.
- It is harmful to family members, who suffer higher rates of depression, anxiety, and post-traumatic stress disorder when their loved ones die in an ICU.
- It is harmful to healthcare workers, who suffer higher rates of emotional burnout and compassion

fatigue.

- It is harmful to the healthcare system, which must bear the higher costs of death in the ICU, and the strain of having ICUs working over capacity.

We should not underestimate the harms of dying in the ICU

Even when faced with a dire prognosis, some patients and family members will say that “We have to try life support, because if we do nothing then he/she will die.” The implication is that the patient will lose nothing in the attempt. In fact, most patients who die in the ICU experience very significant symptoms, including shortness of breath (90%), moderate to severe pain (56%) and moderate to severe anxiety (63%). In addition to physical suffering, there is a potential loss of dignity and well-being. Worse still, most ICU patients are unable to communicate; we may be unaware that they are suffering, and inadvertently doing everything we can to prolong it.

To avoid inappropriate ICU admissions the Canadian Critical care Society recommends:

1. Increasing the frequency and effectiveness of advance care planning (ACP).
2. Improve communication between health care providers and patients/families.
 - i) Develop and implement communication training for front-line physicians and advanced practice nurses.
 - ii) Use of communication competence as a quality indicator and a component of recertification.
3. Publicity and education about the limitations of life sustaining treatment, the harms of dying in the ICU, and the potential for comfort-oriented care to *prolong* life.

Palliative Care Teams do have an important but often unrecognized role in ICU

“Although professional organizations recognize the importance of palliative care in the ICU, most Canadian ICUs do not routinely consult Palliative Care Teams. The potential roles of Palliative Care Teams in ICU include advanced symptom assessment and management; appropriate interdisciplinary communication and collaboration with teams and patient/families; patient/family-centred decision-making, aligning treatments with goals of care, and transitioning from acute to palliative care; emotional, spiritual, bereavement and practical support for patients/families; and emotional and organizational support for ICU clinicians. Palliative Care Teams aim to bridge the quality gap between ideal end-of-life care and the reality of intensive care for many dying ICU patients. They blend the cultures of acute and palliative care to meet patients’ needs along their illness trajectory. And notably, they can do this *without* compromising survival or shortening life.”
Canadian Critical Care Society⁵⁸

Given that some Canadians will continue to die in ICU settings, it is important that we formalize the role of palliative care teams in ICU, so that patients may be given appropriate pain and symptom management, emotional and spiritual support. Families need emotional, spiritual practical and bereavement support, both during the ICU experience, and following the patient’s death.⁵⁹

XIII – Pain Management:

“People in pain have a right to fully adequate pain relief treatment. Indeed for the healthcare professional to act unreasonably in leaving a person in pain is a breach of a fundamental human right of the person. Physicians should not fear that giving adequate pain relief treatment is unethical or illegal; in fact, they should fear the ethical and legal consequences of not doing so. To unreasonably leave a person in pain is medical negligence (malpractice); and, I believe, in extreme cases, it should be treated as criminal negligence – wanton or reckless disregard for human life or safety. It is torture by wilful omission. But rights to pain relief treatment will, however, be nothing more than empty words unless treatment is accessible. We have

serious obligations to ensure fully adequate pain relief treatment is readily available to all Canadians who need it.” Dr. Margaret Somerville, Director of the McGill Centre for Medicine, Ethics and Law; Samuel Gale Professor of Law⁶⁰

Important Facts

- Some 6 million Canadians live with unrelenting and under-managed pain.⁶¹
- The risk of suicide doubles for people with chronic pain.⁶²
- Chronic pain is very costly, with estimates of direct health care costs for Canada being some \$6 billion per year.⁶³
- Chronic pain costs more than Cancer, heart disease and HIV combined.⁶⁴
- Canadians are often left in pain after surgery, even in our best hospitals.⁶⁵
- Inadequate control of acute pain is the leading cause of post-discharge visits to the emergency room and early re-admission to hospital.
- 90% of patients could obtain effective pain control yet only 50% get such treatment.⁶⁶
- Only 30% of ordered medication is given, 50% of patients are left in moderate to severe pain after surgery a situation which is not improving.⁶⁷
- Uncontrolled pain, slows the healing process, and depresses the immune system, leading to increased sickness and even shortened life span.⁶⁸
- Family members are deeply affected by the impact of a loved one’s ongoing pain.⁶⁹

“Poorly managed pain creates a pain cycle that spirals downward towards a life experience where people suffer both physically and psychologically. The cycle begins when pain prevents or interrupts sleep. Lack of sleep increases the experience of pain which in turn promotes distressing emotional responses of fear, anger, anxiety and stress. The ability to sleep is further compromised and the cycle begins again. If the pain cycle continues uninterrupted and its mechanisms are further compounded by isolation, global stress related to life and the lack of effective pain care, the person’s ability to cope deteriorates markedly. Their mood becomes gravely affected, they grieve the significant losses in their lives and they may experience depression for the first time in their lives which is directly attributed to their pain. For some this becomes a desperate, dark place where hopelessness and helplessness reign. For some no longer able to bear the life altering assault of pain, suicide becomes an option. The majority of Canadians with pain are neither familiar with the concept of the pain cycle nor have they had access to training in coping strategies that they can use to break the pain cycle.” (Submission of the Canadian Pain Coalition)

Pain affects a large number of Canadians and its effects are far from negligible. Pain, whether acute or chronic, has devastating effects on the quality of a person’s life, and the social and societal costs both economic and relational are immense. Pain control is gravely deficient in Canada. Acute pain is often poorly managed, despite the availability of pain management knowledge and technology. It is critical to treat acute pain adequately, not only to decrease suffering but to minimize the chances of the pain becoming a persistent chronic condition.

People in long term pain encounter stigma and shame, as others judge them as “malingerers and drug seekers”. They encounter work place difficulties when employers and colleagues, through lack of understanding, fail to make accommodations to enable them to remain at work. Insurance companies, Workers Compensation Boards, and other bureaucratic structures can be unsympathetic, presenting further hardships for people already worn down by pain. Health care professionals often fail to take seriously peoples requests for pain control help. Misconceptions about addiction to pain killers, and inadequate training in pain management, leave patients hard pressed to find meaningful help.

Pain Management Training:

Pain control training is inadequate for health care professionals. Professional schools give pain management a low priority, in terms of class room hours. It is a sad irony that veterinarians receive 5 times more education on pain control than do doctors who treat humans.

“A recent survey of pre-licensure pain curricula in health science and veterinary training programs across Canada has identified inadequate training about pain among health care practitioners. This survey included medical schools and faculties for training nurses, dentists, physiotherapists and occupational therapists as well as veterinary medicine programs. Only one third of the programs could identify time designated for mandatory teaching about pain. The mean total number of hours designated for pain teaching over the entire academic training program was 15 for dentistry, 16 for medicine, 31 for nursing, 28 for occupational therapy, 13 for pharmacy, 41 for physical therapy and 87 for veterinarians.”⁷⁰

Given the lack of pain control education, it is not surprising that physicians, nurses and related professionals, are not adequately equipped to deal with people’s pain control needs. This educational lack includes the technical side of pain control, and the complexities of interdisciplinary approaches needed to treat more difficult pain symptoms. It also involves changing a mind set, which refuses to see pain as a matter of utmost urgency. This mindset is found among many of our health care professionals, as well as in health policy circles.⁷¹

“It is disturbing that in Ontario, the largest province in the country, there is not a single interdisciplinary pain management program that is fully funded by the Ontario Ministry of Health. At present wait times for care are greater than 1 year at over one third of publically funded pain clinics in Canada with vast areas of the country having no access to appropriate care. Patients waiting more than 6 months from the time of referral to assessment experience deterioration in health related quality of life, increased pain and increasing depression. In addition to contributing to ongoing suffering, disability and diminished life quality, it has been demonstrated that uncontrolled pain compromises immune function.” (Submission of the Canadian Pain Society).

Pain Control is an area in need of immediate attention. There are a broad range of issues which need to be addressed if Canadians are to receive adequate pain control. Our recommendation is that all levels of government, the Canadian Pain Society, the various professional associations etc. must work together to develop a National Pain Strategy, laying out the blueprint of how we as a country can proceed towards the goal of adequate pain management for all Canadians. This strategy should not distinguish between cancer and non-cancer pain. Pain is pain and must be effectively treated. People with both acute and chronic pain must be included in the dialogue leading up to the development of the strategy. Fears of opioid addiction and drug abuse, while needing to be addressed, cannot derail the right of countless Canadians to receive adequate pain management. A nuanced approach is needed that balances the need to control restricted drugs, with the fundamental right of human beings to adequate pain management. Finally for a strategy to be effective it will require adequate funding over a period of at least ten years.

Recommendation # 7: We recommend that the federal, provincial and territorial governments along with the various NGO stakeholders (i.e. The Canadian Pain Society) develop and implement a National Pain Strategy, to provide a unified approach in the delivery of pain control methods.

- A research program needs to be developed, with the various levels of government working together to provide direct designated funding for pain control research. Such funding must be measured against expected outcome indicators, to ensure accountability and sustainability.⁷²

Our Committee was told of the need for the various levels of government to:

- Work closely with the Canadian Medical schools to assure minimum standards, and sufficient time dedicated to pain control training for pre-licensure medical students. Levels of training

should minimally be equivalent to that of veterinarians who currently receive more than 5 times the number of hours of pain control training as do human doctors. Such training should integrate patho-physiology, assessment and treatment of pain, in a way that prepares physicians to work within an interdisciplinary team context in treating more complex pain conditions.

- Ensure that similar improvements in pain control training are implemented in nursing schools, pharmacy schools, and related health care professional programs.
- That the Royal College of Physicians and Surgeons allow pain control medicine to become a fully accredited program of specialist training. Financial and other inducements should be given to medical students to enter this field.
- That the College of Family Physicians of Canada and the Provincial Colleges of Family Physicians, begin work to develop pain control protocols and training curriculum for the continuing education of primary care physicians. The majority of pain control support will always come from family physicians. Primary care is the key to a sustainable service model.
- That special billing codes and other incentives should be set up by the provinces and territories, to encourage family physicians to spend the needed time to take care of patient's pain management needs. Adequate pain management is often a very time consuming process, a fact which is not reflected in present provincial billing codes.
- A strong recommendation was made to the Committee that the federal, provincial and territorial governments include pain assessment and care in the upcoming 2014 Health Care Accord. The Accord should also contain the requirement that pain become the fifth vital sign, taken and recorded with the other four in the patient's medical chart
- It was also noted that governments must ensure that all health care institutions in the nation meet the **Accreditation Canada** (AIM –Achieving Improved Measurement) standards on pain control.⁷³
- Develop inter-professional pain management protocols for long term care homes, which address systemic barriers to pain management, educate the staff on pain control issues, and improve pain care communication between staff, families and residents. Various international consensus statements exist to guide this work.⁷⁴
- It was strongly recommended to the Committee that the federal government change the definition of medical practitioner under the Controlled Drugs and Substances Act (CDSA) to include **Nurse Practitioners**. This would allow properly qualified nurse practitioners to prescribe narcotic pain control medication. Nurse practitioners would be a great help in facilitating better pain control, particularly in remote and rural areas, LTC homes, and in hospice and other palliative care settings. With the ability to prescribe, nurse practitioners would also be excellent leaders of palliative and pain control interdisciplinary teams, especially in homecare environments.
- That the federal government formally recognize the **Declaration of Montreal** and its acknowledgement of good pain control as a fundamental human right.⁷⁵

The fundamental dignity of the human person should elicit from each of us and from society in general, a compassionate response seeking to alleviate suffering.

“One of the most rewarding things that can happen to a doctor is when you take someone who has been in deep pain for months, not able to sleep, and you take away that pain. When they finally can fall into a deep sleep, one realizes that this has been a great privilege to be involved.” Dr. Ray Hasel – Montreal – Pain control specialist

The following considerations given to the Committee are also worth reflecting on.

1) Official recognition of serious chronic pain as a medical condition or chronic disease. This will promote an attitudinal shift about pain which will resolve issues surrounding access to pain management and promote a greater willingness to invest in pain control. That the provinces and territories ensure chronic pain is integrated into chronic disease management primary care redesign initiatives.⁷⁶

2) Provincial and territorial governments provide adequately funded regional pain control hubs, so that complex pain conditions are assessed and managed in a timely fashion. Regional pain control centres could provide mentoring and technical support to local doctors and nurse practitioners, as they attempt to address pain issues in the local community. More complex cases could be referred to the regional pain control centre.

3) Law reform commissions, medical associations, and other professional bodies might consider what clarifications to our laws, and to the code of conduct of various professional associations, might be necessary, to ensure that physicians who through carelessness, or failure to exercise due diligence, are responsible for patients living and dying in untreated or seriously undertreated pain; can be effectively disciplined.

4) Law reform commissions, legal and public policy experts, as well as pain control clinicians, consider collaborative development of nuanced protocols that deal effectively with prescription drug abuse, while not preventing and discouraging physicians from giving adequate pain medication to patients in need.

5) Health care practitioners were urged to recognize the foundational importance of adequate pain control, an importance based upon the dignity of the human person; a fundamental right of the person to have unnecessary suffering alleviated. We urge health care professionals to treat pain as a “5th vital sign”, and to regard pain management as a central aspect of their vocation.

“To cure sometimes, to relieve often, and to comfort always -- this is our work. This is the first and great commandment. And the second is like it - Thou shalt treat thy patient as thou wouldst thyself be treated.” Anonymous

XIV – Legal and Human Rights Perspectives on Palliative Care:

“Palliative care is part of a movement for fundamental justice and basic human rights for citizens facing the last fragile stage of life. It challenges narrow, impoverished and dehumanizing ways of dealing with dying. It calls for the building of a culture of care, dignity and support for men and women as they pass from family, friends, and wider communities they have worked, loved, struggled, and contributed to in many known and unknown ways.” Dr. Daniel Cere – McGill University – Montreal⁷⁷

Fragility is a universal feature of human life, we all face our fragility at some point, yet it is a reality that most people wish to ignore. When one is young and healthy, successful and at the peak of one’s powers, it is easy to forget about the contingency of human life; and it is common to try to insulate oneself from any reminder of life’s basic uncertainty. Public policy too tends to be insensible to human fragility. Unintentionally, vulnerable members of society often recede to the margins of the consciousness of public officials, civil servants, and policy makers. There are a range of reasons why this happens. Policy makers by definition focus on developing policies that fit the majority of people. Public policy decisions reflect a compromise amongst a cross section of groups, none of whom are particularly vulnerable, and none of whose economic and political interests naturally coincide with those who are. The most vulnerable in society are not part of the day to day experience of policy planners.

“Each of us is fragile, with deep needs for both love and a sense of belonging. We begin and end our lives vulnerable and dependent, requiring others to care for us. Throughout our lives there are other moments of fragility and dependence. In our states of dependence, our need cries out for attention and care. If this need is well received, it calls forth the powers of love in others, and creates unity around us, the gifts of the vulnerable to our world. If our cry and our need are unmet, we remain alone and in anguish. The vulnerable people, whom your committee is called to reflect about caring for; are often in a precarious state mentally or physically or both. They are often in anguish. The old, those living with illness and perhaps near death, those in depression and with a sense of despair, those living with disabilities; these are all people living in a most fragile state. The danger in our culture of productivity and achievement is that we easily dismiss and ignore as unproductive the gifts and the beauty of our most vulnerable members, and we do so at our own peril, dehumanizing ourselves.” Jean Vanier – Submission to the Committee

Human rights Declarations seek to overcome our natural lack of awareness of the needs of vulnerable persons; reminding us that every human being has a fundamental dignity that should elicit from us a response of compassion and a sense of profound identity in our shared humanity. They are a sign post as it were, pointing to a reality which we overlook to our own detriment, stirring us to consciousness of those basic responses that are due to each human person irrespective of their state, condition, or place in the social hierarchy. When the United Nations implemented the universal Declaration of Human Rights in 1948, it did so, with the recent past in mind; with recognition of what can happen when we are forgetful of the vulnerable, when we allow the fragile to slip from our consciousness. The document was not meant so much to be an enforceable code, as an aspirational beacon of what a human being is at their deepest core; of their grandeur and dignity, and what that should entail in terms of the individual and communal response.

Human Rights Declarations and Pain Management:

On December 10, 2008 the UN Special Rapporteur on the Right to Health, and the Special Rapporteur on Torture, noting the inadequacies of Palliative and Pain control care stated:

“The failure to ensure access to controlled medicines for the relief of pain and suffering threatens fundamental rights to health and to protection against cruel, inhuman, and degrading treatment. International human rights law requires that governments must provide essential medicines—which include, among others, opioid analgesics—as part of their minimum core obligations under the right to health. Lack of access to essential medicines, including for pain relief, is a global human rights issue and must be addressed forcefully.”⁷⁸ Earlier that year on March 11, 2008 Paul Hunt the Rapporteur on Health had noted:

“Many other right-to-health issues need urgent attention, such as palliative care. Palliative care includes pain relief for the terminally ill. Every year, millions suffer horrific, avoidable pain. Very few have access to pain relieving drugs. As always, those in the developing world suffer much more than those in the developed world. Six countries account for 79% of medical morphine consumption. But this is not just a problem of development. Lack of access to pain relieving drugs is partly due to regulatory barriers. Regulations aim to protect populations from drug dependence. But these regulations do not always strike the right balance between this legitimate aim and genuine medical needs. In short, palliative care needs greater attention.”⁷⁹

These two quotes are examples of clarifications made by UN human rights rapporteurs as they clarify basic human rights accords, including the Universal declaration of human rights which states in **Article 25.1** **“Everyone has the right to a standard of living adequate for the health of himself and his family including food, clothing, housing and medical care and necessary social services.”**

The International Covenant on Economic, Social and Cultural Rights in **Article 12.1** states that **“The state parties to the present covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health”** Commenting on the Covenant the UN Interpretive Committee overseeing the ICESCR states in **General Comment #14: “In particular, states are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal**

access for all persons, including prisoners or detainees, minorities, asylum seekers and illegal immigrants to preventative, curative and palliative health services.”⁸⁰ The Committee goes on to note in the section on older persons, that there is a responsibility to give **“attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity.”⁸¹**

These references to International Human rights accords and their official interpretation form the basis of a developing understanding of a fundamental right to adequate pain control and palliative care.

In 2003 for example the European Committee of Ministers in Declaration 24 stated that: **“Palliative care is an inalienable element of a citizen’s right to health care.”⁸²**

Earlier in 1999 the Parliament of the Council of Europe promulgated Recommendation 1418 (1999) **Protection of the human rights and dignity of the terminally ill and the dying** This document gave a ringing endorsement for the right to good palliative care. It noted among other things:

“5. The obligation to respect and to protect the dignity of a terminally ill or dying person derives from the inviolability of human dignity in all stages of life. This respect and protection find their expression in the provision of an appropriate environment, enabling a human being to die in dignity.

6. This task has to be carried out especially for the benefit of the most vulnerable members of society, a fact demonstrated by the many experiences of suffering in the past and the present. Just as a human being begins his or her life in weakness and dependency, he or she needs protection and support when dying. ...

9. The Assembly therefore recommends that the Committee of Ministers encourage the member states of the Council of Europe to respect and protect the dignity of terminally ill or dying persons in all respects:

a. by recognising and protecting a terminally ill or dying person’s right to comprehensive palliative care, while taking the necessary measures:

i. to ensure that palliative care is recognised as a legal entitlement of the individual in all member states;

ii. to provide equitable access to appropriate palliative care for all terminally ill or dying persons;”

⁸³

In Canada our Senate recognized palliative care as a basic right when in 2000, the Standing Committee on Social Affairs, Science and Technology titled their final report on Palliative care **Quality end-of-life care: The right of every Canadian.**

In 2011 Canadians must ask themselves what direction do we wish to take?

It is an interesting historical note that the first draft of what would eventually become the 1948 Universal Declaration on Human Rights, was written by a Canadian Law professor from McGill University John Peters Humphrey. Despite this, Canada initially abstained from voting for the declaration, and only at the very end reversed its abstention and voted in favour. As John Peters Humphrey would note at the time: **“This Declaration is the work of hundreds indeed of thousands, of people and it represents a synthesis of the ideas and convictions of the millions of people of all races and nationalities who spoke through them. ...The final judgement of history will be determined by the impact which the declaration has and will have on the actual conduct of states and of individual men and women everywhere.”⁸⁴**

Dr. Harvey Chochinov in addressing the Senate Committee in 2000 reminded each one of us that:

“Unfortunately, in end-of-life care, we do not have a vocal constituency: The dead are no longer here to speak, the dying often cannot speak, and the bereaved are often too overcome by their loss to speak.”⁸⁵

As worthy successors of John Peters Humphrey, let us be that vocal constituency for Palliative care.

Canadian Law and the Question of Palliative Care

Arguments for palliative care and pain control as human rights carry great moral force; yet in reality these rights are aspirational and not legally enforceable. Dr. Yude Henteleff Q.C. presenting before the Committee November 1, 2010 noted:

“The Supreme Court has in recent decisions determined that international treaties are not binding unless implemented in domestic law, and can only be referred to for guidance as to the meaning and interpretation of certain Charter principles.”⁸⁶

Dr. Henteleff contends that action towards better palliative care is best attained through either:

i) a Charter challenge, or ii) a change to the Canada Health Act.

The Canada Health Act (1984) sets the frame of reference for health care delivery in Canada. Its function is to establish the conditions and criteria that provinces and territories are to meet in order to qualify for federal funding under the provisions of the Canada Health and Social Transfer. With the objective of ensuring reasonable access to quality health care for all Canadians, without financial and other barriers, the CHA sets five criteria that must be met for insured health services. These are a) public administration, b) accessibility, c) universality d) comprehensiveness, and e) portability. Unfortunately the Act makes a distinction between medically necessary/insured services, and so called extended services. The medically necessary services must follow the five criteria in their delivery, in order for provinces to receive full federal transfers. Extended services are left up to the Provinces, to determine if and how they will be delivered.

“Extended health services are described in the CHA as services such as a) nursing home intermediate care service, b) adult residential care service, c) home care service, and d) ambulatory health care service. Extended health services encompass that broader “continuum of care” which would include services such as access to home and community care, long-term and palliative care, and are generally not considered as being medically “necessary” or “required”. Thus these services are not protected under the CHA’s 5 principles and the CHA does not require the provinces to provide funding for these services. ... This in turn leads to a patchwork of uncertainty across Canada.”⁸⁷

Original proposals for health insurance as early as 1945, had envisioned a broad range of services covered, including, doctors, hospitals, and home visiting nurses as a first stage. A second stage was to quickly follow with private duty nurses, dental care, pharmaceuticals, surgical appliances, laboratory services etc., being gradually phased in. Home care would have been a part of Canadian Medicare from the beginning, but unfortunately “earlier proposals crashed on the rocks of federal-provincial disputes, (and) a series of political compromises were made, which began with the most expensive parts of the system.”⁸⁸

As hospital and physician services were the most expensive, these became the core of funded services in a series of acts ranging from the 1957 Hospital Insurance and diagnostic Services Act, through the 1966 Medical Care Act, right up to the 1984 Canada Health Act. The Canada Health Act envisioned: “an illness oriented, hospital-dominated health system with a cure focus. Dying requires care but not cure, and it is only cure-focused care that appears to be insured under the CHA.”⁸⁹

Hospitals and physician services became the “medically necessary” insured services of the Canada Health Act, beginning as early as 1945. Technology gradually changed and services that had once been available