

Expression

NEWSLETTER OF THE NATIONAL ADVISORY COUNCIL ON AGING

Guest editorial

Seniors and Palliative Care

Our society is faced with new challenges brought on by the aging of the population and the ensuing increase in degenerative diseases such as cancer and Alzheimer's disease.

Is our system up to these challenges and can the present palliative care services respond to the needs of seniors? Focused on cure, the medical establishment experiences difficulties when it must minister to people whose illness cannot be cured and whose life is coming to an end. The needs of terminally-ill patients are different from those of other patients. They require another approach, different services defined by different criteria.

When a patient can look forward to cure, he or she can accept a certain degree of discomfort or pain to attain it. But the perspective is quite different when patients are facing certain death. There can then be only one concern:



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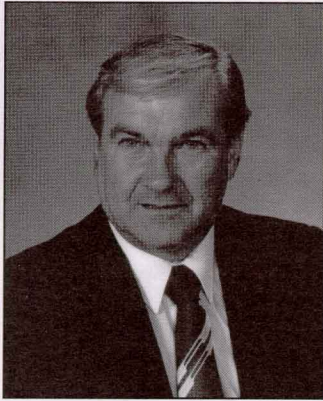
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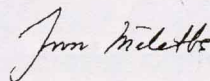


the patient's immediate comfort and well-being.

Palliative care is a compassionate form of health care for patients approaching the end of their life. Should this care be dispensed in special facilities for seniors facing terminal illness? Different models of care have been explored all over the world: **St. Christopher's** in London, the **Maison Michel Sarrazin** in Québec, the **Elizabeth Bruyère Centre** in Ottawa, for example, are highly specialized in pain control and offer supportive care and attention to dying patients. Friends and family are welcome at all times and special training is given to volunteers who can then assist the patients, their family and the caregivers on staff.

In-home palliative care services are provided in collaboration with a care facility. If treatment is balanced, this type of service can ensure the continuum of care and nurturing that will allow terminally-ill seniors to remain in their familiar surroundings for as long as possible. The family also needs to be kept informed and supported by being given clear explanations and directives. For seniors to derive maximum benefits from this situation, the home atmosphere needs to be calm and serene, and services must be of the same quality as those offered in hospital.

Everyone has the right to die with dignity. To ensure this, all levels of government, all health care administrations and the general public, including seniors and their caregivers, need to work together to develop the responses of our society to the challenges of palliative care.



Yvon Milette
NACA Member
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Overview

The palliative care approach is a comprehensive set of knowledge and attitudes seeking to accompany a terminally-ill person and his family and friends in the experience of the last stage of life.

The latin root of the word 'palliative' refers to the alleviation of disease and pain. In palliative care for example, the dying person can be administered opiates to control pain to allow the patient to maintain a certain degree of autonomy and well-being. A warm and inviting environment as well as a competent, interdisciplinary team are needed to respond appropriately to the needs of the dying persons and their families.

Palliative care services are those that are actively and compassionately provided when the disease no longer responds to treatment designed to cure or prolong life; the main objective then becomes the control of the physical, emotional and spiritual difficulties that the patient might experience.

The objectives of general care units are incompatible with the real needs of dying persons. These people seek relief rather than a false sense of hope for a cure. One of their greatest needs is for supportive and caring attention as they prepare for their leaving.

More and more interest in the meaning of death has focused attention on ways of caring for the dying. In 1960, **Dr. Cecily Saunders** opened, at **St. Christopher's Hospital** in London, a separate unit for the care of dying patients. This unit's work has had a significant impact worldwide and many countries now apply the research it has carried out on the alleviation of pain and symptoms.

In Canada, a pilot palliative care facility, the **St. Boniface Palliative Care Unit**, was inaugurated in 1974. Then in 1975, Montréal's **Royal Victoria Hospital** opened a palliative care unit and demonstrated that a general hospital could provide the required services if it had:

- an interdisciplinary team specialized in palliative care;
- a hospital service, a home visitation team and a consultation service;
- nursing care specialized in pain control;
- staff able to respond to psychological, emotional and spiritual needs;
- treatment and care focused on the dying patient and his/her family;
- continuing assistance to the bereaved family.

This concern for the quality of life of dying persons led Montréal's **Hôpital Notre-Dame** to open a palliative care unit, in 1979. The unit is staffed by a highly experienced team. Patients are admitted if they are

suffering from terminal phase cancer (or well-advanced, pre-terminal), have been treated for cancer by a doctor at the hospital, are over age 18, consent to admission to the unit, and the family has been advised that the purpose of the unit is no longer to cure but to alleviate symptoms.

The **Association d'entraide Ville-Marie** in Montréal has offered palliative care services at home for over 15 years, with a view to ensuring that the dying person and his/her family will experience this stage of life as humanely as possible. Its staff is almost entirely made up of nurses. Patients are accepted for home palliative care if they suffer from pre-terminal or terminal phase cancer, wish to die at home, are residents of the Montréal metropolitan area, live in an adequate environment and are treated by a doctor willing to work with the Association.

Author **Madeleine Saint-Michel** stresses that offering good quality of life to a terminally-ill cancer patient implies much more than the simple provision of physical and environmental comfort. It also involves enabling the patient to become aware of deep-seated emotions and feelings and to live through interior transformations at many levels, as well as helping him/her to choose to accept life as it presents itself, enjoying its positive aspects and

relinquishing those that are missing or unattainable.¹

The **Maison Michel Sarrazin**, a 'dying facility' that opened in Québec in 1985, was a first in Canada when it offered a network of care and help aimed particularly at terminal phase cancer patients². Director general **Dr. Louis Dionne** believes that one of palliative care's principal results can be personal growth. He describes palliative care as he sees it:

It is possible to accompany, to hear and to comfort pain; it is possible to create a 'place' that enhances the experience of dying...; it is possible for the person who is nearing the end of life to be treated by family, friends and caregivers as a living human being and to receive answers and solutions to his/her problems; it is possible to see death as a natural event, not a failure; it is possible to recognize the rights of dying people and to honour these rights (right to the alleviation of pain, to a comforting presence, to dignity, to respect and to truth); and it is possible to transform the experience of dying, despite the physical degeneration that comes with it, into a valuable growth experience.²

Dr. Elizabeth Latimer, director of palliative care at Hamilton's **Henderson General Hospital**, is convinced that

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effective palliative care can reduce the number of requests for euthanasia and assisted suicide.



What is palliative care?

The purpose of palliative care is to improve quality of life, not quantity, through physical, psychological and spiritual support to the dying person and the family.

Aimée, a senior suffering from a chronic illness, was offered the choice of being put on a respirator, to help her battle an acute upper respiratory infection. She refused, fearing utter dependence on the respirator, and chose instead to take her chances of living a shorter life with dignity. She later moved to a centre offering palliative care where she was able to lead a quality-filled life and die in relative comfort. People like Aimée, who become increasingly frail in their later years and suffer from terminal illness, are most likely to benefit from palliative care.

Palliative care is a timely issue for seniors. Although seniors live longer, everyone must die eventually. Many seniors suffer chronic health problems or develop severe illnesses, which progress to a terminal phase. When an incurable disease occurs, palliative care geared to the special needs of the elderly is

required. These needs include medication, palliative care including respite care for family members, a greater understanding of depression in the aged and how it affects terminally-ill seniors and training of caregivers in the treatment of the aged.

Awareness, training and research are necessary to address these complex needs.



Facilities

Palliative care services are delivered in all types of facilities, including hospitals, with the patient being admitted to a general ward or to a special palliative care unit, free standing community palliative care units, in the home through home care, or in nursing homes. They may be provided by private or public organizations. The type of facility chosen in consultation with the dying person and family will change if the needs change. For example, a senior with early stage cancer may remain in the home, cared for by a spouse. As the disease progresses, the aging caregiver may be unable to continue care and the patient may need to be admitted to a facility providing palliative care.

A few larger facilities provide palliative care units. Such is the eight-bed palliative care unit serving cancer patients aged 60+ at the **Sunnybrook Health Science Centre**, a chronic care hospital in North York, Ontario.

The Maison Michel Sarrazin is a stand alone hospice that has offered assistance to more than 4,500 dying persons (partly at home, partly at the facility) since its inception. Its care staff is trained to support patients in the last months, in the last weeks, in the last days and in the last hours of their life.

In-home palliative care, where available, is offered in collaboration with a public care centre or a private palliative services business.

Whether in a hospital, in an independent facility or through home care, **Donna Roe**, National Executive Director of VON Canada, believes that "the regional concept model offers the greatest potential for achieving the required range and quality of palliative care services... The regional concept model is not necessarily a regional palliative care centre, but rather a model where all the necessary components for effective comprehensive palliative care are integrated and coordinated."³ The **Ottawa Carleton Regional Home Care Program Palliative Care Services** is a good example of such a service.

We now have a better idea of palliative services offered across the country since the publication of an inventory of these services by the **Canadian Palliative Care Association** in 1997. The problem, however, of

resource and service allocation to palliative care remains.

Services

Palliative services include a wide range of support services, with the main ones being emergency support, daycare services, respite care, psychotherapy, physiotherapy, spiritual guidance, support group counselling and bereavement counselling. Services of particular importance to seniors are daycare and respite care as family caregivers are often overstressed by the burden of care. Unfortunately, these services are in short supply across the country.

The last stage of life

Dying people have social, psychological and spiritual needs. Their suffering encompasses all these aspects and care needs to address them all. Dame Cicely Saunders calls this "total pain", an immense physical suffering compounded by accompanying psychosocial distress. This distress is made up of various fears: fear of losing control, fear of physical and mental deterioration, fear of increasing pain, fear of being lonely or abandoned, fear of dying.

Physical needs

According to Dr. Dionne "analgesics (opiates, anti-inflammatory medication, steroids) can relieve almost all physical pain and symptoms of dying patients when they are well administered. Moral, psychological and emotional suffering can also be alleviated by proper medication associated with the physical presence of a compassionate, attentive human being."²

There needs to be a recognition that seniors have more complex problems than younger people and may require different attention in the control of pain. According to **Ross and McDonald**⁴, "many seniors are being treated for cancer while they also suffer from other chronic illnesses such as diabetes, glaucoma, and rheumatic disorders ". The aged may also suffer from difficulty with breathing, general discomfort, weakness, loss of appetite, dehydration, inability to swallow, confusion, problems with thinking and memory loss, and incontinence. For this reason it is often difficult to identify the source of the pain. Physicians must also be aware that seniors react differently to narcotics and that they need to prescribe accordingly.

Methods other than medication can also be used to maintain physical comfort. The physiotherapist can provide help in maintaining mobility or regaining the use of a limb; the

nurse can advise the caregiver on how to safely transfer a patient into bed. Skin care, the use of electric nerve stimulation machines, acupuncture and hot packs can also relieve pain.⁵

Spiritual needs

The need for spiritual care has been acknowledged since the beginning of the modern palliative care movement. Spirituality is understood to be broader than the usual notion of religion.⁶ In a broad sense, to be spiritual is to be sensitive to the dimensions of meaning in one's own life.⁷ Accordingly, spiritual needs can be fulfilled in different ways. For Aimée, for example, prayer was of immense comfort throughout her life. As her illness progressed and she experienced ever-increasing difficulty in breathing, she welcomed death with serenity and looked forward to meeting her Maker. As for Jane, who was dying of cancer and had always enjoyed outdoor activities and later, the cottage, solace came in time spent on the veranda with her family and friends, in an environment that she had always loved.

Different life experiences lead to different palliative care needs. Death in some cases is anticipated as a relief from pain and suffering. Patients derive comfort from reminiscing about their life as they enter the final

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stage. This awareness makes staff feel comfortable with the terminal patient, but might cause them to neglect certain bereavement aspects which require support either for the patient or the family, such as dealing with unresolved issues. For example, Mary's nurse noticed that she never reminisced about her daughter. Upon further questioning Mary admitted that she had quarrelled with her daughter and wished to make up before she died. Mary's daughter was contacted, they were helped to work through old feelings and the two were reconciled.



Grief and bereavement

"The process of dying may involve some of the most miserable and distressing sensations known to man... Accompanying these debilitating and demoralizing symptoms is the loss of dignity, self esteem and privacy which comes from depending on others to manage each and every aspect of one's bodily and mental needs, 24 hours a day," says **Dr. Scott Wallace**.⁸

The loss of control experienced by terminally-ill patients can be attenuated by ensuring that they are informed enough about their condition to make decisions about their care and ensure that their wishes are respected. Many use advance directives and living wills to

formally express their wishes (see *Expression*, vol. 7, no. 1).

Grief affects the physical, social and psychological realms. The stages of loss (which can apply to the patient, the caregivers and the bereaved) have been well identified as including denial of the illness, feelings of anger that this had to happen, bargaining (e.g. with God to let you live), depression and acceptance.⁹

When death occurs, depriving a spouse or close companion of many years, he/she can be terribly affected by the loss and may require support adapted to his/her needs.

Caregivers also need support in bringing closure to their grief. "You feel badly because your relationship wasn't only personal... you were giving a special part of yourself to the patient and his family... you need time."⁴

Volunteers can provide the link between professional staff and patients, and help the family and patient to cope with their grief. For this they need patience, compassion and training in communication skills.



Barriers

There are many barriers to appropriate care for the dying: death is seen as a defeat; the medical focus is on cure, not

pain relief; family members or doctors are unable to give sufficient time to terminally-ill patients because of work constraints; palliative care is unavailable locally; and lack of funding prevents its implementation.

While these barriers apply to all those in need of palliative care, certain problems affect seniors particularly. **Ross and McDonald** point out that the loss of social supports as people age, the loss of age peers, family members, and friends lead to a "smaller number and variety of social resources upon which to draw."⁴

Even when a spouse is the main caregiver, age and frailty may prevent him or her from providing the necessary support. Also, many older people find it difficult to ask for help and often do not have the money to pay for it.

Community nurses also need support. They reported⁴ receiving limited training in palliative care, aging and gerontology, lacking support from family and friends in regard to their work, feeling isolated in their work and perceiving a lack of coordination between those involved in palliative care. A further barrier is that many physicians are not trained in the care of the elderly.



Hope for the future?

Palliative care education is for everyone, including professionals, patients, volunteers and caregivers. It can be provided in several ways, through formal programs in universities and colleges, in-house training programs, tele-education, etc. It covers all aspects of palliative care from caregiving, pain management, care of the caregiver, to bereavement. Some training material has been published for use by the general public. But there has been no standard for the development of education in this field. The **Special Senate Committee on Euthanasia and Assisted Suicide**⁸ pointed out in 1995 that most medical schools recognized the need for palliative care education, yet none of the 16 existing medical faculties dealt with palliative care in their core courses. However, curriculum and training developments, information sharing activities, advocacy and research initiatives across the country are opening the way to a greater awareness of the need for palliative care.

King's College, in London, Ontario, "offers undergraduate courses, leading to a certificate in Palliative Care and Thanatology, holds a National Conference on Death and Bereavement which professionals from all over the world attend and provides university training in bereavement to caregivers, (e.g. clergy, social workers, nurses). The need and success of these programs, says **Dr. John**

Morgan, is seen through the many letters expressing appreciation". The **Université du Québec à Montréal** offers an interdisciplinary program on death and dying. As well, the **Community Hospice Association of Ontario** publishes a volunteer training manual that deals with emotional and spiritual issues, communication and practical comfort measures.

Advocacy groups have also been actively promoting palliative care: at one end of the country the **Newfoundland and Labrador Palliative Care Association**, which was created in 1993, and at the other, the **B.C. Hospice Palliative Care Association**, now in existence for over 10 years.

Research is also being carried out. The **Canadian Palliative Care Association** and the

Canadian Association for Community Care are currently completing the evaluation of a resource manual to train support workers in palliative care. **Dr. Margaret Ross** (University of Ottawa) and **Dr. Rory Fisher** (University of Toronto) are also working on a manual, this one to suggest national guidelines of care for seniors in the last stage of life. Margaret Ross feels strongly that "seniors must be empowered to be the authors of their lives to the end and provided with the assistance required to make the last chapters of their autobiographies meaningful and their endings good."¹⁰

There definitely seems to be hope for the future.



For Further Reading...

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Tips List

For Seniors

- Be prepared. Get information about local palliative care services at the onset of a chronic illness. Your local palliative care association, spiritual advisor or family physician can assist you.
- Visit palliative care facilities and organizations providing palliative care services in your area. Talk to staff and patients in order to find out if your needs can be met by them.
- Talk openly with your family about your current and potential need for palliative care and where you would like to receive care.
- If you live in an area where living wills are legal, review your living will every year and look at your choices once you get sick. Give a copy of the will to family, friends or your physician and ensure that they understand your wishes.
- Seek out the support of your spiritual advisor in order to help you deal with the issues of terminal care.

For caregivers and volunteers

- Informal caregivers: remember to take good care of yourself. Find out about respite care services in your area, to see if your loved one would qualify. This could give you a much needed break from your caregiving responsibilities.
- Professionals: be clear when providing information to seniors about services and treatment and recognize that anxiety may cloud the reception of this information.
- Respect the freedom of the senior to make choices where he/she remains competent. Respect the last wishes of the patient and those contained in advance directives.
- Provide the family with information about what the dying member is going through, the expectations of the family, their roles as caregivers and what services and supports are available to them.
- If you are recently bereaved, join a self-help group such as a local bereavement support group.
- If you are a caregiver, recognize that you may need support. Seek appropriate help, e.g. grief counselling.
- Find way to show volunteers that you appreciate them.

Notes

- 1 Saint-Michel, M. "Lutter au risque de se perdre." *Canadian Nurse*, (October 1985).
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- 4 Ross, M.M. and McDonald, B. "Providing palliative care to older adults: Context and challenges." *Journal of Palliative Care*, 10, 4, (1994): 5-10.
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- 6 Dudley, J.R. et al. "Unfinished business: Assessing the spiritual needs of hospice clients." *American Journal of Hospice and Palliative Care*, (March/April 1995): 30-37.
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- 8 Senate of Canada. *Of Life and Death*. Special Senate Committee Report on Euthanasia and Assisted Suicide. Ottawa: 1995.
- 9 Rando, T. *Grief, dying and death. Clinical interventions for caregivers*. Champaign, Illinois: Research Press Company, 1984.
- 10 Ross, Margaret. "Palliative Care and Seniors". In *Proceedings of the Invitational Symposium on Palliative Care*. Ottawa: Health Canada, 1997.

Expression is published four times a year by the National Advisory Council on Aging, Ottawa, ON Canada K1A 0K9, tel.: (613) 957-1968 fax: (613) 957-9938 E-mail: seniors@hc-sc.gc.ca

The bulletin is also available on the Internet: <http://hc-sc.gc.ca/seniors-aines>

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ISSN: 0822-8213.

Volume 11
Number 3

