MYELOMA CANADA
MAKING MYELOMA MATTER

InfoSheet

DEMYSTIFYING PALLIATIVE AND SUPPORTIVE CARE

Palliative care is often associated with 'end-of-life'. While this was once the case according to more traditional concepts when curative treatment was coming to an end, palliative care is now often offered after the diagnosis of a serious illness.

Definition

According to the World Health Organization, "Palliative care is an approach that improves the quality of life of patients & their families facing the problems associated with life-threatening illness" - *published on 2 June 2018*. It is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

What is the difference between palliative care and hospice care?

Palliative care is recommended after a serious illness, such as a blood cancer, and should not be based on prognosis or time but rather should be based on what the person needs.

Hospice care is a type of palliative care that is usually provided in the last several months of life. Someone may receive both palliative care and hospice care at the same time or, may only require palliative care and not hospice care. In Canada, hospice care is often provided in a hospice facility. In other countries, hospice care is often provided in the home ('home hospice care'). Both palliative care and hospice care can help prepare people for the physical changes that may happen near the end of life.

Benefits of palliative care

There are benefits of integrating palliative and supportive care earlier in your journey with the disease.

Early delivery of palliative care reduces unnecessary hospital admissions and the use of health services. In multiple myeloma, palliative and supportive care will help optimize and maintain the best possible quality of life, better manage side effects (of the disease and treatments) while treating the whole person, supporting the family and providing an extra layer of support.

Supportive care will notably help meet the following multidimensional needs[1]:

- Physical (pain, fatigue, nausea, function)
- Emotional (anxiety, depression, coping)
- Social (family caregivers, relationships, financial issues)
- Spiritual (hope, meaning, dignity, faith & religion)
- Informational (prognosis/illness understanding, advance care plans)

[1] Hui et al. 2018. CA Cancer J Clin, 68:356–376.

Some research has even found that palliative care can help people live longer than if they didn't have palliative care. In their study on patients with advanced lung cancer, Temel et al (2010) found that the patients who received palliative care not only had better quality of life scores, but they also lived longer than patients who did not receive palliative care. Palliative care can help people live as well as they can for as long as they can.

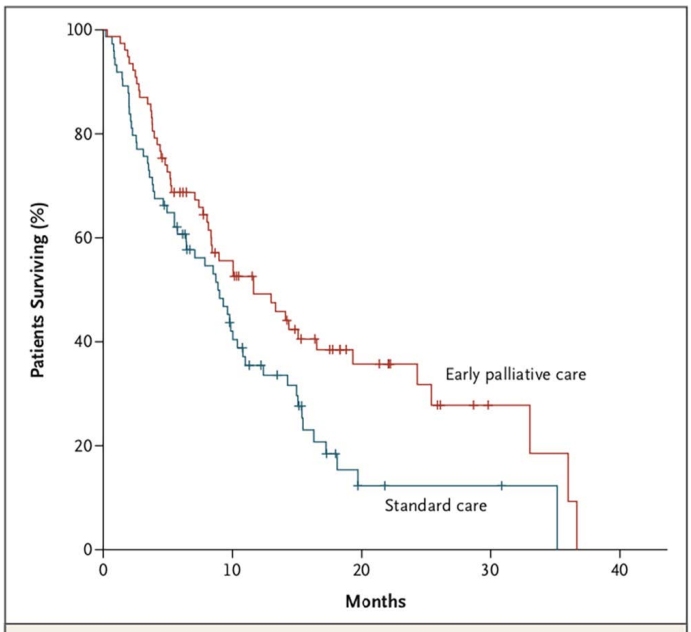
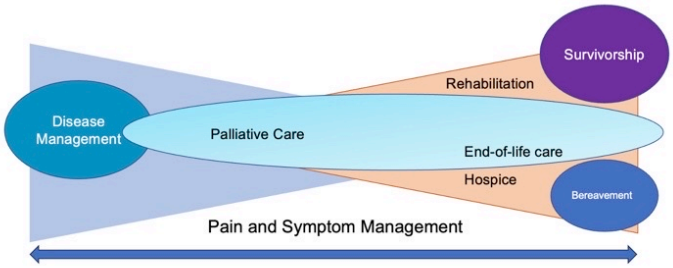


Figure 3. Kaplan–Meier Estimates of Survival According to Study Group.

Adapted from Temel et al., N Engl J Med 2010; 363:733-742.

When should palliative care be started?

Research has found that palliative care can be helpful if provided early in the course of a serious illness. This means that palliative care can be provided right from the time of diagnosis.



Adapted from: Hawley, P. (2015). The Bow Tie Model of 21st Century palliative care. *Canadian Virtual Hospice*.

Palliative care resources available for patients and caregivers

The American Society of Clinical Oncology (ASCO) recommends early integration of palliative care for patients with advanced cancer or those with high symptom burden.

Who provides palliative care?

Any member of your health care team can provide basic palliative care: your primary care provider as well as by your hematology/oncology team. Depending on your needs, your healthcare team might refer you to a specialist palliative care provider or team. In some centres, there are multidisciplinary palliative care teams that may include professionals such as doctors, nurses, social workers, psychologists, spiritual care providers, pharmacists, physiotherapists, occupational therapists, speech language pathologists, dieticians, and volunteers.

Where is palliative care provided?

Palliative care can be provided anywhere, including at home, but also other locations such as:

- Hospital and cancer centres
- Long-term care
- Supportive living facilities
- Palliative home care
- Hospice facilities
- Primary care clinics

Who is palliative care for?

Support is available to people with myeloma, their family members and their caregivers. Various care and services exist to help control pain and symptoms, as well as other of the multidimensional needs we have covered. Here is also a list of different free services that can be found in palliative care homes:

- Day centre
- Support for family and caregivers
- Symptom management clinic
- Home-based support
- End-of-life care
- Bereavement support
- Training
- Research support

Yes, palliative care services are for caregivers too! Research suggests that the earlier palliative care services are introduced to caregivers, the better they will be able to cope with the caregiving experience. They may be guided through the illness/treatments/medications process, educated on ways to manage care problems and helped with decision making, connected with counseling and respite care, and assisted with advance care planning or financial issues.

How does Medical Assistance in Dying (MAID) fit into palliative and end-of-life care?

In 2016, the Canadian government passed legislation to allow eligible Canadian adults to request MAiD. There are specific criteria that must be met before someone is approved for MAiD. The person requesting MAiD does not need to have a terminal condition but does have to be in a state of decline that is not expected to get better and must be experiencing unbearable suffering that cannot be relieved under conditions that the person considers acceptable.

Only medical practitioners are permitted to conduct assessments and to provide MAID. This can be a physician or a nurse practitioner, where provinces and territories allow. Policies and procedures may vary depending on where you live. For more information about MAiD, please visit: www.canada.ca/en/health-canada/services/medical-assistance-dying.

To learn more about palliative and supportive care, watch our InfoWebinar at: www.youtube.com/@myelomacanada.

More information on palliative care services is also available on the Canadian Virtual Hospice at: www.virtualhospice.ca.

Myeloma Canada publications are reviewed by healthcare professionals prior to publication. We thank Reanne Booker from the Tom Baker Cancer Centre and Karine Gingras from the Maison Victor-Gadbois palliative care home for their contribution. The information contained in this document is not intended to replace professional medical advice.

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