

Understanding the Role of Palliative Care:

What Social Workers and Social Service
Workers Need to Know

Objectives:

As the Canadian population ages, and the number of individuals living with chronic illnesses increases, all social workers and social service workers, regardless of their practice settings, will encounter clients facing situations involving life-limiting illness, dying, death, grief, and bereavement.

Presentation goals:

- Define palliative care in the Ontario context
- Review common myths about palliative care
- Discuss supporting family caregivers.
- Describe information needed to navigate the system of palliative care and
- Share practical tools including those for identifying caregiver risk factors.

Why has Palliative Care become such a topic of focus in health and social care?

Changes in our population

- More older adults (23-25% will be over 65 by 2036); ↑ those living 80+ years
- More individuals living with chronic illnesses
- More caregivers

Societal dialogue

- Impact of technology
- Death-denying culture / Medicalization of dying

Demand for better care

What Canadians want, and what happens....

Sometimes the statistics show a very different picture...

- Desire to die at home

- (at least 2/3 express this wish, however the majority of Canadians die in hospital)

- Goals of care:

- In one study 70 per cent of hospitalized elderly patients wanted comfort measures instead of life-prolonging treatment, but more than half were admitted to intensive care units

(Fowler, R., Hammer, M. 2013 End-of-Life Care in Canada. Clin Invest Med)

Some context:

By 2026, the number of Canadians dying each year will increase by 40 per cent to 330,000 people

Each death affects the well-being of five other people on average — families and loved ones — or more than 1.6 million people in all

(Quality End-of-life Coalition of Canada. Blueprint for action 2010 to 2020. 2010)

Palliative care has become the standard for high quality care at the end of life, yet there are also areas in Ontario where patients don't have access to that kind of care

- Best estimates are that only about 20-30 per cent of people who are dying have access to specialized team-based palliative care.

(Health Quality Ontario, End of Life Health Care in Ontario, 2014)

What is Palliative Care?

Palliative care is an **approach** that improves the **quality of life** of patients and their families facing the problems associated with **life-threatening illness**, through the **prevention and relief of suffering** by means of **early identification and impeccable assessment and treatment** of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- ▶ provides relief from pain and other distressing symptoms;
- ▶ affirms life and regards dying as a normal process;
- ▶ intends neither to hasten or postpone death;
- ▶ integrates the psychological and spiritual aspects of patient care;
- ▶ offers a support system to help patients live as actively as possible until death;
- ▶ offers a support system to help the family cope during the patients illness and in their own bereavement;

WHO, 2008

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- ▶ uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
 - ▶ will enhance quality of life, and may also positively influence the course of illness;
 - ▶ 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.

WHO, 2008

Hospice Palliative Care and its origin in Canada

- Dame Cicely Sanders (UK) St. Christopher's Hospice
- Dr. Balfour Mount (Royal Victoria Hospital in Montreal) coined the term 'palliative care'
- Hospice Palliative Care

Today:

- An approach or philosophy of care
- A service
- A special location (ie. Residential hospice, palliative care unit)
- A specialization

Where does Canada rank?

The Economist's Intelligence Unit

Sponsored by Singapore-based The Lien Foundation

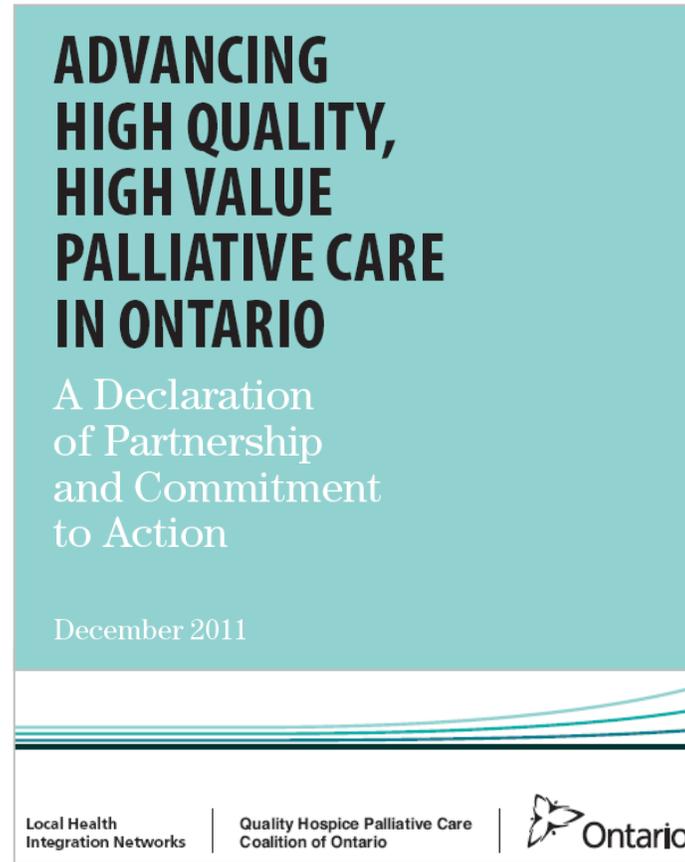
The 'Quality of Death' index measures current hospice and palliative care environments across 80 countries in terms of the quality and availability of end-of-life care.

2010 – 9th

2015 – 11th

(1st UK, 2nd Australia, 3rd New Zealand.... 9th US)

Towards an Integrated System of Palliative Care in Ontario: 'Declaration of Partnership'



What is Palliative care , and what is it NOT...

Let's consider some of the myths and misconceptions about palliative care.

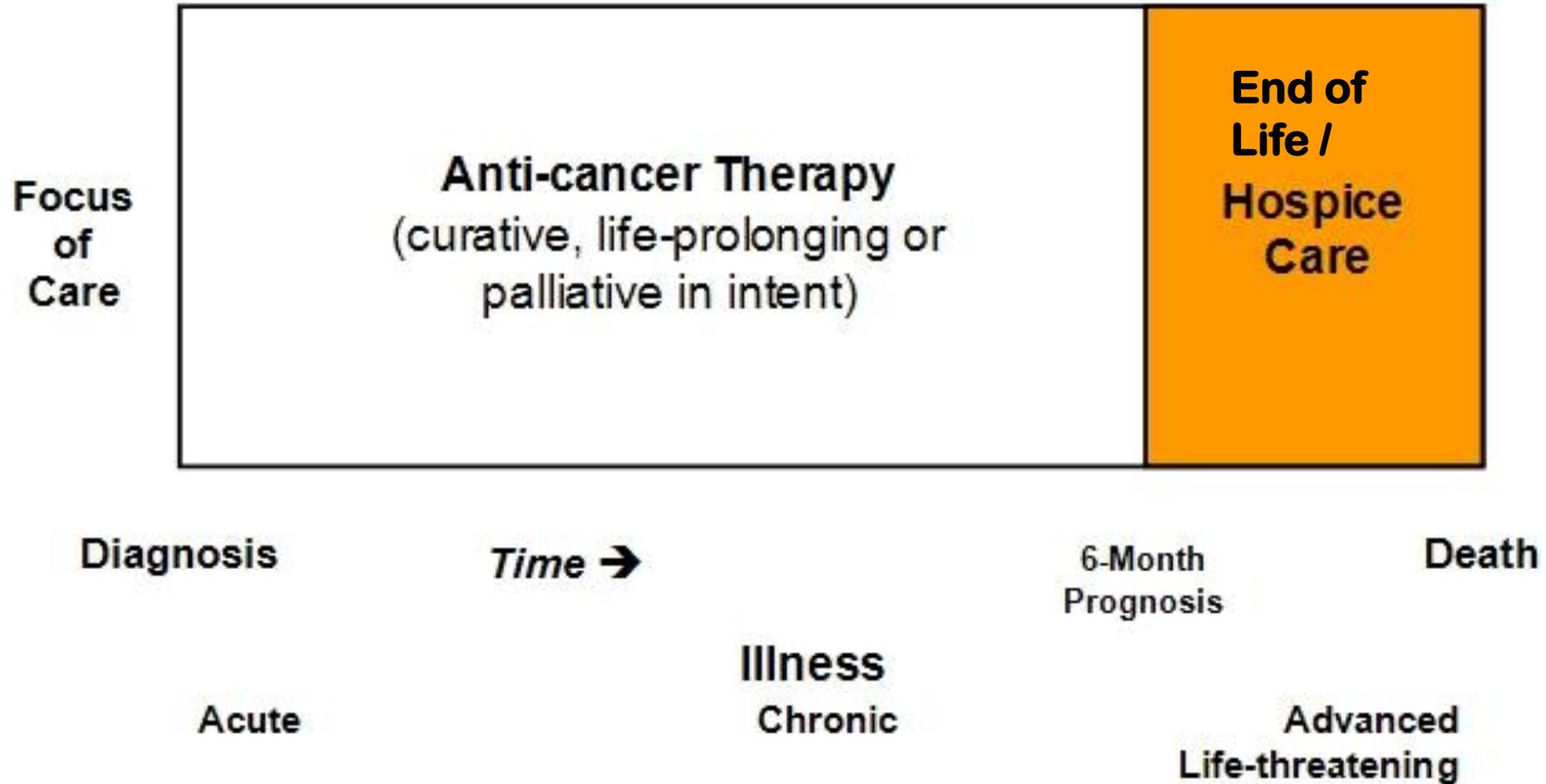
Myth 1

Palliative Care = End of Life Care

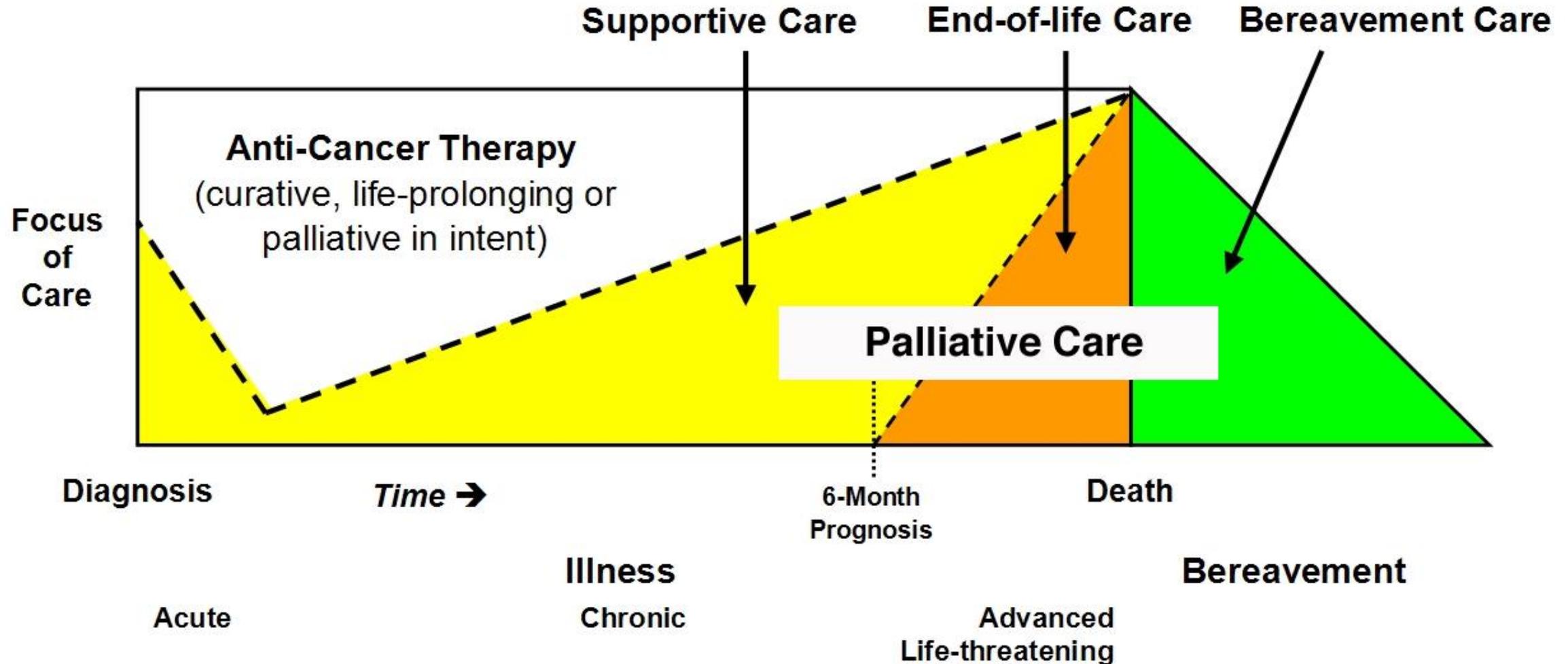
“There is common misconception that if someone is receiving palliative care, it means that treatments to slow the progress of their disease would be stopped. Research has shown the opposite to be true: earlier palliative care can lead to better quality of life throughout the entire process from the time of being diagnosed with a life-threatening illness.”

Health Quality Ontario (2016), pg. 7

OLD MODEL OF CARE



Palliative care



Myth 2

Palliative Care is only for those persons with advanced cancer.

Myth 3

Palliative care can only happen in hospitals

Palliative care can happen in the client's desired location of death

- at home
- in long term care facilities
- in residential hospices
- in other settings designed for specific needs

However, most deaths occur in hospital

“...the majority of people in Ontario have said that they would prefer to die at home rather than in the hospital. However, once someone becomes very ill, the reality of a home death may not be easy to achieve. “

Health Quality Ontario (2016), pg. 7

What are some of the barriers?

- Caregiving demands and skills needed
- Lack of services in the home
- Health care provider accessibility and expertise
- Costs

Guerriere et al (2010). Cost variations in ambulatory and home-based palliative care. Palliative Medicine.

True costs of home death: \$25, 000 per month – factoring in lost income and leisure time, health system costs, third party insurer, out of pocket expenses)

Myth 4

Persons receiving palliative care die more quickly.

Temel et al 2010 –

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

New England Journal of Medicine

Doctors have found that patients with terminal lung cancer who began receiving palliative care immediately upon diagnosis were not only **happier, more mobile and in less pain as the end neared – but they also lived nearly three months longer.**

Subsequent studies are finding similar results.

Myth 5

Palliative care is only provided by specialist teams

There has been a shift in thinking about this statement.

Why?

The demand will far exceed the availability of palliative care specialists.

Now we are talking much more about the skills ALL health care professionals should have, and which types patients will need Specialist Palliative Care and special inpatient/residential settings.

So what does all of this mean for social workers and social service workers?

Have you have worked with a client in the last year that was either living with a chronic /serious illness, or caregiving for someone with a chronic /serious illness?

Was there a death in this circumstance?

We bring a unique lens to :

- Addressing the needs of caregivers and others in the family system
- Providing psychosocial and mental health aspects of care
- Championing advance care planning

Caregiving has a profound effect on
caregivers

Caregiver Strain

- Some of the factors that affect the degree of “caregiver strain” that may be experienced:
 - The number of hours spent caregiving.
 - How prepared the caregiver is for caregiving.
 - The types of care being given.
 - How much the patient is able to do without help (ie. meal preparation, meal set up, bathing and dressing).

Caregiver burden = multiple dimensions of distress that result from an *imbalance* between care demands and the availability of resources to meet those demands.

Most studied aspect of QOL for Caregivers is psychological distress

Some studies report levels of depressive symptoms in caregivers that are similar to, or even higher than, those in patients with cancer

Kim Y, Duberstein PR, Sörensen S, et al. (2005). Levels of depressive symptoms in spouses of people with lung cancer: effects of personality, social support, and caregiving burden. *Psychosomatics* 46 (2): 123-30.

Many factors affect caregiving experience/ability that need consideration

Norms and values about caregiving; degree of choice in being a caregiver

Financial situation of the family; caregiver's own employment status

Age of caregiver; other caregiving demands (ie. own children)

Health of the caregiver

Degree of symptoms experienced by the patient

Degree of social supports

Degree of services available

Positive Impact of Caregiving

Caregivers often speak about:

Discovery of personal strength through adversity

Improved sense of self-worth

Deepening of the relationship with the ill family member or other family members

A sense of personal growth

How do we think about
supporting caregivers?

Palliative Care Approach in Working with Caregivers

- ▶ According to a report produced by the Canadian Home Care Association for *The Way Forward: An Integrated Palliative Approach to Care*, caregivers of individuals with life-limiting illnesses providing care in the home identified two essential needs:
 - Knowledge about the details, extent and prognosis of their loved one's illness, including tools in preparing and planning for the future.
 - Services and supports available to both the caregiver and their loved one.

Key Approaches:

- Early recognition of caregiver distress
- Validation of the caregiver role
- Effective communication by health care professionals

Fleming, DA. 2003 The burden of caregiving at the end-of-life. Mo Med.;100(1):82-6.

Suggested Questions for Assessing Caregivers

Screening question	Area of concern
Do you feel that you are currently under a lot of stress?	Mental health
What aspects of your day are the most stressful?	Mental health
Have you been feeling down or blue lately?	Mental health
Have you been feeling more anxious and irritable lately?	Mental health
Do your family and friends visit often?	Social support
Do they telephone often?	Social support
Do your friends and family watch your relative for you so that you have time for yourself?	Social support
Do you have any outside help?	Resources
Is your relative having any behaviors, such as wandering, that are difficult to manage?	Behavioral mgmt
What do you do to relieve your stress and tension?	Coping

Preparation of Family Caregivers

Common complaints/concerns expressed by caregivers:

- Lack of understand of what to expect
- Who to call for what
- Preparation for what they need to do

Interventions that can make a
difference

Types of support preferred

What Support Do Caregivers of Elderly Want? Results from the
Canadian Study of Health and Aging

Angela Colantonio, Adam J. Kositsky, Carole Cohen, Lee Vernich, CANADIAN JOURNAL OF PUBLIC HEALTH, 2001

- Receiving telephone support from either a professional (44.9%) or a fellow caregiver (41.0%),
- Receiving a newsletter (40.5%),
- Receiving volunteer support (24.2%), and
- Support via computer (14.8%)
- Attending support groups (10.4%)

Benefits of immediate versus delayed palliative care to informal family caregivers of persons with advanced cancer: Outcomes from the ENABLE III randomized clinical trial.

J Nicholas Dionne-Odom, Andres Azuero, Kathleen Lyons, Zhongze Li, Tor Tosteson, Zhigang Li, Jay Hull, Jennifer Frost, Mark Hegel, Konstantin H. Dragnev, Imatullah Akyar, Marie Bakitas
American Society of Clinical Oncologist (ASCO) annual meeting in Chicago on June 3, 2014.

ENABLE (Educate, Nurture, Advise, Before Life Ends)

The care consisted of 1 in-person meeting and monthly phone-based supportive care. The intervention, called Charting Your Course, was developed specifically for the study and covered self-care, building a support network, decision making, and advanced planning

Findings:

- ▶ The earlier palliative care services are introduced to caregivers, the better they will be able to cope with the caregiving experience. Researchers found that overall quality of life, depression, and feelings of being overwhelmed by the demands of caregiving all improved in the group that started the program immediately compared with those who started later.

Tools and Resources for Caregivers to Help the Be Prepared

A Caregiver's Guide: A Handbook about End-of-Life Care.

Canadian Hospice Palliative Care Association.

Canadian Virtual Hospice

www.virtualhospice.ca

Caregiving videos

Advance Care Planning

Advance care planning (ACP) is a process of thinking about and sharing one's wishes for future health and personal care. This process helps others understand what would be important if you were unable to communicate.

-Effective, ongoing communication among the patient, family and health care team is

essential to effective ACP.

- Successful ACP often begins well in advance of serious illness.

Resources for learning more:

Canadian Virtual Hospice

www.virtualhospice.ca

Speaking Up – Advance Care Planning

www.advancecareplanning.ca

Living My Culture

www.livingmyculture.ca

Learn about cultural practices around serious illness, end of life, grief and bereavement

MyGrief.ca

Confidential online forum; Resources for health care professionals also

Reports about Palliative Care

Canadian Hospice Palliative Care Association

www.chpca.ca

Health Quality Ontario.

www.hqontario.ca

End-of-Life Health Care in Ontario. 2014

The Reality of Caring: Distress among the caregivers of home care patients. 2016

Palliative Care at the End of Life. Toronto: Queen's Printer for Ontario. 2016