

# Family Caregiver Resilience and the Important Role of Palliative Care

**Susan Blacker, MSW, RSW**

Director, Cancer Services Planning & Performance, St. Michael's Hospital

Adjunct, Factor-Inwentash Faculty of Social Work and

Lecturer (status only) and Quality co-Lead, Division of Palliative Care, Dept. Family & Community Medicine;  
University of Toronto

# Caregiving...

## A Universal Experience

*“One of my colleagues once said:  
There are only four kinds of people in this  
world:  
those who have been caregivers;  
those who currently are caregivers;  
those who will be caregivers and  
those who will need caregivers.”*

- ▶ Former U.S. First Lady Rosalynn Carter  
during Honorary Chair Speech, Last Acts 1997

# Caregiving

▶ the informal (ie. unpaid) care provided by family members that goes beyond customary and normative social support provided in social relationships.

(Hauser and Kramer, 2004)

# The Context of Caregiving in Canada Today

- Aging population
- More people living longer with 1 or more chronic conditions
- Families smaller, more geographically separated

# Family Caregivers

Canadian Caregiving Coalition has reported that:

- There are 8 million family caregivers in Canada.
- Conditions requiring care
  - 28 % - individuals with age-related conditions
  - 11% - cancer
  - 9% - cardio-vascular disease
  - 7% - mental illness
- For the vast majority (89%) of caregivers the duration of care is one or more years
- On average, they provide between 16 – 28 hours of care per month

# Family Caregiving in Canada

- provide over 80 percent of the care needed by individuals with 'longterm conditions'

Fast, J., Niehaus, L., Eales, J., & Keating, N. (2002). A profile of Canadian chronic care providers. A report submitted to Human Resources and Development Canada. Edmonton: Department of Human Ecology, University of Alberta

- 2009 study estimated the economic cost to replace family caregivers with the paid workforce (at current market rates and usual employee benefits) totalled \$25 billion

Hollander, J. M., Liu, G., & Chappell, N. (2009). Who cares and how much. *Healthcare Quarterly*, 12(2), 42-49.

- Caregiving responsibilities at end of life generally intensify

# What do caregivers do?

“Family caregivers in particular play significant roles in the care of elders with advanced chronic disease and in the context of palliative and end-of-life care. These caregivers typically are involved in **critical medical decisions, provide vital assistance with activities of daily living, and carry out most nonpharmacologic and pharmacologic treatment recommendations for community-based elders.**” (p. 671)

Hauser, J. and Kramer, B. Family caregivers in palliative care. (2004), Clin Geriatr Med.;20(4):671-88

## Caregiver Role includes:

- Seeking information
- Managing insurance claims
- Paying bills
- Renewing prescription medication; administering medications
- Exercising increased vigilance over the patient
- Reporting new symptoms or side effects
- Requesting symptom relief
- Incorporating lifestyle changes
- Encouraging treatment compliance
- Promoting healthy behaviours by the patient

<http://www.cancer.gov/cancertopics/pdq/supportivecare/caregivers/healthprofessional/page4>

And in palliative care....

- Making decisions as a substitute decision maker.

- Over one-quarter of caregivers 2.2 million Canadians could be considered “sandwiched” between caregiving and raising children.
- Most are women between the ages 35 and 44, and helping their parents or parents-in law, while also having at least one child under 18 living at home.

Caregivers in Canada, 2012 Statistics Canada

- Based on a study in Ontario, palliative care clients were cared for primarily by their spouses or partners (57%) or their children or children-in-law (29%).

The Change Foundation, 2011, Because this is the rainy day: a discussion paper on home care and informal caregiving for seniors with chronic health conditions, [www.changefoundation.ca/news.html#informalseniorcare](http://www.changefoundation.ca/news.html#informalseniorcare).

- Caregiving has a profound effect on caregivers

- ▶ In 2007, 23% of Canadians said that they had cared for a family member or close friend with a serious health problem in the last 12 months. Adverse effects on this group of people included: using personal savings to survive (41%) and missing one or more month of work (22%).<sup>1</sup>
- ▶ In 2006, of the 26% of Canadians who said that they had cared for a family member or close friend with a serious health problem in the previous 12 months, adverse effects reported were: negative effect on mental health (41%) and negative effect on physical health (38%).<sup>2</sup>

Excerpt from CHPCA Fact Sheet: The Role of Family and Informal Caregiver

Original references

<sup>1</sup> 10th Annual Health Care in Canada Survey: A national survey of health care providers, managers, and the public, 2007, <http://www.hcic-sssc.ca>

<sup>2</sup> Health Care in Canada Survey 2006: A national survey of health care providers, managers, and the public, 2006, <http://www.hcicsssc.ca>

# 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).

# Many factors affect caregiving experience/ability

- 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

- 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.

# Is Caregiving all bad?

- We also need to consider the flip side of this coin.....as caregiving not always perceived as strain.
- Two hundred and eighty-nine caregivers caring for seniors living in the community were questioned about their experience of caregiving. 73% could identify at least one specific positive aspect of caregiving.

Cohen, C. A., Colantonio, A. and Vernich, L. (2002), Positive aspects of caregiving: rounding out the caregiver experience. *Int. J. Geriatr. Psychiatry*, 17: 184–188. doi: 10.1002/gps.561

# 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?

**“The way individuals who are dying are cared for and their family caregivers are recognized, respected, and valued for the support they provide is a measure of the compassion of a society.”**

Health Council of Canada, 2010 – as quoted in *The Way Forward* report

# re-sil-ience

## Noun

- ▶ 1. the power or ability to return to the original form, position, etc., after being bent, compressed, or stretched; elasticity.
- ▶ 2. ability to recover readily from illness, depression, adversity, or the like; buoyancy.

Source: [dictionary.reference.com/browse/resilience](http://dictionary.reference.com/browse/resilience)

# Caregiver Resilience – as we think about it in social work

- ▶ ability to adapt or to improve one's own conditions following experiences of adversity
- ▶ involves behaviours, thoughts and actions that can be learned and developed
- ▶ adjust to a “new normal”

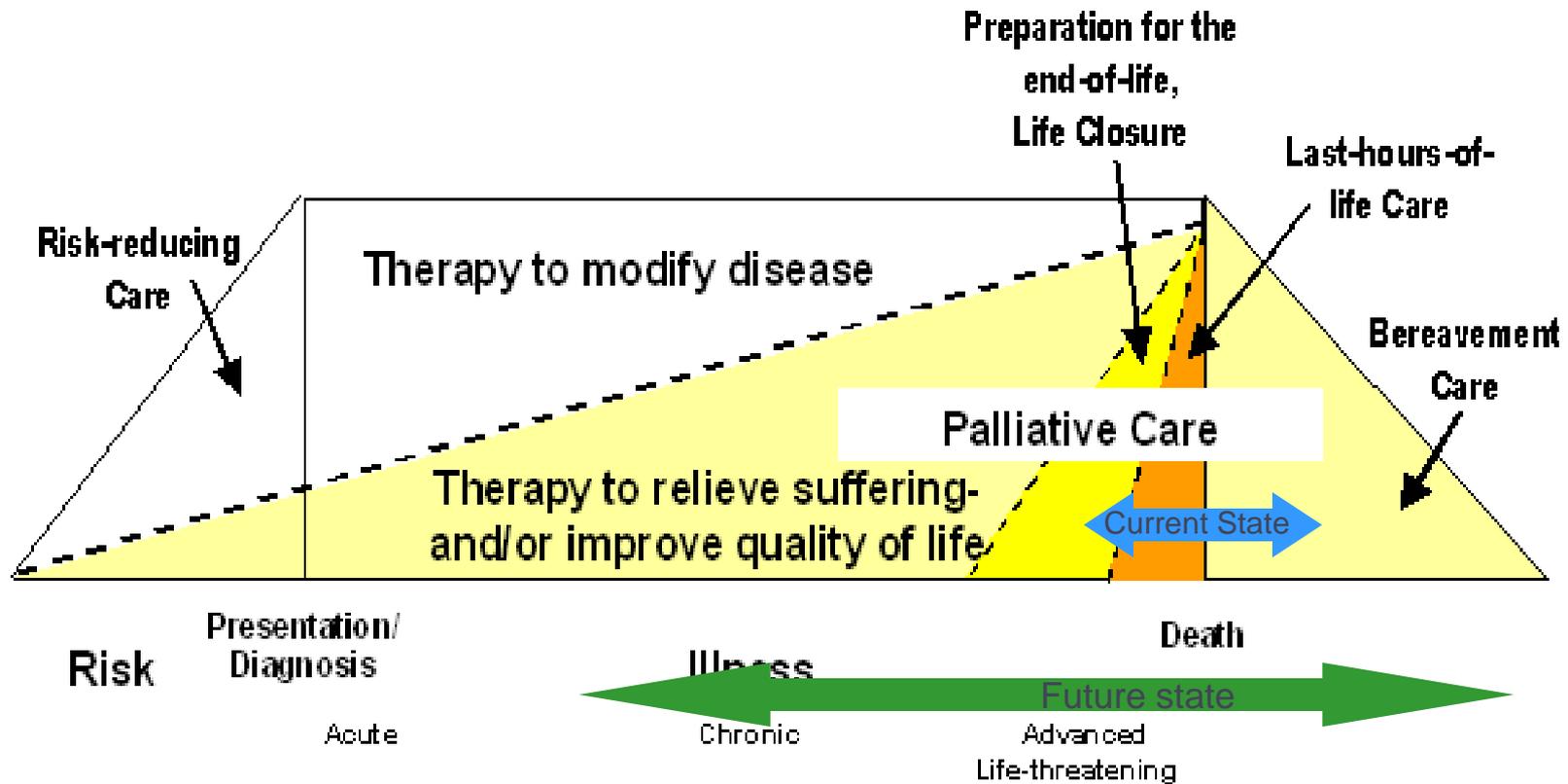
## Definition of Palliative care

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.

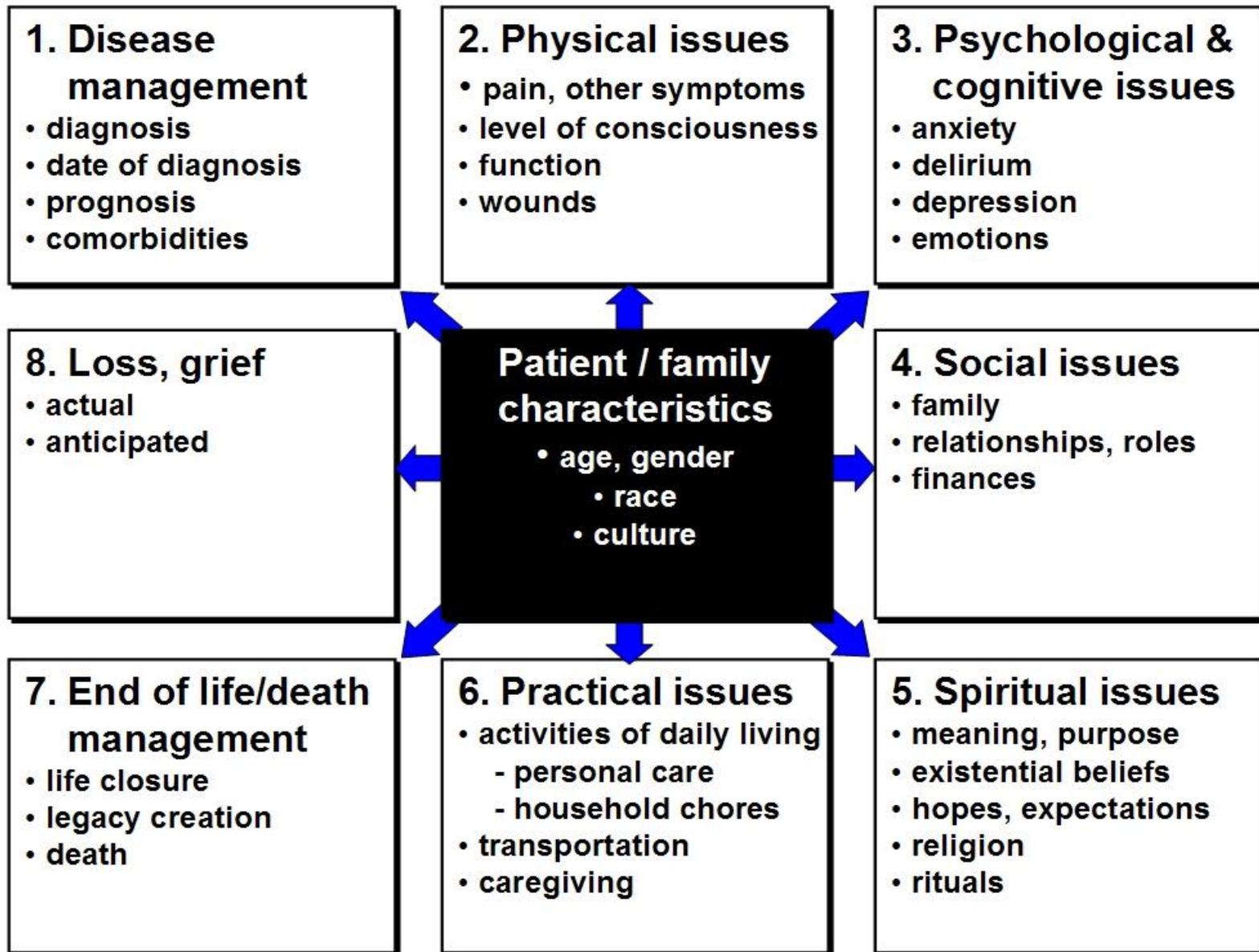
## Palliative care:

- ▶ 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;
- ▶ 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.

# Integrating Palliative Approach to Care



Adapted from Canadian Hospice Palliative Care Association (CHPCA) Model to Guide Hospice Palliative Care (2002)



## EXAMPLE:

# How can palliative care help persons and their caregivers living with dementia?

- ▶ Quality of life is a big concern
  - ▶ Decreased independence over time
  - ▶ Physical changes, such as decreased ability to eat
  - ▶ Focus on person-centered approach
  
- ▶ Care for families is very important,
  - ▶ dealing with grief or caregiver burden,
  - ▶ support of their roles as substitute decision makers in more advanced dementia
  
- ▶ Palliative care approach can be very important for these people and families by helping to decide:
  - ▶ how to help the person have the best quality of life possible
  - ▶ what treatments to try, if any
  - ▶ what care options would be best for the person
  - ▶ how to start with Advance Care Planning (e.g., medical and money decisions when the person can't make these decisions anymore)

# 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 we can use with all Caregivers:

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

## • Instruments for Evaluating Caregiver Burden

- **Brief Assessment Scale for Caregivers (BASC) of the Medically Ill**
  - 14-item rating scale measuring burden and quality of life, plus 8-item subscale measuring negative personal impact
  
- **Caregiver Quality of Life Index—Cancer (CQOLC) Scale**
  - 35-item rating scale measuring physical, emotional, family, and social functioning burden
  
- **Caregiver Reaction Assessment (CRA)**
  - 24-item rating scale measuring burden in self-esteem, lack of family support, finances, schedule, and health
  
- **Caregiver Strain Index (CSI)**
  - 13-item rating scale measuring employment, financial, physical, social, and time constraint burden
  
- **Zarit Burden Interview (ZBI)**
  - 22-item rating scale measuring burden in health, psychological well-being, finances, social life, and relationship with patient

# 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
  - Needing to know who to call for what
  - Needing better preparation for what they need to do



Interventions that can make a  
difference...

## Caregiving near the end of life: unmet needs and potential solutions

Mangan PA, Taylor KL, Yabroff KR, Fleming DA, Ingham JM. (2003). Palliat Support Care;1(3):247-59.

### Qualitative study that looked at:

- (1) General problems and
- (2) Behaviors/activities that were helpful/would have been helpful in alleviating these problems.
  
- Subcategories emerged:
  - medical care (including provision of information, coordination of care, bedside manner, satisfaction with care),
  - quality of life (including well-being, role adjustments),
  - help from others (including practical assistance, social support),
  - positives of caregiving, and
  - unsolicited themes (including job flexibility, impact of the disease on the family, informational needs, relationship with patient).

# Tools and Resources for Caregivers to Help them Be Prepared

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

Canadian Hospice Palliative Care Association.

Canadian Virtual Hospice

[www.virtualhospice.ca](http://www.virtualhospice.ca)

Caregiving videos

# Compassionate Care Benefit (EI)

In January 2004, Human Resources and Skills Development Canada began to offer the Compassionate Care Benefit through the Employment Insurance program. The benefit provides leave to eligible Canadians to care for a dying loved one.

Effective January 3, 2016:

- ▶ the enhanced benefit, allows claimants to collect up to 26 weeks of benefits, up from the previous 6 weeks.
- ▶ Benefits can be shared between family members.
- ▶ Eligibility for compassionate care benefits remains the same, including the requirement for a medical certificate signed by a doctor attesting to the family member's condition (significant risk of death within 26 weeks)

Learn more:

[http://www.esdc.gc.ca/en/reports/ei/compassionate\\_care.page#h2.1](http://www.esdc.gc.ca/en/reports/ei/compassionate_care.page#h2.1)

# 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  
Abstract/Presentation at American Society of Clinical Oncologists (ASCO) annual meeting , 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.

# Interventions for Carers

as discussed in Stajduhar, K. (2013) Burdens of Family Caregiving at the End of Life. Clin Invest Med ., 36( 3).

## Promising interventions:

- night respite service aimed at reducing family caregiver fatigue and sleep promotion;
- three-session group psycho-educational program that increases perceived family caregiver competence and preparedness to care; and,
- program designed to increase a family caregivers' sense of hope

Kristjanson LJ, Cousins K, White K, et al. Evaluation of a night respite community palliative care service. *Int J Palliat Nurs.* 2004;10(2):84-90.

Hudson P, Thomas T, Quinn K, et al. Teaching family carers about home-based palliative care: final results from a group education program. *J Pain Symptom Manage.* 2009;38(2):299-308.

Duggleby W, Wright K, Williams A, et al. Developing a living with hope program for caregivers of family members with advanced cancer. *J Palliat Care.* 2007;23(1):24-31

# Grief and Bereavement

- Pro-active identification of risk factors for complicated mourning/grief
- Ensuring links to the right type of service/support as needed
- Flexible models

# Looking forward

- More studies are needed to demonstrate what the most effective interventions are for family caregivers
- Social work needs to bring this emerging evidence base to practice
- Social workers are the key advocates in the system that are able to ensure caregiver needs are well addressed



Caregivers need our expertise...

How can you make a difference to the caregivers in your practice?