

Caregivers' experiences of palliative care in Canada



Thank you for joining the
National Carers Day 2019
webinar.

WELCOME!

#nationalcarersday



Jeanne Bank

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Project Lead with the Canadian Home Care Association (CHCA).



Christopher Klinger

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Chair of the End-of-Life Issues Theme Team for the National Initiative for the Care of the Elderly (NICE) and Quality End-of-Life Care Coalition of Canada's (QELCCC).



Jeanne Bank

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Project Lead with the Canadian Home Care Association (CHCA).

Jeanne is currently the project specialist for ***Building Operational Excellence for Home-Based Palliative Care***, and will share the learnings from the project and compelling, direct feedback from caregivers about their experiences of palliative care.



Christopher Klinger

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Chair of the End-of-Life Issues Theme Team for the National Initiative for the Care of the Elderly (NICE) and Quality End-of-Life Care Coalition of Canada's (QELCCC).

Christopher will discuss how the informational brochure '***When Someone Close to You is Dying***', helps caregivers support their loved ones through the final years, weeks and days of the lives, arming them with advice which benefits the wellbeing of patients and caregivers.



Caregivers' experiences of palliative care in Canada



Jeanne Bank, Project Specialist,
Canadian Home Care Association

April 2, 2019

What I will be speaking about today

Background on the CHCA Project:
“Building Operational Excellence in Home-Based Palliative Care”

Findings from our conversations with caregivers &
stakeholders about gaps & opportunities

Next steps for project



Project Overview

Purpose:

To explore opportunities for operational process improvement in home-based palliative care, specifically in:

1. assessment and care planning
2. inclusion of advanced care plans and service delivery
3. effective communication strategies and tactics
4. management of equipment, supplies and medications





Project Background

- Builds on the “*The Way Forward: An Integrated Palliative Approach to Care*”
- Pan Canadian multi-phased engagement process to learn about palliative care experiences (summer 2018) :
 - One- on- one interviews with caregivers and patients
 - Key informant interviews
 - Interviews with cultural group representatives
 - 4 regional stakeholder workshops (Vancouver, Edmonton, Charlottetown and Ottawa)
 - Online survey of caregivers and patients
 - 2 round E Delphi process to identify priority areas for improvement





Overall Experience of Caregivers

- Over 60% were satisfied with how their loved one's ACP wishes were respected and acted upon by providers and wishes were reflected in the care plan
- 72% of caregivers told us that the results of assessments were shared with them and 67% of them provided input into the development of the care plan
- Communication is largely a hit and miss situation for patients & caregivers
- 63% were satisfied with access to supplies & medications. Top areas for improvement: getting & managing the medications
- Issues with planning, care delivery and managing supplies and equipment depends a lot of where you live



Advance Care Planning

What we heard



"The plan was developed very well. The problem is in the implementation of the plan. Companies providing the care do not follow the care plan."



"More education and understanding of wish planning is needed."



"We knew what we wanted, but we didn't know how to make everyone else know. I just didn't know what could be done. I'd never done anything at all like this before."



Advance Care Planning

Key Gaps and opportunities



- Hold early and ongoing conversations about end of life wishes and values
- Understand and consistently communicate end of life wishes
- Ensure care plans, documentation and other legal requirements reflect wishes and values
- Gaps between rural and urban



Assessment and Care Delivery

What we heard



"It was only by trial and error that I discovered what services were available - they were not explained or introduced to me by anyone"



"At night is when I needed the most help. Dementia doesn't sleep and neither did I."



"Include the patient in conversations. My dad felt we were talking about him when discussions happened without him. The many meetings and telephone calls to coordinate care and deliveries, took time away from essential care giving"



Assessment and Care Delivery

Key Gaps and opportunities



- Use a palliative approach to care in identifying and responding to patient needs
- Involve patients and caregivers and providers in developing and updating care plans
- Understand and use assessment tools early in the process
- Rural and remote communities access



Communications

What we heard

““It’s important to maintain cultural humility. Don’t presume to understand everything about that patient, everything they want and need”



“We needed to be the middleman in all of it because it wasn’t a team-based approach”



“Written information is critical. I was so overwhelmed at the beginning. The information overload was incredible. I needed more information that was written out so that I could go back later and go over it and digest it when I could.”



Communications

Key Gaps and opportunities



- Recognize and communicate with all members of palliative care team members
- Consistently communicate changes in the patient's condition and needs
- Communicate with patients, family and caregivers in a manner that is appropriate, timely and practical



Management of Equipment, Supplies & Medications

What we heard



"There was an overabundance of supplies. The deliveries were constant. Every time the door was opened it was another delivery. It was so wasteful. And none of it went back."

"After my husband's death, no one seemed the least bit interested in the fact that I still had some very dangerous prescription medications in my home."



"My experience was good however more sensitivity to my non-health professional status would have helped. An example "increase the dose if she is uncomfortable". How do I know, how much etc."



Management of Equipment, Supplies & Medications

Key Gaps and opportunities



- Ensure medications and supplies and equipment are available without duplication and delay
- Organize and manage use of supplies and medications
- Ensure removal of supplies, equipment and medications from the home



Next steps

- Palliative Care Experience Maps developed to share the stories and show opportunities for innovation
- 5 projects have been identified to showcase as High Impact Practices (HIPs) These are currently under development and will be published by summer
- Opportunities to collaborate and assist organizations to understand and implement innovative practices
- Development of Implementation Framework and User Guide to help organizations put HIPs into practice





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For more information:

Dedicated webpage on CHCA website

www.homecarekn.ca/operational-innovations

Jeanne Bank, Project Specialist

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Building Operational Excellence
Home-Based Palliative Care



Canadian Home Care
Association
canadienne de soins
et services à domicile



APRIL 2, 2019

NATIONAL CARERS DAY
RECOGNIZING CARING CANADIANS

#nationalcarersday

Caregivers' experiences of palliative care in Canada



Caregivers' Experiences of Palliative Care in Canada: *'When Someone Close to You Is Dying'*



National Carers Day Webinar
April 02, 2019



NICE

We care together

Ensemble pour le bien-être des aînés

National Initiative for the Care of the Elderly

Initiative nationale pour le soin des personnes âgées

Contact: christopher.klinger@utoronto.ca

Overview/Objectives

- ▶ To introduce the National Initiative for the Care of the Elderly (NICE) as a knowledge translation network
- ▶ To highlight '*What To Expect When Someone Close to You Is Dying*' as an evidence-based, informational caregiver tool
- ▶ To discuss end-of-life needs, advance care planning, pain control and self care
- ▶ To present results from an initial evaluation of the tool
- ▶ To provide an opportunity for questions and discussion

Thank you to the Canadian Home Care Association (CHCA) for this opportunity - and to all of you for attending!



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National Initiative for the Care of the Elderly

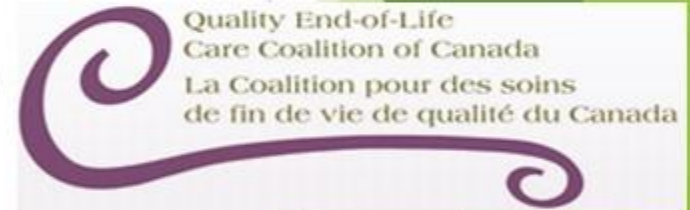
Initiative nationale pour le soin des personnes âgées

Conflict of Interest Declaration



Christopher A. Klinger, PhD

- ▶ Chair, End-of-Life Issues Theme Team, National Initiative for the Care of the Elderly (NICE)
- ▶ Chair, Research and Knowledge Translation Committee, Quality End-of-Life Care Coalition of Canada (QELCCC)
- ▶ Passionate hospice palliative care (HPC) champion



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National Initiative for the Care of the Elderly
Initiative nationale pour le soin des personnes âgées

National Initiative for the Care of the Elderly (NICE)

- ▶ International network of researchers, practitioners, students and seniors dedicated to improving the care of older adults, both in Canada and abroad
- ▶ NICE was founded in 2005 under a grant from the Networks of Centres of Excellence - New Initiative Program (Tri-Council Agencies)
- ▶ The overarching emphases of NICE are networking, education and knowledge transfer - that is, getting good research into practice
- ▶ NICE has three main goals:
 - ▶ Help close the gap between evidence-based research and actual practice
 - ▶ Improve the training of existing practitioners, geriatric education curricula, and interest new students in specializing in geriatric care
 - ▶ Effect positive policy changes for the care of older adults (including in the HPC domain)



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Evidence-Based Tools/ Annual NICE Knowledge Exchange (ANKE)

► Theme Teams ('Divisions'):

Caregiving

Dementia Care

Dental Care

Elder Abuse

End of Life Issues

Age-Friendly

Technology and Aging

Ethnicity and Aging

Financial Literacy

Law and Aging

Mental Health

<http://www.nicenet.ca>



Annual NICE
Knowledge Exchange

S/AGE: Social Dimensions of Ageing

University of Toronto

May 30th ■ Hart House



The Gerontological Imagination

A Special Keynote by
Dr. Kenneth Ferraro

NICE



National Initiative for the Care of the Elderly
Initiative nationale pour le soin des personnes âgées

Research and Knowledge Translation



In collaboration with



THE INVISIBLE EPIDEMIC: A SPOTLIGHT ON THE OPIOID CRISIS AMONG SENIORS

A Scoping Review of the Literature

Prepared for the Canadian Institutes of Health Research

August 2018



Principal Investigator:

P. Lynn McDonald, PhD

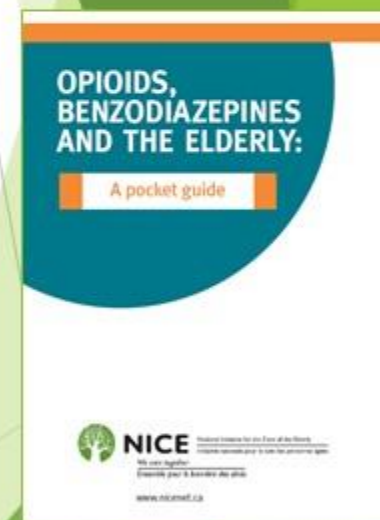
Principal Knowledge User:

Adriana Shnall, PhD



Online Module - Meet the Teaching Team!

- Key themes were divided by stakeholder – each represented with an avatar below
- Different perspectives improve (1) Knowledge Utilization and (2) Understanding of Professional and User roles



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'When Someone Close to You Is Dying'

WHEN SOMEONE CLOSE TO YOU IS DYING

WHAT YOU CAN EXPECT AND HOW YOU CAN HELP



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Government of Canada
Networks of Centres
of Excellence

Gouvernement du Canada
Réseaux de centres
d'excellence

What You Can Expect And How You Can Help

Helping someone through the last years of their life is one of the most difficult journeys anyone can take. As the illness progresses, you may have to make important decisions on behalf of someone close to you. You may be responsible for ensuring that their most basic needs for respect, dignity and physical comfort are sustained until the end of life.

*Things A Person
Nearing End of Life
May Need from You 2*

*What Happens During
the Final Moments? 4*

*Pain Control
and Opiate Use 10*

*Advance Care Planning
& Substitute Health
Care Decision-Making 12*

*Other Things You
Can Do To Help 16*

Things A Person Might Need from You

When Someone Close To You Is Dying

*Things A Person
Nearing End of Life
May Need from You*



Some emotions are common to those who are dying. These include fear of abandonment and fear of being a burden. They may have concerns about loss of dignity and loss of control.

Some ways you can provide comfort are as follows:

- Keep company—talk, watch movies, read, or just be with the person.
- Allow them to express fears and concerns about dying, such as leaving family and friends behind. Be prepared to listen.
- Be willing to reminisce about their life.
- Avoid withholding difficult information. They may prefer to be included in these discussions.
- Reassure them that you will honour their advance care planning and health care choices.
- Ask if there is anything you can do.
- Respect their need for privacy.

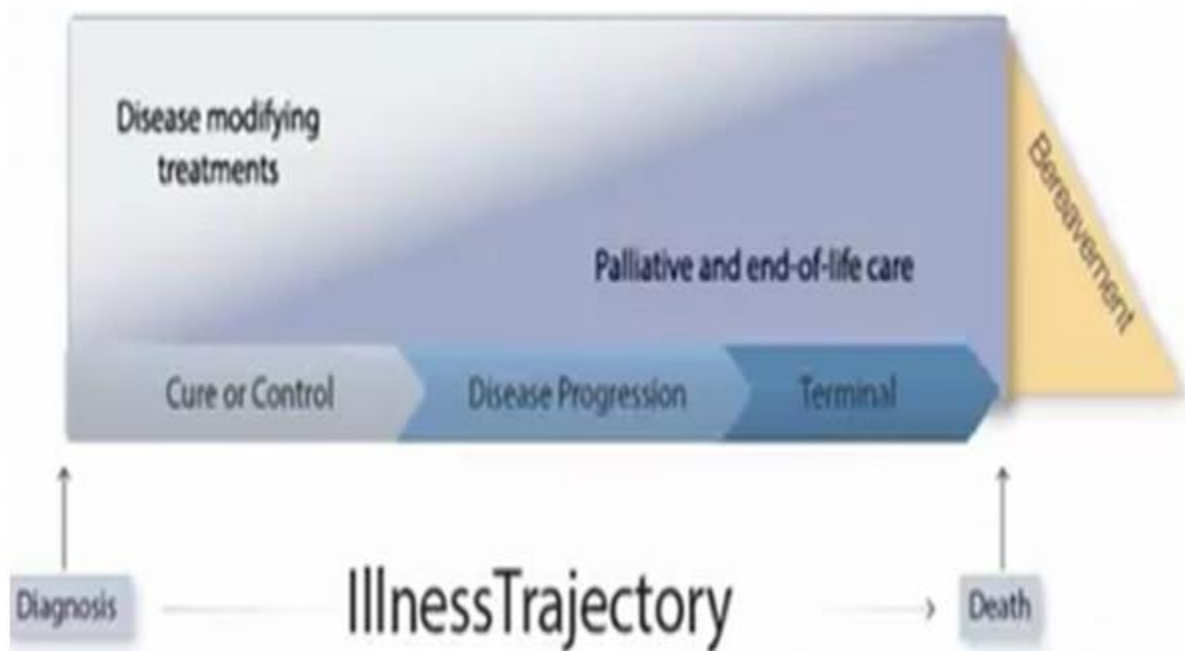
Advance Care Planning/Hospice Palliative Care

*When Someone
Close To You Is Dying*

*Advance Care Planning
& Substitute Health Care
Decision-Making*



What is it?



CANADIAN
 **Virtual Hospice**

*Information and support on palliative
and end-of-life care, loss and grief.*

What Happens During the Final Moments?

When Someone Close To You Is Dying

*What Happens
During The
Final Moments*



- ▶ Changing Sleeping Patterns
- ▶ Restlessness and Agitation
- ▶ Confusion and Forgetfulness
- ▶ Immobility and Involuntary Movements
- ▶ Changes in the Skin
- ▶ Changes in Breathing
- ▶ Eye Care
- ▶ Mouth Care and Difficulties Swallowing



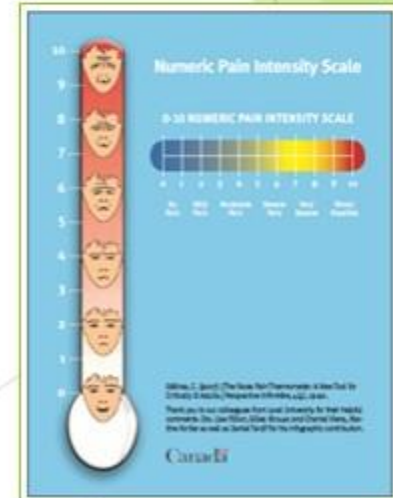
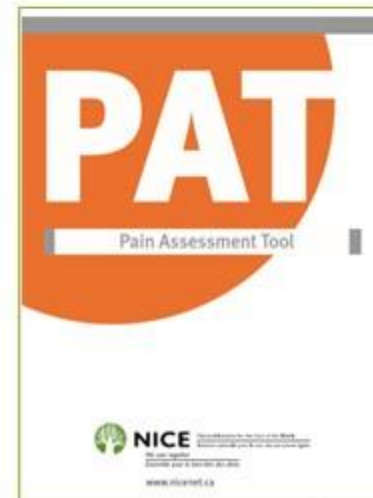
Pain Control

When Someone Close To You Is Dying

*Pain Control
And Opiate Use*



Pain needs to be assessed and treated promptly, with the quantity and frequency of doses of pain medication adjusted according to the intensity and duration of the pain. Opiates (such as morphine and similar drugs) are among the most effective painkillers and often provide the backbone of an effective pain management program. They are sometimes combined with other medications that increase the effectiveness of analgesics or are combined with other classes of analgesics such as anti-inflammatory agents.



Other Aspects

When Someone Close To You Is Dying

*Other Things
You Can Do
To Help*



Other Aspects:

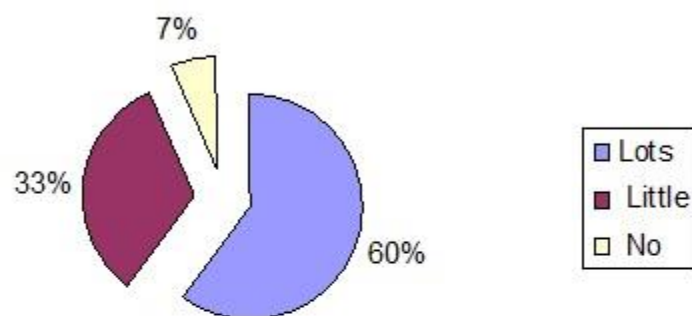
- Alternative Therapies
- Occupational- and Physiotherapy
- Spiritual Care
- Funeral Arrangements

Care for Yourself

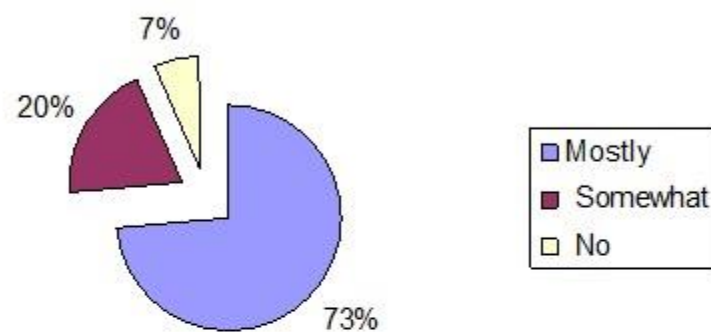
At this difficult time, it may seem natural to abandon concern for yourself and look only to the needs of others. However, you face the danger of depleting yourself so badly that you can no longer help. Please remember to take short breaks, eat and rest at regular intervals and walk each day so that you keep up your strength. Share the burden wherever possible. Let health care professionals and supporters know how they can help you too.

Initial Evaluation

Provision of New Information



Helpfulness of Information



Testimonial:

"I attended a palliative care course last evening and I was given one of the brochures mentioned above. I read through it while I was waiting for the speaker to start. I absolutely love it. It is honest, true and most of all, put in simple terms that families can understand. It does not have a bunch of medical terms that most families do not know. This brochure will be beneficial as the families can go over and over it again as they need to (which I anticipate will be a lot) – especially when a new symptom appears. I would personally like to thank you and thank your supporters for making this brochure and giving us copies of it."



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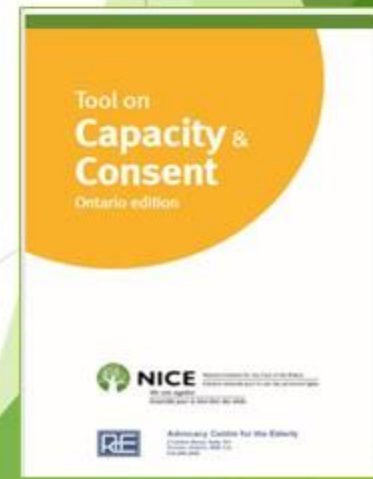
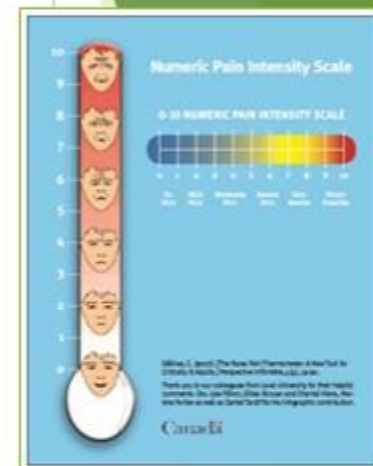
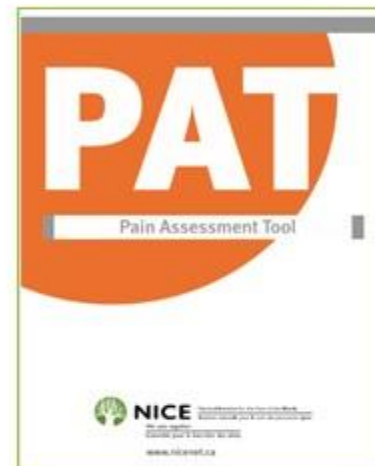
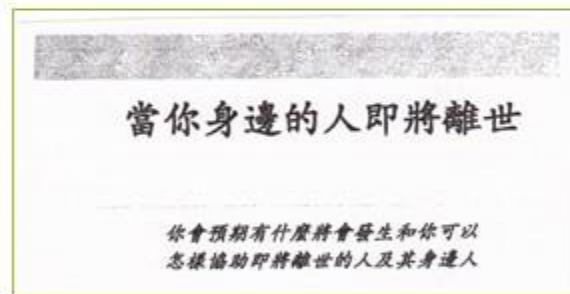
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End-of-Life Issues Tools

<http://www.nicenet.ca/cart-nice/gallery.aspx?pg=132&gp=57&ret=gallery>





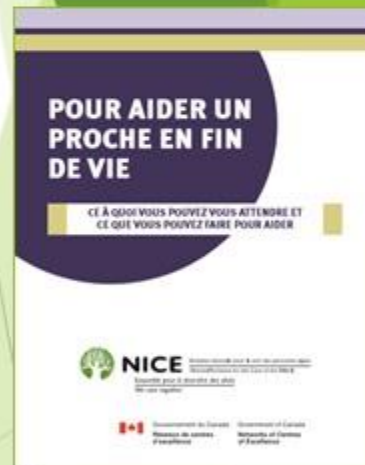
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THANK YOU!



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Q & A

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