A Palliative Approach to Late Life Dementia

A Personalized, Proactive, Palliative Approach to Care

Dr. Kim Adzich
Primary Health Care Integrated Geriatric Service Initiative Workshop 3
May 25, 2018

McMaster University
FAMILY MEDICINE
Palliative Care
Division

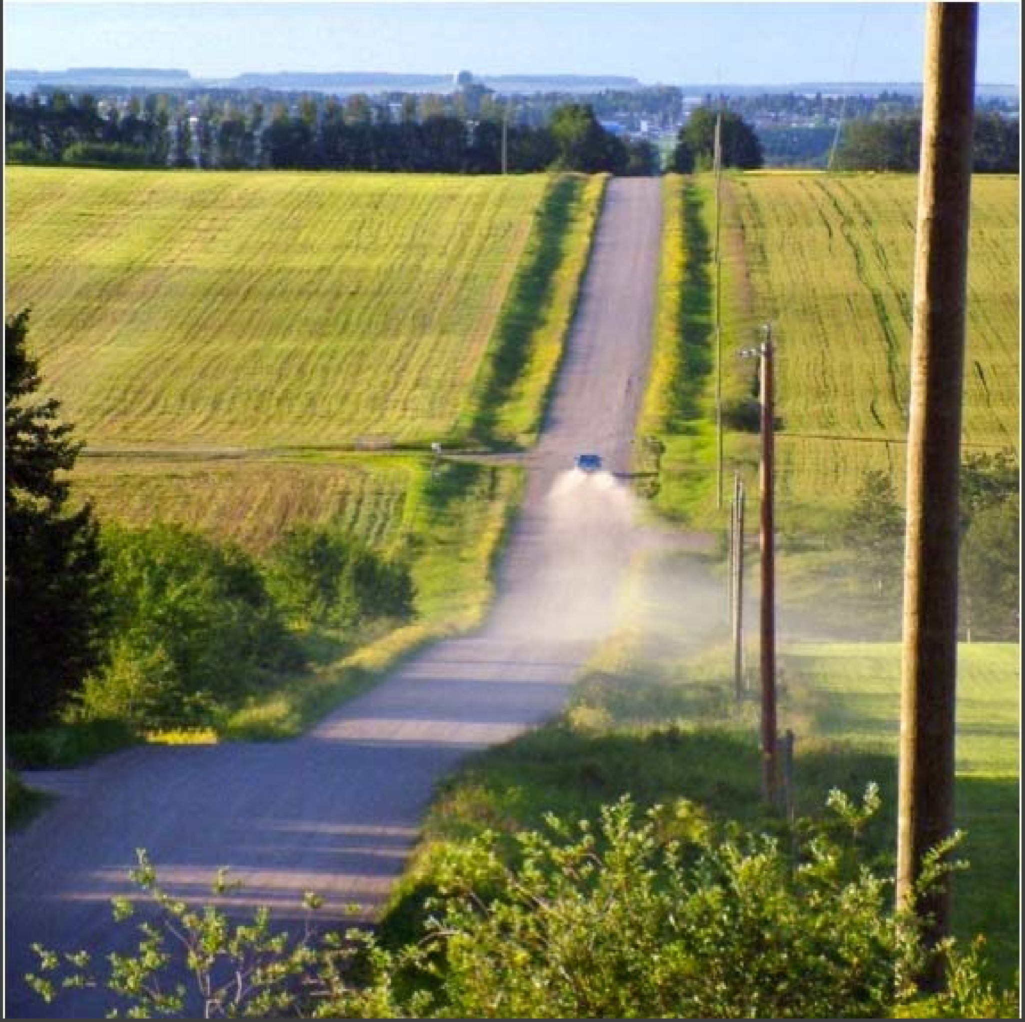
PHC IGSI: College of Family Physicians Canada Conflict of Interest slide

Faculty/Presenter Disclosure

- **Faculty/Presenter:** Dr. Kim Adzich

- **Relationships with commercial interests:**
  - **Grants/Research Support:** None
  - **Speakers Bureau/Honoraria:** Honorarium to present at PHC IGSI Workshop #3
  - **Consulting Fees:** None
  - **Other:** None

Home



Niagara Palliative Care Outreach Team

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VERY RARE PIC
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TORONTO MAPLE LEAF
STANLEY CUP PARADE
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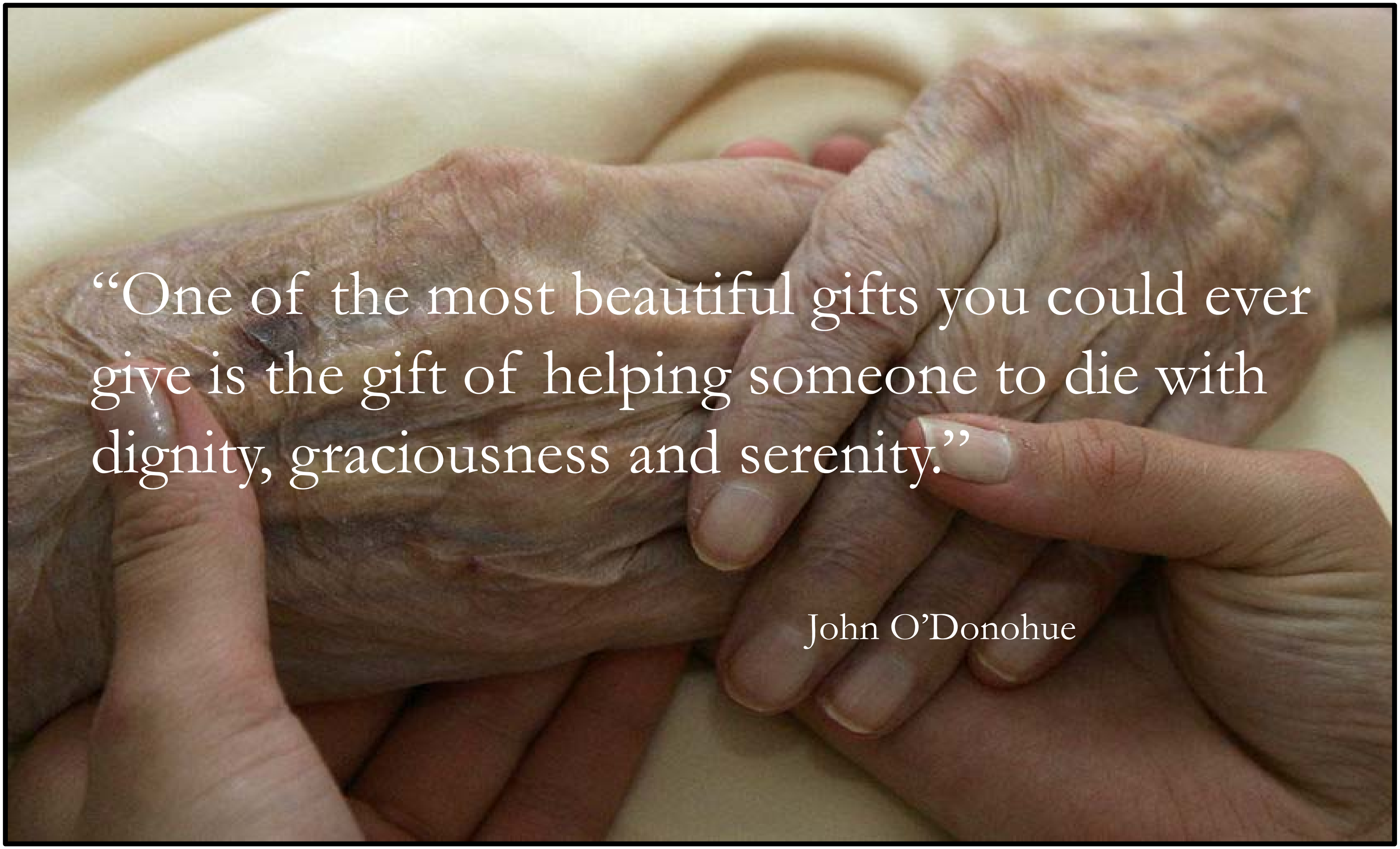
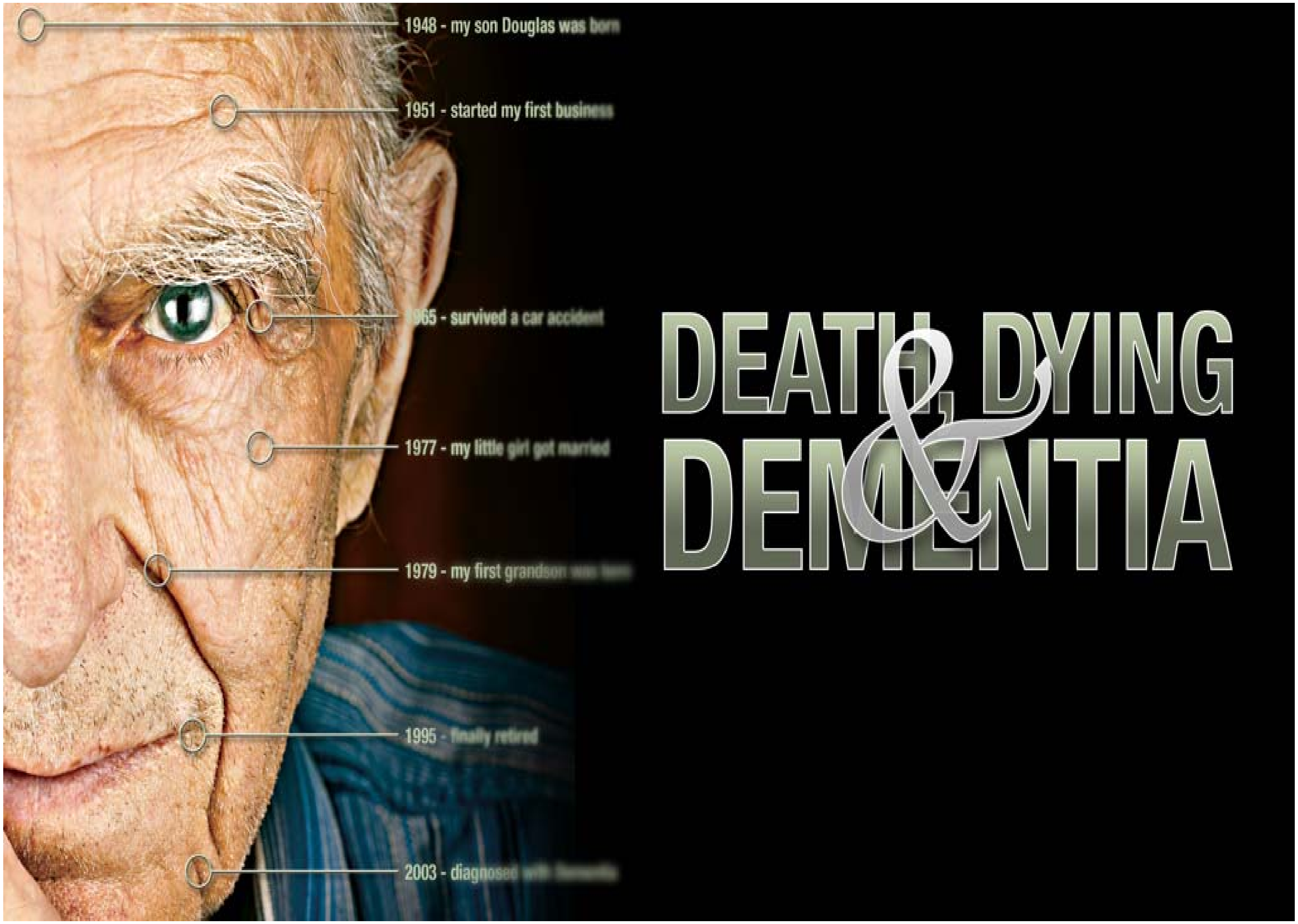


> “One of the most beautiful gifts you could ever give is the gift of helping someone to die with dignity, graciousness and serenity.”
>
> John O’Donohue



DEATH, DYING & DEMENTIA

Palliative Approach to Late Life Dementia

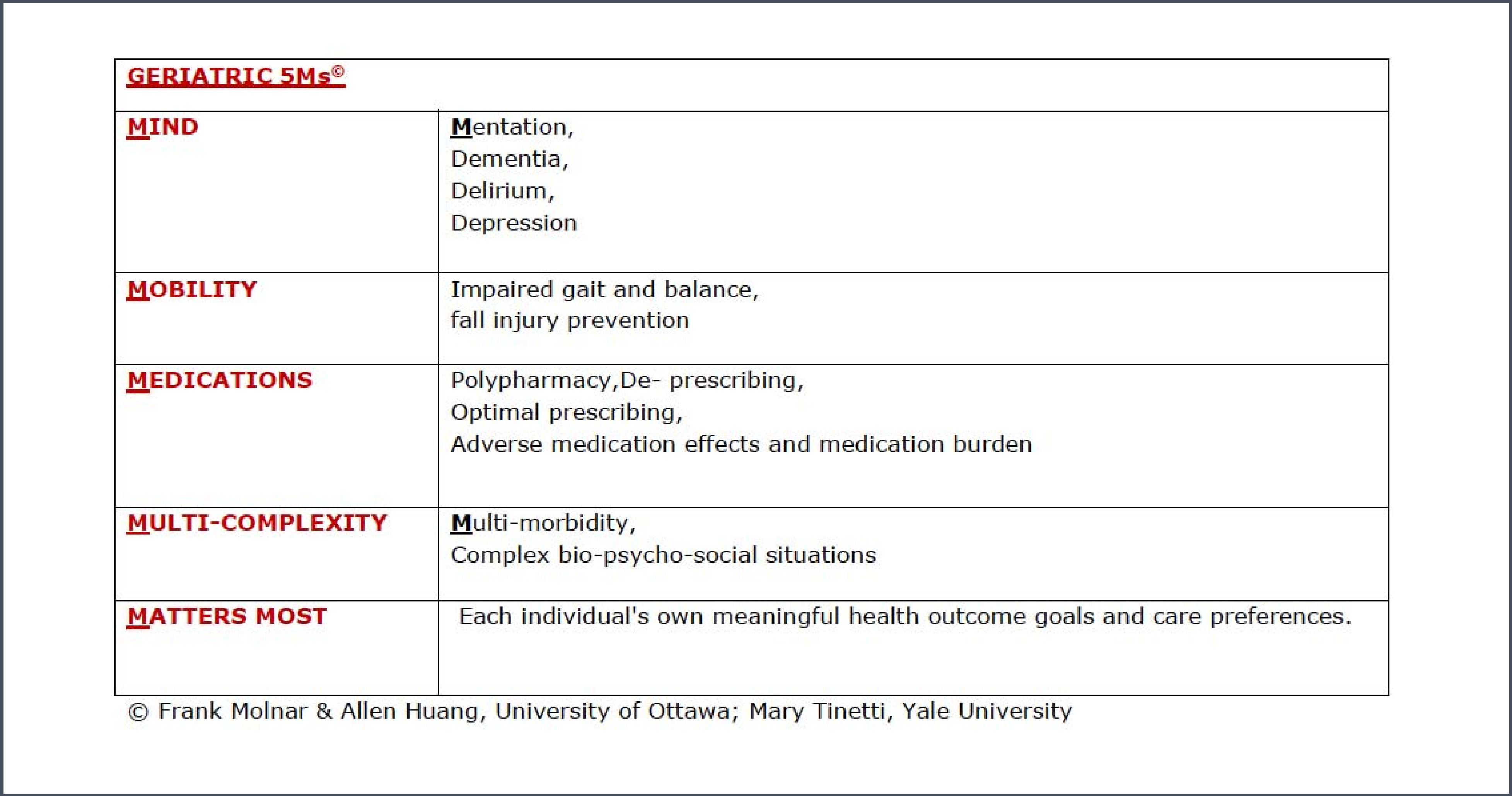
- **Palliative Approach to Care** – What is a palliative approach to care?

- **Personalized** – How do we support people to die in a way that fits with who they are, in the place they want to be, and with whom they want to be with?

- **Proactive** - How do we prepare ahead to support the person, their family/community and ourselves to enable this to happen?

“We want to sound a wake-up call in two directions, for those who care for people with dementia to pay attention to dying, and those who care for people who are dying to include people with dementia.”

Living and Dying with Dementia: Dialogues About Palliative Care, N. Small, K. Froggatt M. Downs, Oxford University Press Inc., New York, 2007.



GERIATRIC 5Ms©

MIND	**M**entation, Dementia, Delirium, Depression
MOBILITY	Impaired gait and balance, fall injury prevention
MEDICATIONS	Polypharmacy,De- prescribing, Optimal prescribing, Adverse medication effects and medication burden
MULTI-COMPLEXITY	**M**ulti-morbidity, Complex bio-psycho-social situations
MATTERS MOST	Each individual's own meaningful health outcome goals and care preferences.

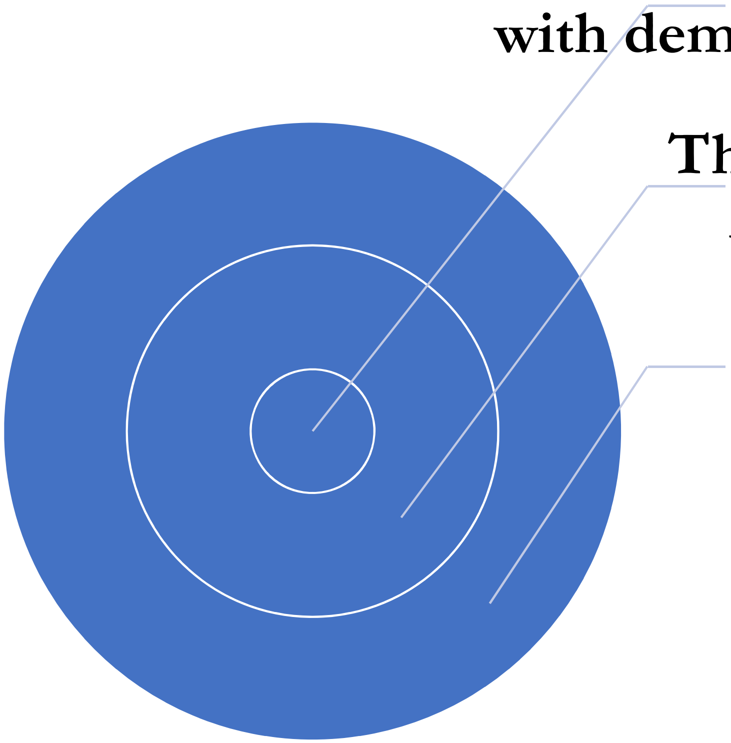
Complexity

Three types of problems:

- **Simple – this is how you do it…**
- **Complicated – it can be done, but it's complicated**
- **Complex – unpredictable, uncertain, many variables**

Getting to Maybe: How the World is Changed, Francis Westley, B. Zimmerman, M. Patton; 2007

What makes this so complex?



The Life-World – the experience of people living with dementia, their families and communities

The Systems-World – the system we work in/our professional assumptions

The Social-World – how our society views dementia, death, value and community

Living and Dying with Dementia: Dialogues About Palliative Care, N. Small, K. Froggatt, M. Downs, Oxford University Press Inc., New York, 2007.

The Challenges…

1. The trajectory of dying with late life dementia – uncertainty – when do we start to consider a palliative approach?

2. Caregiver stress and emotions when it comes to making choices.

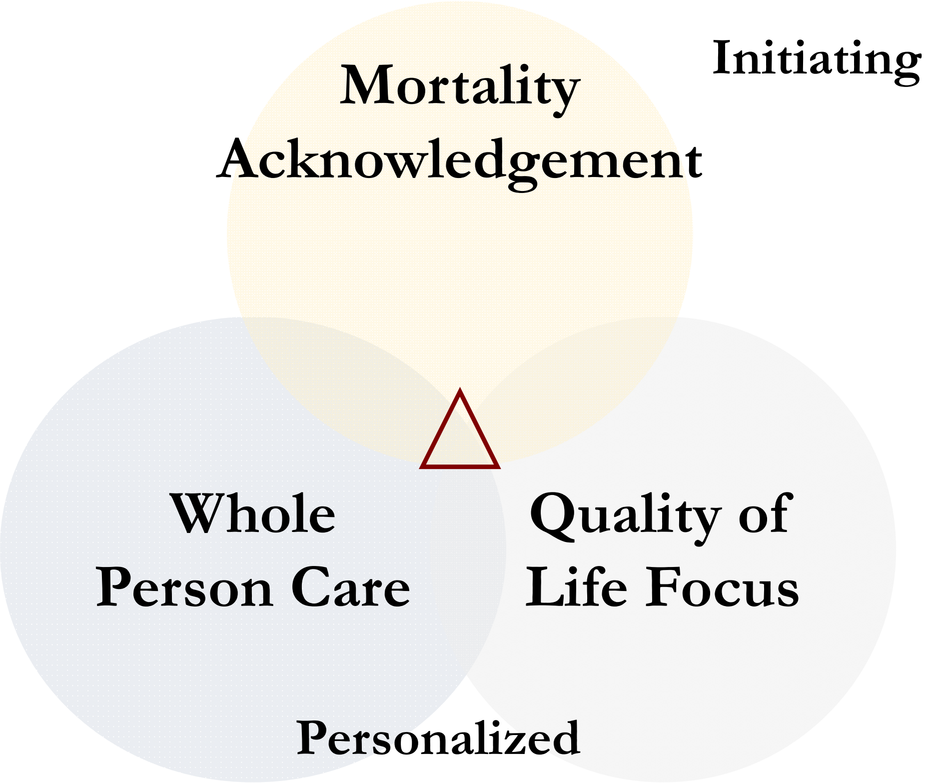
3. Lack of ability to verbally express symptoms complicates assessment and management.

4. Sometimes we, as professional caregivers, make assumptions as to that person's wishes, needs and symptoms.

St. Christopher's, Namaste Care Programme, 2016

A Palliative Approach to Late Life Dementia Care

Initiating a palliative approach



Mortality Acknowledgement

Whole Person Care

Quality of Life Focus

Personalized
and
Proactive

Death comes to the body

Question is not whether or not we will die…

but how, where, when, and with whom… we will die.

BJ Miller

"Any history of death in your family?"

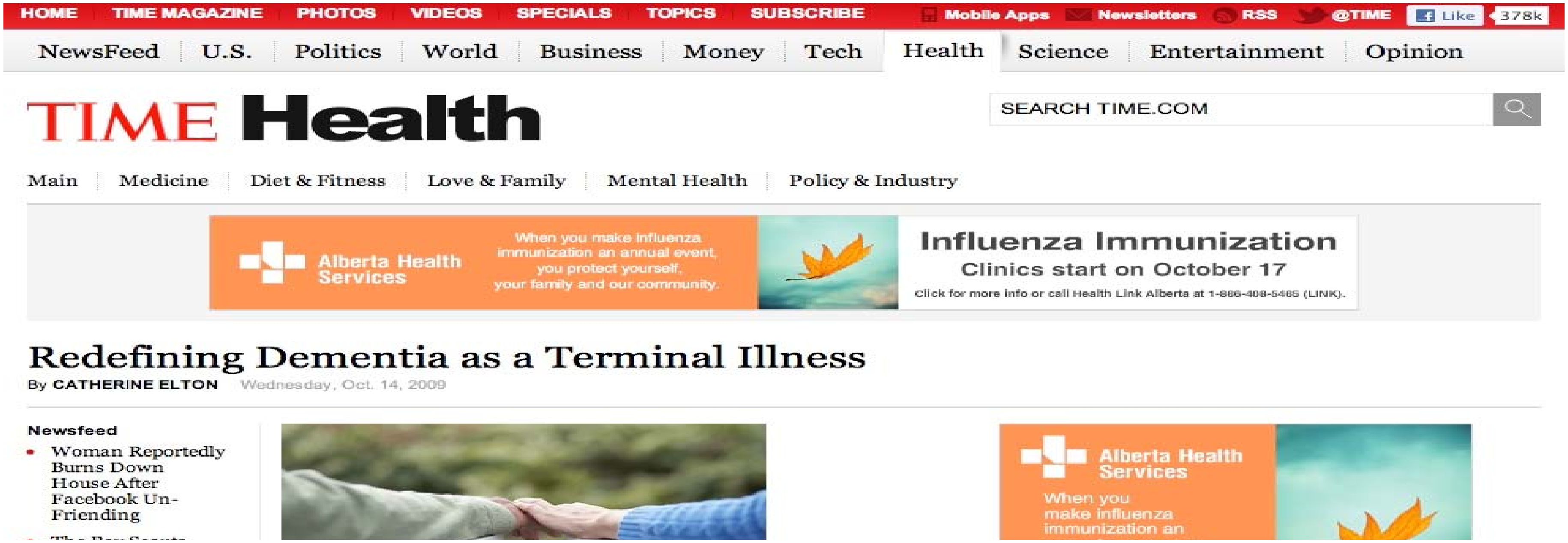
The Challenge of Death

"There are two, apparently different, ways society can ignore the challenge of death. First, by hiding death away and, secondly, by trying everything one can to prevent death happening. They dying can be consigned to a liminal world of "the not yet dead". Or they can become the object of heroic intervention.

Living and Dying with Dementia: Dialogues About Palliative Care, N. Small, K. Froggatt M. Downs, Oxford University Press Inc., New York, 2007.

Death is a natural part of life. We need to focus on living until we die, but death will still come.

Rethinking dementia as a terminal disease.



Redefining Dementia as a Terminal Illness

By **CATHERINE ELTON** Wednesday, Oct. 14, 2009

Newsfeed

- Woman Reportedly Burns Down House After Facebook Un-Friending

"Dementia is most often thought of as a memory disorder, an illness of the aging mind. In its initial stages, that's true – memory loss is an early hallmark of dementia. But experts in the field say dementia is more accurately defined as fatal brain failure: a terminal disease, like cancer, that physically kills patients, not simply a mental ailment that accompanies older age." Catherine Elton

The NEW ENGLAND JOURNAL of MEDICINE

ESTABLISHED IN 1812 OCTOBER 15, 2009 VOL. 361 NO. 16

The Clinical Course of Advanced Dementia

Susan L. Mitchell, M.D., M.P.H., Joan M. Teno, M.D., Dan K. Kiely, M.P.H., Michele L. Shaffer, Ph.D., Richard N. Jones, Sc.D., Holly G. Prigerson, Ph.D., Ladislav Volicer, M.D., Ph.D., Jane L. Givens, M.D., M.S.C.E., and Mary Beth Hamel, M.D., M.P.H.

Clinical Course of Advanced Dementia

323 Nursing Home residents followed for 18 months (advanced dementia - Cognitive Performance Scale 5-6). 22 nursing homes.

During that time 54.8% died.

Pneumonia, febrile episodes and eating problems were frequent complications in patients with advanced dementia, and these complications were associated with high 6-month mortality rates (46%, 44% and 38% respectively).

Distressing symptoms were also common: dyspnea 46%, pain 39%, agitation 54%, aspiration 40%, pressure ulcers (Stage II or higher) 38% .

Mitchell, Susan L, et al. The Clinical Course of Advanced Dementia; N Engl J Med 2009; 361: 1529-38

Prognosis in Advanced Dementia

"As the mortality rates for many leading causes of death have declined over the past decade, deaths from dementia have steadily increased. Patients, families and health care providers must understand and be prepared to confront the end stage of this disease…"

"… dementia is a terminal illness"

"…this study underscores the need to improve the quality of palliative care in nursing homes in order to reduce the physical suffering of residents with advanced dementia…"

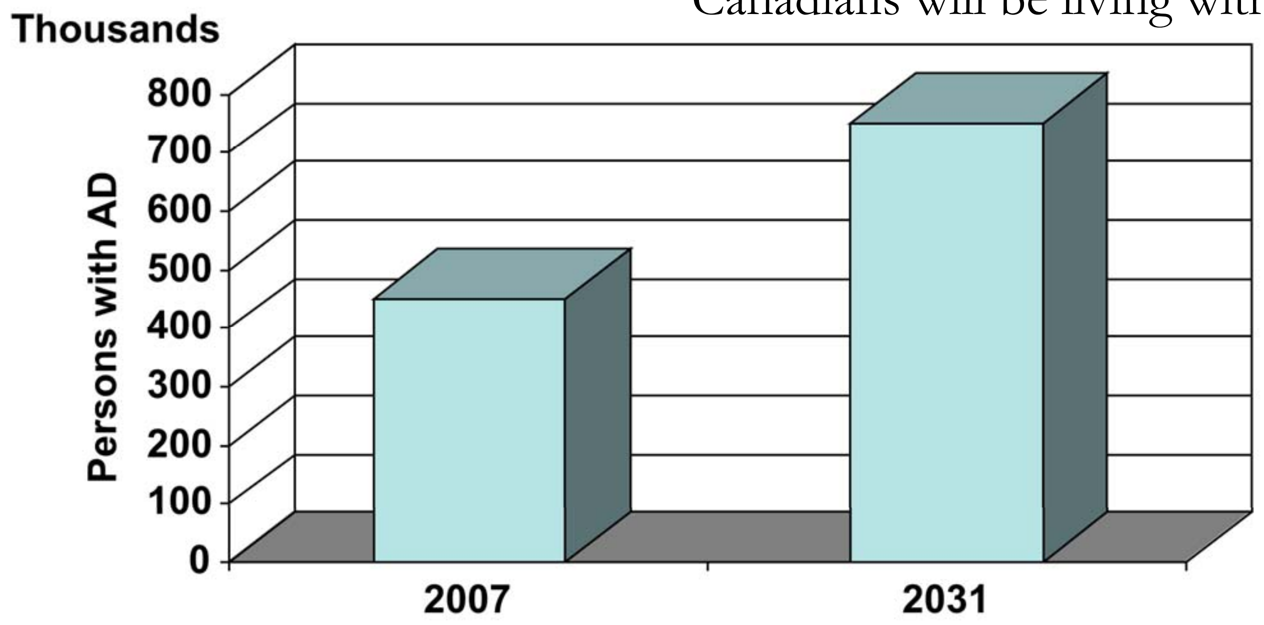
Mitchell, Susan L, et al. The Clinical Course of Advanced Dementia; N Engl J Med 2009; 361: 1529-38

“Dementia is a growing cause of death in this country and we need to pay attention to it.”

— Louise Hanvey, Project Manager,
Canadian Hospice Palliative Care Association

Prevalence of Alzheimer’s Disease in Canadians Over Age 65

CIHI estimates closer to 1.4 million
Canadians will be living with dementia by 2031



Canadian Study on Health & Aging

Dementia in Alberta

As of 2016, just over 42,000 Albertans (about 1%) have been diagnosed and are living with dementia. If nothing changes, this number is expected to increase to more than 155,000 within 30 years.

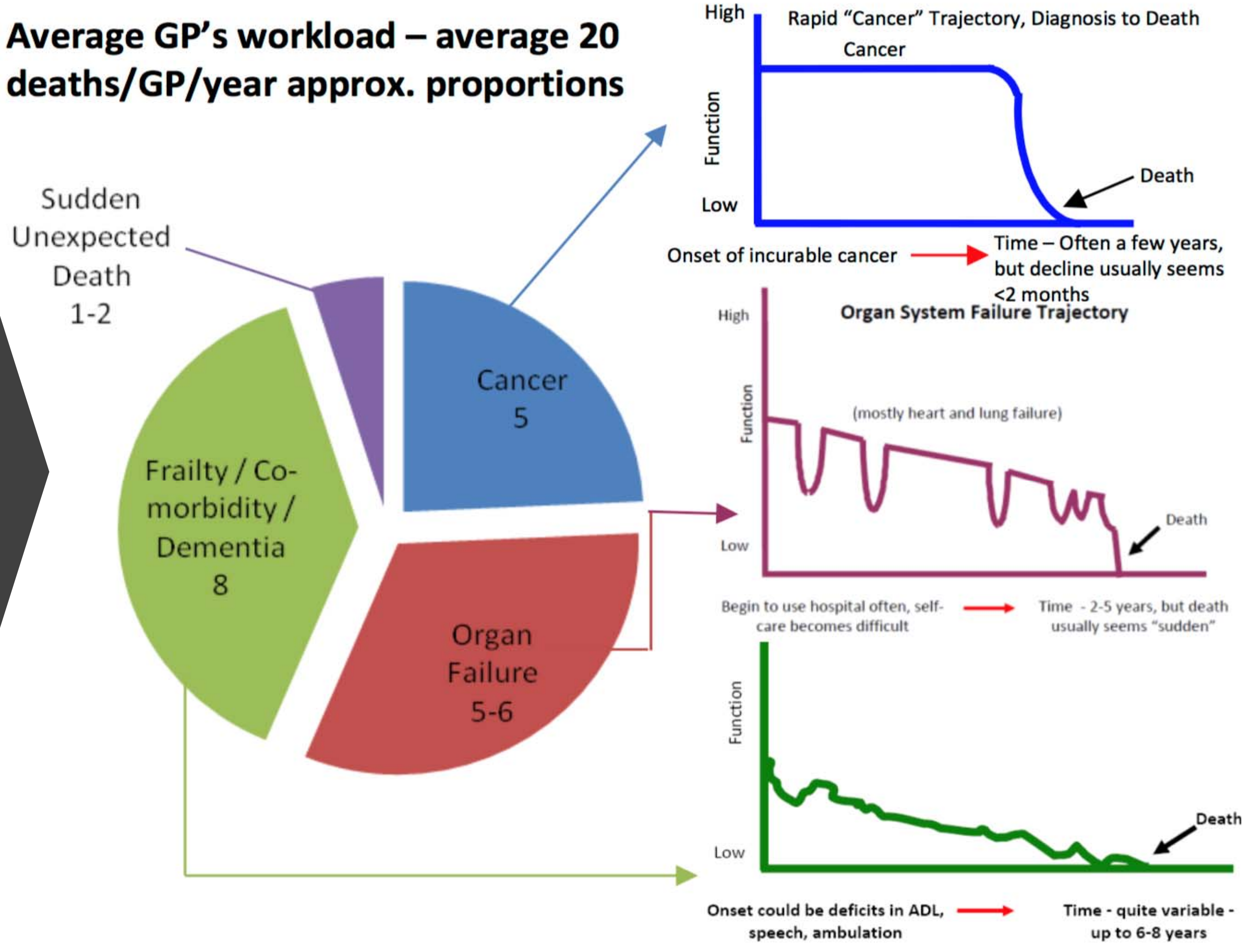
It is believed that one in three seniors will die with a dementia.

(source: the Population Estimates of Dementia in Alberta Working Group).

Alberta Dementia Strategy and Action Plan/Alberta Health, Dec 2017

Disease Trajectories

Average GP's workload – average 20 deaths/GP/year approx. proportions



Prognostic Indicator Guidance (PIG) 4th Edition Oct 2011 © The Gold Standards Framework Centre In End of Life Care CIC, Thomas.K et al
Function

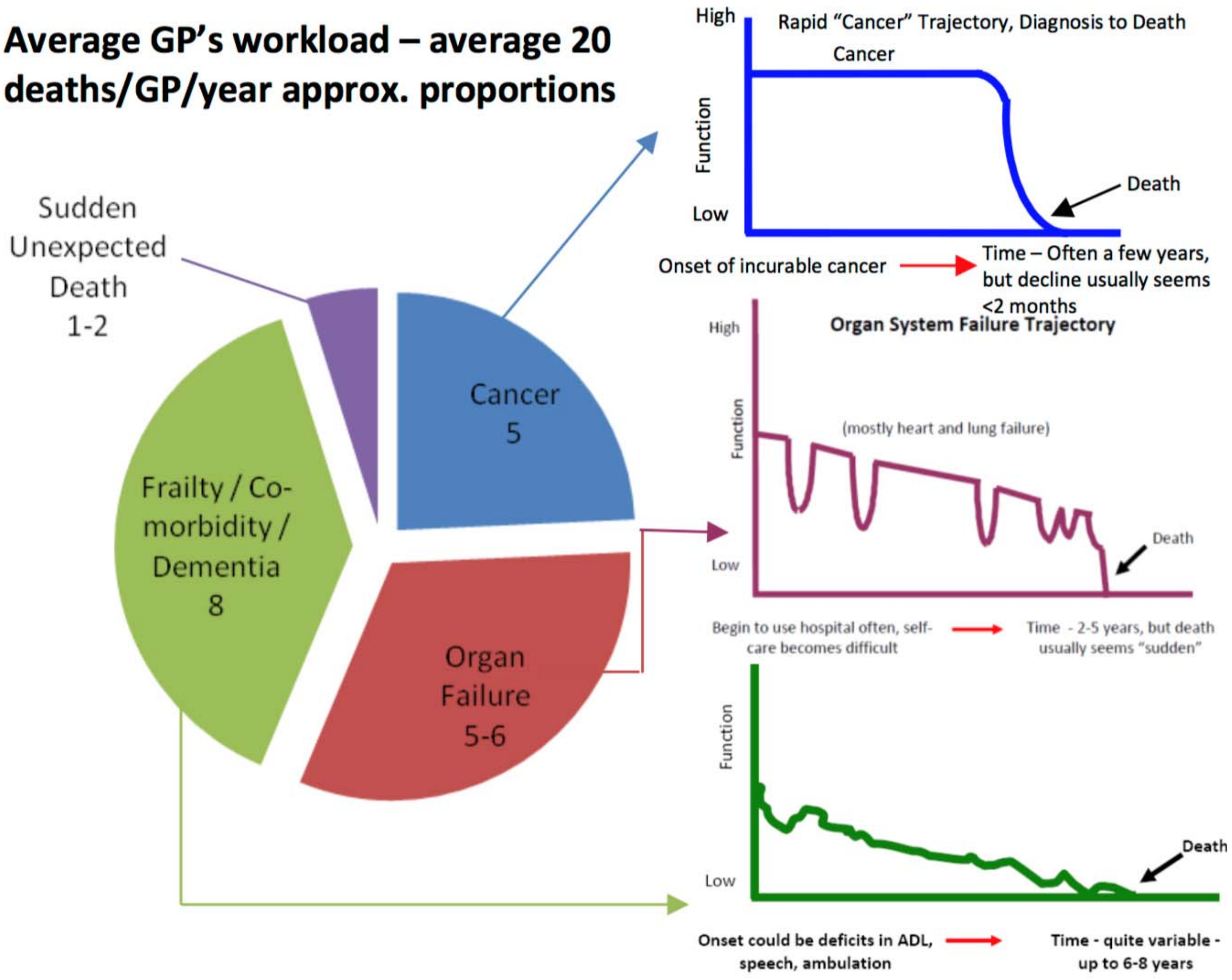
“Let Me Die A Youngman's Death”

Poem by Roger McGough

“Let me die a youngman's death
not a clean and inbetween
the sheets holywater death
not a famous-last-words
peaceful out of breath death

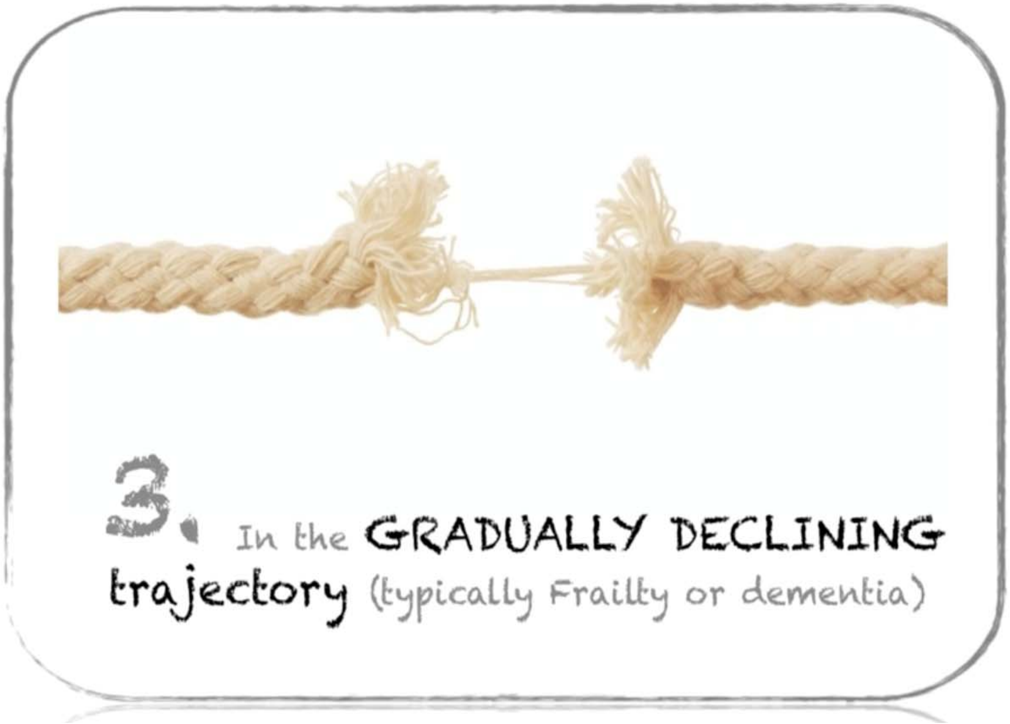
When I'm 73
and in constant good tumour
may I be mown down at dawn
by a bright red sports car
on my way home
from an allnight party”

Disease Trajectories



Average GP's workload – average 20 deaths/GP/year approx. proportions

- Prognostic Indicator Guidance (PIG) 4th Edition Oct 2011 © The Gold Standards Framework Centre In End of Life Care CIC, Thomas.K et al



Dr. Scott Murray, University of Edinburgh

Most people will die with an illness that has no recognizable terminal phase, although they will have lived for months or years in a state of fragile health or "vulnerable frailty." (Lynn, 2005)

full engagement with the world……….peaceful death

Mrs. B.

First met her in late November – referral from family doctor stated that she had dementia, frailty, anxiety and was calling out “just let me go”.

87 years old, multiple co-morbidities, recent hospitalization for delirium secondary to a UTI. PPS 30%. Daughter wanted to care for her at home until the end of her life.

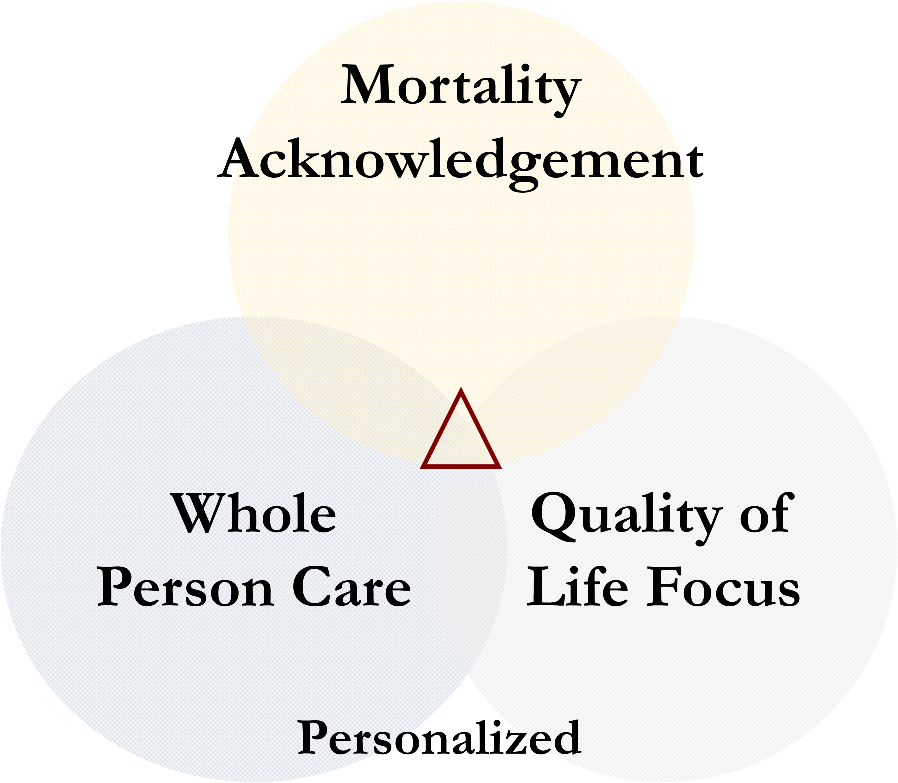
Feb – chest infection, minimal oral intake

March – bed-confined, no oral meds, poor oral intake, “actively dying” PPS 20%

April – opioid rotation for signs of toxicity

May – woke enough to eat a piece of Black Forest cake for Mother’s Day!

A Palliative Approach to Late Life Dementia Care



Mortality Acknowledgement

Whole Person Care

Quality of Life Focus

**Personalized
and
Proactive**

Palliative Care in Dementia

The goal is to use a person-centred, culturally and spiritually sensitive approach to providing care that meets a resident's changing needs and respects his or her preferences regarding end of life care.

Guidelines for Care: Person-centred care of people with dementia living in care homes
Framework
Alzheimer Society of Canada, 2011

“ A Good Death”

Although every individual may have a different idea about what would, for them, constitute a “good death”, for many this would involve:

- **Being treated as an individual, with dignity and respect;**
- **Being without pain and other symptoms;**
- **Being in familiar surroundings; and**
- **Being in the company of close family and/or friends.**

End of Life Care Strategy – promoting high quality care for all adults at the end of life. UK Dept of Health 2008

“ A Good Death” – Holistic, Person-Centred Care

- **Being treated as an individual, with dignity and respect;**

(Emotional and Spiritual)

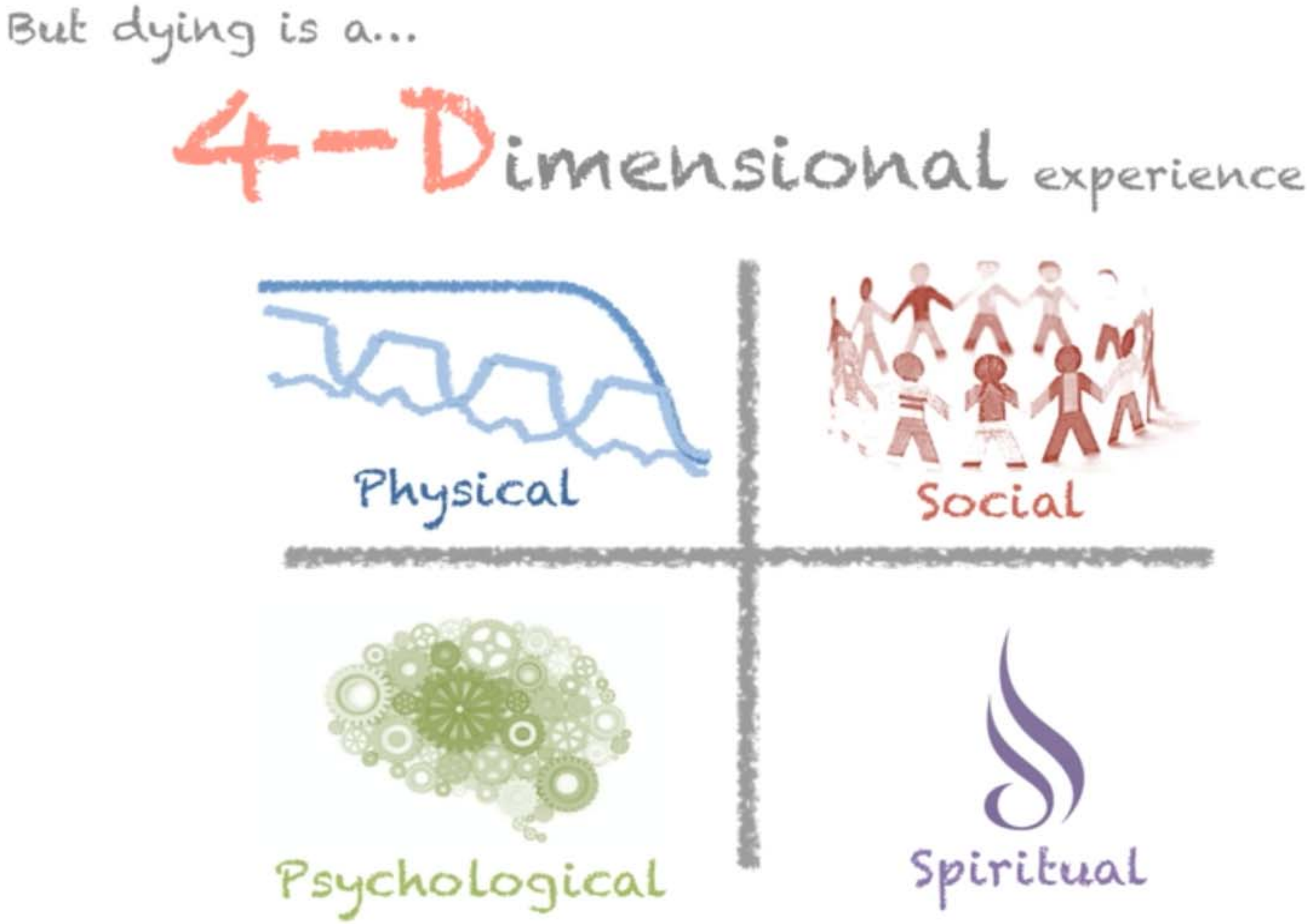
- **Being without pain and other symptoms;**

(Physical)

- **Being in familiar surroundings; and**
- **Being in the company of close family and/or friends.**

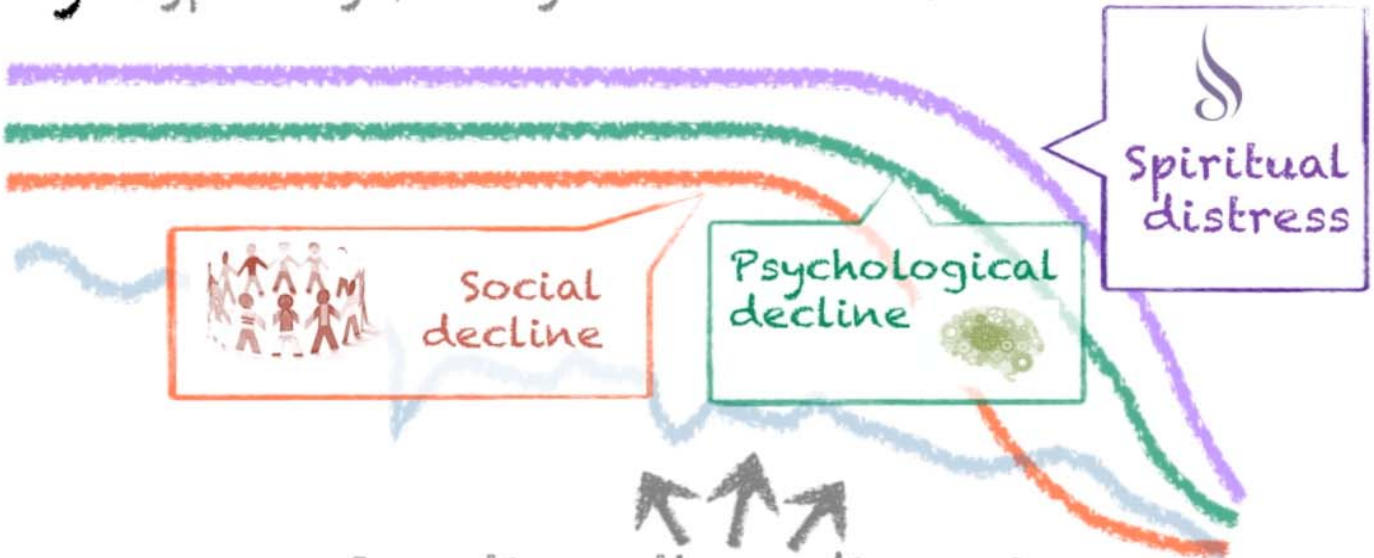
(Social)

End of Life Care Strategy – promoting high quality care for all adults at the end of life. UK Dept of Health 2008



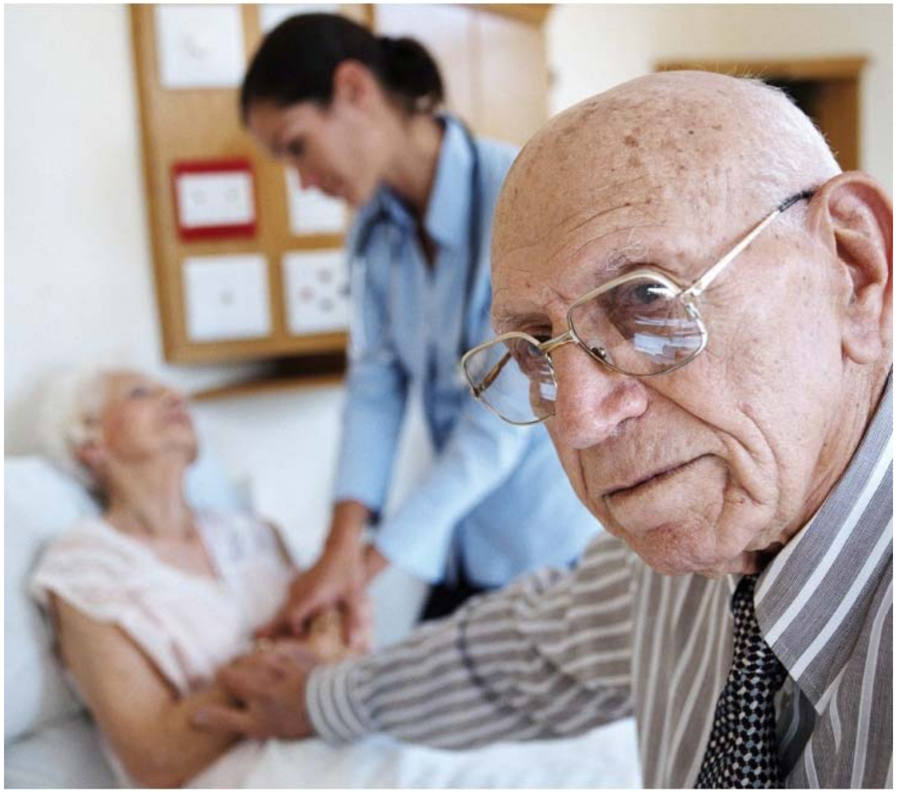
Dr. Scott Murray, University of Edinburgh

3. In the GRADUALLY DECLINING trajectory (typically frailty or dementia)



Sometimes these dimensions can decline before the physical

Dr. Scott Murray, University of Edinburgh



Caregiver Burden

"In caring for a family member or friend with dementia as they approach death, carers regularly experience grief, burden, depression, and guilt, which are exacerbated by the prolonged decline in care recipients' functional state. It is here that a palliative approach to end-of-life care is likely to have its greatest benefits for carers."

Broady, T.R., F. Saich, T. Hinton. Caring for a family member or friend with dementia at the end of life: A scoping review and implications for palliative care practice. Palliative Medicine 2018. Vol 32(3) 643-656.

Palliative Approach to Care

THE WAY FORWARD NATIONAL FRAMEWORK:
A ROADMAP FOR AN INTEGRATED PALLIATIVE APPROACH TO CARE

Canadian Hospice Palliative Care Association, The Way Forward National Framework: A roadmap for an integrated palliative approach to care, The Way Forward initiative, March 2015.

Palliative Approach to Care

"An integrated palliative approach to care focuses on meeting a person's and family's full range of needs – **physical**, **psychosocial** and **spiritual** – **at all stages** of frailty or chronic illness, not just at the end of life."

Palliative care affirms life and regards dying as a normal process. It focuses on whole person care, to improve quality of life and support patients/families using a team approach.

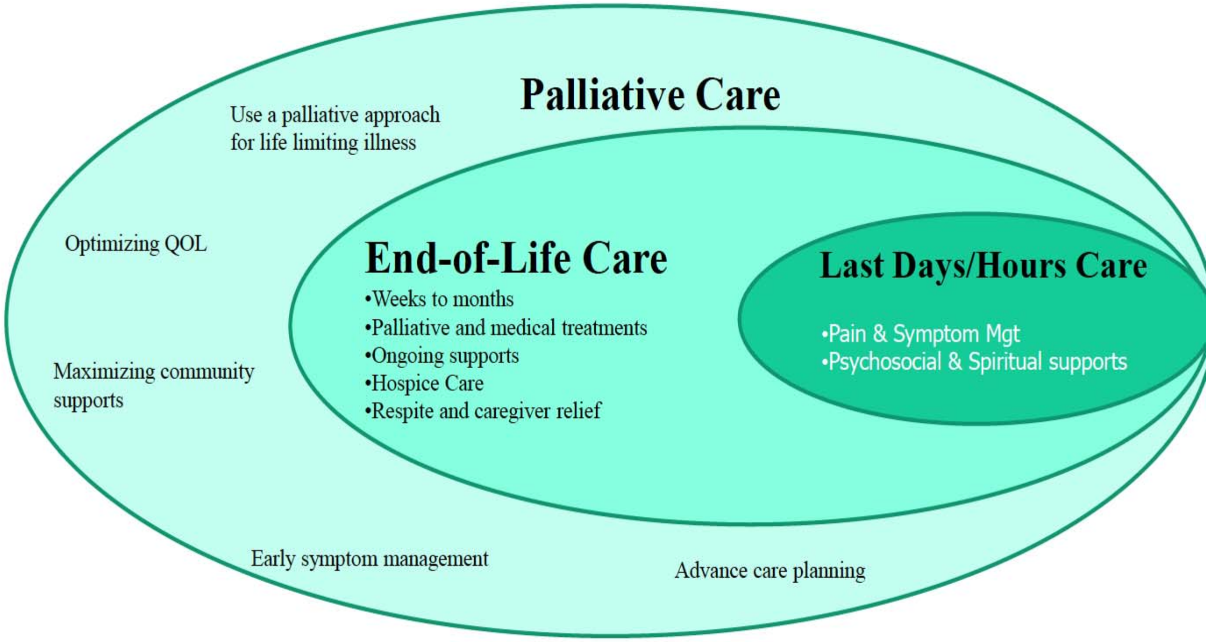
Canadian Hospice Palliative Care Association, The Way Forward National Framework: A roadmap for an integrated palliative approach to care, The Way Forward initiative, March 2015.

New Model of Palliative Care

- More inclusive of patients, family and

.

Palliative Care is more than just end-of-life care



Palliative Care

Use a palliative approach for life limiting illness

Optimizing QOL

Maximizing community supports

Early symptom management

Advance care planning

End-of-Life Care

- Weeks to months
- Palliative and medical treatments
- Ongoing supports
- Hospice Care
- Respite and caregiver relief

Last Days/Hours Care

- Pain & Symptom Mgt
- Psychosocial & Spiritual supports

Integrated Palliative Approach to Care

- Whole person assessment – physical, emotional, social and spiritual
- Pain and symptom assessment/management
- Open and sensitive communication about a person's prognosis and illness trajectory – discussions with family
- Advance care planning discussions
- Family support – emotional, spiritual, social
- Ongoing review of goals of care with adjustment of care strategies and proactive discussions regarding possible future events.

Canadian Hospice Palliative Care Association, The Way Forward National Framework: A roadmap for an integrated palliative approach to care, The Way Forward initiative, March 2015.

SHIFT YOUR THINKING...

TO A PALLIATIVE APPROACH

iPANEL
INITIATIVE FOR A
PALLIATIVE APPROACH IN NURSING:
EVIDENCE & LEADERSHIP

A palliative approach is different than specialized palliative care. It takes principles of palliative care and:

ADOPTS principles EARLY in the course of a person's life-limiting condition

ADAPTS strategies to meet patient and family needs

EMBEDS practices into usual care in settings not specialized in palliative care

Sawatzky, Porterfield, Lee, Dixon, Lounsbury, Pesut, Roberts, Tayler, Voth & Stajduhar (2016). Conceptual foundations of a palliative approach: A knowledge synthesis. *BMC Palliative Care*, 15(5). doi:10.1186/s12904-016-0076-9

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FOR HEALTH RESEARCH
Discover. Connect. Engage.

Shift your view on when people with life-limiting illness could benefit from palliative principles:

Home & community care: When they are referred to home & community

Long term care: When they move into care

Acute care: When they are admitted to hospital

Key features of a palliative approach

WHAT

- Involves life-limiting illnesses such as heart, lung, and kidney disease, dementias, frailty, and cancer
- Integrates chronic disease management and palliative care principles
- Includes conversations about serious illness, personal preferences, and goals of care
- Understands where the person is in the course of their chronic illness
- Orients care to the whole person and their family
- Prepares for illness progression, while recognizing uncertain prognosis

WHERE

- Offered across settings including acute, home, and long term care

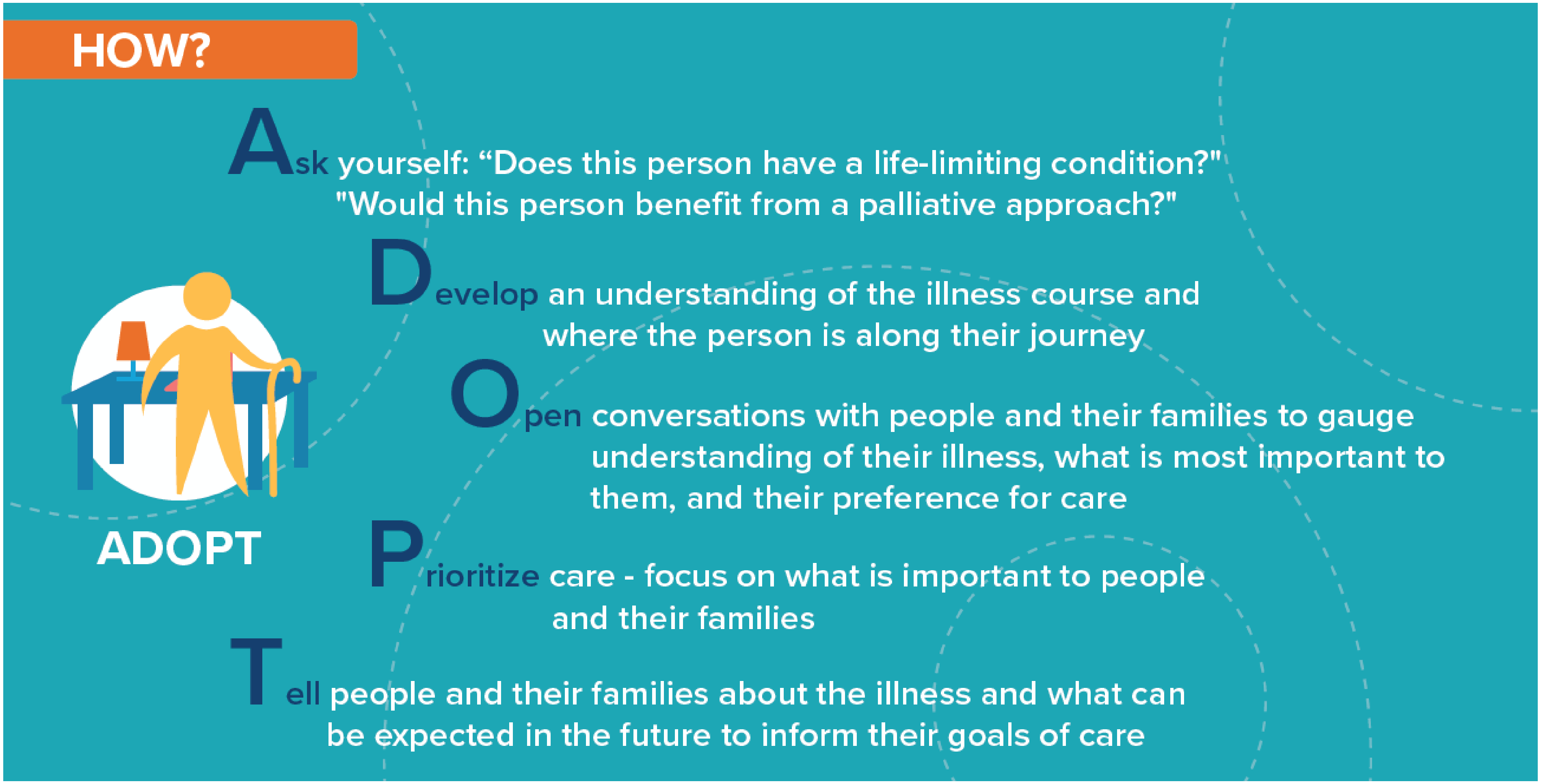
WHO

- Every health care provider is responsible in each care setting

WHEN

- Consults with specialist palliative care providers, as needed

Sawatzky, et al (2016). Conceptual Foundations of a palliative approach: A knowledge synthesis. BMC Palliative Care, 15(5).



HOW?

ADOPT

Ask yourself: “Does this person have a life-limiting condition?" "Would this person benefit from a palliative approach?"

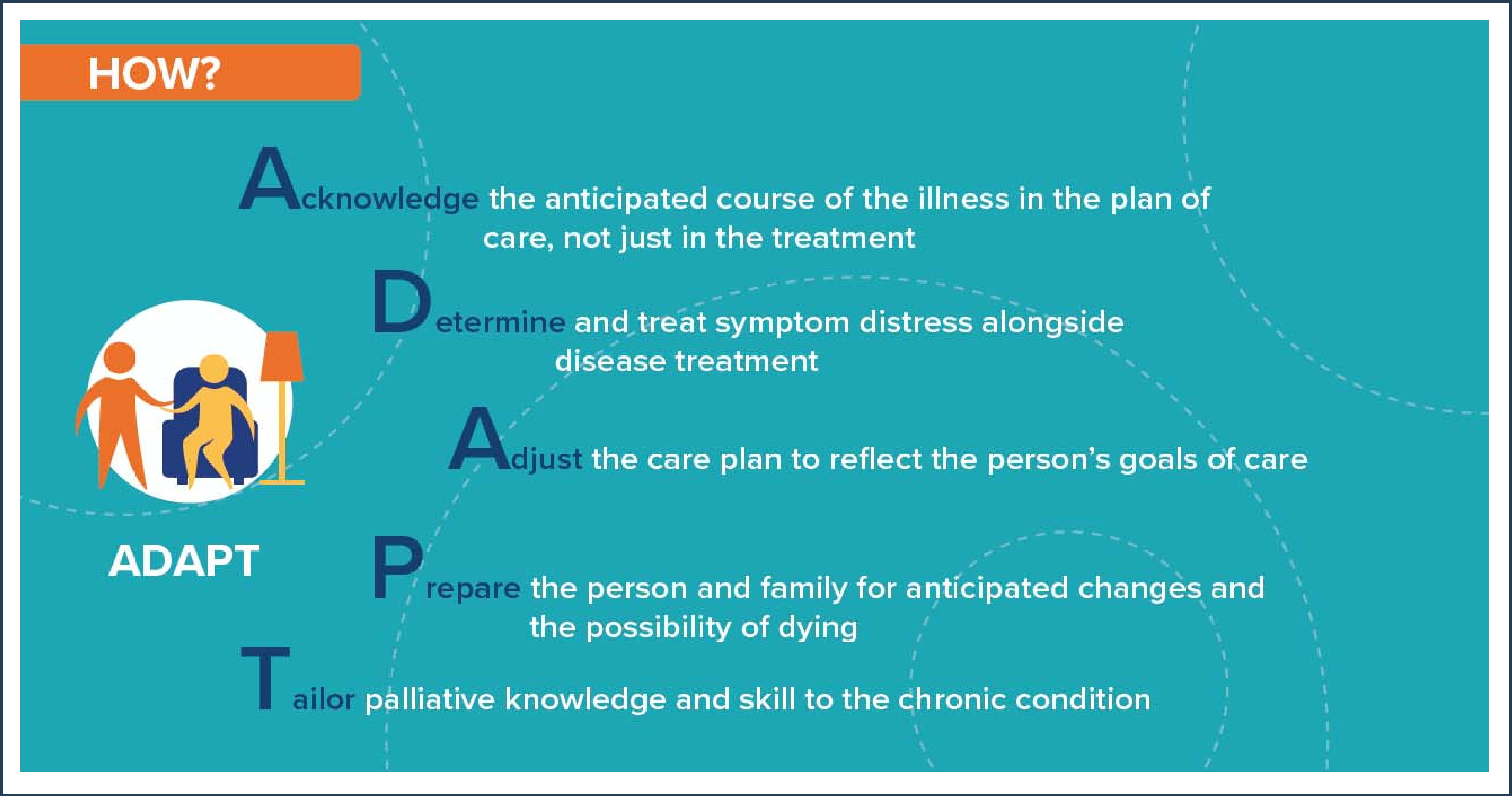
Develop an understanding of the illness course and where the person is along their journey

Open conversations with people and their families to gauge understanding of their illness, what is most important to them, and their preference for care

Prioritize care - focus on what is important to people and their families

Tell people and their families about the illness and what can be expected in the future to inform their goals of care

Sawatzky, et al (2016). Conceptual Foundations of a palliative approach: A knowledge synthesis. BMC Palliative Care, 15(5).



HOW?

ADAPT

Acknowledge the anticipated course of the illness in the plan of care, not just in the treatment

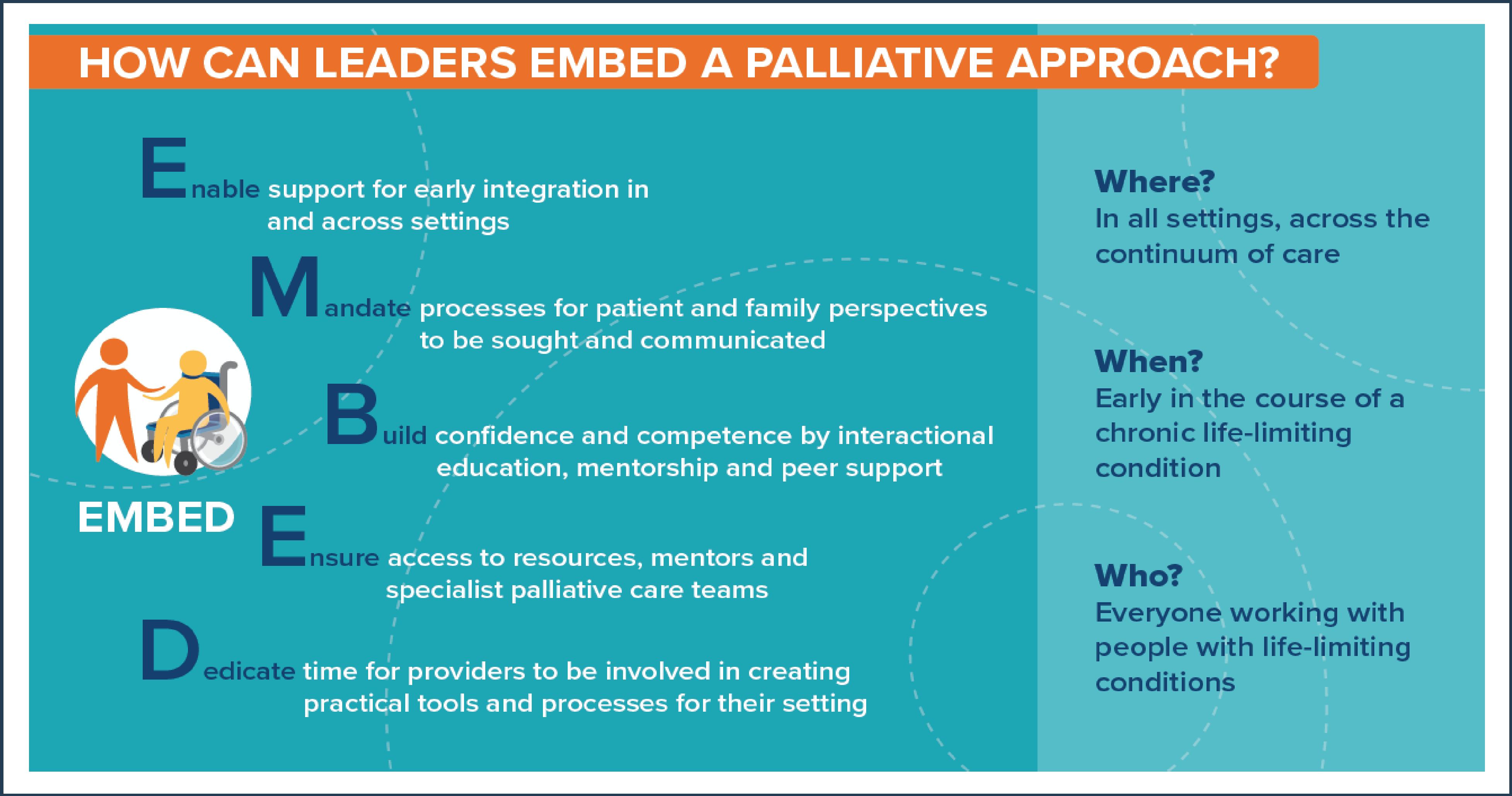
Determine and treat symptom distress alongside disease treatment

Adjust the care plan to reflect the person's goals of care

Prepare the person and family for anticipated changes and the possibility of dying

Tailor palliative knowledge and skill to the chronic condition

Sawatzky, et al (2016). Conceptual Foundations of a palliative approach: A knowledge synthesis. BMC Palliative Care, 15(5).



HOW CAN LEADERS EMBED A PALLIATIVE APPROACH?

EMBED

Enable support for early integration in and across settings

Mandate processes for patient and family perspectives to be sought and communicated

Build confidence and competence by interactional education, mentorship and peer support

Ensure access to resources, mentors and specialist palliative care teams

Dedicate time for providers to be involved in creating practical tools and processes for their setting

Where?
In all settings, across the continuum of care

When?
Early in the course of a chronic life-limiting condition

Who?
Everyone working with people with life-limiting conditions

Sawatzky, et al (2016). Conceptual Foundations of a palliative approach: A knowledge synthesis. BMC Palliative Care, 15(5).

ADOPT

ADAPT

EMBED

WHY?

- Aligns treatment decisions better with goals and wishes
- Improves quality of life when preferences are known and respected
- Reduces inappropriate or futile treatments
- Encourages healthcare teams to "get on the same page" as the person and family
- Supports communication and shared care planning among teams caring for the person
- Gives team members permission to have conversations with the person and family about serious illness

WHY?

In Canada, **~250,000** people die each year

Of these – 72% result from chronic life-limiting conditions such as organ failure, cancer, dementia, and frailty...

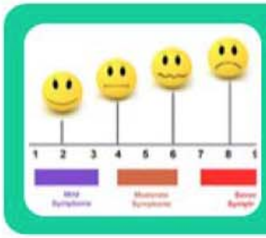
Most were cared for and died outside of specialized palliative care...

This means over 180,000 Canadians per year could benefit from a palliative approach

Sawatzky, et al (2016). Conceptual Foundations of a palliative approach: A knowledge synthesis. BMC Palliative Care, 15(5).

Components of a Palliative Approach to Care

Communication: Goals of Care and Advance Care Planning



Symptom Management and Prevention

Support: Unit of care is the patient and family

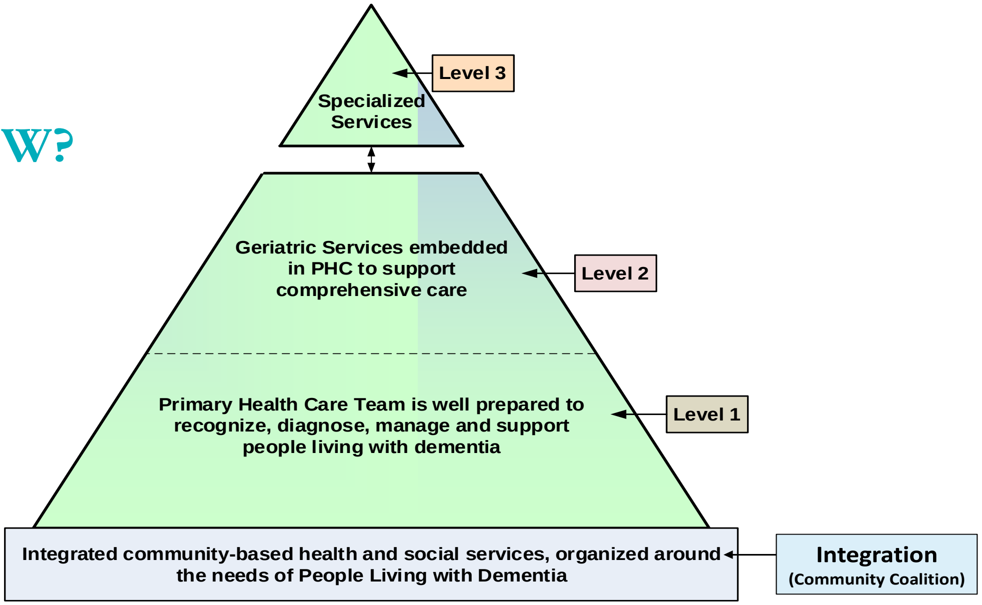
Sawatzky, et al (2016). Conceptual Foundations of a palliative approach: A knowledge synthesis. BMC Palliative Care, 15(5).

Who Provides a Palliative Approach to Care:

Primary Health Care Integrated Geriatric Service Initiative

Anticipating the Future

HOW?



Specialized Services

Level 3

Geriatric Services embedded in PHC to support comprehensive care

Level 2

Primary Health Care Team is well prepared to recognize, diagnose, manage and support people living with dementia

Level 1

Integrated community-based health and social services, organized around the needs of People Living with Dementia

Integration
(Community Coalition)

Who Provides Palliative Care?

Canadian Hospice Palliative Care Association

Association canadienne de soins palliatifs

The Way Forward – Moving Towards an Integrated Palliative Approach to Care:

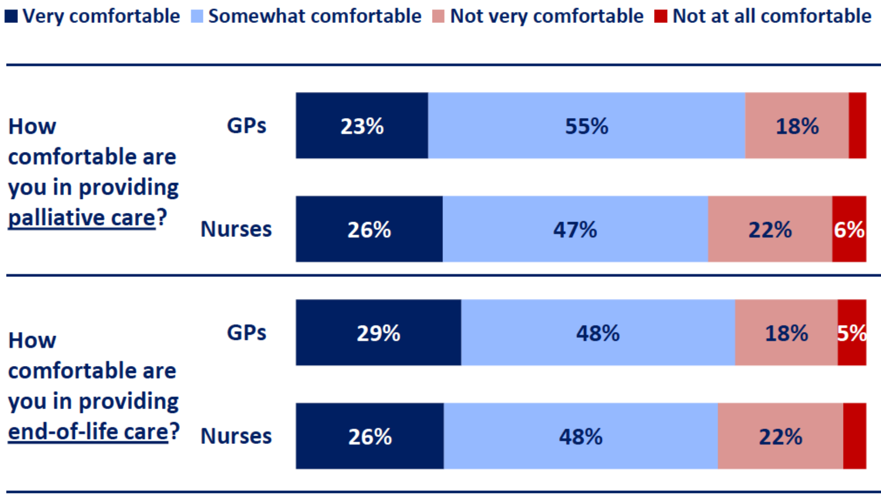
Survey of GP/FPs and Nurses in Primary Care

Ipsos

Final Report, August 2014

Comfort in Providing Palliative and End-of-Life Care

- **Most GP/FPs and nurses are only somewhat comfortable with providing palliative care**.
- On average, one-quarter to three in ten say they are 'very comfortable' providing palliative (23%) or end-of-life care (29%). However, the proportion who are not at all comfortable is very low (5% or less).
- Ontario GP/FPs are less comfortable than other regions.
- Nurses in Quebec are directionally less comfortable than those in other regions.



% Comfortable

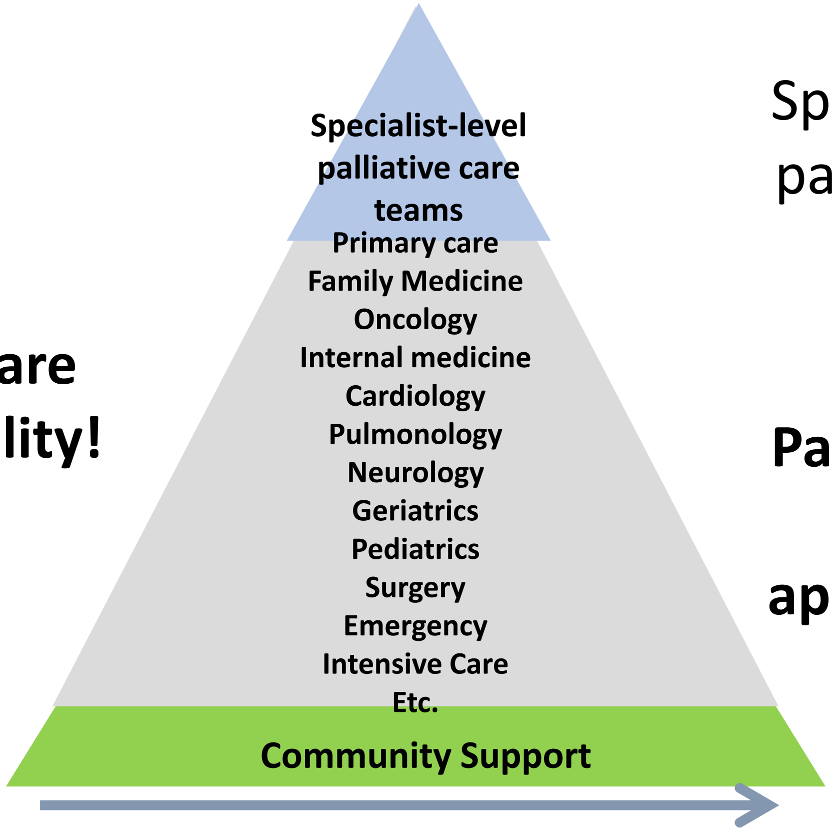
	Total	ON	QB	West	Atl
Palliative care – GPs	79%	65%	80%	87%	100%
Palliative care – Nurses	73%	78%	58%	75%	82%
End-of-life care – GPs	77%	67%	80%	82%	94%
End-of-life care – Nurses	75%	81%	58%	80%	77%

Values 4% and below not labeled

8. How comfortable are you in providing palliative care?
9. How comfortable are you in providing end-of-life care?
Base: All respondents (Physician n=286); (Nurses n=200)

Palliative care: It is everyone's business

Concept



We all share responsibility!

Specialist-level palliative care teams

Primary care
Family Medicine
Oncology
Internal medicine
Cardiology
Pulmonology
Neurology
Geriatrics
Pediatrics
Surgery
Emergency
Intensive Care
Etc.

Community Support

Specialist palliative care

Palliative Care approach

Diagnosis **Illness trajectory** Death

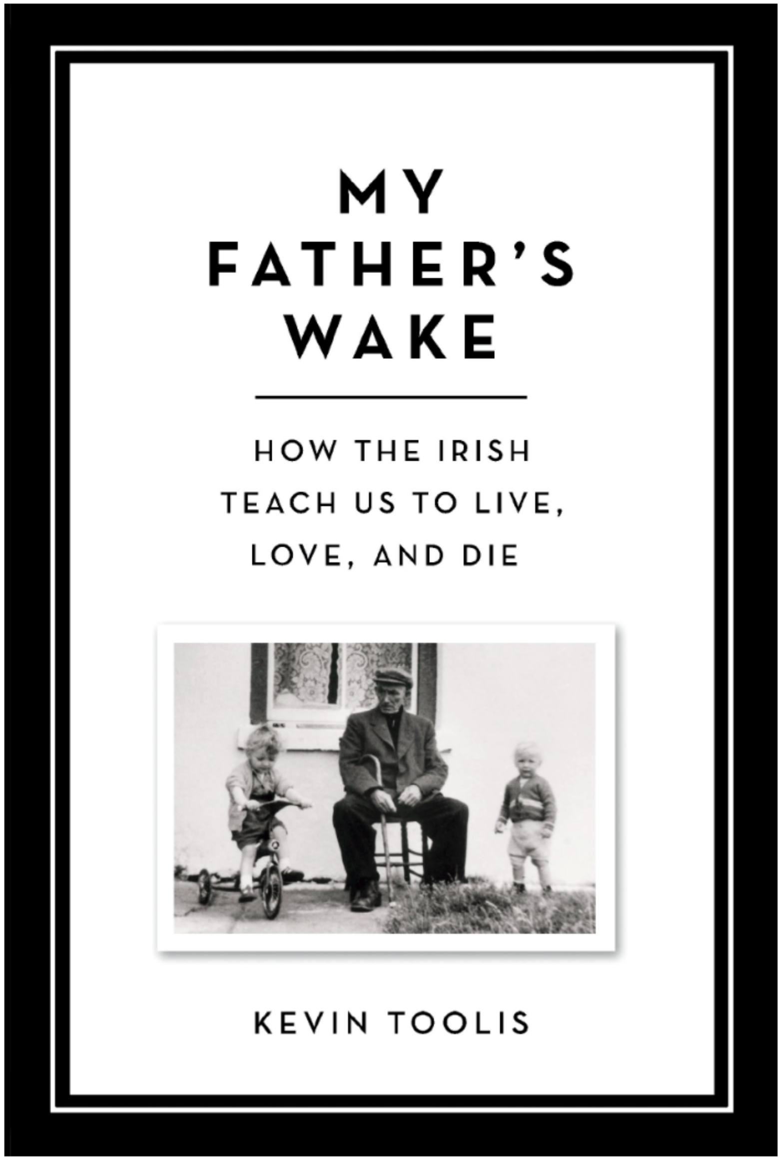
Dying

is not fundamentally a medical event, it

is a social event

that happens in the family and community.

Kelley, M. L. (2016 Presentation): *Bringing Dying Back into the Community*



MY
FATHER'S
WAKE

HOW THE IRISH
TEACH US TO LIVE,
LOVE, AND DIE

KEVIN TOOLIS

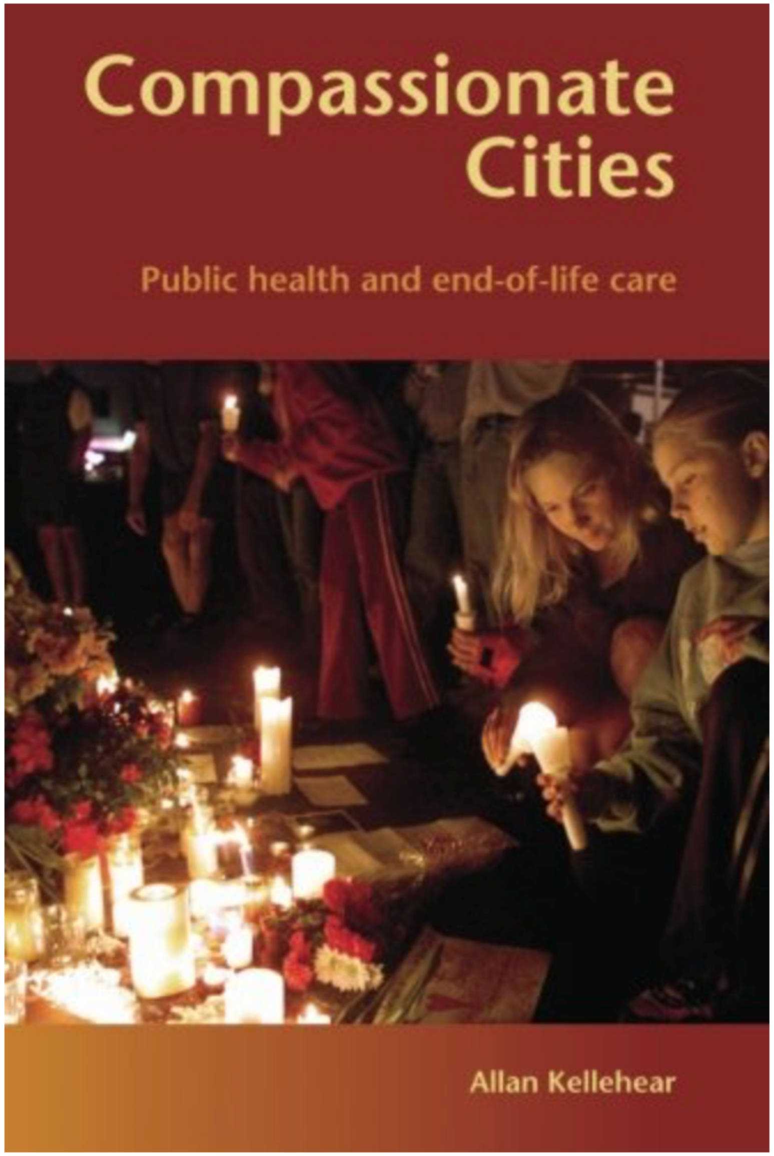
"The 'Western Death Machine' has hidden the dead and dying, but in a remote island off the west coast of Ireland, an almost Homeric society clings to the old ways. The dying are treasured and tenderly watched over, the dead are honored with the ancient rites and rituals. Contemporary western ideas about death are dominated by individualism; My Father's Wake is a lyrical description of how community and tradition help us deal with our mortality."

Seamus O'Mahony, author of The Way We Die Now

DEMENTIA IN CANADA:

A National Strategy for Dementia-friendly Communities

Standing Senate Committee on Social Affairs, Science and Technology, Nov 2016

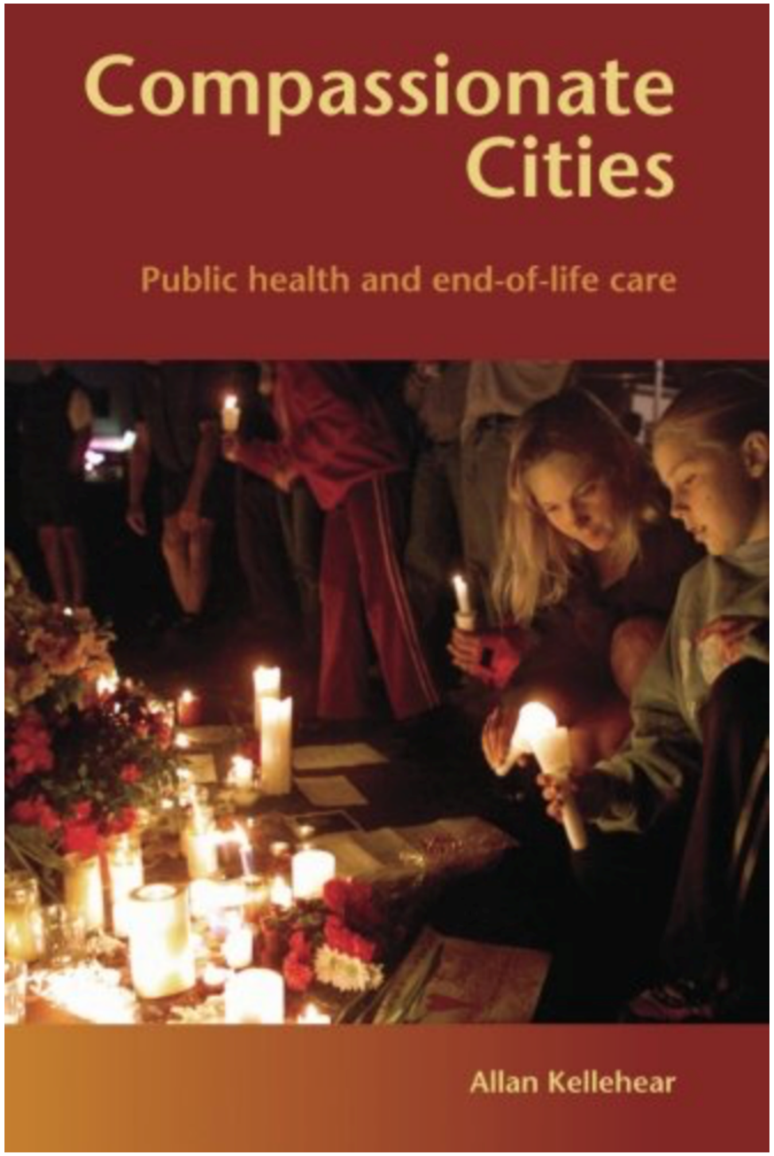


Compassionate Communities

Some steps we might take on this journey:

- **Creating models that help us "live until we die".**
- **Changing medical paradigms to focus on maximizing quality of life in late life dementia.**
- **Deprofessionalize dying – it is a natural and normal part of life.**
- **Public education about dementia, aging and dying.**
- **Reclaim ritual and means to support people.**

Living and Dying with Dementia: Dialogues About Palliative Care, N. Small, K. Froggatt, M. Downs, Oxford University Press Inc., New York, 2007.



Compassionate Communities

"We ourselves are on our journey, but we also journey with each other. A focus on gaining (or regaining) a sense of collective community compassion as proposed by Kellehear will provide us with at least some of the support we need."

Living and Dying with Dementia: Dialogues About Palliative Care, N. Small, K. Froggatt, M. Downs, Oxford University Press Inc., New York, 2007.

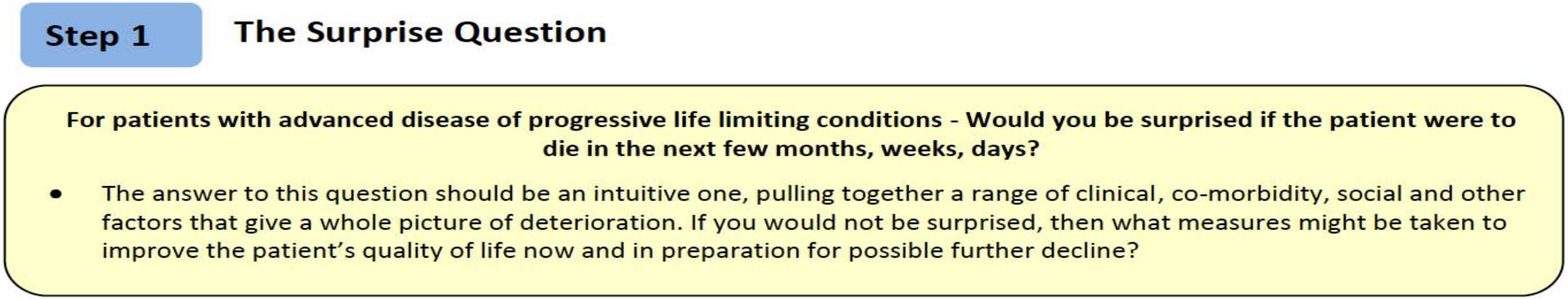
[24] *Dementia in Canada: A National Strategy for Dementia-friendly Communities*

Gold Standards Framework - UK

Three triggers that suggest that people are approaching the end of life:

1. **The Surprise Question: "Would you be surprised if this person died within the next 12 months?'**
2. **General indicators of decline.**
3. **Specific clinical indicators related to their specific condition.**

Prognostic Indicator Guidance (PIG) 4th Edition Oct 2011 © The Gold Standards Framework Centre In End of Life Care CIC, Thomas.K et al



Step 1 **The Surprise Question**

For patients with advanced disease of progressive life limiting conditions - Would you be surprised if the patient were to die in the next few months, weeks, days?

- The answer to this question should be an intuitive one, pulling together a range of clinical, co-morbidity, social and other factors that give a whole picture of deterioration. If you would not be surprised, then what measures might be taken to improve the patient's quality of life now and in preparation for possible further decline?

"Would I be surprised if this person died in the next 6-12 months?"

If the answer is "no", then consider activating a palliative approach if not already done.

But the challenge is "knowing the answer" in late life dementia.

Lynn, Joanne, Living Long in Fragile Health: The New Demographics Shape End of Life Care. Hastings Center, 2005. https://www.rand.org/pubs/reprints/RP1200.html.

Gold Standards Framework – Prognostic Indicator Guidance

- General Indicators of decline:
  - Decreasing activity – spending more and more time in bed, more dependent for ADLs and limited self-care.
  - General physical decline and increasing needs for support
  - Progressive weight loss (>10% in past 6 months)
  - Decreasing response to treatment or no further active treatment to reverse disease
  - Advanced disease with unstable, deteriorating complex symptom burden
  - Co-morbidities
  - Repeated unplanned/crisis admissions

Prognostic Indicator Guidance (PIG) 4th Edition Oct 2011 © The Gold Standards Framework Centre In End of Life Care CIC, Thomas.K et al

Step 3

Specific Clinical Indicators - flexible criteria with some overlaps, especially with Those with frailty and other co-morbidities.

c) Frailty / Dementia – gradual decline

Frailty

Individuals who present with Multiple co morbidities with significant impairment in day to day living and:

- Deteriorating functional score e.g. performance status – Barthel/ECOG/Karnofksy
- Combination of at least three of the following symptoms:
  - weakness
  - slow walking speed
  - significant weight loss
  - exhaustion
  - low physical activity
  - depression.

Stroke

- Persistent vegetative or minimal conscious state or dense paralysis
- Medical complications
- Lack of improvement within 3 months of onset
- Cognitive impairment / Post-stroke dementia.

Dementia

There are many underlying conditions which may lead to degrees of dementia and these should be taken into account. Triggers to consider that indicate that someone is entering a later stage are:

- Unable to walk without assistance and
- Urinary and faecal incontinence, and
- No consistently meaningful conversation and
- Unable to do Activities of Daily Living (ADL)
- Barthel score <3.

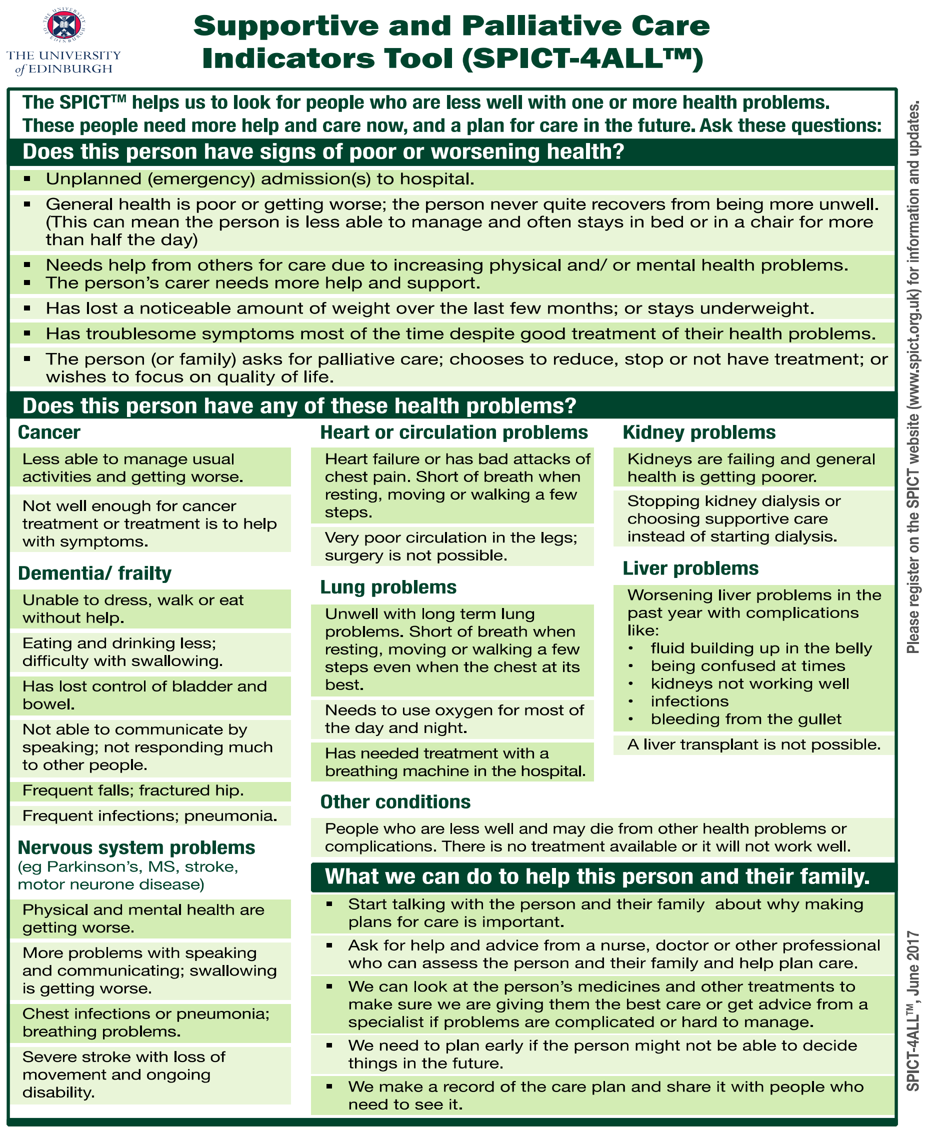
Plus any of the following:

- Weight loss
- Urinary tract Infection
- Severe pressures sores – stage three or four
- Recurrent fever
- Reduced oral intake
- Aspiration pneumonia.

It is vital that discussions with individuals living with dementia are started at an early to ensure that whilst they have mental capacity they can discuss how they would like the later stages managed.

Prognostic Indicator Guidance (PIG) 4th Edition Oct 2011 © The Gold Standards Framework Centre In End of Life Care CIC, Thomas.K et al

SPICT – Supportive and Palliative Care Indicators Tool



THE UNIVERSITY *of* EDINBURGH

Supportive and Palliative Care Indicators Tool (SPICT-4ALL™)

The SPICT™ helps us to look for people who are less well with one or more health problems. These people need more help and care now, and a plan for care in the future. Ask these questions:

Does this person have signs of poor or worsening health?

- Unplanned (emergency) admission(s) to hospital.
- General health is poor or getting worse; the person never quite recovers from being more unwell. (This can mean the person is less able to manage and often stays in bed or in a chair for more than half the day)
- Needs help from others for care due to increasing physical and/ or mental health problems.
- The person's carer needs more help and support.
- Has lost a noticeable amount of weight over the last few months; or stays underweight.
- Has troublesome symptoms most of the time despite good treatment of their health problems.
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Does this person have any of these health problems?

Cancer

Less able to manage usual activities and getting worse.

Not well enough for cancer treatment or treatment is to help with symptoms.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Has lost control of bladder and bowel.

Not able to communicate by speaking; not responding much to other people.

Frequent falls; fractured hip.

Frequent infections; pneumonia.

Nervous system problems
(eg Parkinson's, MS, stroke, motor neurone disease)

Physical and mental health are getting worse.

More problems with speaking and communicating; swallowing is getting worse.

Chest infections or pneumonia; breathing problems.

Severe stroke with loss of movement and ongoing disability.

Heart or circulation problems

Heart failure or has bad attacks of chest pain. Short of breath when resting, moving or walking a few steps.

Very poor circulation in the legs; surgery is not possible.

Lung problems

Unwell with long term lung problems. Short of breath when resting, moving or walking a few steps even when the chest at its best.

Needs to use oxygen for most of the day and night.

Has needed treatment with a breathing machine in the hospital.

Kidney problems

Kidneys are failing and general health is getting poorer.

Stopping kidney dialysis or choosing supportive care instead of starting dialysis.

Liver problems

Worsening liver problems in the past year with complications like:
- fluid building up in the belly
- being confused at times
- kidneys not working well
- infections
- bleeding from the gullet

A liver transplant is not possible.

Other conditions

People who are less well and may die from other health problems or complications. There is no treatment available or it will not work well.

What we can do to help this person and their family.

- Start talking with the person and their family about why making plans for care is important.
- Ask for help and advice from a nurse, doctor or other professional who can assess the person and their family and help plan care.
- We can look at the person's medicines and other treatments to make sure we are giving them the best care or get advice from a specialist if problems are complicated or hard to manage.
- We need to plan early if the person might not be able to decide things in the future.
- We make a record of the care plan and share it with people who need to see it.

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT-4ALL™, June 2017

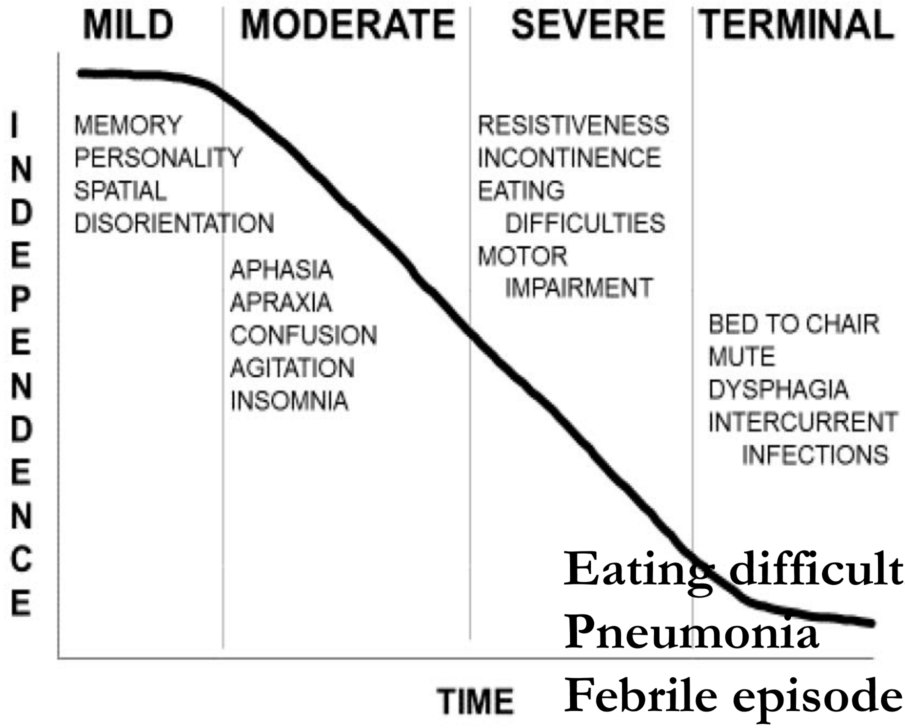
www.spict.org.uk

Toolkit for implementing the Namaste Care programme for people with advanced dementia living in care homes.

M. Stacpoole

Dr. A. Thompsell

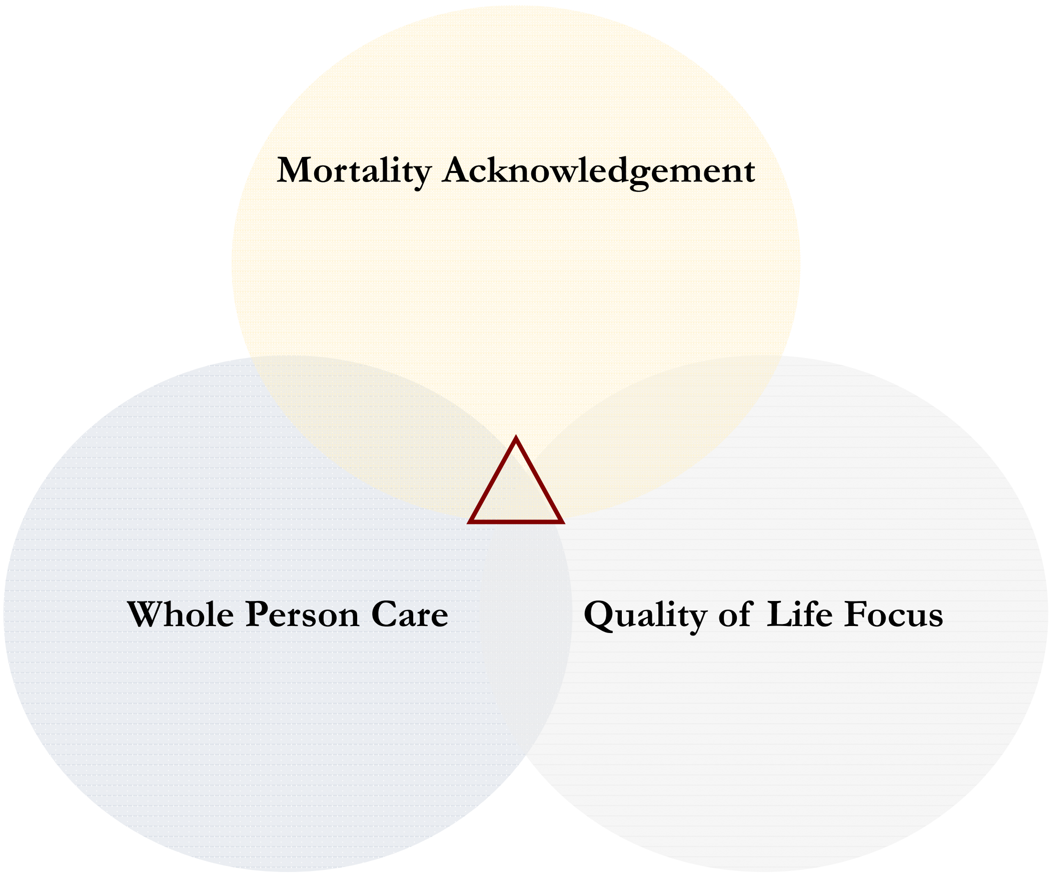
Dr. Jo Hockley



Eating difficulties
Pneumonia
Febrile episodes

Course of progressive dementias. Reprinted from Mahoney, E.K. et al. (2000) Management of Challenging Behaviors in Dementia with permission from Health Professions Press, Baltimore

Integrated Palliative Approach to Care



Mortality Acknowledgement

Whole Person Care

Quality of Life Focus

Personalized
and
Proactive

“ A Good Death”

- **Being treated as an individual, with dignity and respect;**

(Emotional and Spiritual)

- **Being without pain and other symptoms;**

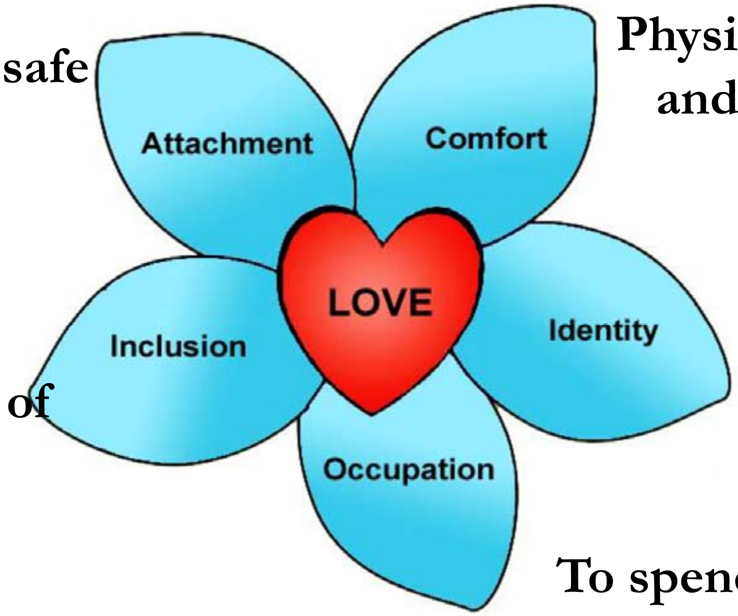
(Physical)

- **Being in familiar surroundings; and**
- **Being in the company of close family and/or friends.**

(Social)

End of Life Care Strategy – promoting high quality care for all adults at the end of life. UK Dept of Health 2008

Fundamental Needs of People with Dementia – Kitwood (1997)



To feel loved and safe

Physically and mentally relaxed and not in pain.

Companionship, feel part of the world, not lonely or excluded.

To be respected as a unique individual and have a sense of self-worth

To spend your time meaningfully and not be bored.

Reproduced with permission from Kitwood T (1997). 'Dementia Reconsidered the person comes first'. Fig. 5.2 page 82. Open University Press, Maidenhead, UK

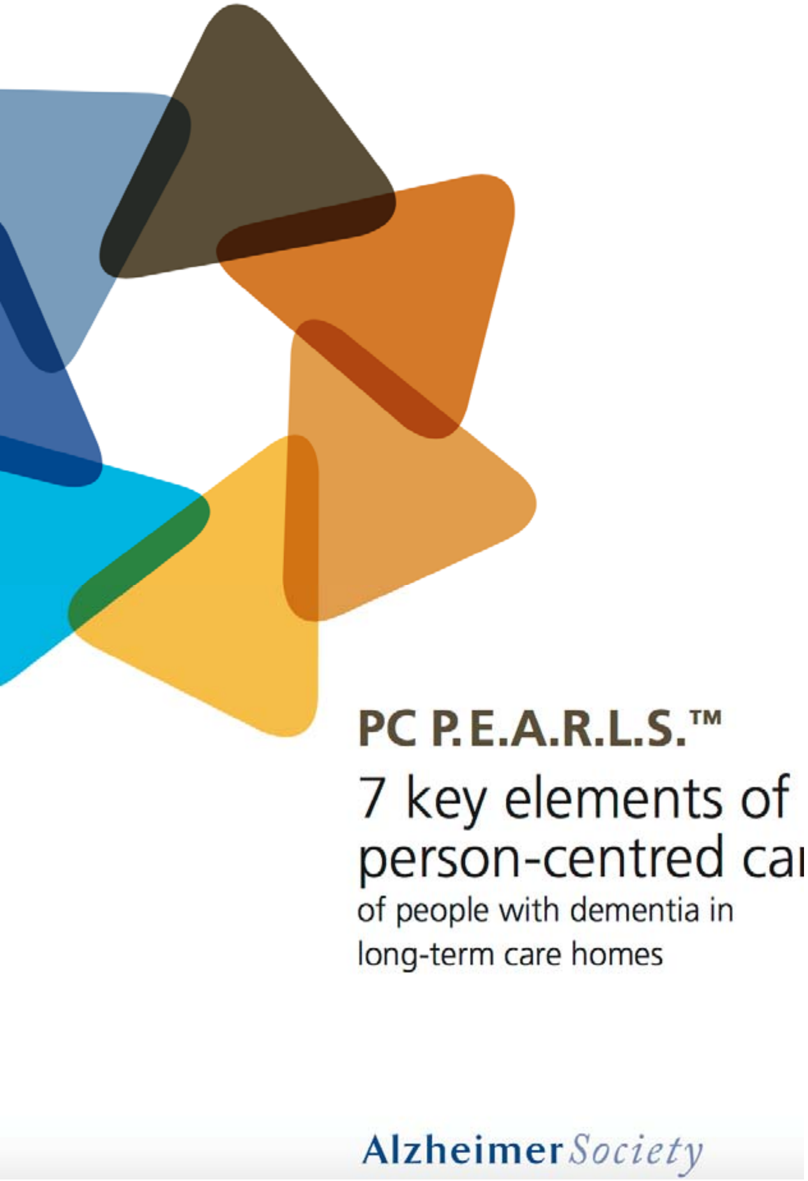
Toolkit for implementing the Namaste Care programme for people with advanced dementia living in care homes
Stacpoole, Thompsell and Hockley, St. Christopher's, 2016.

Guidelines for Care:

Person-centred care of people with dementia living in care homes

Framework

January 2011
Alzheimer Society of Canada : www.alheimer.ca



PC P.E.A.R.L.S.™

7 key elements of person-centred ca

of people with dementia in long-term care homes

Alzheimer *Society*

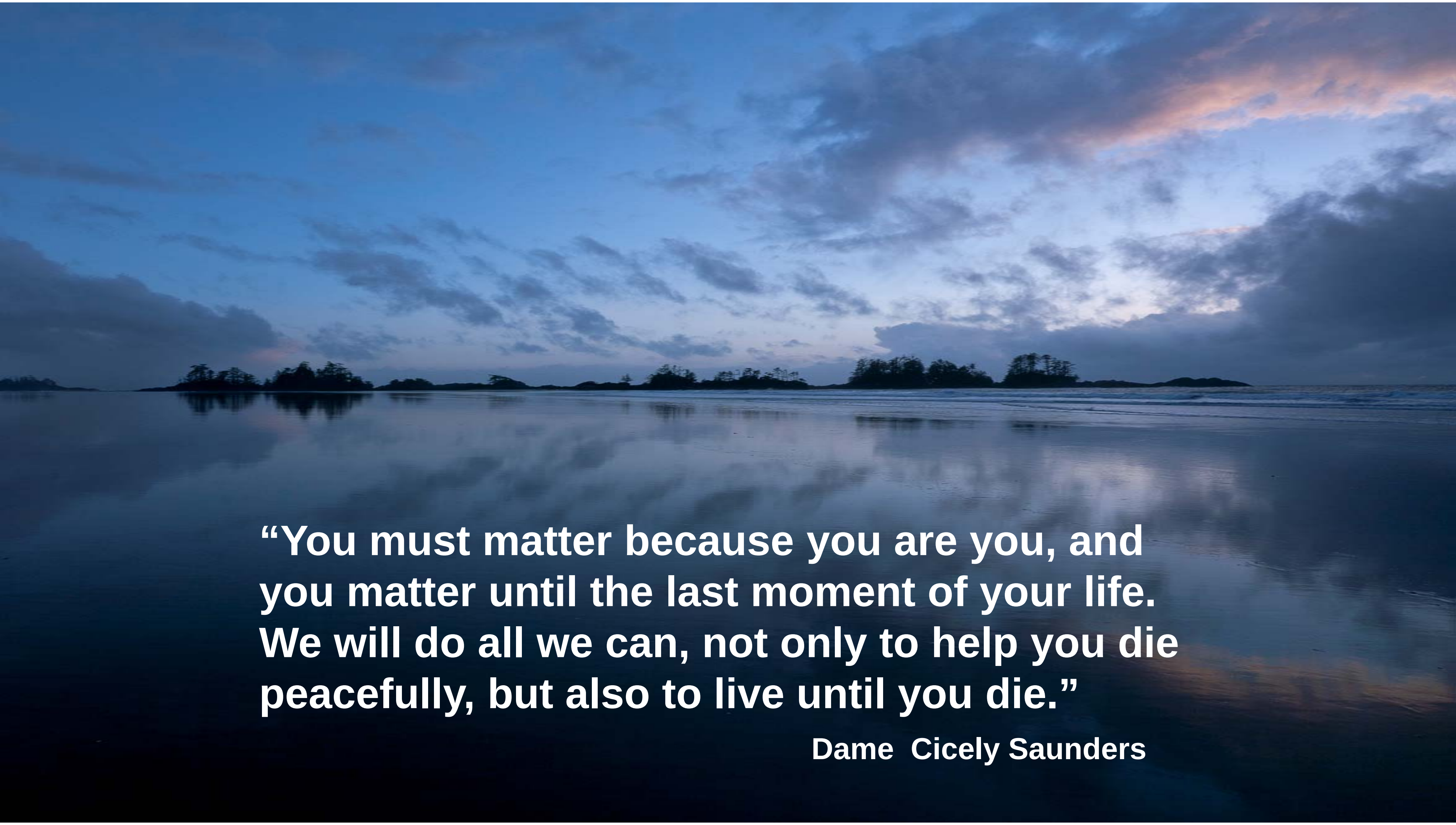
Alzheimer Society of Canada

[http://alzheimer.ca/sites/default/files/files](http://alzheimer.ca/sites/default/files/files/national/culture-change/pcpearls_full_e.pdf)
/national/culture-change/pcpearls_full_e.pdf

A Personalized Approach to Care

Being treated as an individual, with dignity and respect.

Honouring who the person is that we are caring for.



“You must matter because you are you, and you matter until the last moment of your life. We will do all we can, not only to help you die peacefully, but also to live until you die.”

Dame Cicely Saunders

"You matter"

"You are you"

Dignity

from the Latin “dignus” - worthy

Worthy: deserving, meriting
- having worth, value or merit

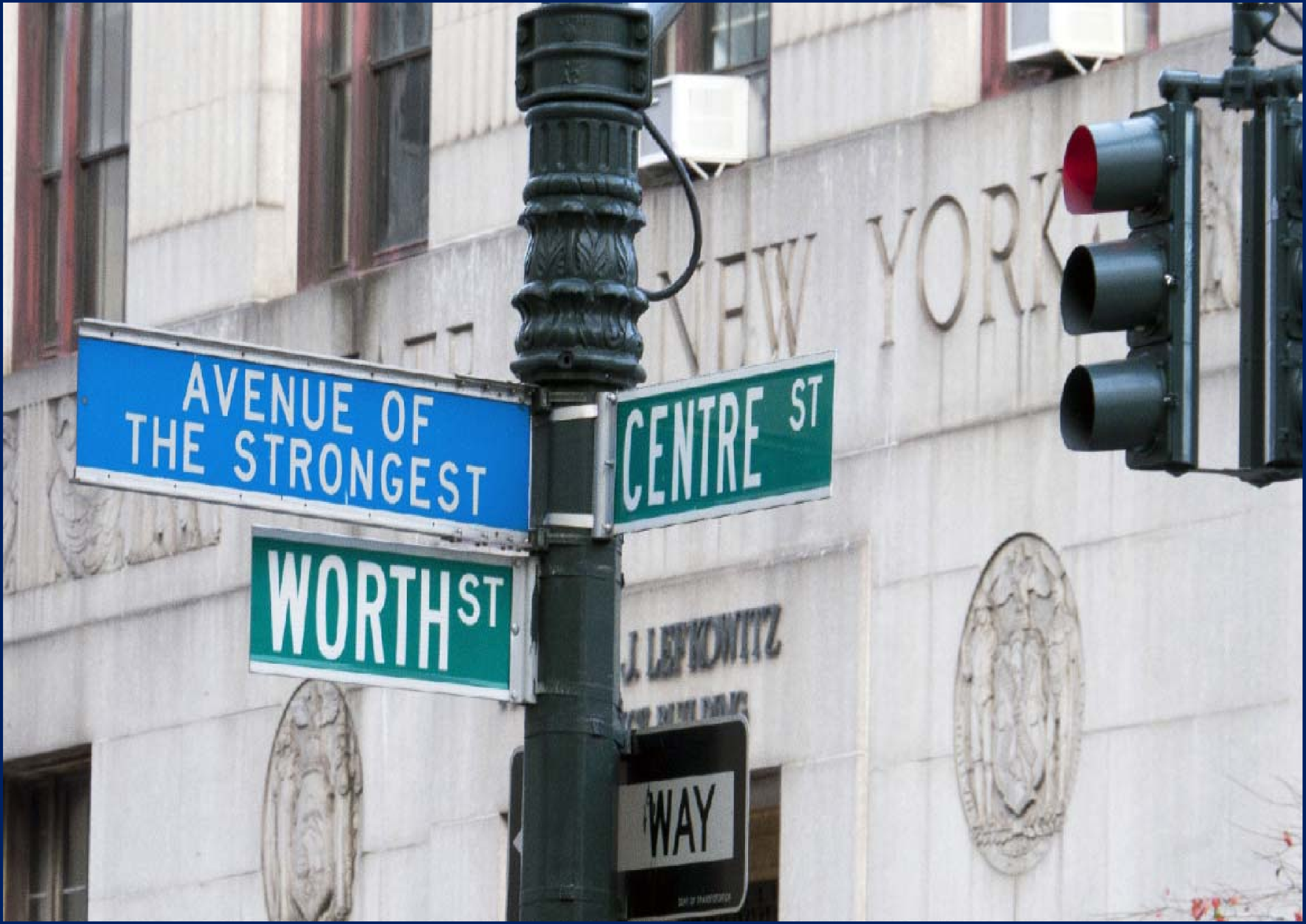
Dignity is:

“ The quality or state of being worthy, honored or esteemed.”

(the intrinsic worthiness as a human being)

“ The feeling that I am respected and worthy of respect, despite what is happening to me.”

H. M. Chochinov


AVENUE OF THE STRONGEST
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NEW YORK
J. LEFKOWITZ
WAY

Dignity is nurtured and supported by the personal relationships with others around us (a sense of how one is treated).

- H. M. Chochinov

“We are a mirror.”

H. M. Chochinov

Personhood - Kitwood

The greatest threat to a person's well-being comes from a potential loss of personhood.

Personhood is created by interaction with others.

Personhood is a "standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust".

Living and Dying with Dementia: Dialogues About Palliative Care. Small, Froggatt and Downs, Oxford University Press, 2007

What if:

"Quality of life"
and dignity

Depended on:

“Quality of Care”

“Quality of Caring”

> “Care is not the task you are doing, but the conversation you are having with the resident while doing it.”
>
> – Client relations coordinator

PC P.E.A.R.L.S.
7 key elements of
person-centred care of people with dementia in long-term care homes
Alzheimer Society of Canada, 2014

ABCD’s of Dignity Conserving Care

A: Attitude : my attitude towards that person – how does it affect them?

B: Behavior: the nature of our interactions – “care tenor” – kindness and respect.

C: Compassion: connecting with our own feelings and consideration of human life experience (hearing their story).

D: Dialogue: acknowledging their personhood and distress

HM Chochinov, 2007

- " … the real event in death takes place in the realm of the invisible. At a deathbed the merely physical eye sees an old man, worn and weary, breathing his last. At a deeper level, however, this death is an event where the inner life of this person is gathering and refining itself to slip through the door of air. No-one dies poor or empty. The subtle harvest of memory collects here: all the days and places of a life, all the faces, the words and thoughts, the images, all the small transfigurations that no-one else noticed, all the losses, the delights, the suffering and the surprises. All the experiences of a life collect together in their final weave."

John O'Donohue, Beauty: The Invisible Embrace

“Alive Inside" - Henry

Source:
www.aliveinside.org

Principles of Dignity-Enhancing Care

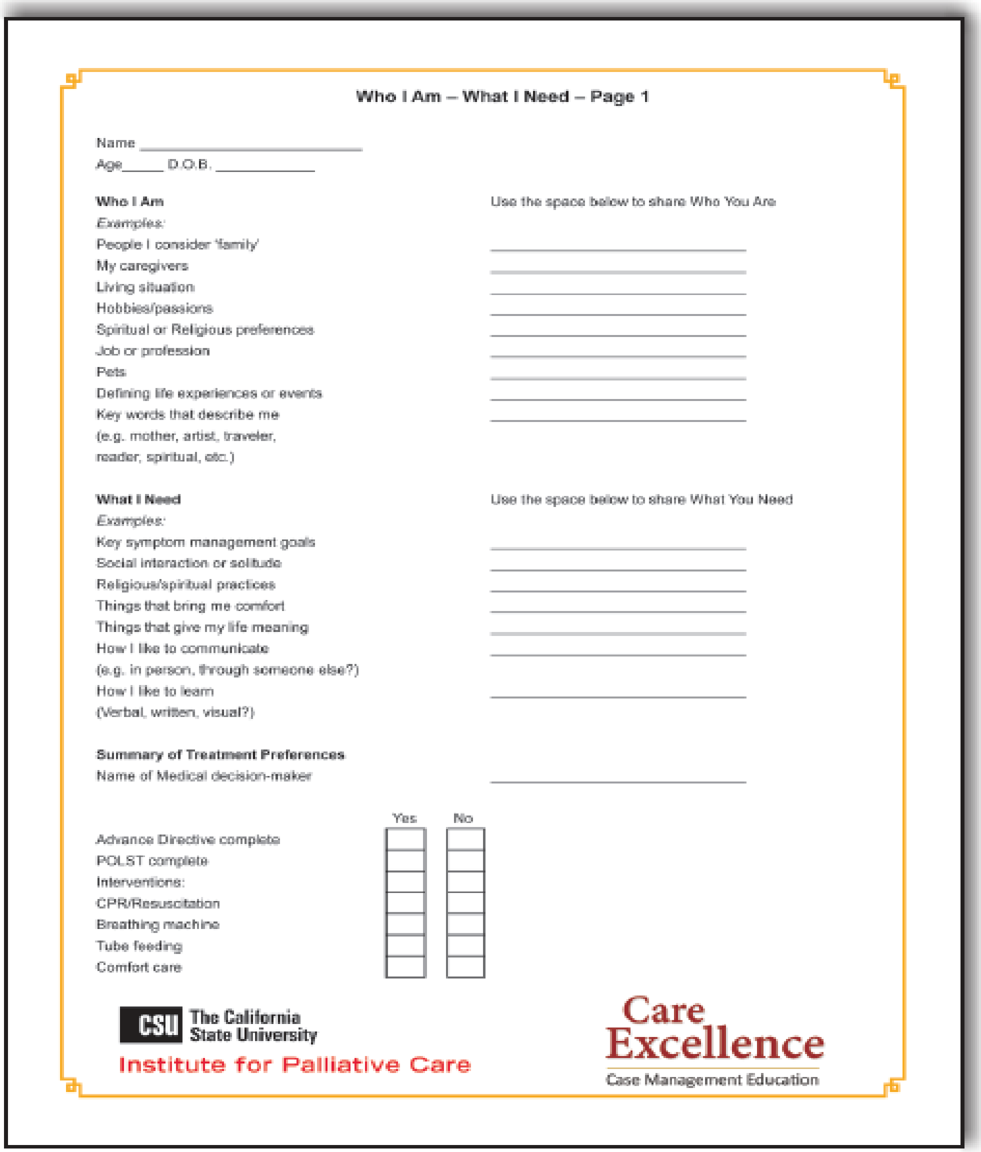
- Affirm the person's value: "You matter."
- "You are you." - "Personhood" vs "patienthood"

Who we are as a person dissolves into who we are as a patient, and "self" begins to disintegrate. We lose our identity as our real selves. We "vanish".

“Who I Am – What I Need”

The California State University

Institute for Palliative Care



Who I Am – What I Need – Page 1

Name ____________________

Age_____ D.O.B. ___________

Who I Am

Examples:

People I consider 'family'

My caregivers

Living situation

Hobbies/passions

Spiritual or Religious preferences

Job or profession

Pets

Defining life experiences or events

Key words that describe me

(e.g. mother, artist, traveler, reader, spiritual, etc.)

Use the space below to share Who You Are

What I Need

Examples:

Key symptom management goals

Social interaction or solitude

Religious/spiritual practices

Things that bring me comfort

Things that give my life meaning

How I like to communicate

(e.g. in person, through someone else?)

How I like to learn

(Verbal, written, visual?)

Use the space below to share What You Need

Summary of Treatment Preferences

Name of Medical decision-maker ____________________

	Yes	No
Advance Directive complete	☐	☐
POLST complete	☐	☐
Interventions:	☐	☐
CPR/Resuscitation	☐	☐
Breathing machine	☐	☐
Tube feeding	☐	☐
Comfort care	☐	☐

CSU The California State University

Institute for Palliative Care

Care Excellence

Case Management Education

Proactive

Anticipating the needs of person with late life dementia and their families.

Advance Care Planning/Goals of Care conversations

Pain and symptom management

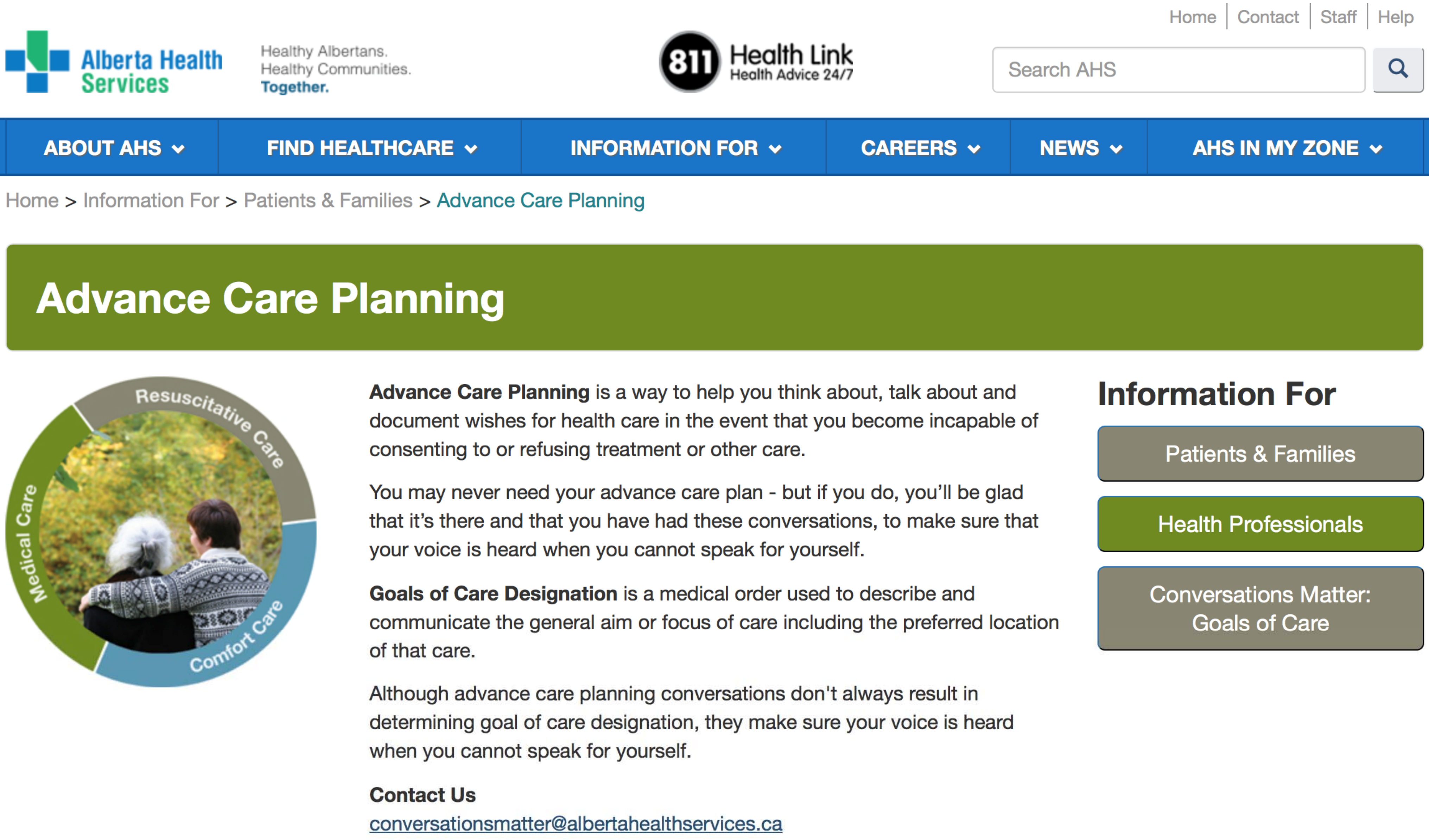
Final days.

Speak Up

Start the conversation
about end-of-life care

It's about conversations.
It's about decisions.

www.advancecareplanning.ca



Advance Care Planning

Advance Care Planning is a way to help you think about, talk about and document wishes for health care in the event that you become incapable of consenting to or refusing treatment or other care.

You may never need your advance care plan - but if you do, you'll be glad that it's there and that you have had these conversations, to make sure that your voice is heard when you cannot speak for yourself.

Goals of Care Designation is a medical order used to describe and communicate the general aim or focus of care including the preferred location of that care.

Although advance care planning conversations don't always result in determining goal of care designation, they make sure your voice is heard when you cannot speak for yourself.

Contact Us
conversationsmatter@albertahealthservices.ca

Information For

Advance Care Planning/Goals of Care

Having conversations with family regarding signs that end of life is nearing:

- The <u>natural progression</u> of dementia
- Loss of the ability to verbally communicate
- Change in the ability to swallow and eat, loss of appetite and intake.
- Changes in mobility and functional decline.
- Recurrent infections – risk of pneumonia, UTIs
- The natural "shutting down" of systems as death nears

Advance Care Planning/Goals of Care

“What are you seeing with your mother?”

“How quickly have you noticed these changes happening?”

“Would you say she is changing week by week or day by day now?”

Advance Care Planning/Goals of Care

What would your mom want? Has she expressed her wishes in the past? How can we honour those wishes?

Can we focus on comfort? What does comfort look like?

Where would she like to be for her final days?

Some of the things we might talk about…

Resuscitation/DNR – “allow natural death”

Artificial hydration and nutrition when not eating or drinking as much

Treating infections like pneumonia.

Some of the things we might talk about…

Under what circumstances would we transfer to hospital? Who to call after hours if something happens. Would you ever call 911?

Decreasing mobility and care needs if in bed.

Do you want to talk about what final days might look like?

Advance Care Planning/Goals of Care

“This is what we see as dementia progresses…”

“This is what we see as they get closer to the end of life.”

These are the things we watch for…

We should plan ahead for some things…

Location of Care

Where is ”home”?

“Where would she be most comfortable?”

(Assess: Is this a feasible option? – caregivers, safety)

“What supports do you need to enable this to happen here?”

Advance Care Planning/Goals of Care

“These decisions are difficult.”

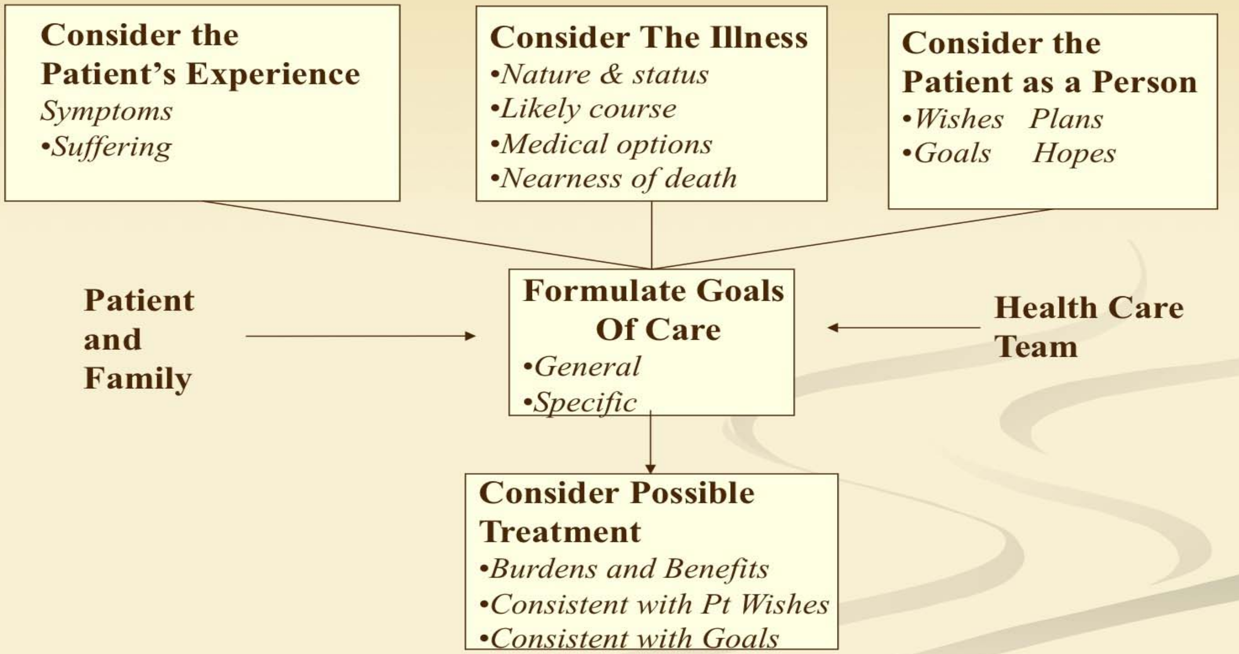
What can we do to support you as a family?

What are your needs to be able to care for her?

Pain and Symptom Management

Treatment options based on Goals of Care

Latimer Ethical Decision Model



Consider the Patient's Experience
Symptoms
- *Suffering*

Consider The Illness
- *Nature & status*
- *Likely course*
- *Medical options*
- *Nearness of death*

Consider the Patient as a Person
- *Wishes Plans*
- *Goals Hopes*

Patient and Family

Formulate Goals Of Care
- *General*
- *Specific*

Health Care Team

Consider Possible Treatment
- *Burdens and Benefits*
- *Consistent with Pt Wishes*
- *Consistent with Goals*

Adapted from:

Latimer, E. (1991). Ethical decision-making in the care of the dying and its applications to clinical practice. *Journal of Pain and Symptom Management, 6*(5), 329-336.

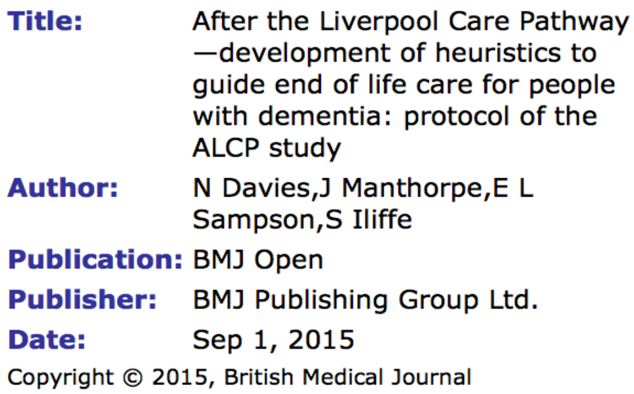
Pain and Symptom Management

- **Pain – Common symptom, often relying on non-verbal assessment**
- **Dyspnea**
- **Swallowing and eating problems**
- **Aspiration/pneumonia/respiratory secretions**
- **Restlessness and agitation/delirium**

Pain and Symptom Management

- Do we have what we need in the home to care for this person until the end of life, with all possible scenarios?
  - Pain/dyspnea – Subcutaneous meds if needed. Opioid.
  - Restlessness/delirium/agitation
  - Foley for urinary retention or to reduce skin breakdown if incontinent.
  - Proper mattress for comfort.
  - Home care support – who to call if an urgent problem arises.

Rules of Thumb for End of Life Care for People with Dementia



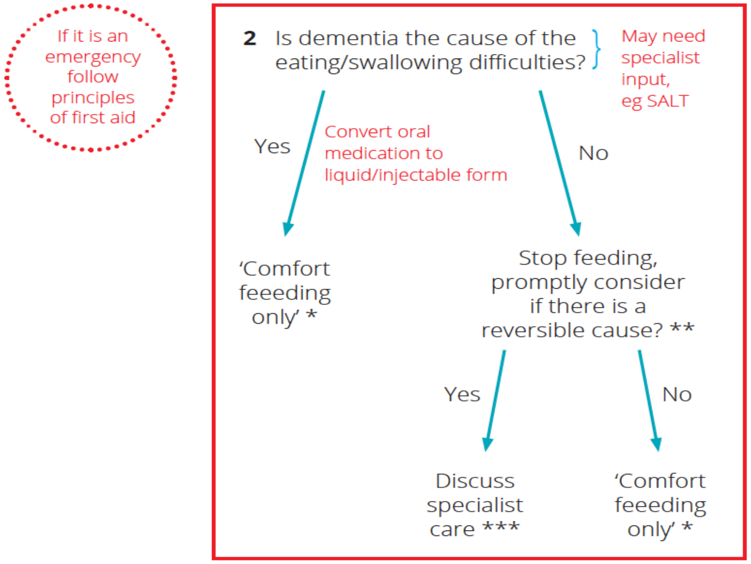
Title: After the Liverpool Care Pathway—development of heuristics to guide end of life care for people with dementia: protocol of the ALCP study
Author: N Davies,J Manthorpe,E L Sampson,S Iliffe
Publication: BMJ Open
Publisher: BMJ Publishing Group Ltd.
Date: Sep 1, 2015

1. **Eating and swallowing difficulties**
2. **Agitation and Restlessness**
3. **Reviewing treatment and interventions at the end of life**
4. **Providing routine care at the EOL**

Rules of Thumb
for End of Life Care
for People with Dementia

Eating/swallowing difficulties

1 Don't let eating/swallowing problems come as a surprise (ensure conversation has occurred with the person with dementia and family or advocate early, around the time of diagnosis). Consider advance care planning (ACP).



If it is an emergency follow principles of first aid

2 Is dementia the cause of the eating/swallowing difficulties?

May need specialist input, eg SALT

Yes

Convert oral medication to liquid/injectable form

'Comfort feeeding only' *

No

Stop feeding, promptly consider if there is a reversible cause? **

Yes

Discuss specialist care ***

No

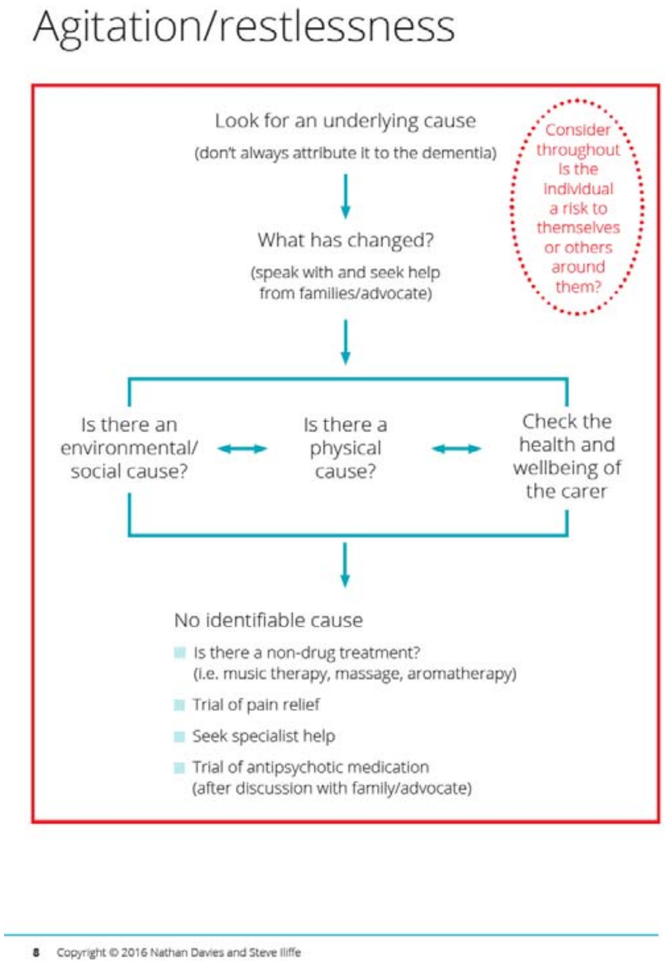
'Comfort feeeding only' *

*Comfort feeding may carry associated risks of aspiration

**Closely observe all intake particularly if changes to swallow function are suspected

*** Consider appropriateness on individual basis

Rules of Thumb for End of Life Care for People with Dementia



Agitation/restlessness

Look for an underlying cause
(don't always attribute it to the dementia)

What has changed?
(speak with and seek help from families/advocate)

Is there an environmental/ social cause? ↔ Is there a physical cause? ↔ Check the health and wellbeing of the carer

Consider throughout is the individual a risk to themselves or others around them?

No identifiable cause

- Is there a non-drug treatment? (i.e. music therapy, massage, aromatherapy)
- Trial of pain relief
- Seek specialist help
- Trial of antipsychotic medication (after discussion with family/advocate)

8 Copyright © 2016 Nathan Davies and Steve Iliffe

Rules of Thumb
for End of Life Care
for People with Dementia

Agitation/restlessness (continued)

- Don't always assume that agitation is due to the dementia, there may be many reasons why the person with dementia is agitated. Look for an underlying cause.
- Think about change, has there been a change with this person? Consider the following three areas and checklists:

Is there an environmental/ social cause? ↔

- Consider the environment e.g: temperature or noise
- Attempt to engage the person in activities of interest to them
- Unfamiliarity
- Boredom
- Consider if cultural values/ beliefs/spirituality are unmet

Is there a physical cause? ↔

If so, then treat the cause. Consider:

- Hunger/thirst – offer food and drink
- Constipation – laxatives
- Urinary retention – catheterise
- Pressure sore/ uncomfortable positioning – wound care and repositioning
- Soiled underwear – address personal hygiene
- Infection or other underlying illness – treat as appropriate/ symptom control
- Pain (consider causes such as arthritis/ill fitting dentures)
- Alcohol/nicotine/ drug withdrawal
- Consider drug/medication side effects

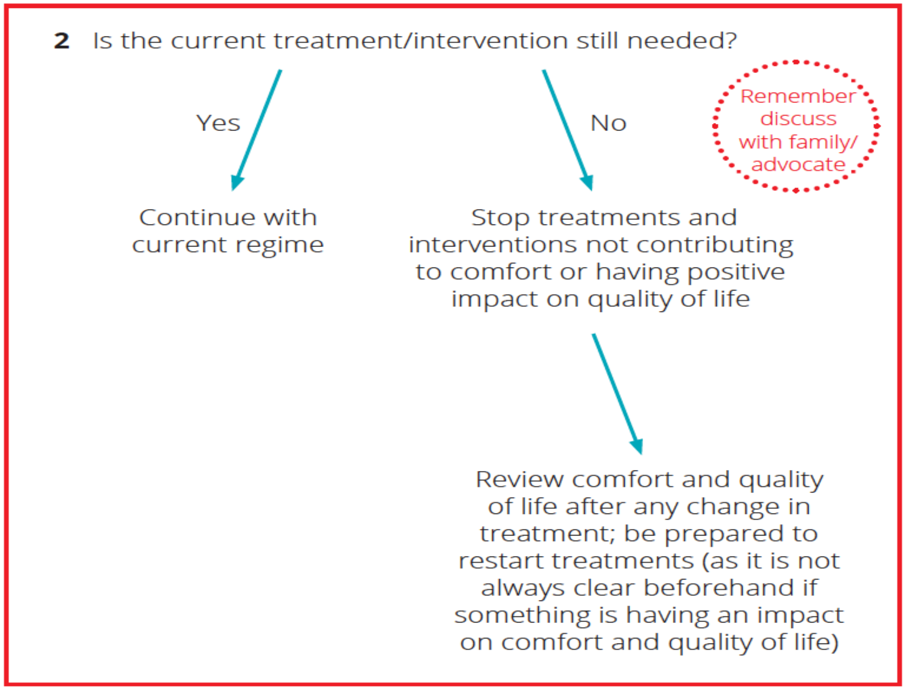
Check the health and wellbeing of the carer

- Consider a carer assessment/review for family/advocate providing care
- Do they have a new or existing condition complicating their ability to provide care?
- Do they feel supported/ have enough support?

Rules of Thumb
for End of Life Care
for People with Dementia

Reviewing treatment and interventions at the end of life

1 Towards the end of life, only continue or initiate medication or interventions that are likely to maintain comfort or have a positive impact on quality of life



2 Is the current treatment/intervention still needed?

Yes → Continue with current regime

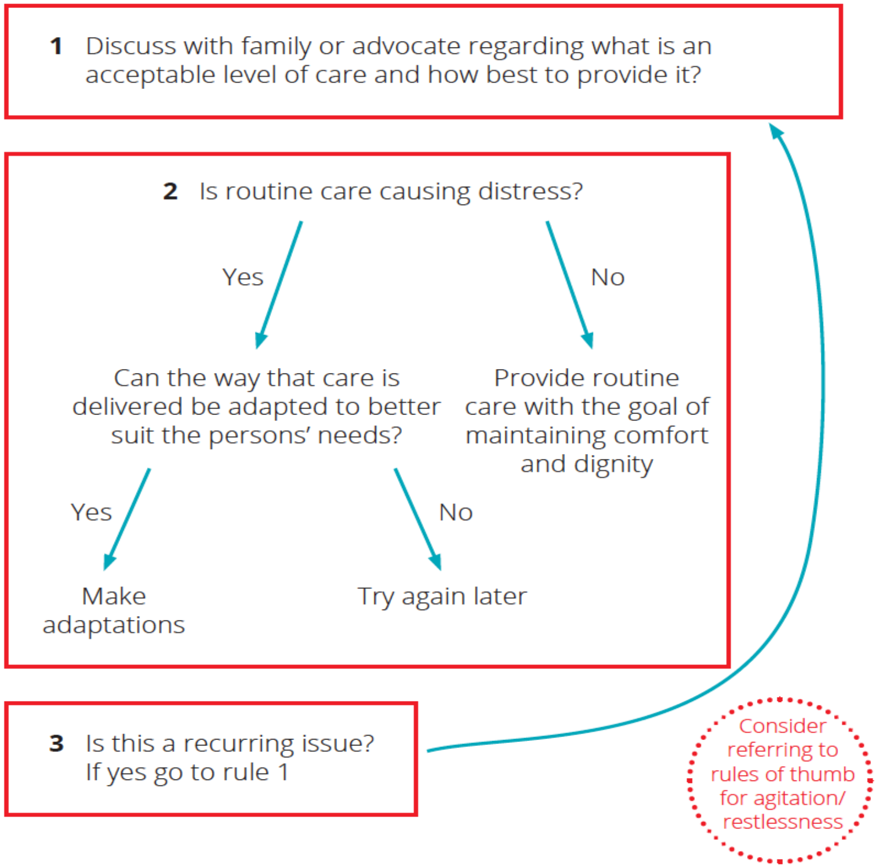
No → Stop treatments and interventions not contributing to comfort or having positive impact on quality of life

→ Review comfort and quality of life after any change in treatment; be prepared to restart treatments (as it is not always clear beforehand if something is having an impact on comfort and quality of life)

Remember discuss with family/ advocate

Rules of Thumb
for End of Life Care
for People with Dementia

Providing routine care at the end of life



1 Discuss with family or advocate regarding what is an acceptable level of care and how best to provide it?

2 Is routine care causing distress?

Yes

Can the way that care is delivered be adapted to better suit the persons' needs?

Yes

Make adaptations

No

Try again later

No

Provide routine care with the goal of maintaining comfort and dignity

3 Is this a recurring issue?
If yes go to rule 1

Consider referring to rules of thumb for agitation/ restlessness

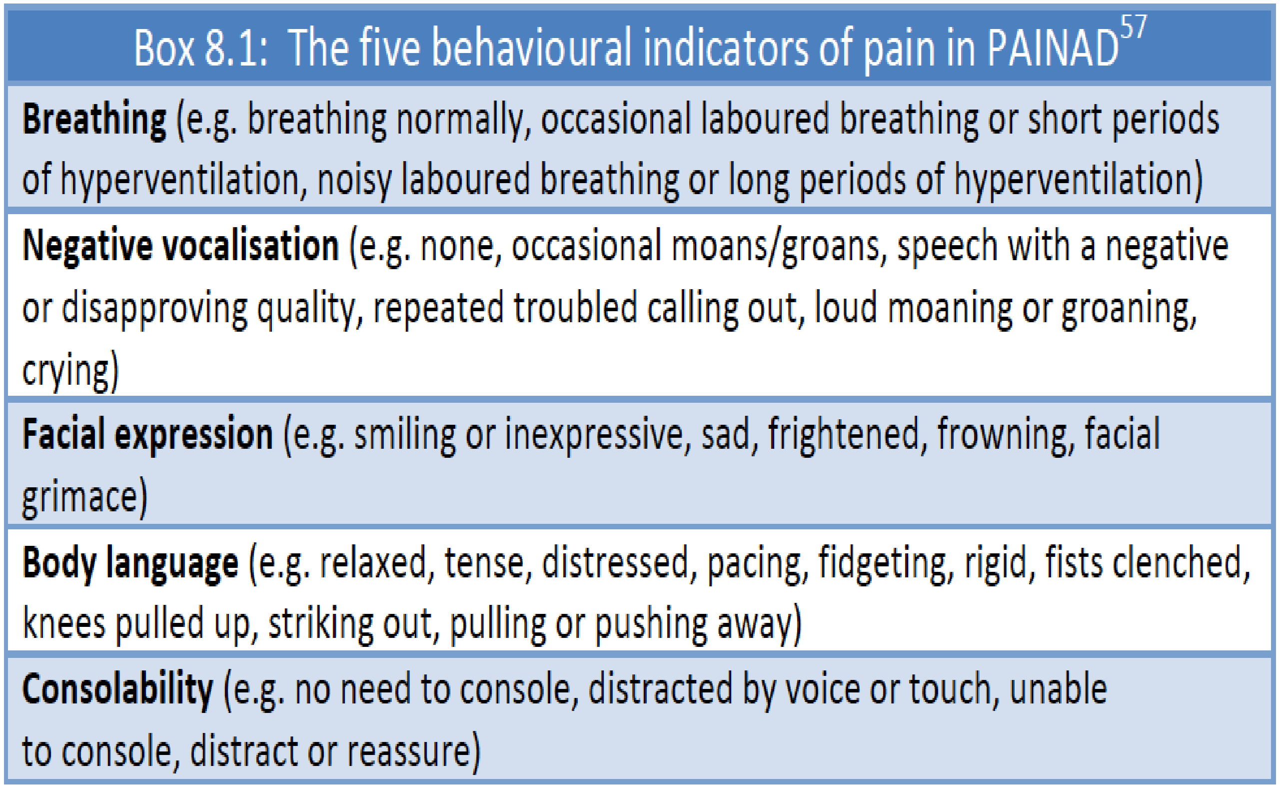
Pain Assessment and Management

Non-verbal cues – agitation/behavior changes

Use tools to assess and monitor response.

Are there non-pharmacological measures to try first? Music, massage, …

Pain Assessment and Management



Box 8.1: The five behavioural indicators of pain in PAINAD[57]

Breathing (e.g. breathing normally, occasional laboured breathing or short periods of hyperventilation, noisy laboured breathing or long periods of hyperventilation)

Negative vocalisation (e.g. none, occasional moans/groans, speech with a negative or disapproving quality, repeated troubled calling out, loud moaning or groaning, crying)

Facial expression (e.g. smiling or inexpressive, sad, frightened, frowning, facial grimace)

Body language (e.g. relaxed, tense, distressed, pacing, fidgeting, rigid, fists clenched, knees pulled up, striking out, pulling or pushing away)

Consolability (e.g. no need to console, distracted by voice or touch, unable to console, distract or reassure)

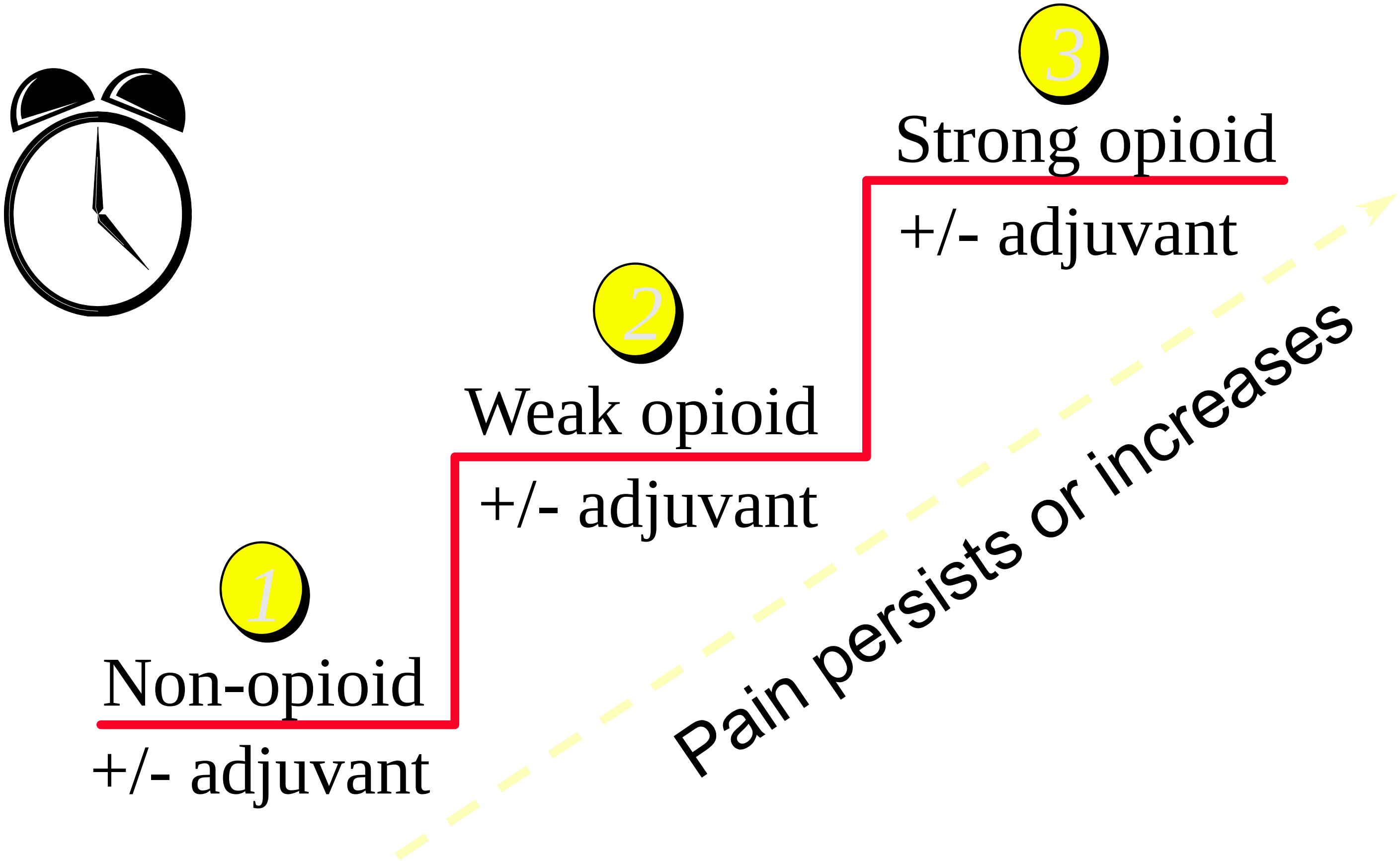
Toolkit for implementing the Namaste Care programme for people with advanced dementia living in care homes
Stacpoole, Thompsell and Hockley, St. Christopher's, 2016.

Pain Assessment and Management

Pain assessment: What is the cause of this pain? Is it somatic (arthritis, pressure ulcer, contractures?) Is it neuropathic?

Tailor treatment to the cause of the pain. Simple analgesics to start, such as acetaminophen, with opioids as a second line.

W.H.O. ANALGESIC LADDER



①
Non-opioid
+/- adjuvant

②
Weak opioid
+/- adjuvant

③
Strong opioid
+/- adjuvant

Pain persists or increases

Non pharmacological measures →

Pain Assessment and Management

Opioids:

Hydromorphone 0.2-0.5 mg po q4-6h and q2h prn(reduce by 50% if given subcutaneously)

Titrate to effect and watch for toxicity.

Don't use opioids for sedation.

Plan ahead for loss of ability to swallow.

Pain Assessment and Management

Bowel routine while on opioids:

- **Sennasides (8.6 mg) 2 tabs qhs (increase to 2 - 4 tabs bid to qid with maximum of 8 tabs /day)**
- **PEG 3350 17 gm in a glass of any liquid daily, increasing up to tid if needed.**
- **Lactulose 15-30 ml once daily, up to 30 ml tid**

- **Dulcolax suppository or fleet enema prn if not moving bowels at least every three days.**

Dyspnea

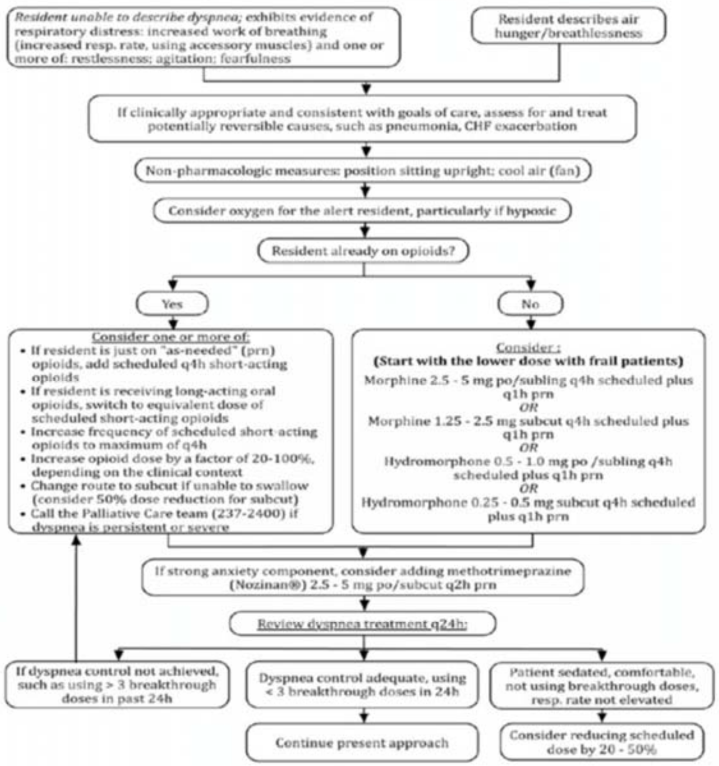
Non-pharmacological measures such as a fan, “presence”, relaxation techniques.

Oxygen in select cases – hypoxia.

Role of antibiotics in pneumonia. Probably prolongs life but may not reduce symptoms.

Opioids if needed – same dosing as for pain.

Pathway E
Dyspnea Management In The Final Days Of Life



Resident unable to describe dyspnea; exhibits evidence of respiratory distress: increased work of breathing (increased resp. rate, using accessory muscles) and one or more of: restlessness; agitation; fearfulness

Resident describes air hunger/breathlessness

If clinically appropriate and consistent with goals of care, assess for and treat potentially reversible causes, such as pneumonia, CHF exacerbation

Non-pharmacologic measures: position sitting upright; cool air (fan)

Consider oxygen for the alert resident, particularly if hypoxic

Resident already on opioids?

Yes

Consider one or more of:

- If resident is just on "as-needed" (prn) opioids, add scheduled q4h short-acting opioids
- If resident is receiving long-acting oral opioids, switch to equivalent dose of scheduled short-acting opioids
- Increase frequency of scheduled short-acting opioids to maximum of q4h
- Increase opioid dose by a factor of 20-100%, depending on the clinical context
- Change route to subcut if unable to swallow (consider 50% dose reduction for subcut)
- Call the Palliative Care team (237-2400) if dyspnea is persistent or severe

No

Consider :
(Start with the lower dose with frail patients)
Morphine 2.5 - 5 mg po/subling q4h scheduled plus q1h prn
OR
Morphine 1.25 - 2.5 mg subcut q4h scheduled plus q1h prn
OR
Hydromorphone 0.5 - 1.0 mg po /subling q4h scheduled plus q1h prn
OR
Hydromorphone 0.25 - 0.5 mg subcut q4h scheduled plus q1h prn

If strong anxiety component, consider adding methotrimeprazine (Nozinan®) 2.5 - 5 mg po/subcut q2h prn

Review dyspnea treatment q24h:

If dyspnea control not achieved, such as using > 3 breakthrough doses in past 24h

Dyspnea control adequate, using < 3 breakthrough doses in 24h

Continue present approach

Patient sedated, comfortable, not using breakthrough doses, resp. rate not elevated

Consider reducing scheduled dose by 20 - 50%

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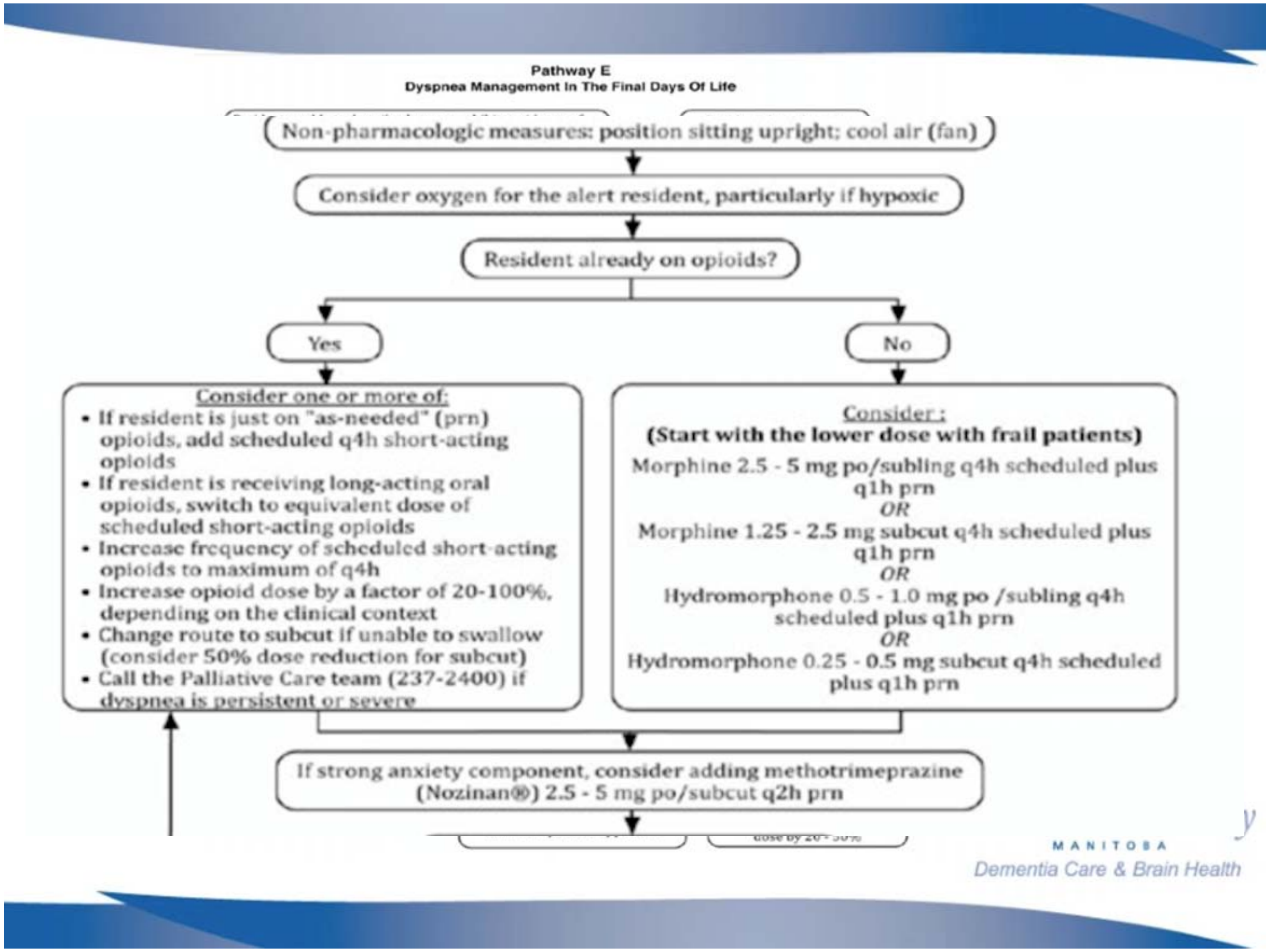

Pathway E

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Respiratory Secretions

Non-pharmacological measures-positioning.

Explanation to the family.

If distressing to family, consider an anticholinergic such as:

scopolamine or glyccopyrolate (0.2-0.4 mg subcut q4h prn)

Delirium/ terminal restlessness

Non-pharmacological measures.

Use meds if distressing symptoms.

Explanation to the family.

If needed, treat the symptoms:

Haloperidol/Olanzepine/Quetiapine or Methotrimeprazine for significant agitation/hallucinations.

May need to add Midazolam 1-2 mg subcut q30-60 min prn for severe restlessness.

Final Days

Talk about what to expect if the family want to know:

- Breathing changes
- Skin mottling of the hands and feet
- Increased drowsiness
- Less oral intake and urine output
- Respiratory congestion

Discuss rituals, cultural and spiritual wishes.

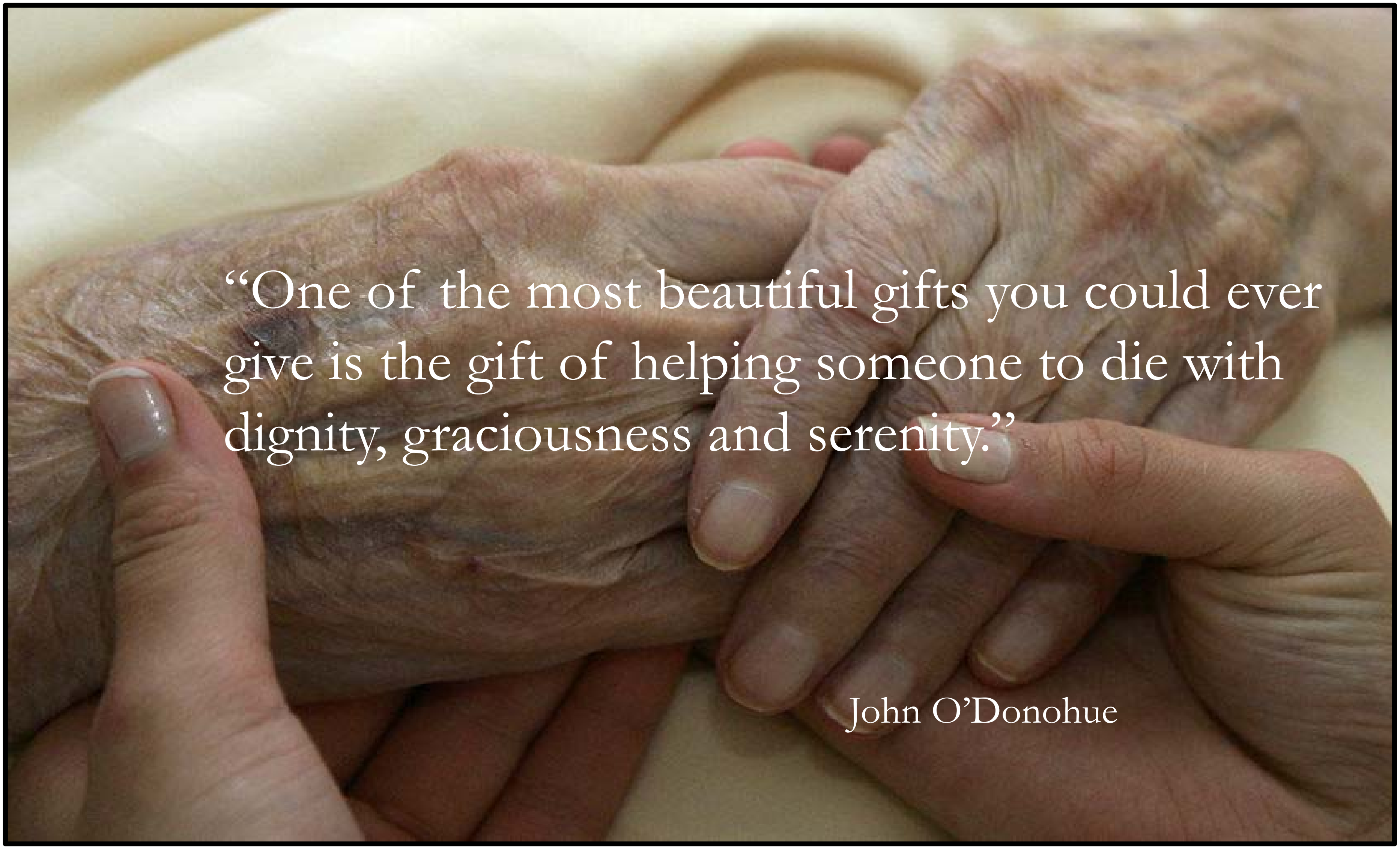
Help them understand mouth care and positioning for comfort.

> *" How people die*
> *remains in the*
> *memories of those*
> *who live on."*
>
> Dame Cicely Saunders

If life is akin to walking a tightrope, the
chance of falling increases toward the end.

Think then, of palliative care as a safety net. No one escapes falling, but palliative care can provide a softer landing. Those of us who work in this field are focused on how to help patients and families achieve that softer landing.”

Harvey Chochinov



“One of the most beautiful gifts you could ever give is the gift of helping someone to die with dignity, graciousness and serenity.”

John O’Donohue

“Good Journey”

by Heather Davidson

“ And as I reach out to touch you one last time
I’ll take you hand and whisper
Good journey my friend, good journey my friend
Good journey, good journey, good journey my friend.”

Living and Dying with Dementia: Dialogues About Palliative Care,
Oxford University Press, 2007