The Best of Both Worlds
A Palliative Approach in Dementia Care

CDRAKE Webinar - November 28, 2012

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BROADMEAD
Care Society
Excellence in Care for Veterans and Seniors

Life & Death Matters

The Best of Both Worlds

- Palliative Care & Dementia Care
- Ambiguous Dying
- The Dementia Difference – Education Workshop
- Integrating a Palliative Approach
- Best Practice Strategies

Kath & Janice

Kath

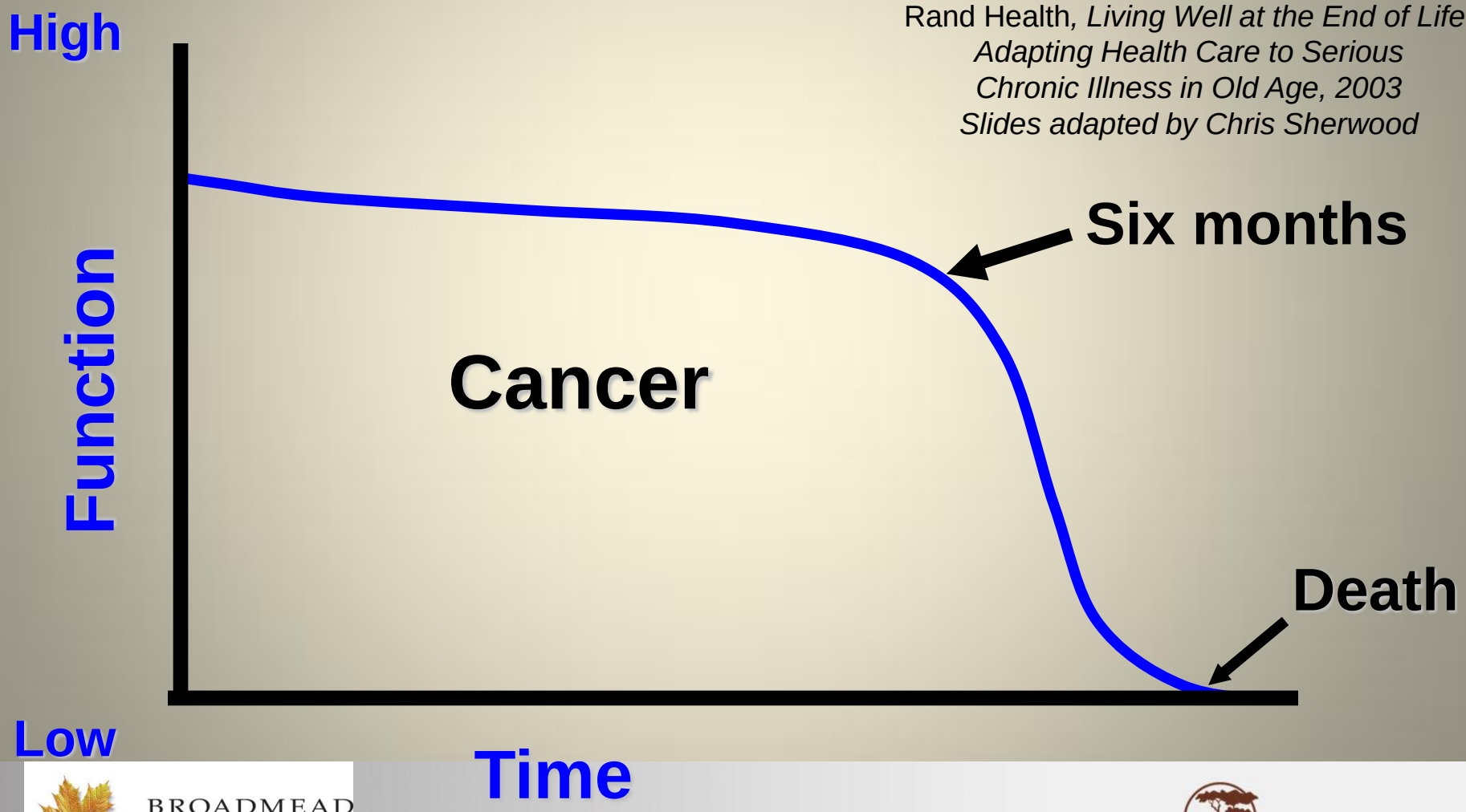
Janice

Kath's world

hospice palliative care nurse, thanatologist

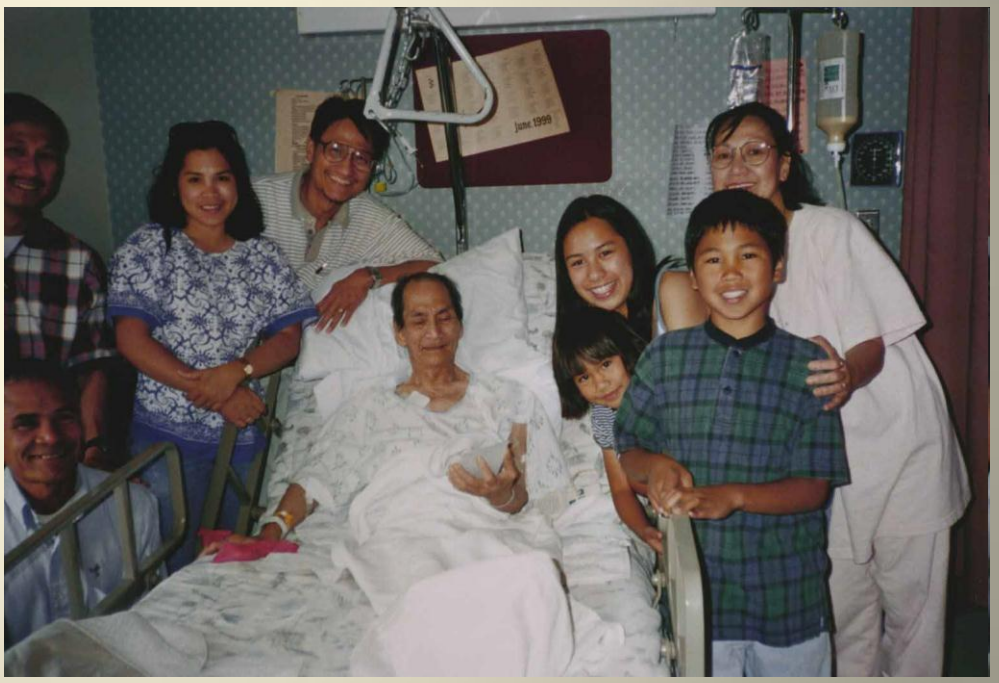
Steady decline (anticipated)

Joanne Lynn, David M. Adamson
Rand Health, *Living Well at the End of Life, Adapting Health Care to Serious Chronic Illness in Old Age, 2003*
Slides adapted by Chris Sherwood



The “death benefits”

- Reconsider care plans
- Gather
- Closure
- Register with hospice



Dying…

You get to:
Eat what you want,
when you want!
AND
You can stay in bed
ALL day if you want to!

Death in the 21st Century

10% sudden deaths

20% anticipated

70% chronic illness

WHAT ABOUT THE 70%
“HOW DYING DO YOU HAVE TO BE TO GET GOOD CARE?”

Stuttering trajectory (chronic illness)

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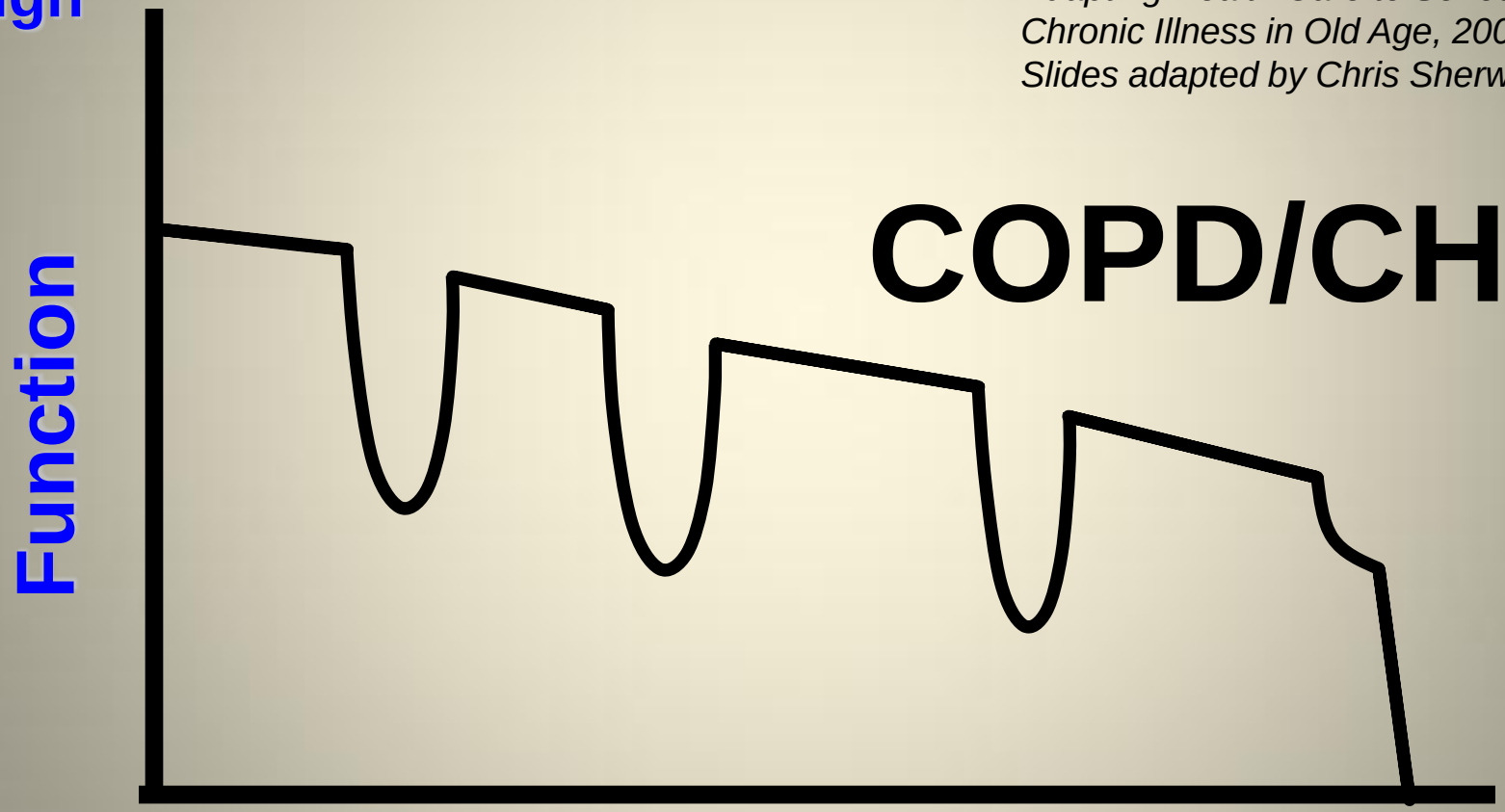
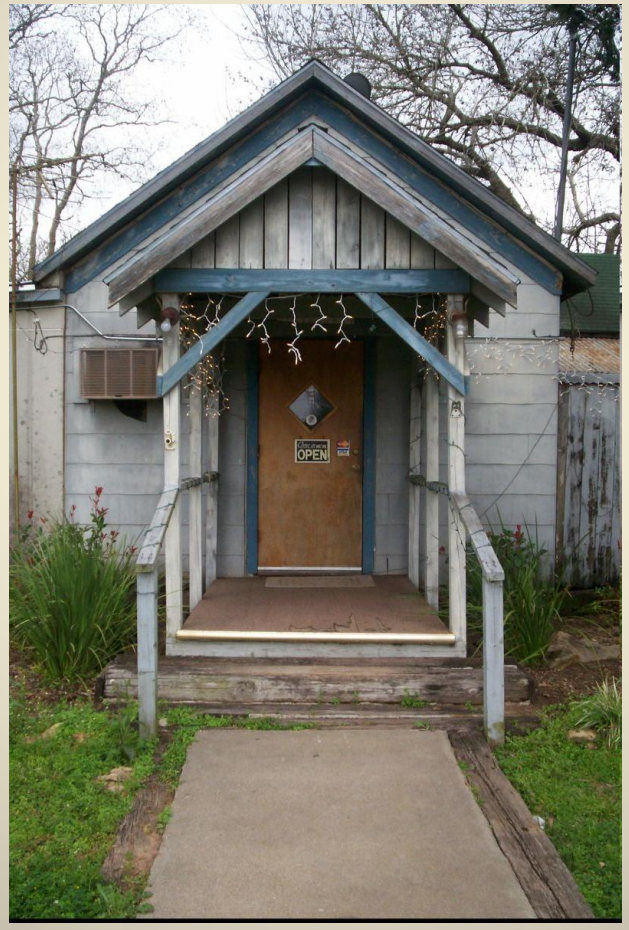


“The week in which we die will start like any other…”

People arrive on deaths door step… unannounced!



Without the transition from “cure”

- People endure more acute treatment**
- Miss registration with hospice

Access to Hospice Palliative Care

- 16-30% of Canadians
- within the last days/weeks of life
- with a cancer diagnosis

HOSPICE PALLIATIVE CARE

Life & Death Matters

"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."

WORLD HEALTH ORGANIZATION DEFINITION

Key points

1. Goal is improving the quality of life.
2. HPC neither prolongs life nor hastens death.
3. Patient and family are the unit of care.
4. Individual and family have the right to:
    - know and discuss the illness and its implications
    - choose the level to which they will be involved
    - receive consistent physical, emotional, spiritual support.
5. Bereavement and counselling is available to families before and after person's death.

Janice - The Dementia Care World

The Lodge at Broadmead Victoria, B.C.

- A publicly-funded, non-profit care home to 225 people
- 60% are Veterans
- 75% have cognitive impairment
- Average length of stay – 1.5 years

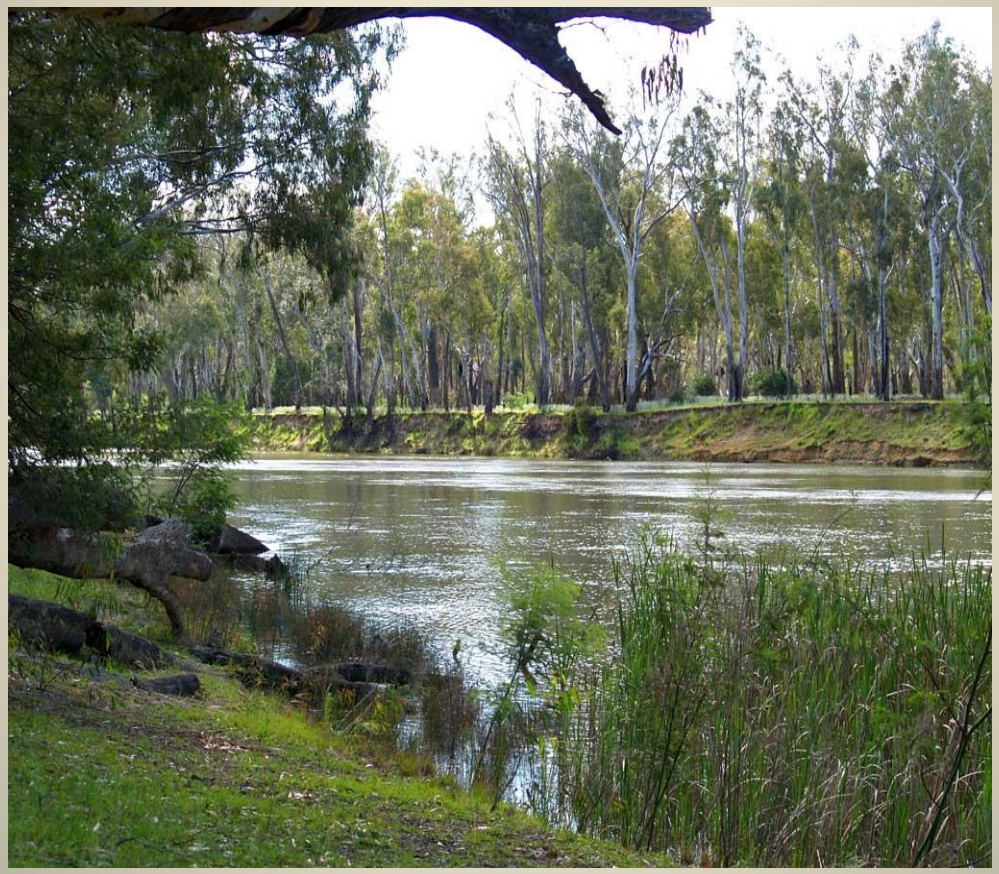
Dementia Care Program

- Dementia Care Program since 2003
  - Renovations
  - Program development
  - Education
  - Evaluation
- Focus on capacity building of team and clinical leaders

What are the principles of dementia care?

- Person-centered [huge and encompasses large number of interventions and principle practice]
- Communication - validation
- Meaningful moments
- Maintaining dignity
- Comfort
- Avoid LABELLING language

Shift in People Moving In



Is dementia…

- A terminal illness with a chronic phase

Or

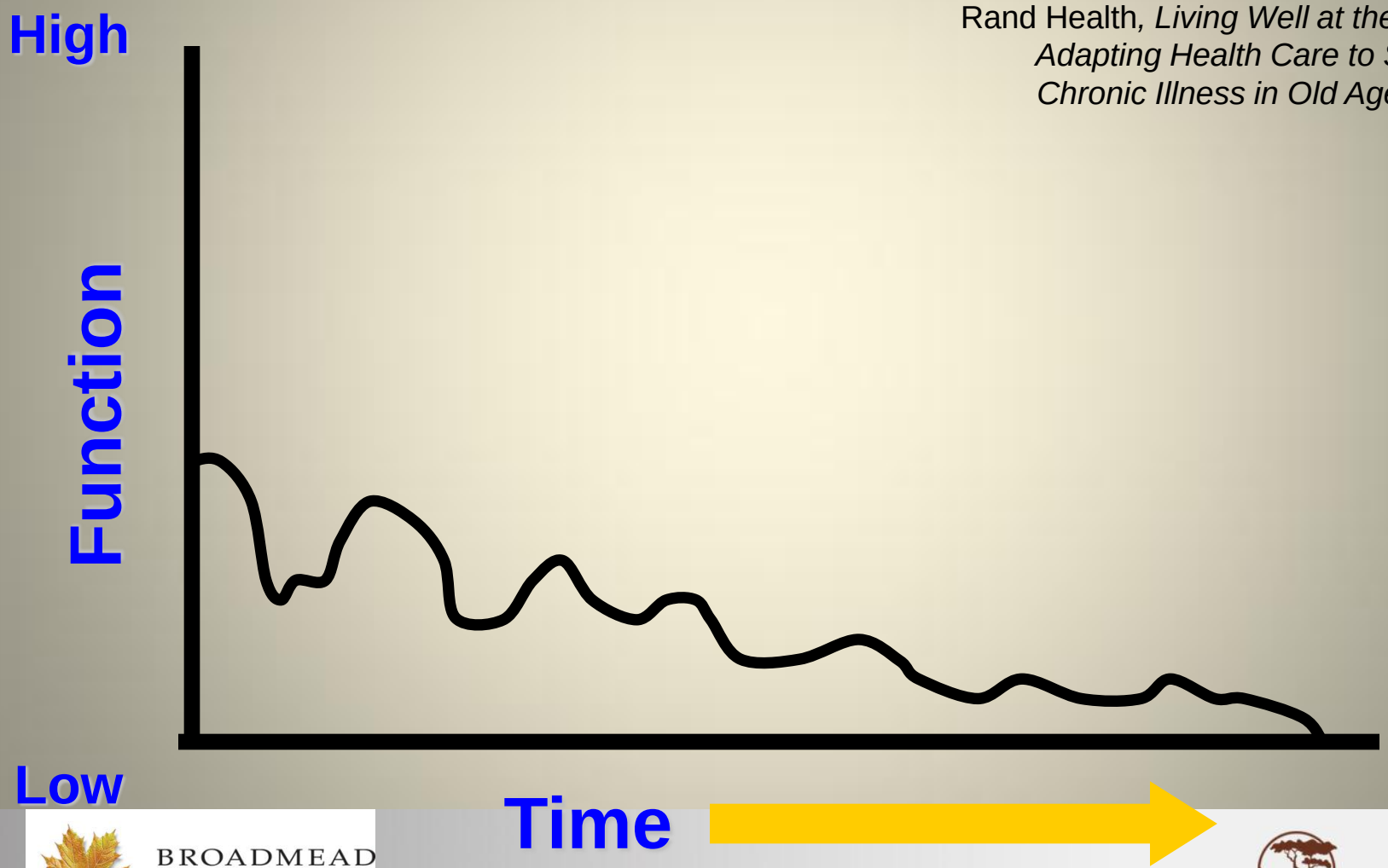
- A chronic illness with a terminal phase?
- What does the “dementia” trajectory look like?

Dementia Trajectory

- Dependent on the type of Dementia
- Dependent on co-morbid conditions
- Dependent on advance care plan

Frailty and Dementia

Joanne Lynn, David M. Adamson
Rand Health, *Living Well at the End of Life, Adapting Health Care to Serious Chronic Illness in Old Age, 2003*



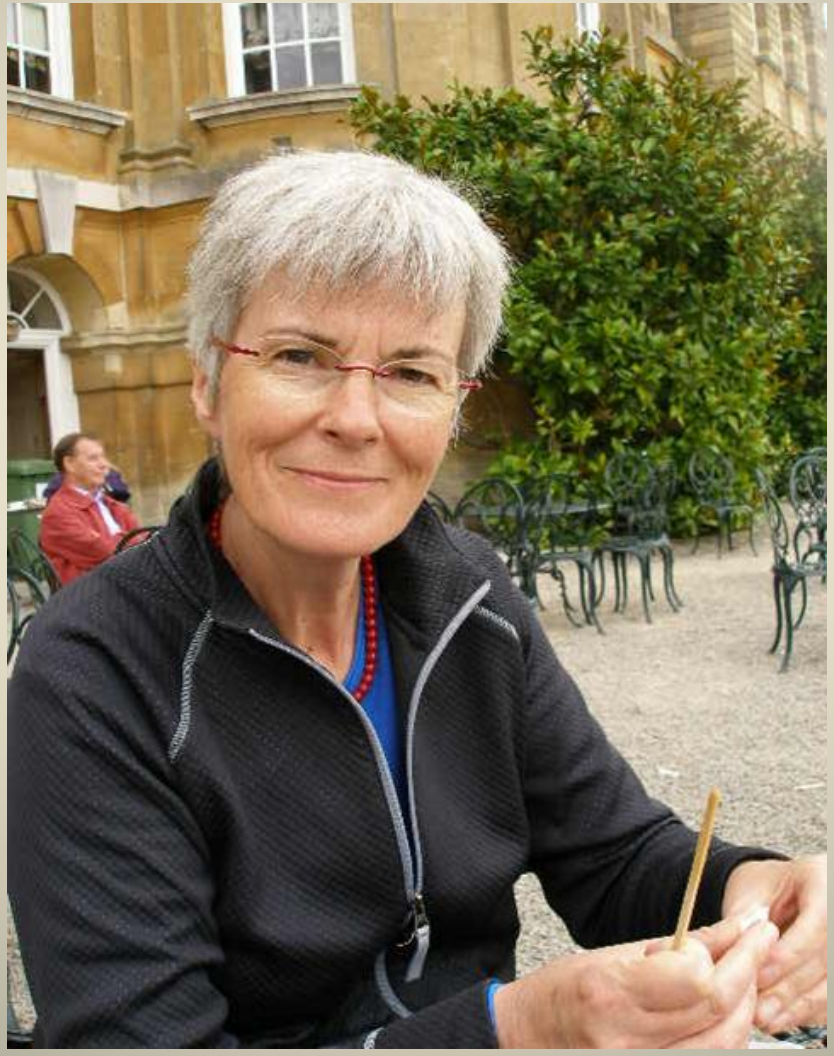
Balancing the focus

People come here to live

But people die here too

The meeting of two worlds

A request from Fiona Sudbury



And learning that they were not different worlds after all!

But there were some differences….

“Ambiguous Dying”

“What most people mean by “dying” bears little resemblance to the days, weeks, and months that typically precede death”… with chronic illness”

(Bern-Klug, 2004)

“Ambiguous Dying”

“There is little formal recognition that most dying now occurs in the context of advanced chronic illness. We avoid admitting that a dying process is taking place until death is upon us…”

(Bern-Klug, 2004)

The Ambiguous Dying Syndrome

" when 'dying' refers only to people whose time until death is 'known' as being in the near future."

Bern-Klug

Gathering evidence

Was there best practice in caring for people dying with dementia?

Why is dying with dementia different?

- Social death may precede the actual death
- Dementia makes it difficult for the person to be fully engaged in life to the end or express their wishes and preferences
- Dying is often protracted – gradual loss of capacities and health problems may build silently

Why is dying with dementia different?

- Difficulty in ensuring optimum symptom control has been achieved

- Social networks may become exhausted & withdraw, or have difficulty letting go

Small, Froggatt & Downs (2007)

Integrate a Palliative Approach

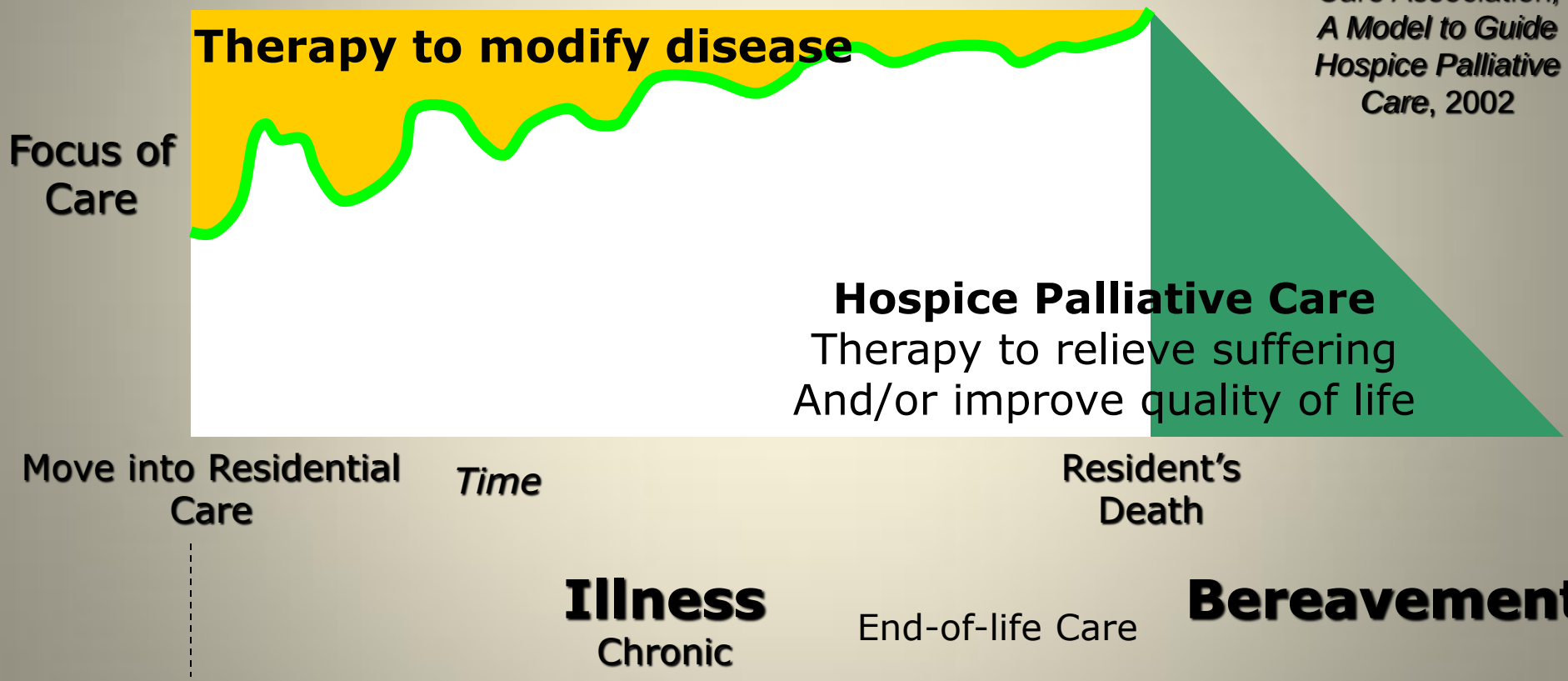
- A **PALLIATIVE APPROACH** is the integration of hospice palliative care principles, practices and philosophy in care for all persons with progressive life threatening illnesses, earlier in the disease process, across all settings.

A PALLIATIVE APPROACH FOR PEOPLE DYING WITH DEMENTIA?

Dying with dementia?

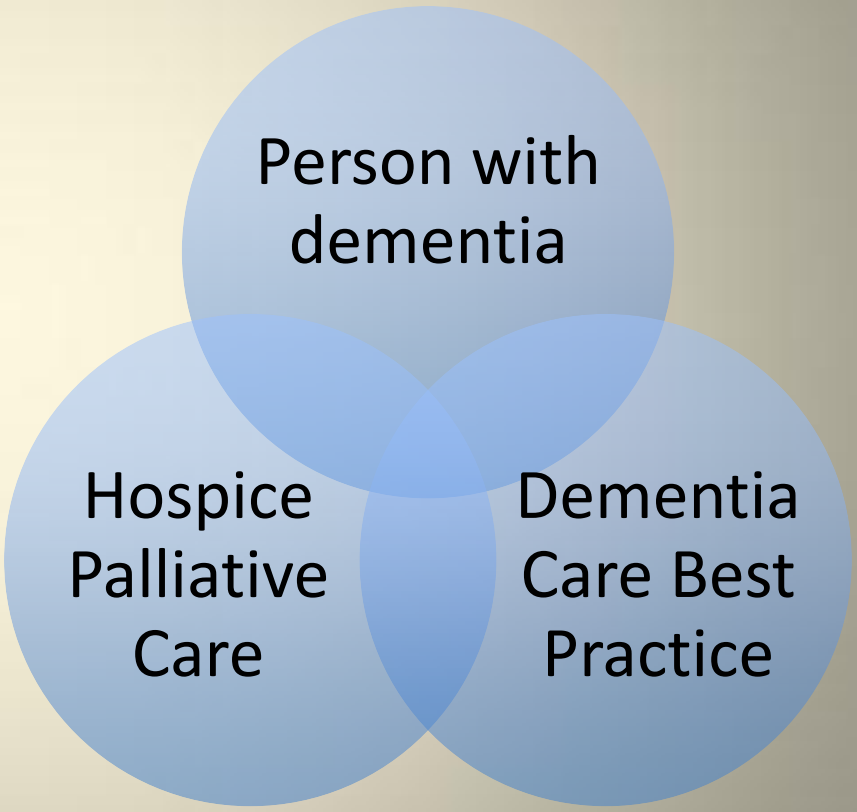
Dying [living] with Dementia

Adapted from The Canadian Hospice Palliative Care Association, *A Model to Guide Hospice Palliative Care*, 2002



What do people need to know?

Application of a Palliative Approach



Dementia Difference Workshop – Day One

Morning

Introduction

- overview and objectives
- how palliative care fits with dementia care
- putting DEATH on the table
- CHPCA Square of Care

Disease Progression and Dementia

- ambiguous dying syndrome
- ineffective interventions (CPR, IV antibiotics, transfer to hospital, tube feeding)
- “Could he/she be dying?”

Dementia Difference Workshop – Day One

Afternoon

Supporting Families

- The Long Goodbye
- Multiple losses
- Disenfranchised grief
- Expressions of grief and ways to support families

Dementia Difference Workshop – Day Two

Morning

Physical comfort

- Pain, Dyspnea, Delirium
- Declining intake/Appropriate nourishment
- Recurrent infections

Afternoon

Making moments meaningful

Last days and hours

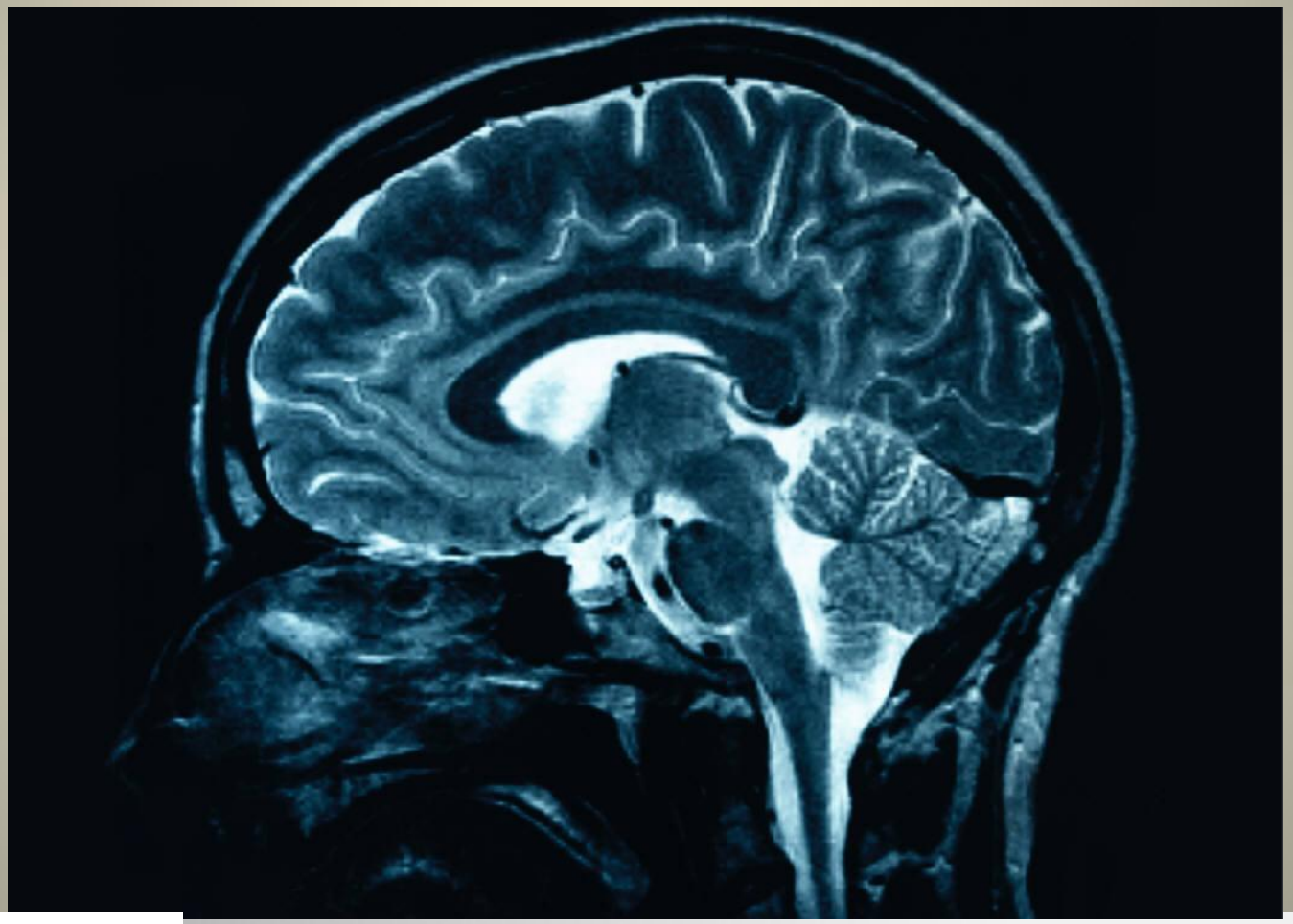
Staff care

Certainties with dementia

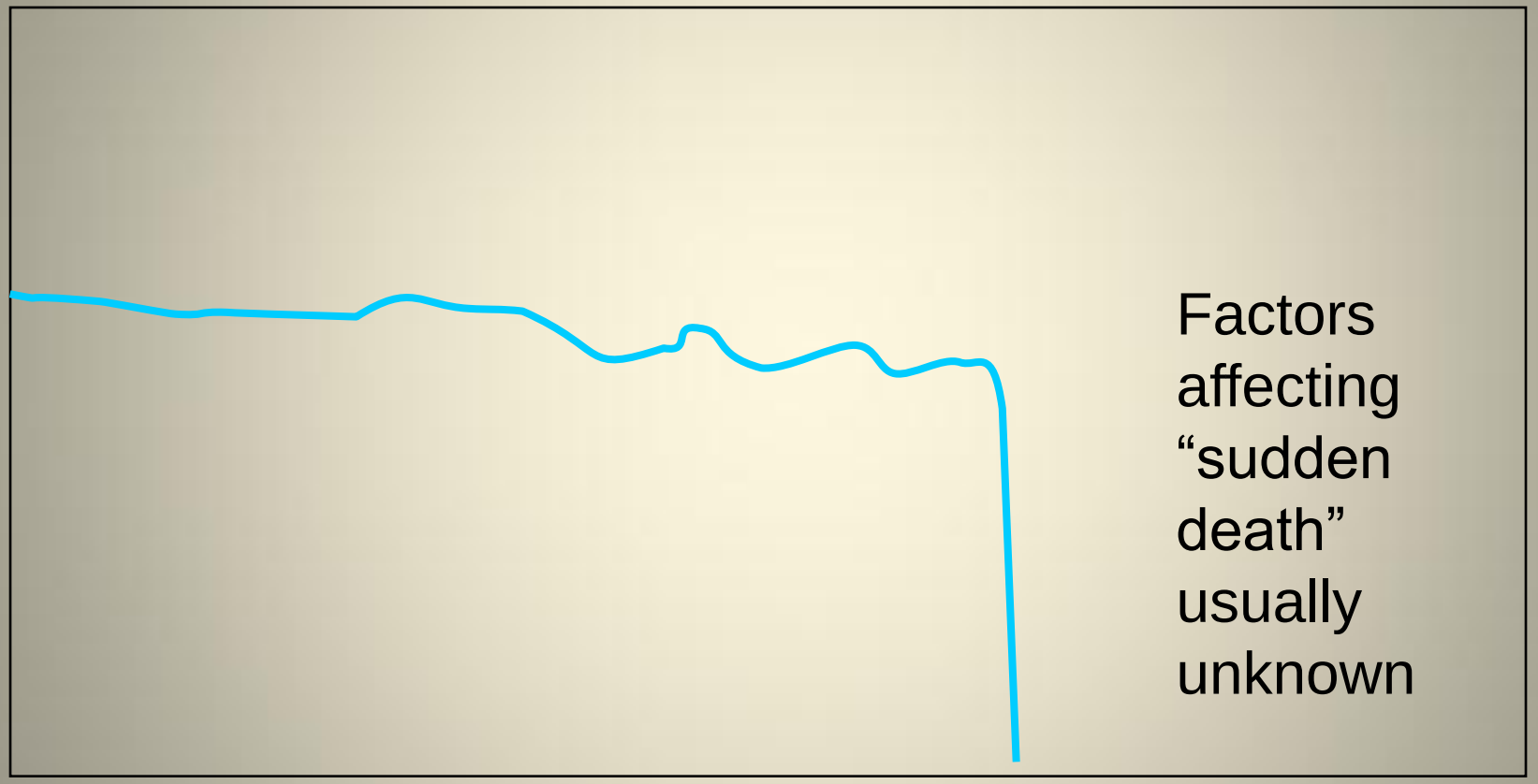
1. Overall trajectory will be a decline.
2. Dementias have unique characteristics.
3. Death is certain.
4. Co morbidities will affect the trajectory.
5. Certain interventions are ineffective in late stage dementia.
6. There are indicators that often precede the active dying phase.
7. Common causes of death.

Certainty 2
Type of dementia will affect trajectory

Alzheimers Disease Progression



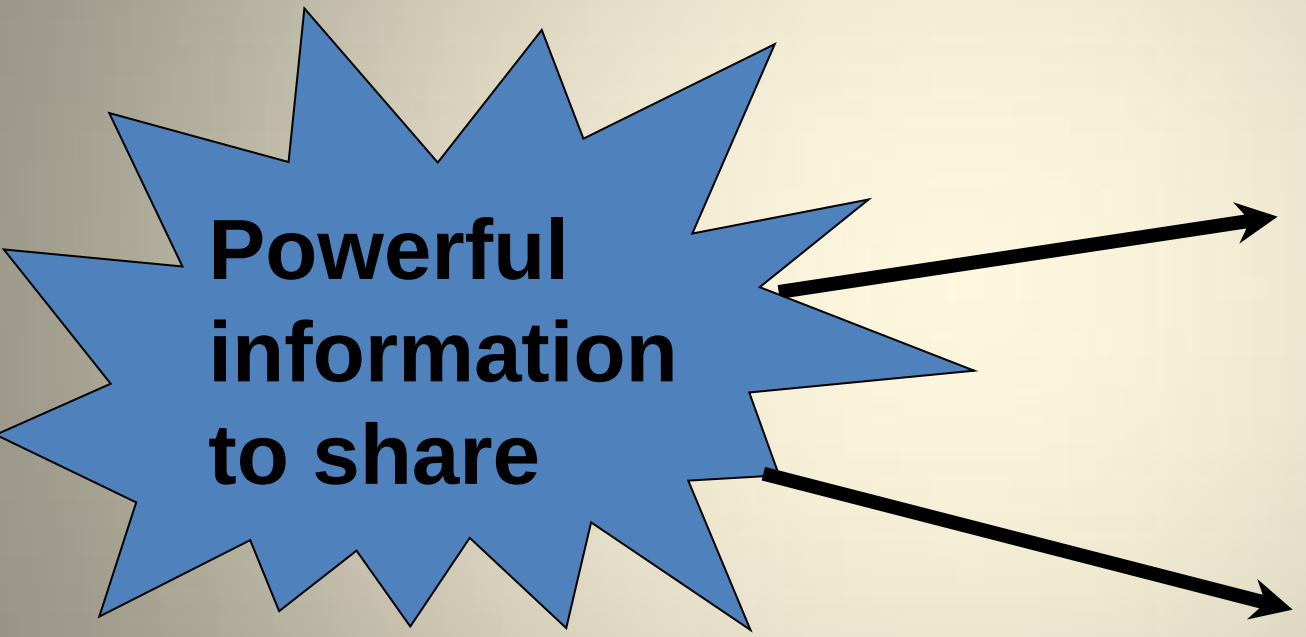
Vascular dementia trajectory



Dementia with Lewy Bodies

- Periods of clarity with periods of confusion and fluctuating levels of physical functioning.
- Life expectancy is shorter than Alzheimer disease.

Certainty 3
Death is certain



- Resident can prepare
- Family can prepare

Certainty 4
Co-morbidities affect the dementia trajectory

- CVD
- COPD
- Diabetes
- Renal failure
- Parkinson's
- Cancer

Certainty 5
Certain interventions are ineffective in late stage dementia

- CPR
- Gastric tubes
- IV antibiotics for recurring infections
- Transfer to hospital for IV antibiotics

Certainty 6
Indicators that precede active dying

- Unresponsive to antibiotics
- Frequent infections
- Unhealed skin ulcers
- Decreased intake
    - Unable to swallow solids, then fluids then NPO (Food the four letter word in EOLC)
- Increased withdrawal
- Increased sleeping

The Dementia Difference Evaluation

Families valued:

- Knowing the person,
- Quality of life until death and
- Acts of kindness

The Dementia Difference Evaluation

Families wanted:

- Accurate health info,
- Care conferences as health declines,
- Spiritual care and
- Information on grief

The Dementia Difference - Top 10 Successes ‘What Staff Say’

- Death is on the table
- Asking could he/she be dying
- More family conferences
- Earlier symptom management
- Documentation Advanced Care Plan

The Dementia Difference - Top 10 Successes 'What Staff Say'

- Creative thinking – focus on the possibilities
- Increased confidence of all staff
- Team Strengths
- Less 'clinical' focus
- Stop the palliative label

What does practicing using a palliative approach look like?

- Start an Advanced Care Plan soon after a person moves into the Lodge.
- Keep death on the table.
- Ask if the person “could be dying” at every transition.

What does practicing using a palliative approach look like?

- Focus on the certainties to reduce ambiguity.
- Manage symptoms when they appear – assess, assess, assess!!!
- Goal is to make moments matter!
- Partner with family members.

Implementing a Palliative Approach
Barriers & Enablers

Barriers	Enablers
• Knowledge gaps	• Communication
• Communication	• Organizational Vision
• Conflicting values	• DEATH on the table
• Varying expectations	• Sharing stories about "Good" deaths

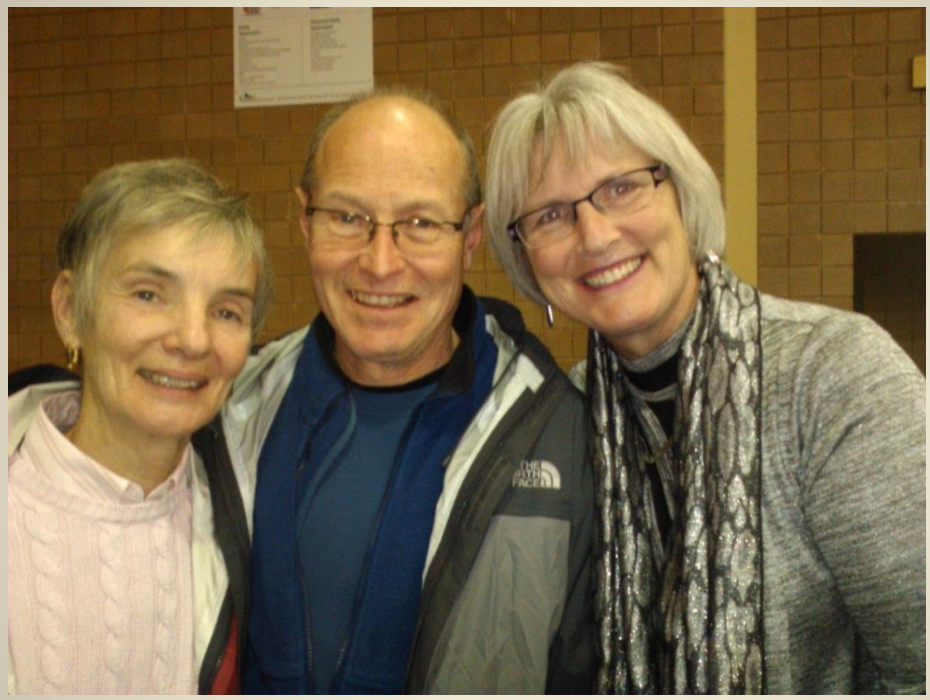
Continued Challenges

- Lots of people working together
- Funding for residential care
- Death avoiding society
- Alzheimer's Disease – a terminal illness?

Future Considerations for Broadmead

- Program Development
- On-going Dementia Difference education for staff
- Supplemental Education
- Clinical Order sets
- Brochure
- Staff Bereavement

Future Considerations for people with dementia



Gary and Judy Quinton Manitoba

Future Considerations for people with dementia

- Integrate a palliative approach early
- Start conversations early
- “Don’t block the exit” with acute interventions when they are not wanted by the dying person

Future considerations for people with other life limiting illnesses

Fabulous Palliative Care Research happening in Canada NOW!

- Quality Alliance for Palliative Care in Residential Care www.palliativealliance.ca
- Understanding of the importance of the work of Personal Support Workers

Fabulous Palliative Care Research happening in Canada NOW!

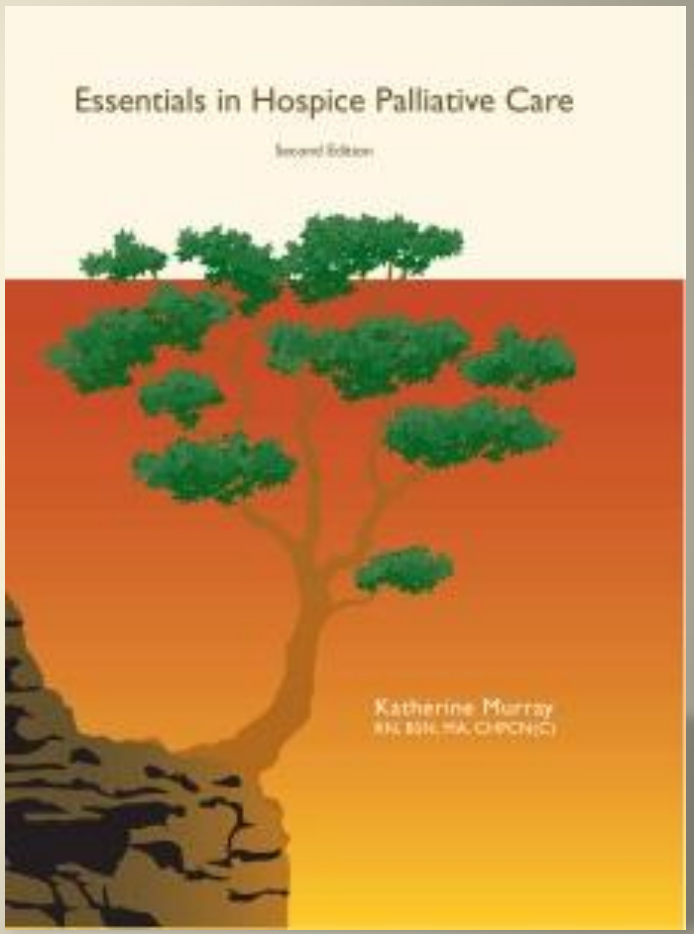
- Integrating a Palliative Approach in Nursing: Evidence and Leadership

  iPANEL

  http://www.ipanel.ca/

Door prizes:

- Set of “Essentials in Hospice Palliative Care” resources: Copy of the Text, Workbooks, DVDs, and PPT series
- Life and Death Matters Online - one free registration for one five week interactive course.



Life & Death Matters

Thank you!

Closing comments

- **Janice**
- **Kath**