"D" WORDS:
DYING AND DEMENTIA

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March 2011 Manitoba Alzheimer's Conference

With special thanks to:
Fiona Sudbury, Janice Robinson &
The team at Broadmead Lodge
Victoria, B.C

Life & Death Matters

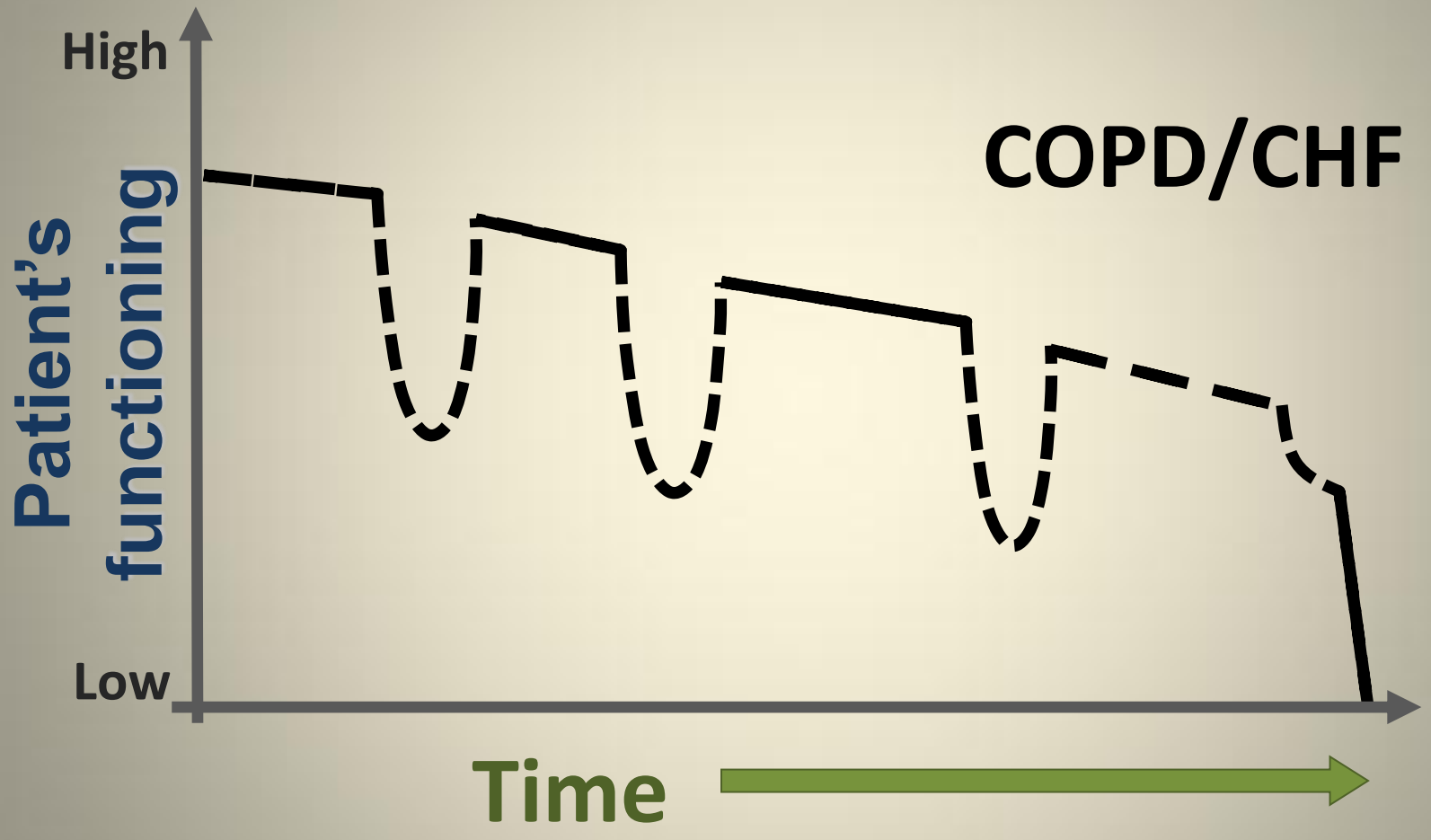
What is dementia?

A terminal disease? OR

A chronic disease with a terminal phase?

Life & Death Matters

Stuttering Trajectory



Frailty and Dementia

“Dying”

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

Mercedes Bern-Klug

“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…”

Mercedes Bern-Klug

Ambiguous Dying Syndrome

Term describes the many uncertainties that can result when “dying” refers only to people whose time until death is “known” as being in the near future.”

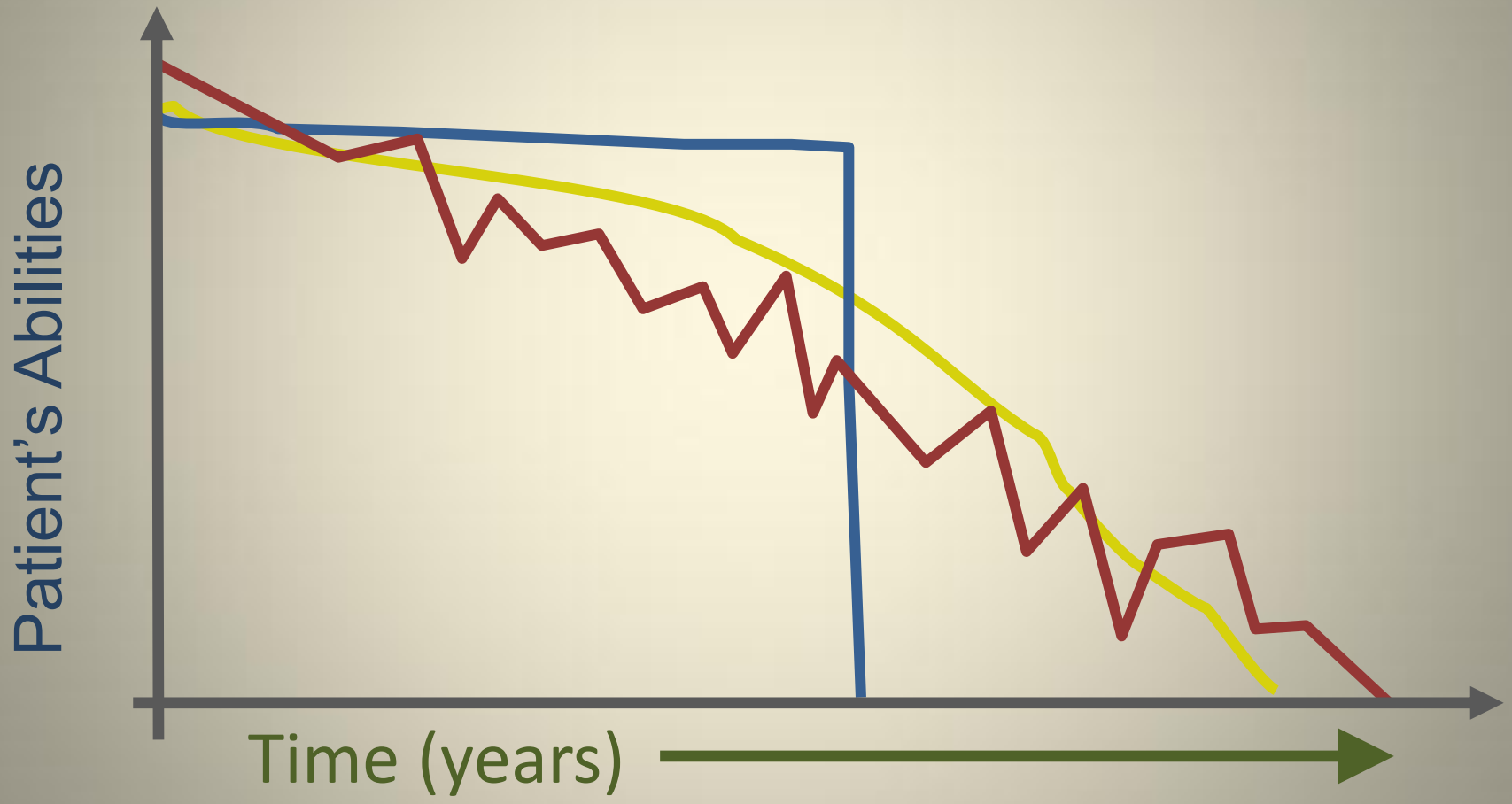
Bern-Klug

Let's not make the dying any more ambiguous than it is

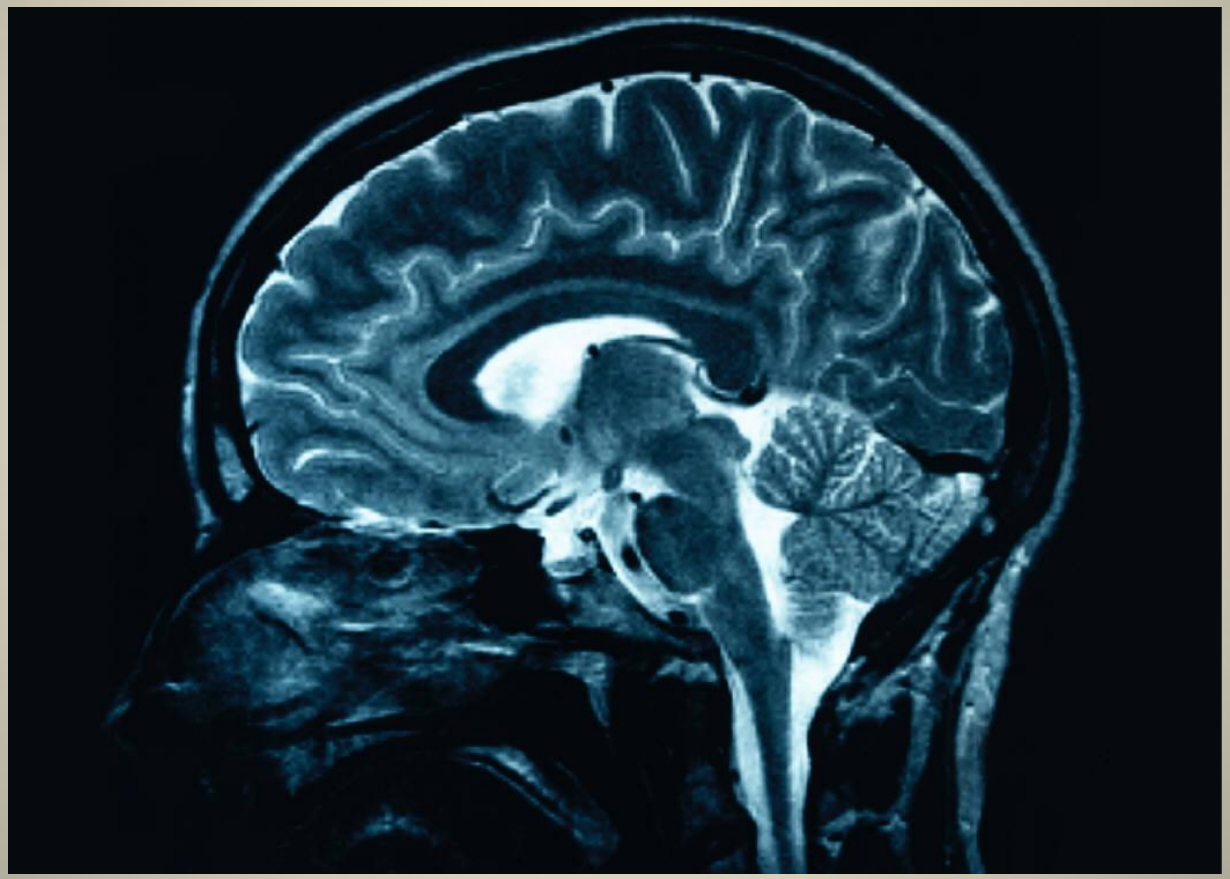
What do we know about dying with dementia?

1. Death is certain.
2. Trajectories all show declining function.
3. Unique characteristics of different dementias.
4. Co-morbidities affect the trajectory.
5. Indicators that may precede the active dying phase.
6. Acute interventions that are ineffective in late stage dementia.
7. Common causes of death.

Trajectories all show declining function



Unique characteristics of Alzheimer - progressive

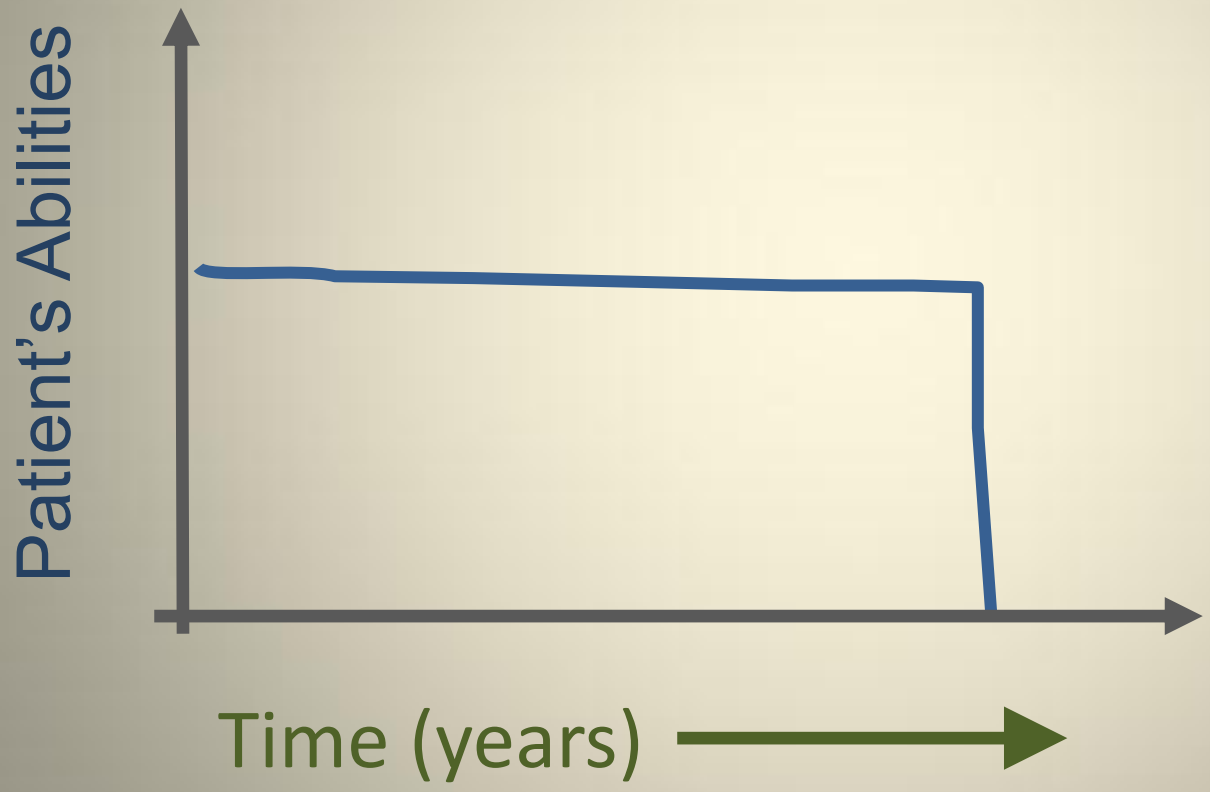


Unique characteristics of a Lewy body dementia

Characterized by

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

Unique characteristic of a Vascular Dementia



Co-morbidities affect the trajectory

- CVD
- COPD
- Diabetes
- Renal failure
- Parkinson’s

INDICATORS that may precede active dying

- Unresponsive to antibiotics
- Frequent infections
- Unhealed skin ulcers
- Decreased intake
- Unable to swallow solids, then fluids then NPO
- Increased withdrawal
- Increased sleeping

Anorexia is common

- Anorexia is the loss of appetite, the decreased interest in food and eating.

- (Discussion of anorexia is concerning anorexia at end of life only!)

This is often difficult for family and staff

Why?

- Role of food in the family
- Cultural beliefs
- Visible
- Food = strength = life

Possible causes of anorexia

- Fatigue
- Shortness of breath
- Pain
- Dry +/or sore mouth
- Aversion to food odors
- Fear of vomiting
- **Cognitive impairment** e.g. can't recognize food/utensils
- **Cachexia**

Cachexia is common

- Involuntary weight loss and accompanying loss of fat and muscle.
- Accompanies severe progressive illness & chronic illnesses e.g. cancer, ALS

Possible causes of cachexia

Cachexia ***is not*** caused by anorexia

- Cachexia may cause the loss of appetite (anorexia),

  vs the loss of appetite causing cachexia

- Immune system, tumours produce cytokines….

Cachexia – simplified explanation

Cytokines – produced by tissue and tumours

Signal sent to the body that "all resources are needed"

Metabolism increases

Fat and protein stores used as fuel

WASTING occurs – called "cachexia

Starvation differs from cachexia

Starvation - metabolism slows down

Cachexia - metabolism speeds up (catabolic)

- Treatments cannot reverse cachexia process late in the disease
- Increased dietary intake and artificial nutrition are not able to reverse cachexiaT
- THIS IS IMPORTANT INFORMATION TO SHARE WITH FAMILIES

Acute interventions that are **ineffective** in late stage dementia

- CPR
- Gastric tubes
- Transfer to hospital
- IV antibiotics

CPR

< 10% of people with end stage dementia* survive CPR.

(*living in residential care)

Volicer, 2005, Teno, 2004

Use of G-tubes with end stage dementia

DO NOT:

- increase survival
- reduce risk of infection
- prevent aspiration
- improve functional status of resident
- improve quality of life
- improve comfort of resident

MacCourt, 2007, Gillick, 2004, Murphy and Lipman, 2003, Meiier et al, 2001

Hospital transfers often cause

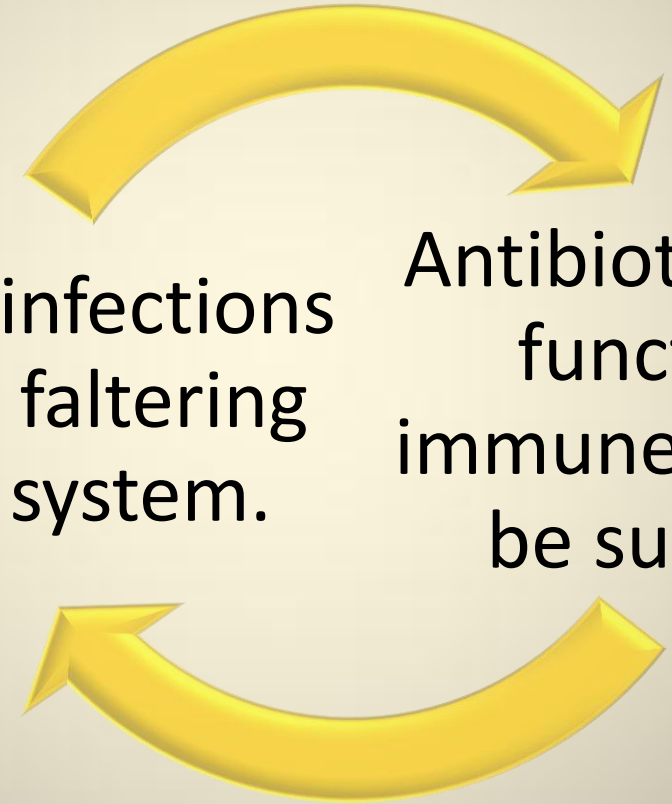
- anxiety,
- panic,
- confusion,
- disorientation,
- delirium,
- declines in functioning

Volicer 2001

Recurring infections are normal

1. Infections are common in persons with weakening immune systems,
2. Infections are a common cause of death,
3. Need to ask:
   - When is it appropriate to treat an infection?
   - When is it no longer appropriate to treat the infection?

IV Antibiotics do not prolong survival in late stage dementia



Antibiotics

- Antibiotics ***may not*** be more effective in providing comfort than palliative medications for symptom management.

Volicer, 2001, Morrison and Siu, 2000

Common causes of death with dementia

- Recurrent infections
  - E.g. pneumonia, influenza, UTI
- Cardiovascular accidents
- Cachexia

"Hospice palliative care aims to relieve suffering and improve the quality of living and dying….people with life limiting conditions"

Canadian Hospice Palliative Care Association (CHPCA)

HOSPICE PALLIATIVE CARE

Principles and philosophy of hospice palliative care

- When does Hospice Palliative Care begin?
- When do you qualify?
- How dying do you have to be to get good care?
- Do you have to wait until you are dying imminently to access good symptom management?
- What about a palliative approach?

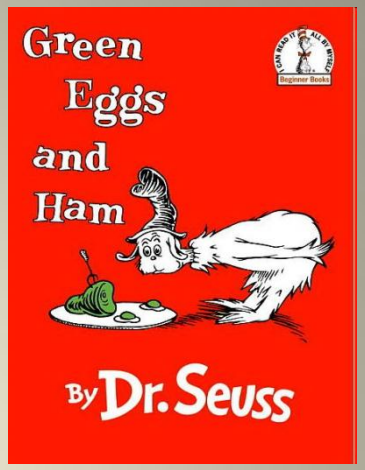
CHPCA Process of Providing Care:

- Impeccable assessment
- Appropriate information sharing
- Support informed decision making
- Develop strong care plans
- Implement plans with continuity
- Evaluate, did we meet person's goals?

Do you like information?

Do you like it here or there….?

Do you like it anywhere?



Information Sharing

How do you like to receive information?....

How much information…

- What version? Pamphlet, text, internet….?
- Setting?

Place death gently on the table

From preadmission through to death…

1. “We welcome your mom to …. We want to take good care of her. We have a great activity program here…”
2. “We also care for people through to death. Most of our residents will die while here, and we strive to provide the best care right through to death.”
3. “Can we talk in our next visit about how we can meet her changing needs, and how we can best support you?”

We talk about the “D” word

- To help decrease the anxiety
- To help plan and prepare
- To avoid crisis from developing
- To avoid decision making in crisis situations

Like Cindy, we can help people navigate…

- Open the door…. “Do you have any questions?”
- “What do you know?”
- “What would be helpful to know?”
- “Who can you ask? Who might know?”
- “How can we help facilitate that discussion?”
- SEE the “Question Prompt Sheet”

Never waste a good crisis!

Not just "another infection"

- Just as medication route changes for someone dying with cancer provides a time to talk….
  - An infection provides an opportunity to review and discuss the needs and goals of care.

Summary

1. A Hospice Palliative Approach can be integrated in care when a person is dying over a long period of time at an uncertain time.
2. People do not have to wait until they are imminently dying to access good comfort measures!
3. The research is IN! Best practice in dementia care is congruent with best practice in HPC.

Best References

- Donnelly, M. & Samaroo, N. (2004). Dementia Coalition Literature Review. Vancouver, BC.
- Gnaedinger, Nancy, Murray, Katherine, Robinson, Janice, “Preliminary Outcomes of “The Dementia Difference” workshop at The Lodge at Broadmead, Victoria BC”, Journal of Palliative Care, (26:2/2010; 130-133).
- Gnaedinger, Nancy, Murray, Katherine, Robinson, Janice, The dementia difference: A palliative approach for people dying with late-stage dementia. Journal of Palliative Care, (24:4/2008; 274-276).
- MacCourt, P. (2007). End of Life Care: Research evidence to support the provincial dementia service framework.
- Volicer, L., (2005), End-of-life care for people with dementia in residential care settings, Alzheimer’s Association.
- Volicer, L., (2001), Care at the end-of life, Alzheimer’s Care Quarterly, 2(3):59-66.

For more information on this presentation and other educational resources.

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