END OF LIFE ISSUES IN ADVANCED DEMENTIA

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PRESENTER DISCLOSURE

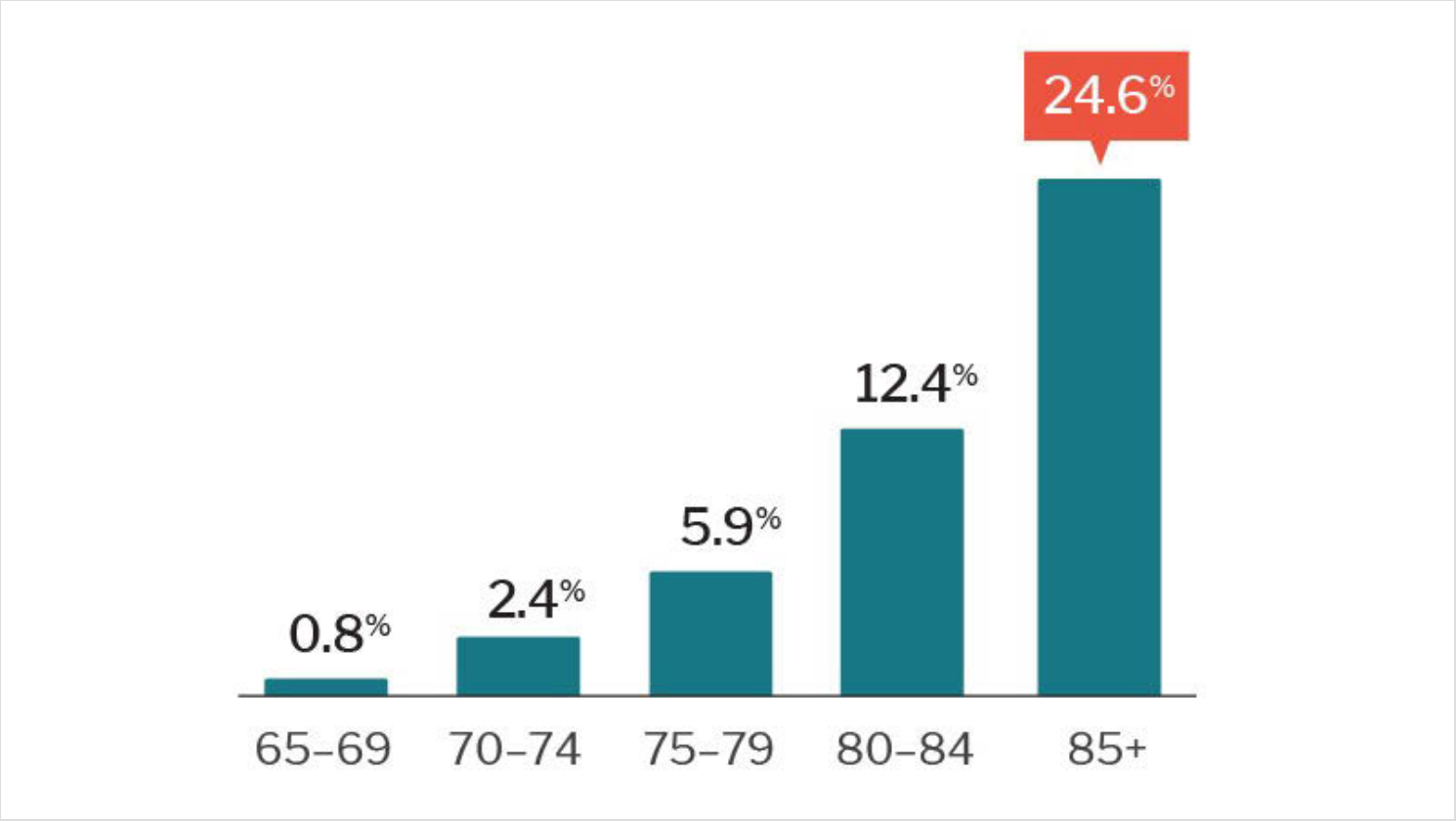
- Speaker: Dr. Krista Lagimodiere
- Relationships with commercial interests: None
- Potential for conflict(s) of interest: None

LEARNING OBJECTIVES

- Understand the clinical course of advanced dementia
- Discuss common clinical problems in end-stage dementia
- Review dementia prognostication and approach to end-of-life care

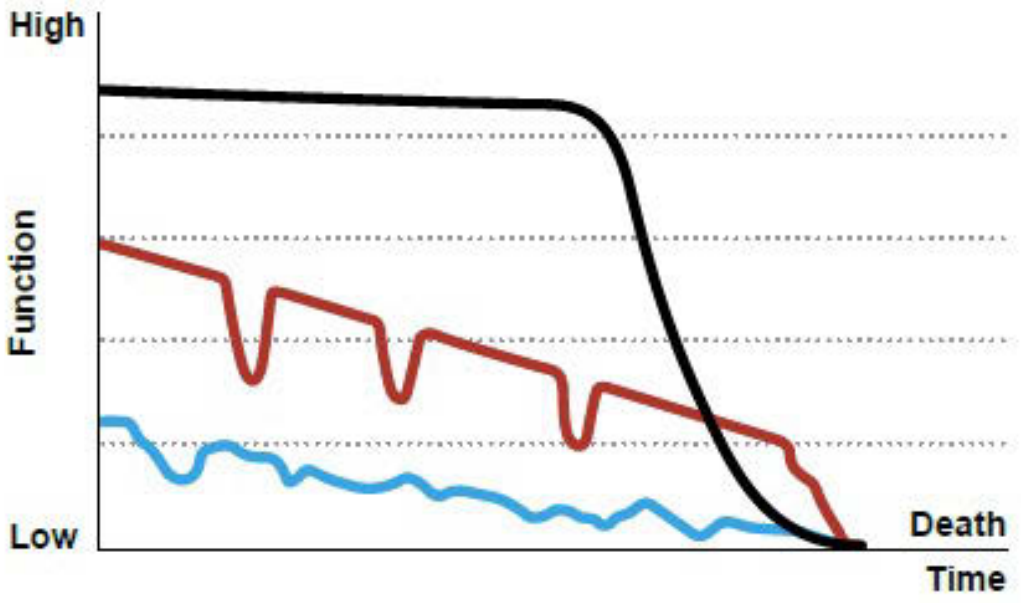
BACKGROUND

- 1 in 4 seniors age 85+ have a diagnosis of dementia
- Prevalence is rising in Canada with aging population



Public Health Agency of Canada. Dementia in Canada. 2018

DISEASE TRAJECTORIES



Source: Murray, S.A. et al[1]

Cancer (n=5)

Organ failure (n=6)

Physical and cognitive frailty (n=7)

Other (n=2)

GLOBAL DETERIORATION SCALE (GDS)

Stage	Deficits in cognition and function	Usual care setting
1	**Subjectively and objectively normal**	Independent
2	• Subjective complaints of mild memory loss. • Objectively normal on testing. • No functional deficit	Independent
3	**Mild Cognitive Impairment (MCI)** • Earliest clear-cut deficits. • Functionally normal but co-workers may be aware of declining work performance. • Objective deficits on testing. • Denial may appear.	Independent
4	**Early dementia** • Clear-cut deficits on careful clinical interview. Difficulty performing complex tasks, e.g. handling finances, travelling. • Denial is common. Withdrawal from challenging situations.	Might live independently – perhaps with assistance from family or caregivers.
5	**Moderate dementia** • Can no longer survive without some assistance. • Unable to recall major relevant aspects of their current lives, e.g. an address or telephone number of many years, names of grandchildren, etc. Some disorientation to date, day of week, season, or to place. They require no assistance with toileting, eating, or dressing but may need help choosing appropriate clothing.	At home with live-in family member. In seniors' residence with home support. Possibly in facility care, especially if behavioural problems or comorbid physical disabilities.
6	**Moderately severe dementia** • May occasionally forget name of spouse. • Largely unaware of recent experiences and events in their lives. • Will require assistance with basic ADLs. May be incontinent of urine. • Behavioural and psychological symptoms of dementia (BPSD) are common, e.g., delusions, repetitive behaviours, agitation.	Most often in Complex Care facility.
7	**Severe dementia** • Verbal abilities will be lost over the course of this stage. • Incontinent. Needs assistance with feeding. • Loses ability to walk.	Complex Care

Adapted by Dr. Doug Drummond from Reisberg B, Ferris SH, Leon MJ, et al. The global deterioration scale for assessment of primary degenerative dementia. American Journal of Psychiatry 1982;139:1136-1139.

Reisberg B et al. Am J Psychiatry 1982: 1136-9

DEMENTIA STAGING

- Important to identify stage as this will direct appropriate treatment e.g. we treat HFrEF 15% differently than EF 50%
- Average time from diagnosis to death in Alzheimer's Disease is 8-10 years
- Important to counsel patients/families/caregivers it is a progressive neurodegenerative disease that is terminal

"END-STAGE" DEMENTIA

- Heterogenous group of diseases, but all look similar in advanced stages
- Median survival varies in the literature depending on:
  - Type of dementia
  - Age of diagnosis
  - Concurrent illnesses
  - Multimorbidity and frailty

The Lancet. 2017 Dec 16;390(10113):2673-734.

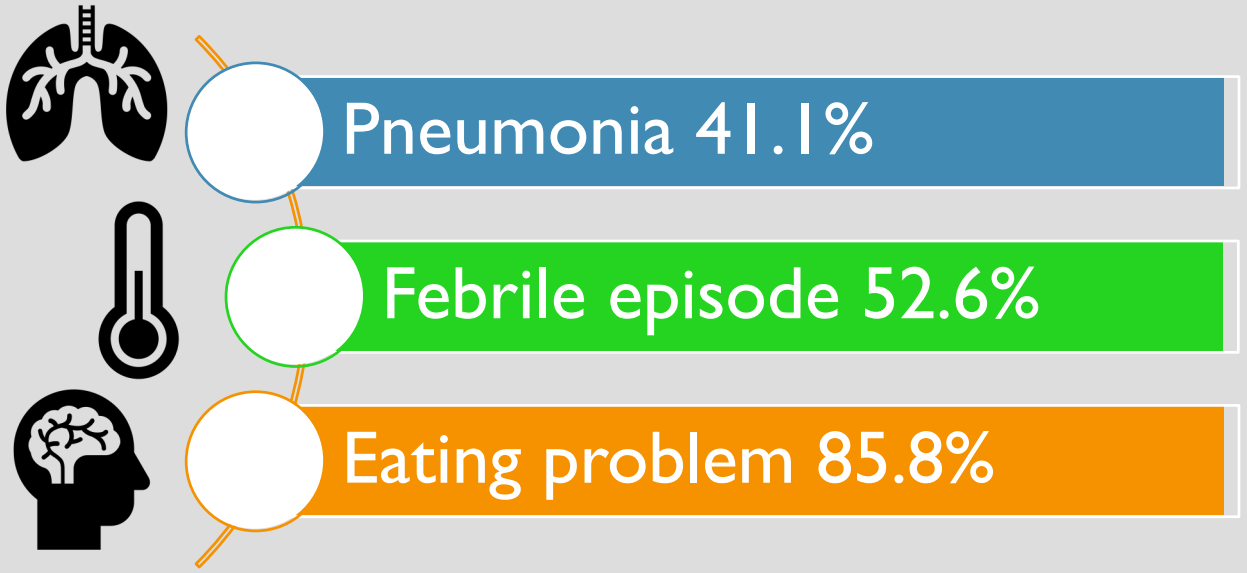
ORIGINAL ARTICLE

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.

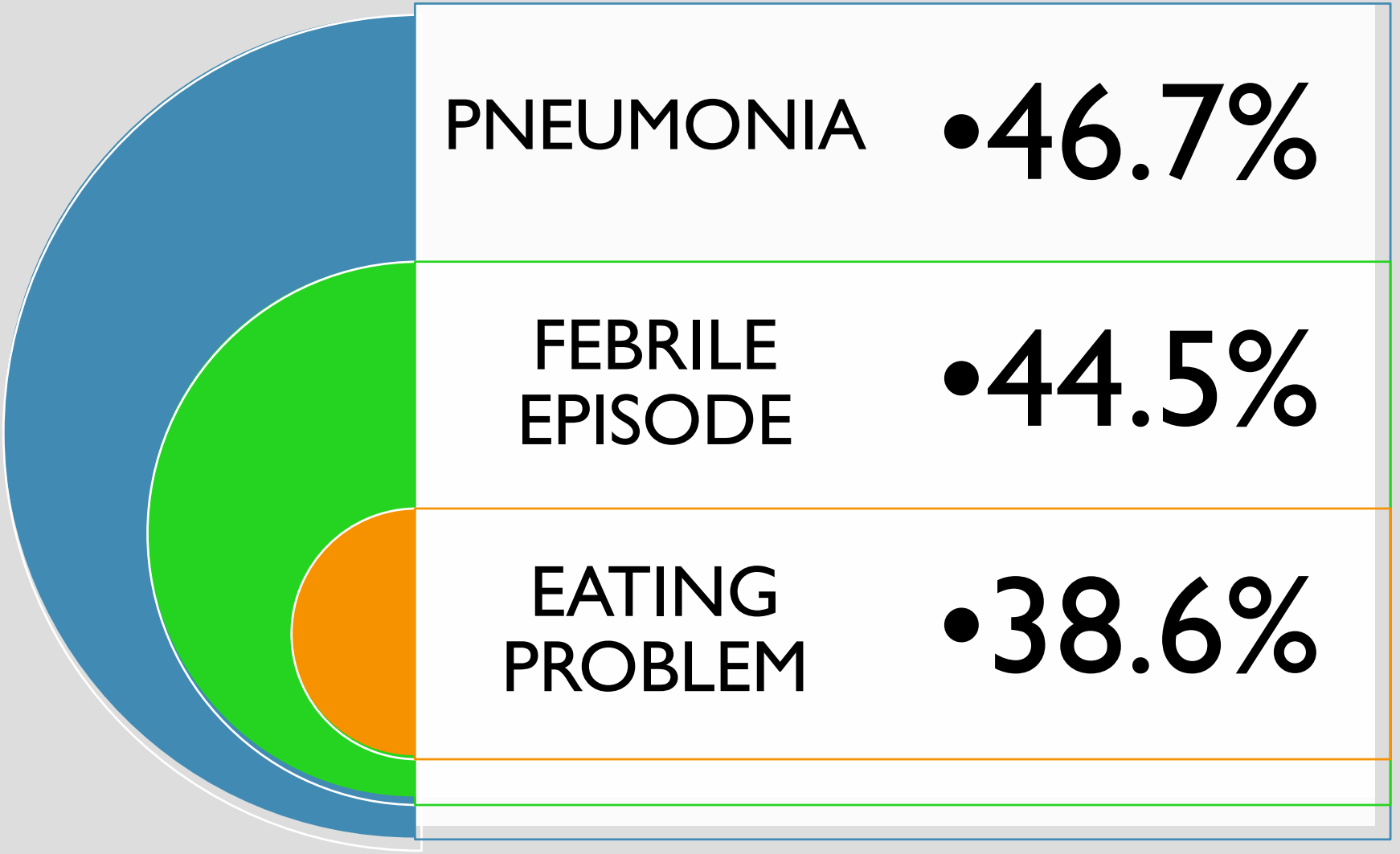
323 nursing home residents with advanced dementia, 22 facilities, followed for 18 months

54.8% died by 18 months



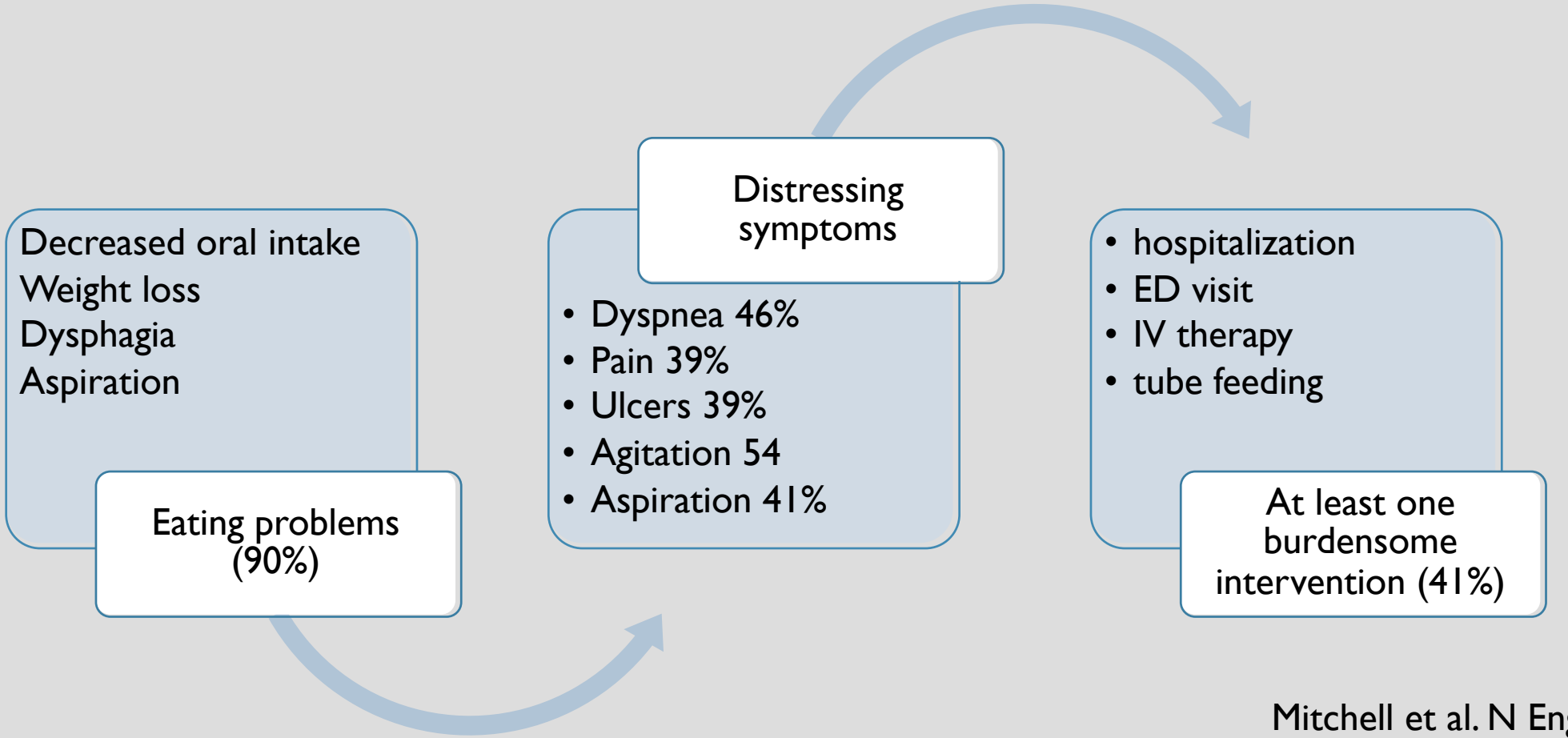
Mitchell et al. N Engl J Med 2009

6 MONTH MORTALITY RATE



Mitchell et al. N Engl J Med 2009

THE LAST 3 MONTHS OF LIFE



Mitchell et al. N Engl J Med 2009

ACUTE MEDICAL CONDITIONS IN END-STAGE DEMENTIA

- Only 9.6% suffered a sentinel event (acute medical condition leading to significant change in health status)
  - Seizure 33%, GIB 26%, hip fracture 7%, other # 9.5%, CVA 7.1% PE 2.3%, MI 2.3%, other for 12%.
- Rarely precipitated death
  - 7 out 177 patients who died had a sentinel event in last 3 months of life

Mitchell et al. N Engl J Med 2009

Individuals whose proxies had an understanding of poor prognosis/clinical complications expected in advanced dementia were much less likely to have burdensome interventions in the last 3 months of life

Mitchell et al. N Engl J Med 2009

EATING PROBLEMS

- Feeding tubes are NOT recommended in advanced dementia
  - ↑ physical and chemical restraint use
    - Antipsychotics ↑ asp risk 60%
  - ↑ agitation
  - ↑ pressure ulcers
  - Decreased caregiver satisfaction at end-of-life
  - **Do not reduce aspiration risk**
  - **No impact on survival, function or quality of life**
  - **May increase mortality (peri-procedurally and at 1-year)**

N Engl J Med. 2000;342(3):206. | JAMA. 1999;282(14):1365. | Arch Intern Med. 2012 May;172(9):701-3. | Brooke et al. Enteral nutrition in dementia: a systematic review. Nutrients. 2015 Apr 3;7(4):2456-68. | Merel et al. Palliative care in advanced dementia. Clin Geriatr Med. 2014 Aug;30(3):469-92. | Candy et al. Enteral tube feeding in older people with advanced dementia: findings from a Cochrane systematic review. Int J Palliat Nurs. 2009 Aug;15(8):396-404.

PEG TUBES IN ADVANCED DEMENTIA VS OTHER CONDITIONS

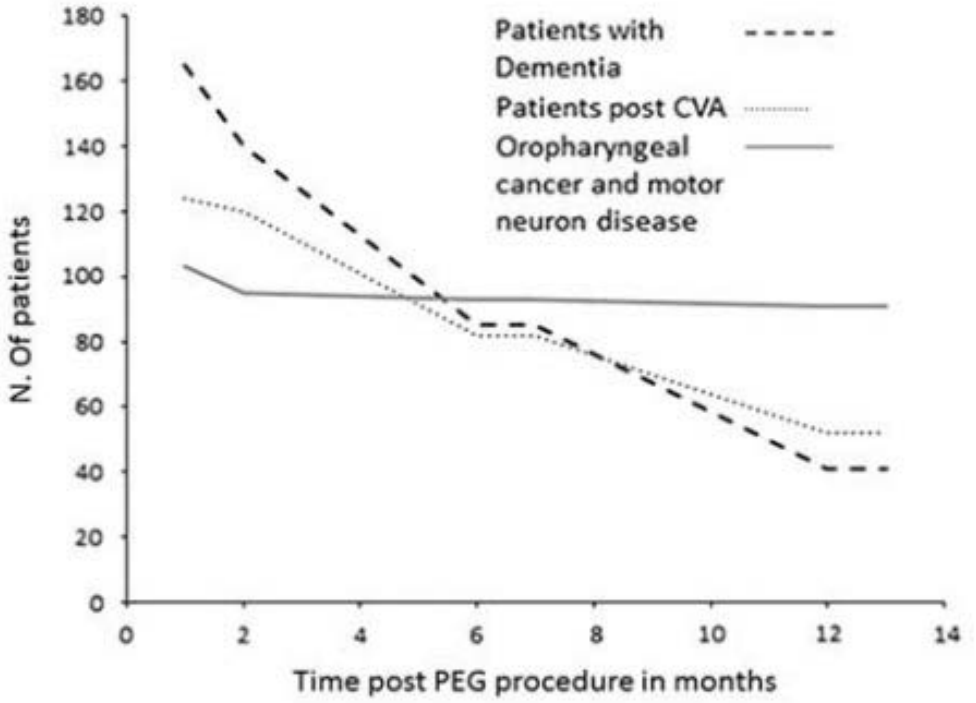
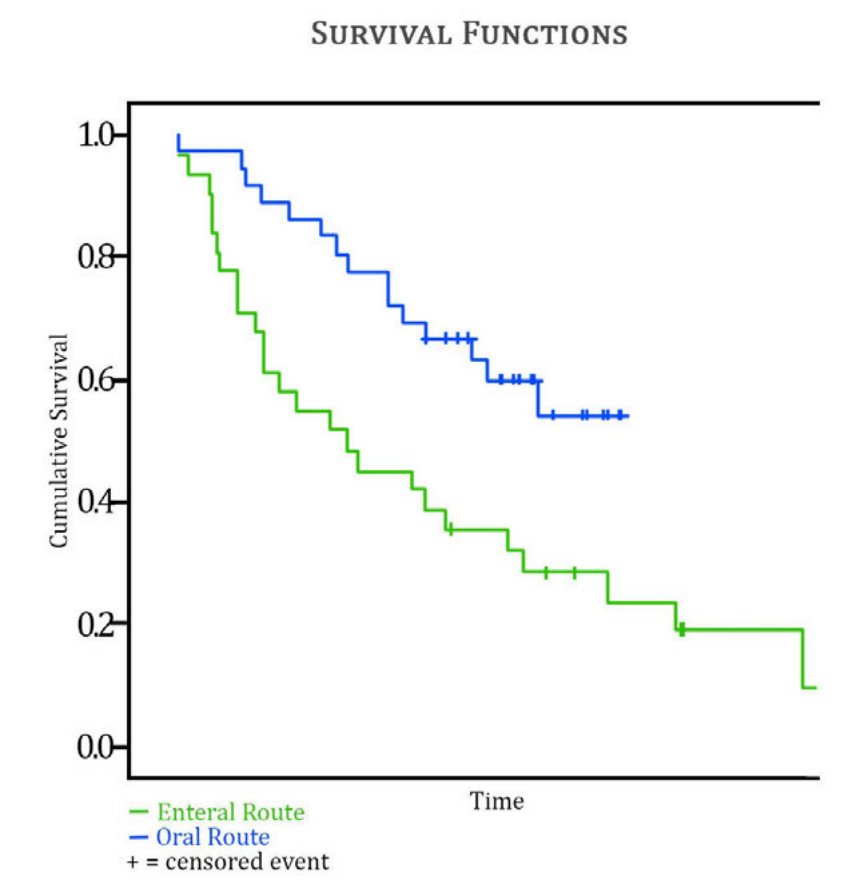


FIGURE 1. Kaplan-Meier survival plot shows no survival benefit of patients with dementia after percutaneous endoscopic gastrostomy (PEG) insertion compared with patients with neurological and oropharyngeal cancer who underwent PEG insertion.

Abu et al. J Clin Gastroenterol. 2016

FEEDING TUBES AND MORTALITY



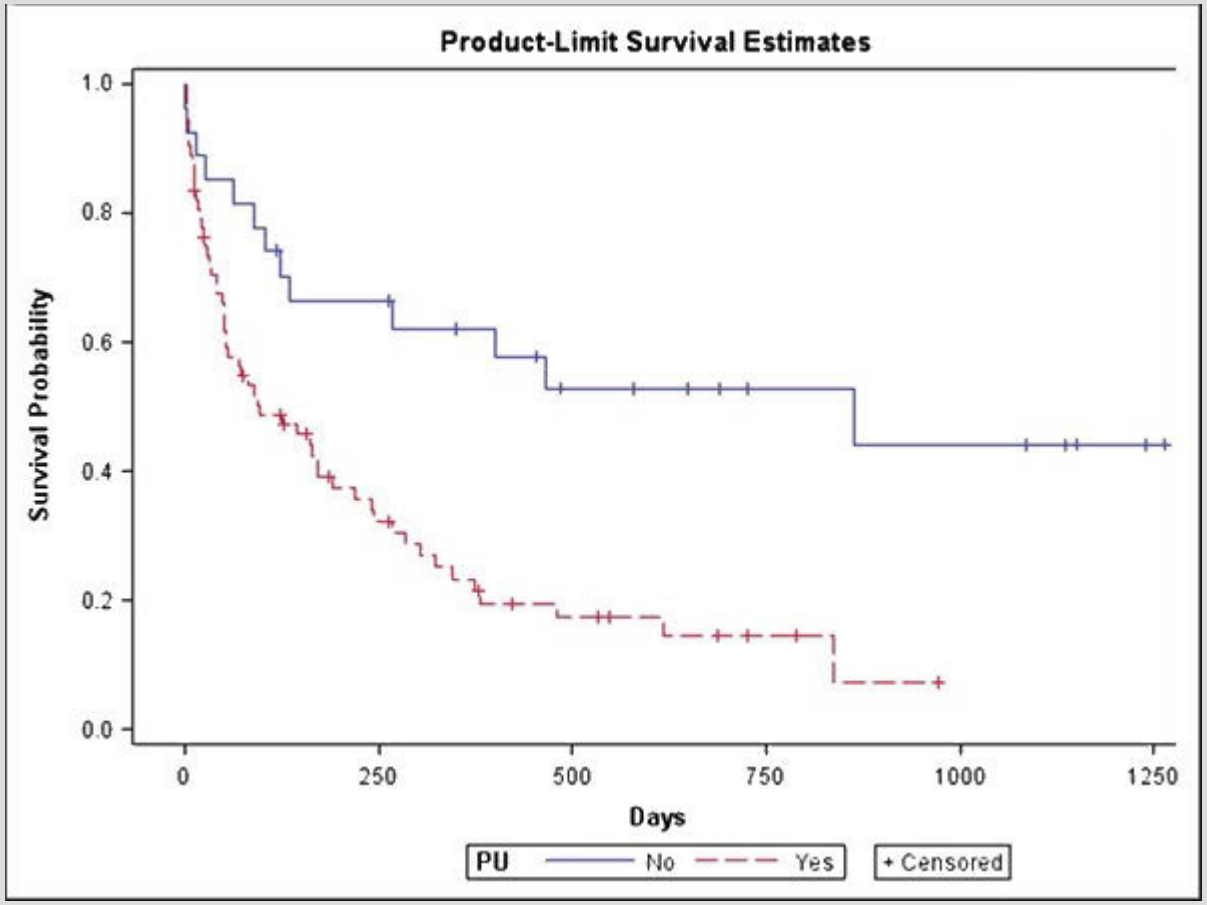
- Increased 3-month mortality (42% vs 11%)
- Increased 6-month mortality (58% vs. 28%)
- More aspiration in the feeding tube group (58% vs 25%)

Cintra et al. J Nutr Health Aging. 2014

Choosing Wisely Canada™

Don’t recommend percutaneous feeding tubes in patients with advanced dementia; instead offer oral feeding.

PRESSURE ULCERS



- Common (2/3)
- Associated with increased mortality
  - Median survival 3 months vs > 2 years

Jaul et al. Exp Aging Res. 2016

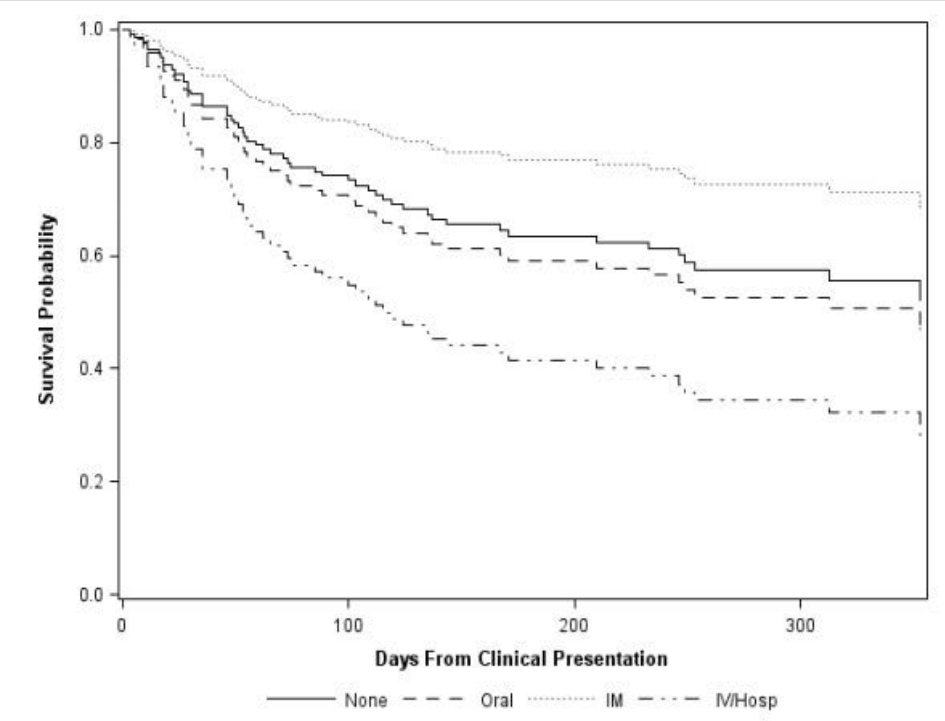
PNEUMONIA

- Antibiotic therapy associated with lower mortality (increased survival time approximately 9 months)
- No survival difference between routes of administration (PO vs IV)
- For those who survived 90 days:
  - Greater comfort scores for those without antibiotics
  - Greater comfort scores for those with less aggressive care (IV significantly associated with lower comfort scores)

Givens et al. Arch Intern Med. 2010

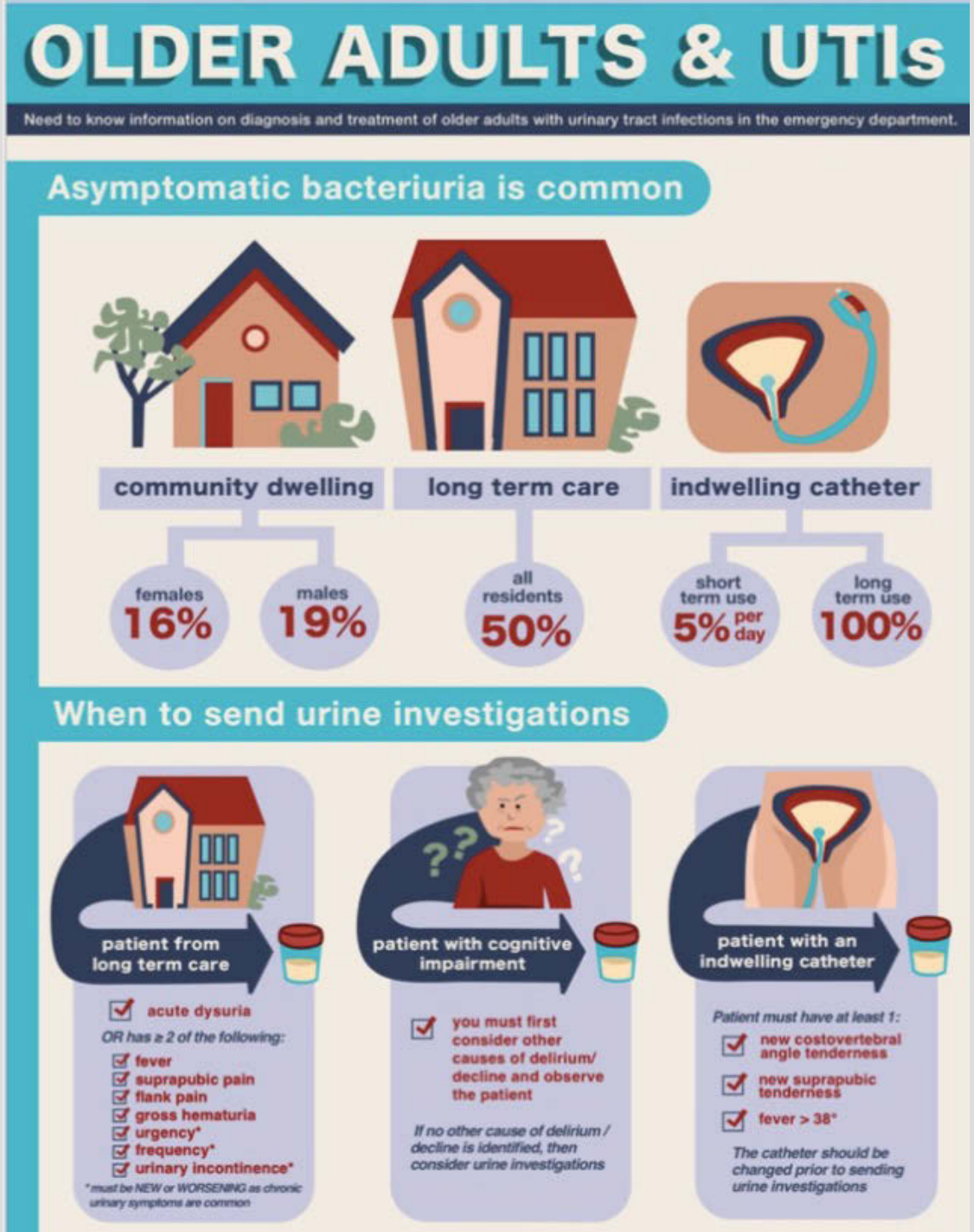
IS IT REALLY A UTI?

- Hospitalization and IV abx associated with shorter survival
- Likely many asymptomatic bacteriuria cases in this cohort
- Iatrogenic harm



Dufour et al. J Am Geriatr Soc. 2015

A FRIENDLY REMINDER TO ORDER U/A'S RESPONSIBLY



Woods, R., Schonnop, R., Henschke, S. *et al.* Just the facts: Diagnosis and treatment of urinary tract infections in older adults. *Can J Emerg Med* (2021).

Choosing Wisely Canada™

Five Things Physicians and Patients Should Question

by

Canadian Geriatrics Society

Last updated: November 2020

1. Don't use antimicrobials to treat bacteriuria in older adults unless specific urinary tract symptoms are present.

2. Don't use benzodiazepines or other sedative-hypnotics in older adults as first choice for insomnia, agitation or delirium.

3. Don't recommend percutaneous feeding tubes in patients with advanced dementia; instead offer oral feeding.

4. Don't use antipsychotics as first choice to treat behavioural and psychological symptoms of dementia.

5. Avoid using medications known to cause hypoglycemia to achieve hemoglobin A1c <7.5% in many adults age 65 and older; moderate control is generally better.

CHOLINESTERASE INHIBITORS – WHEN TO DEPRESCRIBE

Discontinuation should be considered if:

(a) Clinically meaningful worsening of dementia

(b) No clinically meaningful benefit was observed at any time during treatment

(c) Severe or end-stage dementia or limited life expectancy

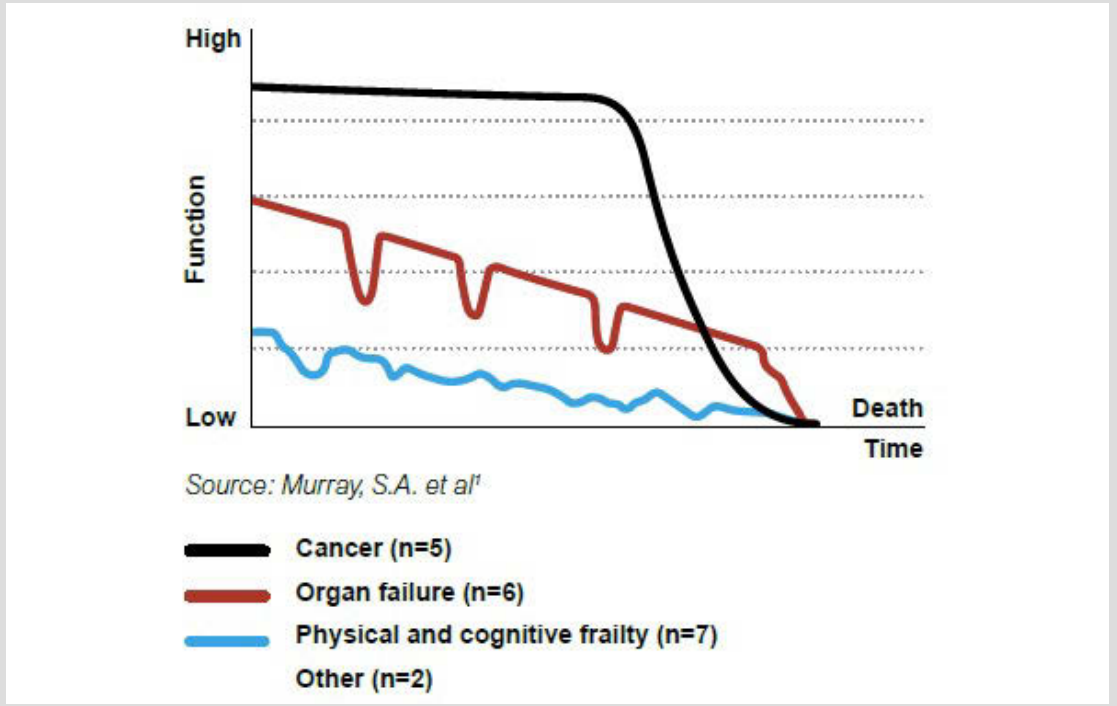
(d) Development of intolerable side-effects (eg, severe nausea, vomiting, weight loss, anorexia, falls)

(e) medication adherence is poor and precludes safe ongoing use of the medication or inability to assess the effectiveness of the medication.

Alzheimer's Dement. 2020;16:1182–1195.

PROGNOSTICATION IS CHALLENGING

- No consensus, standardized prognostic tool in advanced dementia
- Course can be difficult to predict



The Lancet. 2017 Dec 16;390(10113):2673-734.

Clinical Frailty Scale

1 Very Fit – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2 Well – People who have no active disease symptoms but are less fit than category 1. Often, they exercise or are very active occasionally, e.g. seasonally.

3 Managing Well – People whose medical problems are well controlled, but are not regularly active beyond routine walking.

4 Vulnerable – While not dependent on others for daily help, often symptoms limit activities. A common complaint is being "slowed up", and/or being tired during the day.

5 Mildly Frail – These people often have more evident slowing, and need help in high order IADLs (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6 Moderately Frail – People need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing.

7 Severely Frail – Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8 Very Severely Frail – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9 Terminally Ill – Approaching the end of life. This category applies to people with a life expectancy <6 months, who are not otherwise evidently frail.

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia,** recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia,** they cannot do personal care without help.

A Circle Of Care
Victoria Hospice
SOCIETY

Palliative Performance Scale (PPSv2)

version 2

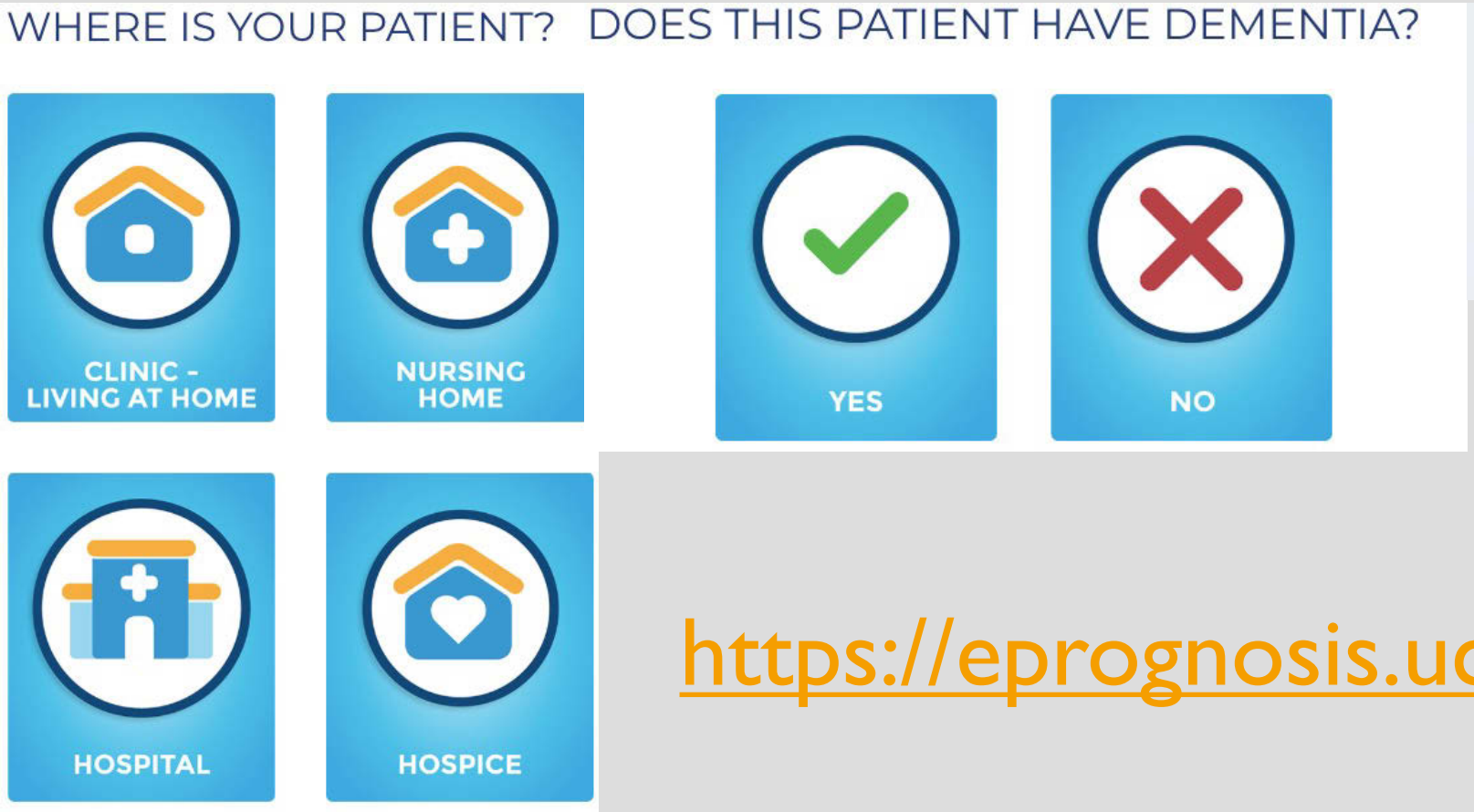
PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity *with* Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

PALLIATIVE PERFORMANCE SCALE

- Developed by Victoria Hospice Society
- Validated in heterogenous population
  - **CANCER** > dementia > lung disease > heart disease > other
- Cancer patients more predictable decline
- Longer hospice stays with dementia and other non-cancer dx
- **Pattern of change** likely more useful in non-cancer dx

Journal of palliative medicine. 2005 Jun 1;8(3):492-502.

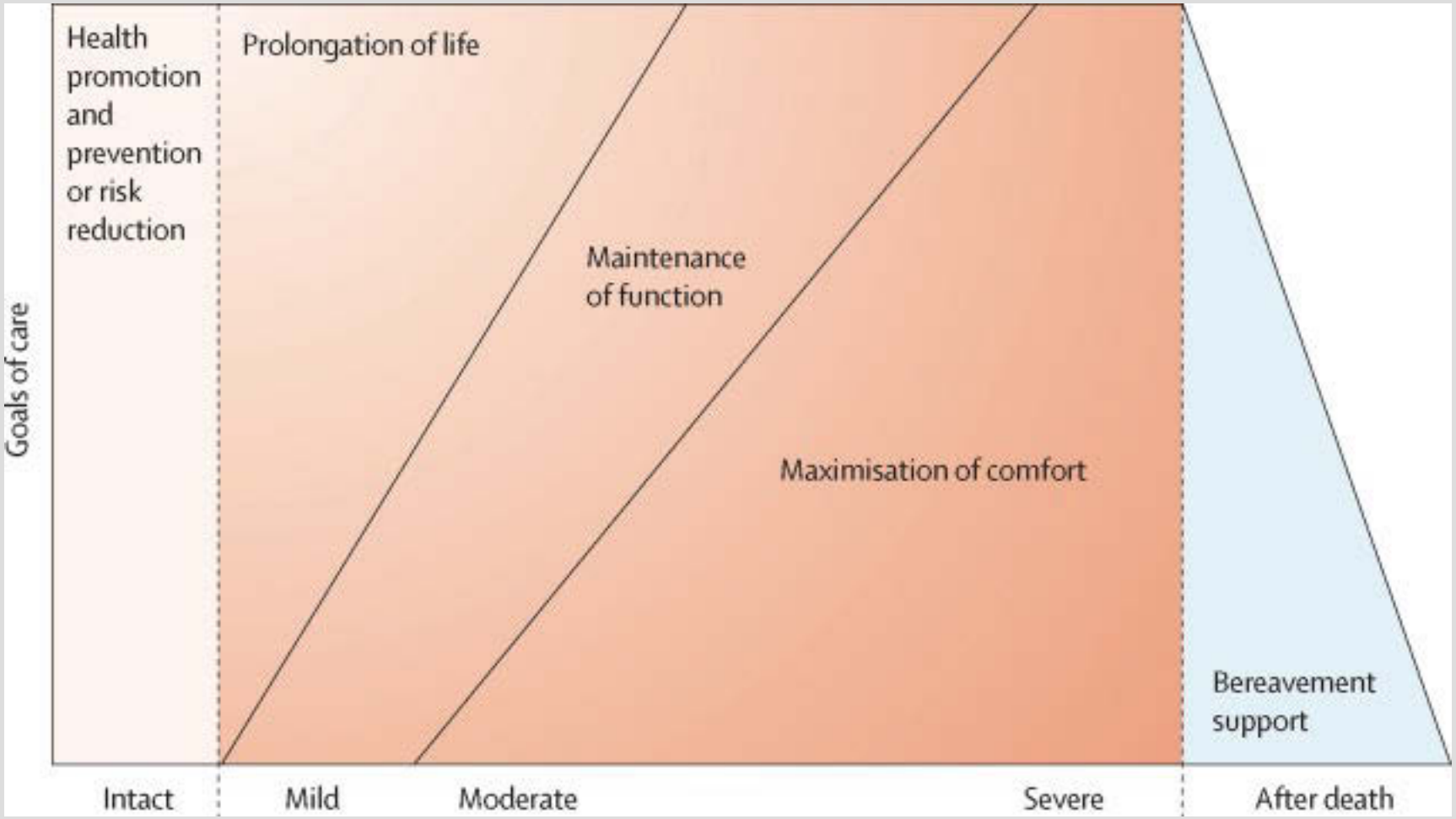
E-PROGNOSIS



Mitchell Index

- Population: Nursing home adults aged 65 and older
- Outcome: 6 month survival
- Scroll to the bottom for more detailed information

https://eprognosis.ucsf.edu/



Palliat Med, 28 (2014), pp. 197-209

WHAT IS OPTIMAL PALLIATIVE CARE IN DEMENTIA?

European Association of Palliative Care – consensus paper

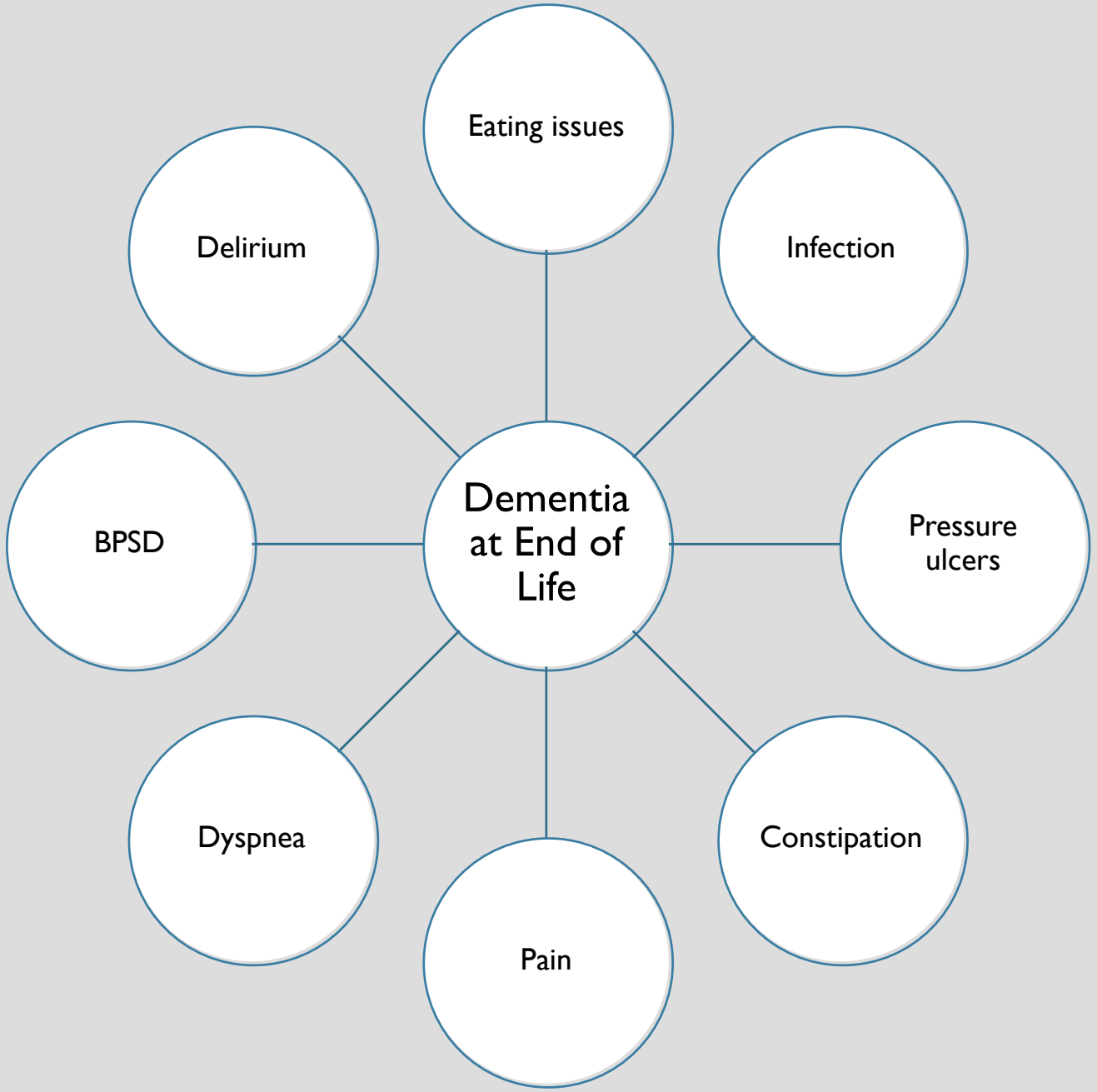
1. Person-centered care
2. Communication and shared decision-making
3. Optimal treatment of symptoms and providing comfort
4. Setting care goals and advance planning
5. Continuity of care
6. Psychosocial and spiritual support
7. Education of health care team
8. Societal and ethical issues

EAPC

Serious Illness Conversation Guide

CONVERSATION FLOW	PATIENT-TESTED LANGUAGE
1. *Set up the conversation* · Introduce purpose · Prepare for future decisions · Ask permission	"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — **is this okay?**"
2. *Assess understanding and preferences*	"What is your **understanding** now of where you are with your illness?" "How much **information** about what is likely to be ahead with your illness would you like from me?"
3. *Share prognosis* · Share prognosis · Frame as a "wish…worry", "hope…worry" statement · Allow silence, explore emotion	"I want to share with you **my understanding** of where things are with your illness…" *Uncertain:* "It can be difficult to predict what will happen with your illness. I **hope** you will continue to live well for a long time but I'm **worried** that you could get sick quickly, and I think it is important to prepare for that possibility." OR *Time:* "I **wish** we were not in this situation, but I am **worried** that time may be as short as ___ *(express as a range, e.g. days to weeks, weeks to months, months to a year).*" OR *Function:* "I **hope** that this is not the case, but I'm **worried** that this may be as strong as you will feel, and things are likely to get more difficult."
4. *Explore key topics* · Goals · Fears and worries · Sources of strength · Critical abilities · Tradeoffs · Family	"What are your most important **goals** if your health situation worsens?" "What are your biggest **fears and worries** about the future with your health?" "What gives you **strength** as you think about the future with your illness?" "What **abilities** are so critical to your life that you can't imagine living without them?" "If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?" "How much does your **family** know about your priorities and wishes?"
5. *Close the conversation* · Summarize · Make a recommendation · Check in with patient · Affirm commitment	"I've heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, I **recommend** that we ___. This will help us make sure that your treatment plans reflect what's important to you." "How does this plan seem to you?" "I will do everything I can to help you through this."
6. *Document your conversation*	
7. *Communicate with key clinicians*	

BC Centre for Palliative Care



Patients dying from dementia have symptoms and health care needs comparable to cancer patients.

There is a disconnect between their needs and services/supports available.

The Lancet. 2017 Dec 16;390(10113):2673-734
Arch Intern Med, 164 (2004), pp. 321-326
Int J Geriatr Psychiatry, 12 (1997), pp. 404-409

BARRIERS TO GOOD END-OF-LIFE CARE

- Economic factors
- Long-term care structural issues e.g. under-staffing
- Dementia education lacking
- Insufficient support to informal caregivers
- Limited hospice access in SK for non-cancer patients
- Limited community palliative care services for non-cancer patients

MY THOUGHTS

- Improve predictive models for prognosis in advanced dementia
- Prioritize early and comprehensive advance care planning and goals of care discussions → SHA ACP Provincial Working Group
- Educate healthcare providers, families and caregivers on common issues seen in end-stage dementia
- Strengthen caregiver support
- Prioritize palliative home care services and hospice care for those with dementia

CONCLUSIONS

- Dementia is a progressive, terminal disease which requires advance care planning and proactive goals of care discussions
- Eating issues, febrile episodes and pneumonia are common and associated with high 6-month mortality
- Dyspnea and pain are common at the end-of-life in those with dementia
- Feeding tubes are not recommended and associated with morbidity and ? mortality
- A palliative care approach is essential for optimal end-of-life care in dementia

THANK YOU. QUESTIONS/COMMENTS?

"A few conclusions become clear when we understand this: that our most cruel failure in how we treat the sick and the aged is the failure to recognize that they have priorities beyond merely being safe and living longer; that the chance to shape one's story is essential to sustaining meaning in life; that we have the opportunity to refashion our institutions, our culture, and our conversations in ways that transform the possibilities for the last chapters of everyone's lives."

— Dr. Atul Gawande, *Being Mortal: Medicine and What Matters in the End*