Dementia and End of Life Care

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Learning Objectives

People will have a better understanding/appreciation:

- **Of end of life (EOL) care for people with dementia**
- **How to help and anticipate the needs of the family and the person with dementia**
- **Recognise the signs and symptoms as death nears**

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Learning Objectives (cont)

- How to respond to difficult questions
- How to access information about End of Life
- What to do when death has occurred

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Dying With Dementia

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Dementia is a Terminal Illness

- **Alzheimer's, Vascular, Lewy body, Frontotemporal**
- **Progressive/No Cure/Fatal**
- **Median Survival 3.2 – 6.6 years from diagnosis**
- **6th Leading Cause of Death in U.S.**
- **5th leading cause of death over age 65**
- **747,000 cases in 2011 → 1.4 Million Predicted by 2031 (CIHI)**

S. Merel et al. Clin Geriatr Med 30 (2014) 469-92
S. Todd et al. Int J Geriatr Physch 28 (2013) 1109 - 24

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When End-of-Life is Approaching

- Forget how to perform simplest tasks: Apraxia
- Loss of speech
- Swallowing difficulties/Aspiration
- Pneumonia and other infections
- Loss of appetite/weight loss
- Functional decline
- Immobility

Final Days

- Completely bed-bound
- Sleeping more and more
- Unable to communicate
- Ongoing Aspiration
- Restlessness/agitation - Delirium
- Pain/Shortness of Breath (Dyspnea)
- Breathing changes
- Respiratory secretions

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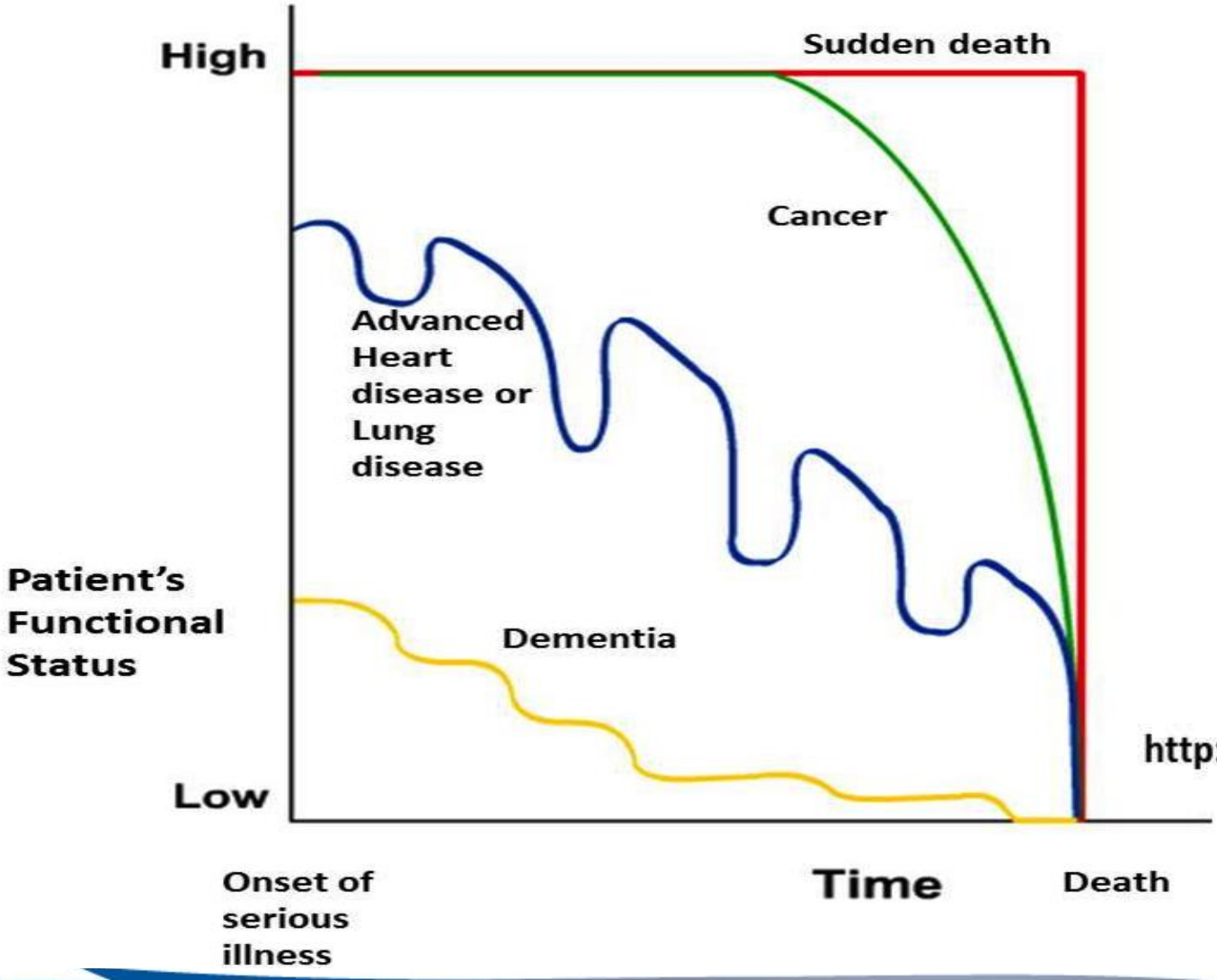
Trajectories of Illness



http://endoflife.stanford.edu

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Palliative Care and Dementia

- Holistic approach to care
- Focus on Quality of Life – Not Prolongation
- Symptom management
- Emphasis on Communication
- Anticipation and Planning
- Respect for the dignity of person
- Importance of individual/family/community

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Difficult Topics

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Foundations of Decision-Making

- **It is essential to understand a person's and family's history, beliefs, values, practices, fears and culture in order to help them make the best decisions.**
- **This knowledge should be the basis for all major decisions**
- **Listen first, speak second**

Advance Care Planning

- **CPR/intubation/ICU admission will not restore health in advanced dementia**
- **Aggressive approach will instead lead to a highly medicalized and possibly prolonged dying process**
- **Instead of hope for cure, offer hope for comfort**
  - **We never give up on a person, or stop striving for comfort**

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Nutrition

"Mom is starving to death, please do something!"

- **Loss of appetite/decreased intake ≠ Starving**
- **Artificial feeding is often considered**
- **Tube feeds are rarely appropriate:**
  - ARE associated with pain, agitation, need for physical restraints, pressure ulcers → **suffering**
  - DO NOT prevent aspiration, pneumonia, pressure ulcers, discomfort and **do not prolong life**
- **Skilled hand-feeding preserves comfort**

American Geriatrics Society Ethics Committee. JAGS 62:1590–1593, 2014

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Role of Antibiotics

- **Infections are exceedingly common:**
  - **Pneumonia**
  - **Urinary tract**
  - **Skin**
- **Antibiotics may modestly prolong life**
- **Do NOT improve comfort**
- **Antibiotic use associated with more aggressive care which may reduce comfort**

S. Merel et al. Clin Geriatr Med 30 (2014) 469-92

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Location of Care

- **Home/long-term care/hospice/hospital**
- **Where does patient feel most comfortable?**
- **Where is home?**
- **Where can goals of care and safety be provided?**
- **Other choices may influence location of care at EOL:**
  - antibiotics, tube feeds

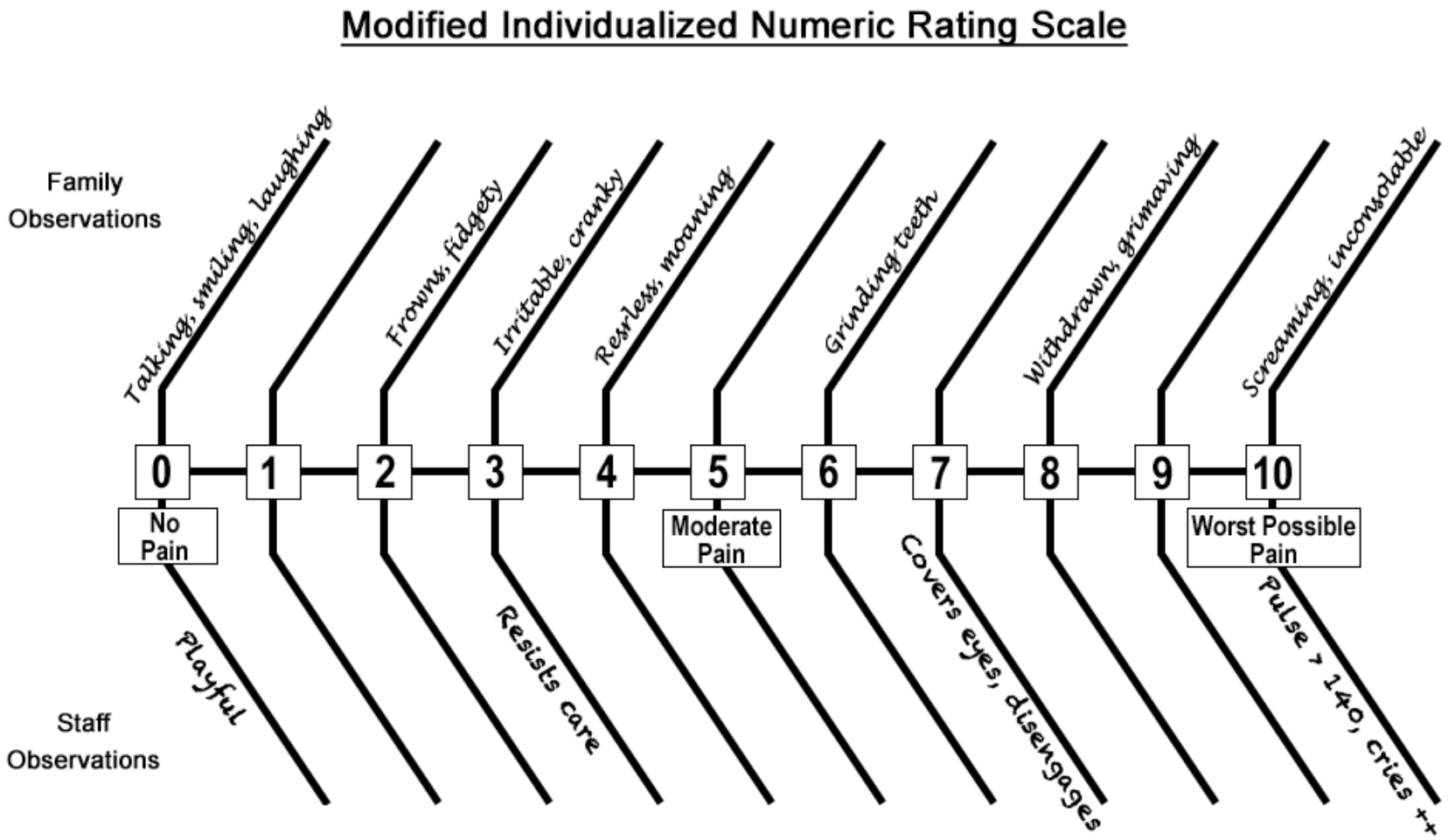
Symptoms at End-of-Life

- **Pain – Often unrecognised**
- **Dyspnea – Shortness of Breath**
- **Delirium – Agitation/Restlessness/Respirator**
- **Respiratory Secretions – “Death Rattle”**

Pain

- **Causes: immobility, arthritis, infections, comorbidities**
- **Difficult to recognise, often undertreated**
- **May manifest as agitation, behaviour change**
- **Learn nonverbal signs:**
  - Behaviour changes, agitation, moaning
  - Grimacing, furrowed brow
  - Reaching to body part
  - Elevated heart rate

A Visual Analogue Scale Developed For Nonverbal Children – May Be Used In Nonverbal Adults



Pain

- **Acetaminophen is First Line**
- **Avoid NSAIDS**
- **Opioids second line (by mouth or subcut)**
  - Hydromorphone/Morphine at low starting doses. (HM 0.25-0.5 mg orally every 4-6 hours plus as needed every 1-2 hours)
  - Cut dose 50% for Subcut route
  - Titrate to effect (Start low and go fast)
  - Monitor for side effects: nausea, constipation, sedation.

Shortness of Breath (Dyspnea)

- **Subjective: may or may not correlate with resp rate, work of breathing, O2 saturation**
- **Causes:**
  - Aspiration pneumonitis/ pneumonia
  - Respiratory muscle weakness
  - Comorbidities: CHF, COPD
- **Treatment:**
  - Air movement, fan, Supplemental O2*
  - Opioids – be prepared to titrate quickly

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Opioids at the End-of-Life

- Can be **safely** given at the end-of-life
- **Do not** hasten death when properly dosed
  - May delay death by relieving stress on the body
  - Breathing changes at EOL (irregular breathing, clusters then apnea) do not resemble changes from opioid OD (slow deep breathing, pinpoint pupils)
- **Powerful relief** of both pain and dyspnea

Delirium / Agitation

- Delirium = Distress
- Consider **pain** as a cause – treat it
- Review meds!
- Delirium at End-of-Life often irreversible
- Treatment:
  - Calm/familiar surroundings
  - Reassurance
  - Antipsychotics – haloperidol/nozinan
    - Avoid in patients with Parkinsonism
  - Benzodiazepines for **sedation** if needed

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Respiratory Secretions

- **Small amounts of secretions in large airways**
- **Often disturbing to caregivers and families.**
- **May not be distressing for the person in bed.**
- **Anti-secretory meds may reduce secretions**
  - Scopolamine or glycopyrrolate
- **BUT:**
  - Can worsen delirium
  - Cause dry mouth
  - Urinary Retention

Rachael's Stories

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Helping Families at the Bedside

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4 Key Elements of Supporting Dignity in a PCH

- **Being Known**
- **Responding to**
- **Respecting Personal Space**
- **Social Engagement**

Dr. Harvey Chochinov

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ABCD'S of Dignity Conserving Care

A Attitude

B Behaviour

C Compassion

D Dialogue

Dr. Harvey Chochinov :

The Dignity Model and Dignity Therapy

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How to Connect with Families

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How to Connect with Families

- **Greet families when you see them enter the unit**
- **Make the effort to have a conversation during their visit**
- **Acknowledge the family as they leave and answer any questions they may present to you**

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How to Connect with Families

- **Physical changes – skin colour; breathing patterns**
- **Individual time alone with patient**
- **Can they hear us?**
- **How do you know they're comfortable?**
- **Missed the death**

Make the Connection with the Family

The First Steps of a conversation:

- **Ask questions**
- **Check out where they are at in their journey**
- **Offer opportunities to be involved in care**
- **Provide information**

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Make the Connection with the Family

- **Offer Suggestions :**

  “Some people wonder if ..”

- **Offer the family opportunity/permission to take a break**

- **Prepare them for the person’s death**

When Death Occurs

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When Death Occurs

What next ?

“How a person dies lives remains in the memory of those who live on.”

Dame Cicely Saunders

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Quotes

"You matter because you are you,

And you matter to the end of your life.

We will do all we can not only to help you die peacefully, but also live until you die."

Dame Cicely Saunders

Founder of the modern hospice movement (1918-2005)

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Quotes

“How people die remains in the memory of those who live on.”

Dame Cicely Saunders

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Quotes

“I have learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel.”

Maya Angelow

Resources

- www.palliative.info Dr.Mike Harlos
- www.dignityincare.ca Dr. Harvey Chochinov
- www.virtualhospice.ca Canadian VirtualHospice
- www.alzheimer.ca ASC's Progression Series
- www.alzheimer.ca End of Life (**a resource in progress**)
- http://hpcintegration.ca/ Quality End of Life Care Coalition of Canada
- tfrymire2@rhc.mb.ca Tim Frymire

  re: template for room blessing

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Questions

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Supplemental Material

- Curtesy of Dr. M. Harlos.
  - Medical Director – WRHA Palliative care Program

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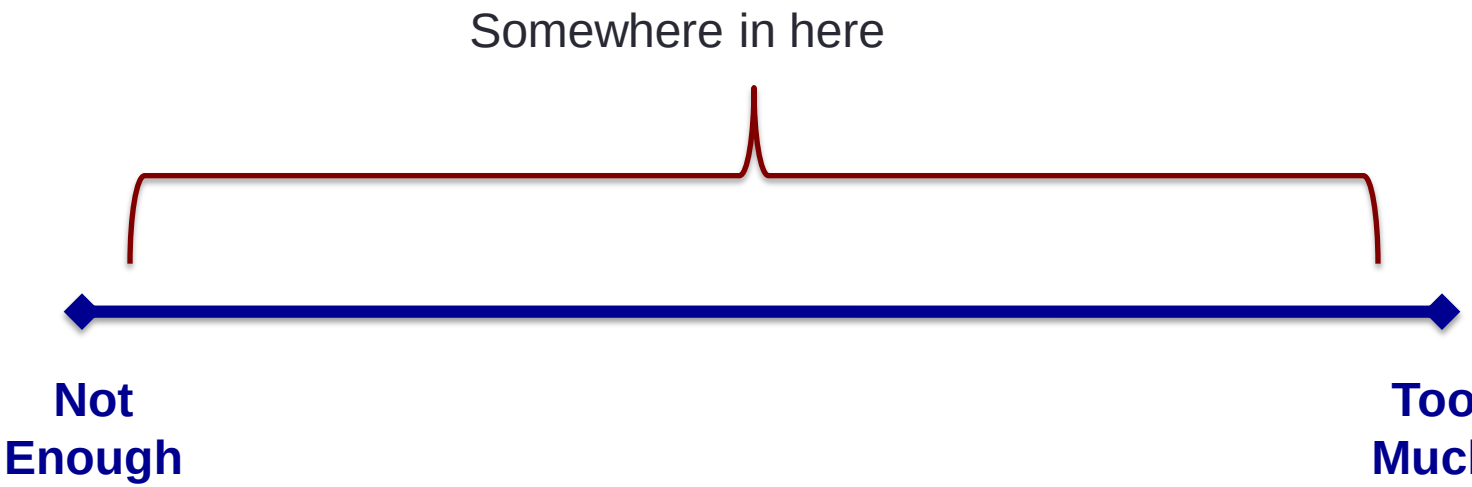
Management of Symptoms

Symptom	Drug	Non-Oral Route(s)
Dyspnea	opioid	• sublingual (SL) – small volumes of high concentration; same dose as oral • subcutaneous – supportable in most settings; same dose as IV = ½ po dose • IV – limited to hospital settings • intranasal – fentanyl – lipid soluble opioid; use same dose as IV to start • Note: Transdermal not quickly titratable
Pain	opioid	see above
Secretions	scopolamine	• subcutaneous • transdermal (patches; compounded gel)
	glycopyrrolate	• subcutaneous
Agitated Delirium	neuroleptic (methotrimeprazine; haloperidol)	• SL– use same dose for all routes • subcutaneous (most settings); IV (hospital)
	lorazepam	• SL – generally use with neuroleptic

Using Opioids/Sedatives In The Final Hours/Days: "Start Low, Go Fast"

- If you start cautiously with an anticipated ineffective dose, be prepared to titrate up quickly
- "prepared" means attentive, proactive, vigilant, available (i.e. don't assume things are fine if nobody calls you)
- "first-dose survival test"
- Reassess early (perhaps later that day even), and consider increasing to a more "usual" dose

Determining The Correct Opioid Dose



i.e. the opioids are titrated proportionately to achieve the desired effect

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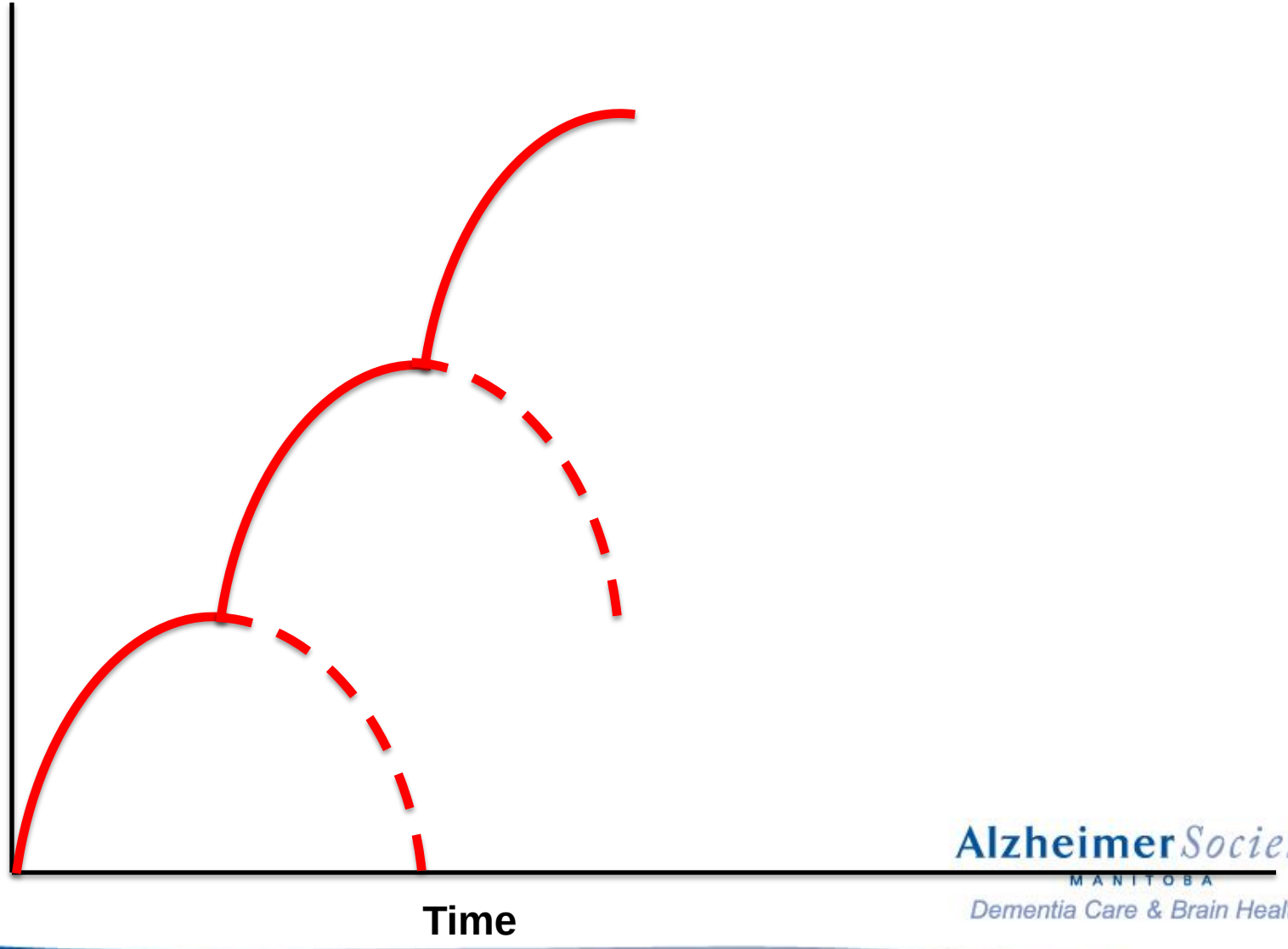
Breakthrough / *prn* Doses

- breakthrough doses are usually 10-20% of total daily dose, or equal to the q4h dose
- the correct dose is the one that works – this may vary for an individual patient, and might be substantially different between patients
- *prn* interval for breakthroughs should reflect pharmacology –i.e. when is it reasonable to repeat? (enteral 1 hr; subcut 30 min; IV 10-15 min; transmucosal 10-15 min)
- if you want to limit the # breakthrough doses due to safety concerns, do so by limiting the # doses over a period, but keep the reasonable interval

Stacking Doses



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Congestion in the Final Hours ("Death Rattle")

- Positioning
- *ANTISECRETORY:*
  - scopolamine 0.3-0.6 mg subcut q2h prn
  - glycopyrrolate 0.2-0.4 mg subcut q2h prn (less sedating than scopolamine)
- Consider suctioning if secretions are:
  - distressing, proximal, accessible
  - not responding to antisecretory agents

Guidelines for end-of-life Care (Winnipeg Regional Health)

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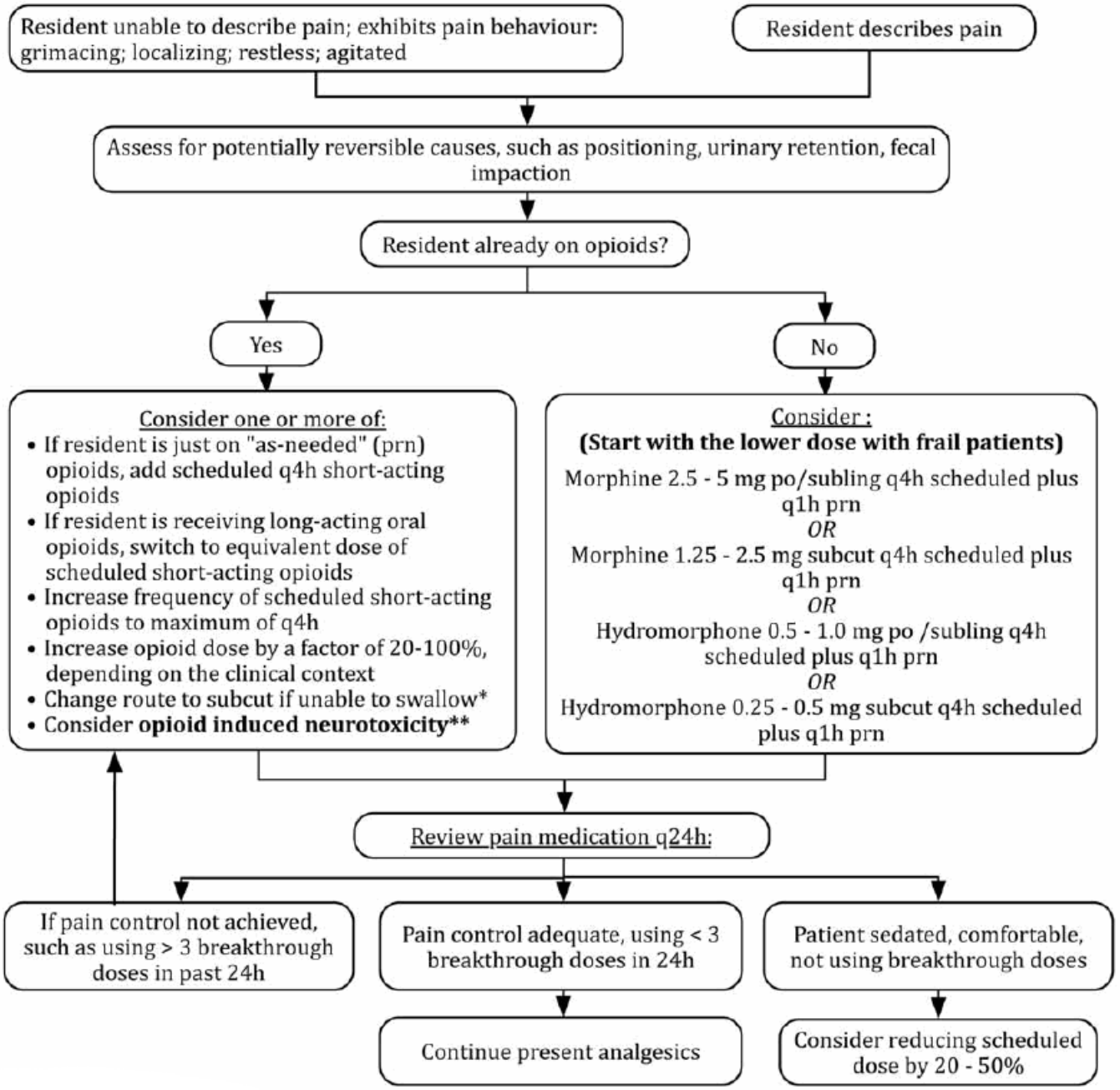
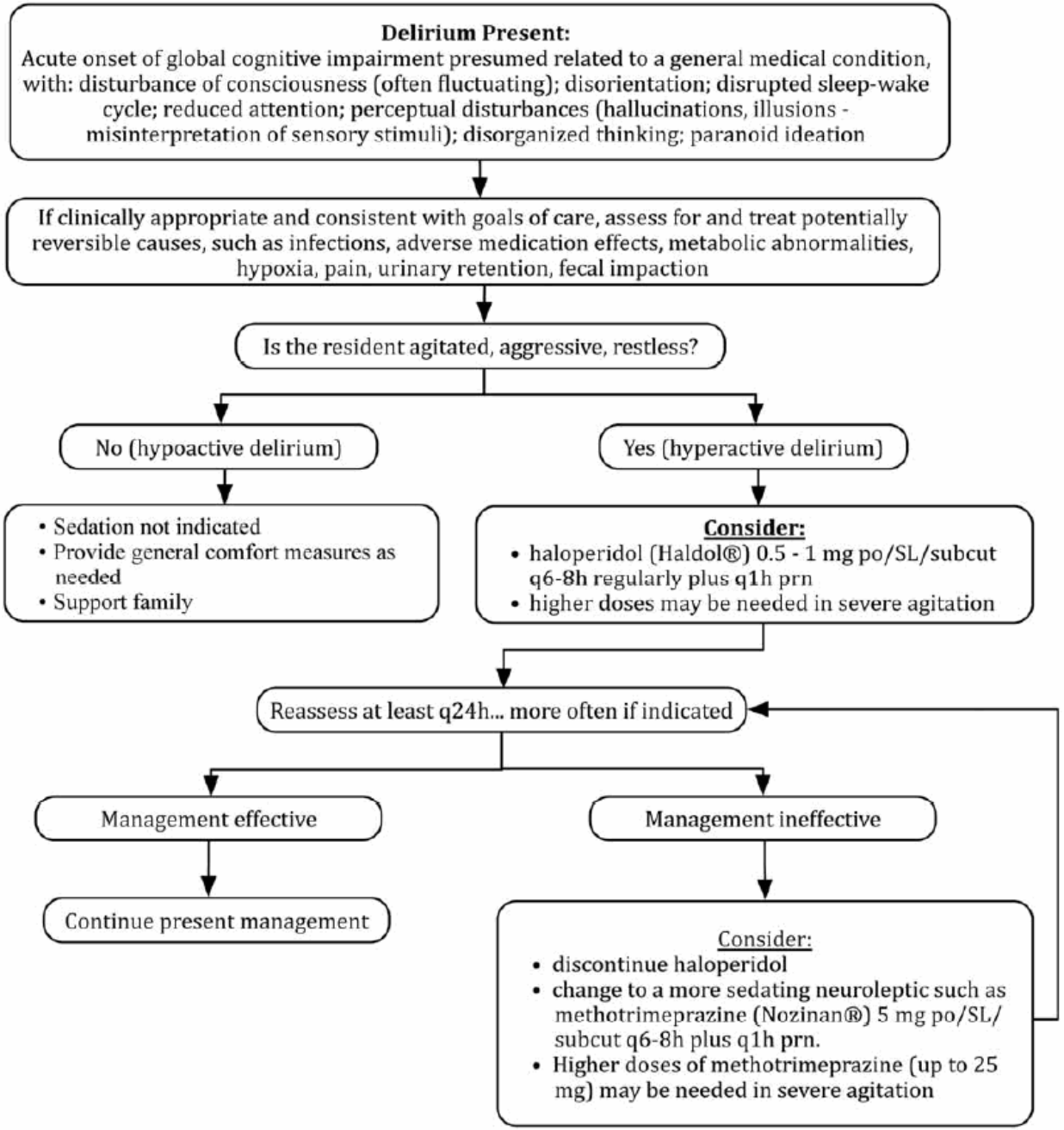
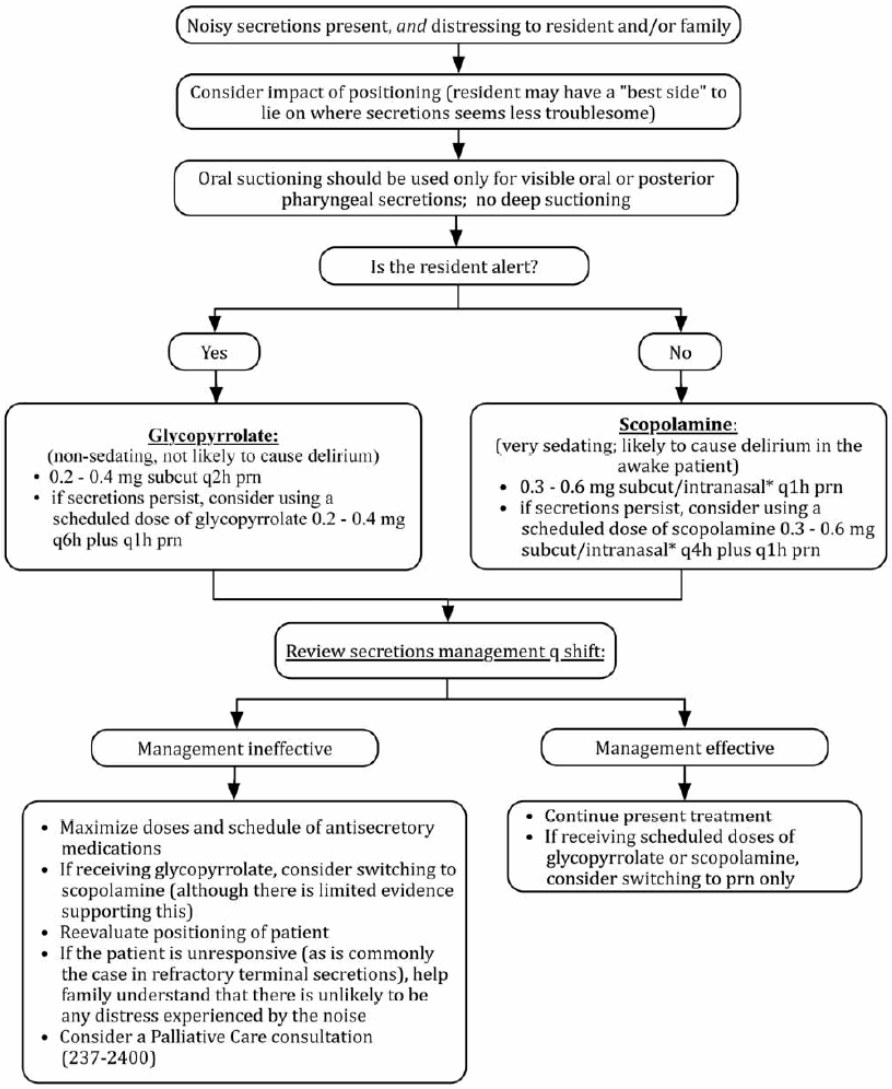
Pathway A
Pain Management In The Final Days Of Life



Pathway B
Management of Agitated Delirium In The Final Days Of Life



Pathway C
Management of Noisy Secretions In The Final Days Of Life



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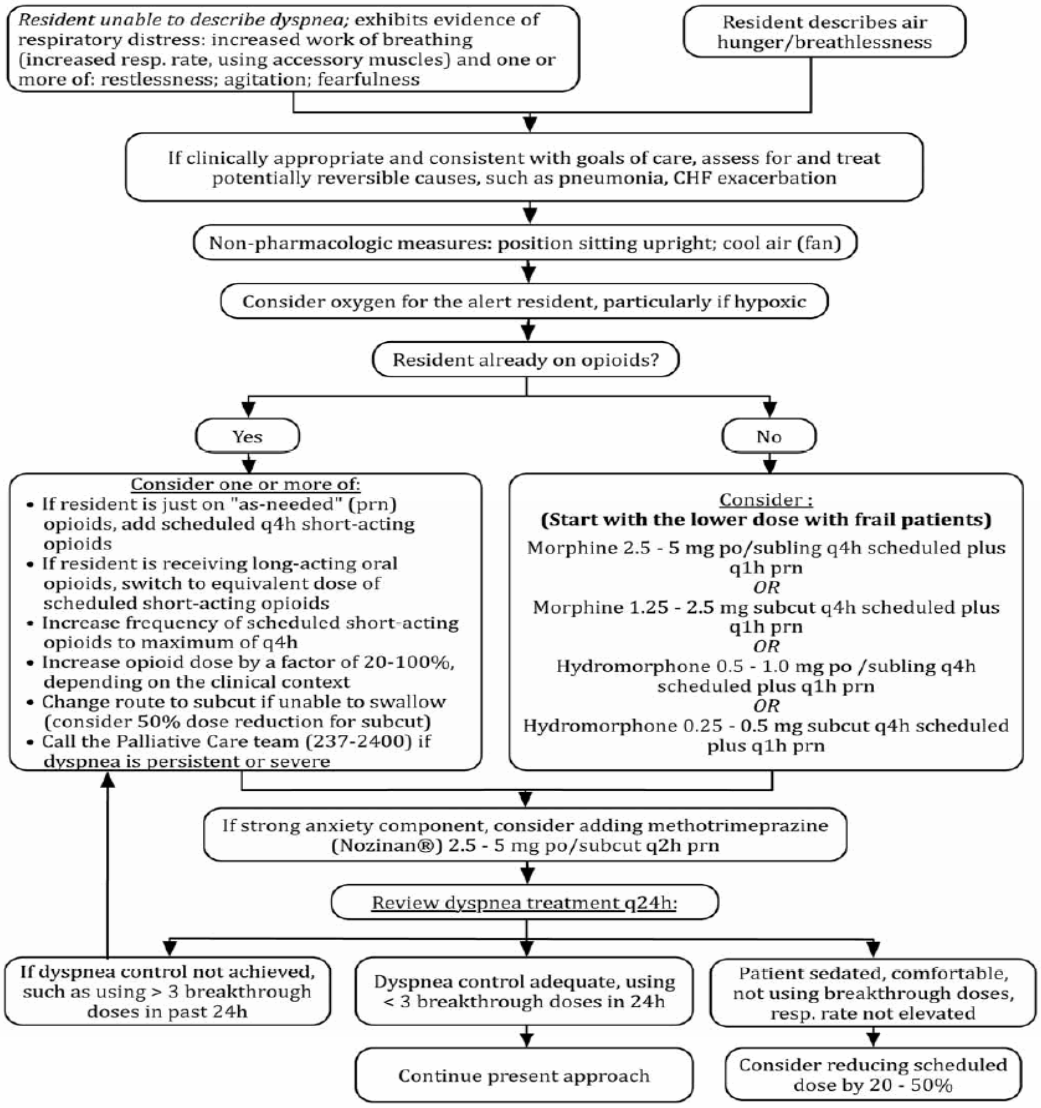
Pathway E
Dyspnea Management In The Final Days Of Life



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