Palliative Care Approach to Complications of Advanced Dementia

Brain Aging Conference 2025 – Professionals Day

Springfield, IL

April 11, 2025

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SIU MEDICINE
FORWARD. FOR YOU.

PC APPROACH TO COMPLICATIONS OF ADVANCED DEMENTIA

Learning Objectives:

1. Recognize common symptoms in advanced dementia

2. Adopt a structured serious illness conversation

3. Translate your knowledge of the patient's condition into language with the patient and family

DISCLOSURES

- No discussion of off-label medication use
- No industry related financial disclosures
- Relationship with Memorial Hospice

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

- Dame Cicely Saunders
- Founder of the Modern Hospice Movement 1967

Definitions

PALLIATIVE CARE IS…

- An approach to care for patients with serious illness, aimed at improving the quality of life of patients and families.
- Appropriate for patients at any stage of their illness, including at the time of diagnosis, and can evolve to fit the patient's needs as their disease progresses.
- It emphasizes relief of physical, emotional, and spiritual distress.
- Communication about care preferences is a critical component of palliative care, and expertise in handling difficult conversations, responding to emotion, and discussing patients' wishes is necessary.

Brizzi, K, Creutzfeldt CJ. Semin Neurol. 2018 Oct;38(5):569-575.

PALLIATIVE CARE IS…

- Objective as possible
- Remaining neutral
  - No agenda
- Patient centered
- Shared decision making
- Accepting of decision maker's choices
  - Especially after shared understanding re: diagnoses, prognosis, goals, values

DOMAINS OF PALLIATIVE CARE

Interdisciplinary Team Core:

- Social Worker
- Chaplain or Bereavement counselor
- Nurse
- Physician

Gelfman, L, et al. *J Am Coll Cardiol HF*. 2024 Jun, 12 (6) 973–989.

HOSPICE IS…

- Hospice
  - Insurance benefit
  - Tightly regulated
  - Comfort-focused, multidisciplinary end of life care
  - Typically provided in home or nursing home setting
  - Patient must have:
    - **Terminal diagnosis**
      - Cannot use
        - Failure to thrive
        - Dementia NOS
        - Debility
        - Symptom codes
    - **Prognosis expected to be <6 months**
  - Cannot continue curative treatments for terminal condition

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- Hospice
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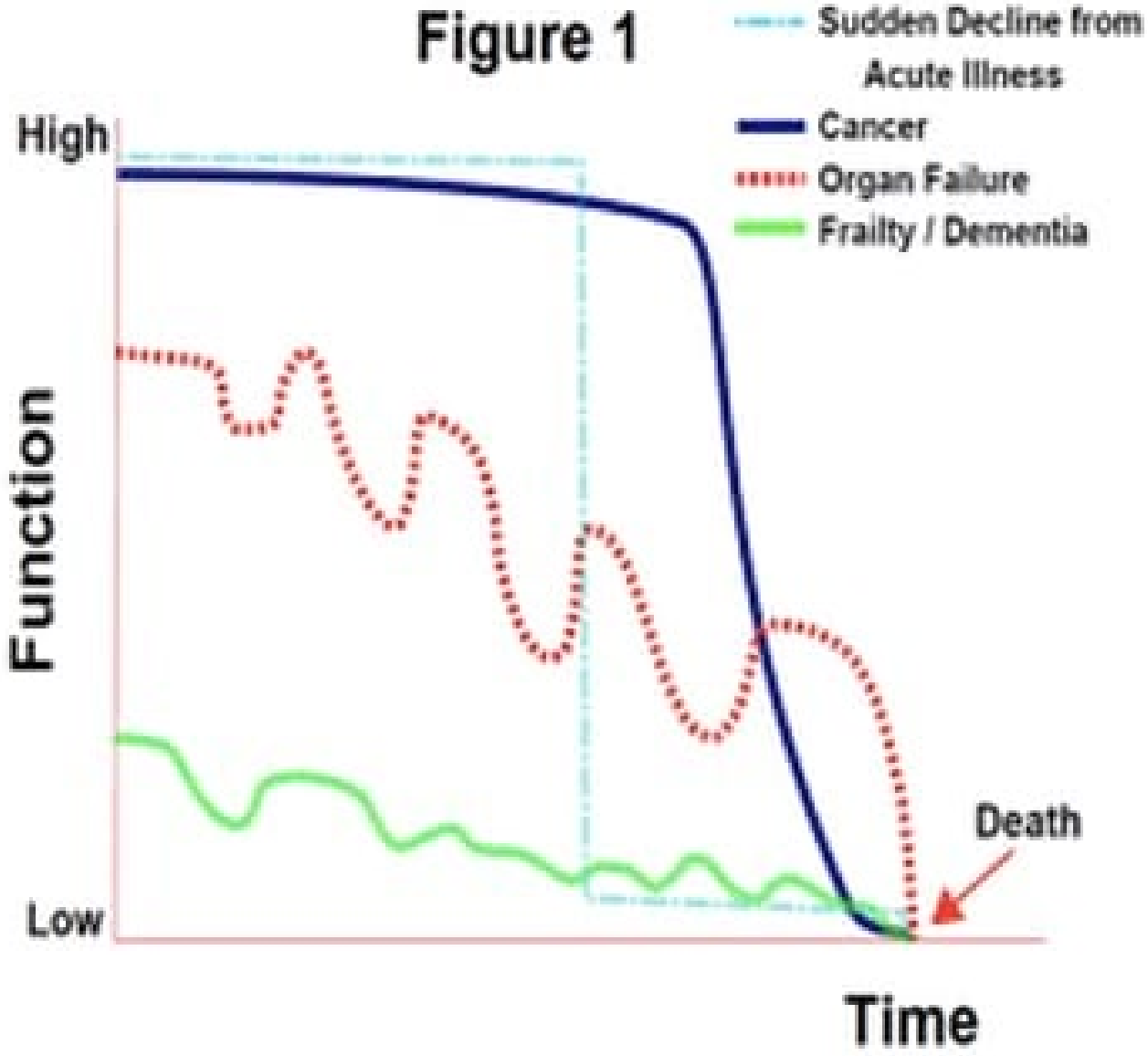
  - Tightly regulated
  - Comfort-focused, multidisciplinary end of life care
  - Typically provided in home or nursing home setting
  - Patient must have:
    - **Terminal diagnosis**
      - Instead, use
        - Specific Dementia
          - Possible / probable Alz
          - Lewy Body Dementia
          - Etc.
        - Protein Calorie Malnutrition
        - Stroke
    - **Prognosis expected to be <6 months**
  - Cannot continue curative treatments for terminal condition

Trajectory

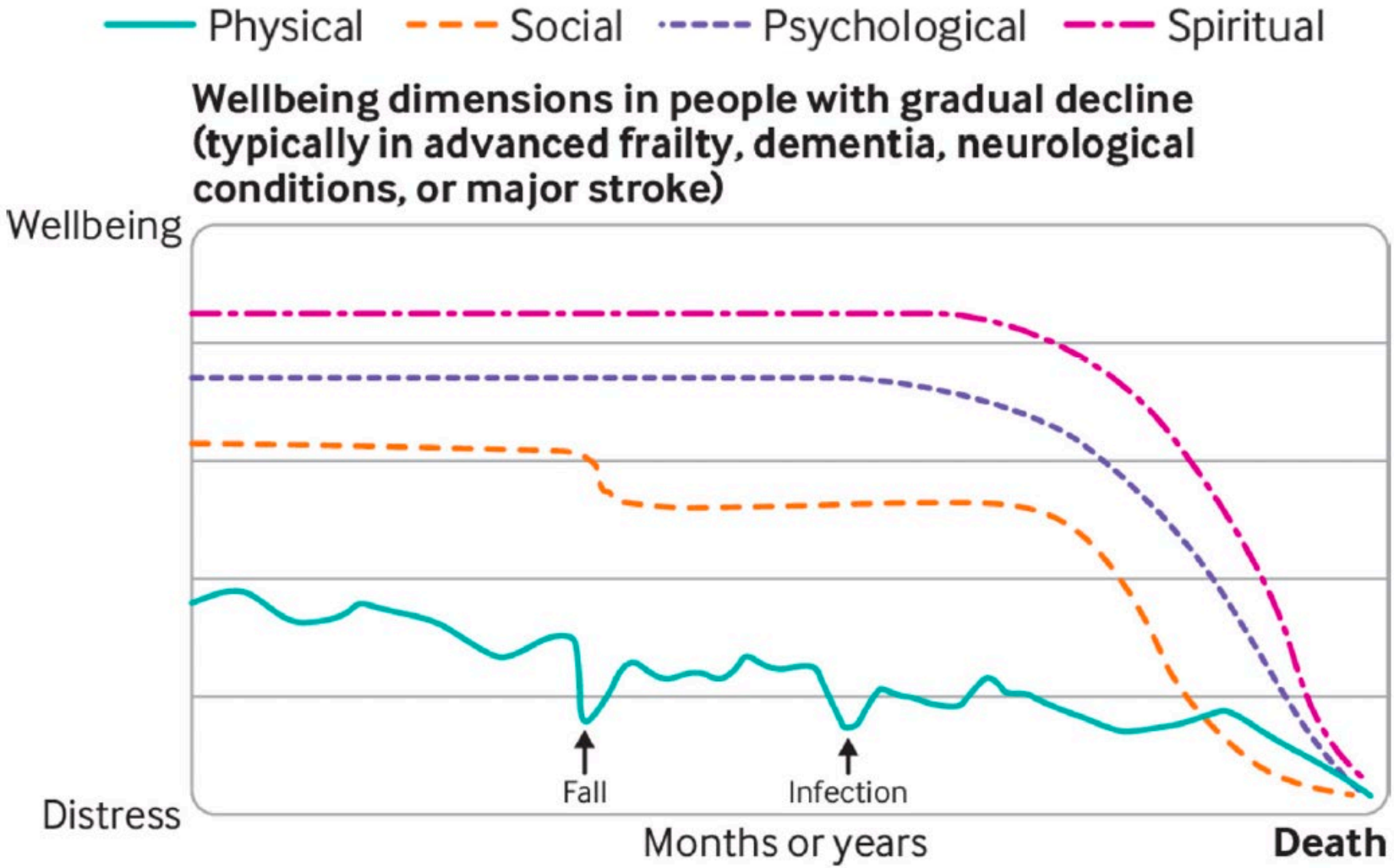
ILLNESS TRAJECTORY
4 MAIN PATTERNS – PHYSICAL FUNCTION



https://www.mypcnow.org/fast-fact/illness-trajectories-description-and-clinical-use/

ILLNESS TRAJECTORY - DEMENTIA

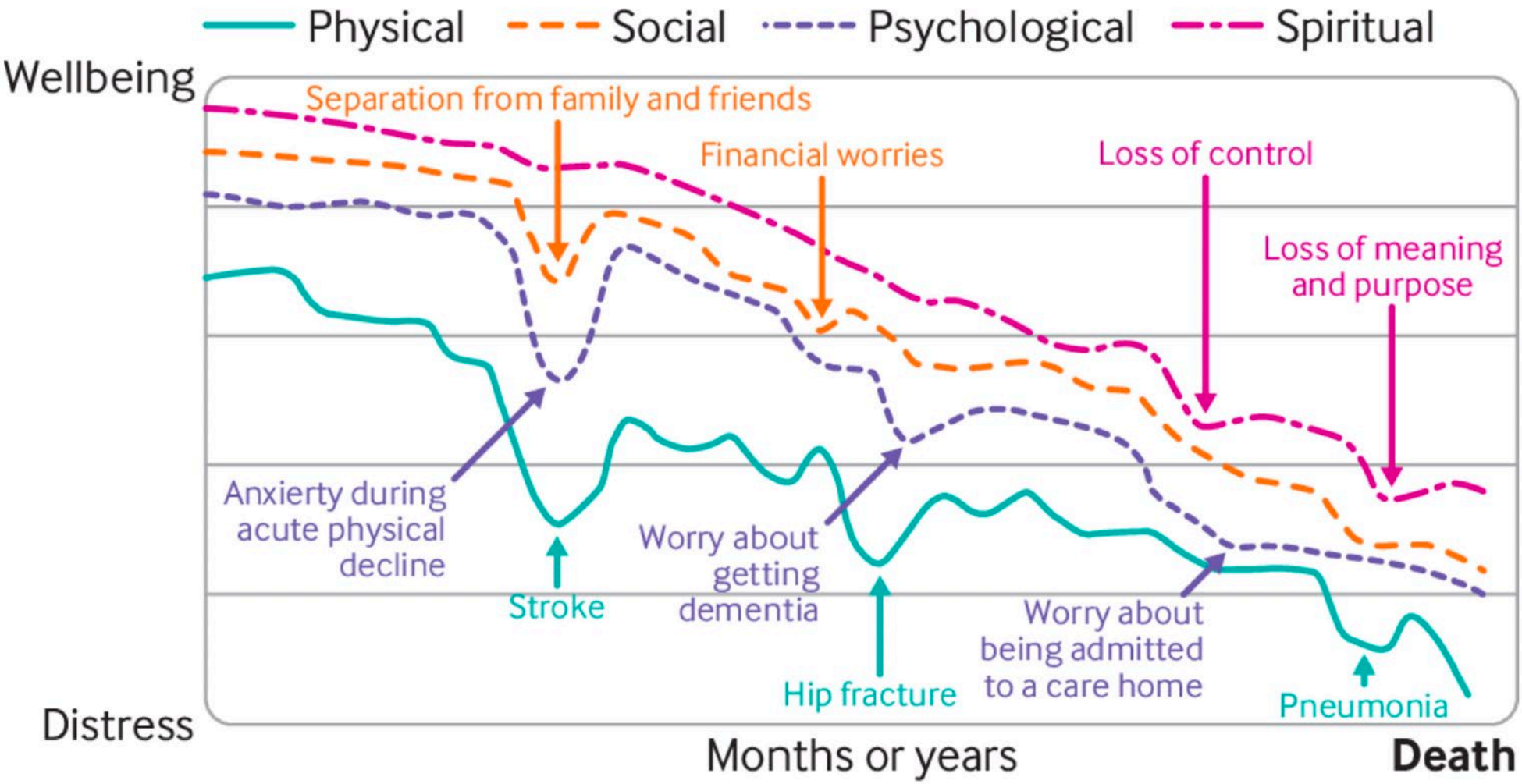
- Multidimensional



Murray, S, et al. BMJ 2024;384:e067896

ILLNESS TRAJECTORY

- Multimorbidity



Murray, S, et al. BMJ 2024;384:e067896

FUNCTIONAL ASSESSMENT STAGING SCALE (FAST SCALE)

- Specific for Alzheimer's Dementia
- Reliable / Valid
- Most patients (75%) progress through sequential stages of functional decline due to Alzheimer's
- Highest consecutive level of disability is the FAST stage
- Hospice appropriate at 7A (avg 6.9 mo, median 4 mo survival)

Functional Assessment Scale (FAST)

1	No difficulty either subjectively or objectively.
2	Complains of forgetting location of objects. Subjective work difficulties.
3	Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity. *
4	Decreased ability to perform complex task, (e.g., planning dinner for guests, handling personal finances, such as forgetting to pay bills, etc.)
5	Requires assistance in choosing proper clothing to wear for the day, season or occasion, (e.g. pt may wear the same clothing repeatedly, unless supervised.*
6	Occasionally or more frequently over the past weeks. * for the following **A)** Improperly putting on clothes without assistance or cueing . **B)** Unable to bathe properly (not able to choose proper water temp) **C)** Inability to handle mechanics of toileting (e.g., forget to flush the toilet, does not wipe properly or properly dispose of toilet tissue) **D)** Urinary incontinence **E)** Fecal incontinence
7	**A)** Ability to speak limited to approximately ≤ 6 intelligible different words in the course of an average day or in the course of an intensive interview. **B)** Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview **C)** Ambulatory ability is lost (cannot walk without personal assistance.) **D)** Cannot sit up without assistance (e.g., the individual will fall over if there are not lateral rests [arms] on the chair.) **E)** Loss of ability to smile. **F)** Loss of ability to hold up head independently.

*Scored primarily on information obtained from a knowledgeable informant.
Psychopharmacology Bulletin, 1988 24:653-659.

Luchins, et al. *J Am Geriatr Soc* 1997;45:1054-1059

Sclan SG, Reisberg B. Int Psychogeriatr. 1992;4 Suppl 1:55-69.

WHAT ABOUT OTHER DEMENTIAS?

- Look for signs of functional decline, complications
  - Inability to walk without assistance
- Vascular dementia tends to progress more rapidly than Alzheimer's
- Age
- Gender
- Use of FAST scale?
- Clinical Dementia Rating Scale
- Global Deterioration Scale

Functional Assessment Scale (FAST)

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Serious Illness Communication

SERIOUS ILLNESS CONVERSATION

- A discussion between a provider and a patient about:

- decision-making preferences
- the patient's understanding of their illness
- prognosis
- hopes and worries
- and medical goals/trade-offs

Brizzi, K, Creutzfeldt CJ. Semin Neurol. 2018 Oct;38(5):569-575.

TRIGGERS FOR CONVERSATION

Triggers for general neurology:

- Age > 80 and hospitalized
- Patient or family request
- Surprise ?: “Would you be surprised if the patient died in the next year?”

For Dementia:

- Periodic with regular clinic visits
- Nighttime wandering
- Concern for driving / giving up car keys
- Caregiver strain
- Hospitalization
- Increased symptom burden / decreased quality of life
- Major decrease in functional capacity
- Decreased / insufficient nutritional intake
- Progression or diagnosis of other comorbidity: Stroke, cancer, CHF, etc.

Brizzi, K, Creutzfeldt CJ. Semin Neurol. 2018 Oct;38(5):569-575.
Creutzfeldt, CJ et al. Neurol Clin Pract. 2016 Feb;6(1):40-48.

SHOULD PROVIDERS GIVE RECOMMENDATIONS?

- When faced with decisions, patients and families will occasionally ask for a recommendation
  - “What would you do?”
- Providers often feel uncomfortable…
- Why?

ADOPTING A STRUCTURED APPROACH

Knowledge
- Assess patient / family understanding
- Provide education / “reset”

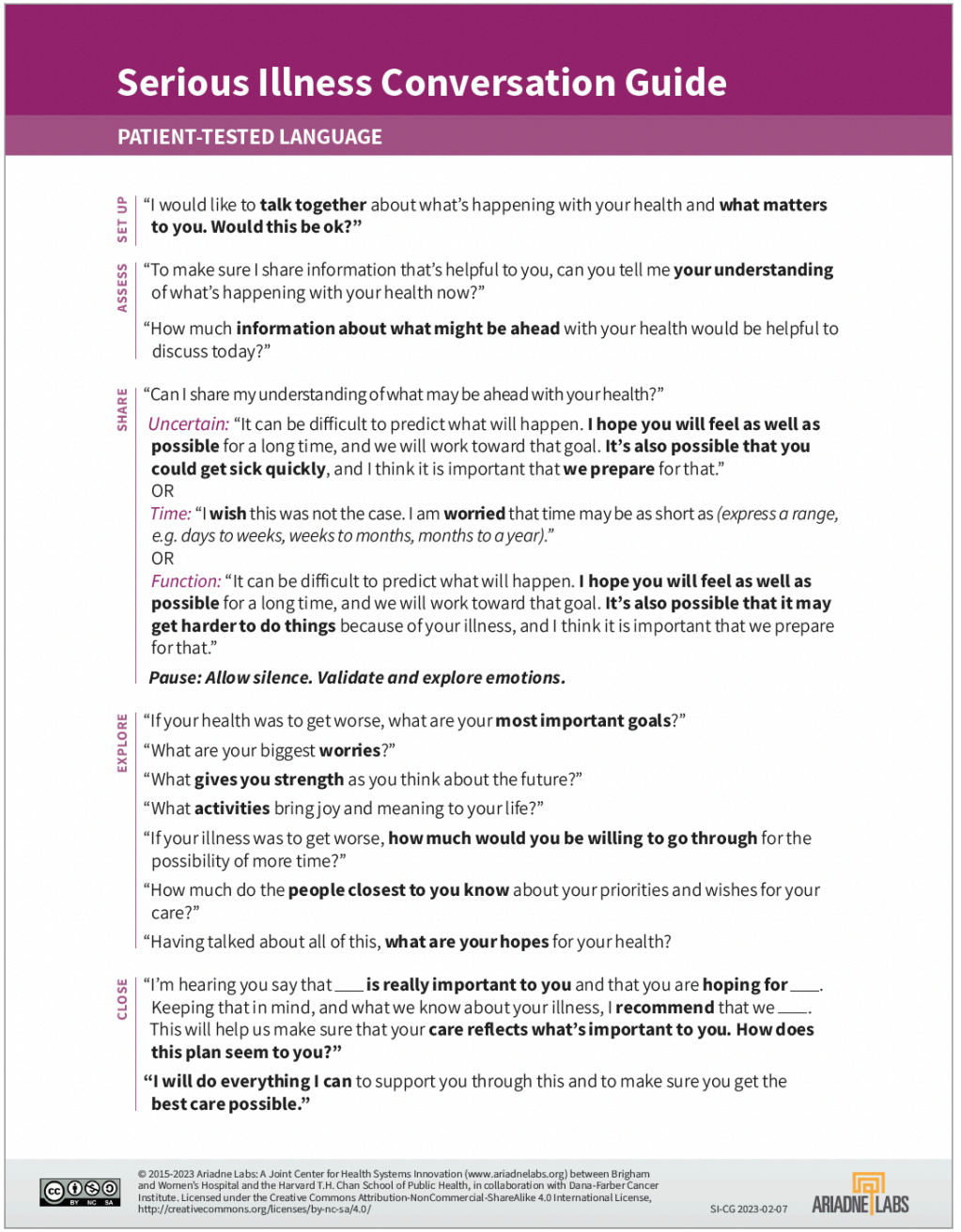
Prognosis
- Share prognosis

Values / Goals
- Explore values and goals

Rec/Plan
- Give a recommendation, plan together

ADOPTING A STRUCTURED APPROACH

- Originally developed for oncology setting
- Broadly studied and adapted / adopted in multiple languages
- Directs questions to the patient
- "Creates space for the unspeakable to be spoken, relieving a weight for the patient and for me." - Physician



Serious Illness Conversation Guide

PATIENT-TESTED LANGUAGE

SET UP

"I would like to **talk together** about what's happening with your health and **what matters to you. Would this be ok?"**

ASSESS

"To make sure I share information that's helpful to you, can you tell me **your understanding** of what's happening with your health now?"

"How much **information about what might be ahead** with your health would be helpful to discuss today?"

SHARE

"Can I share my understanding of what may be ahead with your health?"

Uncertain: "It can be difficult to predict what will happen. **I hope you will feel as well as possible** for a long time, and we will work toward that goal. **It's also possible that you could get sick quickly**, and I think it is important that **we prepare** for that."
OR
Time: "I **wish** this was not the case. I am **worried** that time may be as short as *(express a range, e.g. days to weeks, weeks to months, months to a year).*"
OR
Function: "It can be difficult to predict what will happen. **I hope you will feel as well as possible** for a long time, and we will work toward that goal. **It's also possible that it may get harder to do things** because of your illness, and I think it is important that we prepare for that."

Pause: Allow silence. Validate and explore emotions.

EXPLORE

"If your health was to get worse, what are your **most important goals**?"

"What are your biggest **worries**?"

"What **gives you strength** as you think about the future?"

"What **activities** bring joy and meaning to your life?"

"If your illness was to get worse, **how much would you be willing to go through** for the possibility of more time?"

"How much do the **people closest to you know** about your priorities and wishes for your care?"

"Having talked about all of this, **what are your hopes** for your health?

CLOSE

"I'm hearing you say that ___ **is really important to you** and that you are **hoping for** ___. Keeping that in mind, and what we know about your illness, I **recommend** that we ___. This will help us make sure that your **care reflects what's important to you. How does this plan seem to you?"**

"I will do everything I can to support you through this and to make sure you get the **best care possible."**

SI-CG 2023-02-07

ARIADNE LABS

DEMENTIA-SPECIFIC ADAPTATION

Dartmouth-Hitchcock

Serious Illness Conversation Guide for Dementia

SETUP	"I'd like to talk about what is ahead with *your/your* ___'s illness and do some thinking in advance about what is important to *you/your* ___ so that I can make sure we provide the best care possible – **is this okay?"**
	"I'll be using this Guide to help me assure I don't miss any important information." IF RESISTANT: Hope for best/prepare for bumps in the road; Benefit to family of planning ahead; No decisions necessary today
ASSESS	"What is your **understanding** now of *your/your* ___*'s* illness?" FOLLOW-UP PROMPTS: "What is your understanding of what the future may hold with *your* ___*'s* illness?
	"How much **information** about what may be ahead with this illness would you like from me?" FOR EXAMPLE: "Although it can be difficult to predict what will happen with *your/your* ___*'s* illness, some patients and family members have questions about time and what to expect."
SHARE	"I want to share with you my understanding of where things are with *your/your* ___*'s* illness…" ***General:*** "Dementia/memory loss is a brain disorder which usually **progresses gradually** over time, affecting people's ability to do things for themselves like drive a car, eat independently, use the bathroom, and communicate effectively."
EXPECT & RESPOND to EMOTION (see over)	
EXPLORE	**If patient is unable to participate:** "For the next few questions, I want you to imagine what *your* ___ would have said when they were able to think clearly. We are not thinking about what *your* ___ would want for you or what you would want for *your* ___, but what they would want for themselves."
	"What are *your/your* ___*'s* most important **goals** if their health situation worsens?"
	"What are *your/your* ___*'s* biggest **fears and worries** about the future with their health?"
	"What **abilities** are so critical to *your/your* ___*'s* life that they couldn't imagine living without them?" FOR EXAMPLE: "Some people need do things by themselves to say life is worth living; other people need meaningful interaction with others, and some say life is life, no matter the quality."
	"Are there any **medical treatments** or **types of care** *you/your* ___ wouldn't be willing to accept?" FOR EXAMPLE: "Would *you/your* ___ not be willing to undergo hospitalization, feeding tubes, antibiotics for infection, CPR, etc?"
	"How much does *your/your* ___*'s family/other family* members know about these priorities and wishes?"
	"What gives you **strength** as you think about the future with *your/your* ___*'s* illness?"
CLOSE	"**I've heard you say** that ___ is important to *you/your* ___. Keeping that in mind, and what we know about *your/your* ___*'s* illness, I **recommend** ____. **How does this plan seem to you?"** "We will do **everything we can** to help you (and *your* ___) through this."

Berry CE, et al. Am J Hosp Palliat Care. 2024 Aug;41(8):942-951. Ariadne Labs

DEMENTIA-SPECIFIC ADAPTATION

Serious Illness Conversation Guide for Dementia

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Ariadne Labs

DEMENTIA-SPECIFIC ADAPTATION

EXPECT AND RESPOND TO EMOTION

Responding to Emotion (N.U.R.S.E.)	
	EXAMPLE
NAME name the emotion you see in front of you	"I can see you are frustrated" "This must be overwhelming"
UNDERSTAND try to put yourself in their shoes	"I can't begin to understand how hard this has been" "I can only imagine how difficult this must be" "Caring for someone with dementia can be very, very challenging."
RESPECT	"I can see what an amazing advocate you are for *your* ___"
SUPPORT	"We want to do everything we can to help you and *your* ___ with this very difficult task you are facing"
EXPLORE	"Could you share more with me about…" "Tell me what _____ means to you/*your* ___."

Berry CE, et al. Am J Hosp Palliat Care. 2024 Aug;41(8):942-951.

Ariadne Labs

DEMENTIA-SPECIFIC ADAPTATION

EXPLORE VALUES AND GOALS

EXPLORE	**If patient is unable to participate:** "For the next few questions, I want you to imagine what *your* ___ would have said when they were able to think clearly. We are not thinking about what *your* ___ would want for you or what you would want for *your* ___, but what they would want for themselves."
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DEMENTIA-SPECIFIC ADAPTATION

The Wish/Worry/Wonder framework	
KEY IDEAS **"I wish"** aligns with the patient **"I worry"** allows for being truthful while sensitive **"I wonder"** is a subtle way to make a recommendation	**Align with the DPOA/patient's hopes, acknowledge concerns, then propose a way to move forward:** "**I wish** we could significantly slow down or even halt the progression of *your/your* ___*'s* cognitive decline and other symptoms, but **I worry** that our current tools aren't always very effective at doing that. **I wonder** if we should consider how we should proceed as the disease/condition becomes more challenging."

Berry CE, et al. Am J Hosp Palliat Care. 2024 Aug;41(8):942-951.

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DEMENTIA-SPECIFIC ADAPTATION

TIPS AND TRICKS

Conversation Connectors	
Achieve **thematic saturation**:	"Anything else?" "What else?"
Paraphrase/Summarize:	"So what I'm hearing you say is _____." "Sounds like we need to assure we avoid _____."
Normalization of extremes/Value neutral stance "Some people would choose X, others would choose Y.. and others would be in the middle. How about *you/your* ___?"	Only offer acceptable options!
Parking lot / Bookmarking "You've raised an important concern. Let's bookmark that and return to it after I've heard all of you and *your* ___*'s* goals and priorities."	

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DEMENTIA-SPECIFIC ADAPTATION

MAKE A RECOMMENDATION

C **L** **O** **S** **E**	"**I've heard you say** that ___ is important to *you/your* ___. Keeping that in mind, and what we know about *your/your* ___*'s* illness, I **recommend** ____. **How does this plan seem to you?"** "We will do **everything we can** to help you (and *your* ___) through this."

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"NEVER-WORDS" AND ALTERNATIVES

Never-words	Alternative language	Rationale
"There is nothing else we can do."	"Therapy X has been ineffective in controlling the cancer, but we still have the chance to focus on treatments that will improve your symptoms and, hopefully, your quality of life."	Even with no prospect for cure, the clinician can still convey an ability to treat the patient as best they can
"She will not get better."	"I'm worried she won't get better."	Replace a firm negative prognostication with an expression of concern about the poor prognosis
"withdrawing care"	"We can shift our focus to his comfort rather than persisting with the current treatment, which isn't working."	Clinicians never "withdraw" care, which may imply "giving up" or denial of services to patients and their families. Describe the advantage in refocusing the goal of care
"circling the drain"	"I'm worried she's dying."	Avoid slang terms that objectify and diminish patients .
"Do you want us to do everything?"	"Let's discuss the available options if the situation gets worse."	Instead of using a leading question that may not align with the patient's values or goals, invite dialogue

Lee Adawi Awdish R, et al. Mayo Clin Proc. 2024 Oct;99(10):1553-1557.

"NEVER-WORDS" AND ALTERNATIVES

"Everything will be fine."	"I'm here to support you throughout this process."	Offer support that is realistic and humane
"fight" or "battle"	"We will face this difficult disease together."	Avoid implying that sheer will can overcome illness. Patients may feel as if they're letting their family down if they don't recover ("if only she'd fought harder, she could have won")
"What would he want?"	"If he could hear all of this, what might he think?"	"Want" is often an ill-defined word in a hospital setting, and what families surmise the patient would want may be impossible
"I don't know why you waited so long to come in."	"I'm glad you came in when you did."	Blaming a patient and potentially causing more worry are unproductive. Focus on what can be done realistically in the given circumstances
"What were your other doctors doing/ thinking?"	"I'm glad you came to see me for a second opinion. Let's look at your records and see where we can go next."	Focus on what's still possible. Take positive next steps, rather than casting aspersions on professionals whose cooperation you may still need in moving the patient forward

Lee Adawi Awdish R, et al. Mayo Clin Proc. 2024 Oct;99(10):1553-1557.

Symptoms

SYMPTOM BURDEN

- People with dementia have a symptom burden that is similar to those with malignancies.
- As verbal abilities decline
- Nonverbal communication becomes critical
  - Body tension
  - Turning head away
  - Frequency of breath
  - Paralinguistic signals
- Interpretation of nonverbal communication may vary between health professionals
  - Pleasure while feeding = desire to live?

Eisenmann Y et al. Front Psychiatry. 2020 Jul 21;11:699.
Moens K, et al. J Pain Symptom Manage. 2014 Oct;48(4):660-77.
Mitchell, SL et al. N Engl J Med. 2009 Oct 15;361(16):1529-38

SYMPTOM BURDEN

- Distressing symptoms are increasingly prevalent as patients with advanced dementia approach end of life
- (Nursing home residents with dementia)

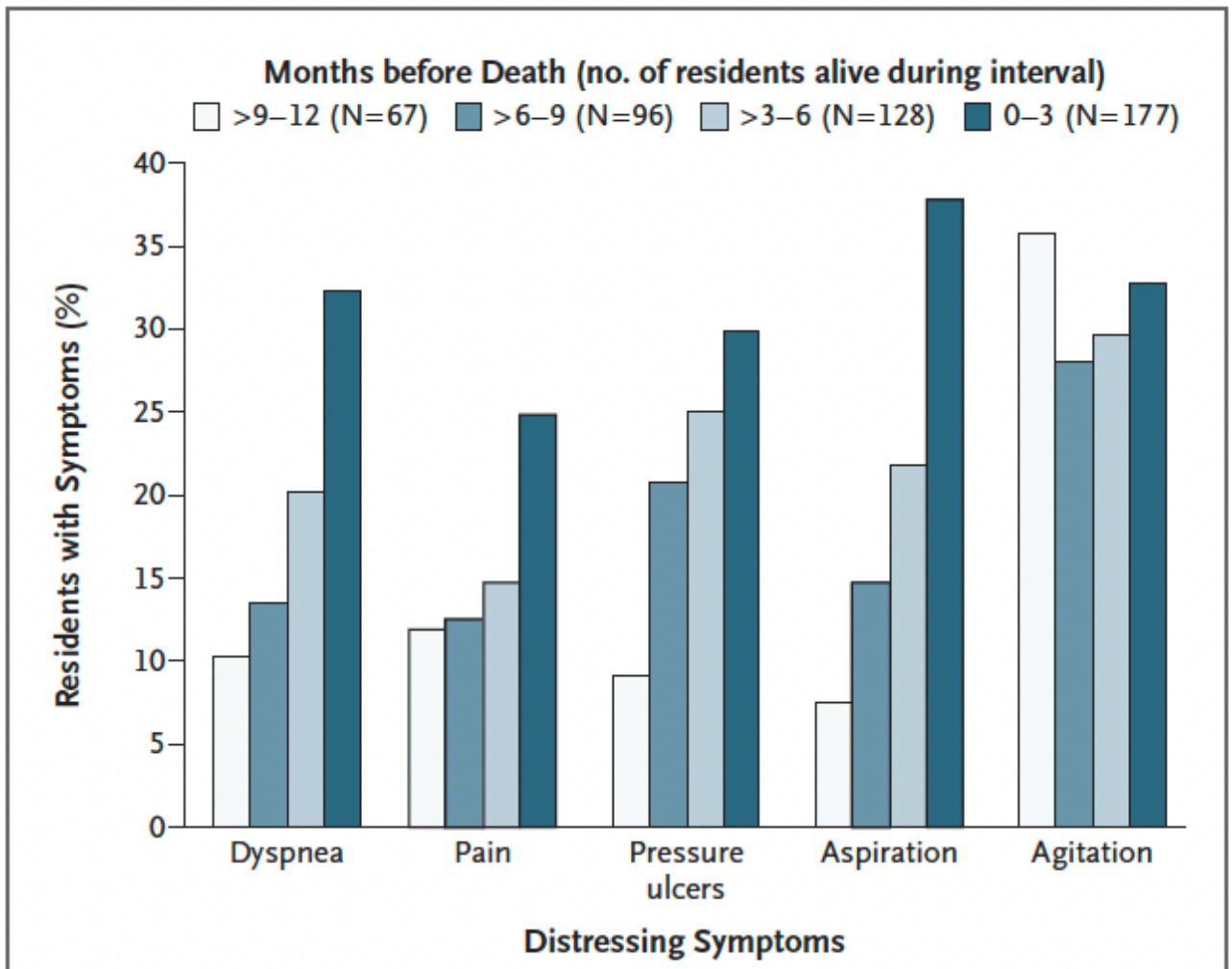


Figure 3. Proportion of Nursing Home Residents Who Had Distressing Symptoms at Various Intervals before Death.

Mitchell, SL et al. N Engl J Med. 2009 Oct 15;361(16):1529-38

Difficulty with eating

CONTEXT

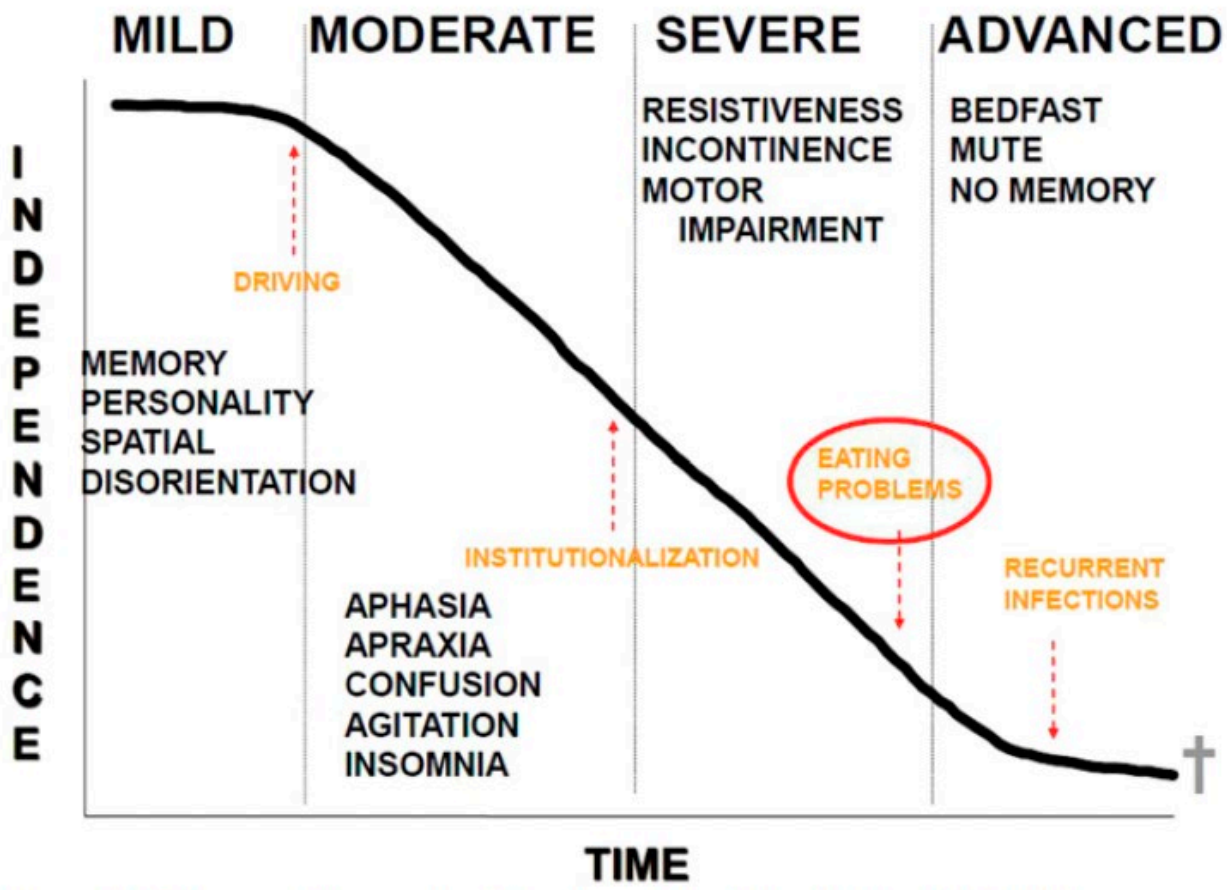


Figure 1. Stages of Dementia. Courtesy of Ladislav Volicer, MD, PhD.

- Patients are commonly in the advanced stage of dementia when eating problems due to dementia develop.

Schneider PL, et al. Perm J. 2021 Jun 2;25:20.302.

EATING PROBLEMS

- Food in culture
  - Social, religious, symbolic
- Dependent on caregivers for food selection / provision / preparation
- Influenced by other medical conditions, medications, dentures
- Eating and feeding difficulties become increasingly common as dementia progresses (40% in last mo)
  - 32% w/ weight loss in last mo

Gupta E, Patel P. Ann Palliat Med. 2024 Jul;13(4):791-807.

EATING PROBLEMS

- As dementia progresses toward end stage, the following become more common:
- Poor oral hygiene
- Insufficient attention to focus on meals
- Pocketing
- Spitting out
- Losing interest in eating / drinking
- Delayed swallow
- Dysphagia, aspiration risk
- May refuse to eat by turning their heads away from food or clamping their mouths shut

Table 2
Dementia-related disorders affecting nutrition in different disease stages.

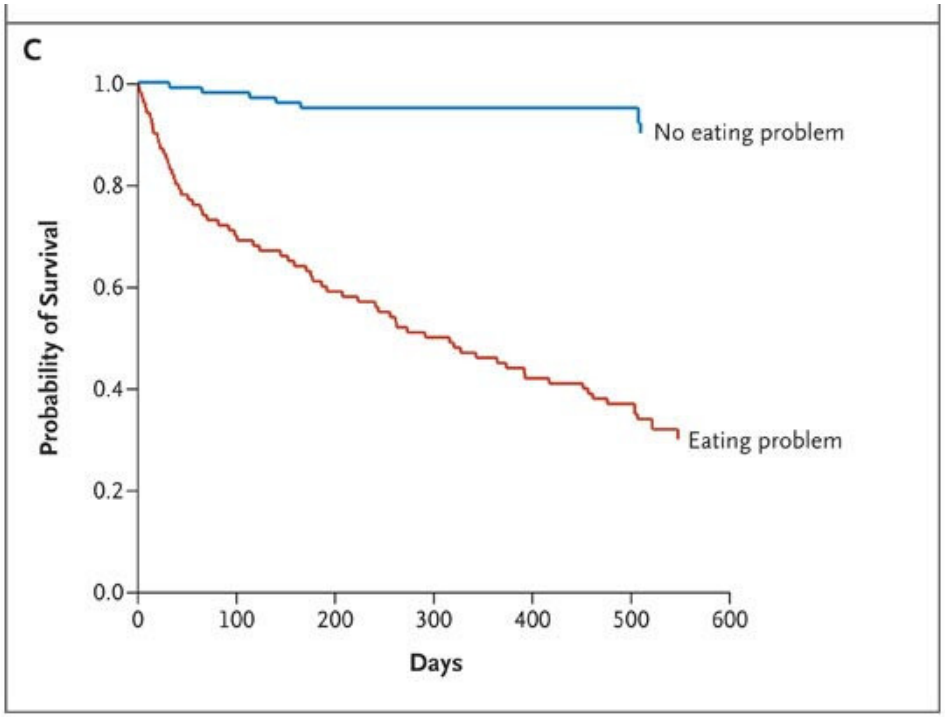
Dementia-related disorder	Stage of dementia
Olfactory and taste disorders	Preclinical and early
Attention deficit	Mild to moderate
Impaired executive functions	Mild to moderate
Impaired decision-making ability	Mild to moderate
Dyspraxia[a]	Moderate to severe
Agnosia[b]	Moderate to severe
Behavioral problems	Moderate to severe
Agitation, wandering	Moderate to severe
Oropharyngeal dysphagia	Moderate to severe
Refusal to eat	Severe

[a] Coordination disorder, loss of eating skills.
[b] Loss of ability to recognize objects or comprehend the meaning of objects, which means that food may not be distinguished from non-food and that eating utensils are not recognized as what they are.

Volkert D, et al. Clin Nutr. 2024 Jun;43(6):1599-1626.
Schwartz DB, et al. J Acad Nutr Diet. 2021 May;121(5):823-831.
Gupta E, Patel P. Ann Palliat Med. 2024 Jul;13(4):791-807.

DIFFICULTY WITH EATING

- For advanced dementia patients in long term care, a new “eating problem” heralds a poor prognosis



“Eating problem:”

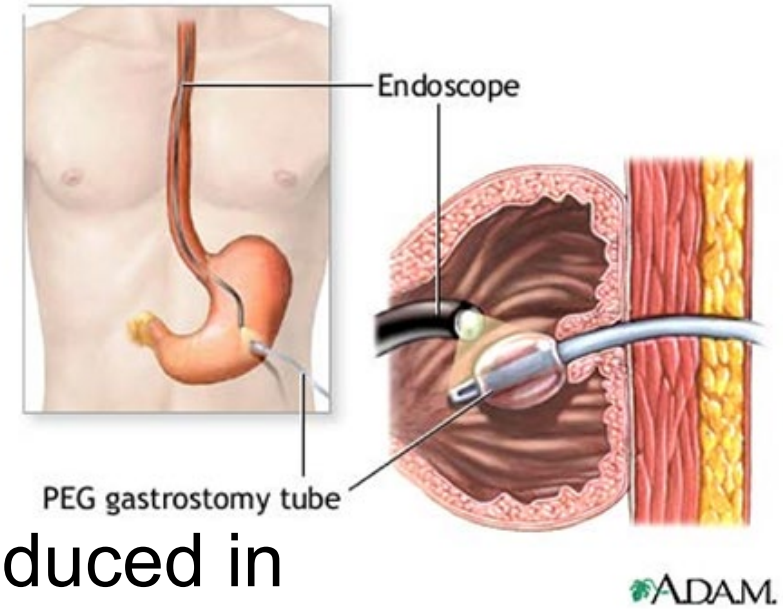
- Refusal to eat or drink
- Suspected dehydration
- Documentation of weight loss
- Swallowing or chewing problems
- Persistently reduced oral intake

- So, what should we do?

Mitchell, SL et al. N Engl J Med. 2009 Oct 15;361(16):1529-38

MEDICALLY ADMINISTERED NUTRITION AND HYDRATION (MANH)

- Family members and caregivers may view enteral nutrition through gastrostomy (G) tubes as a means to recovery
- Intuitively, some think G tube feeding will:
  - Prolong life
  - Decrease aspiration and pneumonia
  - Improve malnutrition
  - Improve pressure ulcers
  - Improve quality of life



- After G tubes (via PEG) were introduced in 1980, this quickly became the standard of care

MEDICALLY ADMINISTERED NUTRITION AND HYDRATION (MANH) IS NOT HELPFUL

alzheimer's association

- *Advanced* dementia

Feeding Issues in Advanced Dementia

- Nutrition via gastrostomy tube (compared to careful hand feeding):
  - No improvement in nutritional status
  - Increased aspiration pneumonia (>2x)
  - Increase in pressure ulcers
  - No survival benefit (some studies show higher mortality rate)
  - No change in hospital readmission

  - Associated with use of physical restraints
  - Not able to enjoy taste of food
  - Less interaction with caregiver

Y.-F. Lee et al. / JAMDA 22 (2021) 357e363
Ijaopo, E. O. et al. J Aging Res. 2019 Dec 19;2019:7272067.

WHEN IS MEDICALLY ADMINISTERED NUTRITION AND HYDRATION (MANH) HELPFUL?

- Earlier in disease process
  - Mild or moderate dementia
- When the main cause of the eating problem is likely to get better
  - Stroke
  - Brain injury
  - Surgery
- Dysphagia, but not at late stage of incurable illness
  - Parkinson's disease
  - Amyotrophic lateral sclerosis (ALS, Lou Gehrig's disease)
  - Esophageal cancer
  - Head and neck cancer

Y.-F. Lee et al. / JAMDA 22 (2021) 357e363
Ijaopo, E. O. et al. J Aging Res. 2019 Dec 19;2019:7272067.

ALTERNATIVES TO MANH

- Careful hand feeding
- Speech and Language Pathology, Dietician evaluations
- Make it social
- Fortify food / drink (protein)
- Modified texture diet (mechanical soft, pureed, etc.) only when necessary
- Accounting for individual habits, preferences (culture, likes / dislikes), abilities, behaviors around eating
- Avoid dietary restrictions that limit food / fluid intake
- Do NOT add appetite stimulant (unless concurrent depression, then mirtazapine)
- Thickened liquids?
  - Consider “Frazier” free water protocol
  - Quality of life... “Some people”

CHOOSING WISELY®: THINGS WE DO FOR NO REASON

Things We Do for No Reason: The Use of Thickened Liquids in Treating Hospitalized Adult Patients with Dysphagia

William C Lippert, MD, MPH[1*]; Romil Chadha, MD, MPH, SFHM, FACP[2]; Joseph R Sweigart, MD, FHM, FACP[3,4]

ʼe363
Dec 19;2019:7272067.
(6):1599-1626.

EVALUATE AND TREAT MALNUTRITION / DEHYDRATION

Table 6
Potential causes of malnutrition and dehydration in older persons with dementia and possible management strategies.

Potential causes	Interventions
Chewing problems	* Oral care * Dental treatment * Texture modification
Swallowing problems	* Swallowing evaluation * Swallowing training * Texture modification
Xerostomia	* Check medication for adverse side effects, remove or change medication if possible * Ensure adequate fluid intake * Use mouth rinse and gel
Mobility limitations	* Physiotherapy * Group exercise * Accompanied walking * Support to go to the toilet in time * Resistance training * Support with shopping and cooking * Meals on wheels
Disability of the upper limbs	* Support with meal preparation, eating and drinking * Special eating and/or drinking utensils
Psychiatric disorders (e.g. depressive mood, depression, anxiety)	* Adequate medical treatment * Eating with others, shared meals * Pleasant eating environment and meal ambience * Group activities, occupational therapy * Soothing sounds, music

Volkert D, et al. Clin Nutr. 2024 Jun;43(6):1599-1626.

EVALUATE AND TREAT MALNUTRITION / DEHYDRATION

Table 6 (*continued*)

Potential causes	Interventions
	* Verbal prompting, remember to eat and drink
Acute disease, (chronic) pain	* Adequate medical treatment
Adverse effects of medications (e.g. xerostomia, nausea, apathy)	* Check medications (see above) * Reduce or replace medications
Social problems (e.g. lacking support, family conflict)	* Support with shopping and meal preparation * Meals on wheels, shared meals * Offers to talk, conflict resolution

Volkert D, et al. Clin Nutr. 2024 Jun;43(6):1599-1626.

DO WE HAVE TO OFFER MANH?

- No ethical obligation to offer medical treatments that are not beneficial

- Similar to…
- Surgeons not offering surgery (“Not a candidate”)
- Nephrologists not offering dialysis
- Withholding of other forms of life sustaining treatment in ICU (CPR/ ACLS)

- Medically administered nutrition and hydration is a medical treatment

- We *should* continue to offer oral assisted feeding.
  - We are not “starving” the patient

Macauley, Robert C., Oxford Academic, 1 Apr. 2018
Schneider PL, et al. Perm J. 2021 Jun 2;25:20.302.

TIME LIMITED TRIAL OF MANH

- If through shared decision making, a trial of MANH is considered
- Set a time-limited trial
- Define what outcomes to look for
  - Benefits
  - Burdens
- While ethically, withholding and withdrawing life sustaining treatment are equivalent…
- Emotionally, withdrawing is harder than withholding

Macauley, Robert C., Oxford Academic, 1 Apr. 2018
Schneider PL, et al. Perm J. 2021 Jun 2;25:20.302.

FROM A PEG PIONEER

- *". . . [B]ecause of its simplicity and low complication rate, this minimally invasive procedure also lends itself to overutilization.*
- *Therefore, as percutaneous endoscopic gastrostomy [PEG] enters its third decade, much of our effort in the future needs to be directed toward the ethical aspects associated with long-term enteral feeding.*
- *In addition to developing new procedures and devices, or to perfecting existing ones, we as physicians must continuously strive to demonstrate that our interventions truly benefit the patient."*

- *Michael Gauderer, MD*

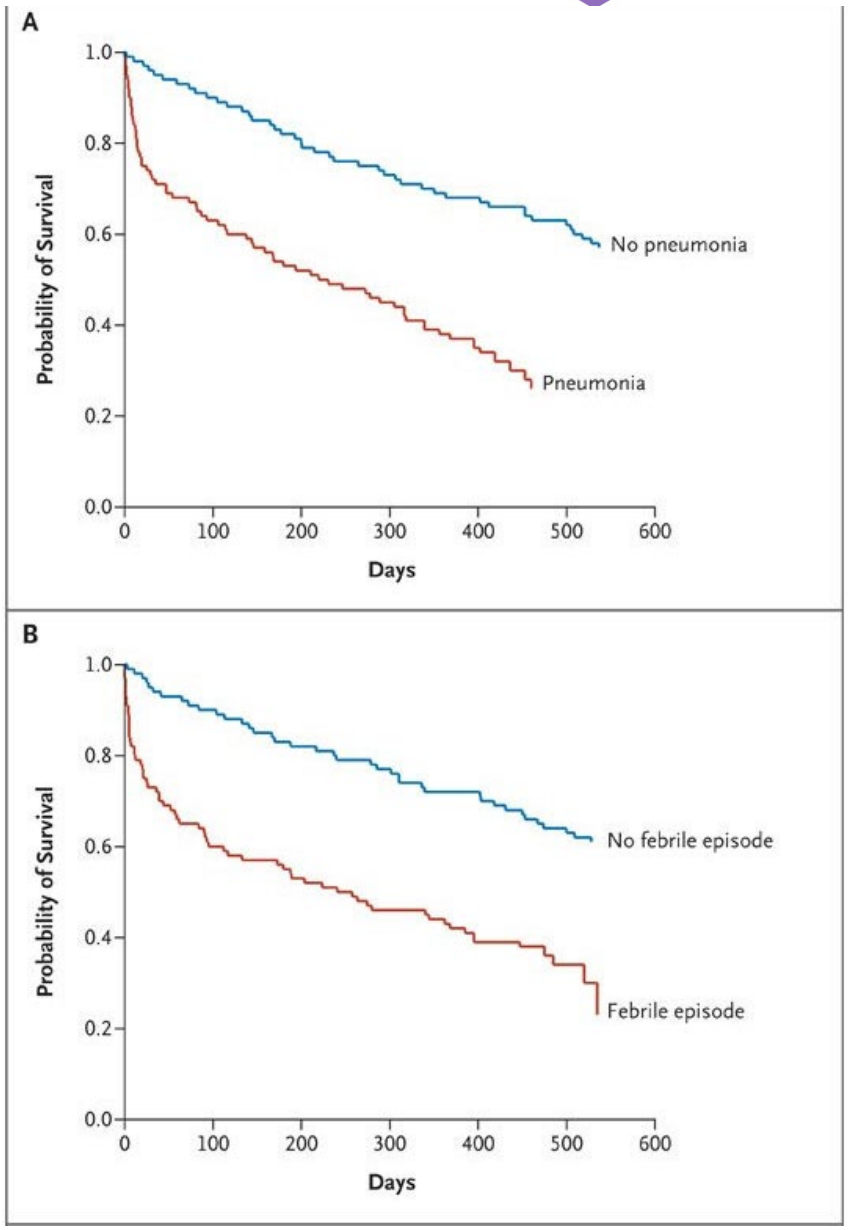
  PEG Pioneer (1999)

Schneider PL, et al. Perm J. 2021 Jun 2;25:20.302.

Infections

INFECTIONS

- For advanced dementia patients in a nursing home, a new fever or pneumonia heralds a poor prognosis
- Pneumonia, urinary tract infections are most common
  - Skin / soft tissue
  - Fever of unknown origin
- People with dementia who develop pneumonia have twice the risk of death compared to those with pneumonia without dementia



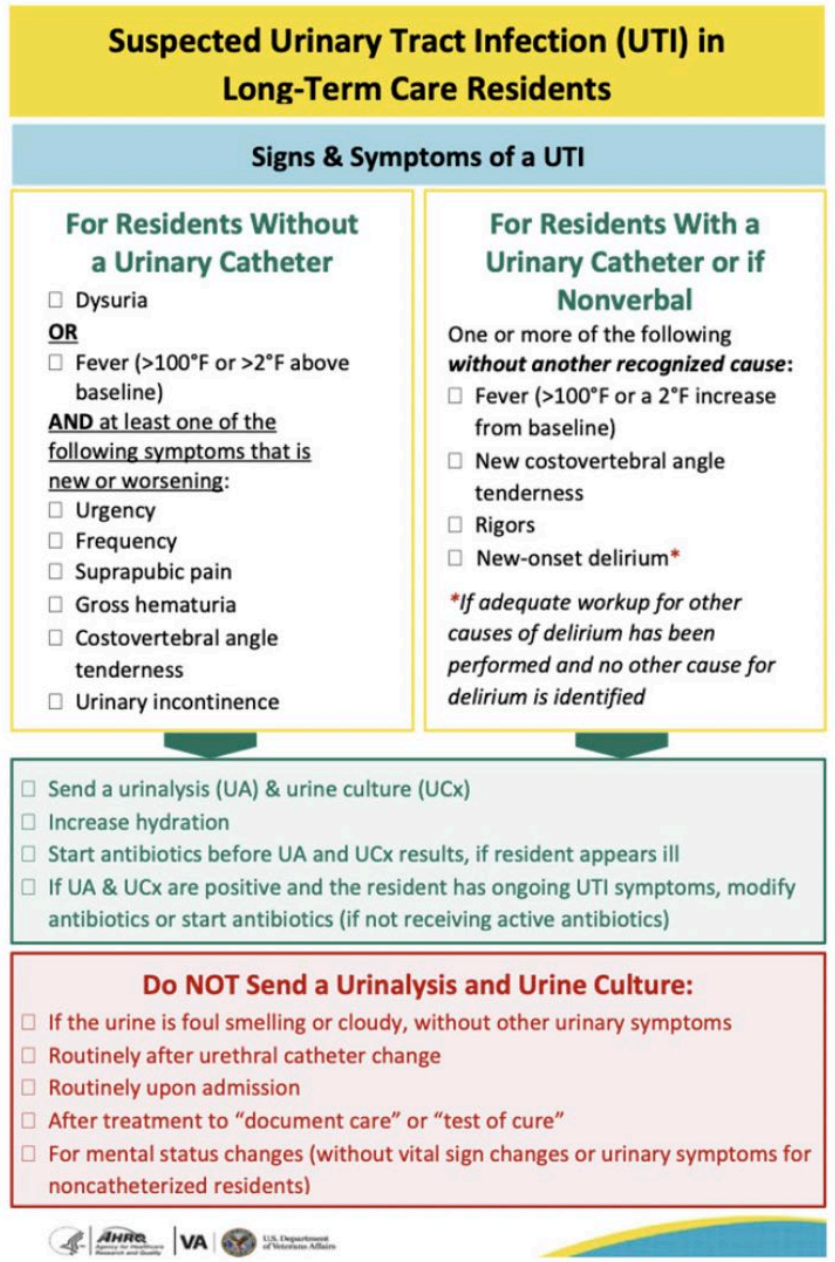
Mitchell, SL et al. N Engl J Med. 2009 Oct 15;361(16):1529-38
Manabe T, et al. PLoS ONE 14(3): e0213825.
Eisenmann Y et al. Front Psychiatry. 2020 Jul 21;11:699.

INFECTIONS

- When antibiotics are given, only 16-44% meet clinical criteria
  - Labs, imaging challenging
- Consider application of criteria prior to considering treatment.

Table 1. Loeb Minimum Criteria for Ordering Urine Cultures in Nursing Home Residents

If patient has a fever (>37.9°C) or 1.5°C increase above baseline on at least 2 occasions over the previous 12 hours **Plus** 1 or more of the following: dysuria, urinary catheter, urgency, flank pain, shaking chills, urinary incontinence, frequency, gross hematuria, and/or suprapubic pain
If patient has an indwelling urinary catheter **Plus** 1 or more of the following: new costovertebral tenderness, rigors, and/or new-onset delirium
If patient has new onset dysuria or 2 or more of the following: urgency, flank pain, shaking chills, urinary incontinence, frequency, gross hematuria, and/or suprapubic pain



Website: https://www.ahrq.gov/antibiotic-use/long-term-care/best-practices/uti-assess.html

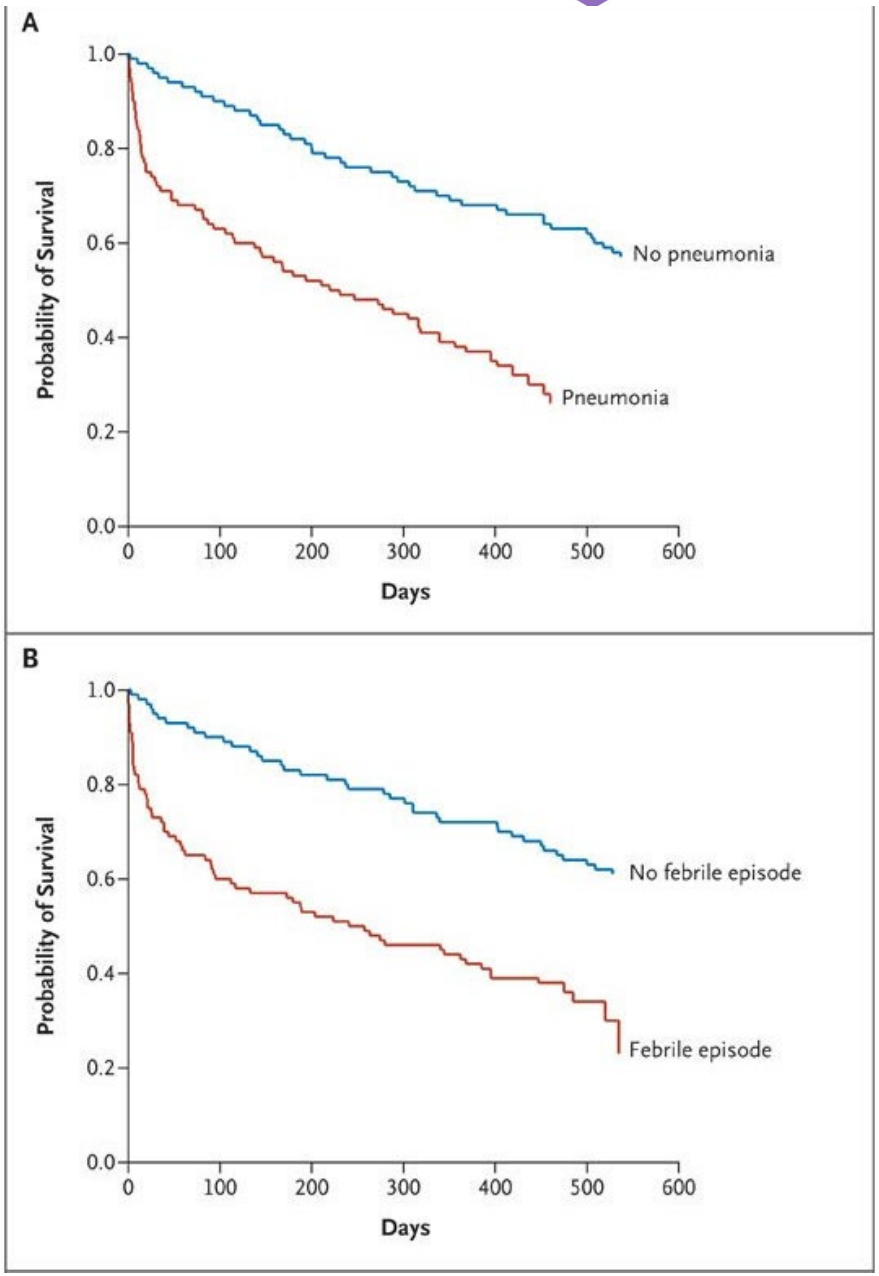
Fig. 2. Agency for Healthcare Research and Quality (AHRQ) decision aid for suspected urinary tract infections in long-term care residents.

Amenta EM, et al. Antimicrob Steward Healthc Epidemiol. 2023 Jan 9;3(1):e4.
Manabe T, et al. PLoS ONE 14(3): e0213825.
Eisenmann Y et al. Front Psychiatry. 2020 Jul 21;11:699.
Gupta E, Patel P. Ann Palliat Med. 2024 Jul;13(4):791-807.

INFECTIONS

- Antibiotics increase survival for pneumonia, but not UTI
  - ? Asymptomatic bacteriuria
    - We should not treat ASB!

- Consider the benefits vs. burdens of treatment in the context of:
  - Severity of infection
  - Burden of treatment
  - Severity of dementia
  - Function / prognosis
  - Goals and values…



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CASE

- Ms. Rose Jackson, 92-year-old woman with advanced Alzheimer's (FAST 7B) is admitted to the hospital for aspiration pneumonia. She has had decreased oral intake, is losing weight (15 lbs in last 6 months), and is slowly declining in physical function. She remains ambulatory with a 4w walker. Husband deceased.
- Stroke and acute encephalopathy are ruled out in the ED
- Speech and language pathology – recommend NPO based on c/f aspiration at bedside, pending VOSS
- *Admission as trigger for serious illness conversation.*
- The patient's daughter (caregiver, POA) seems accepting of her decline.
- Family meeting planned…
- Her son, who normally resides in Kansas City, sees you in the hallway before the meeting and asks for a G tube for long term nutritional support.
- "You're just going to let her starve to death?!"

CASE

- A 92-year-old woman with advanced Alzheimer's (FAST 7B) is admitted to the hospital for aspiration pneumonia. She has had decreased oral intake and is losing weight (15 lbs in last 6 months) and slowly declining in physical function. She remains ambulatory with a 4w walker. The patient's daughter (caregiver, POA) is accepting of her decline. Her son, who normally resides in Kansas City, asks for a G tube for long term nutrition. "You're just going to let her starve to death?!"
- Deep breath / pulse check
- Recognize emotion
- "I can see how much you love your mom. I can only imagine how difficult this must be." (but I'm trying)
- Big picture. Illness understanding -> Prognosis-> Values-> Goals.
  - See serious illness conversation guide!
- "I'm worried that no matter how much we try to support your mom's health, she will continue to decline. She has end stage dementia."
- "I wish we had a treatment to reverse or stop your mom's decline. I wish we could help her enjoy life the way she did before. I wonder if we can talk about what our options are now."
- Focus on what we *can* do. Present acceptable options. Continue to offer feeding. Consider altered diet.

Pain

PAIN

- Common (63% of patients with dementia)
- Pain often starts or increases as patients progress towards advanced stages
- In advanced dementia:
  - 11% at rest
  - 61% with movement
- 45% of dementia patients did not receive any analgesics despite presence of pain
- Often undertreated, even in setting of chronic pain
- When treated adequately, symptoms improve, incl:
  - Depression
  - Apathy
  - Nighttime behaviors

Eisenmann Y et al. Front Psychiatry. 2020 Jul 21;11:699.
Tagliafico L, et al. (2024) *Front. Med.* 11:1393367.
Gupta E, Patel P. Ann Palliat Med. 2024 Jul;13(4):791-807.

COMMON CAUSES

- Arthritis
- Joint stiffness
- Constipation
- Complications of infections
- Orofacial pain, especially among institutionalized
- Back pain
- Constipation
- Pressure ulcers

Eisenmann Y et al. Front Psychiatry. 2020 Jul 21;11:699.
Tagliafico L, et al. (2024) *Front. Med.* 11:1393367.
Gupta E, Patel P. Ann Palliat Med. 2024 Jul;13(4):791-807.

PAIN

- Always attempt to gauge via verbal descriptors if possible, especially for mild to moderate dementia.
- In advanced dementia, may be difficult to detect
- Often reliant on nonverbal assessment
- Signs of pain or undertreated pain:
  - Depression
  - Agitation
  - Behavioral symptoms
  - Psychiatric symptoms

Tagliafico L, et al. (2024) *Front. Med.* 11:1393367.

PAIN

- Causes of under-reporting pain:
  - Lack of pain management education
  - Failure to use standardized pain assessment tool
  - Inadequate documentation
  - Patients not reporting pain due to fear of addiction
  - Assuming pain to be normal part of aging

Gupta E, Patel P. Ann Palliat Med. 2024 Jul;13(4):791-807.

NONVERBAL PAIN BEHAVIORS

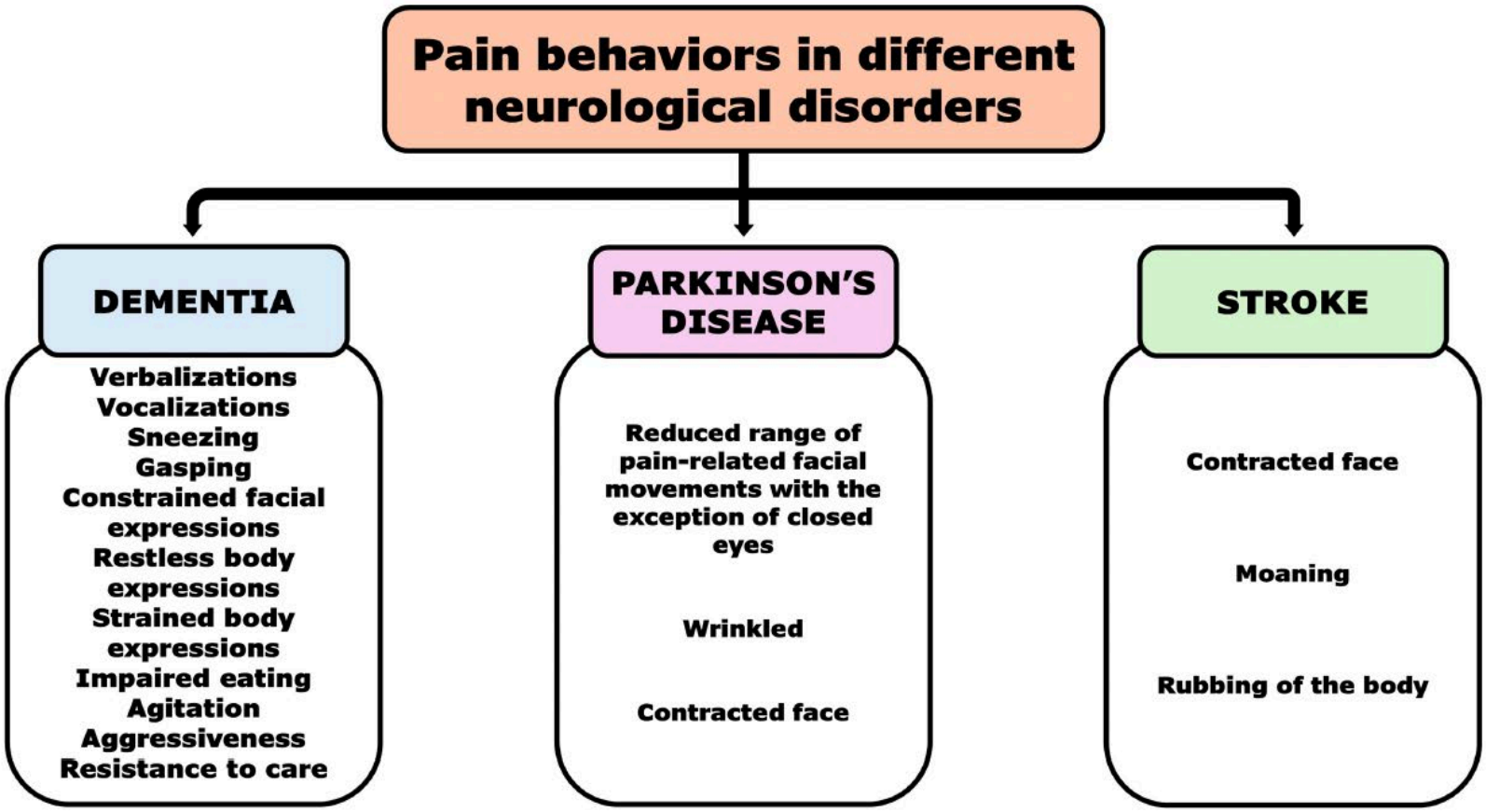

FIGURE 2
Pain behaviors in non-communicative patients with different neurological disorders [Dementia (2, 19, 27–30), Parkinson's disease (36), and Stroke (39)].

- Be careful to consider pain as a reason for behaviors often labelled as "agitation."

Tagliafico L, et al. (2024) *Front. Med.* 11:1393367.

NONVERBAL PAIN ASSESSMENTS

Pain assessment tools administered by healthcare providers, including trained personnel

- Doloplus 2
- Algoplus
- **PAIN AD**
- PACSLAC I / II
- **NOPPAIN**
- Abbey Pain Scale
- CNPI
- REPOS
- PADE
- ADD
- FLACC
- MOBID-2

Pain assessment tools requiring professional expertise

- DS-DAT
- OPS-NVI
- MOBID

Pain assessment tools without requested or indicated professional training

- PAINE
- PAIC
- Observational Assessment of Pain or Distress

Tagliafico L, et al. (2024) *Front. Med.* 11:1393367.

NONVERBAL PAIN ASSESSMENT PAINAD

Pain Assessment in Advanced Dementia (PAINAD) Scale

Items*	0	1	2	Score
Breathing independent of vocalization	Normal	Occasional labored breathing. Short period of hyperventilation.	Noisy labored breathing. Long period of hyperventilation. Cheyne-Stokes respirations.	
Negative vocalization	None	Occasional moan or groan. Low-level speech with a negative or disapproving quality.	Repeated troubled calling out. Loud moaning or groaning. Crying.	
Facial expression	Smiling or inexpressive	Sad. Frightened. Frown.	Facial grimacing.	
Body language	Relaxed	Tense. Distressed pacing. Fidgeting.	Rigid. Fists clenched. Knees pulled up. Pulling or pushing away. Striking out.	
Consolability	No need to console	Distracted or reassured by voice or touch.	Unable to console, distract or reassure.	
			Total**	

*Five-item observational tool (see the description of each item below).

**Total scores range from 0 to 10 (based on a scale of 0 to 2 for five items), with a higher score indicating more severe pain (0="no pain" to 10="severe pain").

Warden, et al. J Am Med Dir Assoc. 2003;4:9-15.

NONVERBAL SYMPTOM ASSESSMENT - PAIN

Pain Assessment in Advanced Dementia Scale (PAINAD)

Assesses pain in patients with dementia.

INSTRUCTIONS

Choose the description that best fits the patient's behavior.

When to Use | Pearls/Pitfalls | Why Use

Breathing (independent of vocalization)

Normal	0
Occasional labored breathing or short periods of hyperventilation	+1
Noisy labored breathing, long periods of hyperventilation or Cheyne-Stokes respirations	+2

MD Calc

Warden, et al. J Am Med Dir Assoc. 2003;4:9-15.

NONPHARMACOLOGIC MANAGEMENT

- Massage
- Human touch
- Reiki

- Application of cold packs or heat
- Person centered showers

- Exercise
- Physical therapy
- Regular gentle movement
- Movement therapy (rocking chair)
- Patient repositioning

- Relaxation therapy
- Music therapy
- Behavioral therapy
- Pet therapy

Gupta E, Patel P. Ann Palliat Med. 2024 Jul;13(4):791-807.
Eisenmann Y et al. Front Psychiatry. 2020 Jul 21;11:699.

PHARMACOLOGIC MANAGEMENT

- ID & Tx underlying cause(s)
- Interdisciplinary approach
- Consider analgesic trial
- Acetaminophen up to 1000mg Q6H scheduled
  - 2000 mg max /24 hr in cirrhosis
- Topical NSAIDs – Diclofenac gel
  - Knee OA
- Lidocaine patches (back)
- Consider NSAIDs
  - Cox1 selective = ↑GI risk
  - Cox2 selective = ↑ CV risk
  - All have renal risks
  - Avoid in decompensated cirrhosis, heart failure, chronic kidney disease
  - Add PPI for GI prophylaxis
- Consider low dose opioids
- "Start low, go slow"
- Tramadol 50 mg Q6-12H PRN
  - Dependent on hepatic metabolism
  - Effect varies person to person
- Hydromorphone 1 mg Q4-6H PRN
- Oxycodone 2.5 mg PO Q4-6H PRN
- Don't forget to tx constipation

Gupta E, Patel P. Ann Palliat Med. 2024 Jul;13(4):791-807.
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STEPWISE APPROACH TO TREATING PAIN

Table 2| **Stepwise protocol for treatment of pain**

Step	Pain treatment at baseline	Study treatment	Dosage	No (%) of residents (n=175)
1	No analgesics, or low dose of paracetamol	Paracetamol (acetaminophen)	Maximum dose 3 g/day	120 (69)*
2	Full dose of paracetamol or low dose morphine	Morphine	5 mg twice daily; maximum dose 10 mg twice daily	4 (2)
3	Low dose buprenorphine or inability to swallow	Buprenorphine transdermal patch	5 µg/h, maximum dose 10 µg/h	39 (22)†
4	Neuropathic pain	Pregabaline	25 mg once daily; maximum dose 300 mg/day	12 (7)

*In nine participants an existing low dosage was increased.
†Dosage was increased in eight participants.

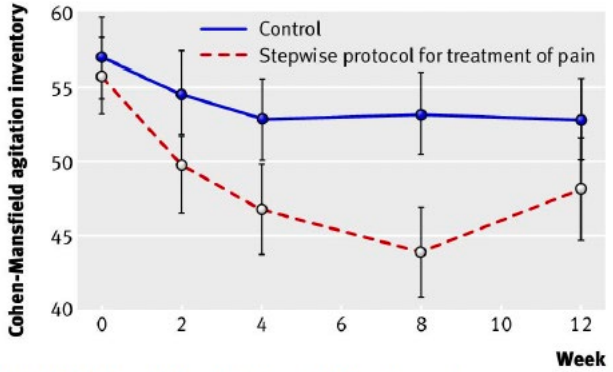

Fig 2 Cohen-Mansfield agitation inventory scores, wit

- Standardized protocol for pain
- 352 residents of nursing homes in
- People with moderate to severe dementia
- Significantly improved agitation, aggression, and pain

Husebo BS, et al. BMJ. 2011 Jul 15;343:d4065.

Questions?

Thank you!

SIU MEDICINE
FORWARD. FOR YOU.