

Palliative Care for Dementia



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Intended Learning Outcomes

- * To learn about progression of dementia
- * To learn about frailty and delirium
- * To learn about palliative care for dementia

Case Presentation

- * 77 yo pleasant happy woman with dementia admitted to LTC 4 months ago. A year before she was referred for knee replacement surgery.
- * Pain is intermittent and not severe but the knee locks and feels like it is going to give out at times.
- * Used to enjoy walking to a nearby stores and chatting with people but now cannot walk that far comfortably and would not be able to find her way home.
- * Enjoys hockey and attends local games with her son.

Case Presentation

- * Psychosis is diagnosed with beliefs a doll is real and people in photos can see and the eyes move.
- * Increasing confusion in recent months; speech is more repetitious; misplacing objects and accusing people of stealing.
- * Help is needed for almost all aspects of daily life.
- * 3 falls in 6 months, 1 related to knee, 2 to low blood sugar.
- * MMSE 17/30

Past Medical Hx

- * Diabetes
- * High cholesterol
- * Urinary incontinence
- * Breast cancer 4 years ago
- * Lt knee replacement 2006 (got along well)

Confer With Each Other

- * Would you recommend total knee replacement surgery for this woman?
- * What questions would you ask?
- * Are there any family dynamics that come into play?
- * Discuss your recommendations and reasons.

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DEMENTIA

DELIRIUM

FRAILTY

COMORBIDITIES

Major Neurocognitive Disorder: Dementia

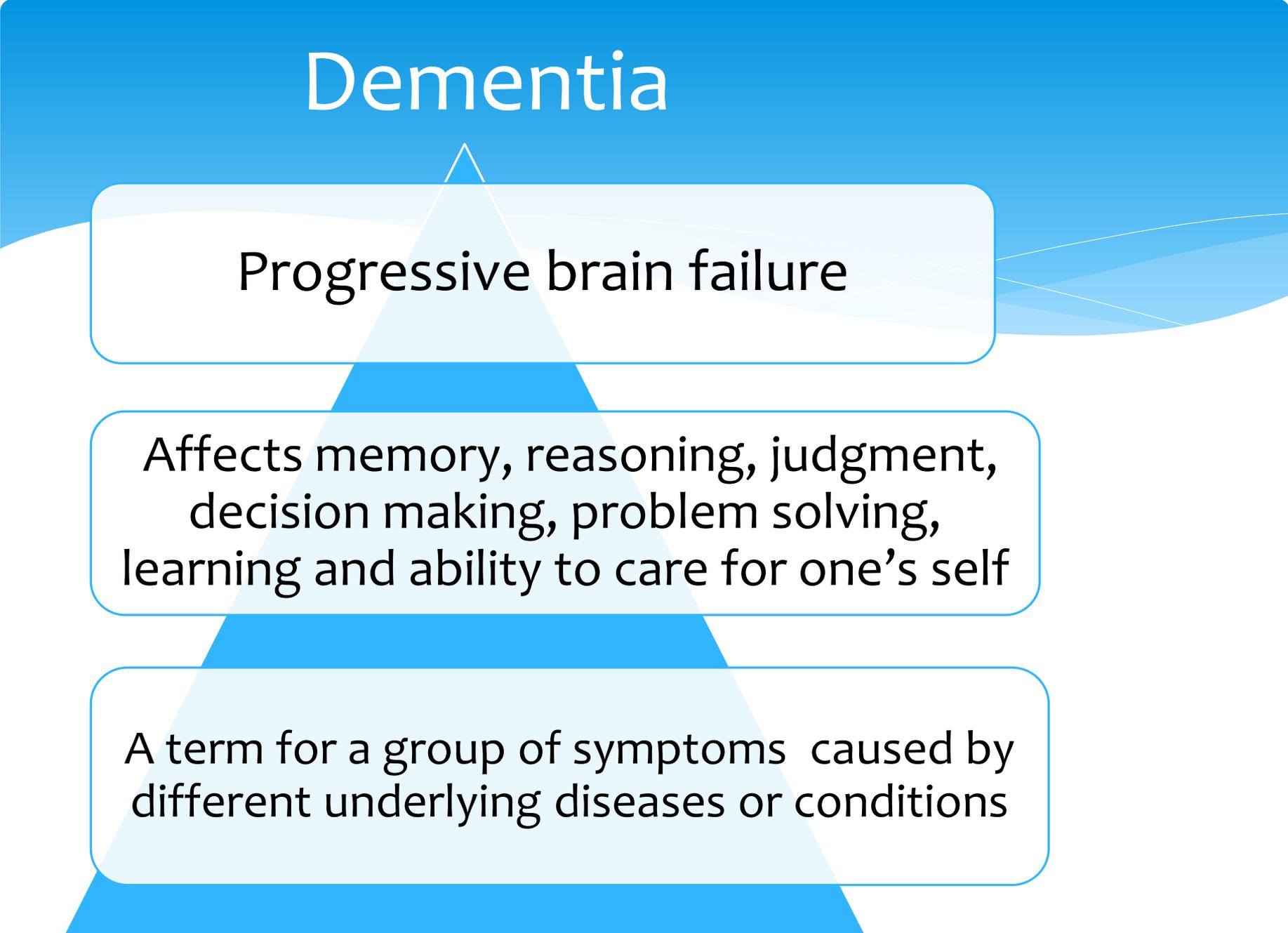
Cognitive
decline-
from a
previous
level

- Complex attention
- Learning and memory
- Language- Aphasia
- Perceptual-motor-Apraxia; Agnosia
- Disturbance in executive functioning

- All leading to decline in functioning

DSM 5 602-614

Dementia



Progressive brain failure

Affects memory, reasoning, judgment, decision making, problem solving, learning and ability to care for one's self

A term for a group of symptoms caused by different underlying diseases or conditions

DEMENTIA

Dementia is an umbrella term that describes a collection of symptoms that are caused by disorders affecting the brain. It is not one specific disease. Dementia affects thinking, behaviour and the ability to perform every day tasks, and brain function is affected enough to interfere with the person's normal social or working life. The most common type of dementia is Alzheimer's disease.

Alzheimer's Disease

Alzheimer's disease is the most common type of dementia accounting for approximately 40-70 % of all dementias.

Vascular Dementias

Vascular dementia is the second most common type of dementia, accounting for approximately 15-25% of all dementias.

Lewy Body Dementia

Lewy Body dementia accounts for approximately 2-20% of all dementias.

Fronto Temporal Dementias

Fronto Temporal Dementia accounts for approximately 2-4% of all dementia.

Other Dementias

Include dementia associated with Parkinson's disease, Huntington's disease, head trauma, human immunodeficiency virus (HIV), alcohol related dementia, Crutzfeldt-Jakob Disease, corticobasal degeneration and progressive supranuclear palsy.

Four Truths About Dementia

- ✓ At least 2 parts of the brain are dying- One related to memory and one other
- ✓ It is chronic- it can't be fixed
- ✓ It's progressive- it gets worse
- ✓ It's terminal- it will kill eventually

“progressive, relentless, devastating”

attributed to Teepa Snow Alzheimer's Research Breakfast 2016.

TABLE 16-5 Functional Assessment Staging Test (FAST): A Seven-Stage System Based on Level of Functioning

Stage 1: Normal adult

No functional decline

Stage 2: Normal older adult

Personal awareness of some functional decline

Stage 3: Early Alzheimer's disease

Noticeable deficits in demanding job situations

Stage 4: Mild Alzheimer's

Requires assistance in complicated tasks such as handling finances, planning parties, etc.

Stage 5: Moderate Alzheimer's

Requires assistance in choosing proper attire

Stage 6: Moderately severe Alzheimer's

Requires assistance dressing, bathing, and toileting. Experiences urinary and fecal incontinence

Stage 7: Severe Alzheimer's

Speech ability declines to about a half-dozen intelligible words. Progressive loss of abilities to walk, sit up, smile, and hold head up

Note: The FAST focuses more on an individual's level of functioning and activities of daily living versus cognitive decline [39]. A person may be at a different stage cognitively (GDS stage) and functionally (FAST stage).

Alzheimer's Disease

Typically progresses over 2-20 years
Average life expectancy 8-10 years from diagnosis



Co-existing illnesses can
develop or progress
Pneumonia most common
cause of death



564,000
Canadians are currently living with
dementia

937,000
The number of Canadians who will
be living with the disease in 15
years

Why Is Dementia Unique?

- Seldom recognized as a terminal illness
 - burdensome interventions of questionable benefit
- Prognosis is difficult
 - Can be hard to tell if someone is within 6 months of dying
- Severe disability may persist for years
- As disease progresses the ability to ask the person what their preferences for care are lost

Dementia is a Terminal Illness

- * End stage dementia is characterized by total dependence for care
 - * pneumonia, recurrent infections, fevers and swallowing/eating problems
- * Near EOL many have dyspnea, pain, agitation, aspiration
- * Causes of death can be sudden
 - * Accidents, falls, heart attacks, stroke, infection
- * Causes of slower onset
 - * weight loss, eating problems, malnutrition, recurrent infections, organ failure, non-compliance with medical treatments for other diseases

Cause of Death in Dementia

- * While complications such as recurrent infections and feeding problems may precipitate death it is the major illness of dementia that is the underlying cause of death

Mitchell et al 2009 NEJM

Advanced Care Planning

- * Survival after the onset of feeding problems and recurrent infections is poor
- * Families should be informed that these complications
- * LTC residents whose SDM's understand the poor prognosis and likely complications are less likely to consent to burdensome interventions in the last 3 months of life

Dementia Specific Markers of Advanced Disease

Unable to walk without assistance

Urinary and fecal incontinence

Unable to communicate meaningfully

Unable to do Activities of Daily Living

Plus any of the following:

- Weight loss
- Urinary tract Infection
- Severe pressure sores
- Recurrent fever (aspiration pneumonia, other)

Prognostication

- Would I be surprised if this patient were to die in the next 12 months?
 - Are they having infections?
 - Hospitalization in the last year?
 - Worsening of other chronic illnesses?
 - Weight loss?
 - Refusing food?
 - Swallowing problems?

All signs that the person is moving closer to end of life

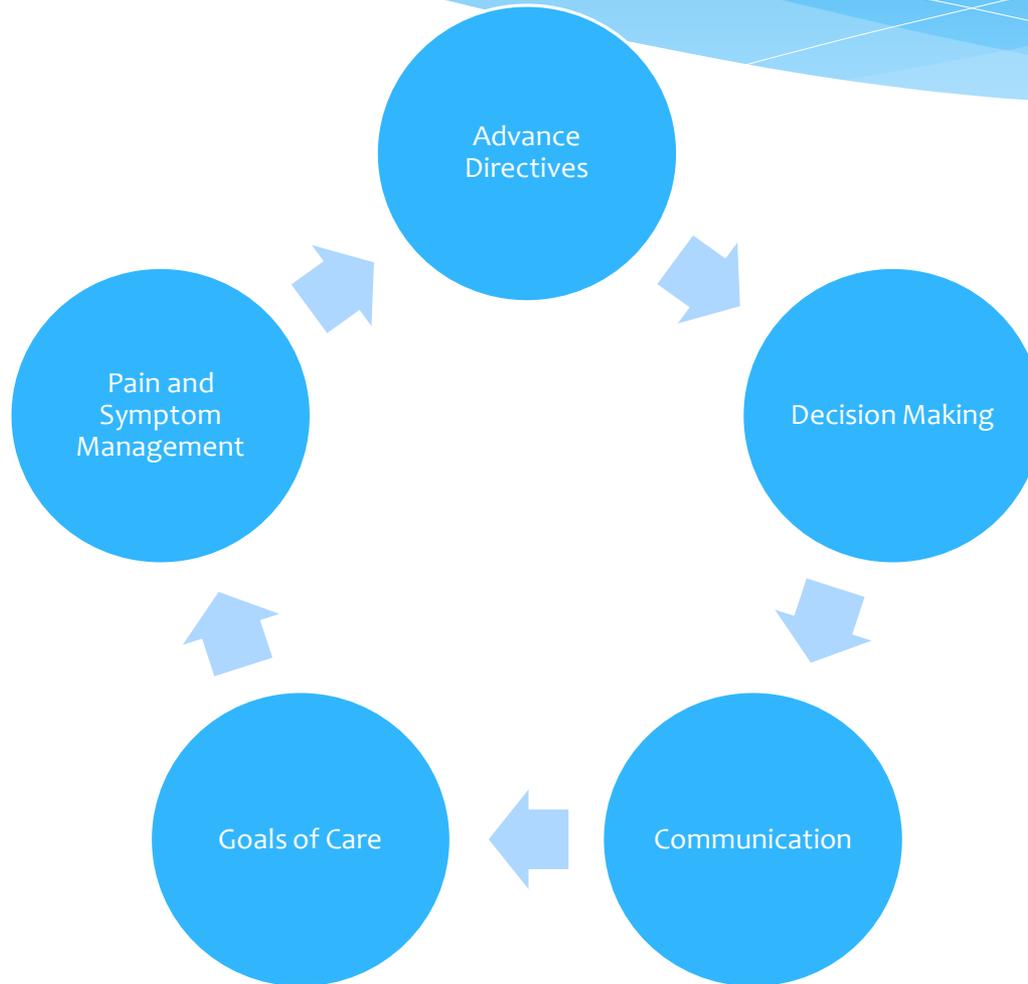
Triggers for Palliative care

1. **The surprise question** – Would you be surprised if this person were to die in the next 12 months? This is an intuitive question considering many factors.
2. **Choice and/ or need** – the patient with advanced disease chooses comfort care only rather than 'curative' treatment
3. **Clinical indicators** -indicate advanced disease

Palliative Care

- * Relieving pain, suffering and symptoms associated with serious illness without effecting a cure

Palliative Care



Surprise
Question

Holistic
- practical issues
of the resident
and family

Patient
Centered

What constitutes
Quality of Life?

Palliative Care
Plan of Care

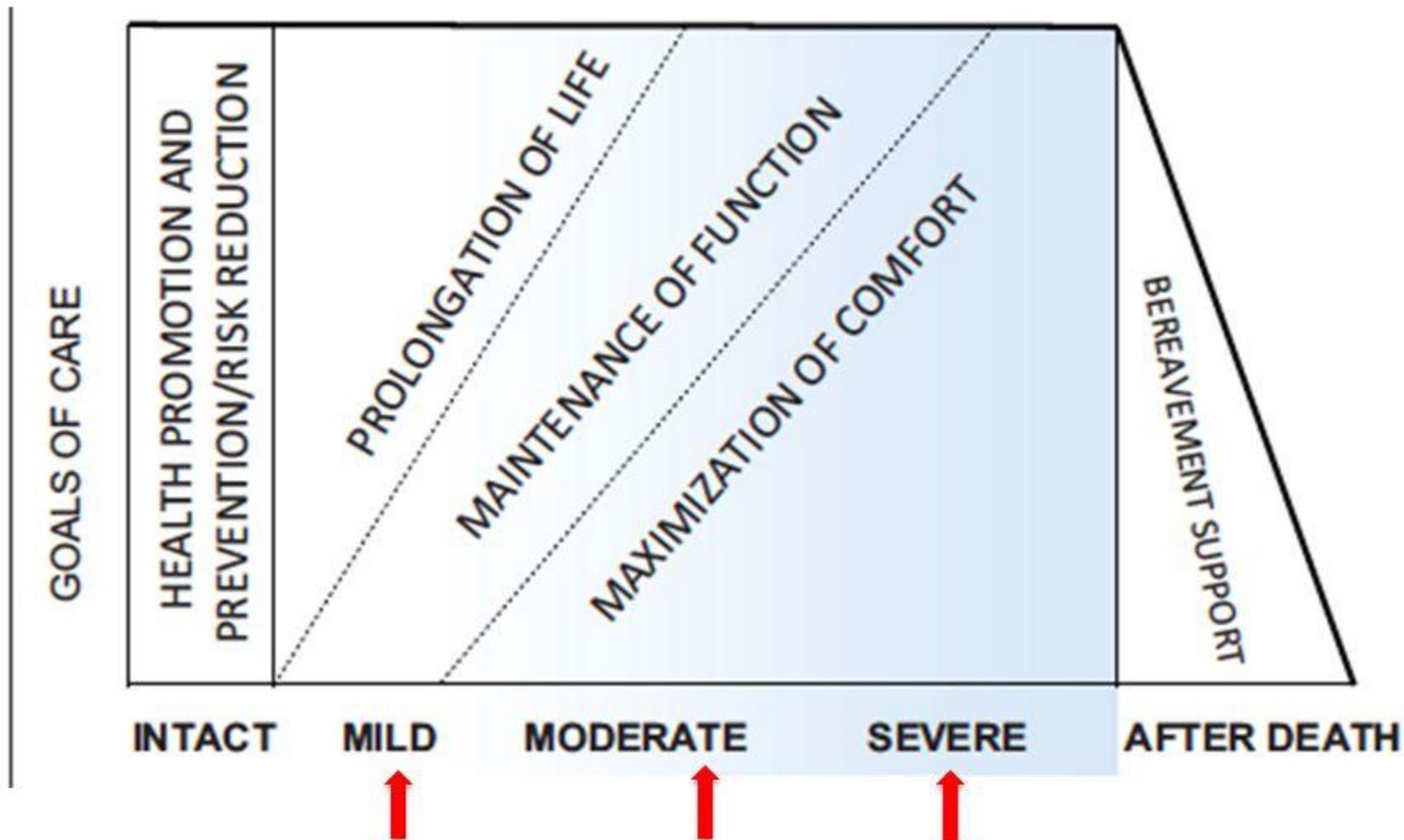
End of Life Care	Palliative Care
When death is inevitable The person is “actively dying”	Begins when a person has chronic or terminal illness or illnesses that cannot be cured
The final stage of the palliative approach	Emphasizes quality of life of the resident and symptom control
Death is expected within the near future: months, weeks, days	Often initiated when death is not unexpected in the next 6 months to a year
Focused on supporting patient and family choices	Focus is resident centered
The final stage of the journey of life	Holistic Care- multidisciplinary approach

Palliative care is an approach not a place!

- * A palliative approach to care integrates with usual care:
 - * Open communication re prognosis and trajectory
 - * Advanced care planning
 - * Psychosocial and spiritual support
 - * Pain or symptom management

- * Durepos, P, Wickson, Griffiths, A, Hazzan, A,

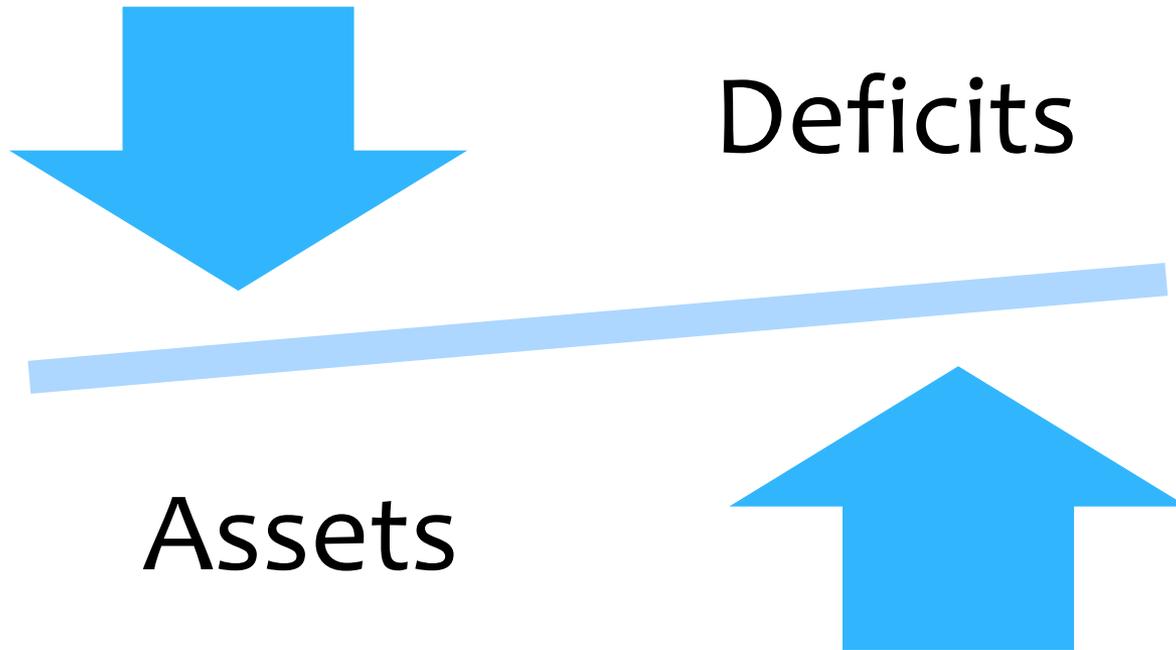
Dementia Progression Prioritization Of Goals

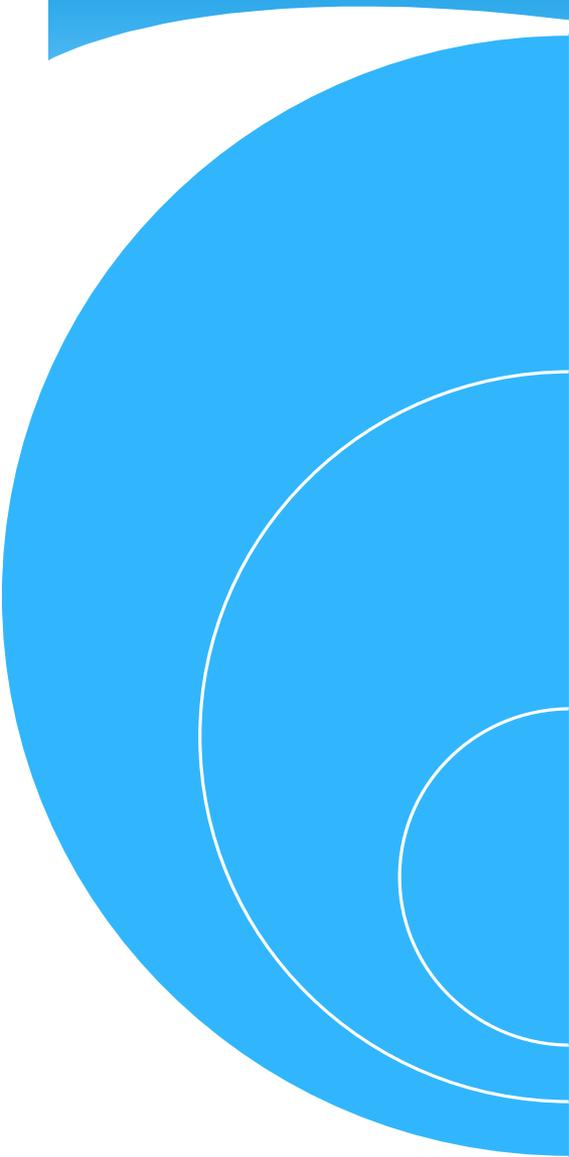


Dementia and Mortality

- * A person with dementia is more likely to die even if they are dying from another illness
- * Increased age and male gender are consistent predictors of mortality in dementia
- * The reasons for increased mortality are not clear but may be due to:
 - * Risks of reduced cognition and performance
 - * Specific disease processes in the brain
 - * Comorbidity

Frailty





What is Frailty?

- A fragile state of health
- Increases vulnerability to illness

Affects whom?

- More common in older people
- Frailty at any age

Affects how?

- Exhaustion
- Loss of strength
- Decreased motor control
- Cognitive impairment
- Slower recovery or partial recovery
- Higher risk of poor outcomes

Frailty: Strong Predictor of Negative outcomes

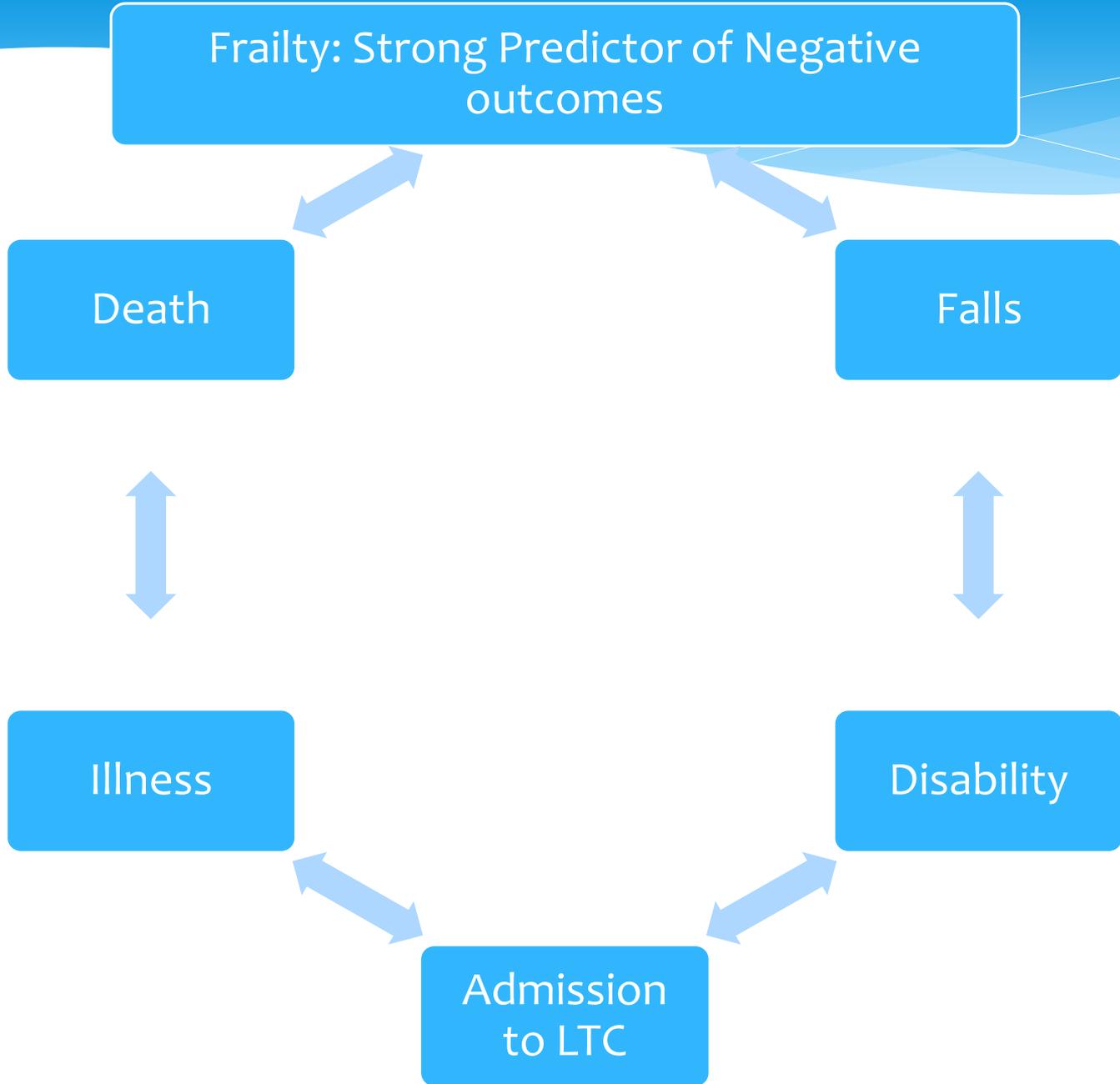
Death

Falls

Illness

Disability

Admission
to LTC



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.

Frailty

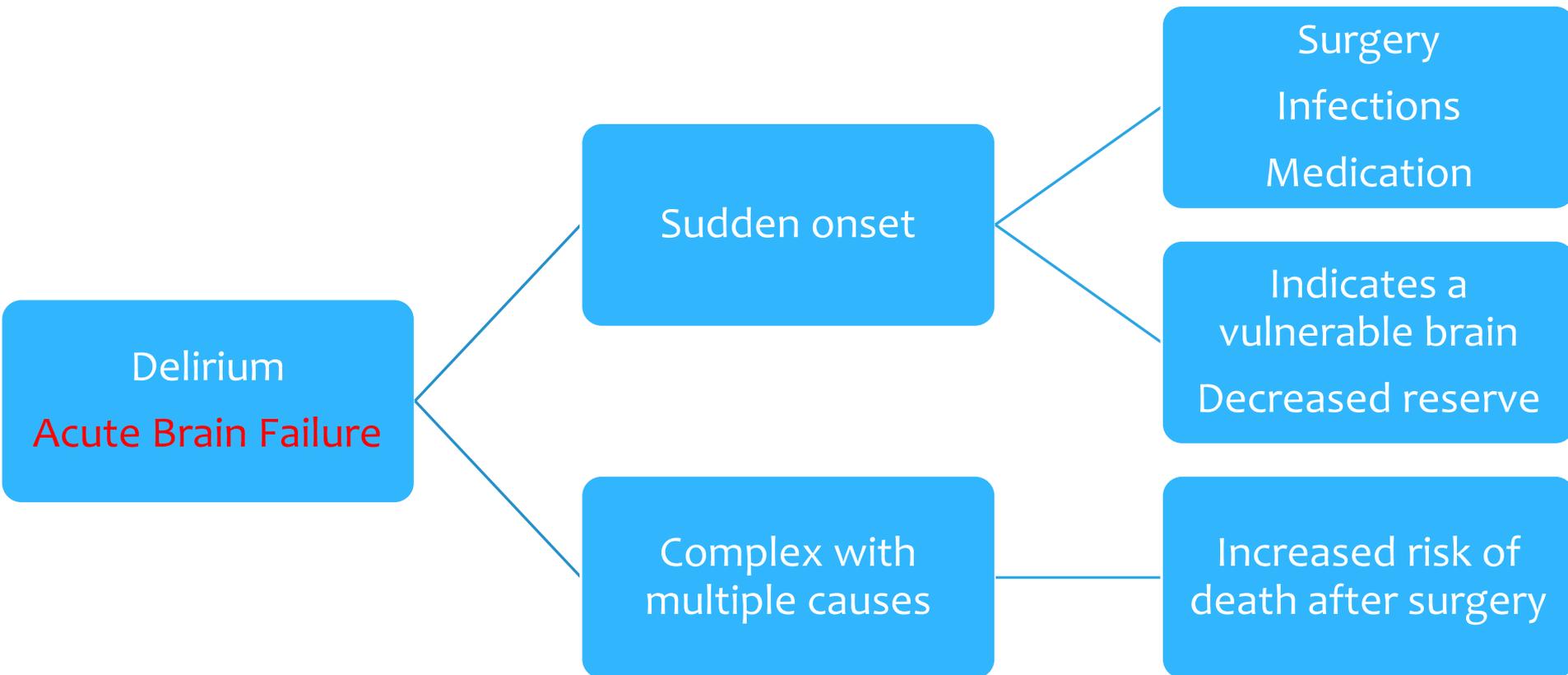
- * Frail people do not respond to treatment the same as younger stronger people do
- * Aggressive treatments may do more harm than good
 - * pain, distress and affect quality of life
- * Complications among frail persons are 60% more likely during a hospital stay
 - * 10 times less likely to return home
 - * Trauma of leaving their environment



Delirium

A higher order
sign of whole
system failure-
Rockwood

A medical
emergency



Delirium

2 Main Features

- * Sudden Onset
- * Fluctuating Course
 - * Reduced awareness of the environment
 - * Decreased ability to focus or sustain attention
 - * Changes in cognition
 - * Hyperactivity to hypoactivity
 - * Emotional disturbances
 - * Perceptual disturbances
 - * Sleep/wake cycle disturbances

Delirium

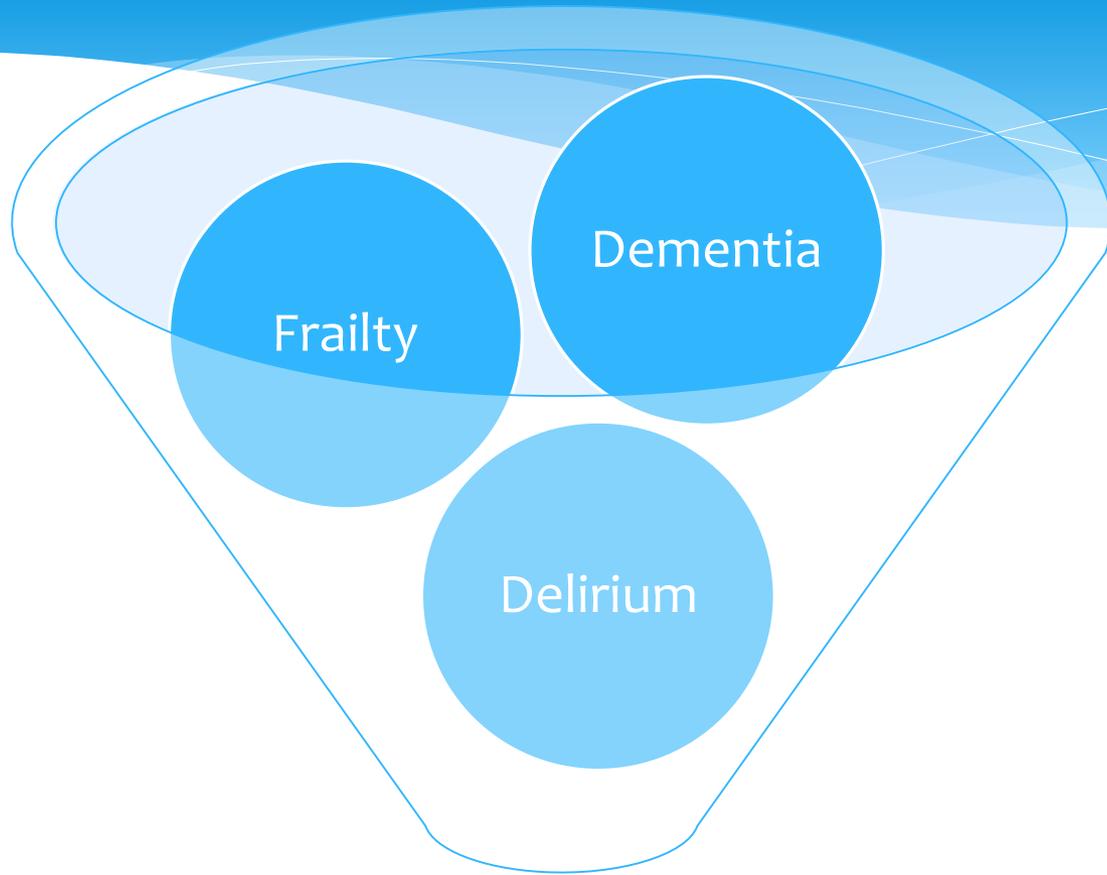
Consistently associated with increased mortality in the elderly

33% never return to their baseline functioning

Post-op may cause cognitive impairments for as long as a year

May lead to permanent cognitive decline and dementia

In elderly with dementia, delirium is associated with increased cognitive decline, admission to LTC and increased risk of death



Complex Care

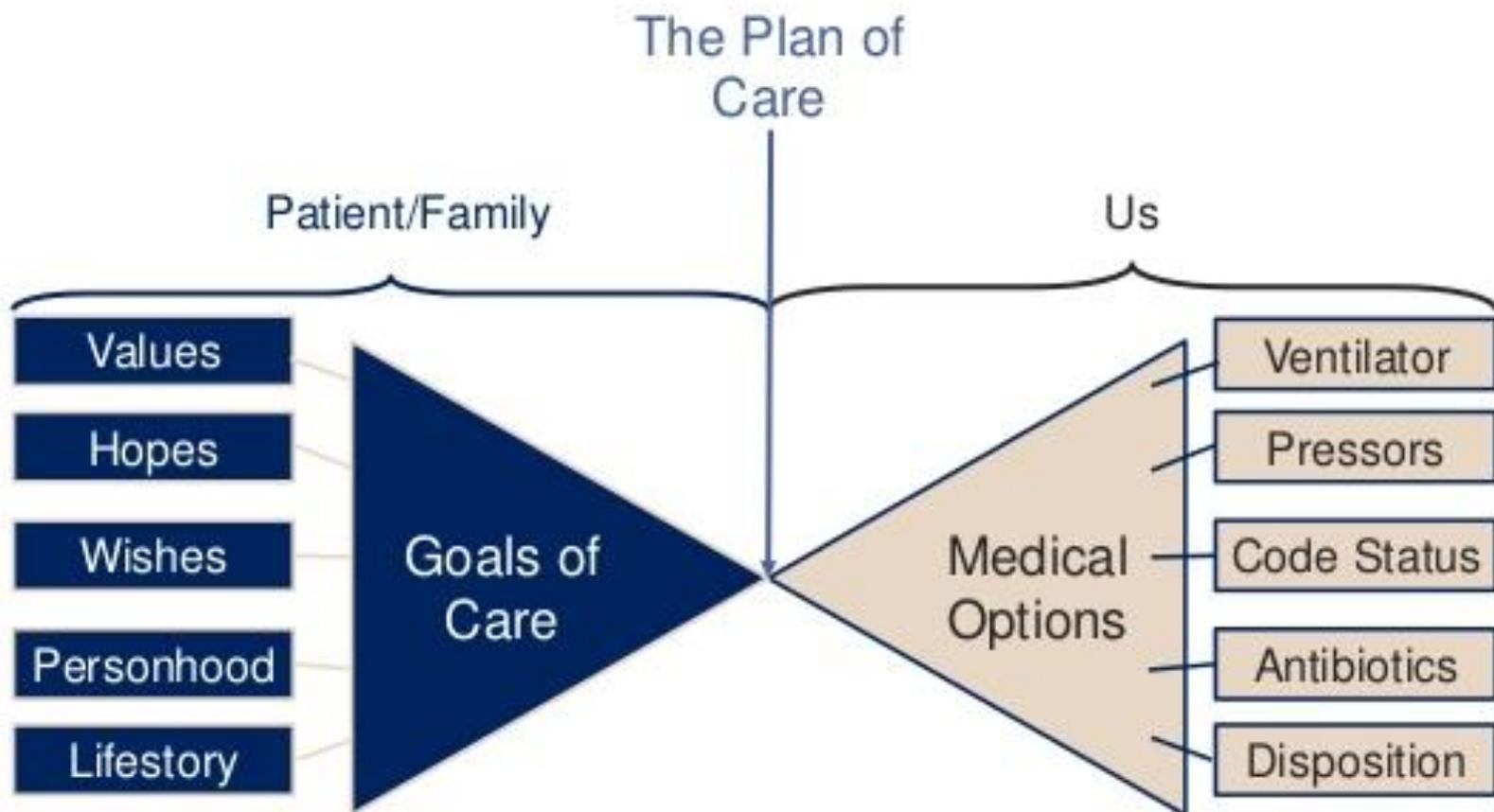
PATH- Palliative and Therapeutic Harmonization

- * For frail older adults with
 - * Advanced medical conditions
 - * Many recent hospitalizations
 - * Unmanaged symptoms
 - * When the Impact of interventional procedures on quality of life is questioned

Goals of Care in Dementia

- * What are the persons wishes as they approach the final chapter of their life? Their values and beliefs?
 - * What is wanted and what is not wanted?
 - * Goals of care should be established and clearly evident in the person's health record
 - * Can be very specific or more general
 - * Who is entrusted with this information?

Goals of Care



Questions to ask when making medical decisions

- * Which health conditions are easily treated and which are not?
- * How will frailty make treatment risky?
- * How can symptoms be safely and effectively managed?
- * Will the proposed treatment improve or worsen function or memory?
- * Will the proposed treatment require time in hospital?
- * Will the treatment allow more quality years, especially at home?
- * What can we do to promote comfort and dignity in the time left?

What is Palliative approach to care in LTC?

- * Begins when a resident has a chronic illness which cannot be cured or a terminal illness
- * Emphasis is symptom control /quality of life
- * Multidisciplinary approach
- * Focus is resident centered and holistic care
- * Implemented when death within the next year would not be unexpected

Barriers

- * Pain management is challenging
 - * Difficult to interpret symptoms so is under recognized and undertreated
 - * Problems with memory, interpretation of sensations and verbal expression
 - * May present as a behavioral issue or a change in mental status
 - * A thorough search for a physical cause is essential
 - * A trial of pain medication should be a first step to treating agitation
 - A trial of pain medication is **always** the first step to treating agitation and other challenging behaviors of dementia

Pain Management

- * Fear to treat pain in dementia due to the cognitive side effects
- * Family involvement is the key as they will know the person is in pain
- * Pain scales

PAINAD score

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**

Pain Management

- * Non-medication treatments:
 - * Heat packs
 - * Cold packs
 - * Acupuncture
 - * Massage therapy

Palliative Care

- * Ideally begins at the time of diagnosis
 - * It should be introduced as a concept
 - * No life expectancy requirement
 - * Can be used to complement curative care

Barriers to End of Life Care in Dementia

- Harder to predict when death will occur
- Prolonged average survival time (3-10 years)
- Clinician and caregiver difficulty viewing dementia as a terminal illness even in late stages
- Our view of palliative care versus EOL care- Institutions and the health system may promote giving treatment often without question
- Withdrawing and with holding treatments
 - Treating infections-normally a routine treatment
 - Not burdensome to an average person
 - Relatively painless
 - Effective in the short term
 - Comfort care in the short term

Case Presentation

- * What was your original response?
- * What would you say now?
- * What information most influenced your answer?

Pallium Canada

- * Video # 2 <https://www.youtube.com/watch?v=-SzA-kWB8-s>

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