

Recognition and Management of Late Stage Dementia

Dr. David Strang


Dementia Care[®]

Alzheimer Society
MANITOBA
Dementia Care & Brain Health





Objectives

- Health care practitioners play a key role in supporting patients and families through the transition to late stage dementia and end-of-life care.
 - Learn how to recognize and manage the symptoms and signs of late stage dementia, support and prepare families to anticipate transitions and clarify goals of care.
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Outline

- Stages of Dementia
- Problems and Management in Advanced Dementia
- Terminology – EOLC, ACP, GOC
- Dying with Dementia
- Prolonging Life in End-Stage Dementia
- ACP Practical Tips



Introduction

- Dementia is common – 8-10% of those over 65, >35% over 85
- New official term for dementia is “Major Neurocognitive Disorder”
- Dementia not directly ‘fatal’ like cancer or cardiac arrest, but is a terminal illness like ALS
- People with late stage dementia have a high mortality and also limitation to quality of life



Stages of dementia

- Reisberg scale, stages 1-7
- Stage 1 – Normal
- Stage 2 – Normal aged forgetfulness
- Stage 3 – Mild cognitive impairment
 - Worse short term memory, possible other symptoms (concentration, word finding)
 - Still little or no effect on day to day functioning, but family notice changes
 - New term “Minor Neurocognitive Disorder”



Stages

- ▶ Stage 4 – Mild dementia
 - ▶ Worsening memory, executive, language and other symptoms, possible mood, behavior change
 - ▶ Affects daily function – earliest functions are work, driving, finances, medications, sometimes neglect of hygiene
 - ▶ Family worried, physician can diagnose



Stages

- Stage 5 – Moderately severe dementia
 - Major forgetfulness, language problems, trouble recognizing people, objects or places, behavior changes
 - Unable to manage most or all household tasks, trouble with some basic tasks e.g. bathing, dressing
 - Some may be in community with family and home care support, many in nursing home



Stages

- Stage 6 – Severe dementia
 - Severe problems with memory, communicating, and dependency with daily care
 - Often personality and behavior changes ranging from withdrawal through types of anxiety or agitation and/or delusions or hallucinations
 - Fewer manage in community even with supports

Stage 7

- Very severe or advanced dementia
- Little or no verbal communication
- Dependent for all daily activities, incontinent
- Lose ability to walk – bed- or chair-bound
- Lose ability to swallow food and fluids
- Most people in nursing home
- Late , terminal complications include:
 - Pneumonia (with or without aspiration)
 - Weight loss from difficulty swallowing and immobility

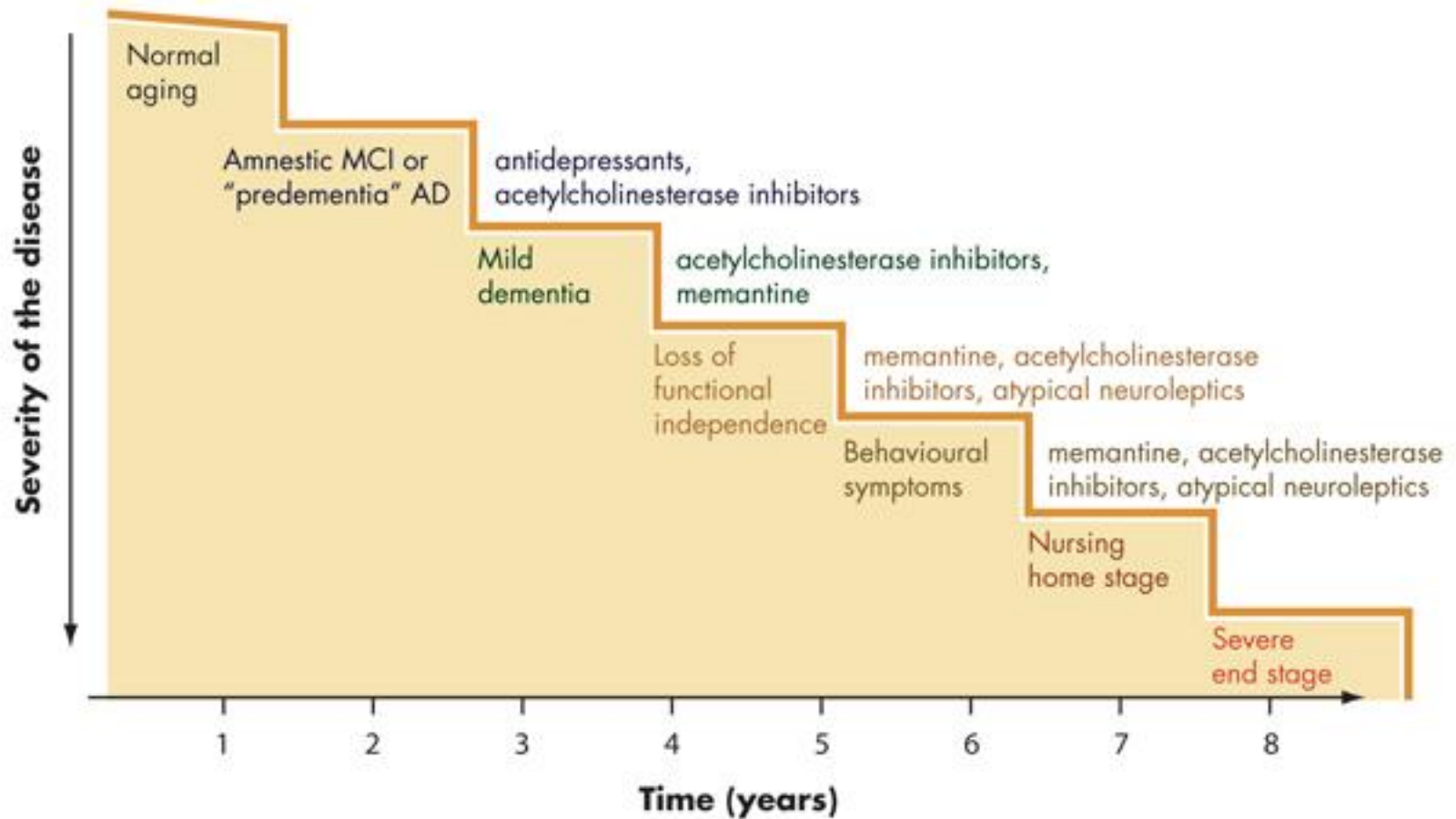


Duration

- Duration of dementia and of each stage varies widely
- On average, about 2 years per stage, but range less than one up to 5 years
- Also varies with cause of dementia and with co-morbidities
 - Generally shorter with Lewy Body dementia, widely variable with vascular dementia

Figure 1:

Natural History of Alzheimer's Disease and Stage-specific Symptomatic Drugs



Modified from Jelic & Winblad, 2004 (unpublished)



Long-term Care (LTC)

- ▶ CIHI data reports that 61% of all Canadians with dementia live outside of LTC
 - ▶ Terminology and rates varies across provinces
 - ▶ Higher use of LTC with more severe dementia, age over 80, with more ADL dependency, with wandering, after hospitalisations
- ▶ 50 to 90% of all LTC residents have dementia



Problems in Advanced Dementia

- Dependency for personal care
- Immobility – high risk of bed sores
- Difficulty having interpersonal interaction or participating in activities
- Responsive behaviors
- Swallowing difficulties – aspiration pneumonia and difficulty maintaining nutrition and hydration



Personal Care and Mobility

- Require assistance with most or all ADL
- Often require assistance with transfers and mobility
- High incidence of incontinence
- Care provided by family members, professional caregivers (health care aides, nurses)




Personal Care

- High risk of caregiver burden, both physical and emotional
- Assessments by Physio, OT for adaptive aids, techniques and equipment may assist
- Community supports, respite, caregiver training
- Attention to high risk of skin breakdown



Meaningful Activities

- Traditional activity programs in LTC require some verbal and/or motor activity by the person
 - Persons with advanced dementia may lack the ability to participate, remain bored and isolated
 - Activities tailored to those with advanced dementia are needed
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Activity for Advanced Dementia

- Programs with weak evidence of benefit:
- Snoezelen
- Multisensory and motor group activity
- Garden experience
- Namaste program



Snoezelen

- Related to Montessori method
- designed to stimulate the senses of sight, sound, touch, smell, and movement
- equipment may include:
 - bubble tubes that change color and speed in response to sound,
 - swing chairs with colorful wall murals around it,
 - music systems,
 - projectors with colored light wheels that rotate slowly, providing gently changing colors and designs.
 - mirrored balls,
 - aroma diffusers,
 - mobiles of fish,



Snoezelen

- Evidence of benefit to reduce agitation is mixed
- Equipment often under-used
- Staff often receive little training how to use it
- May be expensive for room and equipment



Multisensory and Motor Based Group Activity Program

- designed to stimulate the senses of sight, sound, touch, smell, movement, and taste, using natural items
- Presented in a certain order, increasing complexity, 1 to 3 sessions per week
- Requires staff training, also in managing certain behaviors
- Evidence of increased engagement

Multisensory and Motor Based Group Activity Program


Table 2

Sample of Motor and Multisensory Care sessions (reprinted from Trudeau SA. Bright Eyes: a structured sensory-stimulation intervention. In: Volicer L, Bloom-Charette L, editors. Enhancing the Quality of Life in Advanced Dementia. Philadelphia: Taylor & Francis; 1999. p. 93–106) [40].

| Sense | The Beach | Trains | Baseball | Fishing | Gardening |
|-------------|-------------------------------|-------------------------------------|-------------------------------|------------------------------------|--------------------------|
| Olfactory | Coconut suntan lotion | Ground coffee | Fresh-cut grass | Sardines | Garden fresh tomato |
| Kinesthetic | Beachball toss | Balloon volley | Soft baseball toss | Casting with rod and reel | “Digging” with shovel |
| Tactile | Terrycloth towel | Conductor’s cap | Felt baseball hats | Fishing flies (feather and thread) | Potting soil and trowel |
| Visual | Photos from Hawaiian calendar | Black and white train photos | Photo of local ballpark | Calendar of trout flies | Seed catalogs |
| Auditory | Ocean-waves tape | “Atchinson Topeka and the Santa Fe” | “Take me out to the Ballgame” | Seagull sounds | Tape of crickets at dusk |
| Gustatory | Cold lemonade | Chocolate cookies | Nonalcoholic beer | Sardines on saltine crackers | Peeled tomato |



Garden Experience

- Being in a garden
 - Few studies in Japan showed improved relaxation, behavior and lower heart rate
 - Biggest problem is weather, especially here
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Namaste Program

- Namaste “I honour the spirit within you”
- Principles - creating a comfortable environment with the presence of others, and
 - a loving touch approach to all activities
- Namaste care in a reserved space, 2hours twice a day 7 days a week
- Relaxing environment, music, scent, seating
- Individualized greeting, conversation

Namaste

- ▶ Individualized hands-on care e.g. massage, applying face cream, shaving
- ▶ Some weak evidence of: - improved quality of life
 - ▶ Decreased behavioral symptoms of dementia and discontinuation of antipsychotic medications
 - ▶ Decreased rejection of care - the loving touch during Namaste Care may make people less likely to resist care activities involving touch even outside of Namaste
 - ▶ Stimulation during the sessions reducing sleep during the day and decreasing need for hypnotic medications
 - ▶ May decrease depressive symptoms, improve the ability to communicate with family members and staff, and decrease complaints of pain.
 - ▶ Namaste Care is well received by both family members of persons with dementia and by



Responsive behaviors

- Behavioral and Psychologic Symptoms of Dementia
- Apathy, depression, withdrawal
- Anxiety, restlessness, agitation
- Psychotic symptoms:
hallucinations, delusions
- Physical or verbal aggression,
spontaneous or triggered
- Wandering, pacing



Responsive behaviors

- ▶ About 50% of LTC residents with dementia
 - ▶ Varies considerably over time
 - ▶ First line of management is adaptive personal care
 - ▶ Identify triggers
 - ▶ Modify environment
 - ▶ Reassure, redirect, re-engage
 - ▶ Delay care, retry later
- 



Responsive Behaviors


- Historically, high use of physical and chemical restraints
- Successful large-scale efforts to reduce both over recent decades
 - Currently about 10% of LTC residents with dementia have a physical restraint
 - About 15-25% on antipsychotic medication without psychosis

Swallowing Difficulties

- Dysphagia – difficulty moving food, liquids, medications, secretions through mouth and esophagus
- Increased likelihood as dementia progresses
- Earlier with Lewy Body, vascular dementia and other disorders which cause dysphagia
- Leads to dehydration, malnutrition, and aspiration of oral contents into lungs



Dysphagia

- Assessment by Dietician and Speech Language Pathologist
 - Modified texture diets
 - Supported feeding
 - Invasive treatments (IV, Tube feeds) ineffective and burdensome
 - In late stage dementia, a signal of the approach of end of life
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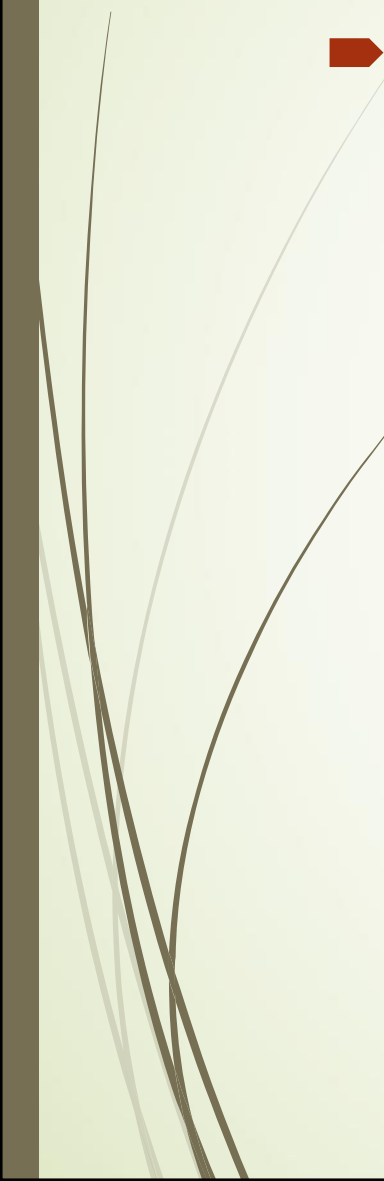
Late Stage Dementia

- Often issues arise around intensity of care in the weeks and months prior to death:
 - Is it worth it for the person to struggle to live longer?
 - How is their quality of life?
 - Is it worth it for them to go to the hospital?
 - What to do if we disagree about intensity of care?




Terminology

▶ End-of-Life Care

- ▶ Health care and supportive care at or near the end of life, especially with dementia
 - ▶ Often hard to predict exactly when someone is approaching the end of their life
 - ▶ EOLC may variably include months or even years prior to death, or just the last few days
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Advance Care Planning

- A process of decision-making for health care contingencies before they happen
 - Informed consent in advance
 - Linked with 'DNR' (or ACP or Goals of Care) policies, living wills/advance health care directives, informed consent, capacity/competency issues, substitute decision-making
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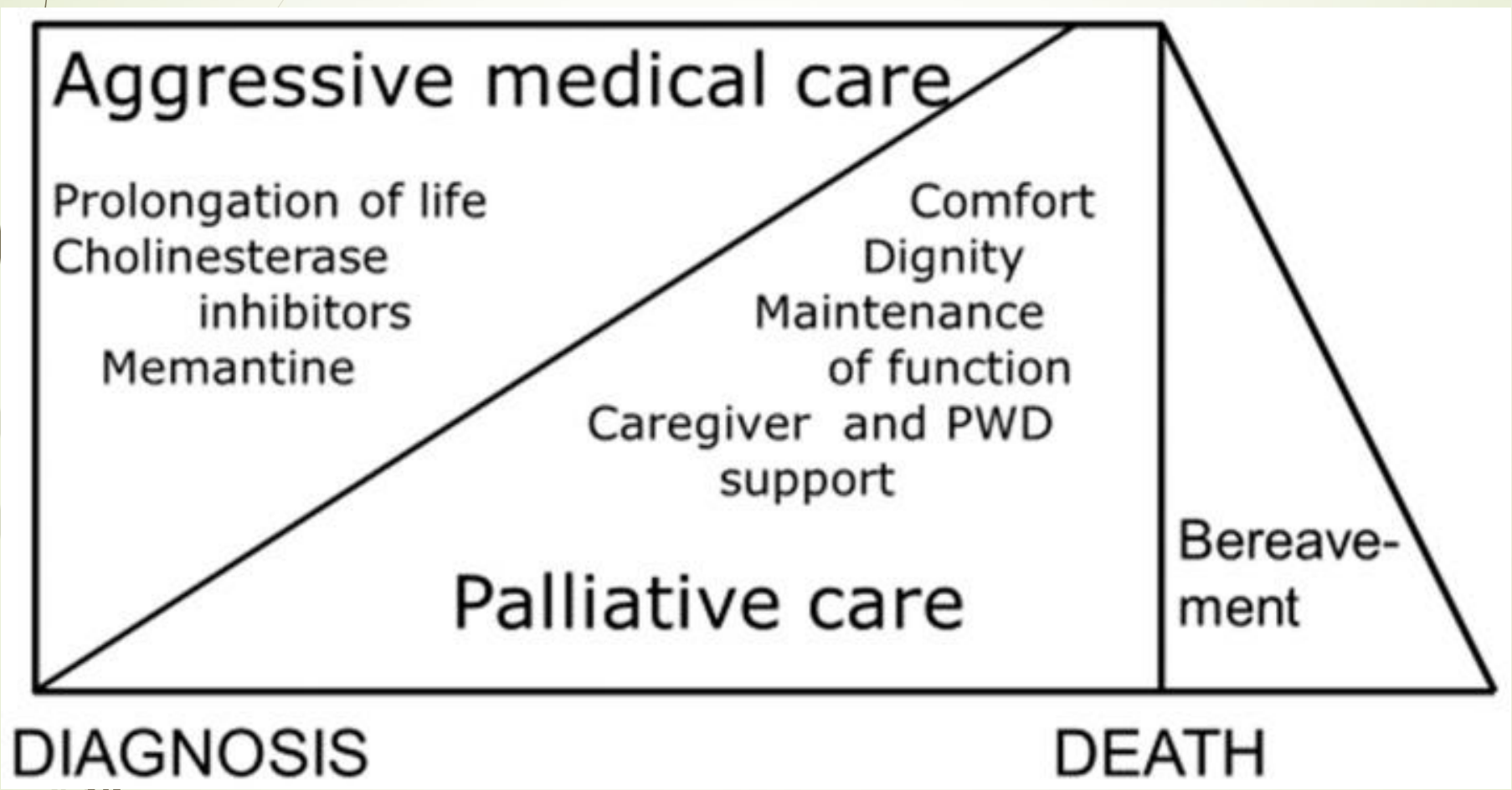
Advance Care Planning

- A consensus process through ongoing communication
 - May be the wishes of a competent person, but usually the opinion of the family or a substitute decision-maker
 - Discussion may include members of interdisciplinary health care team and/or physician
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Goals of Care

- Prolonging life
 - Maintaining function
 - Providing comfort
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Quality vs Quantity

- Quality of Life (QOL) depends on factors such as pain, other distressing symptoms, sense of meaning or purpose, dignity, social interaction, and numerous other values
 - Prolonging life often requires burdensome interventions that at least temporarily worsen comfort and QOL
 - Trade-off is whether expected future QOL is good enough to be worth extra distress now
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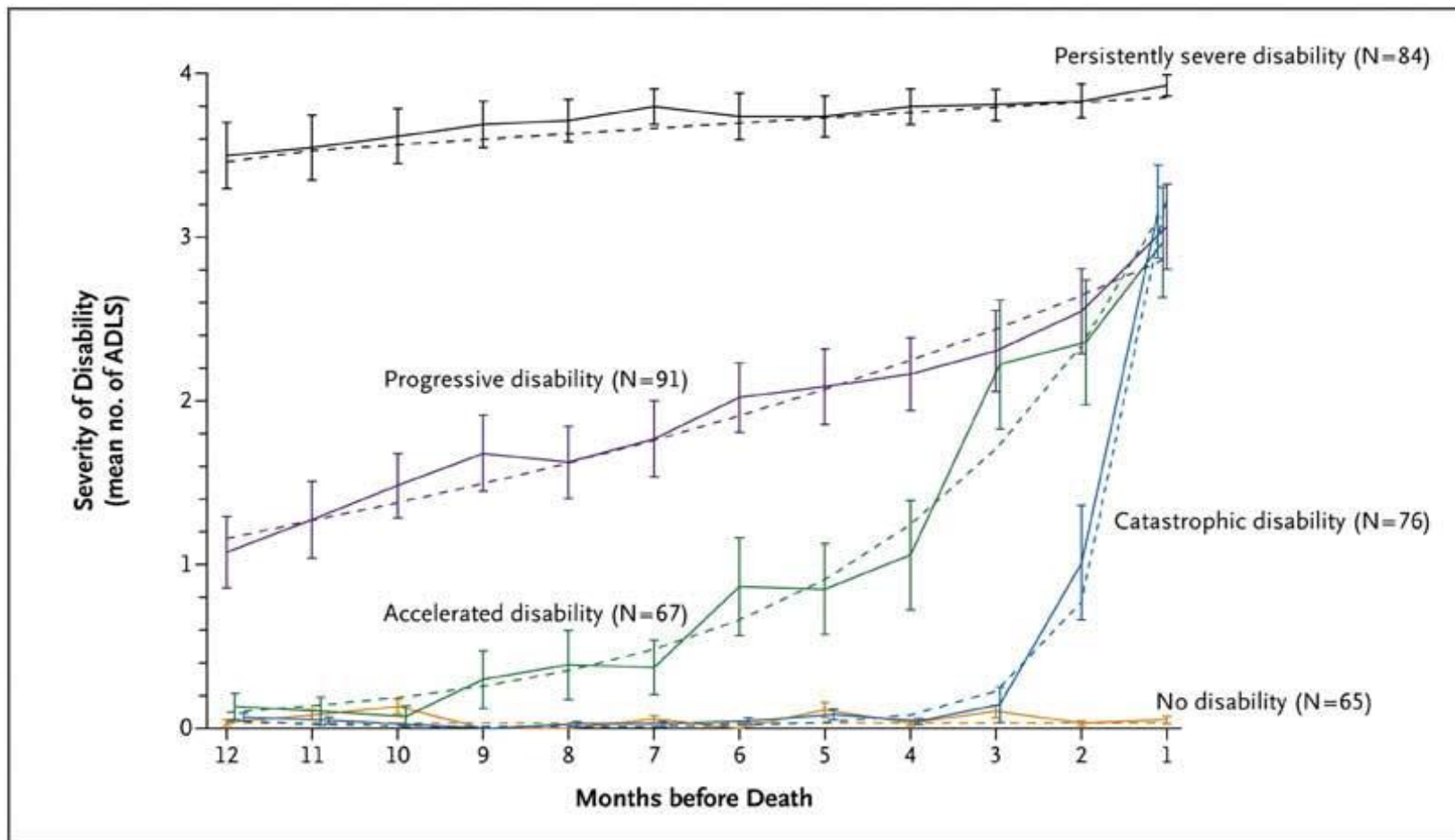
Quality vs Quantity

- Would the person want to live longer like this?
- How much extra pain and discomfort would they want in order to buy them longer survival?
- Would they already want an end to their life due to poor QOL and suffering?

QOL and ACP

- ACP R (Resuscitation)
 - Priority on prolonging life at cost of QOL
 - Person would accept the additional suffering of invasive treatments in order to have a chance of living longer
- ACP M (Medical Care, No CPR)
 - In between, still buys longer life with immediate suffering
 - Person would accept less invasive treatment to live longer
- ACP C (Comfort Care)
 - Priority on comfort at cost of foregoing longer life
 - Person would accept dying sooner to avoid suffering due to invasive treatments and/or poor QOL

Trajectories of Disability in the Last Year of Life among 383 Decedents.





Burdensome Interventions

- ▶ CPR – rarely successful in advanced dementia
 - ▶ Quite invasive, need ICU and ventilator afterward
 - ▶ Most LTC residents do not have ACP R



Burdensome Interventions

- ▶ Tube feeding in advanced dementia does not:
 - ▶ Prolong life, Prevent aspiration or pneumonia, Improve function or nutrition, Decrease prevalence of decubitus ulcers
- ▶ Dialysis – median 1 year survival 26-42%
 - ▶ Most have decline in function, cognition after start



Transfer to Hospital

- High degree of distress from unfamiliar hyper-stimulating environment, unfamiliar staff, burdensome interventions
- Many cases of pneumonia can be treated (if treatment indicated) in DLC especially if caught early
- For bed-bound people, even fractures can be managed conservatively with analgesia



Overall mortality

➤ Risk of dying each year in general population:

➤ At age 60-69 1-1.5%

➤ Age 70-79 3-4%

➤ Age over 80 9-11%

➤ Higher for:

➤ Men

➤ If more chronic health conditions (incl. dementia)

➤ If worse dependency



Mortality from Dementia

- Annual dementia mortality 30-50/100,000 of whole Canadian population, increases by age
- Average life expectancy of a person in PCH in Manitoba is 2 years
- Every year ~135 Deer Lodge Centre Long Term Care residents die (85% on site)
 - 2 or 3 per week



Prognosis of Advanced Dementia

- ▶ Among 323 PCH residents near Boston with advanced dementia followed for 18 months:
 - ▶ 55% died (25% within 6 months)
 - ▶ 40% had pneumonia
 - ▶ 85% had a feeding problem
- ▶ Chance of surviving 6 months:
 - ▶ After episode pneumonia ~ 50%
 - ▶ With feeding problem ~60%



Prognosis of Advanced Dementia

- Only 9% had any stroke, seizure, MI, GI bleed, fracture, other major illness, few led to death
- High prevalence of distressing symptoms:
 - Dyspnea > 5 days – 46%
 - Pain 39%
 - Ulcers 39%
 - Agitation 54%



Burdensome Interventions

- Burdensome interventions (IV, ER/hospital, Tube Feed) in 34%
- Referral to hospice in 22% (30% of those who died)
- Less likely if caregiver thought resident had less than 6 months to live, or understood expected complications, or both




Summary

- Dying with advanced dementia is like dying with terminal cancer
- Appropriate to focus on comfort care
- Need to monitor for distressing symptoms
- Often appropriate to avoid burdensome interventions
 - Need to discuss prognosis and expected complications between family and health care team



Advance Care Planning

- High proportion of Winnipeg LTC residents have a ACP/GOC level indicated
 - Many families choose 'M', many residents receive IV antibiotics and fluids, are transferred to hospital, but no tube feeds for dementia
 - Low involvement of physicians in ACP discussions
 - Variability in extent of discussion when eliciting ACP level
- 



Practical ACP Discussion Tips

- When to discuss:
- At home, as early in the course of dementia (or before) as possible
- In LTC:
 - On admission,
 - Review at first family/team conference
 - AGAIN, when first significant complication arises
 - AGAIN, annually, or with further illnesses, or prn



Who should make an ACP?

- ▶ A patient and/or substitute decision-maker, with a health care team member
- ▶ Team member should be familiar with the process and the patient
 - ▶ Usually social worker, nurse +/- physician
- ▶ Involve all family and others appropriately involved in decision-making

What to consider

- Does the person have a Health Care Directive? If so, must follow it with rare exceptions
- What is the perceived Quality of Life? How would the person consider this QOL?
- Would the person want to live as long as possible with this QOL?
- How much extra suffering from treatments would be worth it to have a chance to live longer with this QOL or worse?
- Should we focus on comfort rather than trying to pull through another pneumonia or episode of dehydration....?

ACP principles

- Voluntary – don't have to indicate an ACP level
- Non-binding – can change your mind at the last minute
- Still important – especially if staff can't reach anyone when something happens
- Will still get try to consent from family at the time
- Consensus process
- Substituted judgement: it's not what the caregiver wants, it's what the caregiver thinks the patient wants



Conclusion

- Advance Care Planning and End-of-Life Care discussions is an ongoing dialogue
- Substituted judgment – we are trying to decide and do what the person would want, not what family or staff would want
- May often be appropriate to avoid burdensome interventions for unattainable goals, or if Quality of Life is so poor the person would not want to live longer