Palliative Care Needs for People with Dementia

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Living Well with Dementia Conference
Person Centred Approaches

Alzheimer's Disease:

Memory affected primarily
Later will involve all domains of brain function:
Mood, Personality,
Reasoning, abstract thinking
Executive function

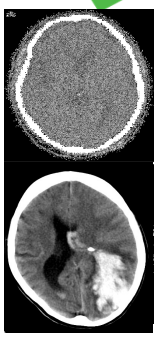
Gradual decline over a long period, physical ability preserved till late (prompting with tasks)

Eventual severe communication difficulties, swallowing difficulties and reduced mobility

- What is dementia; summary of the four common types
- What is palliative care and issues around its delivery for a person with dementia
- Dementia Journey: symptoms along the way

Vascular Dementia

- Often sudden onset
- Unpredictable course
- Communication difficulties
- Feeding difficulties
- Falls/ mobility issue



- Alzheimer's Disease
- Vascular Dementia

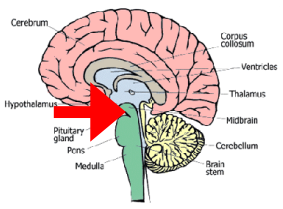
} Mixed

- Lewy Body dementia / Parkinson's disease dementia
- Frontotemporal Dementia
- Others e.g. Normal Pressure Hydrocephalus

Parkinsonian syndromes

Lewy Body dementia
Parkinson's disease dementia

- Fluctuations
- Delusions; Hallucinations
- Parkinsonism
- Falls / syncope

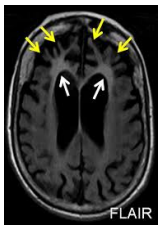


Frontotemporal Dementia (Pick's):

Younger, genetic disposition

Behaviour changes:

- impulsivity,
- disinhibition,
- hyperorality/sexuality,
- withdrawal,
- rituals,



- Speech deficits (word finding, echolalia, → mutism)

Who should be involved?

- GP/PHN/community support services/ NH staff
- Gerontology
- Psychiatry of Old Age
- Neurology
- Alzheimer's Society
- Specialist Palliative Care

What is palliative care?

' An approach to care that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual' **WHO 2001**

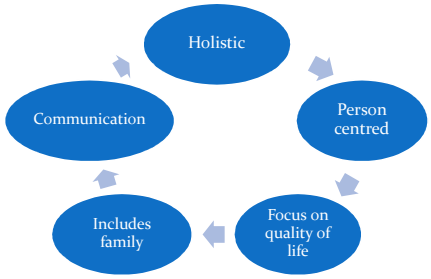
Or

' the continuing active total care of patients and their families at a time when the medical expectation is no longer for a cure. Palliative care extends to support in bereavement and the goal is the highest possible quality of life for both patient and family, as defined by the patient, by maintaining dignity and controlling symptoms'.

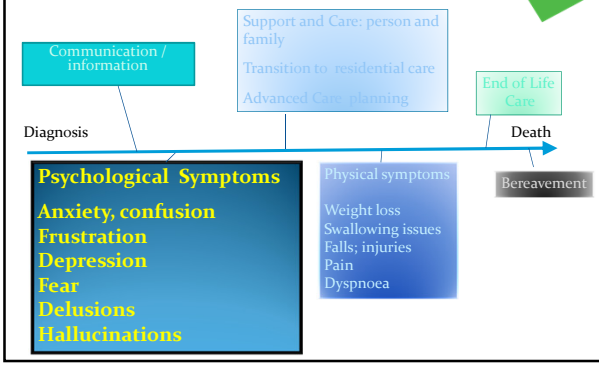
Davies and Higginson 2005

Dementia Journey

What does palliative care offer?



What does person-centred dementia care offer?



Anxiety / depression / quality of life

- Memory
- Attention
- Speech and language
- Organisation / executive function
- Personality

"Functional Ability"

- Independence
- Hobbies
- Social interactions
- Driving
- Sense of worth

.....and direct disease-related depression

Challenging Behaviour

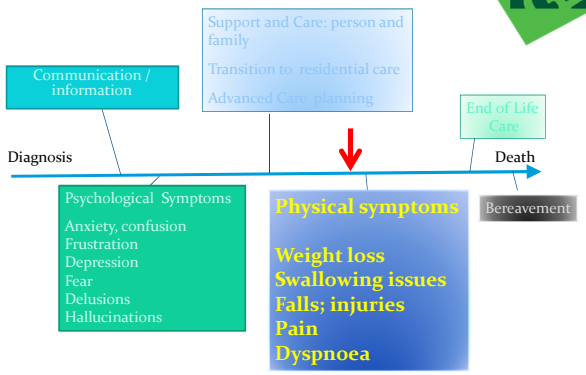
- Reflects an unmet need
- Find the need
- Comfort, company, distraction
- Medications

Anxiety / depression / quality of life

How do I know the person with dementia is depressed??

Geriatric Depression score 5 point, 15 point, 30 point
If MMSE < 15 → Cornell scale for Depression

Trial of treatment: SSRI, MAO-B inhibitor
Choice: sedation helpful? Weight gain/loss helpful?
More anti-anxiety helpful? Side effects important?



Delusions / hallucinations

Delusions / hallucinations

- Specific syndromes - Lewy Body Dementia; Parkinson's Disease Dementia; Fronto-temporal dementia

- **Delirium** = the sudden worsening of severe confusion that can occur when a person is unwell

Swallowing difficulties and weight loss

- Don't always occur together
- Dementia may be associated with reduced hunger
- Check for: constipation, meds, ?unwell otherwise
- Dysphagia- marker of advanced disease

Dyspnoea

Swallowing disorder
Reduced mobility
} pneumonia

Muscle loss

Osteoporosis → thoracic cage deformity

Pain

- **Won, 1999:** 50,000 nursing home residents: over 25% had daily pain, of whom 25% received no analgesia
- **Ferrell 1995:** 17 nursing home residents with dementia (mean MMSE score 12): 62% complained of pain.
- **Morrison & Siu 2000**: people without cognitive impairment received three times the amount of opioid analgesia after hip fractures than those with advanced dementia.
- **Feldt 1998:** people with cognitive impairment received less analgesia post-operatively.

Pain

- Other morbidities – arthritis, angina, shingles, peripheral vascular disease, etc
- Pressure sores
- Injuries
- Contractures

Observational scales:

Checklist of Nonverbal Pain Indicators: vocalisation, grimaces, bracing, rubbing, restlessness and verbal complaints ACUTE CARE

Observational Pain Behaviour Tool

Pain Assessment in Advanced Dementia Scale (PAINAD)

Abbey Pain Scale

How do you tell the person with severe dementia has pain?

Self-report scales: useful in people with mild to moderate dementia who can still communicate (eg MMSE >15/30)

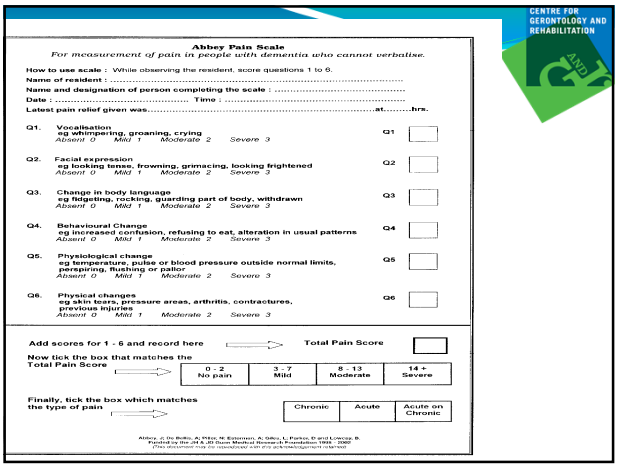
- McGill pain scale
- Pain thermometer,
- Faces Pain Scale

Numerical may be more difficult

The 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	

*Warden V, Hurley Ac, Volicer L. Development and psychometric evaluation of the pain assessment in advanced dementia (PAINAD) scale. J Am Med Dir Assoc. 2003; 4:9-15.



Abbey Pain Scale

For measurement of pain in people with dementia who cannot verbalise.

How to use scale : While observing the resident, score questions 1 to 6.

Name of resident : .....

Name and designation of person completing the scale : .....

Date : ..... Time : .....

Latest pain relief given was..... at..... hrs.

Q1.	Vocalisation eg whimpering, groaning, crying Absent 0 Mild 1 Moderate 2 Severe 3	Q1
Q2.	Facial expression eg looking tense, frowning, grimacing, looking frightened Absent 0 Mild 1 Moderate 2 Severe 3	Q2
Q3.	Change in body language eg fidgeting, rocking, guarding part of body, withdrawn Absent 0 Mild 1 Moderate 2 Severe 3	Q3
Q4.	Behavioural Change eg increased confusion, refusing to eat, alteration in usual patterns Absent 0 Mild 1 Moderate 2 Severe 3	Q4
Q5.	Physiological change eg temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor Absent 0 Mild 1 Moderate 2 Severe 3	Q5
Q6.	Physical changes eg skin tears, pressure areas, arthritis, contractures, previous injuries Absent 0 Mild 1 Moderate 2 Severe 3	Q6

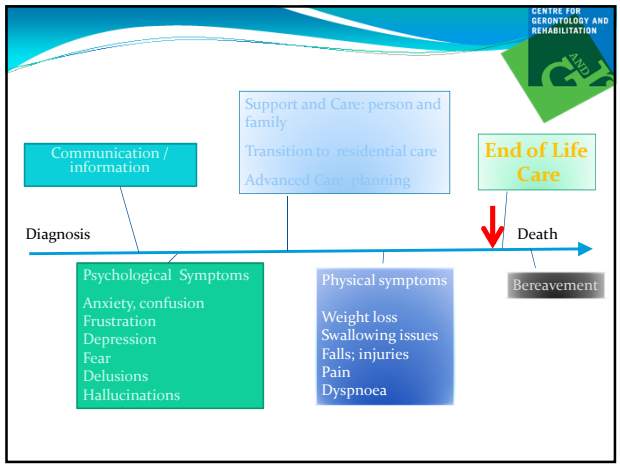
Add scores for 1 - 6 and record here → Total Pain Score

Now tick the box that matches the Total Pain Score →

0 - 2	3 - 7	8 - 13	14 +
No pain	Mild	Moderate	Severe

Finally, tick the box which matches the type of pain →

Chronic	Acute	Acute on Chronic



Observational scales:

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Observational Pain Behaviour Tool

Pain Assessment in Advanced Dementia Scale (PAINAD)

Ask!

Know the person

Trial of analgesia

Common Prognostic Indicators of the last 6 months of life in dementia

- Language/speech loss
- Inability to walk without assistance
- The need for help with all activities of daily living
- Incontinence
- Poor food intake
- Recent weight loss
- Recurrent infections

Gold Standards Framework and Royal College of General Practitioners

Advance Care Planning

- Early in dementia
- Avoid burdensome interventions
- Information required re. pros and cons of treatments
- Challenging for those living at home – transition points: home help, respite, admission to hospital may serve as points of contact

Good End of Life Care

- Stop unnecessary medications - side effects, no benefit
- Avoid unnecessary hospitalisations
- Prepare the family and have a clear care plan
- Continue symptomatic medications using an appropriate administration method -may need specialist input
- Continue to involve the family

Bereavement in Dementia

- Family may not "see the end coming" due to slow deterioration
- "Have already lost the person"
- Separation via residential care
- High care burden for a long time: emptiness/guilt

Summary

- People with dementia (and their families) have complex symptom needs, evolving as the dementia progresses, over a prolonged period of time
- Challenging to provide truly person-centred dementia care within current resources
- But we can all make small changes in our own practice and show leadership in this area

Thank you....

- Atlantic Philanthropies — INAD and NIAD
- Irish Hospice Foundation — Parkinson's disease guidelines; Case studies in dementia
- Genio — Cork IDEAS project

*www.ucc.ie/en/**inad**/*

http://www.muh.ie/index.php/for-patients/dementia-awareness