Neurological Diseases and Palliative Care

St Clare Hospice
Hand in hand we care

LEARNING TOGETHER STUDY DAY

25th June 2024

Dr Joy Ross

To escalate or palliate with dementia – nutrition, pain assessment and management/ recognising dying in advanced dementia patients

StChristopher's

C A R E

THE CENTRE FOR AWARENESS & RESPONSE TO END OF LIFE

To escalate or palliate for patients living with advanced dementia?

- nutrition
- pain assessment
- management / recognising dying

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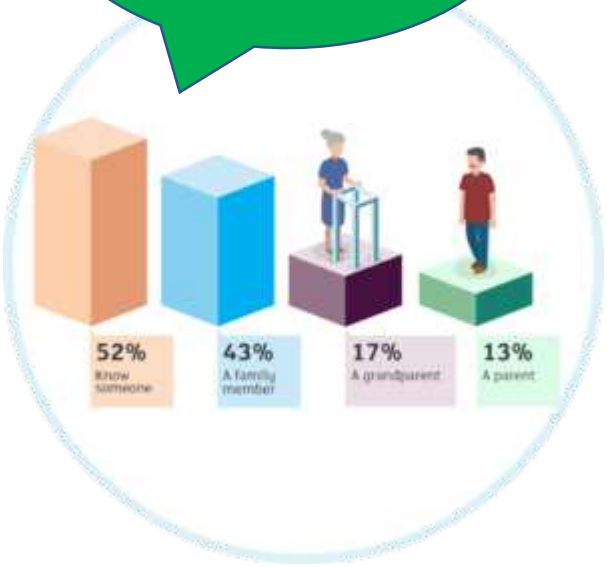
Did you know?

Dementia is now the leading cause of death in the UK?

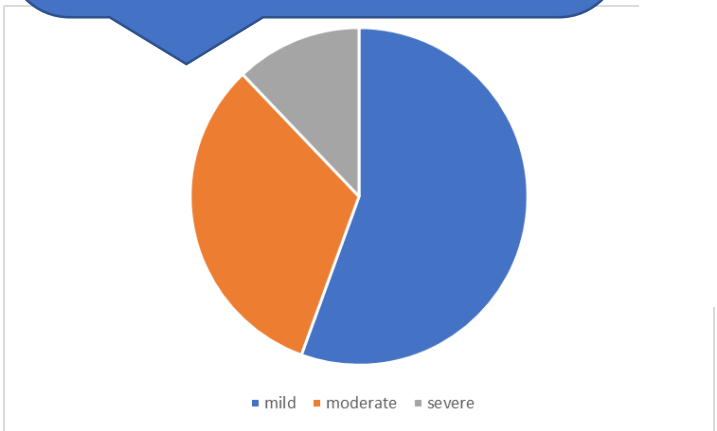
1 in 3 born in UK now will develop dementia in their lifetime

In England and Wales, the number of people living with dementia who need palliative care will almost quadruple by 2040.

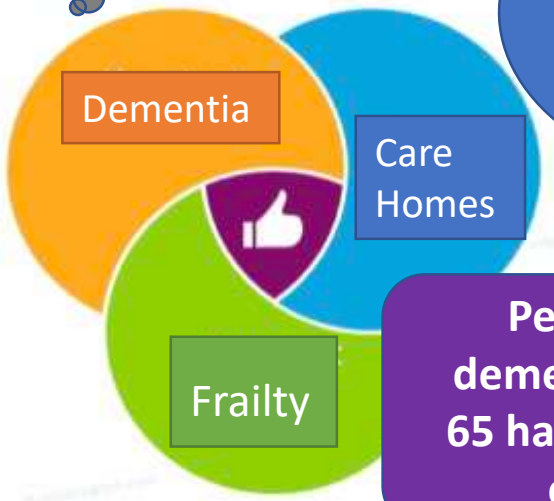
More than half UK adults know someone with Dementia



Approximately 55% of people living with dementia are in the mild stages, with 32% in the moderate stages and 12% in the severe stages.



There is a strong inter-relationship between **dementia**, **care homes** and **frailty**



69% Is the average prevalence of people living with dementia in care homes

People living with dementia who are over 65 have on average four comorbidities

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Getting in the zone

When did you last care for someone dying from dementia?

…Thinking about someone you've cared for recently

- What was most **important** for:
  - the patient
  - the carer
  - you / the health care professional
- What was most **difficult** for:
  - the patient
  - the carer
  - you / the health care professional

Major types of dementia

Alzheimer's	Memory loss Language disorders (eg, anomia, progressive aphasia) Impaired visual-spatial skills Executive functions
Vascular dementia	Many different syndromes. Mood and behavioural changes common Patchy rather than global deficits in cognition
Dementia with Lewy bodies	Fluctuating cognitive function eg excessive daytime drowsiness, staring into space for long periods, episodes of disorganized speech. Visual hallucinations Parkinsonian motor features (slow, rigid) Executive function impaired
Frontotemporal dementia	Progressive word finding difficulties. Dis-inhibition Personal neglect

Advanced, severe dementia, signs and symptoms

- forgets name of spouse,
- disorientated, needs all assistance,
- doubly incontinent,
- increase in psychotic features
- eventually loses all ability to talk, walk, feed, recognise anyone
  - Bedbound
  - Holding food in mouth / loss of swallow
  - Dysregulation of temperature control
  - Skin breakdown (pressure sores)
  - Weaker immune system and increased infections

‘ People living with dementia who are over 65 have on average four comorbidities’

Dying with Dementia

- Underlying illness / trajectory may dominate; prognostication driven by these
- Limited access to treatment options
- Capacity for decision making around place of care (DOLS)
- Memory of information given and/or insight into symptoms variable
- Pain / symptom assessment challenging
- Risk of delirium/agitation
- …….

Dying from Dementia

- Other co-morbidities static
- Progressive increase in frailty
- Continue at very low level of function over weeks to mths
- Carer burden high
- Uncertainty in prognostication
- Limited access to respite / CHC funding

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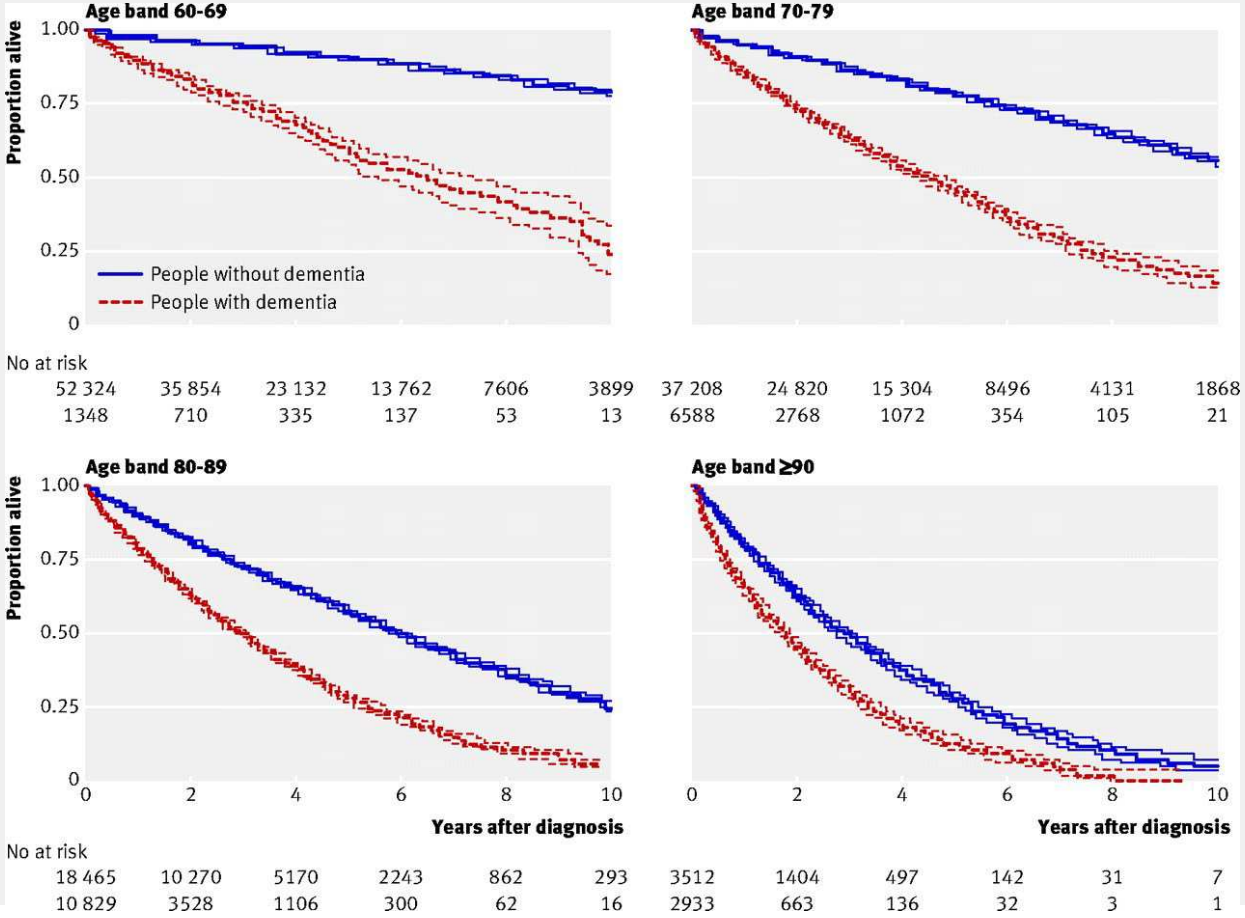
Survival of people with clinical diagnosis of dementia in primary care: cohort study

BMJ 2010; 341 doi: https://doi.org/10.1136/bmj.c3584 (Published 05 August 2010)



Age 60-69 yr

- Median 6.7 yrs

Age >90

- Median survival 1.9 yrs

What about the patient in front of me?

What factors might predict what's going to happen?

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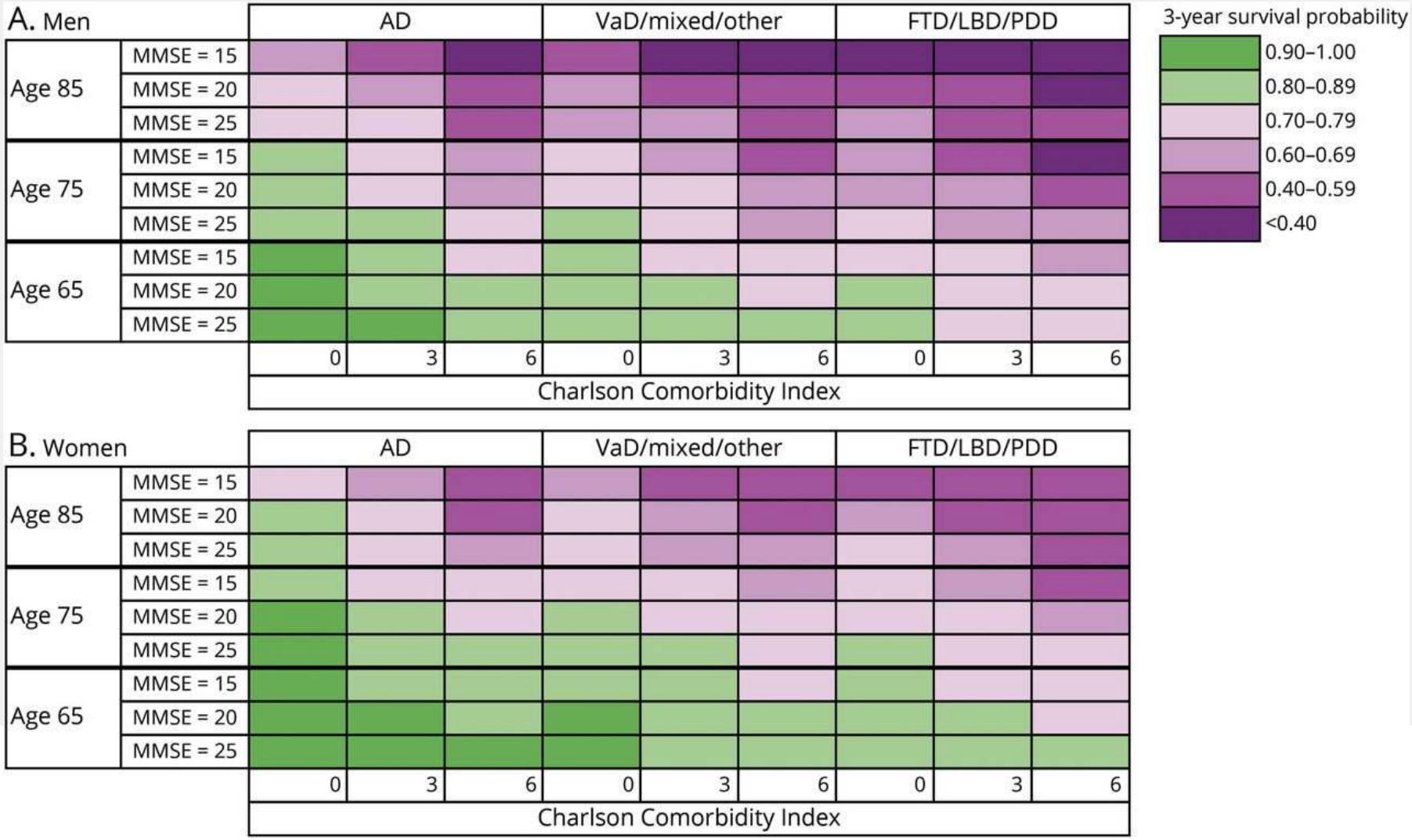
Survival time tool to guide care planning in people with dementia

Haaksma – Neurology 2020: 94 (5) e538-e548



THE CENTRE FOR AWARENESS & RESPONSE TO END OF LIFE

Prognostic Tools in Dementia

- The Advanced Dementia Prognostic Tool (ADEPT): A Risk Score to Estimate Survival in Nursing Home Residents with Advanced Dementia, Susan L. Mitchell. J Pain Symptom Manage. 2010 Nov; 40(5): 639–651.
- Prediction of 6-month survival of nursing home residents with advanced dementia using ADEPT vs hospice eligibility guidelines. Mitchell SL, JAMA. 2010 Nov 3;304(17):1929-35.
- Prognostic indicators of 6-month mortality in elderly people with advanced dementia: a systematic review. Brown MA, Palliat Med. 2013 May;27(5):389-400.
- A prediction model for one- and three-year mortality in dementia: results from a nationwide hospital-based cohort of 50,993 patients in the Netherlands. van de Vorst IE, Age Ageing. 2020 Apr 27;49(3):361-367.
- Association of Prognostic Estimates With Burdensome Interventions in Nursing Home Residents With Advanced Dementia. Loizeau AJ, JAMA Intern Med. 2018 Jul 1;178(7):922-929.

The Advanced Dementia Prognostic Tool (ADEPT)

Predicts survival based on 11 variables in

- demographics
- cognitive status
- functional status
- active diagnoses

A risk score greater than 16 (on a scale of 1 to 32) suggests a six-month probability of dying at greater than 50%.

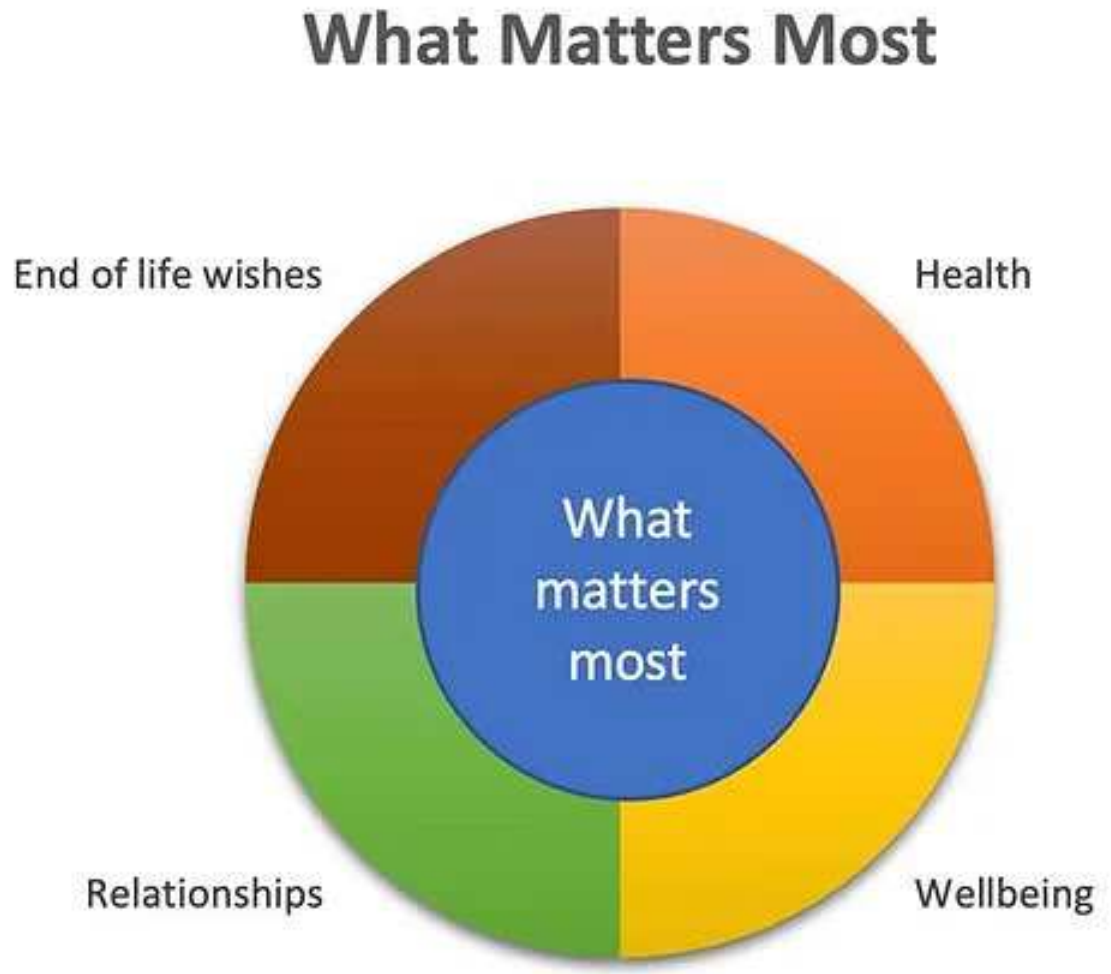
Daisy

- 85yr lady
- Referred by GP to St Christophers
  - ‘end-stage dementia; daughter main carer’
  - Alzheimers diagnosed 6 yrs ago
  - History anxiety and depression
  - CVA 4 yrs ago
  - COPD
- Bedbound (following CVA), had been in NH for >3yrs but now with daughter
- Mostly sleeping
- Dysphagia (fluid thickener)
- QDS Package of Care
- Daughter finding it hard to cope

What are the red flags? – What do we think prognosis might be?

What Matters Most?

- Making the most of life
- What matters most to me?
- What may matter to me when I am less well or dying?
- What makes me feel most at peace?
- What are my networks of support and how can they be supported so that we all remain resilient and well cared for?



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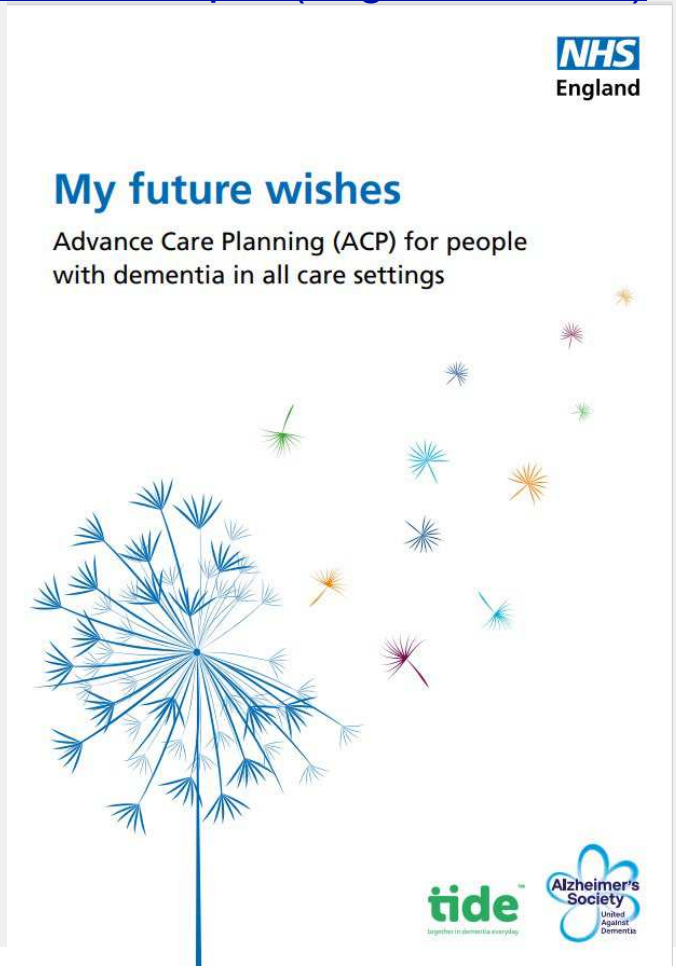
Advance Care Planning

ACP requires honesty @ prognosis

[my-future-wishes-advance-care-planning-for-people-with-dementia.pdf (england.nhs.uk)]

- ACP is not a ‘one-off’ plan-making session.
- It is an inclusive, personalised, proactive and transparent process focussed on what matters most to the person; so that they are involved in decisions about their health and wellbeing, and are more in control of living their life with their conditions.
- It is a multifaceted approach that includes the person diagnosed with dementia and those important to them.
- The more that everyone involved in the care of the person living with dementia takes opportunities to initiate ACP conversations, the more routine it becomes and the more reflective the ACP will be of the person’s priorities



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Advance Care Planning

ACP is fundamental for everyone living with dementia - It:

- provides the basis for delivering person-centred end of life care in line with the wishes and preferences of the individual;
- enables a record of the individual's wishes and preferences, which guides the person's care when they have lost mental capacity and provides crucial support for families and carers;
- offers ongoing vital opportunities to enhance the choice and control an individual has over their treatment and care needs / preferences throughout their care journey

ReSPECT

Recommended Summary Plan for Emergency Care and Treatment

New Urgent Care Plan for London

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Daisy

Altrashot, thickening powder
Inhaler – COPD
Cetirazine 10mg/10mLs
Lansoprazole melt
Clopidogrel 75mg
Risperidone 250mcg OD
Mirtazepine 30mg OD
Folic acid 5mg OD
Amlodipine 5mg

- LAS called – change in swallow, lethargic, coughing on fluids
- Family shocked at suggestion ‘might be reaching EOL’

…… so ACP/DNACPR not explored

- More sleepy, not taking anything orally
- GP has left liquid Ab

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Daisy

- Has the prognosis changed?
  - What factors help you decide where Daisy should be cared for ?

- Home or Hospice or Hospital?
- Impact on ….
  - Daisy
  - Family
  - Healthcare Professionals

Daisy

- Phase illness
  - dying low complexity
- ACP - DNACPR / UCP
  - best interest decision with family
- Feeding & Fluids
- Rationalised medications
- Referral to District Nursing Team
- Fast-track funding

Daisy

Over **weekend** Daughter calls in multiple times ….

- ‘more awake Saturday, swearing at family’
- ‘more sleepy Sunday, concerned Ab not working’

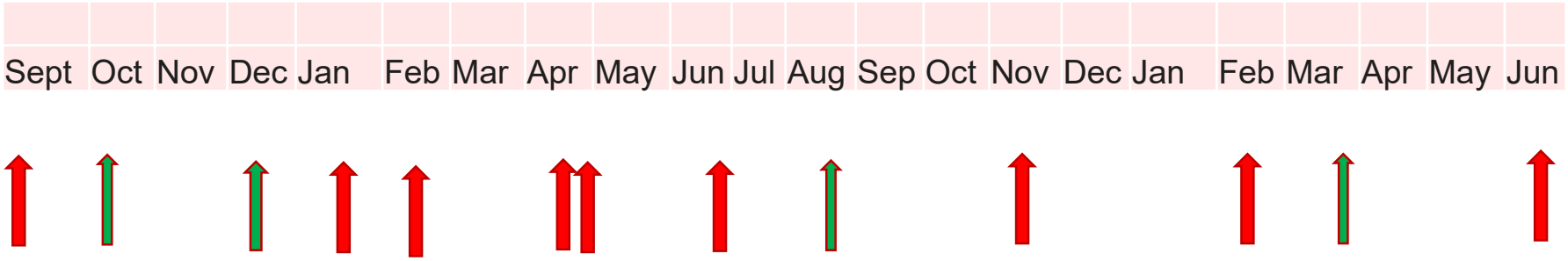
1 week – chest secretions (JIC meds put in place)

- sound asleep, no pain, no agitation, ‘sound asleep and snoring’

Day10 – managing soup

3 week – now chesty again ?aspiration

- 2/7 later SALT assessment (teaspoons only)
- HV – ongoing advice and support daughter
- 2/7 – LAS phone in (stat glycol given for secretions)
- Alternating good/bad days – at most spoonfuls of soup – intermittent antibiotics – risperidone restarted (crying/hallucinating ‘seeing ladies in the room’)



Over next 21 months …..

- Fluctuating levels of alertness
- Minimal oral intake
  - Haloperidol/risperidone/Ab
- Altered sleep wake
- Altered temperature regulation
- Infections

- Agitation / Biting / Hitting out
- Grinding teeth
- Carer distress – family conflict
- Funding for carers

Admissions to hospital …

- Suspected TIA
- Aspiration Pneumonia
- Infected toe
- ?? Seizure
- Covid

(Liaison with LAS; early discharge)

Good bits …..

- Christmas ‘beef hotpot and trifle’
- Brushing out/matted hair
- Nails done
- Devoted daughter caring for her and time with large family

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Daisy

- Holding uncertainty
- ‘attempted dying 5 or 6 times …’
- Strong lady
- Assessing agitation and/or distress at each timepoint
- Re-enforcing, reassuring, being present
- GUT feeling

- As a HCP – what felt most important?
- Being a ‘real person’ who was prepared to talk and explain **and to listen**
- Holding distress (for patient and family)
- Recognising and celebrating strengths
- Connecting in whatever way possible
- Walking alongside

At the end of life ….

Proactive Planning

- Capacity assessments (decision specific)
- Who are the key decision makers
  - LPA (Health, Finance)
  - UCP in place
- Just in case medications
  - Pain
  - Agitation
  - Secretions
  - +/- N&V
- Equipment

Holding Uncertainty

- ‘Sick enough to die’
- Parallel planning
- Moving away from sense of ‘getting it wrong’
- Anticipatory grief, ‘lives on hold’
- What matters most
  - Patient
  - Family

A couple of other stories ….

ES 92 Dementia NH Frailty Bartel 1 T2DM
ANP/GP conveyed to PRUH. Constipation/impacted – symptomatic, felt to be reversible. Multiple hospital admissions recent months. StC team contacted by CNS @ PRUH patient in ambulance. StC team contacted GP StC reviewed in NH with EOLC meds, symptom controlled. Family contacted. Patient RIP a week later
Dignity & Respect Desire for agency & self determination

- Think about the setting
  - Who/what might be needed to hold the risk
- Individual symptom vs bigger picture
  - Weighing up harms vs benefits
  - We ‘can’ but ‘should we’
- Incremental access to more information and holding across the wider health care system
- Involving those important to the person

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A couple of other stories ….

LD 89	
Vascular Dementia	ECH
Parkinsons Disease	
CFS 8	Bartel 6

Recent A&E attendance following fall

Discharged home following x-rays/CT.
Community MDM (community matron)

Urgent visit CNS for pain review following multiple calls. Clinical suspicion ? # humerus.

Multiple contact liason with Frailty Cons
Orthopaedic team - review of scans confirmed #.

High arm sling collected from PRUH & applied. Pain managed overnight pending IPU admission.
Later d/c NH (1 mth).

Comfort
Enhanced symptom management

- Think about the setting
- Challenges of symptom assessment
  - Pain / Function
- Prognostic impact of falls / fractures and the changing picture
- Place of Care
  - Experience in assessing symptoms
  - Parallel planning re outcomes

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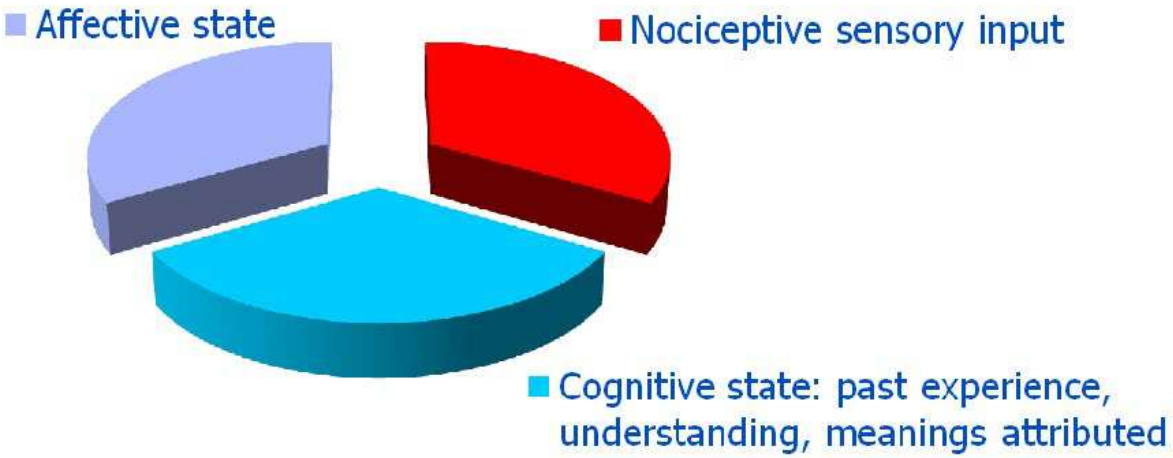
How common is pain in advanced dementia?

Estimates vary from 28-83%.

73.4% of 124 patients had pain at first visit.

23.1% of these were on analgesics

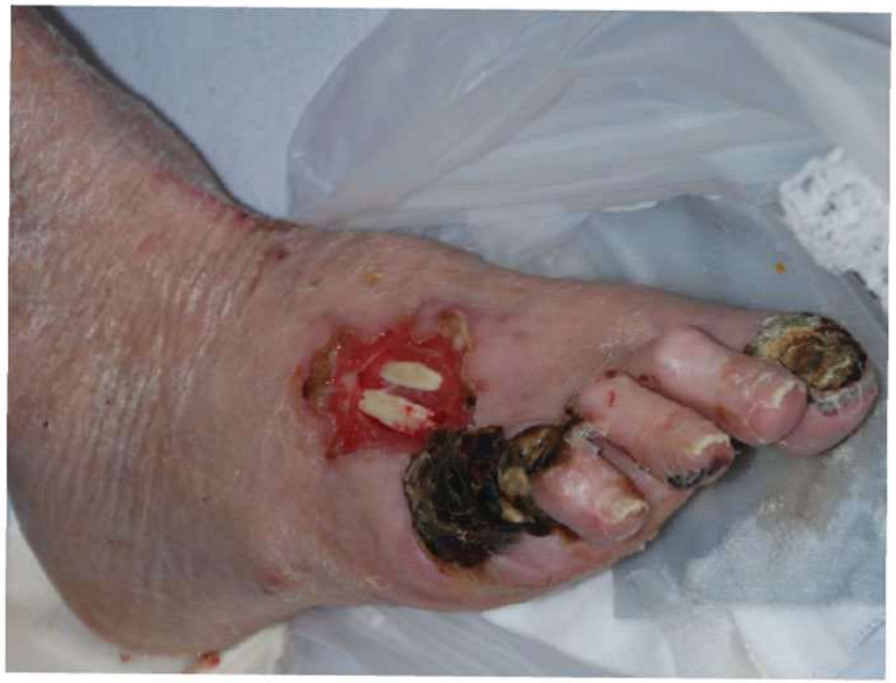
Components of the pain experience



Often undertreated – why?

Table 2 Types of pain in patients with incident dementia and matched controls

Type of pain	Dementia group (n = 1,848) (in %)	Control group (n = 7,385) (in %)	p-value
Back pain	51.7	53.2	0.23
Pain due to arthritis or osteoarthritis	41.2	41.8	0.64
Neuropathic pain	19.4	16.5	0.0037
Pain due to fractures	4.6	3.0	0.0006
Pain due to multimorbidity and care dependency	9.8	4.0	<0.0001
Pain, not elsewhere classified	9.0	6.0	<0.0001
Headache	6.3	5.0	0.0331
Cancer pain	5.0	5.9	0.14
Total (at least one pain type)	74.4	72.5	0.11

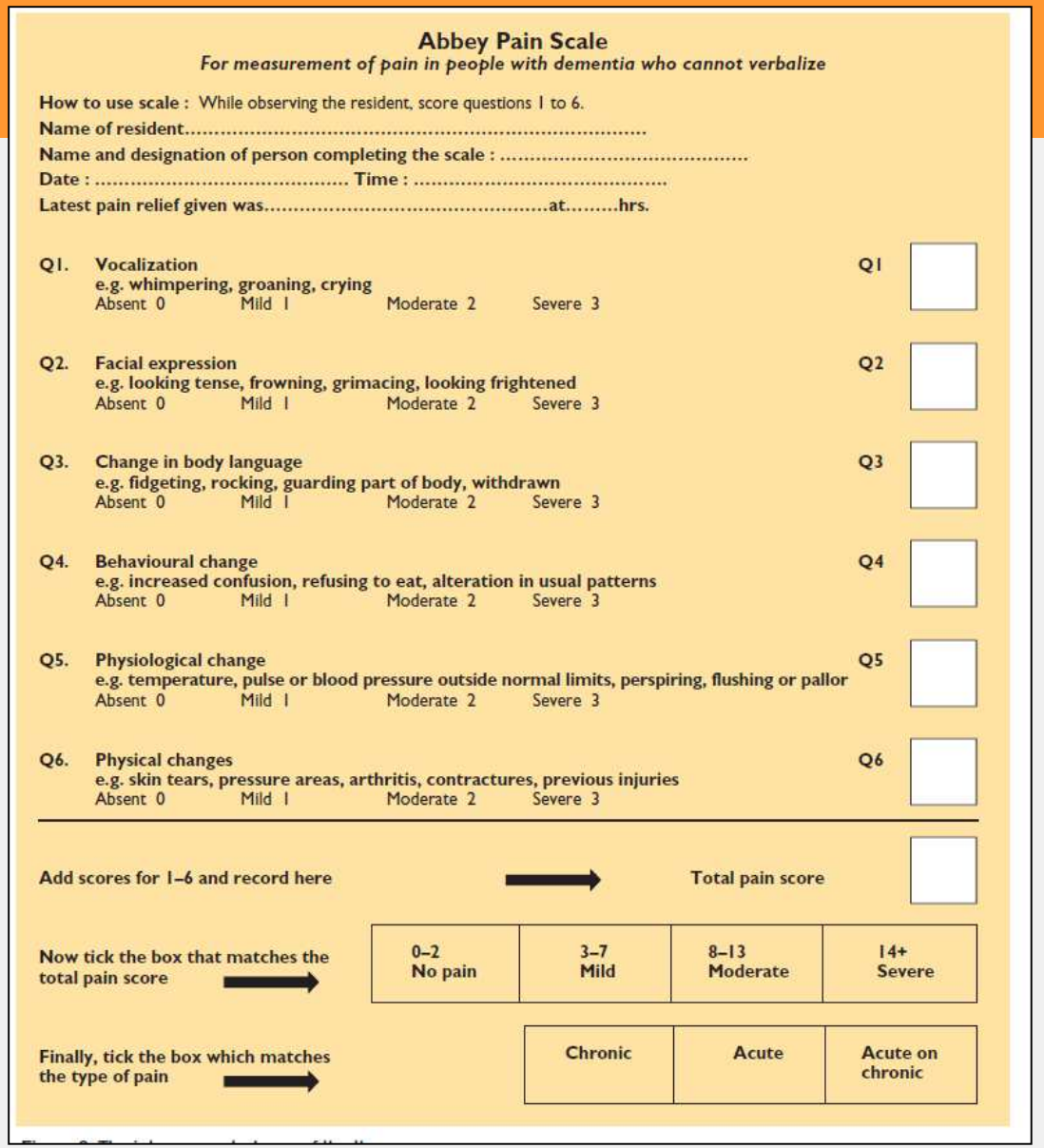


Hoffman *BMC Geriatrics* 2014

Pain Assessment

Pain Assessment

- Always use self report if possible
  - Is it sore? Does it hurt?
- Too many questions can cause distress.
  - Come back a few times if necessary.
- Talk with the carer or care worker who knows the person best.
- Assess pain on movement or during a procedure eg dressing change
- Pain will affect concentration and ability to complete tasks / focus



Abbey Pain Scale

For measurement of pain in people with dementia who cannot verbalize

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.	Vocalization e.g. whimpering, groaning, crying Absent 0 Mild 1 Moderate 2 Severe 3	Q1
Q2.	Facial expression e.g. looking tense, frowning, grimacing, looking frightened Absent 0 Mild 1 Moderate 2 Severe 3	Q2
Q3.	Change in body language e.g. fidgeting, rocking, guarding part of body, withdrawn Absent 0 Mild 1 Moderate 2 Severe 3	Q3
Q4.	Behavioural change e.g. increased confusion, refusing to eat, alteration in usual patterns Absent 0 Mild 1 Moderate 2 Severe 3	Q4
Q5.	Physiological change e.g. temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor Absent 0 Mild 1 Moderate 2 Severe 3	Q5
Q6.	Physical changes e.g. 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 No pain	3–7 Mild	8–13 Moderate	14+ Severe

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

Chronic	Acute	Acute on chronic

Age and Ageing 2020; **50:** 465–471 doi: 10.1093/ageing/afaa159 Published electronically 30 Sept 2020

RESEARCH PAPER

Deprescribing in older people approaching end-of-life: development and validation of STOPPFrail version 2

Who is it for?

Denis Curtin[1,2], Paul Gallagher[1,2],Denis O'Mahony[1,2]

- older people with limited life expectancy
- goal of care is to optimise quality of life and minimise the risk of drug-related morbidity.
- discuss and agree with patient and/or family.

1. Dependant all ADLs **and/or** severe chronic disease **and/or** terminal illness
2. Severe irreversible frailty
3. Surprise question

General

• Any drug that the patient persistently fails to take or tolerate despite adequate education and consideration of all appropriate formulations

• Any drug without a clear clinical indication

• Any drug for symptoms which have now resolved (e.g. pain, nausea, vertigo, pruritus)

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delirium is an acute onset syndrome with disturbance in attention, awareness and cognition

Hyperactive delirium

Hypoactive delirium

Patient living with dementia who develops delirium

- How did you know it was delirium?
- Who was distressed? (scale 0-10)
- What was the first thing you did?
- What was ONE thing that helped the most?

How do I know if it is delirium vs terminal agitation?

Delirium - common causes – what might be reversible?

Drugs

benzodiazepines (OR 3.0, 1.3–6.8)
opioids (OR 2.5, 95% CI 1.2–5.2)
ca channel blockers (OR 2.4, 1.0–5.8)
antihistamines (OR 1.8, 0.7–4.5).

- Long > short acting
- Dose dependant

Anticholinergic burden

- polypharmacy - cumulative
- older adults particularly susceptible to SE
- associated with
  - impaired cognitive and physical function,
  - increased risk of falls
  - vascular events
  - Hospitalisation

Antidepressants Amitriptyline
Antihistamines Cyclizine
Anti-parkinsonian drugs Amantadine
Antipsychotics Olanzapine, levomepromazine
Urinary symptoms Oxybutynin, Tolterodine

Anticholinergic burden: considerations for older adults. Geriatric Therapeutics Review. Lisa O'Donnell https://doi.org/10.1002/jppr.1303

An approach to drug induced delirium in the elderly. K Alagiakrishnan. Postgrad Med J 2004;80:388–393. doi: 10.1136/pgmj.2003.017236
Which medications to avoid in people at risk of delirium: a systematic review. Andrew Clegg, John B. Young. Age and Ageing, 2011;40(1):23–29

St Christopher's Dementia Strategy

Key outputs and outcomes to be achieved

We want **people with dementia** to receive good end of life care and to die where they feel most comfortable, familiar and supported.

- We recognise that this will require a responsive, coordinated service to ensure right care at the right time in the right place
- The physical environment is important to maintain an experience of independence and confidence

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St Christopher's Dementia Strategy

Key outputs and outcomes to be achieved

We want **families and carers** to feel confident, competent and supported to provide care as they wish for the person they love. We want them to understand that we will work alongside them, negotiate and share emerging risks and think creatively about how best to enable the dying person to enjoy good quality of life

St Christopher's Dementia Strategy

Key outputs and outcomes to be achieved

- We want **staff and volunteers** to be skilled and feel confident in caring for people living with dementia as they approach the end of their life and to hold the risk of decision making for those who are unable or not confident to do this. We want others working as part of health and social care to have the same experience.
  - *education, training, coaching and opportunities for reflective thinking to enable us to grow in understanding regarding the complexities of EOLC for people with dementia*

St Christopher's Dementia Strategy

Key outputs and outcomes to be achieved

- We want **partners (individuals and organisations)** to experience us as collaborative and open to learning. We want to create strong links with other agencies to establish integrated cross-boundary working, and share our expertise and insights across the local health and social care systems

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Take home tips

Prognostication is difficult

- Individual patient trajectory over time
- Changing symptom burden

Consider Delirium

- Prevention is best – proactively screen (PINCH ME)

Prioritise Place of Care

- Where possible support to patient and carer in own environment
- Being with/alongside is key
- Work in the wider multi-professional team alongside patients support network

Upstream interventions/conversations are important

- we need ongoing work to consider right point at which to engage specialist services
- Likely flexible ‘dip in and out’ model

Remember the person at the centre

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C A R E

THE CENTRE FOR AWARENESS & RESPONSE TO END OF LIFE

One thing you will take away that was new / surprised you?

One thing you will go away and read more about?

Additional Resources

Dementia: assessment, management and support for people living with dementia and their carers NICE guideline Published: 20 June 2018 nice.org.uk/guidance/ng97

Palliative Care Guidelines in Dementia 2nd Edition (NW Coast Strategic Clin Networks Mar 2018)

- **Involving people living with dementia in decisions about their care**
- **Diagnosis**
- **Care coordination**
- **Interventions to promote cognition, independence and wellbeing**
- **Pharmacological interventions for dementia**
- **Medicines that may cause cognitive impairment**
- **Managing non-cognitive symptoms**
- **Assessing and managing other long-term conditions in people living with dementia**
- **Risks during hospital admission**
- **Palliative care / Advance care planning**
- **Supporting carers**
- **Moving to different care settings**
- **Staff training and education**

- Descriptions of the Dementia Syndromes
- **Assessment in Dementia and End of Life**
- Communication
- Therapeutic Interventions in Dementia
- **General Considerations for Medicines Management in People with Dementia**
- Living with Dementia: A guide to the Care Act 2014 and the Impact on Local Authority Provision, Continuing Health Care and Finances
- Spirituality and People with Advanced Dementia
- The Mental Capacity Act 2005
- Advance Care Planning
- **Clinically Assisted Nutrition and Hydration in People with Dementia**
- **Treating Infection in End Stage Dementia**
- **Identifying Dying in Advanced Dementia**
- **Rationalisation of Medication in Advanced Dementia**
- **Caring for a person with dementia in the final days of life**
- Bereavement
- Carers' Health and Wellbeing

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Additional Resources

- The conversation project (The Institute for Healthcare Improvement)
- Respect (Recommended Summary Plan for Emergency Care and Treatment)
- Starting the Conversation (Compassion in Dying)
- Difficult Conversations (Dying Matters)
- Time to talk (Dying Matters)
- The Dementia adventure Podcasts
- Difficult Conversations for Dementia (NCPC)
- Harrison Dening K, Sampson EL, De Vries K. Advance care planning in dementia: recommendations for healthcare professionals. Palliat Care. 2019 Feb 27;12:1178224219826579.
- Scenario: Management of end-stage dementia | Management | Dementia | CKS | NICE
- Common core principles for supporting people with dementia - GOV.UK (www.gov.uk)

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