End of Life and dementia

Paul Cadger – Dementia Education Lead

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Objectives

- Understand dementia is a palliative illness
- Recognising end of life in dementia
- Challenges for dementia and end of life
- Supporting loved ones and carers
- Supporting someone with dementia with recent and historic bereavement

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Quick statistics end of life and dementia

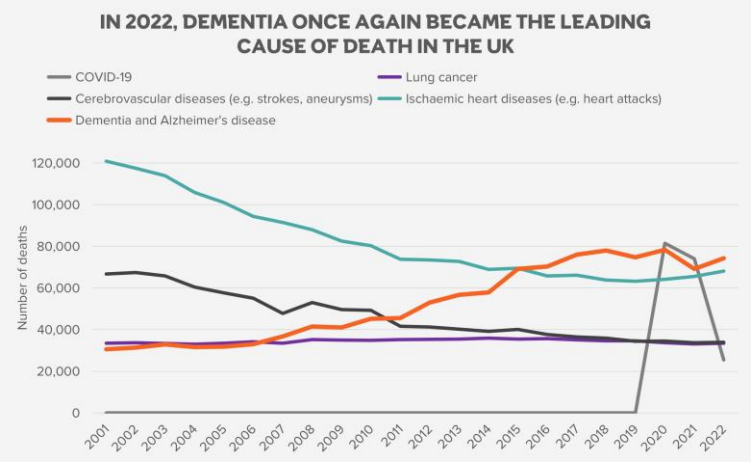
Dementia is leading cause of death in UK (11.3%)

Of top 10 causes of death only one without a cure

Nearly 2x the number of women died of dementia than men in '22 (42,000 / 24,000)

Since 2011 dementia leading cause of death for women, for men it remains heart disease

Cornwall lowest in England at recognising people living with dementia at EoL 6.3% (327/6229) England 19.5% of people diagnosed



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Why is dementia palliative and a cause of death?

What is the difference between palliative and end of life care?

All forms of dementia are progressive disease of the brain

An indirect link between dementia and actual cause of death

Aspirational pneumonia 30% of dementia related deaths
Malnutrition and dehydration
Recurrent infections
Falls

Cause of death subarachnoid haemorrhage ➔ Why

Fall ➔ Why

Reduced reflexes, malnutrition, dehydration, weak immune system, recurrent infections, deconditioned, delirium, etc.… ➔ Why

Dementia

When would the "dying/terminal phase" commence?

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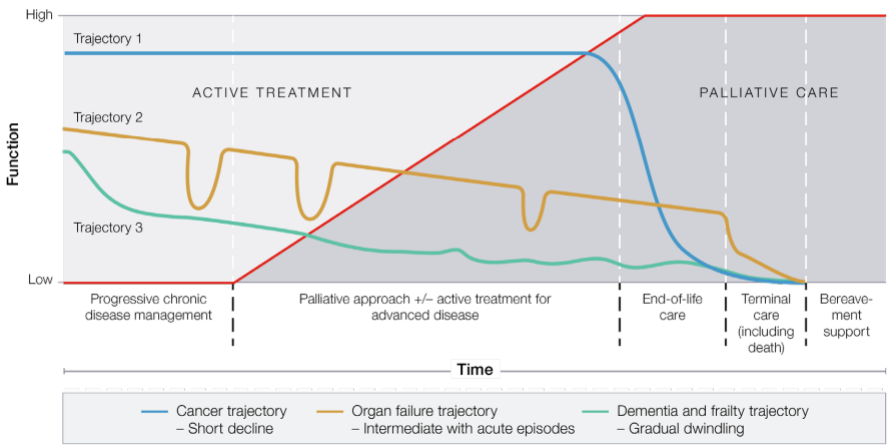
Recognising end of life in dementia?

Figure 1. Typical illness trajectories and palliative care phases towards the end of life



The Royal Australian College of General Practitioners, 2022

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Recognising end of life in dementia?

Supportive and Palliative Care Indicators Tool (SPICT-4ALL™) 2025

Does this person have signs of poor health or health problems that are getting worse?

- Urgent or emergency hospital admission(s) or visits to hospital.
- Less able to manage usual activities; not as well as they used to be. (The person often stays in bed or in a chair for more than half the day).
- Needs more help and care from others due to increasing physical and/ or mental health problems. The person's carer needs more help and support.
- Has clearly lost weight over the last few months; or stays too thin.
- Has troublesome symptoms most of the time despite good treatment of their health problems.
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Does this person have any of these health problems?

Cancer

Less able to manage usual activities; health is getting poorer.

Not well enough for cancer treatment or treatment is to help with symptoms.

Dementia or frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Has poor control of bladder and bowels.

Not able to communicate by speaking; not responding much to other people.

Frequent falls; fractured hip.

Frequent infections; pneumonia.

Heart or circulation problems

Heart failure or heart blood vessel disease. Short of breath when resting, moving or walking a few steps.

Very poor circulation in the legs; surgery is not possible.

Lung problems

More unwell with long term lung problems. Short of breath when resting, moving or walking a few steps even when the chest is at its best.

Needs to use oxygen for most of the day and night.

Has needed treatment with a breathing machine in hospital.

Other conditions

People who are less well with other life shortening physical or mental illnesses

Kidney problems

Kidneys are not working well; general health is getting poorer.

Stopping kidney dialysis or choosing supportive care instead of starting dialysis.

Liver problems

Worsening liver problems in the past year with complications like:

- fluid building up in the belly
- being confused at times
- kidneys not working well
- infections
- bleeding from the gullet

A liver transplant is not possible.

Please register on the SPICT website (www.spict.org.uk) for information and updates

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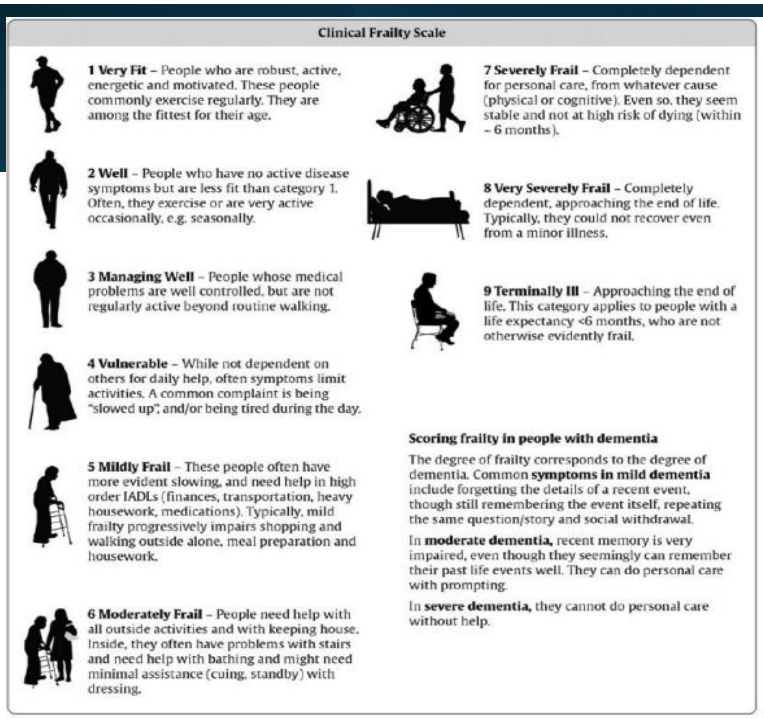
Recognising end of life in dementia?

Clinical Frailty Scale, 2012



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.

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The surprise question?

Would you be surprised if this person died within the next year?

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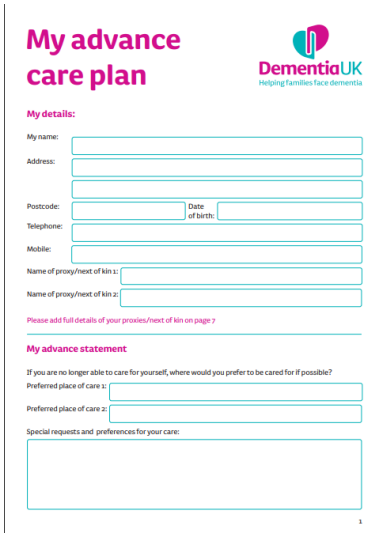
Challenges for dementia and end of life – planning ahead / capacity

Person may undergo multiple losses; personhood, personality, autonomy, mental capacity

Advance Care Planning includes LPoA, Advance decisions to refuse treatment & TEP

- http://doclibrary-rcht-intranet.cornwall.nhs.uk/DocumentsLibrary/RoyalCornwallHospitalsTrust/Forms/FormsToPrint/Accessible/Specialty/PalliativeAndEndOfLifeCare/CHA4308MyAdvanceCarePlan.pdf
- https://www.dementiauk.org/wp-content/uploads/dementia-uk-template-advanced-care-plan.pdf



My advance care plan

DementiaUK
Helping families face dementia

My details:

My name:
Address:
Postcode:
Date of birth:
Telephone:
Mobile:
Name of proxy/next of kin 1:
Name of proxy/next of kin 2:

Please add full details of your proxies/next of kin on page 7

My advance statement

If you are no longer able to care for yourself, where would you prefer to be cared for if possible?

Preferred place of care 1:
Preferred place of care 2:
Special requests and preferences for your care:

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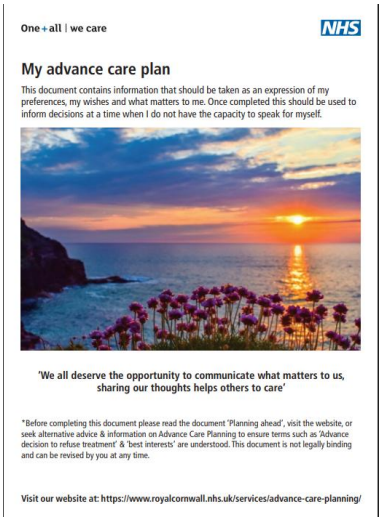

One + all | we care

NHS

My advance care plan

This document contains information that should be taken as an expression of my preferences, my wishes and what matters to me. Once completed this should be used to inform decisions at a time when I do not have the capacity to speak for myself.

'We all deserve the opportunity to communicate what matters to us, sharing our thoughts helps others to care'

*Before completing this document please read the document 'Planning ahead', visit the website, or seek alternative advice & information on Advance Care Planning to ensure terms such as 'Advance decision to refuse treatment' & 'best interests' are understood. This document is not legally binding and can be revised by you at any time.

Visit our website at: https://www.royalcornwall.nhs.uk/services/advance-care-planning/

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Challenges for dementia and end of life – planning ahead / capacity – Benefits of ACP

Benefits of Advance Care Planning for People with Dementia

1.Preserves Autonomy

Ensures the person's values and preferences guide future care, even if they can't express them later.

2.Reduces Family Stress

Loved ones won't have to guess or make difficult decisions in a crisis.

3.Improves Quality of Care

Aligns medical interventions with the person's goals and comfort.

4.Promotes Dignity

Respects the individual's wishes about life-sustaining treatments, living arrangements, and end-of-life care.

5.Encourages Open Communication

Strengthens trust and understanding between the person, their family, and healthcare providers.

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Challenges for dementia and end of life – planning ahead / capacity – How to approach

Ways to Discuss ACP with Someone Living with Dementia

1. Choose the Right Time and Setting (quiet, familiar, fatigue)

2. Use Simple, Reassuring Language

"Let's talk about what matters most to you as we plan for the future."

3. Break It Into Small Conversations

Start with values: "What makes a good day for you?"

Then move to preferences: "If you were very sick, what would you want us to know?"

4. Involve Trusted People

Include family members or friends the person trusts.

5. Use Visual Aids or Written Prompts

Tools like "My Wishes" or "Five Wishes" documents can help guide the conversation.

6. Revisit the Conversation Over Time

Dementia is progressive, so revisit and update the plan as needed.

WHAT MATTERS TO ME 4K_click CC for subtitles on Vimeo

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Challenges for dementia and end of life – Early identification = better management

Anticipatory medications – prescribed at end of life (just in case scenario)

Pain
Anxiety
Delirium / agitation
Nausea and vomiting
Breathlessness
Secretion
Seizures
Haemorrhage

Co-morbidities rather than dementia

To ensure comfort and wellbeing are maximised

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Challenges for dementia and end of life – Interventions

Education of family and carers

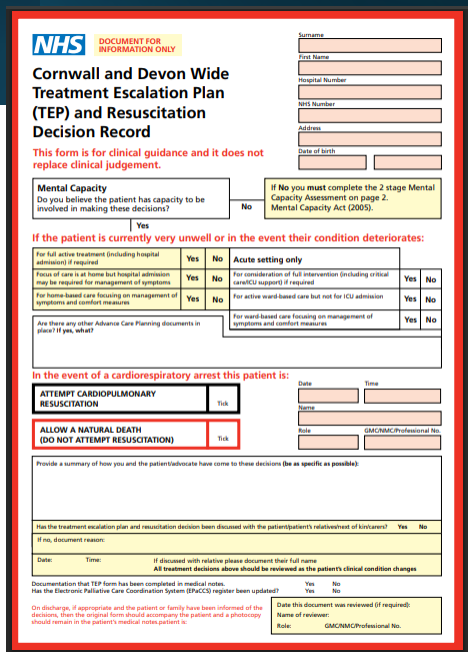
TEP form (accessible and reviewed regularly)

When to stop antibiotics, blood tests, intravenous meds

When to stop recording vital signs (sleep-wake cycle)

Preferred place of death, transport if in hospital

Eating, drinking and swallowing



NHS DOCUMENT FOR INFORMATION ONLY

Cornwall and Devon Wide Treatment Escalation Plan (TEP) and Resuscitation Decision Record

This form is for clinical guidance and it does not replace clinical judgement.

Surname
First Name
Hospital Number
NHS Number
Address
Date of birth

Mental Capacity
Do you believe the patient has capacity to be involved in making these decisions?
Yes / No

If No you must complete the 2 stage Mental Capacity Assessment on page 2. Mental Capacity Act (2005).

If the patient is currently very unwell or in the event their condition deteriorates:

For full active treatment (including hospital admission) if required	Yes	No	Acute setting only		
Focus of care is at home but hospital admission may be required for management of symptoms	Yes	No	For consideration of full intervention (including critical care/ICU support) if required	Yes	No
For home-based care focusing on management of symptoms and comfort measures	Yes	No	For active ward-based care but not for ICU admission	Yes	No
			For ward-based care focusing on management of symptoms and comfort measures	Yes	No

Are there any other Advance Care Planning documents in place? If yes, what?

In the event of a cardiorespiratory arrest this patient is:

ATTEMPT CARDIOPULMONARY RESUSCITATION	Tick
ALLOW A NATURAL DEATH (DO NOT ATTEMPT RESUSCITATION)	Tick

Date / Time
Name
Role / GMC/NMC/Professional No.

Provide a summary of how you and the patient/advocate have come to these decisions (be as specific as possible):

Has the treatment escalation plan and resuscitation decision been discussed with the patient/patient's relatives/next of kin/carers? Yes / No

If no, document reason:

Date: Time: If discussed with relative please document their full name
All treatment decisions above should be reviewed as the patient's clinical condition changes

Documentation that TEP form has been completed in medical notes. Yes / No
Has the Electronic Palliative Care Coordination System (EPaCCS) register been updated? Yes / No

On discharge, if appropriate and the patient or family have been informed of the decisions, then the original form should accompany the patient and a photocopy should remain in the patient's medical notes.patient is:

Date this document was reviewed (if required):
Name of reviewer:
Role: GMC/NMC/Professional No.

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Challenges for dementia and end of life – pain

Barriers to managing pain well

- Unable to communicate feelings
- Can't remember what pain is
- Unable to identify where pain is located
- Error in thinking behaviours indicating pain are "symptoms of the person's dementia

#NOF receive 1/3 analgesia

RCHT NAD 2020 – non-verbal patient still asked to score pain 0-10

Pain assessment tools

RCHT – PAINAD (PAIN in Advanced Dementia)

CFT – Abbey pain scale

Pain Assessment in Impaired Cognition Scale (PAIC)

Checklist of Nonverbal Pain Indicators (CNPI)

Assess pre/post

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Challenges for dementia and end of life – Connection

Senses - Namaste care

↳ touch, taste, smell, sight

Reminiscing

Music



May not know your name, but will know you are a person helping to make them feel safe and loved”

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Challenges for dementia and end of life – delirium vs terminal restlessness

Terminal restlessness is a form of delirium. However, not reversible as associated with dying itself (last few days/hours).

Investigate any underlying cause (PINCHME) more proactive with sedative and antipsychotics than delirium – **still evaluate treatment plan**.

Supportive care for family, understand medication to reduce distress not hasten death



Describe
87 ♂vasc dementia, stopped eating 1 week ago, past 24hrs fidgeting, shouting for help, scared
Investigate
PINCHME, this is me

Create
Adapt environment – namaste
Support Family
Delirium care plan

Evaluate 1
No resolution add medication to reduce distress (low and slow)
Evaluate 2
Titrate – breathing slows, agitation reduces, no longer shouting or scared

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Supporting loved ones and carers

- Individualised care – **what matters to the person dying**
- Involve those closest to the person
- Optimise symptom management
- Mouthcare
- Comfort feeding
- Support identifying funeral arrangements if not pre-arranged
- Explain what to expect when their loved one reaches the end of life – prepare them
- Identify cultural, spiritual and religious needs
- Bereavement Support with Cornwall Hospice Care
- Be able to support family and friends in celebrating the life of the person who has died

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Supporting a person living with dementia through grief

Long ago grief

"Where is my mum??"

Recent grief

"I want to see my husband?"

Whole- truth telling	Looking for alternative meaning	Distracting	Going along with	Lying

Consistency

Validation principle

Distraction

Entitled to grieve

Timeliness

Therapeutic lie

https://www.mentalhealth.org.uk/sites/default/files/2022-09/MHF-dementia-truth-inquiry-report.pdf

What is Truth?

An Inquiry about Truth and Lying in Dementia Care

Mental Health Foundation

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References

Alzheimer's research UK (2025) Deaths due to dementia available at https://dementiastatistics.org/about-dementia/deaths/ Accessed on 17/04/2025
Dementia UK (2025) My advance care plan available at https://www.dementiauk.org/wp-content/uploads/dementia-uk-template-advanced-care-plan.pdf accessed on 29/05/2025
Mental Health Foundation (2016) What is truth? An inquiry about truth and lying in dementia care. Available at https://www.mentalhealth.org.uk/sites/default/files/2022-09/MHF-dementia-truth-inquiry-report.pdf accessed on 29/05/2025
Moorhouse P, Rockwood K. Frailty and its quantitative clinical evaluation R Coll Physicians Edinb. 2012;42:333-340. Available at https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2022/02/rockwood-frailty-scale_.pdf Accessed on 17/04/2025
Royal Cornwall Hospitals NHS Trust (2023) My advance care plan available at http://doclibrary-rcht-intranet.cornwall.nhs.uk/DocumentsLibrary/RoyalCornwallHospitalsTrust/Forms/FormsToPrint/Accessible/Specialty/PalliativeAndEndOfLifeCare/CHA4308MyAdvanceCarePlan.pdf access on 29/05/2025
The University of Edinburgh (2025) Supportive and Palliative Care Indicators Tool SPICT4ALL 2025 available at https://www.spict.org.uk/spict-4all/ accessed on 17/04/2025
The Royal Australian College of General Practitioners. RACGP aged care clinical guide (Silver Book). 5th edition. East Melbourne, Vic: RACGP, 2019, 2020. Available at https://www.racgp.org.au/getattachment/55aea74c-fbe9-4d01-8cbc-425948225cb8/Palliative-care.aspx Accessed on 17/04/2025

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Local policies and guidance

Healthwatch Cornwall Hear our Voice Report March 2023

Cornwall and Isles of Scilly Dementia Strategy 2023-28

Devon Dementia Strategy 2026-29

Aim by January 2027;
Have a CIoS systemwide dementia policy which will set our standards of care and expectations

Have a Dementia Pathway – a go to guide for public and clinicians

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