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Registered Charity Number 1039404

Advance Care Planning: Improving End of Life care for people living with dementia

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Objectives:

- What are Advance Care Plans (ACP)?
- Why we need ACP?
- What ACP covers?
- Introducing ACPs
- Implementing ACPs
- Assessment tools

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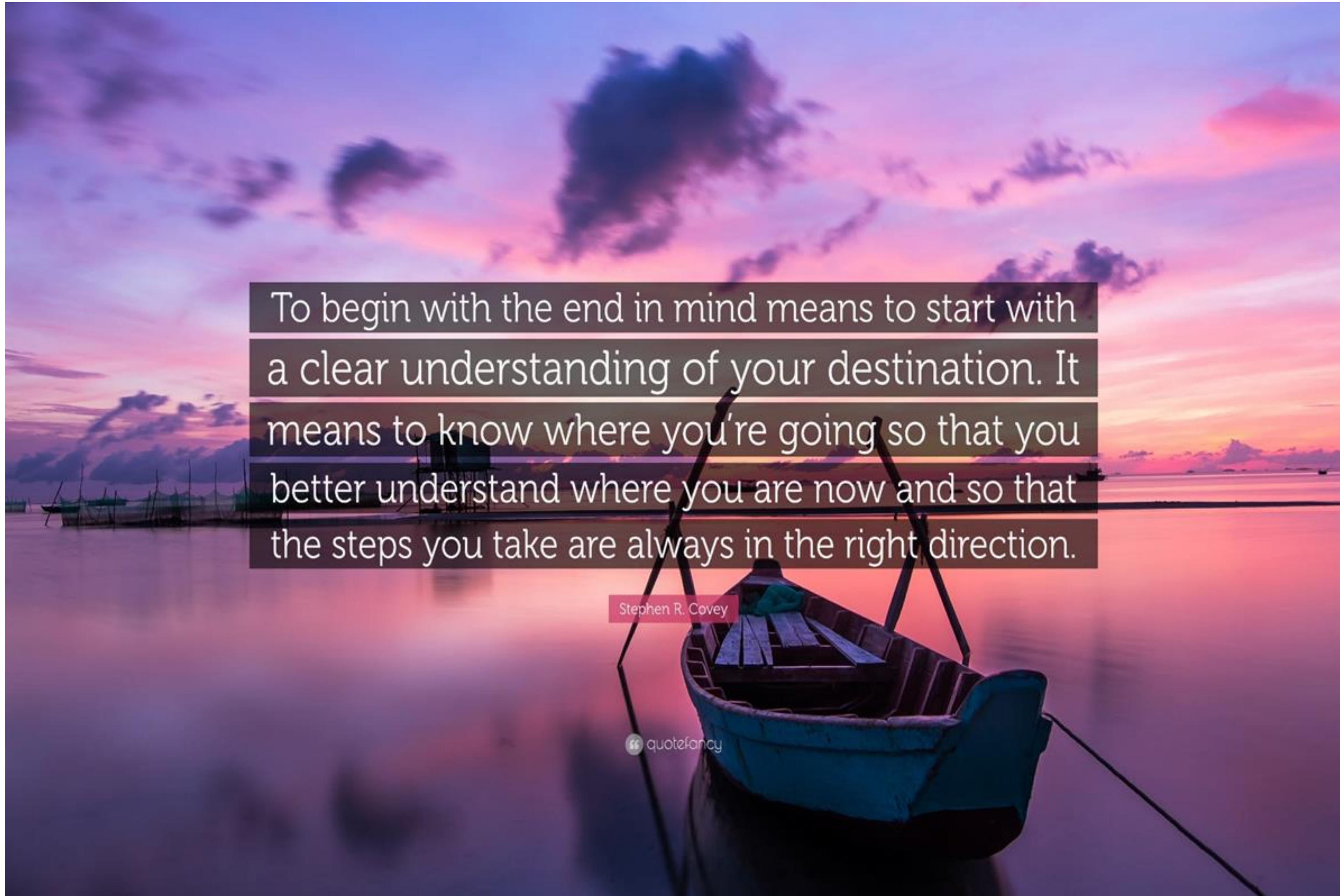

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What are Advance Care Plans (ACPs)?

An Advance Care Plan (ACP) or advance statement is a written statement that sets out your wishes, beliefs, values and preferences about your future care.

It provides a guide to help healthcare professionals and anyone else who might have to make decisions about your care if you become too unwell, to make decisions or to communicate them.

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Why we need ACPs?

Crisis

- Hospital
- Longer stays
- Poorer outcomes

Carers

- Anxiety
- Stress
- Complicated grief

We only have ONE chance to get it right

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Why we need ACPs?

person
individualised
satisfaction
sharing knowledge
sense of control
quality of life
preferences
communications
dignity
anxiety
autonomy

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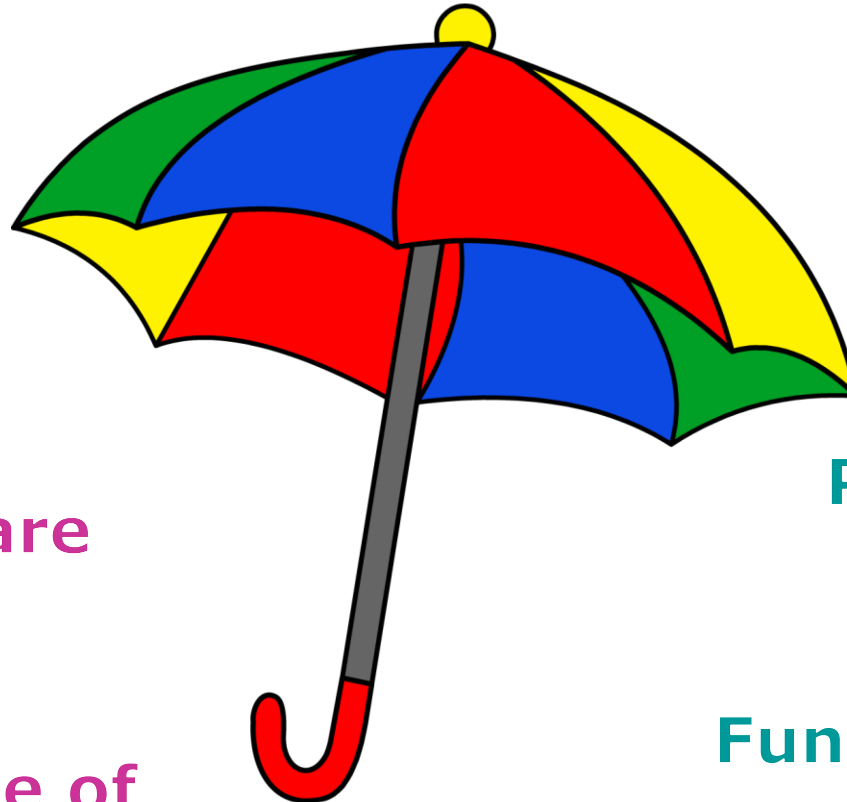
What an ACP covers?

Advanced directive

DNACPR

This Is Me

RESPECT



Priorities of Care

POA / LPOA

Funeral wishes

Preferred place of care / death

Who should talk about ACPs?

Everyone!

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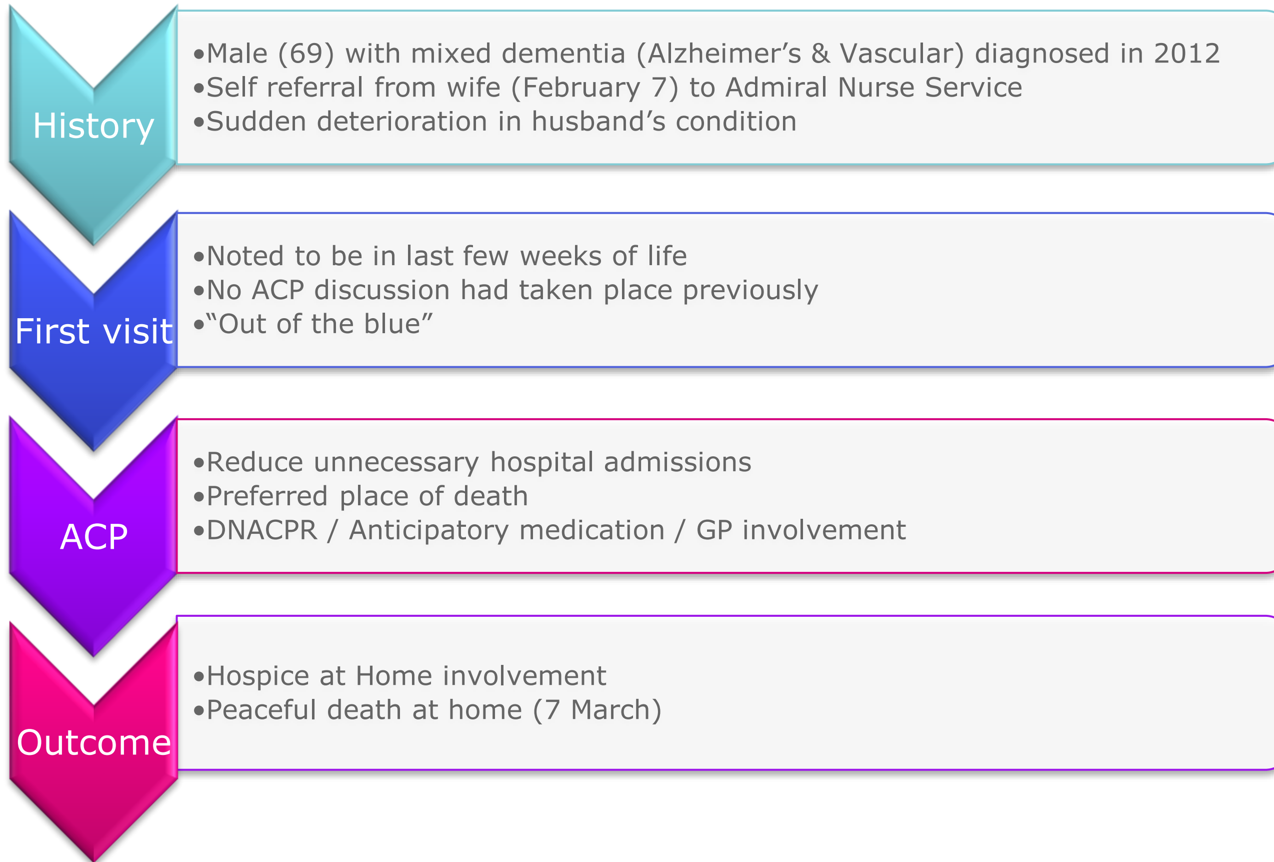
Case Study 1



How to introduce it ? (1)

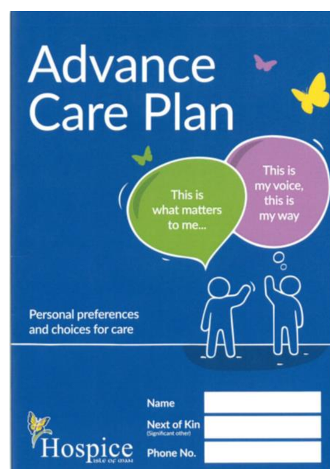
Carer training "Your Time, Your Place"

- Go wish cards
- https://codaalliance.org/go-wish-game/

- FINK cards
- https://finkcards.com/products/advance-care-planning
- FINK video

- Future Wellbeing Toolkit
- Future Well Being Toolkit

- Hospice Advance Care Plan



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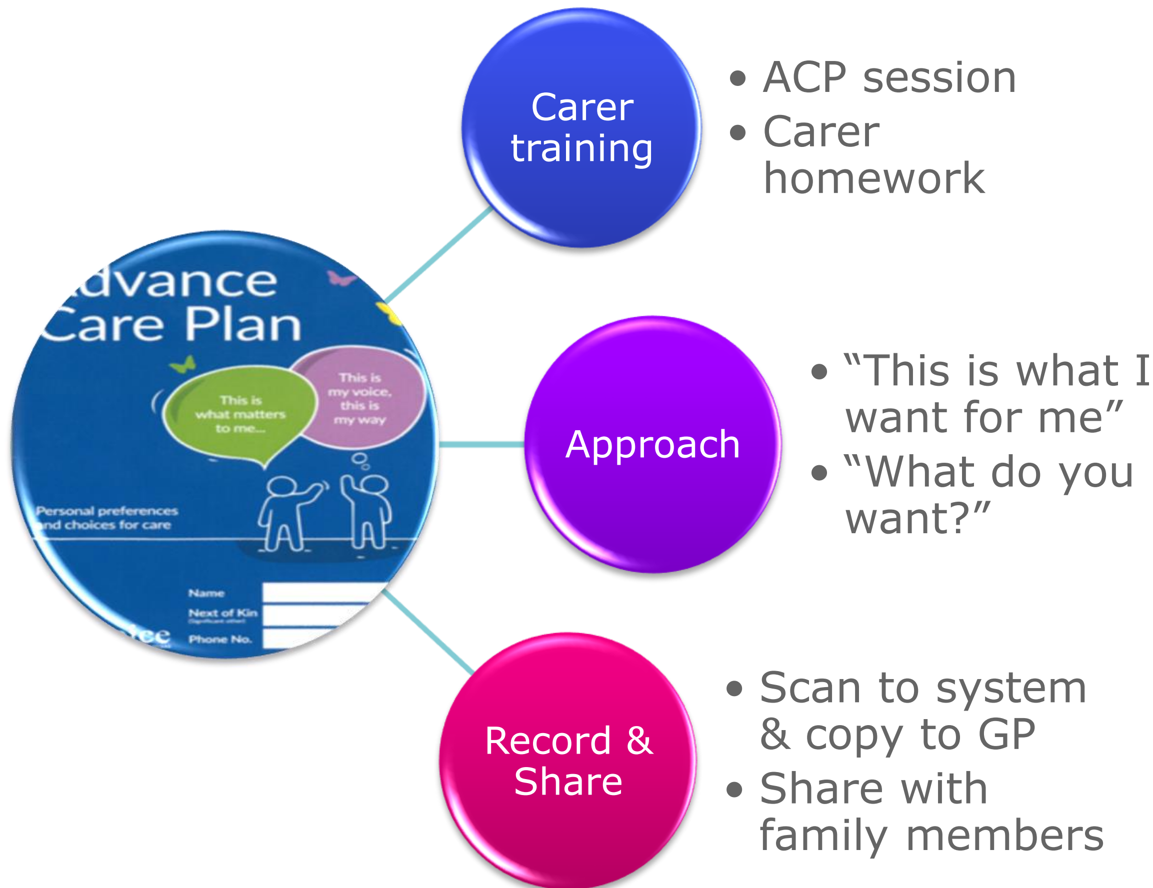
Case study 2



"Hard to have the conversation but I'm glad I did. It's done now"

How to introduce it? (2)
One to one support – case study 3

A.N. Other Health Professional

- ACP discussed
- Agreed for husband to die at home
- No real explanation of 'dying at home'
- Recorded on system and GP aware

Admiral Nurse

- Referred by other health professional to ANS
- Reviewed ACP
- Therapeutic, triadic relationship
- Open and honest conversation
- ACP changed
- Peaceful death for husband
- Piece of mind for wife

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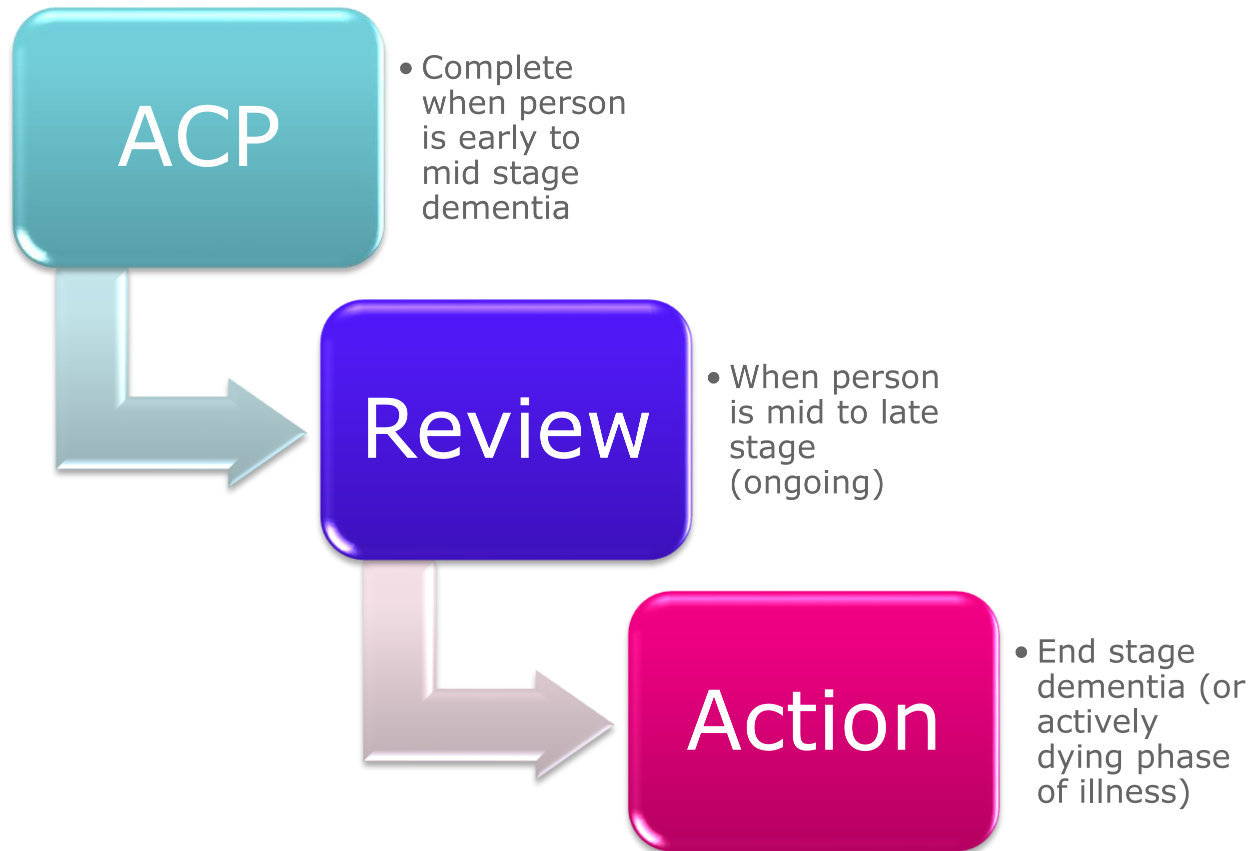
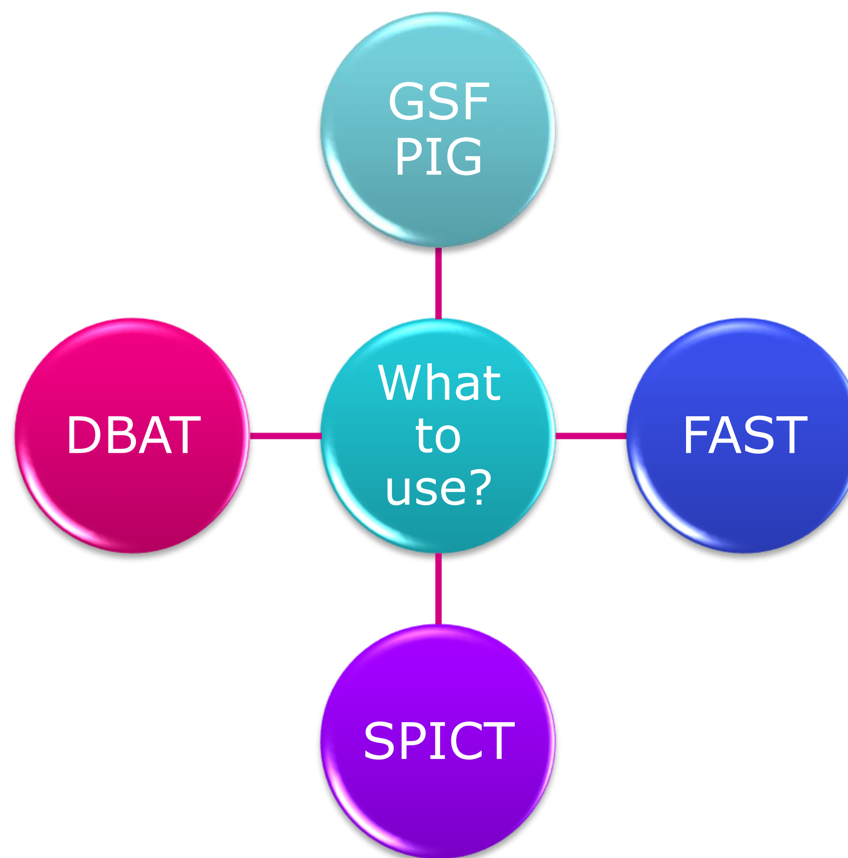
How do we know when to implement ACPs?



Assessment Tools



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Comparison of assessment tools

Functionality	Physical Symptoms	Behavioural Symptoms	Cognition Symptoms	Reduced Mobility / Falls Risk	Urine Incontinence	Faecal incontinence	Reduced oral intake / Weight loss	Reduction in speech / words	Pressure Sores	Loss of smile / facial effect
FAST				FAST 7C	FAST 6D	FAST 6D		FAST 7A; 7B		FAST
GSF PIG	GSF PIG			GSF PIG LATE STAGE	GSF PIG LATE STAGE	GSF PIG LATE STAGE	GSF PIG LATE STAGE	GSF PIG LATE STAGE	GSF PIG LATE STAGE	
SPICT	SPICT			SPICT	SPICT	SPICT	SPICT	SPICT		
DBAT STAGE 4, 5, 6, 7	DBAT STAGE 5, 6, 7	DBAT STAGE 3, 4, 5, 6	DBAT STAGE 3, 4	DBAT STAGE 3, 4, 5, 6, 7	DBAT STAGE 5	DBAT STAGE 6	DBAT STAGE 4, 5, 6, 7	DBAT STAGE 3, 4, 5, 6, 7	DBAT STAGE 7	DBAT STAGE 4, 6, 7

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When it works well?

Jan 22- Jan 23	Admiral Nurse
Visit 1	Information gathering
Visit 2	DBAT completed – stage 5-6 late stage severe dementia.
Visit 3	Discussed POA & DNACPR – both already in place
Visit 4 (SaLT)	Changes to eating & drinking; Swallowing changes Holding tablets in mouth
Visit 5	Changes in skin integrity (pressure sores) Review eating & drinking ACP discussed and recorded
Visit 6	Physical changes DBAT reviewed – stage 7 and GP prognosis of weeks Just in Case medications in place & referral to Hospice at Home
Visit 7	Mum died peacefully at home (November)
Visit 8	Post bereavement support

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Carer Feedback

"Really helpful to know what stage mum is at and what to expect"

"The document to assess the stage of dementia helped us to know when it was the end and to prepare the family for [name] dying"

"The DBAT has really helped me to understand my mothe's dementia and has given me reassurance in knowing where we are in her journey"

"Admiral Nurse was able to get the Hospice girls [Hospice at Home] after doing the assessment [ADAT]"

"The DBAT helped me understand her behaviour and where we are in the journey"

Thank you

Any Questions?

References (1)

https://www.sueryder.org/how-we-can-help/terminal-illness-information/planning-for-the-future/advance-care-plan

https://www.macmillan.org.uk/cancer-information-and-support/treatment/if-you-have-an-advanced-cancer/advance-care-planning/advance-decision-to-refuse-treatment#:~:text=An%20advance%20decision%20to%20refuse%20treatment%20(ADRT)%20is%20a%20written,to%20make%20your%20own%20decisions.

This is Me document.
https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/this_is_me.pdf

https://www.nhs.uk/conditions/do-not-attempt-cardiopulmonary-resuscitation-dnacpr-decisions/#:~:text=DNACPR%20is%20sometimes%20called%20DNAR,your%20doctor%20or%20healthcare%20team.

ReSPECT
https://www.resus.org.uk/respect/respect-healthcare-professionals

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References (2)

Go wish cards https://codaalliance.org/go-wish/

FINK https://finkcards.com/

Gold Standard Framework Prognostic Indicator Guidance (GSF PIG)
https://goldstandardsframework.org.uk/cd-content/uploads/files/PIG/Proactive%20Identification%20Guidance%20v7%20(2022).pdf

FAST tool – Functional Assessment Tool
Reisberg B, Ferris SH, Franssen E. An ordinal functional assessment **tool** for. Alzheimer's-type **dementia**. Hosp Community Psychiatry. 1985 Jun;36(6): ...

SPICT – Supportive and Palliative Care Indicator tools
https://www.spict.org.uk/

DBAT – Dementia Behaviour Assessment Tool
https://www.tamcummings.com/

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