Advanced Care Planning at the End of Life for People with Dementia

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Version: Version of Record

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- 90,000+ people with dementia in Scotland
- Progressive and life-limiting disease
- Complex physical and psychological needs
- Avoid unwelcome and distressing treatment
What is Advance Care Planning?

A *process of discussion about end of life care* involving the person with dementia, those closest to them, and their care worker, that usually takes place in anticipation of a future deterioration in the person’s condition.
what you want to happen

what you *don’t* want to happen
When Should Advance Care Planning be done?

- On admission to hospital
- On admission to care home
- At diagnosis
- When you are ready
Who should be involved?

- Person with dementia
- Family/loved ones
- Healthcare professionals
- Dementia Practice Co-ordinator
What is covered?

“My Anticipatory Care Plan”
Key Information Summary
Main Issues:
- Cardiopulmonary Resuscitation
- Difficulties eating and swallowing
- Antibiotics
- Pain
- Hospitalisation
What does it avoid?

- Inappropriate hospital admissions (and associated costs)
- Burdensome and futile treatment
- Distress for families
Support for Family Members

- More likely to have conversations when supported
- Need emotional support
- Need information on trajectory of dementia
- Need information on palliative and end of life care
The bottom line

We need to provide a window of opportunity for people with dementia to make their wishes and preferences for the end of life known whilst they are still able to do so.

Not talking about it can have real consequences for the person with dementia, as well as for their friends and family and the professionals caring for them.
Government Action

Anticipatory care planning involves discussing an individual's goals and wishes, and recording these decisions so that in the event of a gradual or sudden decline, those providing care have clear guidance on what that person would wish to happen.
Resources to help you
Resources to help you

Anticipatory Care Planning Toolkit
Let’s think ahead
Resources to help you

#2 Information to help those close to someone who is old or ill

#9 Free things you can plan for end of life

#6 Starting the conversation if someone close to you is dying

#11 Starting end of life care conversations with people affected by dementia

There are things you want to raise, but it never seems the right time.

Many of us who are getting on in years, or have a disease that we know will shorten our life, don’t want to ignore the fact that our time is limited. There are things we want to get sorted out – the instructions for what we’d like to happen if and after our death.

We may want to talk to those close to us about our feelings for years, or what possible stand if we become dependent or what happens to children, or to get looked after, but these aren’t easy subjects to raise – especially when those around us seem to want to ignore them.

To find out how to get more help visit www.goodlifegoodgrief.org.uk or call 0131 229 0538
Table Discussion

What are your experiences of Advance/Anticipatory Care Planning?