



Leaflet # 1 1 : Time to talk

Starting end of life conversations with people affected by dementia

Things haven't been right for a while...

A friend or relative has just been diagnosed with dementia. Perhaps you had suspected it for a while. Sometimes it can come as a shock, sometimes diagnosis can actually be a relief. But what can you say to them, how can you help them plan for the end of life? With a dementia diagnosis there's a limited window of opportunity, so it's vital to hold these important conversations early, for everyone's peace of mind.

End of life care for people with dementia is a key part of delivering good quality care but many people put things off until it's too late. It's not always easy to begin conversations but speaking openly about the future can improve quality of life throughout the dementia 'journey'. However conversations must be started early to avoid missing opportunities.

Quick facts: Dementia

Symptoms:

- Memory loss
- Confusion
- Difficulty carrying out daily living activities

Number of people affected:

- Over 35 million people worldwide
- 800,000 people in the UK

Why talk about it?

Reducing anxiety: knowing what to expect and how to respond

Informed decision making: It's not unusual for loved ones to have to make decisions on behalf of the person with dementia. This is much easier if their wishes are clear.

Peace of mind: Knowing that everything possible has been done to ensure quality of care for the person with dementia

Not being a burden: Knowing that things are taken care of, to save families and loved ones unnecessary stress and cost

Getting on with living: Having a clear sense of someone's wishes and doing as much as possible to plan ahead can give freedom to get on with living now.

What to talk about

Dementia: What to expect as things progress

Money: Managing finances in the future (Wills, power of attorney)

Where to live: Where to live if more help should be needed

Type of care: Wishes and preferences about how to be cared for

Emergencies: What will happen to the person with dementia in an emergency?

Funerals/Remembrance: Making a funeral plan, choosing songs, cremation, burial etc

Organ donation

What to do when someone dies: Practicalities

Life after caring: Many carers' and families' lives are on 'hold'. The future can be daunting.

What happens if you don't talk

Unnecessary complexity, for example:

- **Having to be referred to the court of protection because power of attorney couldn't be authorised**
- **Stressful administration of finances after someone has died with no will**

Missing important moments, for example:

- **Not being told that the person with dementia is dying, so missing opportunities to say goodbye**

Missed opportunities, for example:

- **Missing the chance to ask someone's funeral wishes and being left with no idea how they would like to be remembered.**

When to talk

At diagnosis:

- **What is dementia, symptoms and how it can progress**
- **Start thinking about things that will need to be discussed, maybe not now but when people are ready, in particular power of attorney, wills and advance decisions to refuse treatment.**
- **Arrange opportunities to discuss things further**

As things go on:

Make opportunities to speak, for example:

- **Arrange a time**
- **Prompts and triggers: Significant anniversaries, when people retire or events such as specialist palliative care becoming involved can be natural points to think and talk about the future.**

Tips

Reassurance: Offer kind words of reassurance bearing in mind that people are likely to be fearful of the future. For example:

“You can always revisit things, but because you’ve done that first step it will be a bit easier”

“Don’t be scared of planning ahead. It will make life much easier in the end”

“You need to be thinking about these things early on. You don’t need to be frightened. It’s much easier to do it earlier”

“Once you’ve spoken about these things, as hard as it might be, you can put them away and focus on enjoying things”

Speak early on “Too soon is never too soon”

But don’t despair if you haven’t. It can still be possible to communicate with someone about their wishes as their dementia advances, given the right situation and approach.

Things aren’t set in stone: Conversations can be revisited

It’s a process: Discussing the future and end of life is an ongoing conversation

Be supportive and honest: Be kind and try to put yourself in their shoes, but you still need to be honest

Focus: You do need to make thinking and planning ahead a focus of conversation from time to time, and not gloss over it

Be realistic: It’s impossible to plan ahead for every eventuality

Be yourself.

If you're a professional

Don't

- leave people to flounder and 'scratch around' for information
- Let your own fears of talking about dying get in the way of conversations
- Leave the person with dementia or family to broach the subject. Give them the opportunity by broaching it gently
- Be vague

Do

Provide an information pack at diagnosis containing brief information about:

- Power of attorney
- Writing and amending wills
- Advance decisions to refuse treatment and care planning
- Funding/allowances including contact numbers
- Available support/advice including Admiral nurses and carers groups
- Courses about dementia

Further information

Difficult Conversations for Dementia - www.ncpc.org.uk/publications

Planning for your future care - www.endoflifecareforadults.nhs.uk/publications/planningforyourfuturecare

Dementia UK - www.dementiauk.org

Dying Matters - www.dyingmatters.org

Alzheimer's Society - www.alzheimers.org.uk

To find out how to get more help visit www.dyingmatters.org

or call freephone 08000 21 44 66

THE
NATIONAL
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CARE



This is number eleven in a series of leaflets focusing on dying, death and bereavement produced by Dying Matters, a broad-based national coalition which aims to support changing knowledge, attitudes and behaviours towards dying, death and bereavement and through this to make 'living and dying well' the norm.

The National Council for Palliative Care (NCPC) is the umbrella charity for all those who are involved in providing, commissioning and using palliative care and hospice services in England, Wales & Northern Ireland.

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