

# Time to talk?



## #11

Starting end of life care conversations with people affected by dementia

**Dying Matters**

*Let's talk about it*

# 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.

To find out how to get more help visit:

[www.dyingmatters.org](http://www.dyingmatters.org)

or call freephone

08000 21 44 66

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](http://www.ncpc.org.uk/publications)

Planning for your future care  
[www.endoflifecareforadults.nhs.uk/publications/planningforyourfuturecare](http://www.endoflifecareforadults.nhs.uk/publications/planningforyourfuturecare)

Dementia UK  
[www.dementiauk.org](http://www.dementiauk.org)

Dying Matters  
[www.dyingmatters.org](http://www.dyingmatters.org)

Alzheimer's Society  
[www.alzheimers.org.uk](http://www.alzheimers.org.uk)



**Dying  
Matters**

*Let's talk  
about it*

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**

The Dying Matters Coalition is led by the National Council for Palliative Care, the umbrella charity for palliative, end of life and hospice care in England, Wales & Northern Ireland.

[www.ncpc.org.uk](http://www.ncpc.org.uk)

Registered Charity no.1005671