Talking about dying if you or someone you know has dementia

Around 900,000 people in the UK have dementia. Dementia can cause memory loss and make you confused. Dementia can make it hard to do daily activities. Dementia can be hard for family and friends too. That is because dementia can change how people behave.

This leaflet is for people who have dementia and people who look after people with dementia. It should help you plan for the end of life.

We recommend you talk about the end of life as soon as you can. It might not seem easy. But it makes sure everything is taken care of. And it means everyone knows what to expect. You can make the future easier by talking about death now.

What to talk about

We have listed below some things you could talk about.

Dementia
You could talk about how it will change and how that could affect everyone.

Money
You could talk about how you will pay for dementia care and other costs.

Lasting power of attorney
Lasting power of attorney is when someone can make decisions for someone else. This can be useful when a person is not able to make decisions for themselves. It is a good idea for a person with dementia to give someone lasting power of attorney. You can out more at gov.uk/power-of-attorney

Making a Will
You could talk about making a Will. It is important to make sure a Will is up to date.

Where to live
You could talk about where the person with dementia would live if they need more help.

Care in the future
You could talk about types of care the person with dementia wants and does not want.

Emergencies
You could talk about what will happen if there is an emergency.
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Things to arrange
You could talk about practical things. Practical things could include who will let friends and family know if the person with dementia dies.

Funeral plans
You could talk about any funeral plans that have been made. And you could talk about what is involved and where the plans are.

Donating organs
You could talk about whether the person with dementia wants to donate organs like their kidney or liver.

Life after caring
It can be difficult if someone you have cared for dies. It can help to talk about what you will do afterwards. You could put plans in place to help now.

When to talk
The best time to talk is soon after someone finds out they have dementia. It can be difficult. But it will give you time to make plans. It also will not mean the person dies sooner.

Events like birthdays and anniversaries can be a good reminder to talk about planning. You could use the list above to help you.

Websites for more support
You can find more information at these websites. They all have information about dementia:

Dying Matters
hospiceuk.org/dying-matters

Dementia UK
dementiauk.org

Alzheimer’s Society
alzheimers.org.uk

Dying Matters is a campaign run by Hospice UK, Hospice House, 34-44 Britannia Street, London WCTX 9JG