

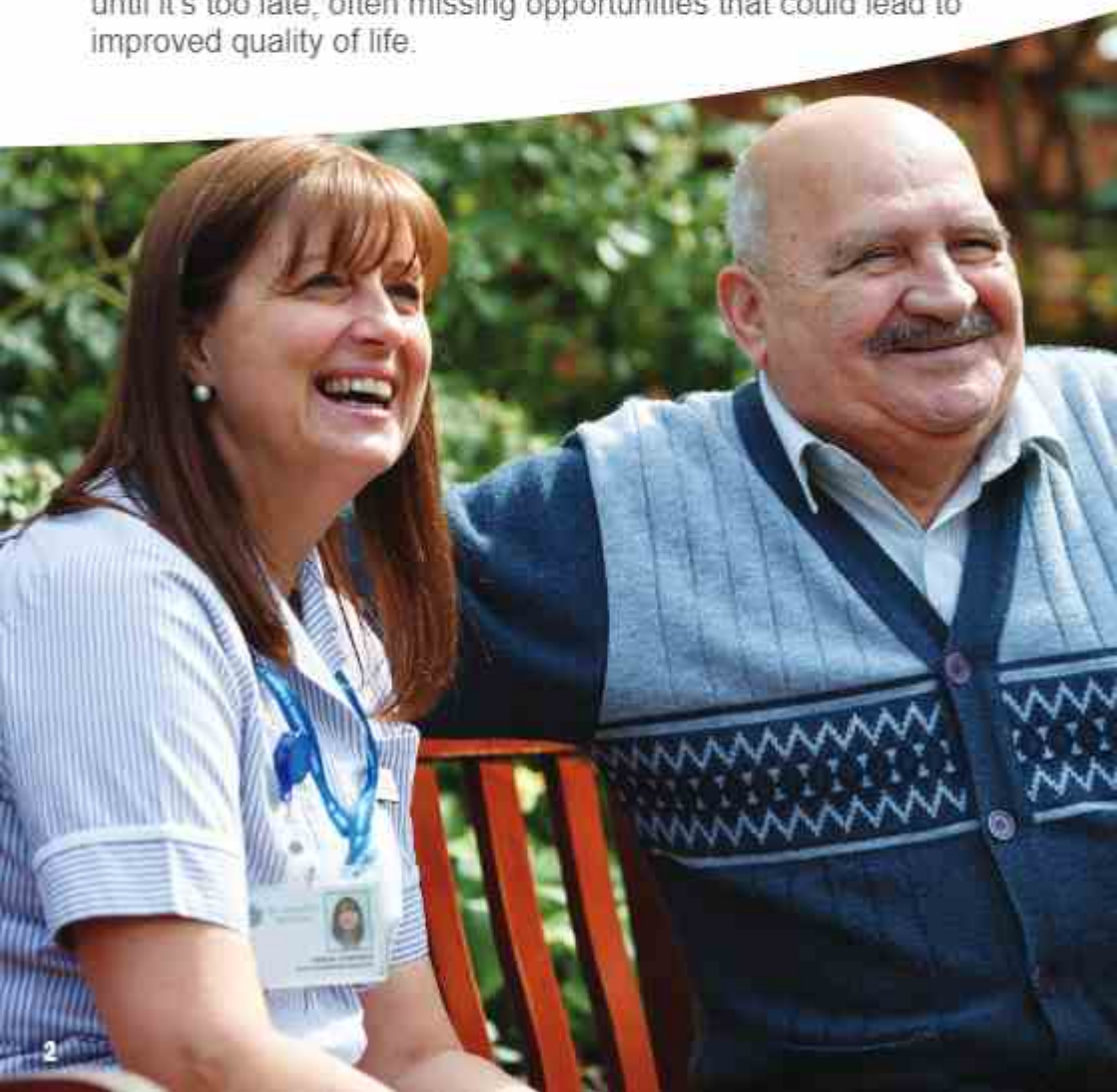


**Talking about dying
with people affected
by dementia**

Supporting people affected by dementia

Dementia, often presenting as memory loss, confusion and difficulty carrying out daily activities, affects about 800,000 people living in the UK.

Providing 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, often missing opportunities that could lead to improved quality of life.



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.

What to talk about

- *Dementia*: What to expect as the illness progresses.
- *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*.
- *Practicalities*: What to do when someone dies.
- *Life after caring*: Many carers' and families' lives are on 'hold'. The future can be daunting, and they will need assistance finding their 'new normal'.

What happens if you don't talk?

- Unnecessary complexity like having to be referred to the court of protection because power of attorney couldn't be authorised, or stressful administration of finances after someone has died with no will.
- Missing important moments like opportunities to say goodbye.
- Missed opportunities like finding out one's funeral wishes or how they would like to be remembered.

When to talk

At diagnosis, when you can cover what dementia is, and what it entails. This is the time to start thinking about things that will need to be discussed like power of attorney, wills and advance decisions to refuse treatment.

Arrange opportunities to discuss things further. Some simple prompts or triggers to talk could be significant anniversaries, retirement or events such as specialist palliative care becoming involved can be natural points to think and talk about the future.

Further information

- **Dying Matters**: www.dyingmatters.org
- **Dementia UK**: www.dementiauk.org
- **Alzheimer's Society**: www.alzheimers.org.uk



Create a lasting memory of someone special. Donate to Hospice UK.

The Dying Matters coalition is led by Hospice UK, the national charity for hospice and palliative care. We support over 200 hospices throughout the UK that care for over 200,000 patients and their families a year.

A gift to Hospice UK is a special way to honour the life of your loved one. By doing so, you are remembering them through helping others to receive the very best care at the end of their life.

You can create a lasting memory of someone special by:

- giving a donation to celebrate their life
- dedicating a leaf on the beautiful Hospice UK Tree of Life in their name
- undertaking a challenge or hosting an event to honour their memory
- leaving a gift in your Will to support the sustainability of our work as a lasting legacy of your loved one.

We are here to help

However you choose to remember someone, we are here to help. To create your memory, please see our website: www.hospiceuk.org/support-us or call 020 7520 8266.



Hospice UK leads the Dying Matters Coalition. Charity registered in England and Wales No. 1014851 and in Scotland No. SC041112.



**Dying
Matters**

*'Let's talk
about it'*

For more information visit:
www.dyingmatters.org