

End of life care

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Dementia is a terminal condition and supporting people at the end of their life to die well, or as they would have wished, is part of good person-centred care.

What does a good death mean?

The Department of Health's End of Life Strategy describe 'a good death' as

- Being treated as an individual
- Being without pain and other symptoms
- Being in familiar surroundings
- Being in the company of close family and/or friends

However, evidence suggests that this is not the case for many people living with dementia.

At a time when dementia is the leading cause of death in the UK, accounting for 11.6 per cent of all deaths in 2015, improvements need to be made.

The Dementia Action Plan for Wales states: "We need to ensure that the options and access to palliative care and end of life care is the same for a person living with dementia as it is for anybody else."

[View transcript](#)

Karen Harrison Denning: "When we're thinking about good quality end of life care in dementia, emphasis doesn't stop with considering living well with dementia.

"Good strategy needs to actually think about dying well with dementia also."

Karen Harrison Denning specialises in end of life care. She believes that one of the problems with it is that practitioners fail to recognise the signs of end of life early enough.

Because there is this failure to recognise when a person with dementia actually is nearing the end, they can often be subjected to unnecessary, and sometimes aggressive, interventions at the end of life.

And what we often see is frequent admissions to hospital, interventions such as tube feeding or intravenous antibiotics, or indeed other interventions that are perhaps not indicated for the end stage that that person's at, and can actually incur more distress for that person than actually any benefit.

She believes person centred care with good advanced planning can cut unwanted hospital admissions.

At Moreton Hill Care Centre in Gloucestershire, a care home with dementia and nursing units, they are taking this approach to ensure people die well, where and how they wish.

"Are you thirsty, mum? Would you like a drink? Nice cup of tea?"

Mairead Smart has Alzheimer's and is at the end of life stage. She's often visited by family members like daughter, Marion Beadle, and grandson, Joe.

"Patricia will bring you in a nice cup of tea in a minute I think."

We've gone from somebody who has Alzheimer's and has no memory and repeats herself but can still have a cup of tea and a conversation, to not even being able to hold a conversation with me.

"Don't stay awake if you don't want to darling, you close your eyes lovely."

Mairead is one of 59 residents who will move into the end of life phase at Moreton Hill.

To ensure staff recognise end of life and can deliver the right care, they have developed a person centred approach using the NHS's Gold Standard Framework.

The Gold Standard Framework looks holistically at all the needs of a person, whether they be physical, spiritual, religious needs. It's also about supporting the family so that the experience and the memories of that person's last few days are the best that they can possibly be.

Staff identify the later stages of dementia using a traffic light system.

The traffic light system is a very simple tool to deliver end of life care. We have blue for when people come in, we have green for when they start to deteriorate, yellow or amber for when their deterioration is noticeable, and then we have the red for when they are in the final stages of life.

"Shall we do the other hand? If you pass me your other hand. That's lovely. Okay. That's it, that's it."

All staff are aware Mairead has entered the red light stage, and due to her care needs she is now in the nursing wing.

"She's got a good sense of humour. Always bright woman, always cup's always half full, you know. There's always everybody worse off than her no matter what problems she had. All she ever wanted to be was a wife and a mum."

"... Jean."

"No, no, no, no."

In end of life care with residents with dementia, it can be difficult to decide when they're entering the end of life care.

It is very important that all staff within the home can identify changes within residents, and one of the advantages of having residents in our home is that we know them well, so quite often those changes will be quite obvious to the whole team, anybody that goes into that room will know how they are normally and will notice changes.

So that may be changes in their breathing, for instance, which might indicate a problem.

What I'm going to do is show you how we're going to move someone if they're at the stage, if they're end of life.

"So what I'm going to do is I'm going to fold the slide sheet..."

Understanding the needs of people with dementia is a skilled area, so those care staff need training, knowledge, skills, investment in really, not just in delivering good dementia care, but also delivering good end of life care, because those two elements will enable that person with dementia to die a good death.

"I want to be here no matter what happens."

"Yes, of course you do."

"But it wouldn't surprise me if she did something like that."

"It wouldn't surprise me at all. We'd get you in as soon as we could ..."

"Yeah."

"... that she'd died."

"As long as it's pain free I'm not ... I don't, you know ..."

"Yeah, she die the way she lived, with dignity."

"Absolutely."

As well as training all staff to identify the dying process, at Moreton Hill they use an advanced care plan to note a person's preferences for their end of life care in a form that can updated.

"You know your mum, is there anything that you think we should do that we're not doing for her now whilst we can?"

"No. As long as she's got all the little things around her that remind her of her family."

"All the things that you do, yeah, everything that you do already is perfect."

"That's fine. Now as mum becomes really, really poorly do you want to ..."

The value of the advance care plan is that there are no surprises, so that we've actually got everything written down for that person to die with dignity and respect, and to have their wishes carried out to the end.

Even though they can't communicate those, we can deliver the care to her as she wants it, and as her family want it.

For Mairead it's an important part of her plan to have family, and especially grandchildren, near her to the end.

"When Mum hears Joe's voice and reacts to it that's very special for me, because she knows his voice and that's why she'll wake up because she knows it's him that's here."

"Can you hear your man on the floor?"

[Laughs]

"Playing in the bushes with his animals."

"She came here a nervous wreck, she is now the happiest, most relaxed, lovely person that I always remember her to be, and that's because of the way she's cared for here."

If at the point of diagnosis people have the opportunity and the space to enable them to talk about their future wishes and priorities in the form of an advance care plan then,

so they can still influence and control what happens to them down-line at a point where they've probably lost capacity, they've lost their language, and the ability to do so.

"I'd like to talk to you, doctor, about Mrs Brown. I did an advance care plan over the weekend and her condition has deteriorated somewhat."

If a multidisciplinary team, including their GP, need to use the Mental Capacity Act to make best interest decisions for residents who've lost capacity,

they can take people's previous life choices into account using the advance care plan.

"... next few weeks. I just wonder whether we could have a look at changing some drugs and taking her off some medication that she doesn't need."

"Okay."

"Is that okay with you?"

With the red light in place, staff at Moreton Hill and their GP implement the Liverpool Care Pathway. This offers an outline of best practice care which a patient can expect in the final days and hours of life.

"... have some agitation there as well, she's getting quite sort of twitchy at times. I just think we could have something to calm her down."

"And what's her view on it?"

"She's okay, she's quite comfortable. She knows she's dying, but I just think it would be nice to have her a little less upset and agitated."

The doctor will sit down with the multidisciplinary team and he put in place drugs for pain, and drugs, they're actually to calm people down,

to make their last few hours as comfortable as possible, and that their loved ones feel that they're being looked after as they want them to be looked after.

"Mairead, cup of tea."

"All the staff care for you like they're part of your family. It's almost like they love mum like she's their own.

And that means that they'll make sure that she'll get whatever she needs or that's important to her between now and when she leaves this world.

And that gives me and my family great comfort."

A number of barriers were identified in the Marie Curie and Alzheimer's Society report *Living and Dying with Dementia in Wales: Barriers to Care*:

- lack of recognition of dementia as a terminal condition
- inaccurate reporting of cause of death.
- ineffective advanced care planning, due in part to a lack of timely diagnosis.

[Living and Dying with Dementia in Wales: Barriers to Care](#)

Advance care planning for end of life

Advance care planning is a process that enables people to make plans about their future health care.

Advance care plans provide direction to healthcare professionals when a person is not in a position to either make and/or communicate their own healthcare choices.

Advance care planning is crucial for anyone with a life-limiting condition, perhaps more so for people with a dementia, as due to the degenerative nature, people will lose capacity to make their own decisions.

Advanced care planning may be about having a conversation about options, identifying wishes and preferences, and the people to consult on the person's behalf.

[Planning your care in advance](#)

The Mental Capacity Act allows future wishes to be expressed in the form of advance directives or Living Wills.

In England and Wales, an advance directive is the only legally binding form of expressing views on care and is situation specific.

[End of life care advice from the NHS](#)

The Act also supports the appointment of a Lasting Power of Attorney to act on the persons behalf when they are unable to make their own decisions.

Lasting Power of Attorney can be appointed for health and welfare decisions and/or property and affairs.

[Advice from the NHS about lasting power of attorney](#)

The Living and Dying with Dementia in Wales report also highlighted unequal access to palliative care, hospice services and funding, resulting in discrimination and inconsistencies in care standards.

A co-ordinated approach is needed to support a person at the end of life, with family carers, social care staff, district nurses, GPs, Admiral Nurses and Older People's Mental Health Teams working together to ensure a good death.

In addition, we need to ensure people receive ongoing support after the person has died, whether that is a family carer or a professional.

Many organisations can provide support at this time, listed in the useful links below.

Useful resources

Find out more about end of life care.

[The Social Care Institute for Excellence has a number of resources about end of life care in dementia, including pain management, eating and drinking, and carers' needs](#)

[End of life care for people with dementia – online course from Future Learn](#)

[Advice about bereavement support from Marie Curie](#)

[Grief, loss and bereavement advice from the Alzheimer's Society](#)

We want your feedback

Help us to improve the Dementia resource for care professionals by telling us what you think about it in our short [four question survey](#).