Difficult Conversations

Making it easier to talk to people with dementia about the end of life.
End of life care for people with dementia is a key part of delivering good quality dementia care. Landmark publications like the National Council for Palliative Care’s “Out of the Shadows”, have emphasised the unique aspects of caring for the dying person suffering from dementia – the need for the whole system to own the challenges of dementia, the need to adapt models of end of life care for dementia and the important aspects of looking across the whole dementia care pathway. Conversations with people with dementia early on in the disease, at the appropriate time, to establish their wishes about their end of life care are of prime importance. As the National Clinical Director for dementia, I am very aware of the need for high quality end of life care and making sure that the quality of the services provided optimises the quality of the experience of the person with dementia, their family and carers, at the end of life.

Difficult Conversations gives extremely helpful guidance to people dealing with individuals dying with dementia. The readable format, digestible concepts and practical approach are extraordinarily helpful in dealing with a condition regarded with huge stigma, still, by many. I congratulate the National Council for Palliative Care in their work around dementia - I have learnt a lot from reading the booklet.

Alistair Burns
National Clinical Director for Dementia
About this document

This guidance aims to help anyone, unpaid or professional, caring for someone with dementia to open up conversations about end of life wishes and preferences, in order to enhance quality of life. It is based on conversations with around fifty people affected by dementia; people with dementia, carers and former carers. We hope their insights will inspire confidence to start and continue these important conversations.

Introduction

‘Dementia’ describes symptoms of confusion, memory loss and difficulty carrying out daily living activities. It is caused by physical and structural changes in the brain. Over 35 million people worldwide¹ and over 800,000 people in the UK² have dementia. People with dementia often receive poor care at the end of life and have unequal access to palliative care.

Speaking openly about the end of life can increase chances of people dying well, with their wishes and preferences fulfilled. In an ideal world, people would speak openly whilst well, to avoid having to start conversations when ill or at an emotional time. Dementia’s unpredictability and symptoms bring a particular urgency to starting conversations, to ensure that people can express their wishes and make necessary arrangements while they are still able.
Why talk about it at all?

Living well now and in the future
Speaking openly can improve quality of life both now and in the future. For example:

Reducing anxiety
Being open can make it clearer what could happen as dementia progresses and how to respond, and reduce unnecessary anxiety.

“We were prepared for the situation that hit us”

“One of the basic causes of fear is ignorance”

Making informed decisions
As dementia progresses, carers often need to make decisions on behalf of the person with dementia. It is easier to do this if their wishes are clear.

“WE THOUGHT IT WOULD BE EASIER TO MANAGE IF WE’D TALKED ABOUT IT IN ADVANCE”
“I’m happy that Mum’s wishes will be carried out and that it’s all so comfortable, and that she’s comfortable with it too”

Peace of mind

It’s important for carers to know that they did all they possibly could for the person with dementia.

“IT’S MUCH EASIER TO KNOW PEOPLE’S WISHES AND TO MAKE SURE THEY'RE CARRIED OUT. IT MAKES IT SO MUCH LESS TRAUMATIC”

“I think I’d have been a better carer if I’d had more information”

Not being a burden

It can be reassuring to know that certain things are taken care of and that families and loved ones will be spared unnecessary stress and expense.

“I’ve planned my funeral to stop my family having to pay”

Getting on with living

Having a clear sense of someone’s wishes, and doing as much as possible to prepare or plan ahead, can give freedom to get on with living life now.

“The thing is, once you’ve spoken about these things (as hard as it might be), you can put them away and focus on enjoying things”
What to talk about

It can help to have conversations about the following:

**Dementia**
Dementia is different for everyone, but knowing roughly what could happen can help with planning ahead and being prepared.

**Finances**
As dementia progresses, there may be difficulties managing finances, and carers may need access to funds both for themselves and the person they are caring for.

*Lasting Power of Attorney* allows the person with dementia to nominate someone to make decisions about finances or care on their behalf when they are no longer able to do so. It must be set up while the person with dementia still has mental capacity. Careful consideration should be given to who is granted power of attorney.

“*I’d like a map of what dementia might look like in the future*”

“I’ve got our finances sorted as much as possible. Everything that can practically be done, I have done. It’s more about coping now”

“You also need to think about where they live. For example, I lived reasonably near the care home so it was easy to deal with the practical things”

“There can be a lot of friction, and some families can bicker about the right course of action. If you’re having several power of attorneys, make sure they all get on”

“It’s important to think seriously about whether they’re going to be alive over the whole prognosis. For example, Dad was older than Mum so may not have been the right person”
Wills must be written or amended while the person with dementia still has mental capacity.

**Place of care**
Being aware of possible options and preferences can enable informed decisions to be made. For example, many people would prefer to live at home for as long as possible. Support and advice from local palliative care teams can enable this to happen. Knowing this and being aware of available support will make it more likely to happen.

"IT WOULD HELP TO KNOW WHAT PALLIATIVE CARE SERVICES ARE AVAILABLE, FOR EXAMPLE HOSPICES/MARIE CURIE, AND WHO YOU CAN ASK FOR HELP FROM"

**Care as dementia progresses**
Advance Decisions to Refuse Treatment (ADRT) and ‘Do Not Resuscitate’ decisions allow people to refuse particular aspects of care, if they feel that quality of life would not be enhanced. ADRT must be carried out whilst the person with dementia has mental capacity.
Planning for emergencies
It’s important to have a plan in place so that the person with dementia is looked after if something happens to the carer.

“"The only thing that really bothers me is what would happen if I had an accident or something – it’s important to have a backup plan because I don’t know what would happen to her if I was away for 24 hours or something”

Knowing what to expect – care at the end of life
Many people have not experienced the death of someone close to them. It can help to understand possible physical changes and symptoms to avoid unnecessary alarm and concern.

“It’s strange, and it was a bit surreal. You get it into your head that they’ll just go to sleep. There was an awful noise when he was breathing. I’ve found out since that it’s very common, and that it was a known thing. They told me that it sounds worse than it is – they reassured me"
At this stage we didn’t know how long Anna had left. They arranged for medication in the house in case she became agitated, including oxygen, pain relief (morphine) and antipsychotics.

“There was always someone I could phone, for example with the syringe driver. They explained to me that he could die that weekend, and told me what I should do. David was logged up as an ‘expected death’. I was told to call the out of hours District Nurses. I was told what to expect and what to do. When it happened, they did come out. They explained that they weren’t just there to give drugs, but to reassure me too.”

Funerals and remembrance
It can help to know the kind of funeral someone would like, their cultural or religious preferences and how they would like to be remembered.
What would be useful would be a leaflet about what to do when someone dies. Even if you’ve been through it before you don’t remember it. Each time you come to it it’s as though it’s afresh.”

“I’ve simplified things for me. I’ve made arrangements for Manchester University to have my body for research. Without research we do not have progress.”

Organ donation
People may wish to donate their bodies for research or to help others after they have died.

Care after death
It is helpful to be aware of practical tasks that must take place after someone has died, such as registering the death and arranging the funeral.

Subjects you may wish to talk about

- Dementia – knowing what to expect as things progress
- Managing finances in the future
- Where to live if more help should be needed
- Wishes and preferences about how to be cared for
- Who will look after you/the person with dementia in an emergency
- What to expect and how to respond when someone is nearing the end of life
- Wishes and preferences regarding funerals and remembrance
- Donating organs or bodies for research or to help others
- What to do when someone dies
- Life after caring

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Life after caring
Life after caring can be daunting for carers. It can help to talk openly.

"IT WOULD BE HELPFUL TO KNOW WHAT I MIGHT EXPECT WHEN MUM IS NEARING THE END OF HER LIFE. FOR EXAMPLE, I’VE BEEN WONDERING WHETHER THEY’D WHISK HER AWAY STRAIGHTAWAY, OR IF I’D HAVE TIME TO BE THERE WITH HER"

"AS THE ONE LEFT BEHIND, YOU DO GET TO THE POINT, EVERY NOW AND THEN, OF THINKING ‘WHAT THE HELL’S GOING TO HAPPEN TO ME?’"

“The big unknown is also about not having been able to think about my future for a while. I’ve been putting that on hold. There are so many unknowns about the immediate future"
What happens if you don’t talk?

Unnecessary complexity

“One of the things regarding capacity is that it took such a while to be taken seriously and get a diagnosis, that by the time we went to set up power of attorney the GP and solicitor wouldn’t sign it off, so we had to go to the court of protection. It is such a lot of work”

“A really good example of what happens if you don’t take care of your affairs is my Mother, who was Italian by birth. Her sister died 5 months before my Mum, also from Alzheimer’s. As the next person in line, it’s my responsibility to sort out her estate. We are still trying to sort it out because there’s no will”

“MY FATHER DIED INTESTATE. IT WAS AN ABSOLUTE NIGHTMARE. MY MOTHER LOST EVERYTHING, BASICALLY. IF YOU ARRIVE AT DIAGNOSIS WITHOUT ONE THEN SOMEONE NEEDS TO SIT DOWN WITH THEM AND GO THROUGH IT”

Missing important moments

“One thing I still get cross and worked up about is that Mum was put on a syringe driver. I wish the nurse had taken me out of the room and said ‘I’m going to increase the dosage now because she’s obviously in discomfort, but there is a chance that she might close her eyes’. Then I could have said my goodbyes in my own way”

Missed opportunities

“I didn’t know what Alzheimer’s would do to him; that his speech and understanding would go. I was left with no idea of what he would want for a funeral or how he would like to be remembered”
When is a good time to talk?

At diagnosis
Conversations at diagnosis can provide a basis for more detailed discussions later on. For example:

- Clear information about symptoms that may occur as dementia progresses
- Advice on things you may wish to discuss, for example wills, lasting power of attorney, advance decisions to refuse treatment and finding support
- An opportunity to return with further questions

"You should have an information pack at the first point of diagnosis, with a note suggesting that you book an appointment to go back soon, to talk things over"

"What would help is, early on, to have a person to sit down with you. There are leaflets around but you have to scratch around for them"

"At diagnosis we were immediately advised by the consultant to get power of attorney, notify DVLA, think about whether the house is too big etc. As a result, we took out lasting power of attorney, contacted the DVLA, downsized and moved much nearer the children. It was fantastic – empowering"
As things go on

Making opportunities to speak

Arranging times
You might want to plan times to meet to discuss and review any wishes and concerns.

Finding the right moment
Although dementia affects communication, it can still be possible for the person with dementia to express their wishes as things progress. Picking the right moment, having conversations on and off over a period of time, and choosing the context can help.

Prompts and triggers
Times of special significance, or moments in the ‘dementia journey’, can be times when people think ahead. Examples include anniversaries, when people retire, when someone moves into a care home or when specialist palliative care nurses become involved in care.

“I made sure I spoke to her in her home environment, and she feels safe there”

“It’s just a question of picking your times to talk, and talking in short bursts, and reading whether she’s understood or taken it in, and is able to communicate what she wants to say”

“It took around 2-3 months”

“I knew that Macmillan wasn’t ‘for years’, so I suppose that prompted me to think about things”
Words of reassurance

It is natural to be concerned about facing the future, but the following comments could be used to reassure people:

“You can always revisit things, but because you’ve done that first step it’s 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”

“The thing is, once you’ve spoken about these things (as hard as it might be), you can put them away and focus on enjoying things”

Who to speak with

There is no ‘right’ person to have a conversation with, but most people are comfortable speaking to someone they have known for some time, who knows them and understands their wishes. Admiral Nurses often explain what to expect as dementia progresses. Sometimes it is helpful to have conversations with an impartial outsider who is not emotionally involved.
Helpful hints

Speak early on....
"It is important to look at all angles as early as possible, but being aware that you might not be able to meet what you'd ideally like to happen"

"Too soon is never too soon"

....but don't despair if you haven't been able to do so
There may be ways of communicating with someone about their wishes even as dementia progresses, and you may understand something of the person's wishes through conversations over the years.

Things aren't set in stone
Conversations can be revisited if wishes, preferences or circumstances change.

It’s a process
Speaking about wishes is an ongoing conversation which can take place over many years.

“it shouldn’t be an isolated topic”

Be supportive and honest
It can feel sad to think ahead to the future, so it’s important to be supportive.

“They shouldn’t just be nice – they need to be able to be honest and clear too”
Focus
It is important to make ‘thinking and planning ahead’ the focus of a conversation from time to time, otherwise it can be overlooked or glossed over.

Be yourself
Be yourself when you have these conversations. Informal conversations can be just as valuable. Be guided by the person you’re discussing things with about how they’re most comfortable.

“\You could go down the pub and do it over a pint”

Be realistic
It’s impossible to plan ahead for every eventuality.
Notes for professionals

Dementia can be difficult to cope with and caring for someone with dementia can be stressful.

- Don’t leave people to ‘flounder’ and ‘scratch around’ for information

“I was talking about Aricept one day, and my friend said ‘have you tried an Admiral nurse?’ He gave me the number and when I rang, I had a phone call straight back. It turns out the Admiral nurse sat not 200 yards away from where the consultant neurologist sat, and he hadn’t mentioned them.”

“At diagnosis you’re not always told much about dementia. You’re not always told that it’s something that will get worse”

“There was no information on what the disease was. You’re just left to flounder’
• **Don’t** let your own fears of talking about dying, death and bereavement get in the way of conversations.

  "I would have liked to know the indicators for the end coming. For example, colour of skin, cold etc. It would have been nice if there had been someone who came to see me every so often. The Admiral Nurse did her best to tell me, but I wonder if she was afraid as to how much to tell me, for fear that it would upset me."

• **Don’t** leave it to the person with dementia or carers to broach the subject.

  “The professionals seemed to be afraid. I wanted to know things, but there seemed to be a reticence on their part, or they just didn’t have the time to answer my questions.”

• **Don’t** be vague.

  “Conversations about her deterioration only occurred when I instigated them. They weren’t forthcoming – I had to instigate them. I wanted to know what stage she was at. Sometimes I noticed changes but the nurses kept saying that she wasn’t dying. I got really angry with them because I knew she was in that process.”

• **Provide** an information pack at diagnosis, containing brief information about:
  – Power of attorney
  – Writing and amending wills
  – Advance decisions to refuse treatment
  – Funding and allowances including contact numbers
  – Available support and advice, such as Admiral Nurses and carer support groups
  – Courses about dementia

  “You need something really clear e.g. what to do if your loved one looks like they’re going to die. There’s a lot of fudging about death in our society.”
Where next?

We hope this guide has conveyed the importance of opening up conversations about wishes for the end of life early on, and provided ideas about how to do so. If the person you are caring for were to die today or tomorrow, would you know their wishes? If not, have a go at broaching conversations. Remember you won’t always get it right, but what’s important is that you’ve tried.

Useful resources

**Dying Matters** has produced leaflets and materials to open up and support conversations around dying, death and bereavement. [www.dyingmatters.org](http://www.dyingmatters.org)

*Planning for your future care - a guide* explains advance care planning and outlines the different options available. [www.endoflifecareforadults.nhs.uk/publications/planningforyourfuturecare](http://www.endoflifecareforadults.nhs.uk/publications/planningforyourfuturecare)

*Advance Care Planning: A guide for health and social care staff* outlines definitions of advance care planning (ACP) and associated terms, highlights the key principles, issues and challenges of incorporating ACP into patient care and indicates how ACP links to the Mental Capacity Act (2005). [www.endoflifecareforadults.nhs.uk/assets/downloads/pubs_Advance_Care_Planning_guide.pdf](http://www.endoflifecareforadults.nhs.uk/assets/downloads/pubs_Advance_Care_Planning_guide.pdf)

Preferred priorities for care is a patient-held document, designed to facilitate patient choice in relation to end of life issues. www.endoflifecareforadults.nhs.uk/tools/core-tools/preferredprioritiesforcare

The living well handbook has been developed to allow people living with dementia to communicate their likes, dislikes, medical and lifestyle needs to carers and healthcare staff. www.southwestdementiapartnership.org.uk/wp-content/uploads/living-well-handbook.pdf

The Modernisation Initiative End of Life Care Programme has developed the following:

Facing the Future is a peer support service for carers of people with dementia in which trained peer support volunteers who have experience of looking after a person with dementia offer one-to-one meetings with carers.

Preferred Priorities for Care: A Plan for the Future supports mental health staff to carry out discussions about planning for the future with people recently diagnosed with dementia and their families. Further information: Mlendolifecare@gstt.nhs.uk or www.gsttcharity.org.uk/projects/eolc.html

NCPC has produced a range of publications about end of life care for people with dementia and the Mental Capacity Act. All are available from www.ncpc.org.uk/library

The Power of Partnership: Palliative Care in Dementia (2009)
Out of the Shadows: End of life care for people with dementia (2009)

Creative Partnerships: Improving Quality of Life at the End of Life for People with Dementia (2008)

Progress with Dementia- Moving Forward (2007)

Good Decision-Making – The Mental Capacity Act and End of Life Care (2009)

The Mental Capacity Act in Practice: Guidance for End of Life Care (2008)
References


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About us

The National Council for Palliative Care is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. We believe that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, and whatever their condition. We work with government, health and social care staff and people with personal experience to improve end of life care for all. NCPC leads the Dying Matters Coalition which aims to change public attitudes and behaviour around dying, death and bereavement.

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