End of Life Care and Post Bereavement Support - Shifting the Conversation from Difficult to Important

Sharing the perspectives of people living with dementia and their carers

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> **“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.”**

Dame Cicely Saunders (1918 - 2005)

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Thank you too for Lena O ‘Connell (Carer Engagement Lead with tide) who supported the organisation of the workshops and very carefully collected the notes, which has enabled us to capture this rich information into this short report.

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Participants in workshop

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Introduction

In Autumn 2017, 'DEEP - The Dementia Engagement & Empowerment Project' (the UK network of Dementia Voices) and 'tide – together in dementia everyday' (the UK network of carers of people with dementia), held a series of three workshops in North West England to stimulate conversations about end of life care with people living with dementia and carers of people living with dementia.

The aim of the workshops was to gather these perspectives and share them as part of the opening plenary for the 2017 UK Dementia Congress in Doncaster. A main theme of this conference was around end of life issues for people with dementia and carers and particularly post bereavement support. From our workshops, we made a short film, and two people with dementia and two carers opened Dementia Congress with their powerful views on the importance of having conversations about death and dying.

You can watch the film here: Re-framing Conversations around End of Life

Our Approach to Creating a Safe Space for these Conversations

We used an approach from the field of narrative therapy called ‘outsider witness’ to create safe and reflective spaces to begin guided conversations about death and dying.The ‘outsider witness’ practice is a method used in narrative therapy developed and pioneered by Michael White and David Epston (1992) to assist people experiencing difficulties to develop an in-depth understanding of their personhood. It allows people to meet together, respond to and acknowledge the preferred accounts of one another’s lives *(Walther and Fox, 2012)*. Outsider witnesses may be part of a person’s existing community – family or friends – or they may be professionals invited from outside these networks *(Carey and Russel, 2003)*. The practice underpinned by shared stories helps people to acknowledge their identity claims as valid and to share what is important to them in life.

Using this approach, the workshops were facilitated by Polly Kaiser, Consultant Clinical Psychologist. Three workshops were held in total, the first workshop with people living with dementia in which six people participated from DEEP groups. The second workshop was held with carers of people living with dementia, some identified by tide and others who were attending local carers support groups held by Making Space. This provided a focused way for people with dementia and carers to separately discuss their wishes, views and hopes around end of life decisions.

> **“I haven’t had any access to honest conversations. This is my first opportunity to talk about this.” (Person with dementia)**

> **“It’s easier to talk about it [the end of life care] with peer support. We need more opportunities for conversations, then go away and reflect about it. The conversations should take place away from the NHS settings, people not patients.” (Carer)**

> **“Nice to know that we’re not alone. Feels like you’re isolated sometimes but there are other people going through the same.” (Carer)**

The third and final workshop was attended also by professionals working in dementia care and end of life care. The workshop provided the opportunity to weave the stories of people with dementia and carers together with professionals, who ‘witnessed’ each other’s stories and perspectives on end of life. This report shares their voices and in particular some of the key messages around the importance of skillfully facilitating advance care planning and end of life conversations. *(1)*

> **“These discussions are a necessity. It’s a difficult subject but for whom? For me – yes, but people with dementia are more comfortable about speaking about end of life than me. It’s about having the courage to have open conversations and respect people’s different wishes” It’s brave to talk about it, including assisted dying.” (Professional working in dementia care)**

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(1) Since these workshops NHS England has launched a new guide: “My future wishes: Advance Care Planning (ACP) for people with dementia in all care settings”. tide, and tide carer members, contributed to the creation of the guide, alongside Alzheimer’s Society.

Key Messages from People Living with Dementia and Carers

Message 1: Discussions around end of life are important for everyone.

A census carried out by the Dying Matters Coalition (2009) found that whilst 68% of the public reported that they are comfortable talking about death, less than a third have actually discussed their wishes around dying.

It is often perceived that conversations with people with dementia and their carers about end of life are **difficult:**

> **“We find talking about end of life difficult. We’ve had a lot of training but conversations aren’t going ahead. Nurses are worried about upsetting the person, about how to respond if the person gets upset.” (A professional from an NHS Trust)**

But people with dementia and carers tell us we should think about them as **important** conversations rather than difficult.

> **“It’s important to plan for end of life. It takes the guilt and worry away from my family. We went around care homes, I put my name down. My daughter was upset, but I have a desire to protect my daughter – I don’t want her to feel the guilt. This is what I want. I can get on with my life now.” (Person with dementia)**

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> “Why is end of life care important to you today? Because it’ll come to that in the end!” (Carer)

> “It’s brought to me the importance of getting round to making arrangements. I need help with having this conversation. If I’d done it a year after my diagnosis, it would have given me a peace of mind.” (Person with dementia)

> “It’s assumed the person with dementia will go first, but what if I go first? I didn’t discuss with mum her plans and it’s too late now. I wish we had done it when she was more lucid if I’d known.” (Carer)

Participants in workshop

Key Messages from People Living with Dementia and Carers

Message 2: Everyone's wishes about end of life are different – it's about choice!

Everyone involved in our workshops had a very individual perspective about their end of life, including how comfortable they felt talking about these issues. It was evident that people wanted to explore choices around end of life care, death and planning for this. People explained that death is part of life and these conversations need to be happening in the context of the person's whole life and their personal values. These facilitated conversations enabled people to talk about their choices along the way e.g. remaining independent and staying in their own home, moving into supported housing or a care home, decisions around the role of hospice care, donating one's body to science and euthanasia.

For many people with dementia and carers, it was their first opportunity to talk about their future wishes and wishes of those for whom they care:

> **"I've been wanting to talk about this for ages but no-one will!" (Person with dementia)**

> **"I told my son I'm not going in a nursing home" (Person with dementia)**

> **"Me and my mum had the conversation. She is a strong lady and wants to die at home." (Carer)**

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> **“I want to stay at home for as long as possible, but I don’t want my daughter to look after me full time.”**
> **(Person with dementia)**

> **“We went around care homes, put my name down. My daughter was upset, she said ‘you are not going’, but I might.” (Person with dementia)**

> **“I’ve always steered towards hospice care at the end of my life if I can’t stay at home.” (Person with dementia)**

> **“I’ve learnt over the years about my mum’s needs but these professional people didn’t know about the conversations we’ve had before. I want to be with my mum and she will die at home.”**
> **(Carer)**

> **“I worked in a hospice. It was wonderful but not the right place for me.” (Person with dementia)**

For many people with dementia and carers, it was their first opportunity to talk about their future wishes and Euthanasia came up as one potential choice in the spectrum of decision making when planning ahead for end of life, which some people living with dementia wanted to discuss openly, but are not always given the opportunity:

> **“I’ve wanted to talk about this but always been jumped on. The law is discussed, but it’s a moral issue as well as a legal issue. It’s more relieving than the medical thing.” (Person with dementia)**

“Euthanasia is on my mind - I think about it in routes - route 1 is the rough route. I want route 5 (to die at home) the comfortable route. I want to stay at home, to lose my powers, bring people in, and then pop out with pneumonia” (Person with dementia)

“What struck me is the euthanasia discussion. As a palliative care nurse my priority is to make people comfortable. But people have the right to talk about it. We assume we know what people want. Also, as a general nurse I’ve had no training around dementia” (Palliative Care Nurse)

Participants in workshop

Key Messages from People Living with Dementia and Carers

Message 3 – Take time to help people with dementia and carers think about, and record, their wishes around end of life

Our workshops provided people with the opportunity of dedicated time to think about and talk about death and dying. People were encouraged to talk about what was important to them in the context of their whole lives and their views on death - and to compare what a ‘good death’ would look like compared to a ‘bad death.’

> **“A good death for me is to have my family and dignity, no pain, my wishes respected. My dad died in pain and didn’t have a good death. My mum was in pain and I asked for morphine for her.” (Person with dementia)**

> **“I have a DNR [Do Not Resuscitate] and no taking mum to hospital in an ambulance to leave her in a cubicle. I want to keep her at home, comfortable.” (Carer)**

> **“Death is death; no one can prepare you for it. All I want is my mum not to be in pain and die in dignity.” (Carer)**

> **“My family has the same outlook as me. I said I’d be in the university [morgue] and they’d be spending my money on the ceilidh!” (Person with dementia)**

> **“We sat down and had the conversation six years ago. She then went to a solicitor and put it into writing.” (Carer)**

And not everyone can talk about it with families:

> **“The discussion brought it home to me the importance of getting round to making arrangements. I need help with having this conversation.” (Person with dementia)**

> **“The whole family is on the same page. DNR sorted, funeral planned. I am the main carer so it’s not so difficult for me, but not for my 2 brothers who have no idea… My dad’s not on board, he can’t handle it. Pain-free and no suffering is important for mum.” (Carer)**

> **“If I could talk about it with people like you – it’s so relieving and so helpful.” (Person with dementia)**

Writing down your wishes in an advanced care plan was thought to be a very good idea; both carers and people with dementia shared their positive experiences of planning:

> **“We planned everything when mum still had capacity. It gives me comfort. She’s a very organised lady, that generation. Now I don’t have to worry cos I know what my mum wanted. It’s comforting for me to know that she’ll have what she wanted. It would be useful for other carers to have these conversations. I’m adamant that my mum will get what she wanted.” (Carer)**

> **“We can make different choices but need to make the plans, get the choices down, make it while you can. I want to be treated with dignity and care.” (Person with dementia)**

However, many people living with dementia and their carers had not heard of advanced care plans.

> **“I have been diagnosed with dementia for four years now and this is the first time I have ever heard of these advanced care plans” (Person with dementia)**

Concerns were raised that Advance Care Plans could be easily ignored by professionals or in a crisis:

> **“Maybe have a copy put on your hospital notes as they’re not going to look at it. If you want something to happen put it on your notes in big red letters.” (Person with dementia)**

Concerns were raised that Advance Care Plans could be easily ignored by professionals or in a crisis:

> **'It's a jolt. I should have organized and encouraged my wife to think about it.' (Carer)**

Participants in workshop

Key Messages from People Living with Dementia and Carers

Message 4: Dementia is not always the biggest concern (multiple morbidities)

It was acknowledged that people are often living with multiple conditions, not just dementia. Other conditions can be more debilitating than dementia, and can affect end of life planning.

> **“Talking personally, I shan’t go through the last stages of dementia. There are other events in life that lead me to believe I’ll die before I get to the last stage.” (Person with dementia)**

> **“You don’t know who will die first. Dying in pain may not be the case, for example, many deaths are from pneumonia.”(Carer)**

Key Messages from People Living with Dementia and Carers

Message 5: Carers need to be fully involved as equal partners and supported around end of life care and post bereavement support

There were two recurrent themes throughout the workshops from carers of people living with dementia; the difficulty in getting their voices heard as an equal partner in the caring relationship and the under –recognition of their needs in their own right as individuals:

The difficulty in getting their voices heard as an equal partner in the caring relationship

Many carers expressed anger and frustration with the amount of unnecessary work that they have to undertake to co-ordinate the care package for the person for whom they are caring, instead of being able to spend quality time with them at this stage in their dementia journey.

> **“Carers are struggling with every level of care.” (Carer)**

> **“The EoL care plan must include carers’ voices, for carers to be listened to.” (Carer)**

> **“I had a lot of support from some quarters but the social work team – I can’t get hold of them, box ticking, going through the motions, not care-centred. They need to listen to me and my mum, ask me how I am” (Carer)**

> **“Calls to podiatrist, not getting a call back. Skin products for pressure sores, I have to order them through the pharmacy. They don’t always have my order, sometimes takes a week to get it. I’m trying my best but nobody’s working with me. I want professionals to listen. Work with me, not against me. Listen to families; they are the voice of their loved ones.” (Carer)**

> **“Nice to know that we’re not alone! Feels like you’re isolated sometimes but there are other people going through the same.” (Carer referring to what it feels like to be listened to in the workshop.)**

Important to recognise the needs of carers in their own right as individuals - In the course of the workshops it became apparent that carers often felt forgotten in the whole process.

This is supported by the evidence that despite carers being 44% of the total workforce across dementia and saving the care economy £11.6bn a year, often at considerable risk to their own health and well being, their contribution is unrecognized, undervalued and not respected. For example, through out the conversations, carers focused solely on making provision regarding the end of life wishes of the person they cared for and did not consider their own end of life care planning needs. Some carers who never thought of planning ahead for themselves pointed out that the issues raised at the workshops made them aware of the importance of thinking and talking about their own wishes.

> **‘Never turned the conversation [about end of life care] round, always discuss my husband’s arrangements but not about me. Today – this has struck me, need my own will, power of attorney.’ (Carer)**

> **‘I want to have everything in place to have a good death.’ (Carer)**

It also emerged that support available to carers when caring comes to an end was a largely neglected area. Many felt anxious about not having been acknowledged into bereavement.

> **‘My wife is worried about losing me and I’m worried about losing her. I won’t know what to do without her as I’m so used to caring. Once you go, I’ll need help and support to get me back into the community.’ (Carer)**

The key messages from carers throughout the three workshops can be summarized as:

- Carers are expert and need to be respected as partners in care
- Carers need support in every setting
- Carers have their own needs and should be enabled to express these
- Caring shouldn’t be a constant battle and a fight with professionals and the care system
- Carers need to be acknowledged into bereavement and post bereavement

Key Messages from People Living with Dementia and Carers

Message 6: The Reality for Professionals and Commissioners – Challenges and Inhibitors to facilitating conversations about end of life issues with people with dementia and their families

In the final of the three workshops, we invited ten professionals working in the area of end of life care / palliative care, commissioning and primary care for people with dementia and their carers. This provided them with the opportunity to 'witness' the discussions between carers and people with dementia and talk openly and honestly about their perspectives. Some key challenges emerged from these discussions including the many challenges professionals face in initiating these conversations with people living with dementia and their carers. These challenges include:

Poor Communication

The reality is that there are poor lines of communication between the people living with dementia and their carers with the range of professionals and services involved in a person's care package.

> **"Communication between the person with dementia, their family, the professionals, A&E, GPs, and the police – people need to be communicating on every level" (Person with dementia)**

> **“There should be one point of contact; instead carers have to chase after district nurses, other professionals when they should be enjoying their time with their loved one” (Carer)**

> **“For each department to know and have on notes that the person has dementia is no good if the person reading about it doesn’t know what it [dementia] is and how to communicate with the person with dementia” (Carer)**

Need for Additional Training and Education

For many professionals, this issue of appropriate training and education related to both dementia, as well as the more specific areas of advance care planning and end of life care, is a critical challenge in making the necessary changes. Carers also expressed concerns around the lack of knowledge amongst general health and social care staff about dementia.

> **“Carers are struggling with every level of care. We need definitions, what’s the EoL? There are prognostic indicators. This will help to describe what good care looks like. We need a national document … I have a short fuse when it comes to poor care. What is good for me may not be good for others. But dignity, respect, general things and education need to be in place. Then you commission and provide it.” (Carer)**

> **“Professionals are scared to talk about the EoL and you need skills to talk about it. We have lots of time to plan other things such as holidays but limited time to try to get death right. It’s’ sad that people thought they may not get either what they want or need. Minor aspects of nursing practice can have a major impact on people. That little thing that you as a professional haven’t got right may have a huge impact on the person. The person not the paperwork!” (Dementia Quality Lead Nurse)**

> **“As a palliative care nurse, I have never had any training on dementia – I am retiring soon!” (Palliative care nurse)**

> **“Changes in nursing and doctors’ training: we need a new attitude, ‘I’m only doing this to tick boxes’ is no longer acceptable. The other level is commissioning – too often GPs try to get support in the community and there’s very little. I keep sending people to hospital who don’t need to be there. We need to have more money in the community.” (GP & CCG Commissioner)**

> **“Professionals are scared to talk about end of life. We have limited time to get death right. It’s sad that people thought they may not get either what they need or what they want.”**
> **(Professional from a Mental Health Trust)**

Litigations and Blame Culture

Some real concerns were raised by professionals that if they initiate these discussions when they are not adequately skilled and competent, they feel vulnerable to litigation and blame within the current culture across health and social care.

> **“There is not enough time; people are struggling to get even the basic access. One of the challenges is that GPs only see people on their own and can’t share confidential information with the rest of the family. Advanced care plan gets scanned into the notes.”**
> **(GP & CCG Commissioner)**

> **“To say that professionals are busy is not good enough. Respect the person, do what you promise. Everyone is worried about a finite pot of money and the individual becomes unimportant”. (GP & CCG Commissioner)**

> **“It’s easy from the commissioning side to be detached. There are a lot of buzzwords but need to make sure that people with dementia and carers are involved in commissioning discussions”. (Commissioner CCG)**

Many of the professional staff involved were incredibly surprised by how open people with dementia and carers had been and that they were so willing to talk about death and dying (including euthanasia). There is an assumption by many professionals that people don’t want to have these conversations, but this was not evidenced when these conversations are carefully undertaken using a sensitive and supportive process. The professional staff felt uncomfortable about initiating these conversations with people with dementia and their families because they don’t feel that they have sufficient knowledge, skills and time.

What this process demonstrated is that avoiding these conversations is ultimately counter-productive and not person centered. It is also not respectful. Raising awareness about the importance of having end of life discussions with people with dementia and carers could help to guide practitioners in their approaches. These conversations need to be set in the context of what is important to people. A useful way to initiate discussion about end of life care is to set them within general conversations around people’s life stories, thinking about what is important about their past lives, their current lives and what aspirations they have for the future, including what is important to them around death and dying. Using life stories in facilitating conversations around end o f life care is outlined in *‘Using Life Story Work in End of Life Care’ in Life Story Work with People with Dementia: Ordinary Lives Extraordinary People .* ***(2)***

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(2) *Kaiser P. Eley R (2017) Life Story Work with People with Dementia Ordinary Lives Extraordinary People (chapter 15). Jessica Kingsley Publishers, London and Philadelphia*

Conclusion and Recommendations

It is evident from the discussion across the three workshops, that people living with dementia, carers and professionals all believe that the emphasis in conversations about end of life care needs to shift to important rather than difficult.

People living with dementia and carers need much more support in enabling and empowering them to have these conversations about death and dying so that they can put some plans in place in a timely manner, whilst the person with dementia is cognitively able to do this.

Interestingly, the discussions revealed that the sense of these conversations being ‘difficult’ was largely felt by the professionals, because of their own personal and professional vulnerabilities and lack of skills, knowledge and competence to initiate and facilitate these conversations. It is clear that professionals need additional education and appropriate training and support to feel more confident to support people living with dementia more generally, but also specifically in their role in facilitating and empowering people living with dementia and their carers to begin discussing their plans around end of life care and post bereavement support.

The workshops highlighted that there are some practical steps that can be taken to support and help people with dementia and their families to begin their own conversations and planning around end of life. These include viewing these discussions in the context of how people live their lives – they need not be undertaken separately or regarded as difficult.

Everyone’s wishes will be different, but starting the dialogue early is helpful to everyone. This requires creating a safe space within which these conversations can be held and, if required, facilitated by a skilled and confident professional, who will listen to the person with dementia, their carer and their wider family. We hope this report helps to raise awareness about the importance of finding ways to talk about and plan for all our ends of life.

> **‘Good care helps people to sustain their sense of self. Good care sustains the person to keep themselves in dignity.’ (Person with dementia)**

Recommendations to Professionals from People with Dementia:

- Initiate conversations with me about end of life - but only when I'm ready
- Help me to think through the choices available to me - to decide on the ones that fit with my values
- Talk to me about what a good death looks like
- Support me to write down my wishes in an advanced care plan
- Encourage me to talk about my advanced care plan with people who are important to me

Recommendations to Professionals from Carers:

- Recognize, respect and involve carers as expert partners in care of the person with dementia.
- Remember that whether the person, for whom the carer is caring for, is at home, in a hospital, supported living or in a care home, they are still their main carer and as such they too will need ongoing support. Ask carers how they want to be involved.
- Carers are individuals in their own right and have not chosen to be a carer. Their needs and rights are equally important and therefore enable and support them in having their ongoing needs regularly assessed (as it is their right) and responded to in an appropriate way – listen to carers. **(3)**
- As a carer (and expert partner) – there should not be a constant battle and fight with professionals and the care system. We all want the best so please listen and work with them.
- Carers give up so much to care (friends, social life and often work and career). As a result, when their caring role diminishes or ends altogether, they will still need to be acknowledged into bereavement and post bereavement support provided.
- Remind carers to take time, space and seek support to think about their own end of life wishes and record these.

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(3) *Care Act (2014) Section 10 Assessment of a carer's needs for support*
http://www.legislation.gov.uk/ukpga/2014/23/section/10/enacted

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2. Epston, D., & White, M. (1992). Experience, contradiction, narrative and imagination. Adelaide: Dulwich Centre Publications.

3. Walther, S., & Fox, H. (2012). Narrative therapy and outsider witness practice: Teachers as a community of acknowledgment. Educational & Child Psychology Vol. 29 No. 2. The British Psychological Society.

Participants in workshop

tide are a UK wide involvement network of carers of people with dementia, using our voices for change. We empower carers of people with dementia, helping them recognise that they are experts by experience. We believe that by working closely with carers, we can help them understand that, as experts, their voice matters, and can be used to bring about real change.

www.tide.uk.net
@tide_carers

DEEP is the UK network of Dementia Voices. It connects more than 100 groups of people with dementia to each other, to magnify people's views, hopes and intentions. It supports groups to share learning and skills and to increase confidence.

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