

EMPOWERING BETTER END OF LIFE DEMENTIA CARE (EMBED-CARE)

SUMMARY REPORT

CONSULTATION WITH DEEP PATHWAYS GROUP

THURSDAY 25TH MARCH 2021



Image taken from the Centre for Better Ageing free library (<https://ageingbetter.resourcespace.com/pages/search.php>)

BACKGROUND

WHAT IS EMBED-CARE ABOUT?

Our goal is to deliver high-quality palliative and end of life care for people living with dementia and their families. We focus on optimising person-centred decision-making to improve quality of life for people affected by dementia, and communication between care providers to enhance continuity of care within and between services.

WHO IS UNDERTAKING THE RESEARCH?

This is joint programme between University College London and King's College London, led by Professor Liz Sampson and Dr Catherine Evans. Please visit our website for full details <https://www.ucl.ac.uk/embed-care>

OUR STEPS

- We use published studies to build an initial model of high-quality palliative and end of life care for people with dementia, detailing what are the important components, how they work and what difference could this make for people affected by dementia.
- We talk with people living with dementia and their carers about our model to explore what's important in how we deliver care and areas that we are unsure about.
- We work to deliver a step change in palliative and end of life care that supports the priorities for people affected by dementia to enable them to pursue their goals.

WHAT IS PALLIATIVE CARE?

'You matter because you are you, and you matter to the end of your life'

(Dame Cicely Saunders, the founder of the Modern Hospice Movement)

- Focus is the person with dementia and their family carers (including friends).
- Cornerstone is careful assessment of symptoms and concerns to identify the priorities for the person with dementia and the family, and to manage care and treatment to enable them pursue their goals.
- Allows the person and their family to live well, maximise comfort, quality of life and manage uncertainty and to help individuals to die peacefully when the time comes.

ON THE EVENING

On the evening, 26 people took part in the virtual consultation. There was a wide range of experiences with multiple types of dementia, this included:

- 7 people living with dementia
- 12 carers (5 current carers and 7 previous carers)
- 1 group facilitator
- 6 members of the research team

The evening began by everyone introducing themselves and explaining their experience with dementia. The lead researcher, Catherine, then explained the research study, EMBED-Care. Catherine explained why the researchers had joined the group on this evening. She explained that the researchers would like to learn from the group on how best to deliver palliative and end of life for people affected by dementia to enable them to live life as well as possible from diagnosis to end of life.

The group then split into three smaller groups. Each group included a mix of people living with dementia and carers. Each group explored different topics. The topics were:

- **Group 1.** Exploring central ideas about how we deliver palliative and end of life care for people affected by dementia, such as ‘person-centred care’
- **Group 2.** Exploring vital components on what to deliver in palliative and end of life care for people with dementia, such as ‘ongoing medical review’, ‘continuity of care’
- **Group 3.** Exploring what is important to deliver palliative and end of life care for people with dementia living at home, such as ‘what is home care’, ‘who is involved?’

Following group discussions, each group fed back and reviewed with the whole group.

FINDINGS: GROUP I

The group discussed the term ‘Person-Centred Care’. This term is often used by practitioners and policy makers. It’s seen as a key part of high-quality health and social care and is a central component of our model of palliative and end of life care for people with dementia. We wanted to understand what ‘person-centred care’ meant to the group.

MEANING OF ‘PERSON-CENTRED CARE’

For most people in the group, ‘person-centred care’ was an unfamiliar term. The term conveyed a sense of....

“To treat the person, not the disease”.

“Be like a suit you have had tailored to you, rather than off the rack”

One member had good knowledge and understanding of the term from involvement in a project about Kitwood’s model of person-centre care for people with dementia at the University of Bradford.

WHAT IS NEEDED FOR THIS TO HAPPEN IN PRACTICE? AND HOW WOULD THIS MAKE YOU FEEL?

Defining and applying person centred care

- The term ‘person-centred care’ may be known by care professionals, but it is not always translated into practice. Some noted that this may be changing over time.

Knowing the person with dementia

- The group highlighted the importance of having care professionals who understand person-centred care and understand the needs of carers.
- A long-term relationship with a care professional, like a GP, can support person-centred care through knowing the person well. Many preferred this

type of care to care from specialists who may have known the person ‘for five minutes’.

Listening to the person and the family carer

- Family carers feel they are not always listened to. This can cause frustration for the carer who is trying to advocate for the person living with dementia.
- The group spoke of the importance of separate appointments with key care professional. This gives the opportunity for both the person and carer to be listened to.
- One member spoke about the tension between making sure that the person is listened to while also listening to the carer’s concerns. And the difficulty in making sure the person living with dementia does not feel ‘spoken about’.

Seeing the person not the disease

- Many spoke of the difficulties when care professionals only focus on the disease and not the person.
- Care professionals at times had preconceived ideas of what dementia looked like and made judgements based on these beliefs, often with little consultation with the person or family. Such as, experience of being admitted to hospital and upon learning of dementia diagnosis, hospital staff issuing a Do Not Attempt Resuscitation (DNAR) order. This was issued without consultation with the next of kin or person living with dementia despite being very independent and able to express views and preferences.

FINDINGS: GROUP 2

The group explored three key areas to deliver palliative and end of life care for people affected by dementia. These areas were identified in national guidance on care for people with dementia as key for high-quality care. But, understanding on how to deliver well was less clear. We wanted to understand what these areas looked like for the group, who would they involve and how could they take place. The three areas included: ‘ongoing medical review’, ‘medical management of symptoms, pain and multiple conditions’ and ‘continuity of care’

ONGOING MEDICAL REVIEW – ‘What would this look to you?’

- Dementia is not just ‘an old person’s disease’. People living with dementia and their carers want care professionals to recognise that dementia is not just ‘forgetting’. It affects the whole person including physical abilities.
- Ongoing medical reviews need to happen regularly and recognise different types of dementia. Care professionals need to ask questions and use tests appropriate to the type of dementia.
- Ongoing medical reviews should provide information and reassurance to the person living with dementia and their carers.
- Ongoing medical reviews will allow people living with dementia and their carers to recognise and monitor the progression of the dementia. They could also empower carers to continue caring at home.
- Carers want opportunities to meet the care professional doing the medical review on their own for them to raise issues and ask questions. This includes knowing more about the type of dementia and what to expect as it progresses. They may not want to do this in front of the person with dementia for fear of causing distress.
- Dementia services could learn from other disease groups. Such as cancer care, which may provide better access to information with someone to ask questions to.

MEDICAL MANAGEMENT OF SYMPTOMS, PAIN AND COMORBIDITIES – ‘What does this mean to you?’

- It is important to have information about the specific type of dementia to know what to expect as the dementia progresses and how to manage the symptoms.

CONTINUITY OF CARE AND CARE CO-ORDINATION – ‘What does this mean to you?’ and ‘Who would this involve?’

- People living with dementia can find it difficult talking to a new care professional as they are a stranger. This often involves re-telling information which can be distressing.
- Care professionals must always address the person living with dementia in appointments. Too often questions are asked directly to the carer.
- Continuity of care is important. It is understood as being seen by the same care professional or the same small group of care professionals.
- Continuity of seeing the same care professional (or a small number of professionals) means that the person living with dementia and their carer are known. The group saw this as good care as there is an understanding of the person.
- Good coordination of care comes from regular and clear communication such as, between a person’s GP, consultant and others involved in a person’s care.

FINDINGS: GROUP 3

This group explored what is important to deliver palliative and end of life care for people with dementia living at home, such as 'what is home care', 'how to deliver' and 'moving from home to hospital when unwell'.

HOME CARE – 'what does this look like for you'

We started by introducing a story of a man with dementia who lives at home with his wife and was visited at home by the GP for a routine check-up. The man told the GP that he had stopped taking his medication as they disturbed his sleep. His wife is worried that stopping his medication is affecting his balance and walking. Using this story, we asked the group what care at home might look like.

Who is part of home care:

- Care professionals, such as district nurses
- Professional care workers
- Family carers - Support from other family carers to relieve the main carer.
Without this support carers could not do other things.
- Mental health nurses

Where:

- In the home of the person living with dementia or carer.
- Involves care professionals, like district nurses and other family carers coming into the home to support the person living with dementia and their carer. This may include activities of daily living, such as assisting with dressing, support with making food, reminding the person to take their medication.
- Day care centre - to support the person living with dementia. Day care centre helps to maintain a social life for the person. It also gives the carer a break to pursue other things, like paid work.

Amount of support:

- The amount of support varied, ranging from once a day to multiple times a day, to up to 20 hours a week.
- The amount of support needed depended on the situation of the person and carer which might vary from week to week.

What is key to home care:

- *Communication:* The group highlighted the importance of communication between care professionals and the family carers. Such as, district nurses should always involve the carer when planning changes to care.
- *Flexibility:* Carers who are coming in to provide support need to be flexible. They need to recognise that the amount of support needed may vary on a weekly basis.
- *Information provision:* Care professionals should make information accessible to people living with dementia and their carers. The group felt they often received information about services, support and care from joining a voluntary group and members sharing their experiences and knowledge, rather than from care professionals. One person reported after being told they had dementia never seeing the doctor again to talk through what this meant.
- *Allowing carers to be involved in discussion:* The group reported experiences of care professionals not listening to the carers and what they were saying. Care professionals were experienced at times as being dismissive about the situation of the person living with dementia. This eroded trust in the relationship with the care professional. It is vital for care professionals to not underestimate or underplay the role of carers in supporting the person living with dementia.
- *Financial and psychological support for family carers:* Carers were at times working both as the main carer for the person with dementia and in a paid job to maintain the household finances. They reported struggling to get support for the person living with dementia while they away from home at work, and when support was received this was often too minimal. Trying to manage this situation caused considerable stress and worry.

A SUMMARY OF OUR FINDINGS

- All care for people living with dementia should be person-centred. Focussing on the person, not the disease, and flexible to that person's needs that may change day to day.
- Care professionals need to have a relationship with people living with dementia and their carers. Carers need to be listened to. Care professionals need to understand that carers are the people who know the person living with dementia best and can offer the most insight. Carers needs must also be considered in care for the person living with dementia.
- People living with dementia, and their carers, require more information from care professionals about the type of dementia and its likely progression, and the support available to priorities and concerns as dementia progresses.

NEXT STEPS

The researchers will use the findings on the priorities identified by the group to refine the vital components to deliver high-quality palliative and end of life care for people living with dementia and their families. This will inform our model of palliative and end of life care for people living with dementia in the community at home or in a care home and managing care when moving between (care) home and hospital.

Please email us with any comments or further thoughts at dop.embedcare@ucl.ac.uk

We hope to see you again in a few months with an update on our work. We will use this opportunity to consult with you further on our work.

The research team would like to take this opportunity to thank all of those who attended. We appreciate you sharing your time and experiences with us. The discussions and your feedback are invaluable to our work.

STAY IN TOUCH WITH THE TEAM



Dr Catherine Evans
Co-Lead for the programme
Catherine.evans@kcl.ac.uk

Dr Charlotte Kenten
Programme Manager
c.knten@ucl.ac.uk



Dr Clare Ellis-Smith
Workstream Lead
Alexandra.c.ellis-smith@kcl.ac.uk



Ali-Rose Sisk
PhD student
Ali-rose.sisk.19@ucl.ac.uk



Tofunmi Aworinde
Research Assistant and PhD student
Jestofunmi.aworinde@kcl.ac.uk



India Tunnard
Research Project Coordinator
India.tunnard@kcl.ac.uk



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