

Living well as dementia progresses: a MOOC for all

Family carers are often left in the dark about the true nature of dementia and its challenges. **Marie Poole** and colleagues chart the development of a new free “massive open online course” – or MOOC – for carers on living well as dementia progresses

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It is well understood that families supporting someone with dementia face many challenges. As dementia advances, family carers often struggle to get co-ordinated care and effective support from primary care. They may not understand that dementia is a life-limiting condition and will often find that primary care services prioritise the needs and wellbeing of the person with dementia over their own (Bamford *et al* 2018; Poole *et al* 2018).

Current guidance recognises the importance of offering carers opportunities to learn more about dementia, to enhance their own wellbeing and the care of the person they support (NICE 2018).

Based on findings from the SEED project (Supporting Excellence in End of life care in Dementia), a five-year research programme, we have developed a new, free, “massive open online course” (MOOC) with the aim of helping carers of people living with dementia to feel more prepared, confident and supported as dementia progresses towards the end of life.

The course, Dementia Care: Living Well as Dementia Progresses, has six key objectives:

- understanding the progression and symptoms of dementia
- involving the person with dementia in decisions
- signposting to services that may be useful to families as the illness progresses
- identifying sources of support for carers and people living with dementia across a range of different settings
- exploring ways to ensure care and communication are person-centred
- determining ways to maintain quality of life and ensure comfort for the person with dementia.

Based on seven themes supporting good end of life care identified through SEED research (Bamford *et al* 2018), learners can explore three key areas in detail. These are:

Week 1 – Conversations around care, comfort and future changes: helps learners to start understanding dementia as a progressive illness and planning for future changes (including decision-making).

Week 2 – Ensuring care and comfort: supports learners to recognise and respond to changing cognitive, emotional and physical needs as dementia progresses.

Week 3 – Supporting carers, recognising me: encourages carers to understand their own needs, including how to deal with difficult emotions and how they might feel better supported and equipped as carers.

In the first run of the course, almost 2,500 people from over 100 countries (see map below) joined to find out more about key issues of advancing dementia. An interactive element supports learners to comment on their learning experience through each step of the course. We share some of their insights, motivations and reflections on what they have learned and whether this reflects the key objectives of the course.

Developing the course

Developing a MOOC was strongly supported by the SEED project patient public involvement (PPI) team and considered a novel way of translating research findings from the project into an accessible and practical educational resource. A key ingredient was a collaborative co-design approach (Robert & Macdonald 2017) involving family carers of people with dementia, health and social care professionals and the research team, led by co-author Professor Dame Louise Robinson.

The course is hosted by Futurelearn (2019),



Countries participating in MOOC

which has an ethos of online learning through storytelling and discussion. Family carers and health and social care professionals from the SEED project were invited to participate in short videos to tell their stories, reflecting a diverse range of expertise and experiences. Quizzes and tips are also integral to the MOOC, which encourages carers to exchange views to promote peer support and provide an interactive learning experience.

We supplemented our research findings with clinical observations and points raised in discussion with participants to create examples of what people with dementia described to us as bringing them comfort and then presented these through quotes and images. Photographs of some of our participants with dementia were also used to illustrate their presence on the course.

Before we launched the first MOOC in spring this year – we will be re-running it at various stages – we obtained critical feedback from family carers, clinicians, SEED researchers, online learning experts and others. We asked them to comment on content, appropriateness of language, missing topics and the practicalities of completing the course, and, since the feedback was positive, we had only to make minor revisions. Quality assurance checks were also conducted by Futurelearn.

Key objectives

We began by outlining the six key objectives and now we will set out how they relate to the content of the course.

Understanding symptoms

Evidence suggests that many people find it difficult to understand and recognise signs and symptoms of dementia progression (Samsi & Manthorpe 2014; Goodman *et al* 2015). They may not grasp that dementia is a terminal condition (Bamford *et al* 2018; Poole *et al* 2018) and may not be told by GPs (for example) that this is the case (Vassilas & Donaldson 1998).

As dementia progression underpins the course content, the first week introduces learners to the common signs and symptoms seen as the illness advances. This is then explored in more detail in week two, where learners can find out how people are cognitively, emotionally and physically affected by advancing dementia.

Through comments on the course pages, many participants confirmed that the course gave them a better understanding of what to expect and explained some of the changes they had already experienced. Some said these changes were daunting, but many felt that they were better prepared to face them.

Involvement in decisions

As dementia advances, making decisions can become increasingly difficult as changes in the brain affect the processing of information and communication. People with dementia may be excluded from decision-making even when they could still be involved.

Mental capacity, best interests and the timing of



Left: Advanced nurse practitioner Julie Young with Bill, a SEED participant. Below: pages from the MOOC

WEEK 1: CONVERSATIONS AROUND CARE, COMFORT AND FUTURE CHANGES

Introduction

We help you to think about and prepare for care and comfort now, and in the future, as dementia progresses. We introduce our motivation for making this course and find out more about you.



1.1 WELCOME TO THE COURSE VIDEO (02:33)

1.2 MEET JACK VIDEO (02:23)

1.3 WHAT DO WE MEAN BY CARE AND COMFORT? VIDEO (03:00)

1.4 WHAT DO 'CARE' AND 'COMFORT' MEAN TO YOU? DISCUSSION

1.5 EXPLORING WHAT BRINGS COMFORT TO DIFFERENT PEOPLE EXERCISE

Dementia as a progressive illness








How life may change for you and the person you support.



1.6 COMMON BELIEFS ABOUT DEMENTIA AND ITS PROGRESSION QUIZ

1.7 RECOGNISING HOW DEMENTIA PROGRESSES VIDEO (05:32)

1 → Each of these images is an example of something that provides comfort f...

			
A walks	B birdfeeder	C fluffy socks	D a blanket
			Finished
E mobile phone	F daily routine	G singing	H Finished



References

- Alzheimer's Society (2017) *This is me* (second edition). London: Alzheimer's Society.
- Barnford C, Lee R, McLellan E, Poole M *et al* (2018) What enables good end of life care for people with dementia? A multi-method qualitative study with key stakeholders. *BMC Geriatrics* 18(1) 302.
- Boots LMM, De Vugt ME, Van Knippenberg RJM, Kempen G, Verhey FRJ (2014) A systematic review of Internet-based supportive interventions for caregivers of patients with dementia. *International Journal of Geriatric Psychiatry* 29(4) 331-344.
- FutureLearn (2019) *Learning on FutureLearn: An effective way to learn*. Webpage at www.futurelearn.com.
- Goodman C, Froggatt K, Amador S, Mathie E, Mayrhofer A (2015) End of life care interventions for people with dementia in care homes: addressing uncertainty within a framework for service delivery and evaluation. *BMC Palliative Care* 14(42) 1-9.
- Kitwood T (1997) *Dementia Reconsidered: the person comes first*. Buckingham: Open University Press.
- McKechnie V, Barker C, Stott J (2014) The effectiveness of an Internet support forum for carers of people with dementia: a pre-post cohort study. *Journal of Medical Internet Research* 16(2) e68.
- National Institute for Health and Care Excellence (2018) *Dementia -*

advance care planning conversations are therefore a key focus in week one of the course. Based on research findings, professional advice and carers' personal experiences, the course provides tips and advice on how learners might broach "difficult conversations" around planning for end of life care, as well as explaining the law and linking to relevant documents in easy to read formats.

Participants commented that the MOOC had clarified a complex subject, but it was the personal narratives shared by individuals which had reinforced messages about the value of advance care planning and the pitfalls of not making decision-making arrangements before people become unable to make decisions themselves.

Signposting to services

Articles and videos in the MOOC signpost carers to a range of support services for the person with dementia and their family. The course was developed based on UK findings, and many websites link to resources and services in this country. However, some signposts and links to non-uk organisations were included to ensure relevance to international learners.

Learner comments continue to assist in building this part of the course. Learners exchanged stories about services which had been helpful, or otherwise; those in the UK highlighted regional variations, while international learners pointed to gaps in their own countries and suggested additional resources which are being incorporated into future versions.

Identifying sources of support

Sources of support from well-known national and international organisations are presented as the course unfolds, including direct links to website resources, free helplines and online forums. Week three specifically focuses on carer support and gives some emphasis to the role of technology, where coverage is potentially global rather than local as is often the case with services.

Online forums can provide carers with a space in which to honestly share experiences (McKechnie *et al* 2014) and we found that learners formed their own supportive community with carers from a range of countries and circumstances, sharing stories, emotions and



Left: Comfort care planning at a review meeting.

Above: word cloud image of carer feelings.

Right: Participants at a care home meeting to discuss the MOOC project.

Below right: reviewer comments on MOOC

practical advice.

During week three we provided a word cloud based on carers' emotions, derived from our research and clinical experience (see image). Some learners explained that sharing difficult emotions in a safe place was cathartic and enabled them to reflect on their situation in a way they had not previously done.

Person-centred care

The values of person-centred care (Kitwood 1997) underpin the MOOC, which encourages learners to use planning documents to support communication and which promote these values. In weeks one and two, carers are introduced to key documents, such as *This is me* (Alzheimer's Society 2017) and the "comfort care daisy" (Young *et al* 2017), and shown how a short biographical profile of the person with dementia can be completed.

Many carers responded positively to having a practical tool for "comfort care planning" at the end of life. Learners shared their fears and barriers to planning ahead and felt that the document templates, advice and tips provided by the course and fellow learners gave them the confidence to proceed.

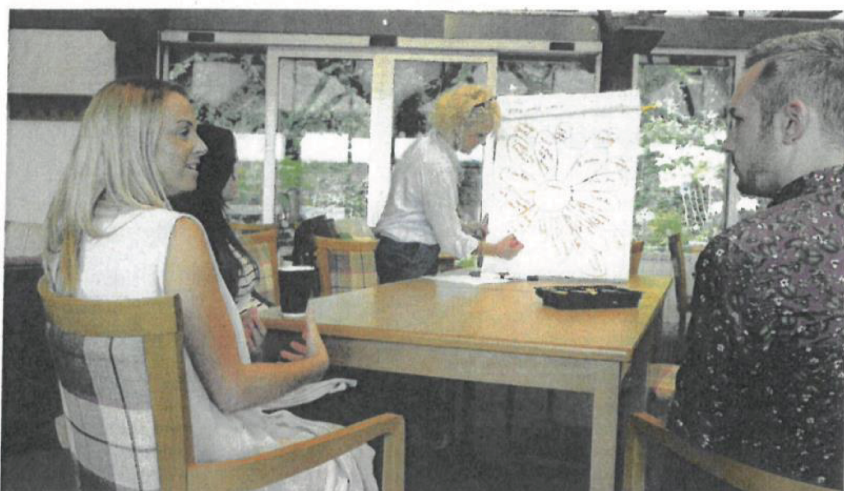
Maintaining quality of life

Maintaining quality of life and ensuring comfort for the person living with dementia is the focus of week two, while helping carers to maintain their own quality of life is emphasised in week three.

In the early stages of the course, we asked learners to share their personal perspective on what care and comfort meant to them and the person they support. The aim was to get carers to reflect on how best to meet changing needs and our request attracted over 300 responses, such as familiarity, love, happiness, expression of autonomy, recognition of individuality and freedom from pain and distress.

Week two goes on to explain some of the common cognitive, emotional and physical changes caused by dementia progression, helping learners to understand and be prepared for them. We then encourage learners to think about meeting these changing needs in the light of a comfort care planning approach.

In week three carers reflect on their own



wellbeing needs and how to maintain their quality of life. Based on our research findings, we look at key factors impacting on wellbeing such as understanding complex emotions and coping with grief. With the help of carers' own stories we consider how to take care of health and wellbeing, and how to access support.

General feedback

Over half of learners in our initial cohort were aged over 46 and almost a quarter were over 65, suggesting that online sources of support are relevant to the family carers who are most likely to be providing care for people with dementia (Boots *et al* 2014). Almost 3,000 comments were generated in feedback and more than 90% of participants were happy with the course.

Many learners were open about the struggles they had faced caring for someone with advancing dementia. They came together to build a supportive global network through sharing their diverse experiences and giving encouragement and advice to other learners. Some participants were care providers rather than family carers, although their motivations for joining the course were similar, namely to better understand dementia and provide better care. Comments suggest that a small number of people with dementia took part; their principal reason for joining was to prepare for the future by better understanding what may be personally in store.

Next steps

Dementia care MOOCs have started to come into their own; there are a number of others available, for example from the University of Tasmania, University College London and Lancaster University.

At Newcastle University we now have two such MOOCs – the one we have described here focusing on living well as dementia progresses and our successful sister MOOC, which introduces family carers to dementia and how to care effectively from the earlier stages.

Both courses are free of charge and we hope dementia care practitioners will encourage family carers to take full advantage of the learning and support they have to offer. They can be accessed as follows:

Dementia Care: Living Well as Dementia Progresses
www.futurelearn.com/courses/comfort-care

Dementia Care: Staying Connected and Living Well
www.futurelearn.com/courses/dementia-care

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assessment, management and support for people living with dementia and their carers. London: NICE.

Poole M, Bamford C, McLellan E, Lee RP *et al* (2018) End-of-life care: A qualitative study comparing the views of people with dementia and family carers. *Palliative Medicine* 32(3) 631-642.

Robert G, Macdonald AS (2017) Co-design, organisational creativity and quality improvement in the healthcare sector: 'designerly' or 'design-like'?, in Sangiorgi D & Prendiville A (eds) *Designing for service: contemporary issues and novel spaces*. London: Bloomsbury.

Samsi K, Manthorpe J (2014) Care pathways for dementia: current perspectives. *Clinical Interventions in Aging* 9 2055-63.

Vassilas CA, Donaldson J (1998) Telling the truth: what do general practitioners say to patients with dementia or terminal cancer? *British Journal of General Practice* 48(428) 1081-1082.

Young J, Gilbertson S, Reid J (2017) Comfort care plans: a collaborative project. *Journal of Dementia Care* 25(6) 18-20

Palliative Care Consultant:
 "Nothing too upsetting. Videos are excellent and just about right length. Views balanced. Clearly recorded."

Current and bereaved carer: "I always find personal engagement from real people more engaging and the videos give this. I think the carers stories are particularly relevant to everything I have experienced and am experiencing."

PPI expert and bereaved carer:
 "Particularly liked the opening video, showing the people who would be talking in the videos."

Current carer: "I think the course is really good. It is clear and easy to follow. I think it strikes the right note – not overly simplified, but also tackling difficult subjects in a straightforward way... I have enjoyed taking part in the development of the course."

LTDS member: "I found it really interesting, thoughtful and considerate/respectful. It normalised dementia and took away some of the stigma and myths, making it real and human, without it being dramatic or emotional. Well pitched, with excellent resources."

Current carer: "I did do the quizzes and thought they helped to cement understanding."