

# End of life care: resources to strengthen support

As more people die with dementia, end of life care discussions are growing in importance. **Alastair Macdonald** and colleagues report on their study and explain how co-designing new resources could help to strengthen support at the end of life

Over the last decade there has been considerable national effort to help people with dementia and their families “live well” through a focus on earlier diagnosis and intervention (Alzheimer’s Disease International 2011; Department of Health 2009). But with increasing numbers of older people dying with, or from, dementia (Public Health England 2016), it is essential that they receive good quality care throughout their illness, including towards the end of life (NICE 2015).

Research focused on improving dementia care should involve people living with the condition and their families, in addition to care professionals. Facilitating such engagement with people with severe dementia is challenging as people’s memory and speech deteriorates (Alzheimer’s Disease International 2016) and families may find talking about end of life issues upsetting.

So it is particularly important for people with dementia to have the chance to talk about their wishes and beliefs about their future care while they are able to do so, enabling their family and the professionals working with them to make decisions on their behalf confidently when they are no longer able to do so themselves (Alzheimer’s Society 2017).

These discussions are usually called advance care planning and people with dementia and their families who take part in them must feel assured that their wishes and preferences will be acted on. Formally writing their wishes and preferences down, and sharing them with care professionals, may assist (National Council for Palliative Care (NCPC) 2015).

Even so, research has shown that having such sensitive discussions about planning ahead is difficult; health professionals struggle to find the right time while patients and families may be reluctant to write their wishes down in case they change their minds (Dickinson et al 2013; Robinson et al 2012). There

appears to be a need for resources or tools to help initiate early discussions about future care planning in dementia, not only for families living with the illness but for care professionals as well (NHS England 2017).

## Supporting Excellence study

Internationally, research looking at improving end of life care in dementia is increasing but is still limited in the UK (Van der Steen 2010). One of the largest studies is the Supporting Excellence in End of life care in Dementia programme (SEED, <http://research.ncl.ac.uk/seed/>), which is exploring how best to enable both service providers and commissioners (Amador et al 2016; Lee et al 2015) to deliver better quality,

## Key points

- End of life care planning discussions are hard to have and practical resources are needed
- Existing resources focus on one aspect of care planning rather than drawing all aspects together
- A Care Plan Guide (CPG) prototype was developed, bringing a wide variety of planning resources together in one tool
- Co-design workshops, including people with dementia and their carers, developed the CPG prototype
- Improvements made following workshops, both to print and app versions, included navigation, colour contrast and type size
- Different stakeholder groups – people with dementia, carers, and professionals – asked for different kinds of changes
- User engagement at all stages of technological development is now advocated as an extension of person-centred care principles.

*Alastair Macdonald is professor and Sandra Neves is research fellow at the School of Design, Glasgow School of Art; Emma McLellan is research assistant and Marie Poole is junior research associate at the Institute of Health and Society, Newcastle University; Karen Harrison-Dening is head of research and evaluation at Dementia UK; Sue Tucker is an Alzheimer’s Society Research Network volunteer; Claire Bamford is senior research associate at the Institute of Health & Society, Newcastle University; and Louise Robinson is professor at Newcastle University Institute for Ageing and Institute of Health & Society*

community-based care to people with dementia towards the end of life. Findings from a large qualitative study identified seven key components which contributed to the provision of good quality end of life care in dementia (Bamford et al 2017). These are listed in figure 1 opposite.

Using these findings, the SEED study developed a dementia nurse-led intervention which is being tested in primary care settings. The data also suggested the need for a care resources kit, containing current and possibly new resources, targeting the seven key components. We thought it could help dementia nurse specialists deliver the intervention, work more effectively with patients and their families, and improve the knowledge and skills of patients’ usual health care teams.

This paper describes how the SEED team used a co-design approach, based on previous successful research (Macdonald et al 2012; Robinson et al 2009), to work with people with dementia, their families and professional carers to create a new resource to support

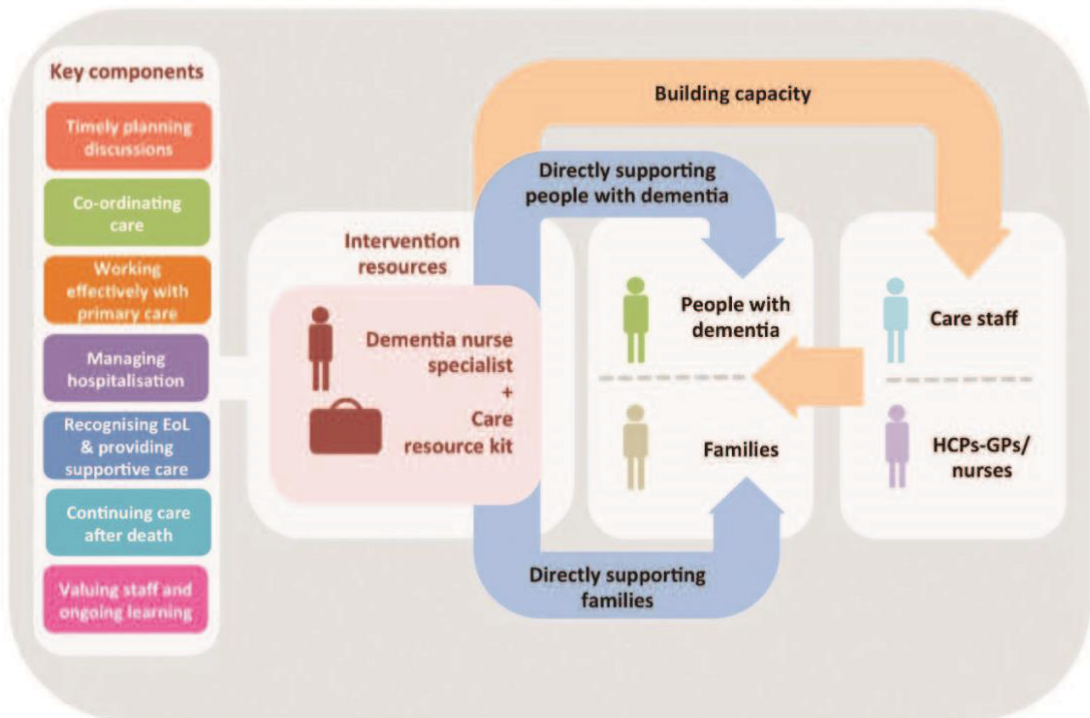


Figure 1: The SEED intervention

discussing, making and documenting plans for future care, particularly towards the end of life.

Development of the new resource comprised two separate but linked pieces of work which progressed concurrently, one informing the other:

- review and mapping of existing resources to assist people with dementia and their families or carers to discuss the end of life
- in the light of gaps in existing resources, a co-design process to develop a new resource.

### Mapping existing resources

Resources were initially identified using specific search criteria, including “end of life care” and “dementia”, and by targeting key websites, for example Alzheimer’s Society, Alzheimer’s Association and the National Council for Palliative Care. Identified resources were reviewed and sifted by a small group from the research team with personal and professional experience of dementia care at the end of life. Resources were initially grouped according to:

- title and content
- relevance to one or more of the seven key components

- general end of life care or specific dementia end of life care content
- target audience (people with dementia, family carers, professionals)
- country of origin.

Format and availability (e.g. downloadable, free or paid for) were also considered as a measure of the accessibility of the resources to professionals and people with dementia and their families. Further exploration of resource content was then undertaken with a focus on quality to determine if the development of the resource was grounded in, or influenced by, research evidence.

In a final review process, the most appropriate existing resources were selected to include in our care resources kit. These were prioritised based on the following criteria:

- dementia-specific
- freely available
- UK-based
- grounded in evidence.

International resources for professionals were selected if they were high quality and had a strong evidence base. International resources for people

with dementia and their families were included if they were accurate, high quality and judged acceptable by lay members of the SEED team.

Our final list of resources demonstrated considerable variation in the quality and quantity available for the seven key components. A large number of detailed resources were found about “timely planning discussions”, but these were either targeted at enhancing professional knowledge and skills or, if patient/family focused, not presented in a simple, accessible manner.

Existing resources for people with dementia and their families also tended to focus on a single area of care planning; there was nothing available to help them bring together all aspects of care planning documentation and information in one place.

This suggested an area of development for our co-design team.

### Developing a prototype

A co-design approach was seen as integral to ensuring that meaningful and useful resources were created. An essential aspect of this approach, says the Design Council, is that it “goes beyond consultation by building and ➤

► deepening equal collaboration between citizens affected by, or attempting to, resolve a particular challenge. A key tenet of co-design is that users, as ‘experts’ of their own experience, become central to the design process” (2014).

Involving all relevant stakeholder groups, people with dementia, family carers, paid carers, doctors, nurses, support workers and occupational therapists, was an important aspect of our co-design approach. It comprised two stages:

1. Development of an initial prototype for the new resource via internal project workshops with i) the multidisciplinary SEED team, which included a patient and public involvement (PPI) representative, and ii) the project’s external PPI advisory group.
2. Refinement of the prototype through external workshops involving newly recruited participants from the key groups listed above.

Design-led researchers from the Glasgow School of Art, experienced in using co-design and stakeholder engagement for co-developing healthcare interventions, added to the more traditional dementia, palliative and nursing care specialists in the research team.

Our initial prototype was a Care Plan Guide (CPG) which brought together in one tool a wide variety of planning resources, including:

- lasting power of attorney (both health and welfare, and property and financial affairs)
- advance statement
- advance decision to refuse treatment (including non-resuscitation)
- making a will
- funeral planning.

Feedback from the SEED PPI advisory group suggested the need for a digital or web-based version, leading the design team to produce a model of an app which could be used alongside the printed version for testing in the subsequent co-design workshops.

### Co-design workshops

One group of professionals (registered nurse and support workers) was recruited from a specially designed community complex with six supported households, which aims to create a family atmosphere for older people requiring full-time care, including those with dementia. Potential participants



Figure 2: co-design workshop set-up

were identified through the service manager and invited to attend a co-design workshop.

Participants in two further groups were invited to take part with the support of the project manager at Alzheimer Scotland for Dementia Circle groups. A researcher presented our study to group members and provided information sheets and criteria for participation.

Of course, only people with dementia and carers who were willing to discuss end of life care participated in the co-design groups. Some people with dementia and their carers preferred not to engage and we cannot assume that their views are similar to those of people who did take part.

The format for each co-design workshop was similar (see figure 2 above).

A full-size mock-up of the print-based CPG was given to participants to mark up with their own suggested improvements. They could also try out the model app version of the guide. In the preparation of these mock-ups, guidelines were referred to for age and dementia-appropriate design (Dementia Engagement and Empowerment Project 2013a, 2013b; Knowles 2014). Participants were also each asked to complete a set of workbook questions to capture their individual comments on key aspects of the CPG.

### Workshop findings

Three co-design workshops were held with 20 participants in all: group 1 had eight support workers and one registered nurse, group 2 had two people with dementia, three family carers and two occupational therapists, and group 3 had two family carers and two people with dementia.

Participants indicated that the CPG, as a general concept, would not only positively address the intended purpose of facilitating timely planning discussions between people with dementia and their families and carers, but would also assist many others in similar situations.

The CPG structure was seen as helpful, in particular its overview, general introduction to each plan, details and links to further information, and the fact that information was kept in a single place together with the record of progress and decisions against each plan.

Suggested improvements, such as to navigation, the way colour was used to differentiate between sections, font size, and arrangement and amount of text, were embodied in further iterations of the CPG (both paper and app versions) for subsequent workshops. Initially, acronyms and formal legal language were used in the guide, but this was regarded as unhelpful and later revised.

Some individuals preferred the printed version to the app version, which they were either unable to use or uneasy about using. But tablet or phone-based interaction was regarded by younger people as convenient, enabling direct links to further web-based resources. Suggestions included customising the format and text-size, and voice-command features to enhance usage.

Each stakeholder group had particular interests typified in figure 3. For example, people with dementia tended to be concerned more about terminology and avoiding unfamiliar jargon, legibility, layout and navigation within and between sections. Family carers were more typically concerned with alternative formats such as websites and apps for more interactive and engaging discussions, and to enable access to further web-based resources. The concern of support workers and specialist nurses was typically more about how the resource could best help them to support family carers.

### Discussion

Our project set out to involve all key stakeholders in the co-design of resources for better quality end of life care. Our experience showed the process to be a positive experience for participants. The iterative evaluation of the paper and app mock-ups helped us identify early not only what was effective, but what was problematic and how features could be improved.

The SEED CPG was conceived specifically to speak directly to people with dementia and their families, so it

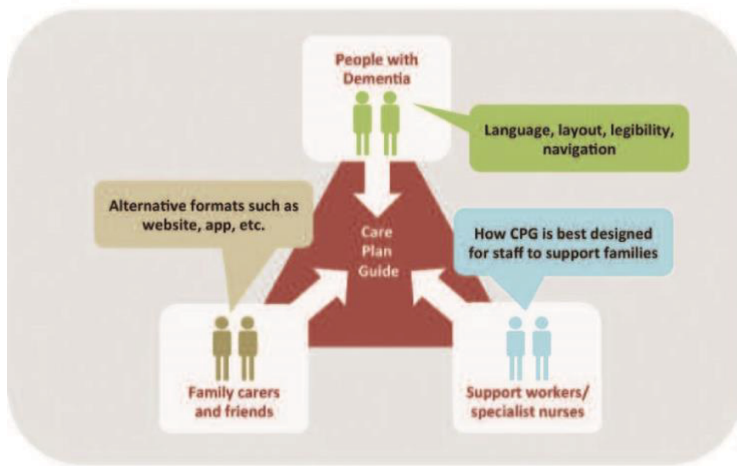


Figure 3. Focus of feedback from different stakeholder groups

had to be accessible and user-friendly in design and language. Interestingly, during the co-design stage, a number of resources aimed at this same audience and with the same general purpose were published, some from established organisations, but our feedback from family carers noted persistent issues with their format and language.

There has been a tendency for new resources and devices to be created for older people by technologists with little reference to the specific requirements of the end users (Brittain *et al* 2010). People with dementia have had very limited involvement in co design and co-development approaches (Span *et al* 2013; Topo 2009), especially in the area of assistive technologies which have the potential to improve quality of life and sustain independence.

Expectations are changing, however, with the realisation that older people can continue to contribute even when compromised by illness or disability. In the case of dementia care, international consensus recently advocated user engagement at all stages of technology development as an extension of the principles of person-centred care (Meiland *et al* 2017).

### Next steps

Our next steps will be to create a workable version of the CPG for user testing in terms of acceptability and feasibility. Despite our concerns and anxiety around the research topic, people with dementia and their families were enthusiastic and welcomed and valued research on this sensitive subject.

While our project advisory group raised

issues about “generational” comfort or discomfort with particular technologies, evidence (Joddrell & Astell 2016) suggests many more opportunities in future for interactive tablet-based technology for supporting decision-making for end of life planning in dementia care. ■

### References

- Alzheimer's Disease International (2011) *World Alzheimer Report 2011 – The benefits of early diagnosis and intervention*. London: ADI.
- Alzheimer's Disease International (2016) *World Alzheimer Report 2016 – Improving healthcare for people living with dementia: coverage, quality and costs now and in the future*. London: ADI.
- Alzheimer's Society (2017) *End of life care (Factsheet 531)*. London: Alzheimer's Society.
- Amador S, Goodman C, Robinson L, Sampson E (2016) UK end-of-life care services in dementia, initiatives and sustainability: results of a national online survey. *BMJ Supportive and Palliative Care*, published online 14 October.
- Bamford C, Poole M, Lee R, McLellan E *et al* (2017) Improving end-of-life care in dementia: key areas for improvement. *Innovation in Aging* 1 (supplement 1) 266.
- Brittain K, Corner L, Robinson L, Bond J (2010) Ageing in place and technologies of place: the lived experience of people with dementia in changing social, physical and technological environments. *Sociology of Health & Illness* 32(2) 272-287.
- Dementia Engagement and Empowerment Project (2013a) *Guide: Creating websites for people with dementia*. DEEP.
- Dementia Engagement and Empowerment Project (2013b) *Writing dementia-friendly information*. DEEP.
- Department of Health (2009) *Living with Dementia: a national dementia strategy*. London: Department of Health.
- Design Council (2014) *Innovative codesign project reinvents the hospital waiting room*. London: Design Council.

Dickinson C, Bamford C, Exley C, Emmett C *et al* (2013) Planning for tomorrow whilst living for today: the views of people with dementia and their families on advance care planning. *International Psychogeriatrics* 25(12) 2011-2021.

Joddrell P, Astell A (2016) Studies involving people with dementia and touchscreen technology: A literature review. *JMIR Rehabilitation Assistive Technologies* 3(2) e10.

Knowles D (2014) *Dementia Friendly Print*. Southend: Solopress.

Lee R P, Bamford C, Exley C, Robinson L (2015) Expert views on the factors enabling good end of life care for people with dementia: a qualitative study. *BMC palliative care* 14(1) 32.

Macdonald A, Teal G, Bamford C, Moynihan P (2012) Hospitalfoodie: An interprofessional Case Study of the Redesign of the Nutritional Management and Monitoring System for Vulnerable Older Hospital Patients. *Quality in Primary Care* 20(3) 169-77.

Meiland F, Innes A, Mountain G, Robinson L *et al* (2017) Technologies to Support Community-Dwelling Persons With Dementia: A Position Paper on Issues Regarding Development, Usability, Effectiveness and Cost-Effectiveness, Deployment, and Ethics. *JMIR Rehabilitation Assistive Technologies* 4(1) e1.

National Council for Palliative Care (2015) *Dementia: Achieving a good death for people with dementia*. London: NCP.

NHS England (2017) *Dementia: Good care planning*. London: NHSE.

NICE (2015) *Care of dying adults in the last days of life*. London: NICE.

Public Health England (2016) *Dying with dementia*. London: Public Health England.

Robinson L, Brittain K, Lindsay S, Olivier P (2009) Keeping in Touch Everyday (KITE project): developing assistive technologies for people with dementia and their carers to promote independence. *International Psychogeriatrics* 21(3) 494-502.

Robinson L., Dickinson C, Bamford C, Clark A *et al* (2012) A qualitative study: Professionals' experiences of advance care planning in dementia and palliative care, 'a good idea in theory but...'. *Palliative Medicine* 27(5) 401-408.

Span M, Hettinga M, Vernooij-Dassen M, Eefsting J, Smits C (2013) Involving people with dementia in the development of supportive IT applications: A systematic review. *Ageing Research Reviews* 12(2) 535-551.

Topo P (2009) Technology studies to meet the needs of people with dementia and their caregivers: A literature review. *Journal of Applied Gerontology* 28(1) 5-37.

Van der Steen J (2010) Dying with dementia: What we know after more than a decade of research. *Journal of Alzheimer's Disease* 22(1) 37-55.

### Acknowledgements

This article presents independent research funded by the National Institute for Health Research (NIHR). Louise Robinson is supported by a NIHR Professorship grant. Views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health. We are grateful to workshop participants and to Charlotte Emmett of Northumbria University for legal advice.