Developing a new booklet for family carers supporting someone who has eating and drinking difficulties towards the end-of-life

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Why a new booklet?

People living with dementia often face eating and drinking difficulties towards the end-of-life, which may include swallowing problems (Arcand, 2015). Family and friends report a lack of information about end-of-life in general and nutrition and hydration in particular (Papachristou et al., 2017). When the person with dementia lives at home, family carers sometimes find supporting their relative or friend with eating and drinking emotionally challenging. We have developed a new booklet that we hope will be of help. We also hope that practitioners will also find it useful and tell carers about it.

We did not want to develop something that would duplicate existing resources. We checked what was available by mapping existing resources through Google and other websites suggested by members of our patient and public involvement group and other experts. Through this search we found 13 resources focusing to some extent on eating and drinking towards the end of life in dementia. They varied widely on the amount of information and detail provided, varying from 4 to nearly 200-page long documents. Overall, they were general documents not focussing on eating and drinking difficulties at the end of life in dementia, not visually attractive (containing plenty of text or only black and white ink), and not designed for a lay audience. It was often unclear whether family carers had been consulted while developing these resources.

What was needed?

When we looked at the research evidence (Barrado-Martín et al., 2020) we found studies had mostly focused on professionals' experiences of supporting eating and drinking, often discussing tube feeding, in hospitals or care homes. However, people living with dementia's views at earlier stages of dementia had not been explored, nor the experiences of families of those living at home towards the end-of-life. We wanted our new resource to be based on evidence but also reflect the views and experiences of people living with dementia and their carers.

We interviewed 20 people living with dementia in the early stages, 24 family carers, and 20 professionals involved with offering advice and help with eating and drinking towards the end-of-life. We found people living with dementia were unaware of the potential eating and drinking difficulties that often appear towards the later stages of dementia. Similarly, family carers often had not known that such difficulties might arise and reported having struggled for some time with them.

So, the limited resources found from our mapping exercise, the research evidence, and the interviews with people living with dementia, family carers and professionals all suggested the need for a new resource for family carers and potentially useful for professionals as well. Our patient and public involvement group supported this idea.

Developing the new booklet

We used a co-design process with family carers and professionals. We incorporated family carers from diverse ethnicities, among 9 carers included in co-design groups, 5 were White British and 4 were non-White British. We recruited 18 volunteers to help our multi-disciplinary team develop the resource. These included former family carers, current family carers, speech and language therapists, General Practitioner (GP), nurse specialists in dementia, occupational therapist, geriatrician, and geriatric medicine registrar. We met as two mixed groups, twice for 90 minutes. We held an additional workshop with GPs and primary care professionals in a GP practice. After discussions at each meeting, the content of the booklet was further developed and refined. Between meetings, we talked further with members of our patient and public involvement group who were five additional family carers. Despite aiming to involve people living with dementia in the co-design process, we found during interviews that people living with dementia at the early stages did not want to know more about future potential eating and drinking difficulties. They would rather focus on the present, where most had not noticed major difficulties, and leave these conversations to happen later in their dementia journey once difficulties arose. Some pointed conversations about these difficulties would need to be held with carers instead, and others realised and accepted it would be their families making decisions on their behalf at that stage. Hence, it did not seem ethical to invite them to co-design sessions where they would be facing information about eating and drinking difficulties they could develop in the future.

Those involved in the co-design process were invited to email us with further feedback. Many participants, both professionals and carers emailed their suggestions to us, which were again used to refine the booklet. Finally, we approached experts individually to ensure the accuracy of clinical information and seek their endorsement.

What information was wanted?

During this study we identified some key topics that would need to be covered in the booklet as shown in Box 1.

Box 1

The main areas covered within the booklet are:
a) eating and drinking difficulties in dementia;
b) end-of-life (including when to flag up eating and drinking difficulties and eating and drinking challenges and strategies as well as top tips);
c) feeding options when there are swallowing difficulties;
d) things to discuss with professionals in future appointments;
e) support for family carers and;

f) further resources (where results from the mapping exercise were incorporated).

We used a mix of formats and presentation approaches in the booklet including: diagrams; quotes from professionals, carers and people living with dementia; top tips; flow charts; prompts and visual images. The format tries to be engaging whilst remaining comprehensive. Finally, the booklet was professionally designed by our funder Marie Curie.

Getting hold of the booklet

This booklet has been designed to be used as a free electronic resource in the first instance but can also be downloaded and printed from XXXXX. While we designed the booklet for family carers we hope that other supporting people living with dementia towards the end-of-life might find it useful. This could include clinicians, social care workers, dementia advisers and carer support group facilitators. We welcome feedback on the booklet.

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