DEVELOPMENT OF A RESOURCE FOR FAMILY CARERS OF PEOPLE LIVING WITH DEMENTIA WITH NUTRITION AND HYDRATION DIFFICULTIES TOWARDS THE END-OF-LIFE

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Background Family carers often struggle to support relatives living with dementia with nutrition and hydration towards the end-of-life. The aim of this study was to co-design with family carers and professionals an information resource to support family carers with this task.

Methods This study consisted of four phases: 1) qualitative systematic review; 2) a scoping review of existing resources; 3) 61 qualitative interviews with people with dementia, professionals, and family carers; 4) data synthesis and co-design development of an information resource.

We constructed a matrix synthesising the key findings from phases 1–3, devising themes of the key content across the evidence and providing summaries from each source of evidence. The matrix provided a transparent pathway of the evidence and content for the design process.

For the co-design phase 18 participants were recruited, 9 family carers and 9 professionals, split into two mixed groups. Four co-design workshops were conducted (two with each group) to develop the resource. During the workshops participants were presented with a summary of results from the matrix. Using modified nominal group processes and a series of tasks including categorisation and ranking we produced an initial prototype of the resource. The prototype was refined in subsequent co-design meetings and via email with individual participants.

Results The main areas covered within the resource include: eating and drinking difficulties in dementia; end of life; managing swallowing difficulties; points to discuss with professionals in future appointments; support for family carers and; further resources. Information is presented in a booklet with a mix of formats including: diagrams; quotes; top tips; flow charts; and visual images.

Conclusions This practical resource is the first to focus on nutrition and hydration towards the end of life in dementia care. This study provides a transparent stepwise approach to developing interventions, key for future similar studies.

DEATHBED ETIQUETTE-SUPPORT FOR BEING AT THE BEDSIDE OF THE PERSON YOU LOVE

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Background People in the UK are often uncomfortable with supporting the dying. As the population ages we are less likely to have supported a loved one who has died.

Methods The Centre for the Art of Dying Well, with palliative care experts and experts by experience, created a resource to support someone at the deathbed of a loved one. This was updated for the COVID-19 pandemic. This abstract describes the wider public engagement with this resource, using content analysis to evaluate public sentiment and understanding of it.

Results Release of the original Guide coincided with a report assessing preparedness for supporting someone who is dying, a podcast and a press release. It was widely quoted in the news media with reports in The Times; local and national news (Radio Oxfordshire, Talk Radio, Channel 5 News). Google Analytics demonstrated 7,341 unique visitors to the Guide under COVID-19 spending, on average, 2 minutes 2 seconds reading it. The version updated for COVID-19 was widely cited in the Financial Times, the Daily Mail, the Sun and Vatican News and an interview on 5 Live Radio. Based on an analysis of article comments, public sentiment and understanding were shown to