evidence & practice / dementia

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Why you should read this article:

- To understand that issues with nutrition are common in all stages of dementia
- To improve your knowledge of nutritional care for people living with dementia in care homes
- To learn how a nutritional guide might improve food and drink intake in this group of people

Improving the provision of nutritional care for people living with dementia in care homes

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Abstract

Issues with eating and drinking are common in all stages of dementia but are most prevalent in the middle and late stages of the condition. This can lead to unintentional weight loss and malnutrition. Previous work by the authors has attempted to understand how to improve the nutritional care of people living with dementia, and has resulted in the development of a guide for care staff to improve their knowledge and skills regarding nutrition in people with dementia.

The aim of this service evaluation was to investigate how use of the nutritional guide for care staff could improve the provision of nutritional care for people living with dementia in care homes. An online survey questionnaire was emailed to care homes who had received copies of the guide between November 2018 and August 2019. Completion of the survey was sought eight weeks after use of the guide. Forty-seven questionnaires were returned from staff working in care homes. Respondents reported that the guide had supported them to increase the appetite and fluid intake of people living with dementia. The guide prompted staff members to monitor for malnutrition using validated screening tools and provided strategies to encourage people living with dementia to eat more at mealtimes. These findings indicated that the guide has contributed to changes in the practice of care home staff when providing nutritional care for people with dementia.

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Keywords

appetite, care homes, dementia, end-stage dementia, fluid intake, hydration, malnutrition, neurology, nursing homes, nutrition, older people, undernutrition

Background

In the UK, there are an estimated 850,000 people living with dementia (Prince et al 2014). Driven by an ageing population, the prevalence of people living with dementia in the UK is predicted to exceed one million by 2025 and two million by 2051 (Prince et al 2014). Dementia is a collective term for a range of conditions characterised by progressive loss of cognition, leading to impaired functioning, communication, mobility and independence, and eventually death (Weuve et al 2014, National Institute for Health and Care Excellence (NICE) 2018). The most common subtype of dementia is Alzheimer's disease, which accounts for 62% of cases, followed by vascular dementia (17%), mixed dementia (10%), Lewy body dementia (4%), frontotemporal dementia (2%), Parkinson's dementia (2%), and other subtypes (3%) (Prince et al 2014). It has been reported that 70% of older people in care homes are living with dementia (Prince et al 2014).

Issues with eating and drinking are inevitable in all stages of dementia but are most prevalent in the middle and later stages (Alzheimer's Society 2020), and are a major factor contributing to malnutrition and the presence of behavioural symptoms (Roque et al 2013). These issues can include loss of appetite, loss of taste perception, dysphagia and change in food preferences (Kai et al 2015).

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FURTHER RESOURCES

Eating and Drinking Well with Dementia – A Guide for Care Staff www.rcni.com/eatingdementia Unintentional weight loss and malnutrition are common in people living with dementia and can occur at any stage of the condition (Kai et al 2015).

By the time someone with dementia moves into a care home, they may already be experiencing significant weight loss and other nutrition-related issues. This can cause further physical and mental deterioration, which means that supporting people living with dementia to eat and drink well can be a significant challenge for care and nursing staff. It is important that care staff have appropriate skills and knowledge to support eating and drinking for people living with dementia in accordance with the national Dementia Training Standards Framework (Skills for Health et al 2018).

With funding from The Burdett Trust for Nursing, the authors' previous research attempted to understand how to improve the delivery of nutritional care for people living with dementia in care homes (Murphy et al 2017). Themes identified from the research informed the development of a new conceptual model to guide improvements for nutritional care in care homes. Personcentred care was identified as the primary theme, alongside six other themes: availability of food and drink; tools, resources and environment; relationship to others when eating and drinking; participation in activities; consistency of care; and provision of information.

This research informed the development of a number of resources, as part of the awardwinning Nutrition and Dementia Care Toolkit (Bournemouth University 2020). This toolkit provides freely available resources such as films, workbooks and guides to deliver person-centred nutritional care in dementia. The resources are designed to improve healthcare staffs' knowledge and skills around nutrition and hydration.

A guide from this toolkit, Eating and Drinking Well with Dementia – A Guide for Care Staff, is one of the available resources. The guide is divided into three sections. Section one consists of information on:

- » Availability of food and drinks such as the importance of eating and drinking well for people with dementia, how to increase food and drink intake, how to plan a menu.
- » Tools, resources and environment, for example monitoring and screening for undernutrition, independence and dignity at mealtimes, care plans and food preferences, the dining environment, and the mealtime experience.

- » Relationship to others when eating and drinking, including family members, care staff and other residents.
- » Participation in activities such as practical activities used to stimulate appetite, evoke memories and create a sense of purpose.
- » Consistency of care, for example improved communication between all those involved with care and the provision and prioritisation of nutrition and hydration.
- » Provision of information, such as advising on access to evidence-based information, training, resources and current guidelines. Section two of the guide includes information on the Eatwell Guide (Public Health England 2018), monitoring food and fluid intake, food fortification, menu planning, 'finger food' and grazing menus, and the dysphagia diet. Section three provides checklists for healthcare staff to evaluate their practice. The guide does not address nutritional care in people with advanced dementia.

Aim

To investigate how use of the nutritional guide for care staff could improve the provision of nutritional care for people living with dementia in care homes.

Method

Respondents

Researchers sent hard copies of the guide to care homes in the UK who had requested it through contacts made at events where the guide was disseminated, and via email requests. Eight weeks after posting or emailing the guide, a questionnaire link was sent to the recipients, as well as to those who downloaded the guide online, to obtain feedback on how the guide was being used and how it had influenced nutritional care for people with dementia. Potential recipients who had downloaded the guide online provided their email address, role and consent to be contacted to receive the questionnaire. The intention was to contact those who had indicated that they were care home staff.

Questionnaire

The survey questionnaire was designed using the JISC Online Surveys platform (www. onlinesurveys.ac.uk) to capture information related to person-centred care, and the other six themes informed by the authors' previous research (Murphy et al 2017). Questions included what the respondent's current role was, how long they had spent in that role, any previous training they had received on nutrition for people living with dementia, and how frequently they were currently using the guide. The full questionnaire can be accessed at www.rcni.com/eating-dementia

A free-text question was included that enabled respondents to provide qualitative comments on their experiences or provide examples of how they had changed or improved practice. Those responding to the survey questionnaire included nurses, front-line care workers, care home managers, dietitians, trainers, speech and language therapists and dementia advisers.

Participation in the self-administered online survey questionnaire indicated consent to complete the survey. An information statement accompanying the survey indicated how data would be used.

Data collection

Data collection occurred between November 2018 and August 2019. There was no time limit given for respondents to complete the survey questionnaire. The findings are presented under the themes of:

- » Availability of food and drink.
- » Relationship to others when eating and drinking.
- » Participation in activities.
- » Consistency of care.
- » Provision of information.
- » Any other changes in the eating and drinking behaviours of people living with dementia.

These were the themes presented in an earlier evaluation (Murphy et al 2017), and were used to design the questionnaire for this evaluation.

Table I. Respondents' roles or job titles			
Role or job title	п	(%)	
Manager*	14	31	
Dietitian or related profession**	9	20	
Care worker	4	9	
Director	3	7	
Learning and development related	2	4	
Dementia adviser	2	4	
Other***	11	24	

*Manager includes general manager, assistant manager, registered manager, peripatetic manager and development manager **Dietitian or related profession includes community dietitian, dietetic assistant practitioner, dietetic technical instructor, dietetics lead, prescribing support dietitian, health promotion dietitian *** Other includes consultant, nurse, quality officer, team leader, cook, speech and language therapist, and catering support officer

Ethical considerations

Ethical approval was not required because this was a service evaluation that took the form of an online survey.

Findings

Quantitative

A total of 47 questionnaires were returned anonymously. It was not possible to determine the number of people the survey reached to determine the response rate, and it was also not possible to determine whether multiple questionnaires were returned from a single care home.

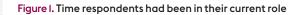
Table 1 provides a breakdown of the respondents' roles or job titles. Two respondents did not reply to this question, meaning that the figures shown in Table 1 are extrapolated from 45 respondents. The majority were managers and dietitians or from a related profession.

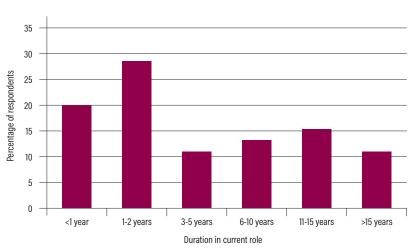
Figure 1 shows the time respondents had been in their current role. Two respondents did not reply to this question, meaning that the figures shown in Figure 1 are extrapolated from 45 respondents. The highest proportion – 13 out of 45 (29%) of the respondents – had been working in their current role for between one and two years.

Twenty-seven out of 41 (66%) respondents reported having some previous training in nutrition for people living with dementia from different sources and of differing quality and provision. The training was mainly dementia and nutrition-related short courses, continuing professional development courses, courses at university or national vocational qualifications. Only one care worker reported having undergone nutrition training, but no details were provided.

Key points

- Issues with eating and drinking are inevitable at all stages of dementia and are a major factor contributing to malnutrition and behavioural symptoms
- The authors developed a guide entitled Eating and Drinking Well with Dementia – A Guide for Care Staff
- This evaluation showed positive improvements in the delivery of nutritional care by staff following the use of this guide
- The guide can positively affect nutritional care practice in care homes for people living with dementia





Forty six questionnaires stated how often respondents used the guide. Table 2 provides a breakdown of how many of the 46 respondents used the guide at least once a month, once a fortnight, once a week, and rarely.

Qualitative

This section describes the findings related to the usefulness of the guide according to the themes.

Availability of food and drink

Thirty two out of 44 (73%) respondents reported that the guide enabled staff to increase the appetite of people with dementia. Examples of actions that were taken by staff included:

- » Increasing the availability and variety of snacks, finger foods and fortifying foods.
- » Sitting with residents during mealtimes.
 » Ensuring the availability of food in smaller quantities but more regularly.
- » Ensuring a relaxed atmosphere at mealtimes.
- » Trying various types of texture and flavour of food.
- » Linking food to activity, for example cooking.
- » Introducing different softer foods for residents with swallowing issues.
- » Providing food in an attractive and timely manner.
- » Encouraging family members to participate during the mealtimes.

One respondent reported to have adopted the 'at-risk' colour code to identify residents in need of more attention and encouragement with eating and drinking. The colour code is recommended in the guide for ease of identification of residents at risk of malnutrition, dehydration or both as identified by a red (high risk), amber (medium risk) or green (low risk) coloured label.

Some respondents reported using the guide as a resource to try different ideas. Another reported plans to organise an event to identify

Table 2. Frequency of the use by the respondents	of guide	•
Time interval	п	%
At least once a month	17	37
At least once a fortnight	12	26
At least once a week	9	20
Rarely	8	17

the areas of optimal practice mentioned in the guide. One respondent commented:

'I was just amazed at what little could be done to make such a big difference. One of my residents has put on a stone (around 6kg) of weight since we have been referring to the advice from the book' (Respondent 2).

Thirty one out of 44 (70%) respondents reported that the guide assisted them with increasing the fluid intake of people with dementia. Actions taken included:

- » Setting up drink stations and increasing the availability of drinks.
- » Offering drinks and reminding the residents frequently.
- » Providing an improved variety of fluids, such as lollies and milkshakes.
- » Developing a meal plan to provide extra fluids as part of their meal.
- » Making a fluid chart for regular monitoring.
- » Increasing the availability of a variety of cups and water bottles with different colours.
- » Documenting increased detail about residents' likes and dislikes in terms of types of fluid.

Respondents reported that the guide supported them with improving their hydration policies and practices. One described how their routine had altered as a result of using the guide:

'Just before I start my shift, I check the fridge and the cupboards where we keep patients' food and drink supplies. If I think more are needed, I call the catering department to provide more' (Respondent 46).

Thirty three out of 44 (75%) respondents reported that the guide prompted them to enhance monitoring for malnutrition. Actions taken to achieve this included:

- » Regular use and review of
- a nutrition care plan.
- » Regular use of a food and fluid chart.
- » Applying food-first principles. These are a way of adapting meals and snacks by adding small amounts of high energy and high-protein foods without increasing portion sizes.
- » Measuring residents' weight at regular intervals and documenting their Malnutrition Universal Screening Tool (MUST) score. The MUST is used to identify adults at risk of malnutrition (Elia 2003).
- » Use of an 'at-risk' colour-coding system to grade those at higher risk of malnutrition.
- » Increased discussion with nursing and care staff, chefs and volunteers about the importance of completing food charts.

Twenty seven out of 43 (63%) respondents reported that the guide enabled them to enhance the mealtime experience of people with dementia. They had implemented methods such as using specialist crockery and cutlery – for example, brightly coloured plates and lightweight drinking glasses – and increasing the availability of finger foods because many residents preferred eating with their hands. One respondent reported setting up a small, quiet dining area for those who did not want to eat with other residents. Others commented on the positive results of using the guide:

'I had a resident with low appetite, dehydrated, and [who] is now eating by themselves, only needs prompting, less urinary tract infection, gaining weight, family happy' (Respondent 3).

'We implemented a grazing menu for residents who walk around almost all day, and we used paper cones to facilitate ease of eating' (Respondent 18).

Relationship to others when eating and drinking

Thirty out of 44 (68%) respondents reported that people living with dementia were encouraged to eat more at mealtimes. This was achieved by sitting with them, assisting them to eat, and talking to them. Respondents also encouraged residents to eat with family members and communally, as well as providing protected mealtimes and a relaxed atmosphere. One described the change in her approach as follows:

'Before I tended to feed people with dementia. Now with my new awareness, I encourage them to eat and I supervise them, and promote their independence and dignity' (Respondent 46).

Twenty out of 44 (45%) respondents reported that people living with dementia were less anxious at mealtimes. The majority of respondents stated that they now attempted to make mealtimes less disruptive and quieter. Many of them reported playing background music, often chosen by residents. One care assistant shared her experience after using the guide:

'A lady will drink more if staff have a drink with her and change the colour of the cup so she can see it' (Respondent 45).

Participation in activities

Twenty five out of 42 (60%) respondents reported that people living with dementia were now involved in different activities that could increase their appetites such as cooking, bread making, preparing drinks, serving fish and chips, setting tables, and exploring life histories to find out about their food likes and dislikes. One respondent reported that carers were given additional ideas for appropriate activities with the support of the guide. Another described how the guide promoted participatory activities that improved food and drink intake:

'Through the hydration challenge, we increase fluid intake with extra fluids at 2pm each day. Mocktail Monday, teatime Tuesday, with special afternoon tea with extra cakes, watery Wednesday, with flavoured fluids, thirsty Thursday, usually with an ice-cream float, and fruity Friday, with a milkshake and fresh fruit. Residents and staff all participate and enjoy' (Respondent 20).

Twenty out of 42 (48%) respondents reported that people living with dementia were more independent and required less support at mealtimes. Increased use of finger foods, readily available snacks, use of coloured plates with a lipped edge, and providing specialised cutlery if needed, were the primary strategies reported as a result of using the guide. One respondent commented:

'One recent experience relates to a resident who was in hospital for three weeks. They were disorientated and not willing to mobilise on return and had lost weight. Smaller, enriched meals taken in the lounge with other residents together with regular encouragement at mealtimes and group activities helped a quicker improvement than seen in the past' (Respondent 35).

Consistency of care

Twenty five out of 41 (61%) respondents reported being involved in activities to promote consistency of care when attempting to improve the appetite of residents, such as staff training on dementia-related issues, optimal communication, speaking with family members abou residents' likes and dislikes, reduced disruption and a more relaxed atmosphere at mealtimes.

One respondent reported that the guide had been made available as a reference to all staff members. Another shared their experience on how optimal communication and consistent person-centred nutritional care as recommended in the guide enabled a resident to consume more:

'I found that one person became very distressed at mealtimes. On observation it appeared that she did not wish to sit at the table with other people. When she was offered her meal on her lap, she was happy and ate all of the meal' (Respondent 19). Eighteen out of 40 (45%) respondents reported that people living with dementia were more independent and required less support at mealtimes due to the improvements in the consistency of care.

Provision of information

Respondents reported that information on finger foods, food fortification, meal environment, changes in set mealtimes, types of diets, monitoring weight, and individual preferences for fluids and food was most useful. They also reported using fact sheets, 'top tips' for mealtimes, checklists, menu ideas, and the International Dysphagia Diet Standardisation Initiative (IDDSI) (2020) framework in practice.

The IDDSI is a framework that enables staff to describe fluid thickness and food textures. One respondent reported that, with the support of the guide, they offered simple courses on special diets and an introduction to the IDDSI framework to staff members. Respondents reported using the guide as a reference to develop the contents of these courses and train staff members.

Twenty four out of 39 (62%) respondents reported that improved access to evidencebased information had enabled them to change their practice, resulting in people with dementia experiencing improved appetite and fluid intake. Respondents reported that they had implemented '100-calorie boosters' food portions to promote weight gain (Bedfordshire Community Health Services 2020), and care staff reported being more proactive in terms of addressing fluid intake. Respondents also reported that with evidence-based information available in the form of the guide, dehydration was recognised more promptly and managed appropriately.

Any other changes in the eating and drinking behaviours of people living with dementia

Eighteen out of 47 respondents (38%) reported positive changes in the eating and drinking behaviours of people living with dementia. Examples included developing a preference for sweet foods, fewer cases of urinary tract infections, increased energy levels and mood, and increased interaction with staff and other residents.

One respondent reported that 'snack fridges' had raised curiosity about food among residents, and that a 'hydration challenge' had stimulated conversation among residents about fluid intake and had now become a social event. One nurse respondent also noticed that increased numbers of people living with dementia were looking forward to mealtimes.

Discussion

This evaluation showed positive improvements in the delivery of nutritional care by staff following the use of a nutritional guide. The quantitative and qualitative data suggest that the guide contributed to changes in the knowledge and practice of care home staff, leading to improvements in the eating and drinking behaviours of people living with dementia in care homes.

The primary reported improvements were increased appetite and fluid intake, enhanced mealtime experience and an increased participation in food-related activities. The effectiveness of using the approaches included in the guide to improve the eating and drinking behaviours of people living with dementia in care homes is supported by previous reviews, although no specific intervention was shown to be effective (Bunn et al 2016, Fetherstonhaugh et al 2019).

Respondents also reported that their knowledge had improved following their use of the guide. They also reported the use of improved practices such as effective monitoring of malnutrition, regular use of nutrition care plans, and documenting malnutrition screening scores using the MUST (Elia 2003).

Limitations

One limitation of this evaluation was the small sample size. Also, respondents were more likely to be engaged in delivering person-centred nutritional care for people living with dementia in care homes, which may have introduced bias into the responses to the questionnaire. However, the respondents represented a diverse set of healthcare-related roles in the context of dementia care and from care home providers across the UK.

Further studies should consider the effect of implementing the nutritional guide over a longer period to improve nutritional status and quality of life for people living with dementia.

Conclusion

The findings of this evaluation indicated that the use of a nutritional guide improved the appetite and fluid intake of people living with dementia in care homes. The use of this guide may also assist care staff to monitor and screen for malnutrition and improve their knowledge and skills. Overall, the guide has potential to make positive changes to nutritional care practice in care homes for people living with dementia. Otate vid expercium facerempor

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