

This is an Open Access document downloaded from ORCA, Cardiff University's institutional repository: <https://orca.cardiff.ac.uk/id/eprint/154786/>

This is the author's version of a work that was submitted to / accepted for publication.

Citation for final published version:

De, Diana and Thomas, Carol 2019. Enhancing the decision-making process when considering artificial nutrition in advanced dementia care. *International Journal of Palliative Nursing* 25 (5) , pp. 216-223. 10.12968/ijpn.2019.25.5.216

Publishers page: <http://dx.doi.org/10.12968/ijpn.2019.25.5.216>

Please note:

Changes made as a result of publishing processes such as copy-editing, formatting and page numbers may not be reflected in this version. For the definitive version of this publication, please refer to the published source. You are advised to consult the publisher's version if you wish to cite this paper.

This version is being made available in accordance with publisher policies. See <http://orca.cf.ac.uk/policies.html> for usage policies. Copyright and moral rights for publications made available in ORCA are retained by the copyright holders.



Enhancing The Decision Making Process when Considering Artificial Nutrition in Advanced Dementia Care: The Nurse's Role

Key words: End of Life Dementia Care, Nurse's Decision Making, Artificial Nutrition and Hydration

Reflective Questions:

- Do you feel better informed about the pros and cons of ANH during end of life dementia care?
- Reflect upon a time when you felt challenged by an end of life care decision, use the article content to critically analyse this further?
- Are you more empowered to lead discussions about hydration, nutrition and comfort feeding with families and fellow colleagues?
- Would the integration of decision making aids encourage you to become more involved?
- Could the incorporation of decision making aids enhance your role?

Abstract

During late stage dementia, nutritional problems often manifest and some families may request the implementation of artificial nutrition and hydration (ANH) therapies. If current trends in longevity continue, nurse's may encounter more patients with advanced dementia related illnesses. Practices relating to this however vary across Europe, Australia, NZ and Canada. In America, an estimated one-third of nursing home patients, with severe cognitive impairment have artificial feeding tubes inserted. Fearing a relative could experience extreme hunger or thirst, if not mechanically fed, tends to be the main driver behind requests for instigating these artificial methods.

Evidence to not do this however supports current UK practice, where artificial hydration is rarely given to older people with dementia; and this applies across all healthcare

environments. This paper therefore challenges the implementation of these invasive methods. It highlights how resorting to ANH does not necessarily lead to improvements in comfort, survival or wound healing. The risk of aspiration does not appear to significantly alter either.

Background

Dementia is a progressive syndrome causing extensive cognitive decline due to neurodegenerative diseases, (World Health Organisation (WHO) (2016). An estimated 850,000 people in the UK have dementia and this number is expected to double by 2040 (Department of Health, 2015). As our population ages, the risk of developing dementia increases too (Xie et al. 2008). More alarmingly, one in three adults over the age of 65 will die from dementia related conditions such as Alzheimer's Disease (Brayne et al. 2006). Dementia is therefore one of the leading causes of deaths in the UK, accounting for approximately 63,000 (12%) deaths in 2016 (Office for National Statistics, 2016); surprisingly more than those linked with coronary heart disease.

As the disease progresses, people with dementia often go on to develop complex physical and psychological needs. Advanced dementia is characterised by profound memory loss, inability to recognise family members, severely limited speech, incontinence, immobility and complete dependency in all activities of daily living, including eating and drinking (Mitchell et al. 2009). Problems with swallowing (dysphagia) become more noticeable as muscles and reflexes no longer work properly and eating and drinking can start to become much more difficult (Mitchell et al. 2015; Alzheimer's Society, 2018). This deterioration can often be extremely distressing for families to witness. Relatives can find themselves emerged in the unexpected situation of having to act as proxy choice makers, implementing emotionally charged decisions at the end of their loved one's life, based around ANH, as well as perhaps resuscitation. It would appear that awareness of these significant study findings though aren't always are being translated to relatives and carers. This has resulted in some patients with

terminal dementia, sometimes being inappropriately, long-term, enterally fed. For others, both ethically and emotionally, the fundamental choice between tube feeding and assisted oral feeding during end of life care can therefore become contentious. A literature review was undertaken to examine the evidence around the two counter stances to offer further support to families or carers when contemplating these feeding choices.

Search strategy

A literature search was undertaken using nursing databases CINAHL, EMBASE, Medline, PsychINFO and Pub-Med in order to maximise access to relevant studies. Searches were limited to literature published between 2010-2017 to reflect the most current evidence (Holland and Rees 2010). Search terms “dementia”, “advanced dementia”, “alzheimer*”, “alzheimer’s disease”; “enteral nutrition”, “percutaneous feeding”, “artificial nutrition”, “artificial hydration”, “percutaneous endoscopic gastrostomy”, “peg feeding”, “liverpool care pathway”, “improving comfort”; “randomised controlled trial”, “randomize*”, “survey”, “cohort study”, “observational study”, “controlled before and after study” were used in the initial searches. These terms were combined with “OR” and “AND” using Boolean operators to synthesise results. Further searches were carried out using the terms “goals of care”, “care goals”, “palliative assessment”, “advance care planning”, “decision aid”, and “improving decision*” combined with OR and AND to incorporate studies which tested decision aids. These initial searches returned a total of 372 papers.

Inclusion and exclusion criteria were then applied to then refine the search. English language articles were included. To ensure the highest quality research, only original peer reviewed research articles were accepted (Gerrish and Lacey 2010). Similarly, only articles using quantitative research were included, particularly randomised controlled trials (RCTs); as considered to be the gold standard in quantitative research (Holland and Rees 2010; Bench et al. 2013), in order to determine causality. Quantitative research was considered to be the most fitting as this type of research measures the relationship between causes and effects (variables) (Polit and Beck 2017; Gerrish and Lacey, 2010). The studies selected in the review all explored cause and effect relationships, for example the relationship between tube feeding and survival. Additionally, for the findings of research to have any real influence on policy and practice the

authors had to demonstrate that concepts had been adequately measured and that the relationship between two concepts were statistically significant (Parahoo, 2014). International papers were included from countries with comparable cultures to boost transferability of findings. The majority of quantitative papers came from America.

Several research papers met the inclusion criteria and were selected for further analysis using the Holland and Rees (2010) framework for critiquing quantitative data. Three main themes emerged from the literature related to the nurse's role in facilitating decisions around feeding options in advanced dementia: whether tube feeding (PEG) lengthens survival in advanced dementia; the effectiveness of a palliative care approach in improving comfort and effective interventions that improve end of life care decision making.

Excluded studies were qualitative studies, grey literature (dissertations) and studies which did not have a specific focus on advanced dementia and quality of life around eating and drinking. Studies which tested the effects of NG tube feeding were rejected and only one study was found which was more than ten years old and was also excluded (Alfarez-Fernandez 2005).

Artificial Nutrition and Hydration (ANH)

ANH can be done via a percutaneous endoscopic gastrostomy (PEG) or nasogastric (NG) tube feeding (enteral nutrition) or through intravenous or subcutaneous routes (parenteral nutrition) (National Institute of Clinical Excellence (NICE, 2017a). These methods, which are considered to be invasive and are not without significant risks; which would have to be weighed against the benefits of their use. Systematic literature reviews have identified these as increased risk of morbidity related to inflammation, infection, blockage and leakage around PEG feeding sites (Clarke et al. 2013, Brooke and Ojo, 2015, Candy et al, 2013, Goldberg and Altman, 2014). Many of the studies demonstrated that ANH did not improve nutritional status, reduce infections, prevent aspiration pneumonia, decrease pressure ulcer development or reduce hospitalisations (Finucane et al.1999; Meier et al. 2001; Teno et al. 2012a).

Not dissimilar to the use of these methods with infants, older patients with dementia are also likely to pull out tubes intended for feeding. NG feeding tube displacement, development of nasal pressure sores, tape reactions, alongside painful ostomy site, altered body image add to the discomfort around these ANH methods. In a bid to improve concordance, these methods have also been correlated with increased use of chemical or physical restraints, (Sampson et al. 2009). Similarly, intravenous hydration has been linked to fluid overload (Mc Callum et al. 2006). This in turn increases pulmonary secretions, urinary output, nausea and vomiting and oedema (Fine, 2006). All of which can have negative impacts on quality of life.

Literature

An American multi-centre study by Teno et al (2012b), involved a large sample of nursing home residents with advanced dementia, was undertaken to test whether PEG tube feeding prolonged survival rates. Findings uncovered that there was no difference in survival between the residents who were tube fed compared with those who were not. In addition, it concluded that earlier commencement of tube feeding was not associated with lengthier survival rates either. Another study which tested the effectiveness of PEG feeding on survival was conducted in Italy by Ticinesi et al (2016) who recruited 184 malnourished patients with advanced dementia discharged from a hospital ward. Findings in this European study not only showed that tube feeding was ineffective in prolonging life (after 18 months follow-up), but it also discovered a higher mortality rate in patients discharged from hospital on enteral feeding compared with those orally fed (70% vs 40%) (Ticinesi et al. 2016). It would therefore appear from recent observational studies, that the use of artificial nutrition (through PEG tube feeding) was not only ineffective in increasing survival, but may conversely, increase mortality. This can also be supported by extensive research by Finucane et al, 1999; Meier et al, 2001; Kuo et al, 2009; Sampson et al, 2009 and Teno et al, 2012b who have all highlight a number of harmful

effects of PEG feeding in patients with advanced stages of dementia. Therefore, nurses **need to** be advocating forgoing tube feeding in favour of simpler, alternative approaches.

Ethics

Ethical dilemmas such as patient autonomy versus best interests occur when patients and families or their carers argue for treatments which the evidence does not consider to be beneficial. Under the Mental Capacity Act (2005) **patients** and their **representatives** have the right to participate in decisions about their care. However, common law states that people can refuse treatment, *but not request it* (Burke versus General Medical Council, 2005). As ANH is considered in law to be a treatment, it cannot therefore legally be requested (Airedale NHS Trust v Bland, 1993). Nevertheless, **in some situations, it could become awkward to** overrule family decisions **after ANH has already been commenced** (Hanson, 2008). Research suggests **that physicians** are **sometimes** reluctant to forgo tube feeding than any other life sustaining treatments (Ahronheim et al. 2000; Hanson 2008). **However, hunger and thirst may not necessarily be experienced** (McCann 1994; Social Care Institute for Excellence (SCIE), 2018). **Nurses are well placed to remind their colleagues and provide reassurance to relatives by explaining that the body does not yearn or require nutritional supplementation at this terminal stage.** Nurses therefore could take a more lead role in advocating palliative care, communicating effectively with families evidence based literature and reminding members of the multidisciplinary team to avoid the potential adverse effects of ANH.

End of life Care

It is inevitable then, that nurses (in most settings) will care for someone with terminal dementia within their career and nurses have a professional, **legal and ethical** responsibility to deliver optimal care, including good end-of-life care (Nursing and Midwifery Council, 2015). There has however, been a growth in policy guidance and end-of-life initiatives in the UK to drive up standards for dementia care over the past decade. These include the Prime Minister's

Challenge on Dementia 2020 (Department of Health 2016), the National Institute for Health and Care Excellence (NICE) (2017) guidelines for dementia and the Gold Standards Framework (2008). Despite all this though, end-of-life care for people with dementia is **still often** seen to be inadequate (Sampson et al 2011).

Consideration needs to be given here to more recent developments in national dementia strategies, following The Neuberger report (Department of Health 2013) review, which led to the Liverpool Care Pathway for The Dying Patient (1997) **being phased out** in the UK. This has been replaced by a new palliative care pathway that was created in by England's Leadership Alliance for the Care of Dying People (LACDP 2014). It focuses on achieving Five Priorities for Care: recognising the dying phase, sensitive communication, involvement of families in decision making/advance care planning, responding to the needs of families and individual care planning. Priority five states that individual care plans should be agreed which includes **feeding and drinking**, symptom control and psychological, social and spiritual support. In places such as Wales, where the Liverpool care pathway was never adopted, the Welsh Government's current National Dementia Strategy (2018), also echoes these priorities.

Palliative Care

There would be no value or **emphasis to** prolonging life if suffering is apparent, so the aim of palliative care **should focus** on alleviating pain and improving comfort and quality of life (World Health Organisation, 2018). **Although dementia is not curable and is a progressive illness with distressing symptoms, with pain and agitation experienced in its advanced stages, it has not commonly been recognised as a terminal illness (Marie Curie, 2015). This could have meant that access to palliative care services may have been traditionally misunderstood (Sampson et al. 2006; Hughes et al.2007) and end of life symptoms sometimes poorly managed (Mitchell et al. 2009; Sampson, 2010). This alongside insufficient comprehension of the pathophysiology of the disease may have sometimes** led to distressing hospital

admissions or in some cases unnecessary interventions being instigated i.e. ANH (Thuné-Boyle et al. 2010). These may have been exacerbated by findings which revealed that some doctors can fail to recognise the terminal stages of dementia and may in some cases, overestimate prognosis (Mitchell et al. 2004). Quality of life in advanced dementia could however be improved when palliative care approaches are adopted. One such suggested approach is by comfort feeding (Palecek et al, 2010). This involves continuing to hand feed the patient provided it is not causing distress, providing regular mouth care, encouraging speaking with the patient and incorporating therapeutic touch.

Comfort Feeding

Comfort feeding involves offering food and liquids to patients by hand as long as it is not distressing (Palecek, 2010). Continuous interaction with the patient should be provided through regular mouth care (every two hours), conversation and therapeutic touch (Arcand 2015; Palecek, 2010). Symptoms of dry mouth should be managed with ice cubes and moistened swabs (Arcand, 2015). Regular reassurance should be offered to families who fear that the patient might suffer from hunger or thirst as research has shown that forgoing ANH in patients with severe dementia is not associated with high levels of discomfort (Pasma et al 2005). In line with the UK's national Gold Standards Framework (2008), which advocates continuing with assisted oral feeding, this argues for palliation over active treatment (as in tube feeding).

Study findings also demonstrate that a palliative care approach for people with limited nutritional intake in the advanced stages of dementia, is effective in both improving comfort and quality of life. A multi-site, randomised control study by Beernaert et al (2017) indicated that the implementation of a care programme (CAREFuL) for the last days of life significantly improved nurse assessed comfort. Similarly, another European study by Brännström et al (2016) carried out in northern Sweden in 19 residential care homes, also

used a palliative care programme as the intervention. This exploratory, controlled, before and after study tested the effectiveness of the Liverpool Care Pathway (LCP) (Ellershaw and Wilkinson 2011) (Swedish adaptation) compared with usual care on symptom distress and wellbeing in dying patients. Findings showed that dyspnoea (shortness of breath) and nausea were significantly reduced in the intervention area, using the LCP, compared with the control area, providing standard care, based on family members assessments. These findings would also influence a move away from invasive ANH methods. They also provide a solid base for nurses to develop confidence for advocating a more palliative approach. In addition, they could also support families and carers to make better management choices during advanced dementia care, when increased risk of malnutrition becomes a concern. Ascertaining whether a decision aid could enhance the nurses role, awareness or the quality of choice making around feeding options within advanced dementia should also be considered further here.

Decision Aids

Most of us would like to envisage that management decisions are reached collectively and always align with current literature and medical goals such as survival, function and comfort. In order to enable families to make evidence based informed choices around feeding and hydration options, it would therefore be deemed appropriate to take account of and share recent research findings with families more. This is considered an important pre-cursor for any conjoint decision making process to occur; an innate expectation, prior to any prescribed palliative regime becoming instigated.

Quality improvements in healthcare are initiatives which aim to make care safe, effective, patient-centred, timely, efficient and equitable (Institute of Medicine, 2001) and implementation of decision aids could be seen to provide such enhancements in palliative care. Discussion and information have been perceived as the most useful part of advance care planning with surrogate decision makers (Detering et al, 2010). However, there is also evidence

that those **families or carers** who view a video of a patient with advanced dementia, are those more likely to opt for comfort as their goal of care; compared with others who receive verbal information only (Vollandes et al, 2009).

In light of this, Hanson et al (2011) carried out a cluster randomised controlled trial, involving 256 residents with advanced dementia in 24 nursing homes in **America**. The aim was to ascertain whether a decision aid improved quality of feeding tube placement or assisted oral feeding decisions and communication between families, carers and health care staff. Families received an audio or printed guide on feeding options in advanced dementia, including information about dementia and the benefits, burdens and risks of feeding tubes and assisted oral feeding. The control arm of the study received routine care. Overall, the decision aid was found to reduce decisional conflict for proxies and increase knowledge and engagement about feeding options with nurses and doctors. Hanson et al, implemented another randomised trial of 302 nursing home residents with advanced dementia across 22 nursing homes was again conducted in 2017. This time the aim was to test **if care decision aids could improve choice making and communication for families of patients with advanced dementia**. Again, it was found that family carers experienced better end-of-life **collaboration** with health providers as a result of **integrating** a decision aid. Further findings revealed that palliative care was more likely to be included in treatment plans **if decision aids were incorporated, there were** fewer hospital admissions and there was more restrained use of medical orders around do not resuscitate(DNR). **It also led to reduced use of tube feeding**. Findings **would therefore** support that decision aids are valuable tools for nurses to **introduce** into shared discussions with families about end-of-life dementia care (Mitchell et al, 2001; Whelan et al, 2004). **Nurses, as patient advocate can therefore promote the alternate option of comfort feeding, over artificial, invasive tube assisted methods or non-feeding**. To help support this, the authors suggest the use of decision making aids. **Information guides, videos and structured discussions which have**

all been shown to be effective catalysts for progressive end of life mutually set care pathway goals. By implementing these, distressing symptoms such as discomfort, nausea and vomiting associated with tube feeding and malnutrition could subsequently be reduced. Using decision aids could therefore provide a more robust structure for nurses to instigate conversations and advance care planning around. Their inclusion could be critically debated more during palliative care training.

Training

In order to improve end of life quality of care, it is important that nurses and other allied health professionals receive adequate education and training around dementia management, pathophysiology and the available palliative care options. The Care Council for Wales (2016) pledged that 75% of all NHS workers who come into contact with dementia will receive training in an appropriate level of dementia care by 2019. Although dementia training and e-learning packages do exist (Health Education England, 2017; NHS Wales, 2017a), there does not seem to be any particular focus on end-of-life care feeding. By increasing personal knowledge and understanding of the dementia trajectory, its prognosis and end stages, nurses can inform families and promote advance care planning to avoid burdensome interventions such as artificial nutrition and hydration which has been shown here to increase discomfort. Reports however, have highlighted that one of the main barriers to good end of life care is lack of effective training (Department of Health 2013; Marie Curie, 2014; Alzheimer's Society, 2015). It is therefore essential that health boards and trusts provide ample opportunities for UK nurses to improve their knowledge and understanding of advanced dementia, particularly in relation to nutrition and hydration, eating, drinking and to introduce the concept of comfort feeding in more detail to other countries like the USA.

Conclusion

This paper was inspired by the challenges some family's may face when confronted with making nutrition and hydration related choices in end of life dementia care. Many of the US based papers reported poor communication and support during this trying time (Givens et al. 2009) and this may be an influencing factor of why artificial methods of feeding and hydration are often adopted there and favoured in some countries over others. However, abundant evidence has also showed that ANH methods neither prolonged nor improved quality of life (Kuo et al. 2009; Mitchell et al. 2009; Sampson et al. 2009, Ticinesi et al. 2016). Thus, at a time when loved one's may be reaching the terminal stage of dementia, nurses are well placed to take a more lead role in assisting family members and carers understand why in countries such as the UK, Europe Australia, New Zealand and Canada, we are being more cautious in instigating and implementing artificial feeding and hydration methods.

References

Ahronheim, J.C., Morrison, R.S., Morris, J., Baskin, S. and Meier, D.E. 2000. Palliative care in advanced dementia: a randomized controlled trial and descriptive analysis. *Journal of Palliative Medicine* 3, pp. 265-273

Airedale NHS Trust v Bland [1993] 1 All ER 821. General Medical Council. 2018. *End of life care: Clinically assisted nutrition and hydration*. Available at: https://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_clinically_assisted_nutrition_and_hydration.asp [Accessed 12 January 2018]

Alzheimer's Society. 2015. *Living and Dying with Dementia in Wales: Barriers to Care*. Available at: https://www.alzheimers.org.uk/download/downloads/id/2510/living_and_dying_with_dementia_in_wales.pdf [Accessed: 15 February 2018]

Alzheimer's Society. 2018. *The later stages of dementia. Eating and weight loss*. Available at: https://www.alzheimers.org.uk/info/20073/how_dementia_progresses/103/the_later_stages_of_dementia/8 [Accessed: 15 February 2018]

Arcand, M. 2015. End-of-life issues in advanced dementia. Part two: management of poor nutritional intake, dehydration and pneumonia. *Canadian family physician* 61, pp.337-341

Beernaert, K., Smets, T., Cohen, J., Verhofstede, R., Costantini, M., Eedoo, K., Van Den Noortgate, N., Deliens, L. 2017. Improving comfort around dying in elderly people: a cluster randomised controlled trial. *Lancet* 390, pp.125-34

Brännström, M., Fürst, C.J., Tishelman, C., Petzold, M., Lindqvist, O. 2016. Effectiveness of the Liverpool care pathway for the dying in residential care homes: An exploratory, controlled before-and-after study. *Palliative Medicine* 30 (1), pp 54-63

Brooke, J., Ojo, O. 2015. Enteral Nutrition in Dementia: A Systematic Review. *Nutrients*. 7(4), 2456-2468. doi: 10.3390/nu7042456

Burke v GMC [2005] EWCA Civ 1003. General Medical Council (GMC). 2018. *Consent Guidance. Legal Annex - Common law*. Available at: https://www.gmc-uk.org/guidance/ethical_guidance/consent_guidance_common_law.asp#requests [Accessed: 12 January 2018]

Candy et al., 2013. Enteral tube feeding in older people with advanced dementia: Findings from a Cochrane systematic review. *International Journal of Palliative Nursing*, 15(8), doi.org/10.12968/ijpn.2009.15.8.43799

Care Council for Wales. 2016. Good work A dementia learning and development framework for Wales. Available at:

https://socialcare.wales/cms_assets/file-uploads/Good-Work-Dementia-Learning-And-Development-Framework.pdf [Accessed: 18 February 2018]

Clarke G, Harrison K, Holland A, Kuhn I, Barclay S (2013). How are treatment decisions made about artificial nutrition for individuals at risk of lacking capacity? A systematic literature review. *PLoS ONE* 8(4) e61475.

Department of Health. 2005. *Mental Capacity Act*. London: HMSO

Department of Health. 2013. *More care. Less pathway. A review of the Liverpool care pathway*. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf [Accessed: 12 January 2018]

Department of Health. 2015. *2010-2015 government policy: dementia*. Available at: <https://www.gov.uk/government/publications/2010-to-2015-government-policy-dementia/2010-to-2015-government-policy-dementia> [Accessed: 12 January 2018]

Department of Health. 2016. *Prime Minister's Challenge on Dementia 2020*. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/507981/PM_Dementia-main_acc.pdf [Accessed: 12 January 2018]

Detering, K.M., Hancock, A.D., Reade, M.C. and Sylvester, W. 2010. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *British Medical Journal* 340, e1345

Ellershaw, J. and Wilkinson, S. 2011. *Care of the dying: a pathway to excellence*, 2nd ed. Oxford: Oxford University Press

Finucane, T.E., Christmas, C. and Travis, K. 1999. Tube feeding in patients with advanced dementia: a review of the evidence. *JAMA* 282, pp. 1365

Givens, J.L., Kiely, D.K., Carey, K. and Mitchell, S.L. 2009. Healthcare proxies of nursing home residents with advanced dementia: decisions they confront and their satisfaction with decision making. *J Am Geriatr Soc* 57 (7), pp.1149-1155

Gold Standards Framework. 2015. *Dementia Care Training Programme*. Available at: <http://www.goldstandardsframework.org.uk/dementia-care-training-programme> [Accessed: 12 January 2018]

Goldberg, LS., Altman, KW. 2014. The role of gastrostomy tube placement in advanced dementia with dysphagia: a critical review. *Clinical Interventions in Aging*, 9 1733-1739

Hanson, L.C., Garrett, J.M., Lewis, C., Phifer, N., Jackman, A. and Carey, T. 2008. Physicians' expectations of benefit from tube feeding. *Journal of Palliative Medicine* 11(8), pp.1130-1134

Hanson, L.C., Carey, T.S., Caprio, A.J., Lee, T.J., Ersek, M., Garrett, J., Jackman, A., Gilliam, R., Wessell, K. and Mitchell, S.L. 2011. Improving decision-making for feeding

options in advanced dementia: A randomized controlled trial. *Journal of American Geriatrics Society*, 59(11), pp 2009-2016. doi: 10.1111/j.1532-5415.2011.03629.x

Hanson, L.C., Zimmerman, S., Song, M., Lin, F., Rosemond, C., Carey, T.S. and Mitchell, S.L. 2017. Effect of the Goals of Care Intervention for advanced dementia: A randomized clinical trial. *JAMA Intern Med*, 177 (1), pp 24-31. doi: 10.1001/jamainternmed.2016.7031

Hughes, J., Jolley, D., Jordan, A. and Sampson, E.L. 2007. Palliative care for people with dementia. *Journal of general internal Medicine* 19(10), pp 1057-1063

Institute of Medicine. 2001. *Crossing the quality chasm: a new health system for the 21st century*. Washington DC: National Academy Press

Kuo, S., Rhodes, R.I., Mitchell, S.L. et al. 2009. Natural history of feeding tube use in nursing home residents with advanced dementia. *J Am Med Dir Assoc* 10, pp.264-270

Leadership Alliance for the Care of Dying People (LACDP). 2014. *One chance to get it right*. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf [Accessed: 15 February 2018]

Marie Curie. 2014. *Living and dying with dementia in England: Barriers to care*. Available at: <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/december-2014/dementia-report.pdf> [Accessed: 12 January 2018]

Marie Curie. 2015. *Living and dying with dementia in Wales: Barriers to care*. Available at: <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/february-2015/living-and-dying-with-dementia-in-wales.pdf> [Accessed: 8 March 2019]

McCann, R.M., Hall, W.J. and Groth-Juncker, A. 1994. Comfort care for terminally ill patients. The appropriate use of nutrition and hydration. *JAMA* 272 (16), pp.1263-6

Meier, D.E., Ahronheim, J.C., Morris, J. et al. 2001. High short-term mortality in hospitalized patients with advanced dementia: lack of benefit of tube feeding. *Arch Intern Med* 161, pp.594

Mitchell, S.L., Terroe, J. and O'Connor, A.M. 2001. A decision aid for long term tube feeding in cognitively impaired older persons. *J Am Geriatr Soc* 49, pp. 313-316

Mitchell, S.L., Kiely, D.K., Hamel M.B., Park, P.S., Morris, J.N. and Fries, B.E. 2004. Estimating prognosis for nursing home residents with advanced dementia. *JAMA* 291(22), pp. 2734-2740

Mitchell, S.L., Teno, J.M., Kiely, D.K. et al. 2009. The clinical course of advanced dementia. *New England Journal of Medicine* 361(16), pp.1529-1538

Mitchell, S.L. 2015. Clinical practice: Advanced dementia. *N Engl J of Med* 372, pp.2533-40

NHS Health Education England. 2017. E-learning for healthcare. e-Dementia. Available at: <https://www.e-lfh.org.uk/programmes/dementia/> [Accessed: 18 February 2018]

NHS Wales. 2018. *Dementia action plan for Wales 2018-2022*. Available at: <http://gov.wales/docs/dhss/publications/180214dementiaen.pdf> [Accessed: 15 February 2018]

NICE. 2017a. *Nutrition support for adults, enteral tube feeding and parenteral nutrition. Clinical guideline (CG 32)*. Available at: <https://www.nice.org.uk/guidance/cg32/chapter/1-Guidance#enteral-tube-feeding-in-hospital-and-the-community> [Accessed: 12 January 2018]

NICE. 2017b. *Shared decision making*. Available at: <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making> [Accessed: 12 January 2018]

Nursing and Midwifery Council (NMC). 2015. *The Code: Professional standards of practice and behaviour for nurses and midwives*. London: NMC.

Office for National Statistics. 2016. Deaths registered in England and Wales (series DR: 2016) Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregisteredinenglandandwalesseriesdr/2016#dementia-and-alzheimer-disease-remained-the-leading-cause-of-death-for-those-aged-80-and-over> [Accessed: 12 January 2018]

Palecek, E.J., Teno, J.M., Cassarett, D.J, et al. 2010. A proposal to bring clarity to decision making regarding difficulty with eating for persons with advanced dementia. *Journal of the American Geriatrics Society* 58, pp.580-584

Pasman H.R.W., Onwuteaka-Philipsen B.D., Kriegsman D.M.W., et al. 2005. Discomfort in Nursing Home Patients With Severe Dementia in Whom Artificial Nutrition and Hydration Is Forgone. *Archives of Internal Medicine* 2005;165:1729-35.

Sampson, E.L., Gould, V, Lee, D. and Blanchard, M.R. 2006. Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study. *Age and Ageing* 35(2), pp.187-189

Sampson, E.L., Candy, B., and Jones, L. 2009. Enteral tube feeding for older people with advanced dementia. *Cochrane Database of Systematic Reviews* Issue 2. Art. No: CD007209. doi: 10.1002/14651858.CD007209.pub2.

Sampson, E.L. 2010. Palliative care for people with dementia. *British Medical Bulletin* 96, pp 159-174

Sampson, E.L., Burns, A. and Richards, M. 2011. Improving end-of-life care for people with dementia. *The British Journal of Psychiatry* 199, pp.357-339. doi: 10.1192/bjp.bp.111.097030

Social Care Institute for Excellence (SCIE). 2018. *Dementia. Eating and drinking at the end of life*. Available at:

<https://www.scie.org.uk/dementia/advanced-dementia-and-end-of-life-care/end-of-life-care/eating-drinking.asp> [Accessed: 12 January 2018]

Teno, J.M., Mitchell, S.L., Kuo, S.K., Gozalo, P.L., Rhodes, R.L., Lima, J.C., Mor, V. 2011. Decision-making and outcomes of feeding tube insertion: a five-state study. *Journal of American Geriatric Society* 59(5), pp.881-6.

Teno, J.M., Gozalo, P.L., Mitchell, S.L. et al. 2012a. Feeding tubes and the prevention or healing of pressure ulcers. *Arch Intern Med* 172, pp.697

Teno, J.M., Gozalo, P.L., Mitchell, S.L., Kuo, S., Rhodes, R.L., Bynum, J.P., Mor, V. 2012b. Does feeding tube insertion and its timing improve survival? *Journal of American Geriatrics Society*, 60 (10), pp. 1918-1921. doi: 111/j. 1532-5415.2012.04148.x

Thuné-Boyle, I.C.V., Sampson, E.L., Jones, L., King, M., Lee, D. and Blanchard, M.R. 2010. Challenges to improving end of life care of people with advanced dementia in the UK. *Dementia* 9, pp. 285-298

Ticinesi, A., Nouvenne, A., Lauretani, F., Prati, B., Cerundolo, N., Maggio, M., Meschi, T. 2016. Survival in older adults with dementia and eating problems: [To PEG or Not to PEG?](#) *Clinical Nutrition* 35 (6) 1512-1516

Volandes, A.E., Paasche-Orlow, M.K., Barry, M.J. et al. 2009. Video decision support tool for advance care planning in dementia: A randomised controlled trial. *BMJ* 338, b2159

Whelan, T., Levine, M., Willen, A., Gafni, A., Sanders, K., Mirsky, D., Chambers, S., O'Brien, M.A., Reid, S. and Dubois, S. 2004. Effects of a decision aid on knowledge and treatment decision making for breast cancer surgery. *JAMA* 292, pp. 235-441

World Health Organisation (WHO). 2016. *The ICD-10 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines*. Available at: <http://apps.who.int/classifications/icd10/browse/2016/en#/F00-F09> [Accessed: 12 January 2018]

Xie, J, Brayne, C, Matthews, F.E. 2008. Survival times in people with dementia: analysis from population based cohort study with 14 year follow-up. *BMJ* 336, pp. 258–62.