

Ngaire Hobbins APD

www.ngairehobbins.com

Minimise weight loss at all costs

- Appetite decline and altered food preference/ eating disturbance are common
- This is a fatal illness this may not be the time to worry about sugar!
 - Use treats
 - Dessert first
 - Old fashioned food
- In diabetes, have a mgt plan that is appropriate for end of life and that predominantly seeks to avoid hypos

Swallowing issues and texture modification

- RESPECT
- Discuss options with family and with the person living with dementia as much as possible discuss risks vs benefits of texture mod
- Work with individual choice as much as possible
- An aged care home is just that 'home'

Delicious, appealing, texture modified food is possible.











End of life : prepare Early

There is no substitute for having conversations around end of life care

- Food of any sort is often overlooked in these talks
- The advanced care plan should include details of food
- Without good advanced care planning (requires good communication) unintended consequences can occur
 - Reduced quality of life
 - Weight loss and malnutrition
 - Possibility of invasive, unnecessary EN or other nutrition support intervention
 - Hospitalisation as a consequence of 'not eating or drinking' should be avoided

End of life planning

- The International Summit on Intellectual Disability and Dementia (2016) - report on End of life care in advanced dementia provides a synthesis statement:
 - defining the state of advanced dementia,
 - proposes use of palliative care services (including hospice)
 - recommends special efforts for enabling advanced directives and advance care planning prior to the extensive progression of dementia.

And recommended:

- integrative efforts between intellectual disability and palliative care providers,
- specialized training for carers on end of life care and supports
- involvement of adults with intellectual disability early on in their advance care planning.

End of life planning

- Reinhardt et al paper: conversations early meant more things in advanced care plan were achieved, families were happier with the care their loved one received
- Rachel Milte et al excellent paper informs what is done as end nears
 - ASK the individual if possible, family, friends, carers.....important to check with close family and confirm – could be poor communication or just one day someone didn't like porridge for example
 - THEN PROVIDE what's been asked for individual preferences, think outside the box if needs be
 - People might want continued involvement in meal prep

End of life considerations

- Education not eating is a part of dying
- Recognise when death is likely (days/hours) and communicate sensitively with all
- Involve dying person as much as is possible assume they can understand no matter what
- Support carers/family etc
- It is an honour to be there

End of life food considerations

- Even with advanced swallowing problems, there are possible ways to allow enjoyment of flavours/some foods
 - Powders (bacon dust, raspberry dust etc)
 - foams, sprays
 - chocolate/ice cream for some
- Regular mouth care is essential to avoid thrush, for comfort, can sometimes incorporate flavours
- In an aged care situation
 - Avoid hospitalisation if possible
 - Poor intake dehydration hospitalisation......
- EN Tube feeling does not necessarily stop aspiration around 1/3 people with end stage dementia who have a feeding tube inserted die within 1 mth of that

Oral HP/HE supplements

- Important place *only* if they are enjoyed
- Can help improve QOL by supporting nutrition, but don't replace contact of care staff
- Prompt and offer foods, treats....
- Some issues with thickening should that be necessary
- Use of HP/HE powdered supps is preferable to accommodate individual preferences
- Puddings/desserts
- Use of high kJ additives cream, cheese sauce, HP gravies etc

At end stage – EN

- Again, needs early discussion with family, carers and other staff to avoid emotional response to end stage
 - Study of clinicians/nursing staff: Artificial Nutrition was more contentious than Antibiotic Therapy or Artificial Hydration emotional influence was part of the reason
- If commenced at this time, what are the ethics around ceasing?
- "Enteral feeding does not show any benefit in preventing aspiration pneumonia, improving nutrition, improving survival, preventing or improving pressure ulcers, or providing additional comfort to those unable to eat or drink compared to hand-feeding. Enteral feeding may also precipitate unintended consequences resulting in increased acute care visits. In contrast to enteral feeding, handfeeding provides the benefits of increased personal care and social interaction as well as the enjoyment tasting food and drink."
- Feeding Issues in Advanced Dementia Nicolin Neal, Angela G. Catic 2017 in Ethical Considerations and Challenges in Geriatrics, Angela G. Catic (ed) Springer, Switzerland, pp 101-109

Books: the science of nutrition and brain health/dementia in everyday language



Eating well in your 40s & 50s to 70s and beyond Latest evidence-based advice | Information on the gut-brain link



Better BRAIN Food Eat to cheat dementia and cognitive decline



NGAIRE HOBBINS APD, BSc, Dip Nutrition and Diet Recipes by MICHELLE CRAWFORD

www.ngairehobbins.com

References

- Kai K, Hashimoto M, Amano K, Tanaka H, Fukuhara R, Ikeda M (2015) Relationship between Eating Disturbance and Dementia Severity in Patients with Alzheimer's Disease. PLoS ONE 10(8): e0133666. doi:10.1371/journal.pone.0133666
- Reinhardt, J. P., Chichin, E., Posner, L., & Kassabian, S. (2014). Vital Conversations with Family in the Nursing Home: Preparation for End-Stage Dementia Care. *Journal of Social Work in End-Of-Life & Palliative Care*, 10(2), 112–126
- McCallion P, et al; Working Group of the International Summit on Intellectual Disability and Dementia. Consensus statement of the International Summit on Intellectual Disability and Dementia related to end-of-life care in advanced dementia. J Appl Res Intellect Disabil. 2017 May 9. doi: 10.1111/jar.12349. [Epub ahead of print]
- Feeding Issues in Advanced Dementia Nicolin Neal, Angela G. Catic 2017 in Ethical Considerations and Challenges in Geriatrics, Angela G. Catic (ed) Springer, Switzerland, pp 101-109
- Pengo, V., Zurlo, A., Voci, A., Valentini, E., De Zaiacomo, F., Catarini, M., Iasevoli, M., Maggi, S., Pegoraro, R., Manzato, E., and Giantin, V. (2017) Advanced dementia: opinions of physicians and nurses about antibiotic therapy, artificial hydration and nutrition in patients with different life expectancies. Geriatr Gerontol Int, 17: 487–493