Redesign of Dementia Consumer Supports

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The Dietitians Association of Australia (DAA) is the national association of the dietetic profession with over 6000 members, and branches in each state and territory. DAA is a leader in nutrition and advocates for food and nutrition for healthier people and healthier nations. DAA appreciates the opportunity to respond to the Australian Government Department of Health regarding the proposed redesign of dementia consumer support programs to help care for those living with dementia across the life-cycle of the disease and improve consistency of support to them and their carers.

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DAA interest in this consultation

As the leading nutrition and dietetic organisation in Australia, the Dietitians Association of Australia considers it vital that the proposed suite of redesigned dementia consumer supports consider the need to:

- identify any dietary issues (e.g. malnutrition or dehydration) or feeding issues (e.g. dysphagia – swallowing issues) at the time of dementia diagnosis, to help those affected by the disease to experience quality of life throughout their time living with the disease.
- include expert dietary support (i.e. services provided by an Accredited Practising Dietitian - APD) in referral services for people with dementia.
- better equip health care professionals and the dementia care workforce with information, skills and tools to identify nutrition risk (e.g. malnutrition, dehydration, dysphagia etc) in people with dementia and provide a clear pathway to follow to assist in the prompt referral to a dietitian.
- include basic (need-to-know) nutrition training in Vocational Education & Training (VET) sector courses and through the Dementia Training Program, for the dementia care workforce in primary, acute and aged care.
- provide credible nutrition information and practical nutrition resources to dementia care staff, carers and families so as to help them to maintain or achieve nutritional wellbeing of the people/person with dementia whom they are caring for.

Information – Foundation Supports

People with dementia often experience dietary-related challenges (e.g. malnutrition and dehydration) and feeding-related challenges (dysphagia - swallowing problems), which require expert dietary advice and nutrition support. Given the high rates of dietary/eating challenges experienced in dementia care, **DAA considers it important to include information in the dementia-specific information line and the Government-branded information website on:**

- how Accredited Practising Dietitians (APDs) can assist people with dementia (e.g. provide guidance on texture modified diets when eating/swallowing is compromised; prescribe a high energy/protein diet for malnutrition or unintended weight loss; recommend easy-to-eat nutritious finger foods for people with a poor appetite or who forget how to eat, etc.)
- how to access an APD locally (via a user-friendly searchable tool)

To support people living with dementia and their families, friends and carers.
The Dementia Australia website currently provides people with dementia and their carers with valuable information on good nutrition and eating for people with dementia\textsuperscript{1,2}. DAA feels this information could be strengthened by providing those affected by dementia and their family/carers with information on how to access an APD, via a user-friendly tool that allows users to search for an APD locally (such as the search tool located on the DAA website).

It is vital that the nutrition information available in the dementia-specific information line and the Government-branded information website is suitable for people with low literacy, poor eyesight, poor computer navigation skills, and those from culturally and linguistically diverse backgrounds.

Some considerations for the nutrition information (as well as other information) presented on the website may include:

- extra-large font for written materials
- a very simple and easy-to-navigate layout for the website
- some vital information presented in video or pictorial format (for people with low literacy skills)
- vital information translated into several languages and culturally appropriate pictures/graphics to accentuate key messages
- cultural food considerations and recommendations for Aboriginal and Torres Strait Islanders and people from various ethnic backgrounds.

### Awareness – Awareness and Stigma Reduction Campaign

DAA agrees that the targeted awareness and stigma reduction program (which aims to improve understanding of, and attitudes to, dementia) should include GPs, pharmacists, practice nurses, registered and enrolled nurses and allied health professionals. **In connecting with allied health professionals, it will be vital for the government to tap into the national associations of these professions (e.g. Dietitians Association of Australia (DAA), Australian Physiotherapy Association (APA), Occupational Therapy Australia (OTA), Speech Pathology Australia (SPA), etc.), as these national associations have the means to connect with their members nationally and assist in the targeted awareness and stigma reduction campaign.** DAA welcomes the opportunity to discuss how this campaign may be rolled out to Accredited Practising Dietitians nationally.
Outreach – Targeted Supports

DAA supports a targeted outreach, offering dementia awareness and support to highly marginalised and vulnerable people living with dementia to connect with local services that can assist them.

In the proposed pop-up clinic for rural & remote areas (i.e. providing dementia education, assessment and local service linking), **DAA recommends the inclusion of a validated nutrition assessment as part of the standard consultation.** A validated nutrition assessment (such as in the form of an ‘App’ for service providers with a checklist, a Mini Nutritional Assessment Short Form (MNA-SF) and referral pathway) would help to identify any dietary issues (e.g. malnutrition or dehydration) or feeding issues (e.g. dysphagia – swallowing issues), and assist in the prompt referral to a dietitian. Undernutrition and dehydration are associated with greater morbidity and mortality, increase the risk of falls, pressure injuries and dysphagia, and negatively impact on cognitive ability3-9.

It should be noted that the Australian Government has permitted medical specialists, general practitioners, midwives and nurse practitioners to deliver specialist video consultations without the time and expense for individuals to travel to major cities. Telehealth provisions have not been extended to allied health professionals, including Accredited Practising Dietitians, which means that many people (and their carers) with dementia who live in rural and remote areas are being denied the right to dietetic care.

To improve accessibility, DAA supports the harnessing of technology, telehealth and digital technology to provide flexible, accessible health services that are responsive to individual needs. Dietetic services are well suited to the medium of telehealth, as demonstrated by the inclusion of telehealth in the pilot of the Coordinated Care for Diabetes reform. There is evidence that telephone counselling by a dietitian achieves dietary behaviour change10-13 and improves metabolic parameters in individuals with metabolic syndrome13. **DAA would like to see provisions for telehealth services extended to Accredited Practising Dietitians (under MBS Dietetics Item 10954) and other allied health practitioners, as an alternative to face-to-face services, so as to help improve:**

- chronic disease management (including dementia) in rural and remote areas;
- management of people (urban, rural or remote based) with health conditions requiring input from a specialist dietitian (e.g. an APD who specialises in dementia care etc.).
DAA is pleased to see early intervention supports for people recently diagnosed with dementia, their family and carers will include information about the range of supports (e.g. early intervention therapies, allied health services, respite) that may be of use at various stages in dementia. People with dementia often experience dietary-related challenges (e.g. malnutrition and dehydration) and feeding-related challenges (dysphagia - swallowing problems), which require dietary advice and nutrition support. Accredited Practising Dietitians (APDs) are experts in medical nutrition therapy with the expertise to assist people (and their carers) with dementia, so as to help them overcome any feeding issues and achieve a nutritious diet, for good health and wellbeing.

In many cases, once a person is diagnosed with dementia, nutritional wellbeing is often overlooked. Many APDs confer this is the case, with reports that dietitian engagement is often left to the advanced stages of dementia where the patient is severely malnourished. Malnutrition in people with dementia has significant impacts on cognitive and functional symptoms, and on the overall clinical prognosis. It can lead to greater functional impairment and dependence due to a rapid decline in mental state and behaviour, and increase the risk of morbidity, hospitalisation, institutionalisation and mortality. Undernourished people with dementia may enter residential care earlier and require longer and more frequent hospital stays.

It cannot be assumed that family carers or community aged care providers are equipped with the knowledge and skills to assess and manage the complex nutritional needs of a person with dementia. Involving an APD from the onset of diagnosis can help minimise the progression of malnutrition and provide timely advice and support to families about what to expect.

Given the dietary and feeding-related challenges often experienced in dementia care, DAA considers it important to:

1. Involve dietitians from the onset of dementia diagnosis to improve the diagnosis (and minimise the progression) of nutrition risk and malnutrition.
2. Include basic (need-to-know) nutrition training in VET sector (Cert 3 & 4) training courses and through the Dementia Training Program, for the dementia care workforce in primary, acute and aged care.
3. Put steps in place for service providers to respond in a timely and appropriate fashion to any nutrition risk or malnutrition identified in people with dementia. This means equipping health care professionals and the dementia care workforce with a clear pathway/plan to follow when a nutrition or eating issue is suspected, and the referral pathway to an APD. As previously mentioned, an ‘App’ for dementia service providers which includes a checklist, mini nutritional assessment and referral pathway could potentially meet this need.
Flexible Grants – Flexible Funding

DAA supports the funding of flexible grants, through the Dementia and Aged Care Services Fund, to help develop scaleable, time limited and strategically innovative approaches to support people living with dementia, their families and carers.

It is important to identify and address gaps in current services (e.g. telehealth provisions currently do not extend to allied health professionals) and trial new models of care to connect people living with dementia, their families and carers with services that may assist and set them on the right path to self-manage and live well with dementia.

DAA would especially like to see funding available for research on the issue of:

- Dementia risk reduction strategies that can be applied on a national scale. Much is already known on how to reduce the risk of dementia (e.g. healthy eating, regular physical activity, keeping the brain challenged, being socially active)\textsuperscript{17-19}, yet little is being done in Australia to apply that knowledge to risk reduction strategies on a national scale.
- Malnutrition risk reduction strategies and malnutrition monitoring among older Australians, especially vulnerable populations such as people with dementia living in care homes located in urban, rural and remote communities\textsuperscript{20}.

Evaluation

DAA is pleased to see each of the service delivery elements in the redesigned suite of dementia consumer supports will be required to be based on an evidence-based philosophy of care. Likewise, DAA strongly supports an independent national evaluation of each component and how they work together, so as to further refine the dementia consumer supports program, ensuring it meets the needs of people living with dementia.

References:


