DEMENTIA NEWS

SPECIAL ISSUE DEDICATED TO THE LEGACY OF HAZEL HAWKE

17 JUNE 2013

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This Dementia News edition is dedicated to the memory of Hazel Hawke, AO, who passed away on 23 May, 2013. Most Australians will know Hazel as both the first wife of former Australian Prime Minister Bob Hawke, and as a passionate advocate for many causes including women’s rights, heritage and the environment and community services.

Many readers will also know that in 2001, Hazel was diagnosed with Alzheimer’s disease. Two years later she became the first well-known Australian to talk publicly about her fight with dementia in an exclusive interview on ABC’s Australian Story in a program titled ‘The Big A’. As her dementia progressed, Hazel gradually retired from public life, and spent her last years close to friends and family in a residential aged care facility in Sydney.

“Hazel embodied a sense of fairness and concern for other Australians, being the first and only well-known Australian to speak publicly about her life with Alzheimer’s disease,” said Ita Buttrose, President of Alzheimer’s Australia.

“Many Australians would have experienced a sense of personal loss with her passing.”

At Hazel’s request, Alzheimer’s Australia established the Hazel Hawke Alzheimer’s Research and Care Fund in 2003 to support dementia care research across Australia. It is one of the few sources of research funding for these important projects which support the best and brightest Australian researchers.

Since it was established, the Hazel Hawke Alzheimer’s Research and Care Fund has supported 14 Australian research projects aiming to improve the lives of people with dementia and their carers:

Hazel Hawke Alzheimer’s Research and Care Fund: Grant recipients and projects

- Professor Cherry Russell, 2005, Dying with dementia: An exploratory study of family caregiver perspectives on best quality care and support practices at the end of life
- Dr Astrid Rogoz, 2006, Cognitive impairment in the elderly homeless
- Dr Jennifer Torr, 2006, Alzheimer’s disease and Down syndrome
- Dr Kate Webster, 2006, Falls risk assessment in people with Alzheimer’s disease
- Dr Matthew Hopcraft, 2007, Evaluation of oral healthcare training for carers of nursing home residents with dementia
- Professor Megan-Jane Johnstone, 2007, The use and misuse of Alzheimer’s disease in the euthanasia/physician assisted suicide debate
- Professor Elizabeth Beattie, 2008, Nutritional Challenges for family caregivers and persons with dementia
- Associate Professor Karen Sullivan, 2009, Good idea! The dementia carers’ healthy thinking project
- Associate Professor Melissa Lindeman, 2009, Evaluation of a dementia education resource for indigenous communities
- Dr Karen Croot, 2010, The right word at the right time: keeping communication going in progressive aphasia
- Dr Maria Kangas, 2010, Treatment of anxiety and depression in distressed carers for persons with dementia-related disorders
- Dr Amee Baird, 2011, Music as a memory aid in Alzheimer’s disease
- Dr Jean Tinny, 2011, Interpreter mediated cognitive assessments - stakeholder experiences informing guidelines and training DVD
- Erin Conway, 2012, Facilitating word-retrieval in conversation: Direct intervention for people with progressive aphasia

This edition of Dementia News will celebrate the legacy of Hazel Hawke by showcasing some of these research projects.

If you would like to support the Hazel Hawke Alzheimer’s Research and Care Fund please click here.

To see an updated version of the 2003 program ‘The Big A’, please click here.
**ORAL HEALTHCARE TRAINING FOR CARERS OF NURSING HOME RESIDENTS WITH DEMENTIA**

**DR MATTHEW HOPCRAFT, 2007 GRANT RECIPIENT**

In aged care facilities, the provision of daily oral hygiene for residents living with dementia rests with nursing home staff. Good oral hygiene can be vital to sustaining a functional and comfortable lifestyle for residents, yet it is often overlooked.

Dr Mathew Hopcraft and a team of researchers from the University of Melbourne conducted a study to investigate both the knowledge and attitudes of staff in residential aged care facilities towards oral health, and the long-term effectiveness of oral health training.

A total of 346 carers from 18 nursing homes in Melbourne provided baseline information on knowledge and attitudes towards oral health. Some staff were then provided with an education program, and changes in knowledge and attitudes were assessed over a 12 month period.

It was found that although only one-third of respondents reported receiving adequate training in oral health during their qualifications, most had positive attitudes towards oral health and demonstrated a sound understanding of oral health and related diseases. However, knowledge about the prevention of tooth decay and the interplay between gum disease and general health was poorly understood by all staff.

The nursing home staff who attended oral health training sessions after the initial survey demonstrated significant improvements in these areas, compared to staff at facilities that did not receive training.

“Nursing home staff had good attitudes towards oral health but lacked knowledge of prevention and the impact on general health,” said Dr Mathew Hopcraft. “ Provision of carer training was effective in improving oral health knowledge, which may in turn improve resident’s oral health.”

“This research has provided further evidence of the importance of oral health education for staff in nursing homes that have responsibility of maintaining oral hygiene for residents with dementia”.

“We are extremely grateful for the support provided for this project by the Hazel Hawke Alzheimer’s Research and Care Fund.”

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**THE DEMENTIA CARERS’ HEALTHY THINKING PROJECT**

**ASSOCIATE PROFESSOR KAREN SULLIVAN, 2009 GRANT RECIPIENT**

When a person is first diagnosed with dementia, family are commonly the primary caregivers. The months before and after a diagnosis are usually a stressful time for most families, and can leave caregivers with both positive and negative role-related emotions, including depression.

Associate Professor Karen Sullivan and a team of researchers from the Queensland University of Technology developed a Carers’ Thoughts Questionnaire to be used as a tool to assess the role-related emotions of carers. The researchers combined their tool with a Geriatric Depression Scale Questionnaire to provide an accurate measure for caregivers negative thought processes when compared with a more narrowly focused test, called the Dysfunctional Thoughts about Caregiving Questionnaire.

The researchers recruited 34 Australian dementia caregivers to complete all three questionnaires online, and compared patterns of responses across the different scales.

The results indicated that some Australian carers experience negative thoughts about care giving, and that the Dementia Carers’ Thoughts Questionnaire was a more accurate way of measuring these thoughts than the more narrowly focused Dysfunctional Thoughts about Caregiving Questionnaire.

“Ideally we would like to see this tool used to structure conversations about carers’ thoughts about their roles, especially if the role is becoming overwhelming, or if unhelpful thought patterns have developed,” said Associate Professor Sullivan. “The identification of such thoughts could be an important sign that extra support or assistance is needed.”

She added, “Our tool is specifically for dementia carers. We have developed this tool with the input of people nationally, in the hope that it will be of particular value to Australian carers of people with dementia, and those that support them.”

“I am humbled to have received the support of the Hazel Hawke Alzheimer’s Research and Care Fund and through it I have built stronger links with other researchers including Professor Elizabeth Beattie from the Dementia Collaborative Research Centre, Carers and Consumers, as well as partners overseas.”
Poor nutritional status among older people is associated with ill-health and mortality. Previous dementia research has focused on the nutritional status of the person with dementia in isolation, but little is known about the nutritional status of people with dementia and their carers who live together at home.

Professor Elizabeth Beattie and a team of researchers from the Queensland University of Technology, aimed to investigate the nutritional status of 26 couples, where both a person living with dementia and their caregiver were living together in the community. They collected a range of nutritional information including bodyweight, body size, and a three-day record of foods eaten.

The results indicated that 60% of people with dementia did not eat enough food to meet their Estimated Energy Requirement (EER; the estimated amount of Calories needed each day, based on height, weight and physical activity levels). Furthermore, in 50% of couples, it was only the person with the dementia at risk of poor nutrition. These findings suggest that couples who frequently share meals may be at risk of suboptimal energy and protein intake, with potentially serious implications for the person with dementia and their carer.

“This study has provided early, strong evidence of the need for increased attention to the nutritional status of people with dementia and carers who live together at home. Previous research has tended to consider only the person with dementia, neglecting the vital role of carers in food choice, preparation, mealtime oversight and the preservation of mealtime habits, pleasure and social interaction” said Professor Elizabeth Beattie.

“Results highlight areas of nutritional concern, particularly weight management and optimal protein and energy intake that can be targeted with interventions. Helping couples maintain healthy nutrition-related behaviours has the potential to improve the general health and wellness status of both people. This is important in preserving the pleasurable social aspects of eating together, reducing carer stress and possibly helping the person with dementia to remain at home longer.”

“Further research is planned to test an intervention focused on couples, designed to enhance meal planning, mealtime habits and home nutritional status monitoring, in a larger pilot randomised controlled trial.”

There is accumulating evidence that music can enhance memory in people with various neurological conditions, including dementia.

The main and most commonly known symptom of Alzheimer’s disease is impaired memory, and there is a urgent need to develop effective memory aids for individuals living with the disease.

Dr Baird from the University of Newcastle is investigating the use of song as a memory aid for people living with Alzheimer’s disease. Her research is one of the first studies undertaken in Australia to examine the effects of musical background on the recall of information.

“These findings have the potential to improve the quality of life of individuals with Alzheimer’s disease and their carers and to provide an important scientific contribution to our understanding of memory,” said Dr Baird.

The project is currently underway with preliminary findings to be released in November, 2013.
ALZHEIMER’S AUSTRALIA’S DEMENTIA ADVISORY GROUP

Alzheimer’s Australia is seeking individuals with dementia of all ages who are interested in having a say about the needs of people with dementia in Australia.

We are looking for people who are interested in being actively involved in advocating for the needs of people with dementia through Alzheimer’s Australia.

The Alzheimer’s Australia’s Dementia Advisory Group is a new group that aims to:

- Determine the priorities of people with dementia.
- Contribute to policy and advocacy work
- Promote dialogue between those with dementia and service providers with a view to promoting a better understanding of their social and care needs.
- Assist in refining and evaluating Alzheimer’s Australia’s national programs.

Communication will be via email and teleconferences and the group may meet face to face one to two times per year.

Members of the group may be supported by their partners or carers to participate in meetings.

New members are being sought from around Australia and experience in a similar role is not necessary.

To express your interest or find out more information, please contact Samantha Blake.

Email: samantha.blake@alzheimers.org.au
Phone: (02) 6278 8909

ALZHEIMER’S AUSTRALIA SURVEY: DEMENTIA CARE IN HOSPITALS

Hospitals can be confusing and dangerous places for people with dementia. The unfamiliar environment of a hospital can cause confusion and distress and may lead to a worsening of cognitive and behavioural symptoms.

Alzheimer’s Australia recently commissioned a report from the Australian Institute of Health and Welfare ‘Dementia Care in Hospitals: costs and strategies’. This report found that nearly half of people with dementia who were hospitalised did not have dementia recorded as one of their diagnoses. Lack of identification can lead to poor quality care and increased risk of complications and longer stays in hospital. The full report can be found here: http://www.aihw.gov.au/publication-detail/?id=60129542746.

Consumers often tell us about their experiences when hospital care was poor and the person did not receive adequate support. But it is just as important to recognise the initiatives being taken to ensure good hospital care for people with dementia. As part of our work to improve dementia care in hospitals, Alzheimer’s Australia would like to identify other local initiatives and programs which are in place to improve dementia care in hospitals. We would welcome feedback on this issue from consumers and health professionals. Please fill out our survey at: https://www.surveymonkey.com/s/H85HL6R.
CARE FOR YOUR CAREER

A new Associate Degree in Dementia Aged Care (ADDC) offers an opportunity for the Aged Care industry to prepare for the expected increases in dementia in the near future, providing career enhancement and professional development for employees in the sector.

This degree is offered part-time and over three semesters per year, taking 2.5 years to complete. The University of Tasmania (UTAS) is currently accepting applications for semester two. Members of Aged and Community Services Australia (ACSA) are eligible for a HECS waiver for study undertaken in 2013.

The residential and community aged care sector faces a critical shortage of skilled Personal Care Workers and Community Care Workers able to provide quality care for people with dementia. This crisis is set to worsen without affirmative action. The Associate Degree will provide significant opportunities to facilitate qualification upgrading for an existing workforce, as well as training of the future workforce.

The design of the course places feedback from the students as a priority, thus adopting a continuous improvement approach. It has also been designed to be accessible to rural students.

There are no entry requirements, no exams and there is a full-time student support officer who provides a range of assistance.

For more information visit: www.utas.edu.au/wicking/dementia-care