Dementia Manifesto

The National Consumer Committee of Alzheimers Australia has released their 2007-2010 Dementia Manifesto for the next Federal Election. The Manifesto sets out for candidates those priorities that would contribute most to improving the quality of life of people with dementia and their family carers over the life of the next Federal Parliament.

The starting point of the Manifesto is to seek a renewal of the commitment to Dementia as a National Health Priority with additional funding for a further five years from 2009. In particular, a commitment is being sought to:

1. Improve the diagnosis of dementia by GPs
2. Expand community care services for people with dementia and their carers
3. Improve access to quality dementia care in residential services
4. Improve access to appropriate care for special groups
5. Ensure a work force able to deliver quality dementia care to all people with dementia
6. Promote advance care planning for people with dementia

Increase dementia research for funding into cause, prevention and care.

The proposal to expand the number of Australian Government funded community care packages by 40% in the Manifesto will be of particular interest to older people from culturally and linguistically diverse (CALD) backgrounds, who like other Australians, prefer to remain for as long as possible in their own homes. There is evidence to suggest that people from CALD backgrounds find care packages attractive, perhaps because they significantly simplify access to care services through a single service provider.

If people are to stay home longer there is an urgent need for more Extended Aged Care at Home (EACH) packages to care for those people with higher care needs including for people with dementia. There is also a big gap between the hours of care provided in Community Aged Care Packages for those people who require low care (about 4-6 hours) and EACH packages (about 14-16 hours). A significant expansion in the number of packages as proposed in the Manifesto might enable intermediate level packages to be introduced to help to bridge this gap.

The National Consumer Committee has recognised the need to find ways to increase the availability of appropriate dementia specific information, services and support for culturally and linguistically diverse groups and indigenous communities. Specifically, additional funding of $1 million has been requested to enable Alzheimers Australia to promote awareness of dementia and co-ordinate better access to services among these groups.

The Dementia Manifesto is available on www.alzheimers.org.au Copies may also be requested by contacting the National dementia Helpline 1800 100 500

Glenn Rees
National Executive Director
Alzheimer’s Australia
New budget measures for the Continence Aids Assistance Scheme (CAAS) were announced as part of the Governments 2007 Budget which will see funding of $98.5 million over five years to expand CAAS to assist more people with the cost of purchasing continence aids.

Changes effective from 1 July 2007.

Under the new arrangements, the Government will extend the age eligibility for the scheme to include children aged 5 to 15 years, and adults over 64 years with permanent incontinence due to neurological conditions. This measure will also expand the eligibility criteria to include all causes of permanent incontinence, not just neurological causes, for those people who hold a pensioner concession card and their dependents.

Recipients of Australian Government funded aged care

People who are living in Australian Government funded residential aged care home and are receiving low level care or who are receiving a Community Aged Care Package (CACP) in their home, are able to apply for CAAS, provided that they meet the CAAS eligibility criteria.

These changes to the scheme's eligibility will commence from 1 July 2007.

CAAS application process

CAAS application forms are available from the CAAS Helpline on 1300 366 455 or can be downloaded from www.intouchdirect.com.au or www.bladderbowel.gov.au.

If a person accessing the CAAS Helpline is a non-English speaker or cannot speak English well, the CAAS consultant is able to access the Translation and Interpreting Service, to ensure an effective communication process.

If you would like more information on eligibility for CAAS, contact the CAAS Helpline on 1300 366 455 or go to the web site http://www.intouchdirect.com.au/healthcare/caas.htm

Web Links

- Alzheimer’s Australia
  www.alzheimers.org.au
- Alzheimer’s Disease International
  www.alz.co.uk
- Australian Government
  www.australia.gov.au
- Australian Multicultural Foundation
  www.amf.net.au

Cultural Diversity in Ageing
www.culturaldiversity.com.au

Federation of Ethnic Communities Council (FECCA)
www.fecca.org.au

New Online Resource on Culturally Appropriate Aged Care:
www.culturaldiversity.com.au

Eligibility for CAAS
A national planning framework to address the aged care needs of people from culturally and linguistically diverse backgrounds, culturally competent workforce development, and greater flexibility of service design and delivery were some of the key recommendations made by peak bodies at the Cultural Diversity in Ageing 2007 National Conference.

Held by the Centre for Cultural Diversity in Ageing at the Sofitel Melbourne over two days in June, the conference attracted around 300 delegates, who came from every state and territory in Australia.

Keynote speakers included Voula Messimeri-Kianidis from the Federation of Ethnic Communities’ Councils of Australia (FECCA), who recommended a whole-of-government approach that encourages partnerships across communities and builds capacity within communities, and greater alignment of aged care strategies with changing demographics. Ms Messimeri-Kianidis also recommended that national standards of cultural competence be developed and adopted by all service providers and linked to accreditation.

Stressing that ‘cultural diversity is core business’, Greg Mundy from Aged and Community Services Australia (ACSA) provided an industry perspective on cultural diversity. Mr Mundy outlined ACSA’s national policy position, including the idea of a ‘cultural pool’ of funding to assist providers in the delivery of culturally appropriate aged care.

Other keynote speakers at the conference included Dr Diane Gibson from the Australian Institute of Health and Welfare, Professor Nicholas Procter from the University of South Australia and Professor Megan-Jane Johnstone from RMIT University. Award-winning writers Dr Arnold Zable and Alice Pung gave voice to some of the many migrant stories that make up our cosmopolitan society, reminding delegates of the privilege of working with elderly people from diverse backgrounds.

The Federal Minister for Ageing, the Hon Christopher Pyne, also addressed the conference, taking the opportunity to announce funding for additional translations of the Online Resident Handbook. Located on the Centre for Cultural Diversity in Ageing website, this function enables residential aged care providers to easily compile and publish resident handbooks in multiple languages and thereby supply residents and their families with essential information in their preferred language.

During the afternoon concurrent sessions, aged care providers from around Australia showcased examples of culturally responsive service initiatives.

Conference papers – including the policy recommendations made by FECCA and ACSA – are available on the Centre for Cultural Diversity in Ageing website at www.culturaldiversity.com.au.

Emma Black
Senior Project Officer – Communications
Centre for Cultural Diversity in Ageing

QUEENSLAND

All members of Aged Care Queensland currently offering care to people with dementia and their carers are invited to send their expressions of interest in joining the ACQ Dementia Services Network. This group was originally set up to provide an industry response to the development of the HACC Dementia Services Strategy and is now continuing to focus on other issues. The purpose and objectives of the network are to identify and work to address gaps, inequities in service planning to optimise outcomes for clients, provide a platform for representing aged care services issues to support optimal service delivery outcomes and to inform strategy development to ensure responses reflect the current and projected diverse needs of Queenslanders and are consistent with accepted contemporary service planning models. Forward your interest to Community Care Project Officer Julie Smeros by email on julies@acqi.org.au.

NSW—CALD Dementia Strategic Models and Plans

The Department of Ageing Disability and Home Care (DADHC) has contracted Cultural Perspectives to undertake the development of CALD Dementia Strategic Models and Plans. The development of the strategic models and plans is based on an evidence-based approach using three pilot CALD communities— the Italian, Vietnamese and Chinese communities.

The initiative of the project is a result of commitments made by DADHC in conjunction with NSW Health under ‘Future Directions for Dementia Care and Support NSW 2001-2006’.

The project involves:
- Implementing the model and the development of a strategic plan and resources for each of the three pilot CALD communities.

The expected outcomes from the project include increased awareness of cultural and language factors, particularly in relation to the three pilot communities, in the delivery of dementia-related services and information.

A reference group of highly experienced people in the area of dementia service development, education, policy and planning in CALD communities has been providing Cultural Perspectives with ongoing advice, feedback and expertise into the strategic modelling and plans for dementia care in the identified communities.

Cultural Perspectives are expected to complete the project in August 2007.

Dare to Care

South West Sydney Ageing & Disability Conference July 2007

A collaborative and Holistic Approach

This was the first community care conference held and organized for South West Sydney for local workers working in the ageing and disability area. The Area Ethnic Aged Health Adviser was one of the members of the organising committee.

The conference was a complete success with more than 250 people attending and participating for two days right until the end.

South West Sydney is the most multicultural region in Australia, making it’s population the most cultural and linguistically diverse both for consumer and workforce. This diversity makes it a fantastic place to work yet generates may challenges and obstacles. The conference provided the opportunity and a captive audience to explore the underlying issues of access and equity through the use of Forum Theatre.

The aim of Forum Theatre is to learn through action and discovery. It was developed by a Brazilian theatre director Augusto Boal in the 1950s. Boal wanted to transform the traditional performance from just the protagonist to inviting the audience to interact thought critical thinking, action and fun.

‘The aim of Forum Theatre is not to win, but to learn and to train. Is an opportunity to discover, through action’. (David van Vuuren, 1995)

At the Conference, Forum Theatre was used to illustrate a couple of case scenarios common and relevant to working with clients and carers of CALD backgrounds. Participants were invited to present their own solutions, come up to the stage and replace one of the protagonists and show their response. The facilitator continued to engage with the audience to come up with other ideas on how the case scenario could be carryout differently.

Forum Theatre provided the opportunity to present scenarios that need resolution and afforded participants the opportunity to provide solutions. The model allows a space to explore solutions until the best outcome is achieved or different approaches are presented with hypothetical but realistic strategies.

A 23% of participants indicated that their favourite part of the conference was Forum Theatre, also 34 % of participants thought that Forum Theatre was “relevant and interesting”.

Some of the comments included:
- ‘The session of forum theatre allowed for active participation and creative thinking”
- ‘good for workers to reflect on how they relate to clients’
- ‘innovative’

Yvonne Santalucia
Area Ethnic Aged Health Adviser
SSW AHS Western Zone
Meeting of ADI Asia Pacific in Perth

The opportunity provided by the Alzheimer’s Australia National Conference in Perth in June was taken to hold a meeting of the Asia Pacific members of Alzheimers Disease International (ADI).

Member organisations from China, Hong Kong, India, Japan, Malaysia, Pakistan, Singapore, Sri Lanka, Taiwan and Thailand shared their experience in expanding services and promoting greater awareness of dementia. In India, new memory centres are being developed; in Pakistan there are two new day care centres; and in Sri Lanka the development of their own dementia centre in Columbia. While these developments represent wonderful progress, it remains the case that very limited services are available in many countries in the region for people with dementia and their family carers.

Member countries also discussed how to build on the publication of the report Dementia in the Asia Pacific Region: the epidemic is here. Since the publication of the report in September last year, Members have taken the opportunity of advocating on the basis of the demographic and economic data in the report to persuade governments to make dementia a national health priority as both the Australian and South Korean governments have done. The availability of the report has enabled members to give presentations to Ministers and senior bureaucrats and to promote a wider understanding of the dementia epidemic in the media.

Member countries agreed at the Perth meeting that they would seek to promote a higher priority for dementia within the World Health Organisation (WHO) at both the international and regional level. Individual member countries were identified to take the lead at the regional level meetings of WHO in September 2007.

ADI at the international level in London are preparing a brief which ADI Asia Pacific members can use to advocate for dementia as a health priority within WHO. It may take two or three years to see progress but a worthwhile start has been made.

Glenn Rees, National Executive Director, Alzheimer’s Australia

The Dementia Resource Guide

The National Ageing Research Institute (NARI) has been appointed by the Commonwealth Department of Health and Ageing to develop a guide containing evidence-based dementia care information, resources, tools, guidelines and best practice principles. The Guide will have a broad target audience including informal carers, people with dementia and the health and aged care workforce. To meet the diverse needs of Australians living with dementia, it is essential that the Guide includes a broad range of resources relevant to groups with specific needs. Resources and information targeted at different cultural and linguistic groups are an important component of the Guide, including a large number of resources that have been translated into various languages.

Two expert reference group meetings have generated a large amount of discussion in relation to the target audience, goals and philosophy of the Guide, resources and contents to be included. A pilot of the Guide will be undertaken between September and October this year and will involve ten agencies across Australia. Agencies have been selected to cover States and Territories, different settings and target audiences, including different cultural groups.

A draft website version of the Guide will be online during September/October this year, during which time we will be asking for feedback on the Guide’s usability and content. If you would like to be on the mailing list for updated information about reviewing the website, please e-mail your name to Sue Hunt s.hunt@nari.unimelb.edu.au.

The Guide is due to be completed in December this year. If you would like more information about the project please contact Kirsten Moore at k.moore@nari.unimelb.edu.au.
Dementia Symbol Research Project

The concept underpinning the Dementia Symbol Research Project arose from the National Consumer Summit on Dementia, held in Canberra in October 2005.

The aim of the Project is to research the viability of developing a symbol for cognitive impairment that could be used by care providers in a variety of settings to indicate that a care recipient has dementia. Key issues such as risk to the person with dementia, legality and privacy need to be explored before any view can be formed.

A symbol or client flag for people with dementia may have the potential to improve service delivery in care settings and could help care workers to respond quickly and apply the appropriate skills if they have received appropriate training. It may be particularly useful for people with dementia and their carers who have special needs or come from culturally diverse backgrounds, when communication is likely to be especially challenging.

The importance of exploring the perceived need, impact, benefits and impediments of such a symbol on people from special needs backgrounds, such as people from CALD backgrounds has been included in the project brief.

The research project will run until 31 December 2007 and will identify the need and potential uses for a dementia symbol in the Acute, Community, Residential Transitional, and Emergency services care settings.

The methodology will include Systematic literature review Focus groups, Carer survey, Stakeholder consultation through a Project Steering Committee; and A Delphi study that consults independent experts.

Your views on the viability of a symbol to meet the needs of persons with dementia from a CALD background and their carers would be very welcome. You might like to comment on:

1. Whether you support the use of a symbol/identifier for people with dementia
2. What you see as the uses of a symbol/identifier?
3. Can you identify any advantages/disadvantages in using a symbol/identifier for persons with dementia?
4. In what settings might a symbol/identifier be used?
5. In what settings would a symbol/identifier not be used?
6. Are there other alternatives?
7. What risks are associated with the possible perception of people with dementia being labelled?
8. What do you think the symbol/identifier might look like and what should it include?
9. Do you feel that there should be anything that accompanies the symbol/identifier, such as advertising, training, public education?

If the use of a symbol/identifier becomes accepted, should it be mandatory for use in any settings?

Please send your comments by e-mail to Helen O’Brien, the project manager, by 21 September 2007. Her contact details are helen@alzheimers.org.au or please phone on 02-6278 8907 if you have any questions about the project.
More than 900 delegates from around Australia and the Asia-Pacific region, recently converged on the Perth Convention Exhibition Centre for the 12th National Alzheimer’s Australia Conference.

The Conference, which was opened by the Premier of Western Australia, the Hon. Alan Carpenter, focussed on the latest dementia research and the latest trends in dementia care from all over the world.

Keynote speakers included renowned international researcher, Professor Alexander Kurz, Head of the Munich Technical University’s Centre for Cognitive Disorders and Sydney-based Professor Henry Brodaty AO, a leader in psychogeriatrics and dementia research.

The most moving presentations came from people who have lived with dementia on a daily basis and whose courage shone through in what they had to say.

Delegates also got the chance to hear from recognised dementia care innovators such as Professor Mary Marshall who championed the need for dementia care services when it was nearly non-existent two decades ago, and Professor Murna Downs, Head of Dementia Studies, Bradford University, UK.

The conference marked the journey since Dr Alois Alzheimer discovered 100 years ago, the disease that would later bear his name.

Since then, Alzheimer’s disease has been recognised as the most common cause of dementia, which currently affects an estimated 220,000 people in Australia. This number is projected to increase to 730,000 by the year 2050.

Topics discussed at the conference included rural issues, hospital care, improving health, understanding behaviours, exploring younger onset dementia, dementia and depression, design and dementia and shaping policy.

The conference was an outstanding success for all involved. We look forward to the 2009 Conference in Adelaide.

Frank Schaper
Chief Executive
Call for abstracts for the Diversity in Health Conference 2008, STRENGTHS AND SUSTAINABLE SOLUTIONS

The 2008 Diversity in Health Conference Older People Working Party would like to extend their invitation to you all to be part of the conference program. The issues to be addressed at this conference will be relevant to a wide range of delegates from government and non-government sectors and form a variety of backgrounds and fields.

The older people stream focus is:

Towards a holistic approach to the health of CALD older people and their carers through the development of sustainable long term health and care solutions in the areas of physical, mental, emotional and social well-being.

This conference provides a unique opportunity to showcase and discuss all the excellent work recently conducted in the areas of research, projects development, programs, partnerships, good practices and/or any other initiatives undertaken in relation to older people and their carers from culturally and linguistically diverse backgrounds. We invite submission of papers from global, national, state, local, community or individual levels.

Subjects of special interest may include, but are not limited to:

- Dementia
- Communication (loss of language, older people and evolution of language, developing meaningful translations - challenges and solutions)
- Anxiety and depression
- Health Management & Chronic Care / innovative models
- Prevention & Health Promotion
- Community and residential aged care (new innovative and successful initiatives)
- Collaboration and partnerships with General Practitioners in health care and support to older people
- End of life care and decisions

Delegates have options to present papers, workshops or posters. All abstracts need to be submitted by 5th September 2007. For more information please refer to the attached Call for Abstracts brochure.

Looking forward to working and learning together to achieve better health outcomes for the older people and their carers from CALD backgrounds.

www.dhi.gov.au/conference