

National Framework for Action on Dementia 2005 Consultation Paper Submission from Alzheimer's Australia Vic Consumer Reference Group

Contact

Debra Parnell
Alzheimer's Australia Vic
Locked Bag 3001
Hawthorn Vic 3122
(03) 9815 7800
dparnell@alzvic.asn.au

The group provides advice to Alzheimer's Australia Vic about policy and other matters.

General

- The Consumer Reference Group applauded the National Framework document and in particular the principles that underpin the Framework and the proposed outcomes.
- Consumers felt more detail is required about the roles and responsibilities of the various levels of government and their departments:
 - **who** was going to make the actions and outcomes identified happen,
 - **how** it was going to happen
 - and the **timelines** for developing and implementing the proposed actions
- There were concerns that announcements of broad funding and policy developments, such as the announcement of dementia-specific EACH packages, sounded good, but all too often the details of allocation and criteria failed to meet the needs of many people.
- Members of the Consumer Reference Group felt the quote provided under the section '*What is the impact of dementia*' (p.7) was a valuable inclusion, as it conveys the feelings of many people with dementia. They also felt that the inclusion of the World Health Organization ICD definition of dementia was valuable.

Public Education

- While a number of the major issues and proposed priorities related to information and education, there was a lack of focus on education and information for the general public.
- Consumers felt very strongly that respect for people with dementia, regardless of their ability or condition, required community understanding and acceptance of dementia. By extension, community education would also result in respect for carers.
- Consumers expressed concern that much of the responsibility for education of people around them, including the broader community, fell to them, and felt it was essential that this responsibility be taken off people with dementia and their carers.

- Both people with dementia and family carers urged the Government to act to 'normalise' dementia and people with dementia in the community. People with dementia should not be hidden away, but feel able to participate and be seen in public.

Medications

The Consumer Reference Group identified access to medications as an area that was not addressed in the Priority Areas or outcomes. They stressed the need for people to be able to access medications on PBS, more easily, to assist them to stay at home and maintain function.

Dementia Coordinators

Consumers suggested the establishment of 'Dementia Coordinators or Educators', similar to the existing 'Diabetes Educators'. These Coordinators could be health professionals with extra training in working with people with dementia. They could be attached to local government or hospitals/health networks, and act as the initial contact person once a person has been diagnosed with dementia to work with the person, their carers and families throughout the course of the disease. This would enable all the services required by the person with dementia to be coordinated.

The Coordinator would give support and information to the person with dementia, their family and carers, GPs, acute care and aged care staff. If the person with dementia was admitted to an acute care facility, the Dementia Coordinator would be able to inform the ward staff of the specific needs of the patient and work with the acute care staff to develop a care plan specific to the person's needs.

Outcomes

- Consumers agreed that cost-effective means of pursuing the key priorities should be identified, as they held concerns that there were current inefficiencies in the system. However, they were also concerned about governments shifting responsibility, and urged governments to work more collaboratively in order to better meet the needs and issues impacting on people with dementia, their families and carers.
- While cost-effectiveness was important, this should not be equated with cost-cutting or short-term cost-effectiveness. It might be necessary to commit to initial expenditure for long term savings and effectiveness, by enabling people to live at home more comfortably and with less stress and difficulties.
- Some consumers raised the issue that while the specification of outcomes were highly desirable, the Framework itself would not guarantee change – it would require commitment from governments to act and implement appropriate dementia policy and programs to have any impact on people where they live.

Principles

- Consumers applauded the inclusion of **person-centred care**, and called on the government to make this a priority and include in national guidelines.
- Members of the Consumer Reference Group felt that in addition to flexibility of care, being '*central to making choices about care*', that people with dementia and families had the right to **real choice** in the services, models and arrangements for care, and that flexibility and choice were not necessarily the same.
- **Value and respect** for people with dementia and family carers was seen as fundamental.
- The Consumer Reference Group applauded the identification of '*more social participation*' as a desired outcome of the Framework, and urged the Government to work to '**normalise** dementia' so that people with dementia were more able to participate in 'mainstream' and community activities and programs.
- **Consultation with carers** and family members in all stages and in all settings was seen as fundamental, as consumers identified that decisions were often made without enough consultation.
- The Consumer Reference Group also saw the need for there to be recognition of the impact of dementia on the whole family, beyond the primary carer, and that **respect for carers and family members** should be identified as a key principle through a commitment to the concept of family carers. Members of the Group called for more support for and education of extended families.
- The Consumer Reference Group identified that there was a lack of recognition of **cost**, in economic terms, as well as social, to the family and individuals in caring for someone for dementia.

Comments on Priority Areas

Priority Area 1 Research

- Research as an area for priority action was fully supported.
- However, members of the Group questioned what sort of commitment the Government would make to ensure that dementia research would become a higher priority (in comparison to other health and medical issues) than was currently the case.
- In terms of risk reduction and prevention it was suggested that screening programs be developed and made accessible to identify "at risk" persons so there could be early intervention.

Priority Area 2 Information and Education

Promotion of healthy lifestyles

- Consumers called for the development and promotion of community activity programs suitable for participation by persons with dementia.
- Consumers also stressed the need for community awareness about the benefits of early diagnosis.

Information and education for people with dementia, families and carers

- Consumers identified the need for GP's and Specialists to be aware of information, education and support that was available, to be able to refer patients to appropriate services to meet their needs, especially in rural areas where the GP may be the only contact point.
- The Consumer Reference Group stressed the need for more accessible information for families and carers, and that the information should be **real** information provided in advance, that could be utilised as services and assistance were required
- Consumers felt that addressing the needs of CALD, rural and isolated people should be particularly identified in this section.
- Funding for and establishment of Support Groups and other means of peer support was also identified as a priority action.

Protection of rights and interests

- Licensing and transport issues were identified by consumers as needing to be addressed. There needed to be commitment to accessible driving assessment, and community transport options, such as Multipurpose Taxi Program (half price), for people with dementia and family carers. There was also a call for national consistency in these programs and policy developments.
- Protection of rights and interests was identified as an important area, and consumers identified the need for information provision to enable them to plan ahead and advocate on their own behalf.
- Issues in residential care settings were also identified and the need for people to be aware of their rights. Consumers suggested the development of structured involvement of carers and family members to address issues.

Priority Area 3 Access and Equity

- The identification of issues and needs of these groups was applauded.
- Needs of people in rural and remote areas were identified as a particular issue to be addressed –
 - need for better trained and informed GPs in relation to early diagnosis, and awareness of treatment options, and support services available;
 - more specialist services available to enable specific early diagnosis and treatment.
- In particular the issues for people with dementia under the age of 65 years in rural areas were identified as needing attention, as options and accessibility of services were limited.
- Issues for people over the age of 65 years, but who are physically active or in need of participatory activities was also identified.

Priority Area 4 Quality, Integration and Continuum of Care

Primary Health

- Specialists and not just GPs were identified as needing to be included in, or targeted for training and information.
- It was noted that the introduction to this section identified *'some people with dementia, their families and carers'* as needing assistance to navigate through the service system. Members of the Consumer Reference Group felt that, in fact, **all** people with dementia, their families and carers needed assistance to deal with the service system. The introduction of dementia coordinators or case managers attached to local governments was identified as a possible initiative that would assist people enormously.

Community Care

- The priority action *'Share information between Governments to avoid duplication of dementia services and meet service gaps'* was felt to be a fundamental issue that should be addressed, but consumers would have liked to have seen a more constructive strategy identified to ensure there was collaboration and connectivity between levels of government and relevant departments.
- Access to and funding of modifications and aids to assist people to stay in their homes, and to assist family carers manage the care of the person with dementia were identified as a priority. This program needed to understand the nature of dementia better and be more responsive to the needs of people with dementia, their families and carers. Consumers felt that the program addressed the needs of people with physical disabilities and didn't understand the impact of cognitive decline on functioning. The process of accessing funding also needed to be reviewed as due to the progressive nature of the cognitive decline, often funding became available too late to be of assistance.

Respite

- Respite was identified as a significant issue for people with dementia, their families and carers, but that this was not adequately reflected in the proposed priorities for action.
- Respite was identified as a particular issue for people in rural areas, as there were limited options, and often the respite available was not appropriate.
- Residential respite was an area that needed to be addressed. Consumers called for dementia specific residential respite, and a range of models to cater for the needs of people at different stages and levels of activity.
- Short term and overnight respite in home and in residential facilities was seen as an area that needed to be improved.
- Joint respite for the people with dementia and their family was also identified as a need.
- Respite services were also identified as needing to better cater for active people and those with behavioural issues.

Acute Care

- The actions identified as priorities were applauded, as the issues arising from acute care episodes for people with dementia and families were significant.
- Training of nurses in acute care was identified as a priority.
- The involvement of families in the care and management of people with dementia in acute care settings was vital and should be supported and facilitated.

Residential Care

- Consumers called for a range of models to cater for individual needs, particularly for more active people with dementia.
- More dementia specific units were identified as a need in residential care, and some consumers identified that currently facilities described as 'dementia specific' could not, or did not, in fact, cater appropriately for people with dementia.
- Consumers identified the need for government funding for residential care beds in rural/remote areas to take into consideration the demographics of the area. It was important to keep the person with dementia within their community as long as possible. Many older people had lived in that small community all of their lives and it was detrimental to their care to have to leave the familiar surroundings and community support because there were no residential beds available. A move to another area increased the person's confusion and removed a lot of their support base from them, including access by family members.
- Funding and costs associated with residential care had not been acknowledged or addressed.

Palliative Care

- In addition to issues related to the transition to the final stage of dementia and palliative care, consumers felt there was a need to address other 'end of life' issues, such as supporting and enabling people with dementia, their families and carers to plan for the final stages.
- Consumers particularly raised issues related to when the medical approach to life support and intervention conflicted with individual and family wishes.

Priority Area 5 Workforce and Training

- Consumers applauded the identified priorities for action, as being comprehensive and covering many of their issues and concerns.
- It was felt that the priorities for action focussed primarily on residential and aged care settings and services, when many other services should also be identified as needing to be addressed, such as Centrelink and other service industries.