



Response from Alzheimer's Australia to the National Framework for Action on Dementia 2005 Consultation Paper

Alzheimer's Australia is the National peak consumer organisation for people with dementia and their families and carers providing leadership in policy and services. State and Territory member organisations provide information, support, advocacy and education services.

Input to the Framework consultation

This submission reflects the views of the National organisation and its member organisations. It has been informed by discussions with consumers across Australia. A number of our members are also working with State/Territory governments to collect the views of stakeholders on the National Framework for Action on Dementia consultation paper.

Alzheimer's Australia is concurrently involved in a consultative process that aims to identify the priorities of consumers - people with dementia and their families and carers - as a guide to our future advocacy and policy action. Our member organisations are running a program of consultation activity prior to our first National Consumer Summit to be held in Canberra in early October. The outcomes of the Summit will be presented to the Australian Government on 6 October. We request that the outcomes of the Summit are made available to Health Ministers in taking decisions on the National Framework for action on Dementia and in the ongoing development of the Framework.

Summary

Alzheimer's Australia supports the draft National Framework, recognising that to achieve its potential there are two great challenges. Firstly, to identify the future funding needs and sources to give effect to the priorities. Secondly, to get national action between all stakeholders in sharing information and innovation and, in systematically promoting best dementia care practice so that what is identified as needing to be done is translated into action for all Australians living with dementia.

Detailed comments are provided on the outcomes, principles and priorities contained in the Framework.

While all identified priorities are important, some are more underdeveloped than others. Key questions that should be addressed as a matter of priority include:

- How to build the capacity of GPs to provide early and accurate diagnosis and manage best practice care?
- What is good practice in acute care for people with dementia and how can it become the norm?
- How to identify and promote the delivery of best practice dementia care across the residential and community care systems?
 - What are the elements of quality dementia care?
 - How to design planning and funding systems that recognise the different needs of people living with dementia in mainstream and dementia specific community and residential services?
 - How best to encourage and support research into quality dementia care and care more generally?
 - How can dementia-related research be transferred into mainstream care practice?
- What barriers remain to be overcome before consumers are able to participate as full citizens in their communities?
 - How can legal planning and decision making be simplified across Australia?
 - What can be done to reduce remaining stigma experienced by people with dementia and their families and carers?
 - How can workplaces become more dementia-friendly?
 - How can people with dementia and their families and carers be supported in awareness and advocacy activity?

Thank you for this opportunity to comment on the draft National Framework

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General Comments

Alzheimer's Australia strongly supports the development of a National vision for action. In particular, we welcome the development of a public health approach to dementia, embracing research, best practice care and preventative approaches.

The Framework provides a valuable starting point in addressing dementia as a National Health Priority by committing to the continued development of quality dementia policy and services today and to the prevention of dementia tomorrow.

Specific points:

- *Need for real action and routine reporting*
The Consultation Paper does not include tangible and measurable actions. The Framework must include a commitment by governments at all levels to report annually on progress made against the agreed priorities for funding and action in the Framework.
- *Balance between priorities*
A particular strength is the comprehensive list of priorities identified and the wide range of actions that address these.

Some measures will yield immediate and widespread benefits for small investment (eg support group facilitation) while other more expensive items will have initial negligible impact but provide greater benefit in the longer term (eg some research). While all measures identified are important, there needs to be a balance to ensure that people currently diagnosed with dementia and their families and carers gain some real benefit from investment into practical and achievable action.

- *Diversity in dementia*
An area that is not well recognised is the specific needs of carers for people with less common dementias such as fronto temporal lobar degeneration. These carers have different information needs, and require education in different behavioural strategies to manage, for example, early loss of insight. Greater awareness and recognition are also needed. The National Framework should reflect the diversity of need within the dementia population.

- *Acknowledgement of extended family in caring role*
The Consultation Paper makes frequent reference to *carers*. Some emphasis should be placed on support provided by the extended family, in a range of household configurations. It has been estimated that nearly 1 million Australians are involved in caring for a family member or friend with dementia¹.

With the demographic increase in single person households and the increasing geographic spread of families combined with an increasing incidence of people with dementia living alone, there is a need to determine how to best support people living alone to remain in the community.

Reference to *families and carers* more generally would indicate a whole-of-family approach as a complement to the whole-of-community approach referred to in the Consultation Paper as a key principle. Counselling for the family is often the key to changing beliefs and attitudes, enhancing the receptiveness to education, information, resources and support.

- *Terminology*
Alzheimer's Australia uses the term '*people living with dementia*' to mean people with dementia and their families and carers. We suggest that the term '*people with dementia*' is used throughout the document to denote individuals with a diagnosis.
- *Dementia as a National Health Priority*
While the Federal and State dementia policy context is outlined with reference to 2005-06 Budget allocations and State dementia frameworks, more explanation of the implications of dementia as a National Health Priority initiative and its relationship to the National Framework would be helpful.
- *Roles and responsibilities*
The Framework would benefit from some description of the roles and responsibilities of Federal, State and Local governments, and particular departments, in the ongoing development and delivery of policy and services and the priorities proposed for action.
- *Training/education needs*
In the section on 'what is the impact of dementia?' (p7), paragraph 4 says '*Over time, the type of dementia services needed will change, as will the skill base and training of the aged care workforce.*' This point merits some clarification. Also, the community services and acute care workforces will also need to have better information, education and training.

¹ *Dementia*, Pfizer Australia Health Report No 6, 2004.

Comment on Outcomes

The desired outcomes are supported and if achieved, will significantly improve the quality of life, well being and treatment of people with dementia, their families and carers.

Specific comments:

- Include an additional outcome to support the involvement of people with dementia as far as practicable in their own care planning and other decision making.
- Include an additional outcome: '*Better promotion and funding for dementia-related research.*'
Research should be mentioned explicitly as it is an integral part of any action plan on dementia.
- Dot point 2: add 'and destigmatisation of dementia'.
- Dot point 3: amend to 'more *satisfying* social participation...'
- Dot point 6: amend to 'better *and more effective* access'.
- Dot point 9: amend to read 'better understanding of *the different diseases that cause dementia and how to delay onset and progression*'.
- Dot point 10 – 'more promotion of healthy lifestyles and ways to reduce dementia risk factors' – is supported but needs to be handled with sensitivity:
 - Some carers are concerned funds for dementia will be diverted into an expensive public health campaign when there is a great deal of unmet demand in dementia care and services.
 - Campaigns need to be sensitive and emphasise that people with dementia are not 'to blame' for their dementia
 - People who have done all the 'right' things all their lives may still get dementia.
- Dot point 11: amend to '... management of behavioural issues *that leads to improved quality of life for people with dementia, that minimises the use of physical and chemical restraint, and that is open to trialing alternatives. Strategies to include carer (family and professional) education in how to avoid behaviour triggers.*'

- Dot point 12: This outcome is vague and open to interpretation. It could refer equally to regional prevalence and incidence data, information about distribution of and access to different types of services or evaluations/ research into aspects of care and services.

This outcome needs to be reflected more clearly in a number of issues and priority actions across the identified priority areas.

- Dot point 14: replace 'comparable quality standards' with '*national minimum quality standards*'.
- Dot point 17: amend to 'a better skilled *and supported* workforce to *diagnose dementia, to understand the implications of a diagnosis and to care for people with dementia, their families and carers*'.

Comment on Principles

The identified Principles for the Framework are generally supported.

These principles potentially have far greater application than stated ie to underpin the planning and delivery of services to people with dementia and their families and carers. For example, they should underpin all government activity involving people with dementia, not just service delivery, and efforts should be made to support their application more widely in the community including the private sector. For example, they are applicable to research priorities.

Specific comments:

- Information is an important aspect of principled service delivery and merits a separate mention eg *information is crucial in supporting people with dementia and their families and carers in making informed decisions*.
- The Principles should recognise that the experience of people with dementia and their families and carers will be different at different stages of their 'dementia journey'. Add another dot point that says something like 'It is recognised that the different stages of dementia create different needs and priorities for people with dementia and their families and carers'.
- Dot point 1: replace second sentence with: '*Dignity and quality of life are fundamental human rights to which people with dementia are entitled*'.
- Dot point 5: emphasise/strengthen the concept of 'support'.

- Dot point 10: dementia awareness training is necessary not just for ‘dementia care workers’ but anyone whose work brings them into contact with people with dementia, eg public transport providers, bank tellers, shop assistants... It is recommended that another dot point be added that says something like ‘Customer service staff in public and private enterprises will benefit from dementia awareness training’.
- Dot point 11: Amend to acknowledge that consultation should include people with dementia as far as is practicable.

Comment on Key Priority Areas

Alzheimer’s Australia supports the inclusion of the five priority areas identified in the Framework. We welcome the inclusion of research as a major priority, as this is an area which has been under-resourced in the past when compared with the financial and social costs of dementia. Possibly 0.3 per cent of the total cost of dementia is spent on research.

The National Framework poses two great challenges. Firstly, to identify the future funding needs and sources to give effect to the priorities. Secondly, to get national action between all stakeholders in sharing information and innovation and, in systematically promoting best dementia care practice so that what is identified as needing to be done is translated into action for all Australians living with dementia.

While all identified priorities are important, some are more underdeveloped than others. Key questions that should be addressed as a matter of priority include:

- How to build the capacity of GPs to provide early and accurate diagnosis and manage best practice care?
- What is good practice in acute care for people with dementia and how can it become the norm?
- How to identify and promote the delivery of best practice quality dementia care across the residential and community care systems?
 - What are the elements of quality dementia care?
 - How to design planning and funding systems that recognise the different needs of people living with dementia in mainstream and dementia specific community and residential services?
 - How best to encourage and support research into quality dementia care and care more generally?
 - How can dementia-related research be transferred into mainstream care practice?

- What barriers remain to be overcome before consumers are able to participate as full citizens in their communities?
 - How can legal planning and decision making be simplified across Australia?
 - What can be done to reduce remaining stigma experienced by people with dementia and their families and carers?
 - How can workplaces become more dementia-friendly?
 - How can people with dementia and their families and carers be supported in awareness and advocacy activity?

Support groups have been omitted from the Framework paper. More investment must be made to assist support groups to help carers, families and people with dementia, throughout the journey, ie from diagnosis to bereavement.

In terms of priorities within the nominated areas, high importance was placed by consumers on:

- *Appropriate respite care.*
- *Timely access to services including diagnosis, (ie meeting unmet needs. This includes eliminating long waiting lists and making more services available in rural and remote areas, and for special needs groups, eg Aboriginal/Torres strait islander communities).*
- *Education and information:* for health care workers including GPs, family carers, other service providers and the general community.
- *Empowering consumers* – eg by providing comprehensive, written information (including contact numbers for different services) at the time of diagnosis so that the person with dementia and carer can absorb the information at their own pace, and not have to ask for help every time they need something.

Public health messages regarding risk reduction are critical because:

- The community - and particularly the baby boomers - have a right to the best evidence available in respect of risk reduction.
- The prospect of delaying the onset of dementia by even a few years will greatly reduce health costs and improve quality of life.
- Dementia, like other chronic diseases, will become preventable as science makes new advances.

Any campaign must

- Draw on the best evidence available as regards risk reduction and stress that measures may reduce risk but do not guarantee risk reduction.
- Be sensitive to the fact that people with dementia are not to blame for their condition and, indeed, many people may have practiced all of the risk reduction measures throughout their lives and may still have dementia

Consumers acknowledge that governments have provided increasing levels of funding for dementia care and services, and that public health messages are important. However, care would need to be taken to ensure a balance between awareness and service activity so that any public health campaign does not adversely divert attention and funding from the care and services necessary to meet the needs of people living with dementia.

Priority Area 1. Research

While services and research are both important issues in dementia and their inclusion in the one framework is appropriate, it is considered necessary that different areas be separately evaluated so that good progress in one area does not 'cover up' a lack of progress in another.

A clearinghouse would be particularly valuable in providing ready access to best practice service examples.

Specific comments:

- Issue 1: amend to ' ... research into cures *is* important, research is also needed into ~~possible~~ risk reduction and ...'
- Issue 2: amend to 'Dementia research *findings* need to be shared and *in particular*, be made more *accessible to the general public and health professionals*.
There are two points to make – that quality research findings need to be accurately reported and available to the public, as well as available to health professionals in a form to facilitate translation into practice.
- Issue 3: amend to 'Dementia research priorities need to be *identified*.'
- Priority action 1: amend to 'Fund more research into risk reduction *strategies* and *the* prevention of dementia.'
- Priority action 6: amend to 'Make research *findings* publicly available *with due care* through websites, publications and public seminars'
The irresponsible or ignorant application of novel research findings could do more harm than good.
- Add priority action: '*Make research findings readily accessible to health professionals to facilitate translation into practice.*'
- Add priority action: '*prioritise research on psycho-social aspects of people living with dementia.*'

- Add priority action: ‘*Fund research into how family carers can be best supported in caring for a person with dementia.*’

Priority Area 2. Information and Education

Promotion of healthy lifestyles

It will be crucial to ensure that health promotion messages are evidence-based and accurate.

Information and education for people with dementia, families and carers

It must be recognised that support for carers and the person with the diagnosis needs to be ongoing but with the flexibility to change over time as capacity is increasingly lost.

GPs must be a major part of the approach, so it will be important to find out how to engage GPs and create an acceptable model that involves them.

Specific comments:

- Issue 3: Amend to ‘People diagnosed with dementia *and their carers* can benefit from the support of others in the same situation.’
- Emotional support is very important to people with dementia and their families and carers and requires strategies different from those for information and education. It is acknowledged that emotional support is recognised here as an issue however, it is suggested that ‘emotional support’ deserves to be an issue on its own.
- Priority action 1: Amend to ‘Find out the best ways and the best time to provide dementia information, education, advice and support *and implement them.*’ This is a high priority.
- Priority action 2 is important – need to ensure a co-ordinated National approach, for example through the Centres of Excellence proposed by Alzheimer’s Australia.
- Priority action 3: While this action is supported, there will need to be arrangements in place to ensure that resources are accessible for people with limited IT skills or those without suitable computer access.
- Priority action 4: Amend to ‘Provide more emotional support and education for people *throughout the course of their dementia including those with early stage dementia.*’

Protection of rights and interests

Improving information, education and practice across legal and other planning areas will improve outcomes for people with dementia and their families and carers. Providing medical and legal professionals with better education and information will, for example, minimise misuse or abuse of powers.

Remaining stigma and discrimination in access to diagnosis, services etc can be overcome by improving the understanding of dementia and the implications of a diagnosis of dementia across the whole community. In this context, practices of Government agencies such as Centrelink were seen as particularly onerous and inappropriate for people with dementia and their families and carers.

Specific comments:

- Issue 8: this should be a priority for action.
- Issue 9: Amend to 'The rights and interests of people with dementia in the workplace *and on the road (ie driving)* are growing issues that are not well understood.'
- Priority action 1: Amend to 'Find out how best to encourage informed and supportive communities *and implement those strategies.*'
This is a high priority across all age groups including children.
- Priority action 2: Add in 'people with dementia, their families and carers need to be made aware of alternatives to public guardianship such as enduring power of attorney, as soon as possible after diagnosis.'
- Priority action 5: amend to include 'police services and commercial institutions'.
This is a high priority.
- Add in new priority action: '*investigate and implement ways to simplify legal, financial and advanced care planning, improve implementation of plans and reduce barriers to recognition across different jurisdictions.*'

- Add in new priority action: *‘review government processes including to improve their relevance and appropriateness for people with dementia and their families and carers.’*
- Add in new priority action: *‘develop a coordinated national strategy to deal with the issue of dementia and driving in the context of road safety, access and dignity.’*
- Add in new priority action: *‘consider the circumstances of people with dementia and their families in the review and development of consumer protection laws.’*
- Add in new priority action: *‘people with dementia have a right to appropriate and affordable medication.’*

Priority Area 3. Access and Equity

The best outcome for people living with dementia would be if **all** people with dementia were diagnosed accurately and expeditiously and left the surgery with the information that they will need about their diagnosis, disease progression and available community support services, etc. This involves issues related to access, capacity and quality in primary care, with appropriate assessment etc for special needs groups.

Consumers report that access to appropriate support and care services varies across Australia, particularly in outer suburban and rural or remote areas. Adequate transport options support people with dementia in taking the decision to cease driving while remaining active in their communities.

Alzheimer's Australia supports the recognition of issues related to people from culturally and linguistically diverse backgrounds, indigenous communities and people with younger onset dementias. These issues should be further emphasised as their needs are high, multiple and complex, and current program support is limited. People with dementia who live alone should also be identified as a focus for policy and program development.

We support the community capacity building principles underpinning such actions as “... making culturally sensitive and inclusive practice a requirement for all programs, services, standards and guidelines...”, and “...strengthen data collection, planning and reporting requirements by mainstream services on their response to people with diverse and multiple needs...”

Specific comments:

- Issue 7: addressing this should be a high priority.

- Priority action 3: amend to ‘ all people *with possible* dementia.’
- Priority action 9: this should be a high priority.
- Priority action 10: amend to ‘Support *and expand* the work of the National Cross Cultural Dementia Network.’
- Priority action 12: implementation will be just as important.
- Add in new priority action: ‘*Identify suitable support and care options for people with dementia living alone in the community.*’
- Add in new priority action: ‘*recognising that many carers (especially of people with younger onset dementia) are still in paid employment, review and change policies and practices that are insensitive to continued workforce participation.*’
Examples include eligibility rules that consider proximity of day centre to residential rather than workplace address; carer education in work hours.

Priority Area 4. Quality, Integration and Continuum of Care

Australia has some 15 years of experience in providing mainstream and dementia-specific care. This experience should be reviewed in a consensus meeting or conference to take stock of what has been learned. One of the outcomes of such a meeting (or otherwise) might be a statement outlining acceptable pathways of care through the stages of dementia and which outlines for example, the transition between community care and residential care.

Primary health

Alzheimer's Australia supports this emphasis on primary health. The focus on GP support is appropriate and warranted and needs to be founded on a well co-ordinated and well-resourced approach.

There is an urgent need for comprehensive research into primary health issues and dementia, including the development of Nationally consistent guidelines for GPs around diagnosis, management and care of people with dementia. Another outcome of this research should be the development of a comprehensive program of incentives, training and support, similar to the Better Outcomes in Mental Health Program.

Planning for primary health service development also needs to recognise the role of specialists given that physicians are increasingly becoming part of initial entry services through memory centres and similar services. Access to medications is also dependent on timely access to specialist diagnosis.

There is a need to also recognise that professional referrals may also occur in the reverse direction. For example, a person with yet-to-be-diagnosed younger onset dementia may have initial contact with a psychiatrist.

Specific comments:

- Priority action 3: this is critical and should be a high priority.
- Add in new priority action: 'recognise that dementia occurs in populations under 65 years – around 10,000 Australia-wide in 2005'

Community care

Community care is particularly important for people with dementia and their families and carers, as many will remain in the community for a considerable period of time if appropriately supported by services. Access to services can be facilitated for many by providing 'key' or 'link' workers to act as case managers after diagnosis.

The provision of dementia-specific EACH packages provides an innovative way to meet high level need. The evaluation of this program component will provide crucial guidance to inform the provision of future community-based high level support.

Alzheimer's Australia supports the intention to "...develop evidence-based guidelines for the design of community environments for people with dementia..." and the recognition that design extends beyond residential aged care facility environments. The needs of people with dementia should be taken into account in all aspects of community design.

Specific comments:

- Priority action 2: add at end 'including through consumer directed care pilots'.
- Priority action 3: it is recommended that a folder of written material be given on diagnosis, and that this information includes phone numbers and descriptions of various services as well as explanatory information about dementia.
- Add in new priority action: 'Identify and resolve the unintended consequences of management arrangements to ensure that people with dementia and their families and carers receive continuous support and minimal disruption to services.'
For example carers need respite support even when the person with dementia is in acute care.
- Add in new priority action: 'Develop best practice housing design embracing new technologies'.

Respite care

The multiple actions identified reflect the importance of this high priority need area. Services need to provide sensitive, responsive, flexible and age-appropriate respite options that meet the needs of people with dementia and their families and carers. This includes, for example:

- Extended hours, including overnight or week-long stays;
- Individualised care plans that reflect interests, abilities and health considerations;
- Respite options (or ‘therapy centres’) that help people with dementia to maintain their skills;
- More regular respite for families with children;
- Providing transport options with respite;
- Secure respite for those for whom safety is an issue;
- Respite that is appropriate to the needs of younger people with dementia and that reflects their interests.

Specific comments:

- Add in new issue: ‘respite care is calculated by financial year but this is not consistent with the ACAT review form.’
- Priority action 1: the care plan should not compel the involvement of family who may have rejected involvement for whatever reasons. Revise the last part of the sentence ‘... that *may* involve ...’
- Priority action 2: amend to ‘Review, develop, promote *and implement* ways to provide flexible respite that meets individual needs.’
- Add new priority action: ‘*make respite care period calculation consistent with ACAT review period.*’
- Add new priority action: ‘*review assessment tables and documentation – too complex and time consuming.*’
- Add new priority action: ‘*review the conditional requirements of Carers’ Allowance.*’
Dementia is a condition that does not ‘get better’ and therefore it is unnecessary and intrusive to demand information annually.
- Add new priority action: ‘*increase availability of short-notice/emergency respite.*’

- Add new priority action: *'respite care must be appropriate. It is harmful to place people in earlier stages and people without behavioural issues into 'secure dementia units' with people who have severe behavioural problems or who are at end-stage.'*

Acute care

Acute care may present one of the greatest opportunities to improve the support available for people with dementia and their families and carers. The challenge is to apply the lessons of successful projects and pilots across the acute care system in every region of Australia.

The Consultation Paper rightly identifies the need for "...ensuring smooth transition in and out of hospital when required...". There is also a need to ensure a transition into respite care (in and out of home). This is partially recognised under Residential Care in terms of "...developing guidelines for workers to better manage the movements of people with dementia between residential options..." but it equally applies to any flexible respite options, as any change of environment and/or principal carers can be disruptive and distressing for the person with dementia.

Specific comments:

- Issue 2: people with dementia should also be consulted whenever practicable.
- Add new issue: *'All acute care staff need to have basic dementia awareness and knowledge.'*
- Add new issue: *'The management and practices of many acute facilities do not take into account the impact of dementia on management and care.'* Examples include taking medical history from a person with advanced dementia, excluding any consideration of dementia from the triage system.
- Priority action 3: amend to *'Identify models/methods that support people with dementia and carers' involvement in decision-making, planning and the provision of care.'*
- Priority action 5: amend to *'Develop and implement systems to help people with dementia and their carers provide feedback on the quality of care they receive.'*
- Priority action 6: amend to *'Develop and implement national design guidelines for acute care wards to help health workers provide quality dementia care.'*

- Add new priority action: *‘investigate discreet methods to alert hospital staff to the fact that a patient has dementia, eg there is a red band for people with allergies, perhaps another colour for people with dementia.’*

Residential care

Many of the issues in residential care will be affected by current developments around the funding of residential care for people with dementia, both mainstream and dementia-specific. These developments provide real opportunities to explore how funding arrangements might affect the delivery of quality dementia care in residential facilities.

A strategic approach to improving access to and quality of care revolves around:

- Allocating up to 10% of residential care places to dementia-specific places;
- Ensuring that financial incentives reward those service providers that provide quality dementia care; and
- Establishing a standards/quality regime that ensures that approved dementia providers are required to meet defined standards in both mainstream and dementia-specific places.

Specific comments:

- Issue 1: amend to *‘the ageing of the population and the increasing incidence of dementia mean that demand for residential care for people with dementia will continue to rise.’*
- Priority action 1: amend to *‘Improve the design of residential aged care homes for people with dementia and assure better physical accommodation through the certification instrument under the Aged Care Act.’*
- Priority action 2: add *‘including the identification and allocation of dementia specific places.’*
- Priority action 3: amend to *‘Develop national care standards for people with dementia in residential aged care and implement better quality of care through the accreditation standards under the Aged Care Act.’*
- Priority action 5: amend to *‘Develop, promote and implement guidelines to help health workers and carers better manage the movement of people with dementia between home, hospital and residential aged care.’*
- Add new priority action: *‘allocate sufficient resources to support the provision of quality person-centred care in residential facilities.’*

- Add new priority action: *'make sure all aged care residents have access to medical care – if not from a GP then from a salaried medical director position.'*
- Add new priority action: *'Commonwealth and State Governments should give priority to planning appropriate care for those with very severe or extreme BPSD.'*
- Add new priority action: *'Residential aged care provision needs to respond to the needs of younger people with dementia.'*

Palliative care

Alzheimer's Australia strongly supports the inclusion of palliative care in this Framework. Access to palliative care is important to support

- people with terminal dementia and
- those with a diagnosis of dementia together with a terminal co-morbidity.

Alzheimer's Australia has commissioned a discussion paper in this area from Professor Jennifer Abbey that will be available shortly.

There is a need to highlight the sensitivities involved with addressing the issue of "...promotion of information about end stage dementia...". This needs to be handled with great sensitivity and seen as an issue that involves families, clinicians and service providers working together to achieve a satisfactory outcome for all.

Specific comments:

- Add new issue: *'carers require access to ongoing support to facilitate adjustment following the death of the person with dementia.'*
- Priority action 3: amend to *'Develop and implement education and training initiatives for health professionals and community care providers about palliative care and end stage dementia.'*
- Priority action 4: amend to *'Help carers plan ahead for when their caring role ceases.'*
- Priority action 6: this needs to also include *'provision of support required.'*

Behavioural issues that impact on care and support

It is important to remember that each person with dementia is unique and has a unique experience of dementia.

The impact of changed behaviours can be ameliorated by best practice treatment and care. The impact on staff can be further reduced by appropriate dementia education and training.

Brodaty's triangle² indicates that at any time 10% of people with dementia require specialist support because of changed behaviour; the vast majority can be supported by mainstream staff if they are sensitive to and educated about behavioural change. A small percentage of people with severe or extreme BPSD require special care.

² *Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery*, Brodaty H, Draper B M and Low L, Medical Journal of Australia, Vol 178, March 2003

Specific comments:

- Introduction second sentence: amend to ‘these behaviours can be very distressing for *the person with dementia as well as for families and carers ...*’
- Issue 1: amend to ‘Better ways need to be *implemented* to prevent or safely manage behavioural issues associated with dementia.’
We have identified them – it’s just that they are too rarely put in place.
- Add new issue: ‘*Access to appropriate care for those with the most severe behavioural symptoms (less than 1%) is frequently problematic.*’
- Add new issue: ‘*Access to specialist advice and resources may be difficult in some regions.*’
Improved access to specialists and health professionals generally can help to identify the untreated health issues or inappropriate treatment that can contribute to changed behaviours.
- Priority action 5: vague phrase but important nonetheless. Support should underscore the entire Framework.
- Priority action 6: amend to ‘Develop *and implement* service models and funding arrangements for assessment, management, support and accommodation of people with dementia across care settings.’
In dementia, people’s behaviour always impacts on their care so the last phrase of this dot point is redundant.
- Add new priority action (perhaps after priority 1): ‘*The Australian and State and Territory Governments should give priority to the planning and implementation of appropriate care places for those with very severe or extreme BPSD.*’
- Add new priority action: ‘*Offer general dementia education to all non-cognitively impaired residents in facilities, as well as to non-care staff.*’

Priority Area 5. Workforce and Training

An over-arching issue is the need for mandatory minimum qualifications for all staff providing care in residential and community care.

Specific comments:

- Issue 1: amend to ‘Health, community and aged care workers providing dementia care need improved training, higher level skills, *better pay* and appropriate conditions.’

- Priority action 1: Need to improve pay.
- Priority action 2: amend to 'Increase the availability of accredited education and training courses in dementia care *at vocational and tertiary levels.*'
- Priority action 3: useful to identify how training should be 'better' eg improved access, financial support, wider range of training options, etc.
- Priority action 5: amend to 'Set *and implement* training standards for acute care staff in person-centred dementia care and involving older people and their carers in decision-making.'
- Add new priority action: '*implement national aged care workforce strategy in both the residential and community care sectors.*'
- Add new priority action: '*Implement mandatory minimum qualification levels for all staff working in residential aged care and community aged care – with an appropriate lead-in time and training availability during this lead-in time.*'