

NATIONAL FRAMEWORK FOR ACTION ON DEMENTIA 2005 CONSULTATION PAPER

National Stakeholder Consultation Feedback Form

In January 2005, Australian Health Ministers jointly agreed to the development of a National Framework for Action on Dementia. This Framework's development will be guided by a nation-wide consultation, which will result in a National Framework that includes the combined input of governments, health care providers, peak bodies, people with dementia, their families and carers. This consultation will help develop a draft National Framework, which will be considered by Australian Health Ministers in November 2005.

Organisations and individuals are welcome to provide comments on the consultation paper and priority areas for action.

Email comments can be sent to dementia@health.gov.au

Written submissions are also welcome and can be posted to:

The Australian Government Department of Health and Ageing
Dementia Feedback
Special Needs Strategies Section
MDP 32
GPO BOX 9848
CANBERRA ACT 2601

Please ensure your comments are submitted by 15 July 2005.

Name of Individual or Organisation: **Australian Association of Gerontology**

Postal Address: C/- Centre for Ageing Studies, Mark Oliphant Building, Laffer Drive Science Park, BEDFORD, SA, 5042

Email address: angelj@sesahs.nsw.gov.au (for matters relating to this submission)

Type of Organisation: **Research/academic** * Other (Peak body of groups and individuals interested in ageing)____
(please specify)

Key areas of service provision or interest: **AAG is a multidisciplinary group interested in the study of ageing generally and includes, researchers, educators, practitioners and providers.**

For privacy reasons, individuals may choose not to supply their details, but please indicate what State or Territory you live in.

NSW	VIC	QLD	SA	WA	TAS	ACT	NT
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What do you think should be the Outcomes of a National Framework for Action on Dementia to improve dementia care and support across Australia? (see Consultation Paper, page 8)

The outcomes as listed are comprehensive and cover the key areas, which influence the quality of life for dementia sufferers and their carers.

As a general comment, grouping of the outcomes may make the paper easier to follow and the overarching outcomes easier to understand. For example many of the listed outcomes fall generally under the overarching objective of “a better quality of life” and the document might benefit from some more formal structuring. The overarching outcomes could be

- “better quality of life for people with dementia their families and carers (currently no 1)
- A theme which incorporates issues such as involvement of patients and carers in decision making combined with access to good information
- An overarching outcome relating to access to care and appropriate living/care environments.
- Timely access to quality, affordable health care
- An overarching outcome relating to research and treatments i.e. which supports efforts which allow for better treatments or methods to delay or avoid dementia onset
- A theme relating to the availability of a skilled workforce both now and in the future.

The AAG stresses that rapid population ageing in Australia, particularly over the past three decades, is the primary determinant of the need for a National Framework for Action on Dementia. It is now extensively documented that Dementia is an age-related disorder, which increases exponentially with advancing age over 65 years. It is uncommon (albeit important to affected individuals and carers) in those less than 65 years and very common and equally important in those 85 years and over, where it affects up to 30% of the population. Dementia care is rapidly becoming an important driver of Community Services, Community Health and primary health care. Service provision for frail older people with decline in cognition and mobility as well as people with dementia and their carers needs an effective local community base.

What do you think should be the Principles guiding the planning and the delivery of services for people living with dementia, their families and carers? (see Consultation Paper, page 9)

These twelve principles are comprehensive and cover most key issues. They seem well structured and considered.

The AAG considers a further principle needs to be defined and enunciated to support the preceding twelve principles and in particular the important final principle outlined in the National Framework to ensure that the provision of person centred care and provision of appropriate services, with coordination and flexibility of care to provide “A whole-of-community approach [which] ensures better care for people living with dementia, their families and carers.”

One principle, which the Australian Association of Gerontology would like to add, relates to the importance of focusing care at the local level. The coordination and delivery of dementia services on the ground requires a local, community oriented, on an appropriate geographical and population base involving the local community and networking existing service elements. Frail older people, like mature wines, do not travel well and their carers need local support systems. The importance of this

local service delivery is in ensuring person centred care is such that it should be reflected in the framework principles.

What do you think should be the key Priority Areas for a National Framework for Action on Dementia? (see Consultation Paper, page 10)

The five priority areas are appropriate. At this point in time it seems that the real needs in the areas of research and workforce and training are less well developed than the other three priority areas.

In terms of priority 4 the AAG supports adoption of an integrated model for health care. The provision of quality health services is a fundamental right of older people. As a general principle, all older people in Australia should have access to planned and properly resourced integrated quality health care that is flexible, equitable, accessible and affordable, that recognizes diversity and promotes choice and respect for users. The aim is to develop a model system of health care for the increasing numbers people with dementia, which gives the best care for the older person, in the best setting, using best practice to achieve maximum physical and mental capacity and minimum disability.

The essential elements of the model are:

- 1. An affordable and accessible primary health care service which ensures that all older people have access to GPs or other service providers as needed, and not relying on acute hospitals to fill gaps in service availability. This will require ensuring there are sufficient primary health care providers to meet growing needs, plus a system for ensuring that primary health care services can reach those with limited mobility. This service must be well integrated with acute, residential care and community services.*
- 2. Community and care centred services, which provide to older people the nursing, allied health and personal services needed to allow them to stay at home as long as possible. Adjuncts to this service are carer support services, respite care and day care facilities, which could be provided through acute hospitals, RAC, local government or independent providers.*
- 3. Hospital community interface programs including as far as possible Post acute care services and "hospital in the home or nursing home" type services which may avoid unnecessary hospital admissions or reduce length of stay and a specialist support network, which is integrated with all care settings and is able to provide support for GPs and patient review and assessment.*
- 4. An efficient quality residential aged care health system (RAC) for frail older people not longer able to reside in the community. This must be integrated with hospital outreach services to prevent avoidable admissions. Residents must have access to primary care, rehabilitation, or palliative care as required.*
- 5. An acute hospital system, which has the capacity and skills to manage complex older patients. Adjuncts to the hospital service must include adequate subacute/ rehabilitation places. The acute system must adapt to the growing older population by integrating specialist gerontic care into hospital activity, initially at the point of entry (usually through ED), but also by providing trained gerontic staff and/or specialist advisory services in other areas of the hospital.*

There is also room to make more specific comments on each of the identified Priority Areas, and their associated major issues and priorities for action, in the 'Comments' columns on the following pages.

Priority Area 1 RESEARCH

Major issues	Comments	Proposed priorities for action	Comments
<ul style="list-style-type: none"> • The focus of most dementia research is on cause and cure. While research into cures remains important, research is also needed into possible risk reduction and into support, care and education for people with dementia and their carers. • Dementia research results need to be shared and be more widely available. • Dementia research priorities need to be agreed. • More funding is needed for dementia research activities from a wider range of sources. 	<p><i>In addition to cause, cure and risk reduction there is need for research into treatment of dementia and most importantly delay of dementia onset.</i></p> <p><i>Identification of agreed research priorities is essential but needs to be handled with some caution. Research priorities are ever changing as a research finding answers one key question but opens up many others. Priorities will change therefore need to be regularly reviewed and updated. "Agreed" priorities run the risk of becoming fixed and difficult to change. If agreed priorities are used to allocate scarce research dollars then it will be essential to build in a regular process of priority review.</i></p> <p><i>Even where there are well-defined and agreed research priorities, some funding should be available for "other research" since often it will be the unusual or indirect research that serendipitously yields the unexpected big breakthrough.</i></p> <p><i>Research into models of care is strongly supported but care should be taken to avoid the trap of "research" programs that have just a short-term life. Too often there are programs, which obtains funding, support for the trial or demonstration phase, but once the trial period finishes there is no ongoing support, even if the trial is effective. Their needs to be integration of funding for "research" with funding for programs or this discontinuity will continue.</i></p>	<ul style="list-style-type: none"> • Fund more research into risk reduction and prevention of dementia. • Fund research to identify better ways of providing dementia care. • Identify further gaps in research. • Prioritise research topics. • Develop a broader, better co-ordinated dementia research funding base. • Make research results publicly available through websites, publications and public seminars. • Find new ways to fund dementia research and to fund new researchers through scholarships, partnerships or mentoring arrangements. 	<p><i>Study of ageing requires a commitment to long-term research. One difficulty often encountered by researchers is the insecurity of funding sources and especially commitment to employment. Postdoctoral researchers often are appointed only on short-term contracts for the period of the research grant. This can be very disruptive especially if the period is relatively short i.e. 1-2 years, since a substantial effort needs to be directed at securing future employment whether through additional or extended research grants or through new projects or positions. The desirability of having a competitive research environment where the value of research grants is fully justified is well recognised and supported. However a balance needs to be made between the need for research accountability and the need for longer-term commitment. In the absence of long-term security and support many larger projects especially those with long research times will not be initiated. Unlike tasks in government or industry where projects may be (and generally are) passed from person to person and often attached to a position not a person, research is very individualised and is usually the outcome of the particular passion or interest of individual researchers. For senior academics and researchers this may not present a major problem as they have the track record to attract research grants or will have been granted tenure at a university. For emerging researchers it may not always be a major problem since they will typically link in with other researchers and will benefit from a diversity of projects and positions.</i></p> <p><i>However there is a very real problem for middle career researchers, who may need to be competing for research grants and positions but because of family commitments, lack the flexibility needed to move between a series of short-term appointments.</i></p>

Priority Area 2 INFORMATION AND EDUCATION - Promotion of healthy lifestyles

Major issues	Comments	Proposed priorities for action	Comments
<ul style="list-style-type: none"> • Everyone needs to know that healthy living, keeping physically, mentally and socially active, may help to prevent dementia. • Older people’s well-being depends on positive community attitudes, having a safe place to live, financial security, and being able to work, learn, enjoy leisure time and contribute to their community. • More services are needed to help people keep physically, mentally and socially active. • Reducing depression and promoting self-esteem help maintain a healthy lifestyle. Depression may increase the risk of dementia. 	<p><i>The issues discussed here are of high importance but run the risk of being treated superficially.</i></p> <p><i>Addressing these issues required establishing structural conditions that allow for older people to remain active. In terms of social isolation availability of sufficient programs and access to those programs remains the real challenge. People are likely to use a program if A) they can get there easily, B) they can afford it, C) it is within their sphere of interest and D) once there the program and atmosphere are congenial.</i></p> <p><i>One of the key issues to develop is diversity of interests for older people. In the past there was often stereotyping of older people’s interests the “bingo and bowls” scenario, but it must be recognised that the diversity of older people will parallel that of the entire community. This is true of people with dementia who will typically retain interest in previous activities. It will be even more true for carers who do not want to spend precious leisure hours in activities for which they have no interest or (and this seems rarely acknowledged) with people they find uncongenial.</i></p> <p><i>As dementia progresses, language skills may decline, adding another layer to the complexity of providing meaningful, rewarding social interaction.</i></p>	<ul style="list-style-type: none"> • Find out how to support physical health and wellbeing and reduce social isolation. • Find out what works to promote healthy ageing for people at risk of and living with dementia, and their carers. • Increase availability of information on healthy, active living and positive ageing. • Promote ways for older people to play an active role in their community. • Include people with dementia and their carers in health promotion strategies. • Include ways to reduce the risk of dementia in national health promotion strategies. • Adopt a national approach to promotion of prevention of dementia, reduction of risk and early intervention. 	<p><i>Use of the words “find out” in this section should be avoided. These terms relate to research and fit well within the objective of research into preventing, treating or managing dementia.</i></p> <p><i>Although there is still much to research and study in terms of education and promotion and adoption of healthy lifestyles a key aspect for good quality of life for people with dementia is implementation of what is already known. This should be the foundation of this priority area, rather than further “finding out”.</i></p> <p><i>Something similar can also be argued for health promotion strategies. Healthy living involving exercise (both MIND and body) plus a good diet is known to promote healthy ageing including but not limited to reducing dementia risk. Therefore the AAG would like to see even more attention given to implementing programs known to be effective. This will require money, time and commitment but is considered a priority. The emphasis needs to be on models of delivery rather than investigation of what to deliver. Emphasis should be on how best to get the service established and used.</i></p>

Priority Area 2 INFORMATION AND EDUCATION - Information and education for people with dementia, families and carers

Major issues	Comments	Proposed priorities for action	Comments
<ul style="list-style-type: none"> • Lack of information about dementia services remains a barrier to gaining access to services. • Information on dementia is often not available when people need it or in a form that is easily understood. • People diagnosed with dementia can benefit from the support of others in the same situation. • Carers can be in poor health and have high emotional stress as a result of their caring role. • Carer education programs can reduce stress and delay the need for residential care. • There is limited access to education programs for people with dementia, their families and carers. 	<p><i>These action priorities are fully supported. The need to support carers in the future is seen as especially important, since it is quite likely that in the future carers will on average be somewhat older and more likely to have other responsibilities and even to have full time employment, as more older women participate in the workforce. Providing physical and emotional support for carers will be essential if they are to continue in this important role.</i></p>	<ul style="list-style-type: none"> • Find out the best ways and the best time to provide dementia information, education, advice and support. • Develop a coordinated, national approach to developing information and educational material. • Establish a national database of educational resources. • Provide more emotional support and education for people with early stage dementia. • Provide more emotional support and education to carers throughout the course of dementia. • Develop information on support and care options at each stage of dementia that can be adapted for local use. 	<p><i>There may not be a "best way" to communicate. All means available should be used.</i></p> <p><i>This will include</i></p> <ul style="list-style-type: none"> ❖ <i>Professionals medical and allied health</i> ❖ <i>Government agencies eg Centre link or Vet Affairs</i> ❖ <i>Community organisations</i> ❖ <i>Libraries,</i> ❖ <i>The internet</i> ❖ <i>Book and coffee shops</i> ❖ <i>Shopping centres</i> <p><i>There can never be too much information so the effort should simply be on spreading it wherever and whenever possible.</i></p> <p><i>Linking education and emotional support may be inappropriate as the two needs are very different with the types of programs needed quite distinct. The linkage may be detrimental to both, with education being seen as a substitute for emotional support or with those tasked with providing emotional support expected to also be responsible for delivering education.</i></p>

Priority Area 2 INFORMATION AND EDUCATION - Protection of rights and interests

Major issues	Comments	Proposed priorities for action	Comments
<ul style="list-style-type: none"> • An informed and supportive community can help people with dementia, their families and carers participate and live in the community for as long as possible. • A diagnosis of dementia can lead to discrimination and can result in people with dementia being denied their rights. • People with dementia become dependent on others for care and protection of their rights and may be at risk of abuse or neglect. • Carers of people with dementia may be at risk of emotional distress and physical abuse as dementia progresses. • Earlier diagnosis allows people in the early stages of dementia, their families and carers, to plan ahead for financial, lifestyle and health care choices. • Planning ahead can reduce the stress on families and carers, address issues of consent and include the wishes of a person living with dementia. • Attitudes to ageing and planning ahead can be a barrier to decision-making in the early stages of dementia. 	<p><i>The potential for financial abuse of older people and especially those with dementia should be added as a major issue. This is to be discussed at the AAG Conference in November 2005.</i></p> <p><i>Older people, especially those with dementia are often vulnerable, in terms of finances and asset management. They are potentially vulnerable to the demands and interests of relatives and also to the interests of the financial sector (banks, superfunds, financial planners) where assets may not be managed to best advantage.</i></p>	<ul style="list-style-type: none"> • Find out how best to encourage informed and supportive communities. • Increase availability of information on options for planning ahead and health care rights and responsibilities. • Find out how best to involve people with dementia, their families and carers in decisions and expand these methods. • Promote ways to protect the rights and interests of people with dementia and their carers among health workers and staff in residential and community care facilities. • Develop co-ordinated education initiatives for health professionals, carers, residential care sector and legal profession about assessing capacity and substitute decision-making. • Identify and introduce ways to protect the rights and interests of people with dementia in the workplace. 	<p><i>These action items are fully supported although once again the words "find out" should be removed. Any relevant research actions should be considered under Priority 1.</i></p> <p><i>The priorities actions are non-committal. Although it may still be premature to identify all the necessary or desirable actions, it would be encouraging to include one or two specific commitments, designed to protect the rights of those with dementia.</i></p>

Major issues	Comments	Proposed priorities for action	Comments
<ul style="list-style-type: none"> • Lawyers, health staff and the business sector need to be made aware about planning ahead and decision-making. • The rights and interests of people with dementia in the workplace are growing issues that are not well understood. 			

Priority Area 3 ACCESS AND EQUITY

Major issues	Comments	Proposed priorities for action	Comments
<ul style="list-style-type: none"> • Better ways are needed to identify, assess and support all people with dementia. • Validated dementia assessment tools are needed to assess people from CALD backgrounds, people from Aboriginal and Torres Strait Islander communities and ageing people with an intellectual disability. • More research is needed into dementia in people with diverse and multiple needs. • More flexible care and support services are required for people with an intellectual disability who develop dementia. • There is a need to identify service gaps and to support the continuum of care for all people with dementia including those with multiple needs. • Dementia information, support and care services need to be more flexible, responsive and inclusive. • Dementia services need to be innovative to respond to the needs of people with dementia in rural and remote areas. 	<p><i>Stronger consideration should be given to the development of culturally specific facilities.</i></p> <p><i>For people with dementia where English is not the first language serious communication problems may be encountered where the carers cannot communicate effectively. This may be best achieved in facilities (or with services), which specifically cater to the person's needs and particularly their preferred language. It is common that as dementia progresses ability to communicate in English may decline, even if previously quite proficient, with profound implications for social isolation, mental health and quality of life.</i></p> <p><i>Cultural sensitivities are of course very important both for those with dementia and for their carers or family. These needs must be addressed in developing programs.</i></p> <p><i>For people from indigenous communities it is often particularly difficult to access culturally appropriate and sensitive services and this need must be addressed. It is to be expected that as improvements are made in indigenous health there will be an increase in the number of people needing indigenous specific care.</i></p>	<ul style="list-style-type: none"> • Find out the best ways to diagnose and provide dementia care and support for people with diverse needs. • Adopt a national approach to the development of appropriate assessment tools. • Support usage of appropriate assessment tools, when developed, with all people suspected of dementia. • Conduct national research into dementia in the Aboriginal and Torres Strait Islander population. • Identify suitable support, care and accommodation options for people with dementia aged under 65. • Identify the most effective programs to provide suitable support, care and accommodation options for people with an intellectual disability who develop dementia. • Make culturally sensitive and inclusive practice a requirement for all programs, services, standards and guidelines. • Strengthen data collection, planning and reporting requirements by mainstream 	<p><i>These priority actions are strongly supported.</i></p> <p><i>It is noted again that the use of "find out" should be avoided in this location and substituted by specific actions.</i></p> <p><i>The need for cultural sensitivity in all care services is very strongly supported and is seen as a fundamental requirement. However it should be noted that s dementia progresses even high levels of cultural sensitivity might be insufficient to overcome the challenges posed by language barriers or deeply held cultural beliefs and practices. More specifically targeted services will be needed.</i></p> <p><i>Being culturally sensitive will be insufficient and there is need for "culturally appropriate" services that involves language, food and general environment.</i></p>

Major issues	Comments	Proposed priorities for action	Comments
		<p>services on their response to people with diverse and multiple needs.</p> <ul style="list-style-type: none"> • Develop ways to promote innovative, responsive and flexible care services. • Support the work of the National Cross Cultural Dementia Network. • Set up a national register of dementia resources in community languages, identify gaps and prioritise the development of additional resources. • Find out how best to deliver flexible and co-ordinated dementia services in rural and remote locations. • Develop quality housing, community care and outreach options for elderly homeless people. 	

Priority area 4 QUALITY, INTEGRATION AND CONTINUUM OF CARE - Primary health

Major issues	Comments	Proposed priorities for action	Comments
<ul style="list-style-type: none"> • People with dementia, their families and carers need to know who to contact for assistance. • There is a wide range of skill levels among primary health professionals in diagnosing, assessing and care for people with dementia, and making links to other support services. • There is a need for primary health care professionals to consult with families and carers and involve them in dementia care planning. • Primary health care professionals need better links with geriatricians, psycho geriatricians, neurologists and other dementia specialists. • Primary health care professionals in rural and remote areas have a particular need for training and skills in dementia care, due to shortages of specialist services. • More GPs should make use of care planning and case conferencing that can help in diagnosing, assessing, managing and referring people with dementia. 	<p>The role of GPs in the care of people with dementia (and the frail elderly in general) cannot be underestimated. As the primary health care contact for most community living older people and their carers, the role of GPs is expected to grow as the population ages. However while the need for primary care is growing there has been a decline in the provision of home visits by GPs. If frail older people and especially those with dementia are to be able to live in the community, they must have access to primary health care. However for those with dementia and with poor mobility (most people with dementia will not have a license and often may have physical disability), access to GP surgeries is difficult in office hours and impossible at night. Home visits by primary health carers (typically GPs but other health providers are also important) must become a routine and integral component of community care.</p> <p><i>Whatever funding or administrative models for service delivery is selected it will be essential that the full range of multidisciplinary services is delivered to the patient/consumer, preferably while still residing in their own homes. Essential ingredients will be:</i></p> <ul style="list-style-type: none"> • <i>A system for co-ordination of services</i> • <i>A system of tracking service delivery and</i> • <i>A system of patient monitoring and follow up</i> 	<ul style="list-style-type: none"> • Promote and coordinate the different entry points to care and support for people with dementia, their families and carers. • Develop and promote resources that help primary health professionals to better diagnose, assess, care for and refer people with dementia. • Support primary health care professionals and provide incentives for GPs to broaden their skills in the management and care of people with dementia. • Identify training needs in dementia assessment for Aged Care Assessment Teams, community health and allied health staff. • Prepare for growth in demand for primary health services for people with dementia and their carers. • Increase the availability of innovative ways to access specialist services, such as videoconferencing. • Add dementia to the GPs' Practice Incentives Program. • Develop screening tools and prompts to address carer issues in GP computer programs. • Provide programs for developing GPs with a special interest in dementia and aged care. 	<p><i>All methods by which primary health carers can be encouraged to expand their role with the older people including home and out of hours visits, should be encouraged. A range of tools will needed to be used including financial incentives, better education and support and improved infrastructure.</i></p> <p><i>There will be an increased need for multidisciplinary geriatric services, which will include specialist geriatricians, psycho geriatricians, geriatric nurses and a range of specialist allied health professions to support general practitioners in their delivery of primary health care in the community.</i></p> <p><i>Much of this can be managed through an effective system of Dementia Plans. Ideally these should be developed using existing services and structures such as Aged Care Assessment Teams (ACATs), Divisions of GPs, or other planning areas used for residential care, CACP allocation or generalist community nursing. Currently there are 72 ACATS in Australia roughly servicing populations of 200-4000,00 and if additional multidisciplinary specialist staff were attached to such teams, they could form the basis of a LOCALISED highly skilled support team, which could act as a resource for GPs and other primary care providers, as well as providing effective integration with acute hospital services.</i></p>

Priority area 4 QUALITY, INTEGRATION AND CONTINUUM OF CARE - Community care

Major issues	Comments	Proposed priorities for action	Comments
<ul style="list-style-type: none"> • There is an increasing demand for community care services. • Access to community care services for people with dementia needs to be clear and straightforward. • Community care services for people with dementia need to be better coordinated to avoid duplication and identify service gaps. • The design of physical environments can support or hinder people with dementia to remain in their community. • There is a need for more skills and training in providing quality community care for people with dementia. • Specific training in quality dementia care is needed. 	<p><i>The objectives outlined are fully supported. Community care has many advantages for the dementia patient and for their family and should be supported where practical. Especially where dementia is mild, the familiarity of a home environment is likely to minimise the confusion and hence disability of the dementia affected person.</i></p> <p><i>Strong support is given for measures that redesign living environments to maintain community living. The addition of locks, gates and safety system may be needed for those at living at home with dementia and also modification of appliances etc. However it must be recognised also that people with dementia have needs for company and human contact. Living at home or in the community in secure surroundings should not become a form of solitary confinement for those with challenging behaviours.</i></p> <p><i>It is important to recognise that dementia is a continuum. It is to be expected that for every person who is clearly affected with dementia, there is likely to be a person with mild cognitive disorder often other conditions associated with increasing frailty. The gradation of disability due to dementia and the other infirmities of old age (including the mobility reducing conditions such as gait slowing or Parkinson's Disease and sensory losses especially hearing and sight) must be reflected in the types of services available.</i></p> <p><i>As the population ages the expected numbers of people living in the community with mild – moderate dementia is expected to increase. Largely as a result of population ageing but also because of preference to “age in place”.</i></p>	<ul style="list-style-type: none"> • Include dementia issues in the Australian Government’s Community Care Review process. • Identify and promote the best ways that assist people with dementia, their families and carers to navigate the care system. • Share information between Governments to avoid duplication of dementia services and meet service gaps. • Promote best practice models for community care among Governments and service providers. • Develop evidence-based guidelines for the design of community environments for people with dementia. • Develop ways to train more community care workers to meet different needs for care. 	<p><i>The introduction of dementia specific EACH packages is an initiative, which is welcomed as providing a real option for “ageing in place” for people with dementia. The expansion of the program is strongly supported.</i></p> <p><i>Some caution should be exercised about becoming overly optimistic about the scope for community care to satisfy a growing demand for care for those with severe dementia especially those prone to wandering or who have severe behavioural problems.</i></p> <p><i>There is need for more gradation in the support packages available. There is a considerable difference in support provided under CCPs and EACH, but the onset of dementia (and other frailties of old age) is gradual and the introduction of additional care and support should reflect this gradual decline.</i></p>

Major issues	Comments	Proposed priorities for action	Comments

Priority area 4 QUALITY, INTEGRATION AND CONTINUUM OF CARE – Respite care

Major issues	Comments	Proposed priorities for action	Comments
<ul style="list-style-type: none"> • Respite care should be part of a co-ordinated range of supports available to carers. • Many carers value and need more support of family, friends and the community. • Carers of people with dementia should have a range of respite choices available when they need them. • Respite care services should be flexible and responsive to individual, diverse needs. • Some families and carers need help to find respite services that meet their needs. 	<p><i>Respite care should be readily available to all people with advanced dementia. If the availability of respite care generously and when needed, allows carers to continue supporting dementia people with dementia in the community, the net benefit can only be positive, since the alternative would be permanent residential care rather than shorter term respite care.</i></p> <p><i>The need to promote respite care as a positive experience for carers and people with dementia is considered as particularly important. This task should not be underestimated, because many people with dementia will find respite care threatening, confusing and destabilizing. Familiarity with the respite centre will be particularly important so models of respite care which are integrated into the community and which are part of the regular environment of the people with dementia are more likely to prove successful.</i></p>	<ul style="list-style-type: none"> • Promote respite as part of an integrated care plan that involves other family members. • Review, develop and promote ways to provide flexible respite that meets individual needs. • Promote the availability of respite care. • Promote respite as a positive experience for both carers and people with dementia. • Increase the availability of National Training packages for people working in dementia respite care. • Provide the support necessary for providers to achieve best practice in quality dementia care. 	

Priority area 4 QUALITY, INTEGRATION AND CONTINUUM OF CARE – Acute care

Major issues	Comments	Proposed priorities for action	Comments
<ul style="list-style-type: none"> • Health services will experience a rise in the numbers of older people with dementia requiring acute care. • There is a need for health care professionals to consult with carers and involve them in decisions about care. • People with dementia often stay longer in hospital and are more likely to experience other problems such as falls, increased confusion and infections. • The physical environment of hospitals can make it difficult to provide good care. • Better links are needed between hospitals, and GPs, community health, community services and residential care providers on admission and discharge of people with dementia. 	<p><i>For older peoples, particularly if frail and unwell or if dementia has begun, the objective should be to minimise disruption and to reduce the need for moving between care settings. Hospital admissions should be avoided wherever possible, through provision of quality and timely primary care or home delivery of services. However it is important to acknowledge that there must be adequate access to acute hospital care for people with dementia when needed and accepted that older people will always form a large portion of the hospital population. Currently people over 65 represent 35% of admissions and 49% of total acute hospital bed days. These proportions are set to increase as the share of the population over 65 increases and will become even more apparent as the share of the population aged more than 85 increases.</i></p> <p><i>A well-staffed acute hospital sector where most staff have training in management of older patients should become the core of the health service for older Australians.</i></p> <p><i>The AAG stresses that the acute hospital is likely to be the most appropriate location for a number of essential services, which also extend into the community, including specialist geriatricians and gerontic nurses. Community hospital extension programs operate in many places and have typically proved successful where the acute sector provides a central hub of expertise.</i></p> <p><i>The AAG recognises that effective service delivery requires co-operation between both public and private service providers. In particular it stresses the important role for primary care providers and the need to integrate these (generally privately provided) services with the acute health sector.</i></p>	<ul style="list-style-type: none"> • Explore ways to care for people with dementia where they live, when appropriate, and ensure smooth transition in and out of hospital when required. • Develop and implement best practice principles and guidelines to assess for and manage dementia and delirium in acute care. • Identify models/methods that support carers' involvement in decision-making, planning and the provision of care. • Provide suitable information for people with dementia, families and carers that explain options for care. • Develop systems to help people with dementia and their carers provide feedback on the quality of care they receive. • Develop national design guidelines for acute care wards to help health workers provide quality dementia care. • Review accreditation standards for acute facilities to ensure they address dementia care needs. <p>Support the development of</p>	<p><i>There is a wide range of potential "hospital outreach" programs which may provide a seamless interface between care settings. These include</i></p> <ul style="list-style-type: none"> ❖ <i>GP Emergency Clinics to support local GPs who have older dependent community living patients requiring a complex assessment. These could support, not replace, general practitioners in chronic and complex care.</i> ❖ <i>A hospital based Ambulatory Care Unit to complement domiciliary based and primary health care services. This can bring patients in for essential treatment, avoiding overnight stays</i> <ul style="list-style-type: none"> • <i>Ambulatory services should not be limited to just hospital services but should connect people with the full range of community delivered health services. Given the importance of fitness (both in mind and body) ambulatory services which get older people to health, welfare, fitness or educational activities, should also be established</i> • <i>Post Acute Care Services (PACS) to provide acute and post acute care outside the confines of the acute hospital. The service should cover 7 days with evening and on-call services included. It can provide medical co-management, pre- admission, discharge planning and rehabilitation of older people with fractures or joint replacement surgery, post-acute respiratory outreach services for chronic obstructive pulmonary disease patients, and home based rehabilitation of complex dependent older people.</i> <p><i>There needs to be a systematic upgrade of geriatric medicine in hospitals. Older people are</i></p>

Major issues	Comments	Proposed priorities for action	Comments
	<p><i>Hospitals should be truly integrated with other elements of the health system and ideally would provide services at the interface between acute episodes and return home to provide a truly seamless care across the acute/aged care/community care continuum.</i></p> <p><i>The introduction of Hospital in the Nursing Home and Hospital at Home services is fundamental to a successful ageing in place strategy. Programs of this kind exist already in NSW (Prince of Wales Hospital) and can be established more widely possibly integrated with effective Post Acute Care Services.</i></p> <p><i>While the best setting for health care of older people is often in their own homes or residential care settings, significant numbers of acutely ill older people will always need the facilities of the modern hospital and this number will increase in absolute terms as the population ages. No matter how efficient ambulatory, community based or residentially care based services become, the ageing of the population will mean that acute hospitals must adapt to delivering services to an increasing number and proportion of chronically sick, frail elderly, displaying a wide variety of multifactorial geriatric conditions. Essential elements of a well-targeted acute hospital system for ageing Australians are:</i></p> <ul style="list-style-type: none"> <i>• Efficient emergency department</i> <i>• Effective comprehensive multifactorial care for complex geriatric patients</i> <i>• Well integrated discharge procedures which take responsibility for the long term welfare of people once discharged.</i> <i>• Access to sufficient sub acute rehabilitation and transitional care beds.</i> <p><i>Care pathways embed evidence-based guidelines and protocols for particular conditions within an action plan for everyday use by clinicians with individuals. They anticipate the elements of care and treatment, including</i></p>	<p>admission and discharge processes that include the person, family and carer and integrate with the GP, community health, community services and residential care.</p>	<p><i>already a substantial component of the demographic and this will increase steadily.</i></p> <p><i>The emergency department is very often the face of the hospital system and is for many the first place they will see. Older people are presenting to the Emergency Departments of hospitals with a variety of multifactorial syndromes – delirium and behaviour disturbance, motor slowing and immobility, pressure sores, gait and balance disorders, falls and fractures, brain-bladder disorders and incontinence. EDs must be staffed and set up to manage and assess people with (or potentially with) age related conditions (e.g. dementia, incontinence and poor communications) while still in emergency care. In addition to usual ED capacity the increased incidence of age affected people will require integration of geriatric specialists into routine ED activities. Depending on community profile and ED activity, this could involve including specialist geriatric trained medical and nursing staff in the ED or close integration with specialist geriatric hospital staff through rapid response advisory services. However, this service must be available 24 hrs/day. It must include also assessment staff for identifying patients with cognitive disorders and for managing discharge and transfer procedures. Hospitals must be staffed and set up to manage patients with age related conditions such as dementia induced wandering, delirium (exacerbated by the hospital environment), continence issues, and communication issues due to combination of sensory loss and cognitive impairment.</i></p> <p><i>There must be an adequate (and steadily increasing) number of specialist geriatric beds available to care for a core group of patients who do not reach criteria for initial admission to</i></p>

Major issues	Comments	Proposed priorities for action	Comments
	<p><i>their sequence and timing, for all members of the multidisciplinary team in order to achieve agreed outcomes. Currently they are not widely used throughout Australia but have many advantages especially in optimizing individual care and enhancing satisfaction.</i></p>		<p><i>another specialized service or program, and who do require the care of a multi-disciplinary aged care team. Current supply of such beds is woefully inadequate and must be expanded substantially.</i></p> <p><i>All patients whether in general wards or geriatric units must have access to multi-disciplinary services essential for rehabilitation. These include Clinical neuro-psychologist– expertise in assessment and setting up behaviour management programs for demented and delirious patients and with expertise in mental capacity and guardianship. All older hospital patients should have access to physiotherapists and occupational therapists for prevention of deconditioning, mobilization and restoration of function, rehabilitation, discharge and pre-discharge home visits.</i></p> <p><i>Hospitals must take an active role in discharge planning establishing discharge support programs including plans for rehabilitation. There must be an effective assessment team to review all older people with potential for complex multi-system disorders and to identify and co-ordinate any necessary home support, whether additional support from geriatric medicine is needed and pre-operative assessment of most older patients regarding fitness for surgery.</i></p>

Priority area 4 QUALITY, INTEGRATION AND CONTINUUM OF CARE – Residential care

Major issues	Comments	Proposed priorities for action	Comments
<ul style="list-style-type: none"> • Demand for residential care for people with dementia will continue to rise. • New homes, renovations and building maintenance programs should include a focus on providing the best care for people with dementia. • Aged care workers need better training and education about quality dementia care. • People with dementia in residential care need better access to medical and specialist services. • People with dementia often have trouble moving between home, hospital and residential aged care. 	<p><i>One additional issue to address is the expectation that as the population ages the disability levels of those in nursing homes will increase on average. This has already occurred in the last decade and as more people take up packages to allow them to remain in the community this pattern will increase. This pattern must be incorporated into planning for RAC needs in coming years. It follows also that there will be a corresponding increase in the number of people living in the community with mild to moderate dementia, who in previous times may have lived in RAC</i></p> <p><i>The issues of quality assurance and accreditation have not been addressed although they will continue to be of great importance. Much work is on going but a comprehensive strategy should address these issues.</i></p>	<ul style="list-style-type: none"> • Improve the design of residential aged care homes for people with dementia. • Plan to provide the number of residential care places that may be needed in the future. • Develop national care standards for people with dementia in residential aged care. • Increase the availability of training and education programs for aged care workers that focus on providing quality person-centred care. • Develop and promote guidelines to help health workers and carers better manage the movement of people with dementia between home, hospital and residential aged care. • Improve ways for health, community and aged care workers to share medical and other information as people with dementia move between home, hospital and residential aged care. 	<p><i>The development of national care standards is very strongly supported and is seen as a fundamental requirement before other key issues such as workforce strategy can be effectively addressed.</i></p> <p><i>Rather than focussing on the movement of people between care settings, emphasis should be on avoidance of admissions. Services generally delivered to homes should be extended to RAC. For example Hospital in the Aged Care Facility may be continuation of inpatient treatment at the residence or avoidance of admission. It may include for example intravenous antibiotics, or management of anticoagulation therapy.</i></p> <p><i>Requirements for ongoing visits by medical professionals to RAC should become mandatory. All residents should have regular medical reviews, generally by GPs but also be geriatric specialists. Decisions to call for medical assistance and review should not be at the sole discretion of the RAC but should be incorporated systematically into the care system.</i></p> <p><i>Feed back systems on the quality of care are important. Special provision should be made for residents who have few visits from family or friends. The use of “independent visitors” could be considered as a means of helping communication with residents about the quality of care received.</i></p>

Priority area 4 QUALITY, INTEGRATION AND CONTINUUM OF CARE – Palliative care

Major issues	Comments	Proposed priorities for action	Comments
<ul style="list-style-type: none"> • Families, carers and service providers need better understanding of end stage dementia and the type of care required. • People in the final stages of dementia need better access to palliative care services that provide the best possible quality of life in all settings. • Better ways are needed to diagnose the transition from late stage to end stage of dementia. • Better ways need to be found to communicate with people with dementia in end stage dementia. • Some carers need help in making decisions about their ongoing caring role. 	<p><i>It needs to be noted also that palliative care is not just about cancer and pain relief and includes care for people with severe disability of any kind. The guidelines for a palliative approach in residential aged care provide a model for palliative volunteering in residential aged care. The guidelines are recognised in the priorities and the last priority will likely be addressed by the model.</i></p> <p><i>However, a palliative approach is an active approach that is not only applicable in the final stages of dementia. Including as a major issue that "better ways are needed to diagnose the transition from late stage to end stage dementia", is simplistic and misses the fact that a palliative approach is applicable throughout the trajectory of any life limiting illness on a needs basis. This is entirely compatible with concurrent active treatment in many instances. Compartmentalising palliation so that it is only available after a person reaches a milestone in the progression of their dementia could only disadvantage that person.</i></p> <p><i>The framework has avoided active promotion of advanced care directives in so far as they relate to palliative care and active treatment. While recognising the sensitivity of these issues it is probably not helpful in the longer term to avoid consideration of these issues, given the profound impact upon carers and people with dementia.</i></p> <p><i>The comment regarding communication with people in end stage dementia needs clarification. The definition of "end stage" is problematic, however if dementia is truly advanced communication is not practical and the way this is phrased, seems based on a conception of</i></p>	<ul style="list-style-type: none"> • Find out what works best internationally and nationally in providing palliative care, communicating with and caring for people in end stage dementia, their families and carers. • Promote information about end stage dementia, palliative care and advanced care plans for people in early stages of dementia, their families and carers and aged care workers. • Develop education and training initiatives for health professionals and community care providers about palliative care and end stage dementia. • Help carers plan ahead for when they can no longer continue in a caring role. • Increase awareness among residential aged care staff of the Guidelines for a Palliative Approach in Residential Aged Care. • Work out how best to support palliative care volunteers in residential aged care. 	<p><i>The proposed priority actions are supported and for the most part avoid repeating the misconceptions outlined in the Major issues.</i></p>

Major issues	Comments	Proposed priorities for action	Comments
	<p><i>dementia as a brain mis-direction or communication barrier rather than the outcome of prolonged extensive neurological degeneration.</i></p> <p><i>Communication with carers and family must be promoted as far as possible.</i></p>		

Priority area 4 QUALITY, INTEGRATION AND CONTINUUM OF CARE – Behavioural issues that impact on care and support.

Major issues	Comments	Proposed priorities for action	Comments
<ul style="list-style-type: none"> • Better ways need to be found to prevent or safely manage behavioural issues associated with dementia. • The use of chemical and physical restraints for people with dementia needs to be reduced. • Better co-ordination, referral and case management is needed across services caring for people with dementia whose behaviour impacts on their care. • There is a need to increase dementia training that focuses on behavioural issues associated with dementia. 	<p><i>The use of chemical restraint is excessive and needs careful regulation and reduction.</i></p> <p><i>It is usually possible to withdraw all physically restraining drugs from residents with proper care and appropriate surroundings</i></p> <p><i>It is not usually appreciated that the chemical restraint drugs generally prescribed, work by slowing the patient's brain functions and mobility, resulting in functionality that mimics Parkinson's disease and which if used in excess, can cause Parkinson's Diseases. Therefore it is incumbent upon medical practitioners to use great caution in prescribing these drugs and to be careful to ensure that the prescription is in the best interests of the patient.</i></p>	<ul style="list-style-type: none"> • Clarify the roles, responsibilities and referral mechanisms in the care and management of people with dementia whose behaviour impacts on their care. • Implement the Review of Pricing Arrangements for Residential Aged Care recommendations for people with dementia. • Find out what works nationally and internationally in providing care for people with dementia and behavioural issues, and share the information. • Develop improved training in managing behavioural issues associated with dementia for the workforce, including community, residential and acute care staff. • Support carers by providing support, education and respite care. • Develop service models and funding arrangements for assessment, management, support and accommodation of people with dementia across care settings and whose behaviour impacts on their care. 	<p><i>The introduction of regular medication reviews for all residents receiving care packages or living in RAC would be one positive and substantial step towards improving outcomes for residents.</i></p>

Priority area 5 WORKFORCE AND TRAINING

Major issues	Comments	Proposed priorities for action	Comments
<ul style="list-style-type: none"> • Health, community and aged care workers providing dementia care need improved training, higher level skills and appropriate conditions. • Careers in dementia care need to be more highly valued by the community. • Health, community and aged care workers providing services for people with dementia, their families and carers need to have a good understanding of dementia, good interpersonal skills and a commitment to meet individual needs and preferences, with involvement of families and carers. • There is a need for improved access to dementia specific tertiary courses and accredited competency-based training. • Ways need to be found to attract and retain specialists to support the needs of people with dementia. • Ways need to be found to attract and retain well-trained dementia care workers and specialists in rural and remote areas. • Staff need to be aware of issues for people with dementia from different cultural backgrounds. 	<p><i>This is a very important issue and success or failure will underpin the overall effectiveness of our dementia care strategies</i></p> <p><i>However the first issue to address is not just the work force but also the overall quality of care we expect and are willing to provide for people with dementia. The issues that need to be considered are the quality of care- how many hours of assistance and the types of assistance</i></p> <p><i>Secondly what quality of care are we willing to provide. The costs may vary depending upon the skill and training of the staff.</i></p> <p><i>These are important issues to address. It is preferable that these quality issues are addressed early before staff shortages become critical. If this is not done then it is likely that the availability of staff will become the driver and definer of the quality of care rather than the desirable position where the quality of care is defined first and the staff demand is then managed to meet this care standard.</i></p> <p><i>It is stressed therefore that discussion of staff demand, training and shortages is predicated on the development of realistic quality benchmarks which establish the standard of care needed for those with dementia to live and die with dignity and comfort.</i></p>	<ul style="list-style-type: none"> • Develop a national workforce strategy to improve work structures, deliver better training and increase and retain the numbers of workers providing dementia care. • Increase the availability of accredited education and training courses in dementia care. • Provide better training in dementia care for health, community and aged care workers in rural and remote areas. • Develop guidelines and a resource guide for dementia education programs for acute care staff. • Set training standards for acute care staff in person-centred dementia care and involving older people and their carers in decision-making. • Establish cultural competencies for the health, community and aged care workforce. • Identify the most effective programs for supporting workers in dementia care. 	<p><i>The need for a comprehensive work force strategy is fully supported, although as noted it should be predicated on establishing quality care benchmarks as drivers for assessment of staff needs.</i></p> <p><i>Of greatest importance is the need to recognise that costs could well rise if the demand for trained staff increases. The usual play of market forces will drive pay increases which if not addressed will lead only to reduction in staff skill levels.</i></p> <p><i>Increased training can partly overcome these demand drivers but not without risk of reducing overall care quality.</i></p> <p><i>It will be essential that staff move from the mindset that focuses on a specific organ problem ignoring the complications of age and sometimes relegating the elderly to lower priority. The hospital staff must therefore be capable of assessment and management of medication use, cognition, delirium and acute behaviour disorder and of preventing deconditioning and functional decline. This will require training of ALL acute care staff in general hospitals in the basics of geriatric care.</i></p>