Productivity Commission Inquiry
into the Care of Older Australians

Submission by

July 2010

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1. Introduction

Alzheimer's Australia WA welcomes the opportunity to make submission to the Productivity Commission's Inquiry into Caring for Older Australians, in order to promote the interests and highlight the issues for people living with dementia[1] as they attempt to navigate the fragmented and complex system that has evolved to provide "appropriate care and support services as they age" (DoHA 2009, p.xi). Consumer and community expectation for reform of the current system includes major improvement in their experience and the outcomes of their engagement with the system. An improved experience will require a far broader conception of the 'aged care system' than that currently conceived, a system that is financial sustainable, has the capacity to meet the challenges of an aging population and takes seriously the human cost, not just the economic cost, of a rapidly increasing prevalence of dementia.

Structural reform must address the ageist fundamentals that currently drive societal and government perspective, policy, planning, funding and service provision that impact to the detriment of aging Australians, and particularly people living with dementia. The case studies included are but a miniscule snapshot of the lived experience of people living with dementia in Western Australia, and demonstrates there is not a one size fits all solution for caring for older Australians.

2. "Aging Well" – A Paradigm Shift

There is no denying, Australia's population is aging and, on average, we are living longer. Government policies on health and aging and strategies to address the anticipated impact of a significant increase in the demand for and spending on health and aged care will therefore have a major and long term impact on Australian society. A paradigm shift to a new vision and framework for "aging well" is urgently required to mediate the impact of an aging population, with both health and aged care spending projected to grow as a consequence by 7.1 per cent and 1.8 per cent of GDP in 2049-50.respectively (the 2010 intergenerational report).

"Aging well' is a life span approach to the aging process, with the objective of contributing to the health and wellbeing of all members of the Australian community. Health and the capacity to remain independent are important aspects of older people's lives, are intrinsically linked and thus government policy and spending on one aspect is likely to impact on outcomes of the other. Recently different levels of government have developed policy promoting healthy aging and encouraging independence, with a focus on the older person taking active control of their health and wellbeing. The Home and Community Care program which provides services to 'frail' older people and people with a disability has, in various states, implemented a range of approaches focussing on healthy aging and independence: the Active Service model in Victoria; the Wellness Approach in Western Australia; the Better Practice Project in NSW. However such policies do risk focussing attention and primary responsibility with the individual, rather than recognising government and community responsibility to support healthy aging and independence.

A national vision and framework for "aging well" is required to ensure a consistent message across all areas that impact on the lives of all older Australians. "Aging well" then becomes a key outcome consideration across multiple social and economic policy and program areas and for all levels of government with responsibility for health, housing, transport, education, employment, technology, community attitudes, and service delivery in rural, remote and urban areas, to people from diverse backgrounds and cultures. This shift to "aging well" would then be a key driver for better integration of care which would have a positive benefit for people living with dementia, by delivering policies and programs that would better meet their needs.

Proposed Outcome: A national health, social and economic system that delivers short and long term "aging well" outcomes for older Australians that promotes consumer involvement and choice.

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[1] People living with dementia include the person diagnosed with dementia and their informal caregivers, ie. their spouse or partner and their immediate family, all of whom are impacted by dementia

Recommendations:

(i) The “Aging Well” agenda is rolled out as a National Health Priority

(ii) Identify clear and measurable objectives and outcomes to be achieved through a restructure of the current system of caring for older Australians

(iii) Map, measure and implement an ongoing review of the restructure process and associated spending across the next 40 years (in line with Treasury projections to 2049-50)

(iv) Encourage Commonwealth, State and Territories to review the operation and effectiveness of relevant legislative Acts, based upon a) the concept of “aging well” for older Australians and b) an active questioning of the presumption that service delivery models linked to levels of dependency are more appropriate than a more holistic model based on need, particularly for people with younger onset dementia, and people from ATSI or CALD backgrounds

(v) Reduce national fragmentation and different policy objectives in health and aged care by creating Commonwealth, State and Territory Portfolios and Ministerial positions with responsibility for promoting and implementing an “Aging Well” agenda in Australia

(vi) Develop quality standards for policy development and planning that directly involves consumers, including people living with dementia

(vii) Older Australians and specifically people living with dementia, are included as a priority in the social inclusion agendas of all levels of government.

3. Ageism and the stigma of dementia – a double whammy

The notion that the vast majority of older Australians need to be ‘looked after’ and are therefore a burden on the community is challenged by findings of ‘Older Australia at a glance, 4th edition’ (2007). Yet the ‘commonsense knowledge’ that as people age they get needier has contributed to and supported the development of Commonwealth, state and local government policies that frame older people as frail, dependent and requiring some level of ‘care’, support or assistance from the aged care system. Thomas (2004) describes our fear of dependence and the common myths around being independent and dependent, and suggests that “interdependence” should describe the nature of our relationships with others as we age. Gawande (2007) explains that “we have settled on a belief that a life of worth and engagement is not possible once you lose your independence”. This belief is exacerbated when a person receives a diagnosis of dementia.

The stereotypic view of an older person, when combined with a dementia diagnosis, or even an assumption of dementia, contributes to the risk of a person being doubly stigmatised as an older person –with – DEMENTIA. Attitudes to dementia are founded on fear, ignorance and poor understanding. Shifting attitudes and changing policy in the human service areas, particularly in health, aged care and support, and housing can have a positive influence, reduce the obstacles and, in the longer term, improve the “aging well” outcomes for people living with dementia. This organisation has observed an increasing trend for those “baby boomers” starting to experience symptoms of dementia or mild cognitive impairment, who attend or reside in mainstream community based facilities eg. Senior Citizens Centres and Retirement Villages, to be told that they are no longer welcome to participate in social type activities provided.

Proposed outcome: A reformed human services system that provides timely and appropriate social and practical support, from pre-diagnosis to death and beyond, in all settings for people living with dementia.

Recommendations:

(i) All levels of Australian government demonstrate leadership and agree to expose and counter ageism and the stigma of dementia as a central plank of the “Aging Well” agenda

(ii) All levels of Australian government review and change policies and procedures (eg. funding arrangements, certification standards, planning laws etc) that entrench ageist attitudes and stereotypes; contribute to the framing of older people and people with dementia as dependant; and restrict consideration of alternative models for their support, care and accommodation.

(iii) Development of a national program aimed at increasing community awareness and reducing the stigma associated with dementia (similar to ‘Beyond Blue’)

(iv) Incentives for mainstream centres and services to provide suitable programs to people experiencing symptoms of memory loss, and employ trained staff who understand memory loss and act as program facilitators

(v) Resourcing support groups for people experiencing memory loss and their families

4. Improving outcomes - "aging well" with dementia

There are lessons to be learnt and hopefully parallels to be drawn from gains made in the past 20 years or so in the area of disabilities. A paradigm shift in how people with disabilities are perceived, has potentially reduced the stigma and improved outcomes for people with disabilities across a range of policy and service provision areas, including employment, housing, education, support and care services, although there is still a long way to go. (Disability Services Commission, WA, 2010). Since Tom Kitwood (1997) first challenged the medical or disease model view of dementia and promoted "person centred care" for people with dementia, there has been increasing recognition that people with dementia can experience autonomy, dignity of risk and respect in their daily lives. People with dementia can be empowered to assert their rights and preferences, to expect dignity in their care and relationships with health care professionals. In the context of an aging Australian population and associated increase in the prevalence of dementia, the goal of improving outcomes for people living with dementia within an "aging well" framework is an imperative (see Attachments – Case Study 1).

5. The dementia journey

Dementia is a condition that has a major impact on the person with dementia, their family and the broader community. For people living with dementia, their journey and experience of the social, clinical and institutional aspects of the current health and aged care system in Australia is not a gradual transition from one stage to the next, without any abrupt changes (by definition - a continuum). The dementia journey is a very individual one, characterised by many challenges and obstacles along the way (see Attachments - Case Study 2), with transitions between different parts of the health and aged care system often occurring abruptly along the journey. This is often due to a crisis that could have been averted or prevented, had timely and appropriate supports been available. People living with dementia are more likely to experience occasions or unforeseen circumstances when they require emergency or crisis intervention services related to carer health crisis, family dynamic related issues, or rapid deterioration in the health status of the person with dementia (See Attachments – Case Study 5.3). Structural reform that provides access to proactive and comprehensive dementia specialist services to facilitate early intervention and support community based outcomes for people living with dementia throughout their dementia journey is essential.

6. Service Delivery Framework

An integrated health and social services[2] delivery model is required to enable achievement of "aging well" outcomes for older Australians. The importance of integrating primary, acute, short and long term community and institutional based care services to improve the quality of care, ensure more efficient delivery of services and control costs is a consistent and global theme in the aged care literature reviewed for the New Zealand Ministry of Health (2001). Achievement of improved integration of service delivery for older Australians in the short and long term should be defined and measured as an outcome by the extent to which services are coordinated across people, function, activities and locations or settings over time, so as to maximise the value of services provided.

The current support and care service delivery system for older Australians is fragmented, frustratingly complex and at times inefficient and ineffective. This is a consequence of the diverse and confusing proliferation of community, residential, flexible and respite care programs and services available. There is a lack of demonstrated cohesiveness between service types and poor interface with primary and acute care. Services are defined by their funding source, intensity or level of care

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[2] Social services are not limited to aged care services ie. assessment and information, community and residential care and mixed delivery services, but also include eg. housing, transport, employment, education and technology

they provide, and the type of care, or place in which it is provided. This further compounds the complexity of a system which has different eligibility criteria, fee structures, standards and quality of care (See Attachments – Case Study 5.6). Fragmentation does not support or promote collaborative approaches between services set up to support and care for older Australians. Instead it often results in competiveness, a lack of cooperation and an unwillingness to share information. This is particularly burdensome and delivers poor outcomes for people living with dementia who require services in all settings to be based on a good knowledge of the individual needs of the person living with dementia and their family, to be flexible and adaptable, able to respond effectively in a crisis, and ideally based locally in the community where suitably trained staff are available 24 hours a day, 7 days per week, providing continuity and familiarity of care.

The consumers' experience is of a system that is services and funding model driven, not based on, or responsive to individual needs. The disconnect between the system and the needs of older Australians is further highlighted by the utter disregard within the current funding or service delivery models for the differing levels and types of needs of older Australians associated with their age, physical or cognitive status. This has a major impact on people living with dementia, who are likely to require a greater and more sustained level of support to maintain their independence and wellbeing at home, than the frail elderly person without a diagnosis of dementia. Current limitations on service hours and inflexibility imposed by current funding models often results in premature admission of people living with dementia to residential aged care. People living with younger onset dementia and people with dementia living on their own in the community, are particularly disadvantaged in this regard (Alzheimer's Australia, 2007). At least differing age based needs are recognised in the Danish health care system with a classification system that distinguishes between a 3rd age group for people over 60 and a 4th age group for people over 80 (Alzheimers Europe, 2010). Studies on European systems of funding and delivering long term care for older people can inform the development of an integrated service delivery model here in Australia, and a report on the Dutch system by Mot (2010) is useful in this regard.

Proposed Outcome: An integrated health and social services system for older Australians that is funded to provide a range of services according to individual need, not arbitrarily set levels of dependency, and is accessible across all accommodation settings (including acute care) so that people living with dementia have access to a suite of choices for support and care that are flexible, timely and available when and where required

Recommendations:

(i) Legislation, agreements and guidelines pertaining to health and social services delivery include specific reference to people living with dementia (not just older Australians)

(ii) Facilitate integration, improved efficiency and effectiveness of services by reducing areas of bureaucracy in DVA, HACC and DoHA where there is program duplication in delivery of health and aged care

(iii) Introduce a simplified and consistent National eligibility, reporting and regulatory standards framework that is applicable for all levels of need, across all support and care settings, and across all jurisdictions and funding sources

(iv) Assessment of eligibility for services based on individual need which will determine the intensity or level of support or care required, and no longer linked to the setting where support and care is provided

(v) Access to, availability and funding of services is no longer linked to accommodation setting, ie. a person with dementia living at home can access services provided in either setting – community or residential care based, and if appropriate rehabilitation in a primary or acute care setting

(vi) Long term investment nationally in the development and implementation of information communication technology that facilitates clinical and service integration

(vii) Develop and implement measurable and realistic outcomes for improving the interface between different care service settings (acute care hospitals, nursing homes, primary, secondary and community care) based upon an improved understanding of the movement of people into and through the system

(viii) Develop, implement and evaluate a range of "aging well" models of care that are evidenced based and meet the needs of all older Australians, who face different challenges according to their disability, cultural background, place of residence etc

7. Service planning and choice

The age and demographic structure of the population varies across the different geographical regions of Australia, which has implications for the provision and funding of services for older Australians and people living with dementia. Many regional and rural areas are characterised by older populations, allied with fewer younger family members living locally and a shrinking labour force. National comprehensive social and economic planning is required urgently to ensure the provision of services needed by all Australians, wherever they choose to live (see Attachments – Case Studies 2, 3.2 and 5.1).

There is overwhelming evidence of older Australians' preference for staying in their own home, supported if it becomes necessary, by community services and informal care (AIHW, 2007; Runge et al, 2009). Ageing in place is the term often used to refer to an older person's preference to remain in the home, community and environment they are familiar with – growing old without having to move. However Australian government policy on aging in place is limited to enabling residents of residential aged care facilities with appropriate accommodation and care facilities, the opportunity to remain in the same care environment when their care needs increase (DoHA, 2004).

The importance of community based support and respite services for people living with dementia is also consistent with their desire to remain living at home as long as possible (Access Economics, 2009). Yet information about the number of people living with dementia accessing community care packages (CACP, EACH and EACH-D) is not generally available, as routine data about dementia status of package recipients is not collected (Runge et al, 2009). This information, combined with information about services delivered by HACC, NRCP and DVA funded programs, is essential for national planning of services to support people whose preference is for aging in place in all settings in the community, not just residential care. This social and economic modelling must include capital needs for home modifications and equipment, and dementia specific aspects of care to meet the needs of people living with dementia and allow them a real choice of aging in place. Consumers of care and support services will also benefit from clear, simple and accurate information about the costs of services and the sustainability of the system overall, to enable them to make more informed decisions about choice of services.

The reliability and effectiveness of needs based planning for services could well be improved using small area data and spatial microsimulation modelling of individuals and households. Potential use of this new modelling infrastructure is illustrated for home based aged care services planning for persons aged 70 years and over who are living alone, in the report by Harding et al. (2009). Involving and consulting users, the general community, and people living with dementia about their ideas, expectations and experiences, why services need to change, how services might change, how to make the best use of resources, should also be foremost in needs based planning.

Obtaining services more tailored to individual preference and need has been an outcome of self directed care and personal budget policies and programs that have been widely adopted internationally over the last decade, for home and community based long term care services, particularly for people with disabilities and older people (Alakeson, 2010). A variety of approaches to 'individualised funding' for people with disabilities have been implemented in different states in Australia, with Western Australia's program running for approximately 20 years (Fisher et al, 2010). Limited 'consumer directed care' arrangements are to be offered in community care programs for older people in Australia, with a 2 year pilot to be delivered and evaluated under the Innovative Pool Program for 2010-2011.

People living with dementia could benefit from the opportunity to tailor care to their own needs through 'consumer directed care' arrangements. People with dementia do retain the ability to indicate who should make decisions on their behalf, to make their preferences known about services and identify who they wish to receive support and care from. There are however specific challenges for people living with dementia participating in 'consumer directed' programs because of complex symptoms and progressive decline in cognitive functioning, so it is important to ensure that carers of people with dementia have the help they need to manage services and assure quality. This involves providing assistance to carers, ensuring that program staff have dementia care expertise, and monitoring quality of dementia support and care (Tilly and Rees, 2007).

Proposed outcomes: People living with dementia across Australia: 1) have access to a range of flexible support and care services that are sufficient in number to meet current and future projected demand, and have capacity to respond to a range of needs, and 2) have access to self-directed control of their services if they choose

Recommendations:

(i) Develop and implement, as a matter of priority, mechanisms for comprehensive information gathering, economic, demographic and spatial modelling and analysis for national and regional needs based planning of services

(ii) Funding of services, based upon improved population aging and needs based planning, that adequately meets the demands for services, particularly for people living with dementia who choose to remain living in the community for as long as possible

(iii) Information about service fees and charges that is simple, transparent and readily available so that consumers can make informed choices and decisions about care in the context of sustainability of funding arrangements, given the anticipated increases in demand

(iv) Government social and economic policy that encourages greater engagement with rural, regional and remote areas of Australia where there are higher aging demographics, to promote and support enterprise and growth; recognise and foster innovation, and provide incentives to ensure access and availability of quality local services that meet the needs of older Australians, particularly people living with dementia

(v) In consultation with people living with dementia and other stakeholders, identify, implement and evaluate, over a longer time frame than 2 years, an appropriate model for 'consumer directed care' that addresses the specific needs of people living with dementia, as a means of addressing inequities in the current funding and service delivery model for people living with dementia

8. Assessment

An "aging well" assessment is the beginning of an older person's relationship with the system set up to support them. In an integrated service delivery model, the purpose of assessment is to create, over a person's life span, a comprehensive picture of their health, medical, social and emotional wellbeing, and support and care needs. Assessment is not a one-off process but should aim to deliver a single comprehensive record of the person's changing needs over time. This can only be achieved through urgent investment in the development of communication and information technology, agreed protocols and processes, resourcing and training required to implement a national electronic "aging well" individual's health and medical information record, that is accessible across all relevant functions and settings.

Assessment then becomes an independent person-centred process, instead of an integral part of service provision. Assessment should consider the global situation and circumstances of the older person and include their overall network for support, thereby providing comprehensive information about the person to all service providers, no matter what setting they work – primary, acute, secondary, community or residential care. This will not eliminate the tension between the two perceived purposes of assessment: identification of individual need and allocation of scarce resources, a recurring theme in aged care literature (Ministry of Health NZ, 2001), unless there is recognition and agreement that identification of need is in and of itself an outcome of an "aging well' assessment. Certainly as a consequence of assessment, a person's identified needs at the time may require a service response. It will be the kinds of support and care needs identified that should determine the allocation of resources, rather than an arbitrary classification of low, medium or high dependency level. In Australia the current system of classifying a person according to their level of dependency is done repeatedly using different tools according to which system a person finds themself in, and which state or territory in Australia they reside. Currently an older person residing in WA, in the process of accessing HACC or Commonwealth funded services, will likely have had the Aged Care Client Record (ACCR) completed by an Aged Care Assessment team, the Client Needs Assessment (CNI) completed at least once, if not multiple times by different local HACC funded service providers, and the Aged Care Funding Instrument (ACFI) by a residential aged care provider. Meantime two new nationally consistent assessment community care assessment tools, the Australian Community Care Needs Assessment (ACCN-R) and the Carer Eligibility Needs Assessment (CENA-R) have been under development and evaluation by DoHA since 2008.

The current system of multiple eligibility type assessments is burdensome and stressful for people living with dementia, and does not deliver positive outcomes. Early referral for a comprehensive assessment, undertaken by appropriately qualified dementia trained staff, and in conjunction with early detection and dementia diagnosis, should be best practice in Australia. Assessment of people with dementia is a complex and evolving task, should proceed in a step-wise manner and be tailored to the needs of the individual (Christensen and White, 2007). This requires a comprehensive approach that focuses on both the person with dementia and their family, particularly their primary carer. Assessment of cognitive, behavioural, functional changes, and emotional issues and consideration of the needs and well-being of the caregiver are necessary components of a comprehensive dementia needs assessment. This approach is likely to facilitate and encourage more timely access by people living with dementia along their dementia journey to suitable services.

Proposed outcomes: (i) Identification of individual need will be the primary outcome of an “aging well” assessment that will be utilised across all care and support service settings, (ii) allocation of resources to meet care and support needs will no longer be determined by an arbitrary classification of dependency levels but according to types of need, and (iii) all people receiving a dementia diagnosis will be provided with a comprehensive assessment of individual needs by appropriately qualified dementia trained staff

Recommendations:

(i) Develop and implement, in consultation with stakeholders, an efficient and effective national electronic “aging well” individual’s health and medical information record, which includes relevant dementia specific information and is mandated for use across all functions and across all settings

(ii) Identify, in consultation with stakeholders, a suite of dementia specific key assessment tools that are accredited to quality standards, and implemented nationally and consistently across all health and social services settings, and included as attachments in the personal electronic “aging well” health and medical record

9 “Aging Well” Support and Dementia Support Networks

“Aging well”, managing the consequences of the aging process and particularly the consequences of a diagnosis of dementia, requires varying levels of support along the journey. Dementia has a profound impact on people’s lives and requires an integrated approach to care and support that is not currently available across the health and aged care system in Australia. New approaches to care for older people with dementia were trialled and evaluated through the 2 year Aged Care Innovative Pool Dementia Pilot in 2003-2004. More hours of assistance, coordination from one point of contact, and specialist help for diagnosis and behaviour management were identified as improving the longer term outlook and quality of life of people living with dementia (Hales, et al., 2006). The Extended Aged Care at Home Dementia Program (EACH-D), as it currently exists and given the lack of integration across the system of care, is unable to meet the needs of people living dementia, is limited in its availability to meet current demand and demonstrates inconsistent standards of quality dementia care provision (see Attachments – Case Study 5.6).

“Aging Well Support Networks” comprising multidisciplinary teams, would take a proactive and preventative approach to support the “aging well” of older Australians by identifying strengths and capacities as well as functional limitations, pathology, impairments, and disability, and by seeking to identify and provide timely interventions and address an individual's support and care needs as they arise. To address the more complex of needs of people living with dementia, "Aging Well' Dementia Support Networks would provide individualised dementia service planning, facilitate early intervention and provide ongoing coordination and support for community based outcomes throughout the dementia journey. These Networks, comprising multidisciplinary teams appropriately qualified to provide dementia services planning, would operate from Support Centres that are co-located with other community based services providing support and care to older Australians to enhance collaborative and consultative work practies. Local service providers would be required to have a certain number of staff, based upon local dementia prevalence, qualified to meet the support and care needs of people living with dementia across a range of settings. Support Centres should ideally be separate from hospitals or other medical type establishments, so as to promote the paradigm shift to "aging well" and away from disease, dependency and decline.

Many children caring for their parent living with dementia will recognise and empathise with Rauch's (2010) sentiments that today's caregivers require "public acknowledgement and *proactive* assistance… to get help, you have to go look for it, which means you have to have some idea of what you need…for experts to tell me what I needed, and indeed, to explain why I needed it". Rauch also highlights another common reality, that of "convincing caregivers they need help isn't easy, at least not until they need it too much" (2010).

Proposed Outcome: People living with dementia, given its impact and the complexities associated with it, have access to ongoing information, support and services planning from a multidisciplinary team that enables them to make timely decisions about their health, medical, care and support needs and quality of life issues, and 2) support and care services that are tailored to their circumstances, to meet their individual needs

Recommendations:

(i) Develop and implement nationally consistent care management and care planning protocols for people living with dementia, including protocols and process for individualised dementia service planning

(ii) Creation, in consultation with stakeholders, of a national "Aging Well" Support Network to assist older Australians and their families access information, support and care services to

(iii) Creation, in consultation with stakeholders, of a national "Aging Well" Dementia Support Network to provide care management level support for people diagnosed with conditions that have a major impact on older Australian's capacity to "age well", ie. dementia, Parkinson's, stroke etc

(iv) Develop and implement measurable and realistic outcomes for improving consultative and collaborative approaches to support and care for people living with dementia across all health and social services settings

10. Workforce

It is projected that there will be a substantial and growing deficit in the dementia care and support workforce, based upon current trends (Access Economics, 2009). The workforce providing support and care to older Australians, and more particularly to people with dementia, is predominantly comprised of two distinct parts. The first is the gratis provision of informal care, undertaken in the main by one or more family members, most often the spouse or partner of the person with dementia, or an adult child. There are also increasing numbers of younger people, who are experiencing family life with a parent who has been diagnosed with dementia. The second is the funded formal care provision. An additional part of the workforce not included here, is the role played by volunteers in providing support and care.

The key aims of support and care for a person with dementia should be to enable the individual to "age well", engage in meaningful or purposeful activities as appropriate, maintain a sense of wellbeing and make the most of their remaining cognitive skills. Both informal and formal providers of this level of support and care require certain skills, attitudes, strategies and approaches to support the individual needs of a person with dementia. (see Attachments – Case Study 3.1).

10.1 Informal support and care

The importance of informal carers[3] to people with dementia cannot be underestimated. Often they are the only source of care and support for people with dementia (Access Economics, 2009). Urgent policy and planning responses are required to address the projected workforce supply constraints in relation to informal carers. Measures should include recognition of the productive value of informal carers, the fact they are providing an “indispensable good”, a form of contribution that is not simply one of economic participation. This recognition should extend to funding comprehensive, dementia specific education and training for informal carers and providing incentives for their participation.

Recognition of the value of informal carers underscores the importance of providing them access to appropriate and individualised information, advice and counselling, financial and practical support, and respite services to assist them to provide informal care for as long as they choose. Measures aimed at reconciling the conflicting pressures of paid work and care should be addressed through workplace-based policies that allow flexible work, time off and paid care leave and/or home care and other services that can substitute for informal care so that informal carers can take or retain paid employment.

Proposed outcomes: Informal carers, living in all areas of Australia, rural, regional and remote included, 1) are recognised for their productive value, 2) have access to individualised support to assist them in their caring role and, 3) have access to appropriate education and training to enhance the skills required to perform their caring role.

Recommendations:

(i) A national social policy on supporting people with caring responsibilities, including informal carers of people with dementia, which aims to address the balance between carer burden and capacity.

(ii) Review and increase in the carer’s allowance and carer’s payment to truly recognise the productive value of informal care in Australian society;

(iii) Incentives for workplaces to provide infrastructure for “Aging well’ support for employees who are also informal carers of people with dementia –eg. flexible work and study arrangements, part-time job opportunities, etc similar to childcare provision, and as a conduit or venue for dementia awareness, information and training.

(iv) In consultation with people living with dementia, develop, promote and implement a flexible education and training program and personalised toolkit for informal carers

(v) Incentives for informal carers of people with dementia to participate in education and training programs that will be of benefit to both themselves and the person with dementia whom they support

10.2 Formal support and care

The workforce providing formal support and care to people living with dementia is not limited to direct care staff currently employed in the aged care system by community or residential care providers. Staff working in a range of settings including health and hospitals, general and specialist’s practices and community based emergency services regularly come in contact with, and provide direct care and support services to people living with dementia.

An integrated health and services delivery model could potentially involve appropriately trained staff working within and across different care settings. This would support a more flexible approach to service delivery, particularly in times when demand, need or availability of staff fluctuates, and given future projections of supply constraints in the dementia care workforce. To achieve this type of integrated approach to services delivery for people living with dementia requires comprehensive dementia care workforce needs based planning. Small area data and demographic modelling is required to identify areas of workforce need across Australia. Comprehensive workforce education and training is required to ensure the quality of care provided to people with dementia supports quality of life and “aging well” outcomes (See Attachments – Case Study 5.8).

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[3] Informal carers are family, friends or neighbours who are directly involved in providing support and care to a person with dementia

Proposed outcomes: 1) People living with dementia, in all areas of Australia, rural, regional and remote included, receive support and care from staff who are appropriately recognised, remunerated and trained in dementia support and care practices and approaches 2) Sufficient numbers of appropriately dementia trained and experienced staff are available across Australia to provide intervention support services, and when required, provide supervision, mentoring and practical support to both informal and formal carers as required (see Attachments – Case Studies 7 and 8)

Recommendations:

(i) In consultation with stakeholders, implement quality competency standards that apply to all staff in direct contact with people diagnosed with dementia in all settings – hospital, general practice and other secondary care settings, community, home-based, residential or specialist care. A minimum standard according to current qualification level, could be either the compulsory unit of competency CHCAC319A (in Certificate III Aged Care Work/Home and Community Care); a Post graduate interdisciplinary unit - Introduction to Dementia Care, developed by the Curtin University School of Nursing and Midwifery in conjunction with the Dementia Training Study Centre; and the Certificate IV in Dementia Practice (in development)

(ii) Fund the role of one or more, according to need and numbers, dementia specialist Liaison Consultants, who are responsible for dementia advocacy, liaison, coordination, clinical mentoring of other staff in all settings that provide direct care and support to people living with dementia

(iii) Increase levels of remuneration to staff who provide direct support and care to people with dementia in all settings, particularly in community and residential care, to appropriately reflect and value the attitudes and skills required to provide quality support and care to people with dementia

(iv) Recruit and retain the support and care workforce in rural, remote and regional areas, particularly those working in community and residential care, by offering competitive remuneration and adequate subsidisation, in recognition of the costs of living in these locations

(v) Fund the role of a dementia specialist trained Nurse Practitioner who has access to the MBS and PBS, to work within the primary health care system alongside GPs,

(vi) Fund the role of a dementia specialist trained GP to provide timely, targeted and appropriate clinical management to people with dementia living at home and in residential care settings.

11. Supported living environments

The living environments of older Australians are predominantly comprised of private residences, retirement villages, and various forms of low and high care residential facilities. Whilst retirement villages might be seen as a housing choice for the independent older Australian, residential care facilities continue to be seen as ‘the last resort’. In her study on the growth of specialised spaces in the community for older people, Peterson (2009), found evidence of how attitudes to aging influenced purpose built aged housing in Australia, in particular residential complexes. She proposes that the environments built to accommodate older Australians are both the cause and effect of ageism. It is perhaps worth noting that the ‘places’ where frail, dependent older Australians live are synonymous with the terms ‘bed’ or ‘aged care beds’, and older people are conspicuously absent from the discourse. There are a number of parallels to be drawn from the stigma and negative perception associated with social housing (Atkinson and Jacobs, 2008) and that of residential care facilities.

Surprisingly, given aging population concerns and a projected increase in the prevalence of dementia, a coherent housing policy for older Australians does not exist. The system of housing for older people in Australia, of residential care facilities and retirement villages, has evolved by default (Peterson, 2009). This is in stark contrast to Europe, where many governments in the 1980s, including those of Sweden, Denmark, Netherlands and Great Britain, faced with a rapidly increasing elderly population, began to re-examine fiscal policies that encouraged institutionalisation of older people. As a consequence the building of additional nursing homes was discouraged and an expansion of a range of housing alternatives and increased home support and care was encouraged.

In Denmark, innovative models of nursing home care to replace the medical model, were also encouraged, including self-care models to foster independence and decision making as long as possible. In Denmark the *Housing for the Elderly Act 1987* housing policy encourages the provision of homes adapted to the needs of older citizens and discourages the building of nursing homes.

In 2005, with much fanfare, the government launched “Building the Future – a plan for better communities”, an initiative to encourage reshaping of housing design so communities into the future catered for all age groups, but the outcomes of this initiative are not obvious. Despite the overwhelming evidence that people prefer to age at home, increasingly large residential complexes and retirement villages that incorporate low and high care facilities are being built by developers. In fact, Peterson suggests that residential complexes could be perceived as Australia’s answer to a housing policy for older people (See Attachment – Case Studies 6.1 and 6.2).

Locally and internationally, there has been development of a range of community based group and other housing models, which could potentially provide alternative accommodation opportunities for older Australians. eg. the Green House, Eden Alternative, Humanitas, and Abbeyfield, However, without significant investment, a comprehensive state and local government review and revision of planning laws and regulatory standards, and a review of the Aged Care Act 1997, progress in this regard will be very slow. Social housing will also not be a viable alternative accommodation source for older Australians without a significant capital investment, and comprehensive and concerted action to address the level of stigma associated with social or public housing (Atkinson and Jacobs, 2008). Opportunities for current housing and accommodation environments of older Australians to be made more supportive and enable older Australians to “age well” in the setting of their choice require exploration, as there are limited alternative options available in the short term. There will always be a need for alternative accommodation for elderly people and people with dementia who are on low incomes, lack a strong informal care network to support them as their needs increase, and at present the only accommodation option available for them, now and into the future, is residential care.

Perhaps one opportunity lies in the current stock of residential care facilities, if the Danish experience could be applied in the Australian context. Thirty years ago Denmark embarked on a social experiment to shift from reliance on nursing homes in favour of a more integrated system of home and community services for the elderly. In Skaevinge, the community transformed its one nursing home into a hub for community support services. Instead of closing older people off from the community, it opened up opportunities. The nursing home became a combo-site, hosting a senior centre, day care, rehabilitation, 24-hour home care, and assisted living. Nursing home staff was guaranteed jobs in the new plan. During the transition process from nursing home to community care, staff had to learn to avoid taking over responsibility for tasks residents could do for themselves, and residents had to relearn self-care skills.”

11.1 Design for dementia

The implementation of good dementia design principles is essential to support people with dementia and other cognitive impairments “age well” in all environment settings, including hospitals, private residential properties, social housing, independent living units, retirement villages and residential care facilities (see Attachments – Case Study 3.2). Despite the rhetoric, the recently released ‘Living Housing Design Guidelines’ omitted any reference or recommendations for universal design principles to support people with cognitive impairment or dementia, excluding assistive technology and smart house features; additional space to provide access for the family carer or paid carer to provide personal care assistance, and dementia specific and “dementia friendly” supportive environments. Security and safety were the only areas identified to be of particular concern in relation to aging-in-place in Australia, in a report by McG Tegart (2010).

Part of the paradigm shift to “ageing well” is recognition that the current construct of residential care is institutionalised nursing care. However when people with dementia require a more supportive environment than that provided in their own home, it is not nursing care that they need but environments and trained staff to support to them “age well” with dementia (See Attachments – Case Studies 5.1, 5.2, 5.4). Neither the government nor residential care facilities are prepared, resourced, designed or staffed adequately to meet the support needs of people entering residential care in the future. Their needs are likely to be higher, and predominantly associated with dementia, based on future dementia prevalence projections, and a community preference to remain living at home if they can be supported to do so. I

Proposed Outcomes: 1) Comprehensive housing and accommodation plans and policies for older Australians, which enable people living with dementia to have access to a range of appropriate supported living environments that meet their needs and circumstances, both social and financial. 2) Standards of design, construction, retrofitting and modification of current accommodation and living environments that meet the needs of older people and people with cognitive impairments

Recommendation:

(i) Undertake a comprehensive review of European and other countries' policies and models of home care and support for the older population to inform development of policies and practices for the Australian context.

(ii) All levels of Australian government review and change policies and procedures (eg. funding arrangements, certification standards, planning laws etc) that entrench ageist attitudes and stereotypes; contribute to the framing of older people and people with dementia as dependant; and restrict consideration of alternative models for their support, care and accommodation.

(iii) Investigate the funding mechanisms, processes and protocols, including eligibility criteria, for subsidising the cost of retrofitting or modifying the homes of older people to support and enable preferences and principles of ageing in place

(iv) Develop appropriate housing policies to influence the proper and appropriate use of technology in home care, as ownership would influence the responsibility and ability of tenants to adapt homes to their possible needs

(v) Private, public and not for profit providers of accommodation – residential care, retirement complexes, and other alternative forms of social and group housing are required to demonstrate consultation and collaboration with the local community in planning, upgrading or creating alternative uses for accommodation for older people

11.2 Assistive technology in dementia support and care

A range of devices and systems are available to assist people with dementia "age well" - increase and maintain their independence and daily living skills, assist them live at home for as long as possible, reduce risk and maintain wellbeing for themselves and their families. Communication aids, calendars, personal alert and location devices, have valuable application along the dementia journey, but are frequently given low priority in discussion on the benefits of smart or assistive technology, including the recent 'Smart Technology for Health Longevity' report (McG Tegart , 2010). With mild cognitive impairment and in early stage or younger onset dementia, people have insight into the benefits of devices: to maintain their independence, support social inclusion, provide reassurance to both themselves and their partner. For people in mid to later stages of dementia who are often living alone, or lack insight but agree to assistive technology for their or families' sake. For people with dementia who are "aging in place" or living in "low care" hostels it supports their independence and their families' desire to maintain a person out of residential care facilities. However, increased awareness, ongoing consideration and discussion of ethical issues associated with assistive technology in dementia support and care, is required so that application and usage reflects ethical practice by balancing risk and protection.

Proposed outcome: People living with dementia in all settings have access to a range of assistive technology that meet their individual needs for support and care

Recommendations:

(i) Quality standards that support provision of information and access to appropriate assistive technology for people with mild cognitive impairment, newly diagnosed with dementia and in the early through to later stages of dementia

(ii) An Assistive Technology Benefits Scheme along similar lines to the PBS, to provide an agreed range of devices at agreed prices, through a network of approved providers with prescriptions written by certified agents such as ACAT or specialist community care

(iii) providers. (Equipment provision to assist people with disabilities to stay in their homes is currently funded via multiple and confusing pathways according to eligibility – Disability Services through Community Aids and Equipment Program (CAEP), hospitals, Aged Care through community aged care packages (CACP), and Dept Vet Affairs)
(iv) Information and training for informal and formal carers, community based and residential care service providers on the range, use and benefits of assistive technology
(v) Post graduate training for allied health, particularly Occupational Therapists on availability, range and benefits of assistive technology
(vi) Develop and implement, in consultation with stakeholders, regular and recurrent evaluation of the costs and benefits of technologies in providing support for older people

12. Managing risk, reducing over regulation and improving quality of life

Current policies and regulation in Australia, like long term care policies and programs in the United States (Kane, 2001) are balanced toward a model of care that, regardless of its technical quality, tends to be associated with a poor quality of life for consumers, and in particular for people with dementia whose right to a quality of life, in whatever setting they choose, is easily compromised in a heavily regulated environment. Regulatory approaches to managing risk, particularly in relation to populations such as the ‘elderly’, ‘disabled’ and ‘demented’, are strongly influenced by societal attitudes and perceptions about vulnerability, frailty and dependency. As a consequence, regulation of services to these populations often serves to manage political risk and minimise negative publicity, rather than providing ‘sustained and focused control … over activities which are valued by a community’ (Walshe, 2003).

Efforts to bring about cultural change in services to the elderly, related to the growing awareness of person centred approaches to meet the wellbeing needs of people with dementia, have been hugely hampered, particularly in residential care, by the current ‘hard’ regulatory regime. Understandably, there are fundamental concerns regarding duty of care, ensuring safety and security outcomes, however these have to be balanced with supporting dignity of risk and ensuring quality of life outcomes - dignity, privacy, autonomy, choice, meaningful activity, relationships, comfort, functional competence and spiritual wellbeing (Kane, 2001).

The current emphasis in Australia on ‘hard’ regulation, defined by Wadmann, et al. (2009), as consisting of surveillance, control and interventions (sanctions) in cases of non-compliance or poor performance, occurs when the regulator regards service providers as basically self-interested and likely non-compliant. ‘Hard’ regulation however, does nothing but enhance and maintain ageist and paternalistic attitudes to support and care service provision, and requires immeasurable amounts of time and energy focussed on reporting and compliance requirements, to the detriment of maintaining quality of life and care outcomes. A paradigm shift to “aging well”, increasing preference in the community for aging in place in settings outside of residential care, combined with a ‘consumer directed care’ focus, should support a ‘softer’ regulatory approach which aims to support service providers deliver service improvement by identifying strengths and weaknesses, offering consultant assistance and providing constructive feedback from service users and other stakeholders. By implication this will occur if regulators perceive service providers as more collaborative and compliant.

Understanding the purpose, objectives and outcomes for regulation, and informing the community, service users and providers of these will enhance and improve the way regulation is implemented and managed. In order to achieve a reduction in over regulation in the system that provides care to older Australians, we must first ask ourselves “what sort of system do we want as a society?” We need to understand the activities that we value and how we want these controlled, before we can expect and undertake regulatory change. A further question should be “what do consumers want?” “More from life than safety” was how an 89 year old woman with congestive heart failure and disabling arthritis, who had just moved into a nursing home after a series of falls at home, described her expectations (Gawande, 2007).

Proposed outcomes: 1) Increased community understanding and awareness of the issues associated with managing risk and agreement on acceptable levels of risk in achieving quality of life and care outcomes 2) a single point of accountability and a consistent set of support and care regulatory standards across all settings – community, residential and hospital that enable a consumer-centred emphasis on quality of life and care outcomes – dignity, privacy, autonomy, choice, meaningful activity, relationships, comfort, functional competence and spiritual wellbeing.

Recommendations:

(i) Initiate immediate and ongoing opportunities for community, consumers, providers and regulators to discuss, reflect upon and develop a common understanding of the desired objectives and outcomes of managing risk in achieving quality of life and care outcomes as part of the reform process. This then becomes part of the normal process of ongoing legislative and system scrutiny.
(ii) Review and make amendments to the Aged Care Act 1997, particularly in relation to Part 4.1 Quality of Care and to any other relevant parts, to better reflect policies and programs for older Australians that are balanced towards a model of "aging well" and quality of life outcomes, that support aging in place in settings other than just residential type care
(iii) Develop or amend regulations that are specific to the purpose of a future model of residential type care that meets the needs of people who require a more intensive level of support and care than can be provided in another setting, eg. end of life care
(iv) Review and implement simplified, nationally consistent, and useful reporting arrangements across all care and support settings that have a quality of life and care outcomes focus
(v) Review and improve the mechanisms designed to achieve quality and compliance outcomes in all support and care settings (including hospitals and multi purpose services), in consultation with all stakeholders, to better reflect policies that are balanced towards continuous quality of life improvement outcomes rather than just compliance and complaints, and enables a high degree of recurrent feedback from all stakeholders
(vi) Redesign the approach to inspection and compliance so it is more targeted and proportionate to the actual risks being managed and provides a focus on outcomes for people who use services
(vii) Develop and implement processes to enable measurement of quality of life domains that then form the basis for audit criteria used at the service level to improve the quality of support and care outcomes
(viii) Engage with the stakeholders and consumers in the dementia and disability sectors to gain insight into the ethical and practical considerations and solutions for managing risk in the provision of care and support to "vulnerable" populations

13 Structural Reform - Transitional Arrangements

Australia requires a vision and a plan for caring for older Australians that will address the reality of an aging population, an increased prevalence of dementia and a changing demographic and social environment. The challenge for a federal system of government, where powers and some responsibilities are divided between Commonwealth and seven state and territory governments, is to deliver fundamental wide reaching and long term structural reform to achieve an effective and integrated system that supports "aging well'. This requires active engagement with all stakeholders, at all political levels, and a level of agreement and shared commitment unparalleled in Australian health and social care policy and practice. Reforms to our current system will have major and far reaching implications for the future support and care of people living with dementia in Australia.

Many reports have been commissioned, structural reforms implemented and evaluated, so there is much to be learnt from our own and international experience (Strandberg-Larsen and Krasnik, 2008, Alzheimer Europe, 2010). Notably, in Denmark after 12 years of implementing integrated systems for home and community based services in 275 municipalities, growth in Danish long-term care expenditures has leveled off; expenditures appear to be decreasing for the over-80 population and have dropped as a percentage of the gross domestic product. Access and quality of long-term care services reportedly remained satisfactory (Stuart and Weinrich, 2001).

Reflecting upon policy, practice and prioritising actions to support structural reform can occur in many ways, and it is important ensure that all stakeholders in this process continue to have a variety of genuine opportunities to contribute to improving the system of Caring for older Australians into the future.

14. Recommended Priority Actions:

1) Develop and implement, in consultation with stakeholders, a national framework to guide the process of reforming the system of caring for older Australians
2) Review and make amendments to relevant legislation that is required to support and enable the process of reforming the system of caring for older Australians
3) Include in all transitional arrangements for structural reform a comprehensive mechanism for determining the potential impact and benefit of the arrangements for people living with dementia
4) Develop and implement mechanisms to involve and consult older Australians, and particularly people living with dementia, in the planning, delivery and evaluation of a reformed health and social services system
5) Identify the manner and process whereby reforms will be evaluated – transparent criteria, appropriate timeframes and frequency of reviews
6) Utilise current information to plan the care and support needs of older Australians, including economic and demographic modelling and dementia projections (Access Economics 2010), which is regularly reviewed and adequately funded
7) Develop and implement information communication technology that facilitates clinical and service integration, including a national electronic “aging well” individual health and medical information record that includes relevant dementia specific information and is consistently implemented across all functions and settings, with a long term investment commitment nationally for maintenance, improvement and evaluation
8) Create “Aging Well” Dementia Support Networks located across Australia in consultation with people living with dementia and other appropriate stakeholders. This requires a change management process that includes Aged Care Assessment Team members and other health and care service providers to enable successful transition, and an evaluation and review process to assess the impact and make recommendations for creating Support Networks in stroke, Parkinson’s etc
9) Develop, implement and evaluate, in consultation with people living with dementia and other appropriate stakeholders, appropriate ‘consumer directed’ care arrangements that address dementia specific needs
10) Improve wage parity across all health and social services sectors to assist in attracting, recruiting and retaining staff
11) In consultation with stakeholders, identify and communicate clear criteria for deciding how to shift resources between and among the current components of the system
12) Develop and implement, in consultation with stakeholders, mechanisms to collect and communicate information about service costs - what is publicly funded and what the user pays

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ATTACHMENTS

Case Study 1 – Regional Services Mandurah

Case Study 2 – Regional Services York

Case Studies 3.1 and 3.2 – Dementia Behaviour Management Advisory Service Bunbury

Case Study 4 – Metropolitan Respite Service

Case Studies 5.1, 5.2, 5.3, 5.4, 5.5, 5.6, 5.7 and 5.8 – Regional Services Albany

Case Studies 6.1 and 6.2 - Consultancy and Assistive Technology

Case Study 7 – Metropolitan Dementia Behaviour Management Advisory Service

Case Study 8 - Metropolitan Dementia Behaviour Management Advisory Service

CASE STUDY 1 – Regional Services Mandurah

This is the experience a family carer had when trying to find respite for her Mother.

This family carer cares for mother who has Alzheimers and is 91 years old.
The family carer had booked 3 weeks of respite with a local residential facility. It had taken her many weeks to find a facility that would take her mother.

A week before the respite was due the facility phoned the family carer at home and advised her that she would have to bring her mother into the facility for an assessment.
The family carer advised the caller that her mother was frail and did not cope well with travelling in the car; however the facility staff member was adamant that she must attend the assessment or the respite would not be able to proceed.

Reluctantly the family carer agreed to bring her mother in the next day at 11am.
Upon arriving at the facility the family carer struggled to escort her 91 year old mother in to the administration building, finally they entered the building only to be kept waiting for 20mins, by this time her mother was becoming increasingly agitated.

The facility staff member finally arrived for their 11am appointment, it was now 11.30am.
The family carer surveyed the office where the assessment was to take place and observed there was no suitable seating for her mother, none was offered.
The family carer asked if she could have a pillow or a small cushion for her mother as she suffers from acute back pain, none were made available.

By this stage her mother became very distressed and was shouting and voicing her displeasure with the situation, it became unbearable for the family carer and her mother so they prepared to leave.
At no stage was any help offered to manage the situation.

Before getting into there car to leave the staff member put some forms in front of the family carer and asked her to sign them, these forms were signed on the bonnet of her car with her mother by this time screaming and crying.

The family carer expressed to me that was the single most distressing situation that she has had to put her mother through.
At no time did the facility offer a home assessment, even when the family carer explained the difficulties involved in transporting her mother.

The family carer had an up to date ACAT which the facility had a copy of .
The family carer was given no explanation regarding why the assessment needed to be at the facility or what the purpose was.

So many of our family carers are expressing how difficult it is to find a facility that is secure and safe for the loved ones. Many of our family carers have travel outside of the local community to find respite.

This story demonstrates the need for person centred care and the flexibility that is necessary when supporting family carers and people with dementia.

July 2010
Alzheimer's Australia WA

CASE STUDY 2 - Regional Services York

Husband with Alzheimers dementia

Carer very sick herself and receiving Govt funding to have special “immune” medication provided’ secondary to her having had one lung removed and needing this medication to reduce risk of severe lung infections. This medication was ceased as a result of “lack of Govt funding assistance”. No amount of lobbing by the carer’s specialist could convince the Govt to reconsider their decision which ultimately reduced the carer’s health status dramatically over a short period of time.

Two children living locally/ one with young daughter and very supportive but single working mum/ other daughter also works & was not accepting father’s condition and not very supportive at all & only added extra stress to mother/carer.

PWD very demanding /tagging/ not recognizing wife .PWD dementia status rapidly getting worse at accelerated speed.

Carer started attending MDRT Moora Carer Support group meetings which she stated gave her a lot of support and stress relief.

Carer declined in-home respite services at first. When carer agreed to have respite services, we were unable to employ a worker locally. Team approached all local services including TAFE, local hospital and community services and advertised many times in local papers all to no avail.

With carer’s permission arranged emergency respite at Perth facility which caused more stress as carer received numerous calls from facility about husband’s behaviours. As carer was so unwell she could only address the issues by phone which left her very stressed and feeling extremely guilty for having organized the respite so far away.

Trip to Perth respite caused more stress as carer unwell and had to drive husband who is a very poor traveler. During the trip he kept wanting to get out of the car all the way to Perth. No one was able to go with her as everyone was working

As Petrol prices had risen to a very high level this also caused carer financial stress and meant that even if she wanted to visit her husband during respite / financially she could not afford to

When PWD returned home he was very distressed and was refusing to ever go back to” that place” which caused carer more stress to the point she was not going to accept respite in Perth again. Apart from myself the carers at the AAWA Carer Support Group reassured her & encouraged carer to accept the respite for her own health needs pointing out that if her health failed more she would not be able to care for husband anyway.

Planned Respite at the local hospital was not available a lot of the time when requested and on the times it was carer received a call after 24 hours asking carer to come and take husband home as he was “too intrusive and they did not have enough staff to look after him”

MDRT spoke to local Community services many times to arrange ADL/personal care and gardening services for family but none were ever agreed to or instigated.

Carer’s GP was not that helpful and even when he did admit the PWD into the hospital carer would be phoned and asked to take him home within 24 hours.
At one stage carer was being tested for Swine Flu and the GP and local services told her she must go home and not have any visitors what so ever until the test results proved negative.Carer was not given any assistance at all and had to still care for a very demented husband whilst she was extremely sick herself. I was on leave interstate when this was happening and only found out when it was too late to do anything about it. The test results proved negative!

MDRT eventually employed two workers who lived kms from Moora but were able to provide 12 hours of weekly respite. Our team allowed the workers to provide this respite on days that carer nominated so that she could meet her own health and personal needs.
We also arranged many additional Planned Respite stays for PWD at numerous facilities in Perth for regular and emergency respite. We also allowed our worker to travel to Perth with carer to transport PWD to and home from Planned Respite.

Team also placed family on a full waiver for AAWA's respite and also arranged CCRC funding for each Perth planned respite session.

As carer's own health continued to worsen & carer eventually decided to sell her house and move to live with her sister in Bunbury where she placed her husband into a permanent secured dementia specific N/H. This meant that carer had to leave her children and granddaughter & friends back at Moora.
We assisted carer with the move as best we could.
Carer still keeps in phone contact with our office.

Carer states that she hates living in Bunbury and hopes that a secured dementia specific N/H with Planned Respite facilities is built in the area so others don't have to go through the same heartbreaking torment. This area also requires a Secured Dementia Specific Day Centre.

There are numerous families living in the area and up along the north coast that could relate similar circumstances where local services or lack of services have given them no other choice but to leave the area or place their loved ones in permanent care kms from where family live and where they have often lived their whole lives.

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CASE STUDIES 3 – Dementia Behaviour Management Advisory Service Bunbury

3.1

Mrs. E. has vascular dementia and lives at home with Mr. E who is her main carer. Mr. E is disabled from suffering with sever osteoarthritis. Mrs. E's. needs at most involve activities of daily living along with meals and medication prompting. A person centred approach.
Mrs E. has limited home support from professional carers who have varied professional knowledge base and therefore there are many inconsistencies and approaches to the care given. This in turn leaves Mrs. E. confused and upset on most days after the professional carer leaves all this due to inconsistencies in the approach of care given.
This is common in our rural communities where staffing is limited and also the staff available has diverse skill levels.

All this puts extra pressure on Mr. E. who is now thinking of placing Mrs E. in an aged care facility sooner than she wants or needs to go.

3.2

Mr. T. has been moved from his loved rural country property to an aged care facility in a large town, neither close to his family nor close to his childhood homeland in which he wants to be.
Mr T. has Korsikoff's Syndrome and is now unable to be managed at home however the facility also is unable to deliver on environmental needs for Mr. T as he is of aboriginal ethnicity and now in need of outside environmental interventions to help him reminisce and feel comfortable. Mr. T likes to go and see, hear and smell the garden and surrounds. Be as one with the land.
The facility is small, with out secure outdoor area and is not equipped for Mr T's. cultural needs. There are very few or any facilities in rural South West of WA who cater for elderly aboriginal people.

Facility and Community supports and services that are not meeting the needs of some rural people living with dementia are:

- Location of aged care facilities
- Suitability for cultural needs
- Size of the facility and
- It's design to suit the environmental needs for our special needs group
- Knowledge base of staff
- Resources and there availability to staff and carers such as information about Dementia and the services available in rural WA.

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CASE STUDY 4 – Metropolitan Respite Services

This is a recent referral I received through Support Services.

The daughter in the family called our helpline in desperation. Her father was the family carer for his wife who as it turned out was quite advanced in her journey with Dementia.

On receipt of the referral, the family carer was “at breaking point” and was physically and mentally exhausted. On discussions with the daughter, it turns out the PWD had been diagnosed with dementia (type unknown) and was clearly deteriorating and along with this had quite “marked” changes in behaviour.

Over a period of 18months, they had visited the GP and expressed concerns each time in regards to the continual deterioration in the person’s condition but also tried to highlight the changes in behaviour. Each time this was not “heard” by the GP.
The family carers health by this time was also deteriorating rapidly.

The daughter then visited the GP herself with her mother and stated her father was not coping and they required a referral for an ACAT. The GP not only refused to make the referral but “accused” the family of trying to just put her in permanent care. The daughter’s comments to me were “he made us feel guilty each time we asked for an ACAT”

Services were not an option by this point. The family carer needed a long term break (residential respite) and needed it promptly. This not only was held up because no ACAT was in place but no facility could take the PWD because of her extreme behaviours!

By the time we got the referral the family were in “crisis”.

After a few days I followed up with the daughter to see how things were and what had transpired. It turned out the PWD had gone to stay with her son for a few days, had a “turn” and was taken to RPH. To cut a long story short, she was not coming home and would be in CAP until a permanent care place became available. Because of the changed behaviours, RPH were calling in DBMAS.

This all happened in a matter of days. The family are angry at the fact the GP would not refer for an ACAT and the fact they were made to feel guilty for asking for one!

A very sad story indeed.

This is a brief overview of the whole story!

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CASE STUDIES 5 – Regional Services Albany

5.1

We had a client whose wife could no longer cope so he went into residential care. This man was a farmer and he absolutely hated being confined so he kept climbing the fences. The residential care facility couldn't cope with him so asked his wife to come and get him. No other Great Southern residential facility would accept him. His wife couldn't care for him so we ended up having to take him to hospital. The local hospital then sedated him incredibly heavily. When I went in two days later he was quite literally covered in bruises where he had fallen so often, he took three people to transfer and he was doubly incontinent. This was a man who had two days earlier been scaling fences. The hospital tried an internal transfer to Bentley but were told there was a six week wait. I knew the man would not live this long so arranged a community transfer from home and got the local hospital to discharge him. His terrified family took him up to Bentley in their car the next day.

5.2

We had another client, a lady with dementia who was addicted to morphine for MS. The GP tried to reduce this while giving large antipsychotic depot injections which rendered her practically catatonic so she had to be admitted to Albany hospital. In Albany hospital she was put in the locked adult mental health ward, a totally inappropriate place for someone with dementia. She was terrified of the other patients. She lived in Mt Barker so when a bed became available she was transferred to Mt Barker hospital. She was known there as a morphine addict. Due to an administration error the correct paperwork did not go with her so she did not have any morphine for 24 hours, an incredibly cruel thing to do to a morphine addict with dementia who cannot communicate her needs. She was understandably unmanageable and returned to the locked Albany ward.

5.3

We had another client who became violent at home and was admitted to Albany hospital. He was put in a private room with a guard on the door. The nurses were frightened of him so tried to avoid going in there. This did not improve his behaviour. He was given large amounts of medication. Our staff who continued to visit him found he could no longer walk and took him for walks around the hospital in a wheelchair. After a few days this man, who was active and vigorous the previous week, died.

5.4

We have numerous examples of clients who go into residential care where they are not happy to be, exhibit challenging behaviours as a way of trying to communicate this, are medicated to reduce behaviours, and then die.

5.5

We had a client who lived with his wife and son. His memory loss was quite severe and he was constantly fretting and questioning his family. He would be up and anxious and asking questions all night. His wife became very angry with him and the relationship deteriorated. He stayed with us a great deal, and was always frightened to go home. His wife begged us to keep him every time he came to stay. He had an ACAT assessment and was approved for *low* level care. This is because the ACAT assessment is focused on physical abilities. One residential care facility accepted him, had him for two weeks then asked the family to take him away because he needed too much looking after and they could not get adequate funding for this. Then all the other facilities in the Great Southern said they could not take him because he only attracted minimal funding because he was independent in all aspects of personal care, but actually took a huge amount of staff time because of his dementia. For some time we were seriously concerned that a serious act of violence was going to take place in the home. The ACAT and ACFI need to take greater consideration of dementia and the staff time involved in giving constant prompting.

5.6

We had another client who had dementia and lived on her own at home. She was not able to prepare food, threw away food that was left for her, and would only eat if someone was with her. Her family covered some meals but she really needed an EACHD so that she could have the hours of care she needed. The ACAT assessor would not approve her for an EACHD. They said that according to the guidelines you have to require "high level residential care" in order to qualify for an EACHD. This lady would manage well in a low care facility as there was someone there at all times to prompt her to eat and she would have company while eating, and someone would assist her to wash and dress as necessary and prompt her to carry out other ADLs. She was *high* care level at home but if she had gone into a facility she would have been *low* care therefore did not qualify for an EACHD. This lady had to go into residential care because an EACHD approval was refused. This has been an issue numerous times since then and is dementia specific. The symptoms of dementia often mean that someone will cope well if they are monitored and prompted 24 hours a day which can be achieved in low level care, therefore they cannot have an EACHD. The EACHD providers in Albany find that by the time someone gets onto an EACHD, by the time they actually qualify for high level residential care, then they very soon have to go into care because the family cannot manage. It means a huge amount of assessment, administration and setting up of services is done unneccessarily.

A different criteria for EACHD is required, and a CACPD is essential if we are to assist people with dementia to stay at home.

5.7
A client has asked me to pass on to you a request about "not for resuscitation". When her husband went into residential care she filled out a form saying that he was NFR. This caused her a great deal of grief, but she made the decision and came to terms with it. When her husband went into hospital a while later she was asked to fill out an NFR form again. She was very upset by what was happening to her husband and having to confront this issue again made everything worse. Her husband has been admitted to hospital twice since then and every time she has to make an NFR declaration. She would like the first declaration to remain effective.

5.8
Diagnosis is a huge problem in residential areas. GPs are not able to make reliable diagnosis as they do not come across the problem often enough to become experienced and practiced. There are no MRIs in the country. Travelling to Perth is often too traumatic, and often the GP thinks it is not worth the bother. Rural areas need memory clinics that provide expertise on all aspects of dementia so GPs have somewhere that they can refer on to. This would improve levels of diagnosis and reduce incidents of inappropriate medications being given. Albany, a large regional centre with a large elderly population, currently has just one visiting geriatrician one day every three months. We have just been given funding for a psychogeriatrician for one day every three months, but it is not known how long this funding will last. This is a pitiful amount of expertise for such a large issue.

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CASE STUDIES 6 – Consultancy & Assistive Technology

6.1

Mrs R. Cares for her brother who recently accidently took an overdose of his medication – the hospital cannot let him return home as he required 24 hour care.
Mrs R. was really upset to find there is nowhere fro him to go, waiting lists are long, there are no rooms available in Res. Care. He will be kept at hospital until a room is available.

6.2

Mrs S. cares for her Mother who is at risk of walking and getting lost. Her Mother is currently in hospital awaiting placement with a guard at her bed. No aged care facility will accept her because of this. There are no beds.

I get phone calls almost every day now, from family members who are desperate for help, there are many people really struggling with family members who have dementia.
And its getting more and more desperate every week. The government has to start to plan, to put strategies into place very quickly, but I have not heard anyone mention Aged care and the increase in dementia we are facing.

Prior to working at AAWA I worked in residential aged care for 7 years. The last 3 years made me realise the whole system was on the verge of collapse. I started writing letters to MP's. In response I received a standard letter from Justine Elliot. I had a much more promising reply from the opposition minister for ageing etc – however she has not putting any case forward in addressing the current issues, and as far as I am aware has not been heard of or is in the public eye at all. Very disappointing.
I went to see my MP, and Mal Washer – standard reply, I felt it was in the too hard basket for these people to consider except to agree with me the system is in trouble.
Justine Elliot wants to increase police check's, increase spot checks from the accreditation board to make sure residents are not being abused. I agree this abuse of our vulnerable must not happen, **but it needs to start with getting the right people for the job in the first place,** and if they can earn more at working at Ikea ($26 hour, no responsibilities, no emotional stress or heavy work) then people will not want to work into this specialised and very rewarding area of care for $17 – 20 an hour.

The issues are:

1. Staff work in a highly specialised area of care. These are care staff, Therapy staff, everyone who works with people with dementia needs skills, especially communication skills..
2. People working in aged care are very low paid for the skills required and the jobs that they do. There is ongoing training all the time in aged care. New staff enter into the facilities as new Australians wanting to settle here. Many have little English language and writing skills. Current staff have to "carry them" in regards to constant paper work documentation needs. Many new staff members have little understanding about the cultural backgrounds of our residents. *(However there is training and awareness for current staff to accept new people of African / Asian backgrounds into the work force*) Many people take these jobs because its their only way to enter Australia, and aged care facilities are desperate for staff.
3. **In my opinion the whole system requires a complete overhaul from the ground level.**
4. I feel there needs to be at least one year's full time certificate / diploma course prior to any person working in aged care, followed by another year of on the job training and evaluation. People need to pass all stages of training, not just given a certificate for just attending and "doing a course." This should cover many aspects of Dementia care, Communication skills and English spoken and written needs to be of a high standard in order to do the job required in Australia. Manual handling techniques. Infection control, observation skills, behaviour management, grief, and working with family members etc. There is a great deal of documentation required in facilities, and everyone who works with people with dementia are required to observe and document behaviours, medication etc..
5. There needs to be a career structure for people in aged care to work towards. More qualified, senior staff to supoprt new carers / staff members, and a pay structure to go with this. If staff are not rewarded for the job they do, they will leave.
6. There needs to be new facilities built, with guidelines from AAWA for environment design. If there isn't, new facilities will go back to the "Old Days" of huge horible big square buildings with long dark corridors that no-one want to go in, or work in. Many facilities are not dementia friendly, that's why Jason is called out to try to "fix" the problems.
7. Only by starting here, can excellent care and support be given to the people and their families who are living with dementia.

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Case Study 7 – Metropolitan Dementia Behaviour Management Advisory Service

Initial Information from Aged Care Facility

Mr S is an 89 year old widowed gentleman who migrated to Australia from Italy 60 years ago. Since his admission to the Nursing Home 6 months ago he has reverted more to his first language of Italian. He has become increasingly frustrated that he is unable to communicate with staff and other residents in the facility which has resulted in physical aggression and verbal abuse towards them.

Information from the assessments of all areas

Behaviour	Person with Dementia	Physical and Social Environment	Care Environment	Carer Characteristics
Reluctant to accept care or direction from staff. Uses his walking stick as a machine gun and attempts to “shoot” staff and residents. Verbally abusive in Italian towards staff and residents. Mr. S spits in inappropriate places.	Physical Health: Chronic obstructive airways disease, ischemic heart disease, renal impairment, gout . Neurological Impairment: Diagnosed with dementia. MMSE 8/30 (possibly under scored related to his inability to communicate in English). Life Story: Unable to read or write in English. Attended school until aged 10 in Italy. Served in the Italian army for 5 years. Has three children and a large extended family. Widowed 28 years ago. His two daughters were his primary carers for the three years prior to his admission. Personality: Family describes him as outgoing, happy and carefree.	Social Environment: A very sociable man who enjoys the company of others and visits from family. Enjoys listening to Italian opera, Italian radio and television, gardening, playing cards. Structured social activities are held with residents in groups where English is spoken. Physical Environment: Resides in a small Nursing Home and shares a bedroom with another gentleman. Shared bathroom facilities. Facility lacks dedicated activity/quite areas for residents.	No staff or other resident in the facility speak Italian. Both staff and other residents are frightened that Mr. S will hit them.	Strategies used by care staff have been reactive to his behaviour e.g. attempting to reason with him in English. Staff state that if behaviour continues, he will not be able to remain in his current accommodation.

	Mental Health: No previous history of mental health problems. Medication: Prescribed analgesia PRN and an anti-psychotic at night.			

Analysis:
Mr S’s frustration is related to his inability to express his needs in English. He experiences difficulty sequencing steps of a task, transitioning between tasks and becomes anxious when he does not know what is going to happen in his day.

Problem Statements:

- Physical aggression and verbal abuse is expressed related to his frustration of not being able to communicate with others in the Nursing Home.
- Social needs are not being met related to his inability to join with other residents who speak Italian.
- Staff unaware of the range of aids available to engage and communicate with Mr. S
- Spitting in inappropriate places as no alternate routine has been put in place.

Plan:

- Reassess mobility aid and change to a Zimmer frame to minimise its inappropriate use.
- Provide Mr. S with a box of tissues and a plastic bag tied to his Zimmer frame for inappropriate spitting.
- To be assessed by a Speech Pathologist for communication aids which outline a schedule of routine activities and activities that he could choose to participate in during the day.
- Speech Pathologist to develop a communication system for him to express messages and to ask for assistance.
- Training session to be delivered to staff on the value of using communication aids and how to use them.

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Case Study 8 – Metropolitan Dementia Behaviour Management Advisory Service

Miss T is 69 years old and has been living in a high care dementia specific facility for the past five years.
She has a diagnosis of Alzheimers disease is also an insulin dependent diabetic, has limited vision and has marked osteoarthritis in her neck and hips.

Staff at the facility are concerned about her calling out in a loud voice for most of the waking hours. In fact her calling out has so upset some of the other residents on the unit that Miss T now spends most of her day in her room.

This has developed into a new set of problems where, spending so much time alone in her room has led to staff removing the taps from her bathroom and all bath products to prevent the bathroom from being flooded or the walls and floors from being smeared with toothpaste and shampoo.

Prior to her diagnosis of dementia Miss T worked variously as a graphic artist and photo re-toucher. She was an accomplished craftswoman specializing in textile art. She had travelled Australia widely and
loved bushwalking and tennis.

Her only surviving relative is her brother who can no longer visit her as he is unwell. She has one old friend who still visits occasionally but on the whole as her dementia progressed her friends found it too difficult to keep up contact.

Miss T is currently a client, having been referred by the facility to assist with providing strategies to minimise the calling out and reluctance to accept assistance with care. During the period of involvement the following issues have been identified:

- Staff at the facility were unaware of the link between fluctuating blood sugar levels a heightened agitation
- Staff at the facility had limited understanding of the impact of the presence of pain on the behaviour of a person with Dementia
- The facility had limited access to specialist assistance with diabetes management as Miss T was unable to attend an appointment due to the extent of her cognitive deficit.
- The facility had very limited access to allied health professionals to assist with the implementation of a specialised programme of management. What hours the allied health professionals had were devoted to primary assessment and documentation.
- The allied health/lifestyle staff had limited training on the special needs of younger people with dementia.
- On assessment it became evident that other factors contributing to Miss T’s behaviour were: sensory deprivation and under detected pain .
- An analysis of Miss T’s daily activities based on a three day chart of every intervention by any staff showed that the only environments she had spent any time in were her bedroom bathroom and the dining room. The only activities other that staff putting on music in her bedroom were associated with primary care. No evidence of any interaction with staff on a personal basis and no involvement in meaningful activity was recorded

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