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(Dementia)

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INQUIRY INTO DEMENTIA: EARLY DIAGNOSIS AND INTERVENTION



KinCare

“THE KIND OF CARE WE WANT FOR OUR LOVED ONES...”

Prepared for:

**House of Representatives
Standing Committee on Health and Ageing**

Submission Response to
Inquiry into Dementia: Early diagnosis and Intervention

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1. Introduction

KinCare is one of Australia's leading specialist providers of in-home care and community nursing services operating across seven states and territories. We have extensive experience in provision of assessment, intervention and support services within the fields of aged care, nursing, allied health and disability. Our capabilities are further enhanced by the expertise and resources of other members in our KinCare Group, which include a registered training organisation and a telereponse service.

Our national service portfolio includes:

- Packaged Aged Care: Community Aged Care Packages (CACP), and Flexible Aged Care Packages (EACH and EACHD), including packages designed specifically to assist people with Dementia and their carers.
- Transitional Aged Care Programs
- Home and Community Care (HACC) programs Personal Care, Domestic Assistance, Community Nursing, Social Support - Dementia Monitoring, Respite
- NRCP Dementia Live In Respite
- Veterans Nursing and Home Care Services
- Disability Housing
- Disability Community Services

We employ over 1500 staff, including registered nurses, allied health, personal care and homecare workers. In total, we support 9800 clients per year; a large proportion (76%) of our clients are aged 70 or over, and 39% are aged 85+. Many of their carers also have poor or declining health status, and exhibit strain associated with their caring function.

Everyday, our staff operate in the homes of individuals who have progressive, life-limiting illnesses, including dementia. There are many instances where we identify signs of memory loss, confusion and behaviours that are associated with dementia in the absence of a diagnosis. In all cases, we work collaboratively with care recipients, their families and carers, and other service providers (including client's GPs, medical specialists, Aged Care Assessment Teams, pharmacists, allied health, transport providers, day centres and community groups) to deliver targeted interventions and support as appropriate.

We would strongly support a program that promotes early recognition of symptoms, leading to timely diagnosis and access to person-centred interventions. We believe such an objective requires a cooperative approach involving government, primary health services, medical specialists, in-home care providers, peak bodies and community representatives.

2. Common Barriers to Early Diagnosis and Appropriate Intervention

A recent Alzheimer's Australia paper¹ provides an excellent summary of the major barriers to early diagnosis of dementia. We would like to emphasise the following barriers encountered in our experience:

Individuals and family members often avoid raising concerns with GPs and health professionals due to a number of factors:

- Dementia carries a strong stigma and is not well understood within the community.
- Individuals fear loss of independence and ostracism as a consequence of diagnosis eg loss of driving license, residential care, loss of decision making powers and positions of responsibility
- Individuals affected by dementia may not recognize the signs of dementia

GPs and health professionals may not directly address potential signs of dementia due to:

- Signs of dementia may be disguised or explained away by the individual and/or family members
- Lack of confidence by the health professional in their counseling skills and fear of upsetting the person
- Lack of awareness of the importance of early diagnosis for prevention and appropriate intervention
- Assumption that someone else will identify and address symptoms
- Failure to notice signs due to limited time/exposure eg short consultations

Once diagnosed with dementia, a person may not always gain immediate access to appropriate services due to a number of factors such as:

- Appropriate services may not be readily available in the region
- Lack of awareness of services available by individual and treating practitioners
- Lack of acceptance of diagnosis by the individual
- Unwillingness or inability of health professionals to provide education and advice on supports available to assist with informed choice
- Delay in diagnosis may reduce decision making capacity of individual, requiring alternative arrangements such as power of attorney and enduring guardianship to be arranged

The implications of these barriers can be illustrated through the following case example:

¹ Phillips, J, Pond, D, Goode, S, *Timely Diagnosis of Dementia: Can we do better?* A report for Alzheimer's Australia, Paper 24, September 2011

At 80, "Mary", was living alone in a retirement village and leading an active life:-playing table tennis, swimming, walking 4 km a day, babysitting the grandchildren, driving across Sydney in traffic and playing competitive scrabble. By 83 years, her family noticed she was exhibiting signs of memory loss, irritation in social settings, increased anxiety, and depression:- she continually mixed up appointments, lost keys/glasses, became lost while driving, and refused to try new things eg foods. Her friends recognised the extent of her difficulties before her family, who lived a distance away and initially dismissed her problems as being an exaggerated version of her "normally forgetful self". One of her children felt she was depressed and one concluded she was "lying like the old woman on Mother and Son". Her GP was unaware of any problems as she presented well and confident in his brief consultations, and she did not like to complain. Her family finally intervened one night after she presented with disturbing hallucinations. On investigation they identified signs that she had not been managing her affairs for some time: she had not renewed her license, was purchasing items from mail order catalogues that she would never need (eg handiman magazine subscriptions), and was donating to 32 charities without realizing (via mail, direct debit and phone donations). She was no longer confident about walking or swimming as she was experiencing dizzy spells.

The family arranged a consultation with her GP who conducted a screening test for dementia using the Mini-Mental tool, and referred her for blood tests and CT Scans. He also reviewed her medications which included tablets for high blood pressure, arthritis and a heart condition and concluded inconsistent administration may be causing the dizzy spells. The family arranged for the local pharmacy to deliver medication in a Webster pack and monitored her more closely. Following receipt of test results she was referred to a geriatrician and an Aged Care Assessment Team (ACAT) and placed on a waiting list for a Community Aged Care Package (in-home support services).

Although the GP was able to facilitate the assessment process, he did not attempt to discuss the diagnosis and implications with her and was unaware of community supports available to assist her to remain living at home. There was a wait of 2 months to see the ACAT, followed by several more weeks to see a geriatrician for a specific diagnosis and to the commencement of in-home care services. By this time, her friends were leaving her out of social activities because she became irritated and spoilt their fun. She became convinced people were trying to break into her home, and became too frightened to remain living there. One day, a week before CACP services were about to commence, she packed up and went to live with family. This meant moving away from her familiar environment, GP and friends, further isolating her. She lived with her children for 6 months, becoming increasingly confused and dependent until a residential care place became available.

3. Dementia and Quality of Life

KinCare has studied the research evidence into factors which most influence a person's perception of their quality of life. While individuals may describe their quality of life variously - in terms of happiness and well being; life satisfaction; functional independence; a life of value, purpose, usefulness – we have identified six primary domains that are the prominent determinants:

KinCare Quality of Life Domains



As dementia progresses, individuals will experience decline across all these domains. Early diagnosis and intervention has the potential to lessen and/or delay the impact of the disease on the quality of life of both the individuals and their carers/family.

3.1. Health

People with dementia experience decreasing cognitive function, associated frailty and **health** conditions (such as diabetes, COPD, arthritis, visual impairment), which can affect all aspects of their quality of life,. While their health-care needs become more complex, their ability to manage medications and treatments declines.

Benefits of early diagnosis and intervention:

- The introduction of medication management aids and/or provision of medication monitoring and administration services has potential to improve physical and psychological health, reduce pain and avoid secondary complications from overdose, under-dosage or incorrect administration of medications.
- Provision of personal hygiene, carer education and professional dementia-monitoring services can reduce frequency of infections (eg UTI) and aid early identification, reducing associated exacerbation of symptoms such as confusion and irritation
- Forward planning for care, including potential advanced care directives and appointment of an enduring guardian

3.2. Social Connectedness

Social Connectedness typically declines, as individuals lose confidence in social situations, communication skills decline, relationships change, and their membership status shifts. Some may develop social dis-inhibition, others may lack social judgement in the early days.

Benefits of early diagnosis and intervention:

- Education of individuals, family members and friends about the true nature of the disease will assist all parties in understanding and managing changes in behaviours and relationships. This may prevent some of the social exclusion that occurs due to inexplicable changes in personality, or what socially inappropriate behaviours
- Increased community awareness would help to reduce stigma associated with diagnosis which contributes to social withdrawal and exclusion
- Individuals can link to social activities that help maintain and maximise their level of function through physical/mental activity, engagement with community, social connection and emotional satisfaction
- Family can be linked to support services such as self help groups, education programs, counselling and respite services. This will help to maintain their quality of life, while they continue to care for their loved one with dementia
- Individuals can join peer support groups
- With planning, individuals can continue to enjoy outings and activities post diagnosis. In contrast, without a diagnosis, they may start to avoid things they have previously enjoyed due to inexplicable negative experiences
- Allows an individual to communicate/document their interests, hobbies, social activities, career and significant life events which would assist carers and service providers to incorporate meaningful activities into care even in the later stages of the disease. This has many benefits: increasing engagement with family/friends/activities and reducing anxiety.

3.3. Independence

Independence suffers as individuals with dementia find they need assistance first with complex tasks (eg tax return, holiday planning, learning a new skill) and then with simpler tasks such as shopping, dressing or making a cup of tea. Carers and family may further undermine this in an effort to keep the person safe, and cover up their deficits. Ultimately, individuals may find they lose the ability to live independently in the accommodation of their choosing.

Benefits of early diagnosis and intervention:

- Strategies can be developed to support the individual to continue managing tasks independently, or with minimal assistance
- Security measures such as modified mobile phones and tracking devices may provide sufficient confidence to enable the person to continue independent outings
- Home modifications can be made to improve safety as their illness progresses eg remove shower hob to improve safety of showering, Hot water systems can be turned down to avoid scalding accidents
- Bill paying can be automated and monitored by a power of attorney
- In-home care services can be introduced to support the individual to remain living in their own home.

3.4. Sense of Achievement

An individual's **sense of achievement** may decline as they become less able to participate in work, hobbies and interests, and they start to experience failures in areas where they were previously competent.

Benefits of early diagnosis and intervention:

- Individuals and their carers can be encouraged to set achievable goals
- Modifying the expectations of the those around them will reduce negative communications
- Individuals can avoid decisions which would set them up for failure eg moving neighbourhood

3.5. Sense of Security

Sense of security may be eroded as the world makes less sense. Individuals may believe things that are lost have been stolen; if they go out, they don't know if they'll be able to find their way home; if they don't have family to take care of them, they don't know if their needs will be met as their condition progresses.

Benefits of early diagnosis and intervention:

- Provides an opportunity for individuals and their carers/family, to make informed choices for both the short and long term
- Individuals can plan ahead for their own health care and communicate their preferences to friends/family, with arrangements for Enduring Guardianship when applicable
- Strategies can be developed to manage lost items eg key kept at neighbours house;
- Personal monitoring systems and alarms can be installed for peace of mind eg smoke alarms, door sensors

3.6. Standard of Living

Standard of living may decline due to loss of earning power; inability to arrange purchase of important items or complete maintenance tasks; or failure to make advance provisions.

Benefits of early diagnosis and intervention:

- Individuals can arrange their financial affairs in advance to ensure the ability to pay for essential and desired goods and services security
- Arrangements can be made to secure their choice of accommodation
- Power of attorney arrangements can be made and wishes communicated
- In-home interventions can be initiated before signs such as excess clutter, poor maintenance or standards of cleanliness threaten standard and tenure of accommodation

4. Community Awareness and Communication Strategies for review

Community Awareness and Communication Strategies should be targeted to both the broader community and specific audiences including:

- Older Australians
- School Aged Australians
- Concerned family/friends
- Community Services Providers
- General Practitioners, and
- Other Health Professionals

We would recommend a variety of mediums be used with the objectives of conveying the following messages:

- While dementia is more likely to develop in older age, it is not a normal part of ageing (avoid stereotyping of older people and dementia)
- Dementia is an illness like cancer or diabetes. If diagnosed, it may be arrested or delayed.
- Individuals can maintain quality of life after dementia, with appropriate support and forward planning
- Services are available to assist individuals to remain living in their homes in the community
- Services are available to assist friends and family

4.1. Traditional Media trusted by older age group

- Real life examples such as the recent film “Iron Lady” about Margaret Thatcher go a long way toward raising awareness and empathy for people with dementia
- Recognise achievements of people with dementia
- Newspaper articles on incidence, treatment and management of dementia
- Talk back radio interviews with people with dementia
- Talk back radio interviews with carers of people with dementia
- Campaign encouraging healthy lifestyles as a preventative measure, crossing primary health care, community care, TV, radio as well as social media.

4.2. Community Service Providers

- Social media targeting individuals, families, carers particularly adult children and grandchildren of people with dementia using Facebook, YouTube, blogs and twitter to breakdown stigma, share real life stories that validate carers and families’ concerns, provide practical insights and support

4.3. Primary Health Care Organisations

- Education programs aimed at upskilling in-home care providers to facilitate family discussions and referrals to GPs for diagnosis

- Engage and support in-home and allied health services to assist individuals with advanced care planning

4.4. Primary Health Care organisations

- GP education through Medicare Locals and Divisions of General Practices.
- Implement measures to actively foster (and measure) engagement between Medicare Locals and in-home care services, in addition to their traditional focus on GP and allied health services
- Promotional material in GP waiting rooms eg DVDs, posters, slogans
- Work with Royal Australian College of General Practice to update guidelines for diagnosis and intervention with dementia
- Development of an internet web-site dedicated to promoting awareness of dementia and strategies for management

4.5. School Education Campaign

- Awareness education program in schools, involving people in the early stages of dementia and/or carers of people with dementia
- Incorporate education on the causes of dementia and importance of lifestyle choices
- Community Service and Residential Providers could invite primary schools to conduct concerts to entertain clients incorporating an element of interaction
- Consider incorporating films such as “Iron Lady” into high school curriculum, supported by factual material on prevention, intervention and services available.

4.6. Advanced Care Planning

- Introduce a campaign to encourage all adults aged 65 years or over to complete an advance care plan and communicate this with family and carers
- Further education of all health providers and systems to support communication of individual wishes.

5. Conclusion

KinCare would strongly support an awareness campaign and enhancement of systems to support uniform approach to earlier diagnosis and intervention. This would enable preventable conditions to be treated, reducing the incidence and/or impact of dementia conditions. It would also provide individuals and families with greater control over decisions affecting future lifestyle and well being. Any diagnosis must be accompanied by appropriate support and intervention. Government will need to leverage the combined power of local communities, community service providers and the primary health care sectors to deliver service options including education on the disease process and services available, counseling, peer support groups, advanced care planning, advanced care directives, family consultations, in-home support services, legal and financial planning services.

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