



- INQUIRY INTO DEMENTIA: EARLY DIAGNOSIS AND INTERVENTION

Central Coast Local Health District: Dementia Care Services

Examples of good practice and current barriers in the area of Early Diagnosis and Intervention as per 'Terms of Reference'

It is imperative to remember that there is no definitive test for diagnosing Alzheimer's disease or any of the other common causes of dementia. Findings from a variety of sources and tests must be pooled before a diagnosis can be made, and the process can be complex and time consuming.

Early diagnosis and intervention can improve quality of life and assist people with dementia to remain independent for as long as possible:

There is evidence that the currently available medications for Alzheimer's disease may be more beneficial if given early in the disease process. These medications can help to maintain daily function and quality of life as well as stabilise cognitive decline in some people; however, they do not help everyone and they are not a cure. Early diagnosis allows for prompt access to medications and medical attention.

Early diagnosis can also help in the management of other symptoms which often accompany the early stage of dementia, such as depression, anxiety or agitation.

Memory problems may interfere with a person remembering to take important medications for diabetes, heart disease or high blood pressure early diagnosis can alert carers and health professionals to review current medication practises and implement systems to address issues before problems arise due to medication omission. (Critical to chronic disease management.)

Memory clinics incorporate a range of specialists involved in the diagnosis of dementia. While they provide diagnostic services for all types of dementia, they often offer specialist services for younger-onset or rare forms of dementia.

Good Practice Examples:

- Dementia Care Services operates a Memory screening service to assist local General Practitioners (GP) with the early diagnosis of dementia. A health professional visits the person with memory problems completes a comprehensive assessment and screening tools, report is supplied to the GP.

- Dementia Care Services operates a successful Geriatric Memory Clinic with a dementia nurse specialist and Geriatrician in the Wyong Shire
- Dementia Care Services operates a successful joint Geriatric / Neurological Outpatient clinic targeting early diagnosis. Access to Geriatrician, Neurologist, Neuropsychological testing, counselling and advice from a dementia nurse specialist (Gosford Shire)
- Dementia Care Services provides 'Early Intervention Focus Talks' for clients with memory loss/dementia and their carers. These talks provide information on normal aging, memory changes; mind your mind, an introduction to resources and future planning.
 - Dementia Care Services operates 10 dementia carer support groups per month (attendance is approximately 100+ per month) Key components of the group include education, information, guidance and support.
 - Dementia Care Services provide education/ guest speaking to CALD communities on the Central Coast
 - Dementia Care Services has a Dementia specific home assessment team for people with a cognitive disorder likely to be diagnosed as a dementing illness (Dementia Care Services). This service provides a comprehensive assessment in the client's home. A copy of the report is sent with recommendations to the GP to assist in diagnosis and referral to specialists services. The Health professional is also able to support the client and carer and advice through the journey ahead.
 - Dementia Care Services in partnership with Alzheimer's Australia facilitates 3 Living with Memory Loss Programs throughout the year on the Central Coast. This program specifically targets early onset dementia.
 - Dementia Care Services coordinates and delivers 5 Memory Loss Public Education Forums across the Central Coast per year to raise awareness of dementia and how to access services should they be required.
 - Dementia Care Services in partnership with Alzheimer's Australia participates every September in Dementia Awareness week through a series of organised events across the Central Coast.
 - Dementia Care Services in partnership with Alzheimer's Australia provide a venue and referral service for individual counselling for people with dementia and their carers/families
 - Dementia Care Services access culturally sensitive services on a needs bases to assist with translation of screening procedures, objectives and outcomes

Barriers:

- Demand outweighs service provision due to funding shortfalls for key worker positions
- Current Memory Screening model is a time consuming process, funding limited to one key worker.
- Funding for Public Forum advertising.
- Funding for administrative support which would assist with booking and planning Public Education Forums and Carer Support Groups
- Funding for the outpatient Geriatric clinics.
- Accessing GP's is particularly difficult on the Central Coast. Most practices are full and have closed books. There is an acknowledged shortage of GP's on the coast. Doctors appear reluctant to label their patients with the diagnosis of dementia.
- Dementia Services for Aboriginal and Torres Strait islanders needs to be extended and have own funding.
- Client non participation or refusal to engage and service referral criteria

Early diagnosis and intervention can increase opportunities for continued social engagement and community participation for people with dementia:

Good Practice Examples:

- Dementia Care Services in partnership with Alzheimer's Australia facilitates 3 Living with Memory Loss Programs throughout the year on the Central Coast. This program specifically targets early onset dementia.
- Dementia Care Services provides a Dementia Resource Centre to enable people of the Central Coast to access information (books, DVD's) advice, support and guidance from staff members of the Dementia Care Services.
- Dementia Care Services provides 'Early Intervention Focus Talks' for clients with memory loss/dementia and their carers. These talks provide information on normal aging, memory changes; mind your mind, an introduction to resources and future planning.
- Early diagnosis of Younger Onset Dementia and their special needs allows Dementia Care Services referral to Younger Onset Services.
- Early diagnosis enables Dementia Care Services referral to community based services to preserve existing lifestyle. (Community Memory Lane Cafes)

Barriers:

- Social stigma often inhibits people seeking diagnosis and health interventions
- Social support and social services is underprovided in Younger Onset Dementia
- Lack of financial assistance for Younger Onset Dementia. Often working with younger families and mortgages.
- Availability of services and resources

Early diagnosis and intervention can help people with dementia and their carers to plan for their futures, including organising financial and legal affairs and preparing for longer-term or more intensive care requirements:

If people have an early diagnosis families/Carers are able to attend Dementia Carer Support groups which can provide information on legal and financial planning often with guest speakers, access to specialists' teams such as aged care assessment teams (ACATS).

Good Practice Examples:

- Dementia Care Services operates 10 dementia carer support groups per month (attendance is approximately 100+ per month)
- Clients of the Dementia Care Services Memory Screening Service, Outpatient clinics, and Community Home Assessments are provided with information and links to further resources about Wills, Enduring Power of Attorney, Enduring Guardianship and Advance Care Planning.
- Dementia Care Services provides 'Early Intervention Focus Talks' for clients with memory loss/dementia and their carers. These talks provide information on resources and future planning.
- Dementia Care Services in partnership with Alzheimer's Australia facilitates 3 Living with Memory Loss Programs throughout the year on the Central Coast. This program specifically targets early onset dementia. Here they receive information on legal and financial planning.

Barriers:

- Transport for carers to Carer Support Groups, Living with Memory Loss Programs.
- Group co-ordinator relief.
- Funding for advertising.
- Funding for Administrative support which would assist with booking and planning of speakers
- Funding for Community Dementia Nurses that would increase capacity for the Memory Screening Service and Home Assessment Service.

How best to deliver awareness and communication on dementia and dementia-related services into the community:

Early diagnosis can allow the individual to have an active role in decision making and planning for the future while families can educate themselves about the disease and learn effective ways of interacting with the person with dementia.

Good Practice Examples:

- Dementia Care Services coordinates and delivers 5 Memory Loss Public Education Forums across the Central Coast per year to raise awareness of dementia and how to access services should they be required.
- Dementia Care Services provides 'Early Intervention Focus Talks' for clients with memory loss/dementia and their carers. These talks provide information on resources and future planning.
- Dementia Care Services operates 10 dementia carer support groups per month (attendance is approximately 100+ per month) where information, guidance and emotional support is provided.
- Dementia Care Services in partnership with Alzheimer's Australia participates every September in Dementia Awareness week through a series of organised events across the Central Coast.
- Dementia Care Services Dementia Care Service provide education/ guest speaking to community organisations (eg: Parkinson Assoc, Probus, View Club)
- Dementia Care Services Dementia Care Service provide education/ guest speaking to CALD communities on the Central Coast
- Support ongoing education for all clinicians relating to dementia

Barriers:

- Fear, stigma and lack of understanding of dementia can prevent people from seeking advice and support.
- Availability of services and resources plus coordination across services.

Note: Further information regarding good practice and current barriers in the area of Early Dementia Diagnosis can be sourced in "The NSW Dementia services Framework 2010-2015"