Shared care pathways for people living with dementia in the community

Roles and Responsibilities

This document outlines the roles and responsibilities of different services and clinicians involved in the diagnosis and support of people living with dementia in the community. Please see the accompanying charts for visual representation of the pathways.

Glossary

The **General Practice Team** consists of General Practitioners (GP) and practice nurses or nurse practitioners.

Hospital staff include medical, nursing, allied health and other professionals involved in the care of a patient presenting to a public or private hospital.

Medical Specialists are geriatricians, psychogeriatricians and neurologists.

Memory clinics are multidisciplinary, specialist assessment services for dementia and cognitive decline. The multidisciplinary team may be employed within the Clinic or engaged via established referral networks

Dementia Specialists are health professionals (excluding medical practitioners) with specialist dementia expertise such as dementia clinical nurse consultants or outreach nurses or allied health from geriatric, community or older person mental health teams.

Allied Health professionals include occupational therapists, speech pathologists, physiotherapists, exercise physiologists, clinical psychologists or neuropsychologists. They may be working in private practice, for community health, or a community organisation.

Dementia Pathway

Part 1 – Assessment and Diagnosis

The General Practice Team (GPs and practice nurses) should:

- Suggest investigation of cognitive difficulties to patient and/or carer if cognitive difficulties are suspected.
    - Dementia trained GPs could diagnose dementia or refer to medical specialists or specialist services for diagnosis or confirmation.
- Perform the following explorations for dementia:
    - Speak to a family member or carer.
    - Review of the medical and psychological history (including medication, timeline of symptoms and assessing instrumental activities of daily living).
    - Assess psychological health and behaviour
    - Cognitive screening using tools such as MMSE or GPCOG.
    - Order and review basic blood, urine tests and relevant scans.

GP referrals to medical specialists:

- Where applicable, GPs should refer to the following medical specialists for diagnosis, or diagnostic confirmation and management advice:
    - **Geriatrician** for diagnosis, or diagnostic confirmation and management advice if the person has atypical symptoms or complex comorbidities.
    - **Neurologist** for diagnosis, or diagnostic confirmation and management advice if the person has neurological signs, particularly if under 65 years.
    - **Psychogeriatrician** for diagnosis, or diagnostic confirmation and management advice if the person has mental health or behavioural comorbidities or complications.
    - **Memory clinic** for diagnosis, or diagnostic confirmation and management advice for a person of any age with mild cognitive difficulties, complex or atypical symptom presentation, differential diagnostic difficulties.
    - **Dementia Specialist** for assistance with assessment, diagnosis and management when dementia is more advanced.

Hospital staff, Aged Care Assessment Teams (ACATs) or Regional Assessment Services (RAS) and Community aged care staff should:

- Refer to the General Practice Team for investigation if cognitive difficulties are suspected.

Medical specialists and memory clinics should:

- Provide consultation (verbal and/or written advice) to GPs on dementia diagnosis and management, dementia specific medication.

- Use the Australian Dementia Network (ADNeT) memory clinic guidelines when assessing for and diagnosing dementia.
- Provide a written management plan after diagnosis to the GP, person with dementia and carer.

Dementia Specialists should:

- *Help* GPs in diagnosis and management.
- Provide brief interventions (e.g. short term case management, therapy) for people with dementia in collaboration with General Practice Team.
- Provide ongoing case management and support for people with dementia with high psychosocial needs in collaboration with General Practice Team.
- Provide carer education and support.

Dementia Pathway

Part 2 – Medical and Psychosocial Support

Current service gap: *Ideally, one service should have responsibility for coordinating health and non-health services for people with dementia. Currently, there is no service with the responsibility or capability of coordinating health and non-health services for people living with dementia.*

ALL practitioners and services involved:

- **should actively collaborate in supporting the person with dementia by providing a copy of their care plan and/or treatment and outcomes to the GP and to the person with dementia and carer.**

The General Practice team should:

- Coordinate medical management after dementia diagnosis.
- Provide health-related management and support which aims to maintain health, function and minimise decline.
- Use a Chronic Disease GP Management Plan or Chronic Disease Team Based Management Plan for dementia.

- Discuss the following topics with the person with dementia and carer in the first six months after diagnosis and as required:
    - Dementia diagnosis (including dementia subtype) with opportunity to ask questions
    - Address misconceptions and stigma around dementia
    - Help with and referral for adjustment to diagnosis (anticipatory grief and loss)
    - Legal and financial planning
    - Personal mobility (including driving, alternative mobility and transport options)
    - Medications. Both those prescribed for Alzheimer's Disease and those that should be avoided
    - General health and well-being for both patient and carer including information about sources for support and information
    - Lifestyle and brain health including current behavioural and mood changes or symptoms
    - Continuing interests
    - Emotional supports
    - Communication difficulties including aphasia
    - Improving function and independence
    - Aged care or disability support

- When needed, make the following referrals:

- For information about dementia: refer to Dementia Australia and Forward with Dementia website.
- To help with adjustment to diagnosis (anticipatory grief and loss): refer for counselling through Dementia Australia or privately.
- For additional or complex medical management: refer to geriatrician, psychogeriatrician, or other medical specialists.
- To help with communication difficulties: refer to speech pathology.
- For help with daily function and independence: refer to occupational therapist.
- For help with exercise or mobility: refer to physiotherapy or exercise physiology.
- For aged care services: refer to My Aged Care.
- For services for people with younger onset dementia (i.e. onset before age 65 years): provide help to access the National Disability Insurance Scheme (NDIS).
- For assessment of safety to drive: refer to roads authority or occupational therapist driving assessor.
- For peer support: refer to Dementia Australia and Dementia Alliance International (online support groups).
- For carer services: refer to Carer Gateway or Dementia Australia.

- Take the following actions when <u>exploring and managing behaviour or mood changes</u>:
  - Consider differential diagnosis such as delirium.
  - Exclude physical factors including infections, medications, electrolyte disturbances, constipation, urinary retention or untreated pain, hearing and vision impairment and alcohol and drug use.
  - Identify psychosocial and environmental factors such as triggers, over or under-stimulation, boredom, routine or lack thereof, carer approach and carer stress, social isolation, loss of role or identity and other unmet needs.
  - Recommend patient-centred strategies focusing on improving psychosocial and environmental factors.
  - Only commence pharmacological management *after* non-pharmacological strategies have been considered *(in the management of mild to moderate behaviours).*
  - For mild to moderate behavioural symptoms: refer to Dementia Support Australia (DSA), or local dementia specialist team for assessment, carer education and support.
  - For severe, distressing behavioural symptoms or unresponsive to treatment: refer to Dementia Support Australia, Older Persons' Mental Health services or Geriatric Services.
  - If risk of suicide or self-harm, person has history of comorbid mental illness and severe or distressing symptoms: refer to Older Person's Mental Health.
  - For mild depression and anxiety, consider a Mental Health Management Plan and refer to a clinical psychologist for psychotherapy, or Dementia Support Australia for carer education and support, recommend patient-centred strategies focusing on improving psychosocial and environmental factors.
  - For moderate to severe anxiety or depression or unresponsive to interventions, refer to Older Persons' Mental Health services.

This pathway was developed by the Dementia Together Team:

- Prof Lee-Fay Low, University of Sydney
- Prof Nick Goodwin, University of Newcastle, Central Coast Research Institute
- A/Prof Lyn Phillipson, University of Wollongong
- Prof Henry Brodaty, University of New South Wales, Prince of Wales Hospital
- Assoc/Prof Kate Laver, Flinders University
- Assoc/Prof Tracy Comans, University of Queensland
- A/Prof Mark Yates, Deakin University, Ballarat Health Service
- Dr Stephanie Ward, University of New South Wales, Monash University, Prince of Wales Hospital
- Prof Dimity Pond, Newcastle University
- Dr Monica Cations, Flinders University
- Dr Annica Barcenilla-Wong, University of Sydney
- Robert Day, Dementia Policy Team, Commonwealth Department of Health
- Kate Swaffer, University of Wollongong
- Glenn Rees
- Dr Meredith Gresham, University of New South Wales
- Caroline Gibson, Ballarat Health Service, University of Newcastle
- Ian Corless, Wentwest, Western Sydney Primary Healthcare Network
- Dr Xiaoping Lin, Monash University
- A/Prof John Ward, University of Newcastle, Hunter New England Local Health District
- Dr Louisa Smith, Deakin University
- Bobby Redman
- Emma Craig, Dementia Australia