DEMENTIA ENABLEMENT

PATHWAYS FORWARD AFTER DIAGNOSIS

*Tools for People diagnosed, Families, Carers and Doctors*

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DEMENTIA IN AUSTRALIA

- 413,106 + living with dementia
- 55% female 45% male

By 2025 number expected is 536,164
- May be 1,100,890 by 2056

Around 244 people diagnosed daily
- 318 people daily by 2025, over 650 people by 2056

Estimated 25,938 younger onset dementia

By 2025 - 255,800 carers needed in the community
- 122,100 carers in cared accommodation sector.
By 2056 - 525,540 in community, 250,420 carers in residential aged care

Dementia the single greatest cause of disability in older Australians

third leading cause of disability burden overall
DEMENTIA AROUND THE WORLD

- Worldwide more than 46.8 million people with dementia, 131.5 million predicted by 2050

- Social media giving voice to people living with dementia.
  - sense of isolation, stigma, frustration, fear and often helplessness

- Often feeling abandoned by the medical profession
  - other diagnoses eg. cancer, heart disease or stroke result in medical and/or non-pharmacological therapies

- Dementia diagnosis met with a sense of futility
  - ‘You have dementia, I’m sorry. There is nothing we can do’.
  - failure to refer on to enabling support

Those diagnosed, as well as supportive partners in care, report feeling ‘written off’ and unsupported
TALES OF DESPAIR

Teresa – USA
• Get my affairs in order as life expectancy is 2-10 years
  • I was dumped in a deep, cold hole with no way out

Paul and Sue – England
• Nothing curable, fast degeneration
  • no support offered besides 6 monthly consultant check-ups

Steven – USA
• Diagnosed quickly, not offered help in finding support
  • Speech Pathologist (organised by work cover) helped with coping strategies

Cathy – Australia
• Told at diagnosis she would have to move into Residential Care immediately. 3 years later she has completed a post graduate diploma and still enjoys living alone
FEAR OF DEMENTIA

• Hard to come to terms with diagnosis
  • support is imperative.

• Dementia leads to disability
  • disability support includes early intervention & ongoing assistance

• Need to:
  • adjust to changes
  • develop coping strategies
  • maintain maximal independence
  • improve quality of life.

*Holistic assistance to reach personal potential cornerstone of good care*
HPs SKILLED BUT MAY LACK CONFIDENCE AND AWARENESS

- ‘How can we help them – they won’t remember what we do’
- ‘How can they have goals?’
- ‘If we open up the floodgates to PLWD, we’ll never be able to cope with our workload’.
DEMENTIA ENABLEMENT GUIDES

• Early feedback suggests GPs often encounter difficulties with referral pathways,

• In the private sector, lack of good dementia knowledge amongst health professionals is a factor.

• The DEG pathways document a concept map that suggests disciplines or directions for support
  • software being developed for GPs for immediate referrals to support

GPs can have conversations about support, rather than ‘I’m sorry you have dementia’
Dementia Enablement Guide

People diagnosed with dementia, their care partners, and family and friends can find it hard to come to terms with a dementia diagnosis. Dementia is a terminal illness for which support such as grief and loss counselling is imperative. Support includes both early intervention and ongoing assistance to adjust to changes, develop coping strategies, maintain maximal independence and improve quality of life. Assistance to maintain general, physical and mental health as well as chosen lifestyle and social / community involvement should be considered and a holistic care plan generated. Care plans which detail abilities, disabilities and goals should be reviewed regularly and referral to appropriate therapeutic interventions offered.

Holistic assistance which encourages a person to live to his or her personal potential is the cornerstone of good care. By adopting an enabling approach focused on preferred occupation and meaningful activity, independence and well-being, people diagnosed with dementia and their care partners have an opportunity to live to their post-diagnosis potential. Additionally, care partners may benefit from targeted education and access to peer support.

See over for role descriptions
Living with dementia

If you live with dementia, you might notice some changes in the way you live your life and your responses to what happens around you.

Symptoms of dementia vary – you might notice lots of changes or few.

Maybe you don’t need any help, maybe you will in the future.

We are all individuals and there is no right or wrong way to feel or adjust to changes.

If you would like some help adjusting, talk to your doctor/GP about all of the people who can help you.

Useful contacts

Aged Care Assessment Team (ACAT)
1800 200 422

Alzheimer’s Australia
1800 100 500

Carers Australia
1800 242 636

Commonwealth Respite and Carelink Centres (CRCCC)
1800 052 222

Financial Information Service
132 300

My Aged Care
1800 200422

Peer support

Dementia Alliance International (DAI)
www.dementiaallianceinternational.org/

Alzheimer’s Australia
1800 100 500

Ozcare (Qld)
1800 692 273
Dementia Enablement Guide – Person Living with Dementia

I would like my affairs in order e.g. Enduring Power of Attorney, Will and Advanced Health Directive:
- Social Worker, Solicitor, Public Trustee, Financial Advisor

I would like to talk to someone about what the diagnosis means:
- Alzheimer’s Australia, Dementia Alliance International (DAI), Dementia Advisor, Psychologist, Social Worker, Chaplain, Peer Support Group

What if I notice changes with my speech, conversation, voice or swallowing?
- Speech Pathologist

What if I feel unsteady on my feet, or I am worried about falling?
- Physiotherapist, Occupational Therapist, Exercise Physiologist

I want advice about nutritional needs:
- Accredited Dietitian

What if I need help with day to day activities?
- Occupational Therapist

Is there any support for my family and friends?
- Alzheimer’s Australia, Dementia Advisor, Dementia Alliance International (DAI), Aged Care Assessment Team (ACAT) Psychologist, Carers Australia, Commonwealth Respite and Carelink, My Aged Care

I want to better understand my medications:
- Pharmacist, Registered Nurse (or Doctor)

What if I notice changes in my bladder or bowel control?
- Continence Advisor

Will dementia affect my driving?
- Occupational Therapist (OT) - some OTs specialise in driving assessments
THE ROLLOUT

• The DEG is being promoted to GPs via:
  • clinic visits
  • GP liaison officer newsletters
  • conferences and presentations.

• Hope to:
  • educate GPs about equitable access to support after diagnosis of dementia
  • see people with dementia being offered choices

• Choice whether people want further support or not
  • importantly it’s their call, not anyone else’s.

*People may choose not to accept support, but being offered options is a critical step towards communicating respectful, person centred care*
CONSUMERS AT THE HELM OF THEIR OWN HEALTH CARE

• GPs need to:
  • understand abilities, disabilities & goals of PLWD
  • review care plans regularly
  • offer referral to appropriate therapeutic interventions wherever possible

• We want GPs to:
  • see the person, don’t stop at the diagnosis
  • treat the person holistically to facilitate the best possible quality of life
  • encourage PLWD to choose the level of enablement that they want, not have this decided by others

We MUST keep consumers at the helm of their own health care