

Introducing

**"Dementia
Enablement Guide:
A new post-diagnostic
pathway"**

**Denise Craig,
Senior Psychologist**



Presenting to DAI's Webinar: A Meeting of the Minds

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**DEMENTIA
ALLIANCE
INTERNATIONAL**

SEE THE PERSON

NOT THE DEMENTIA

Dementia Enablement Guide

A new post-diagnostic pathway

Denise Craig

**Senior Psychologist
ACAT & Memory Service, Cairns**

Today's webinar looks at

- Dementia support options
- Does life change after diagnosis?
- The roles health professionals play
- What dementia 'enablement' means
- Enablement in action – an example
- Life goes far beyond health professionals – it's whatever works!

My background

- Mum – we noticed changes from age 59
- Sometimes she knew & was desperate
 - She felt ‘foggy’ and tried to walk it away
 - Aware it was terminal, goal 50th Anniversary
 - We felt hopelessly inadequate
- Later find a book on terminal illness
- Refused ACAT help – kept working (BigW)
- LWML – good for Dad
- Mum died 6/12 prior to 50th Anniversary (we toast her with her favourite drink)

My impressions

- PWD are often left 'shocked' to do their best with little or no support.
- Sometimes offered medication, but usually not a lot of hope
- Not a lot of awareness of enablement & promoting independence
- Insight → despair/frustration
- ↑ perceptive of 'vibes'

- PWD generally aware that changes are not well understood and too much/too little is expected of them (fluctuations, taking over)
- Doctors & health professionals often negative about benefit of referral Where do people go for help? Why? What difference does help make?
- GP about YOD FTD: ‘No one can help him, he has dementia. What good can YOU do!’ He & his wife felt afraid for their future & no idea where to turn
- Families overwhelmed & uncertain (media hype)
- Kate asks: ‘If the diagnosis was not dementia, would there be more options discussed (that feel right to you)?’

- Some GPs believe that dementia support does not exist, so they don't even talk about the possible benefits of it.
- Health Professionals need to hear what is important to PWD, and then discuss support options.

Project background

- My roles – psychologist ACAT/Memory Service and SDCN. (I'm within 'the system' looking at faces of PLWD, & seeing the issues for Health Professionals too)
- 2012 – YOD Facebook page to help link people to peer support and flush out wisdom so I could do better
- Led to Kate and Christine: confronting conversations about **experiences** (confronting because there is a lot of dedication to dementia and it would nice to think we are helping! When HPs are criticised, that's me and my colleagues too).
- YOD page highlighted pattern of criticism towards HPs
 - Little help after diagnosis
 - Limited awareness of perspectives of PWD
 - Health Professionals address carers at expense of PWD
 - PWD and care partners left to work it out themselvesThese are the things that I, and my colleagues, try to do right. We need to do things differently or better!

Snapshot of Facebook feedback

Adelaide

- I made my family GP aware of my diagnosis but unfortunately he wasn't terribly 'up to date' with dementia, so I relied on my neurologist's guidance.

USA

- Hearing that I should get my affairs in order as life expectancy is 2-10 years felt as though I was dumped in a deep, cold hole with no way out.

Victoria

- There is no doubt that dementia is disabling, challenging and life changing, but there is much more to the story than that.

Somerset, England

- I was told that it was nothing curable and would degenerate at a quick pace. At no time was any support offered other than the 6 monthly appointments with a consultant.

USA

- I was diagnosed pretty quickly, but I wasn't offered any help in finding support for myself or my family. I started seeing a Speech Pathologist (organised by work cover) who helped me work out some strategies to cope.

Committed to action – Guide for GPs (and consumers)

Pathways Guide

Role of Health Professionals in support.

- **1. GP is VERY important**
- Key point - GPs need to be aware of your values, wishes & goals, and the potential benefit of referral

By discussing values, wishes & goals with you, we are communicating that we respect your choices and that there is life after diagnosis.

Care plans which detail abilities, disabilities and goals should be made with your GP and reviewed regularly. Referral to services which can help should be offered as needs or wishes change.

Pathways Guide

Role of Health Professionals in support.

- **2. Allied Health – the role we can play.**

I've heard health professionals say:

- How can we help them when they have dementia?
- PWD can't have goals. Can they?
- How can they understand treatments?
- How can they remember what we do?
- They're patients – not consumers. I like to think we are all consumers of health services – we have choices, and we're not always 'sick' and identifying as being 'a patient'.

Sometimes Health Professionals just don't realise what they can do to help. I'd like to change that!

'For some a small village, for you the whole world'. Colleen Cartwright

Pathways Guide

Putting together the guide: SDCN group.

- Multidisciplinary - Geriatrician, RNs, OTs, dietitian, speech path, GP, physio, consumer and psychologist. We did the work mostly over the phone and email.
- A second tier of advisors included a group PWD, care partners, clinicians and academics. Work on a consumer version nearing completion

Operation 'raise awareness' and trial phase:

- GPs are being visited with PHN support
- Educate GPs - equitable access to support post diagnosis
- It is critical that PWD are offered options
- Kiama, NSW, as a part of their DFC project

DTSC Fellowship providing valuable assistance

Dementia Enablement Guide

Statewide Dementia Clinical Network

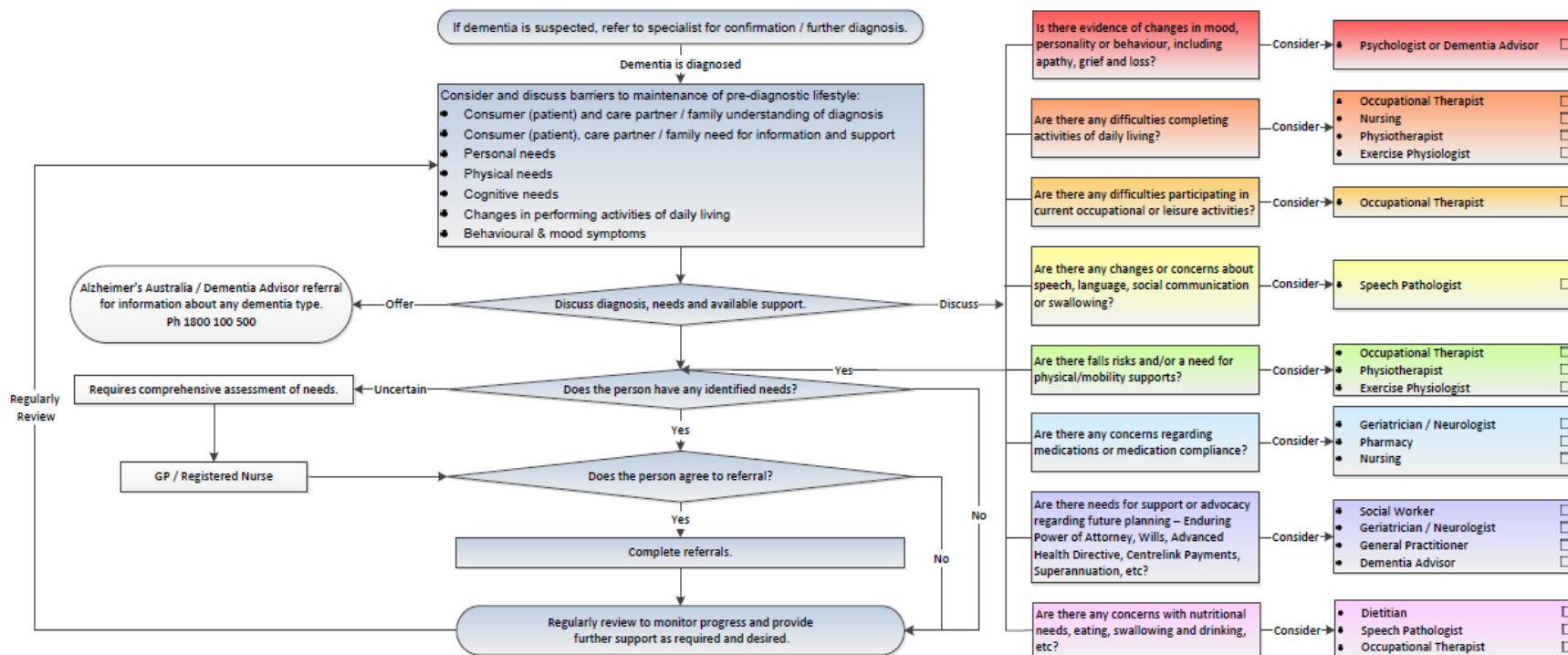
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People diagnosed with dementia, their care partners, and family and friends can find it hard to come to terms with a dementia diagnosis. Dementia is a terminal illness for which support such as grief and loss counselling is imperative. Support includes 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



Queensland

Meet the Health Professionals.

Accredited Exercise Physiologists specialise in exercise for people with chronic/ complex conditions or injuries. They can give advice about lifestyle changes.

Accredited Practicing Dietitians / Nutritionists focus on nutritional needs and provide expert nutritional, dietary advice and practical strategies to ensure the best food choices and health outcomes.

Continence Advisors assist people to cure or manage bladder and bowel problems. They can help if you have toileting problems such as needing to toilet urgently, or very often, or have leakage

Dementia Advisors offer counselling and dementia education. They can refer to other services and support groups.

Occupational Therapists (OTs) help you to remain independent and involved in everyday activities at home, work or leisure. OTs provide advice about: adapting tasks; specialised equipment; and modifying your environment to help you to be independent and safe at work, at home and in the community.

Pharmacists can advise about prescribed and over the counter medicines or natural remedies, their uses, side-effects and interactions. It is important to understand their impact on thinking and memory. Pharmacists help to find ways to make sure medicines are taken correctly.

Physiotherapists help people to move safely, manage pain, increase strength, improve balance and reduce the risk of falls. They also teach carers to assist you safely, and they can advise about mobility aids.

Psychologists can help you to improve your physical and mental health. They can help you to manage your emotional reactions to dementia through counselling, and they can help you to make personal decisions, manage pain, understand behaviour, mood and memory changes.

Registered Nurses work with clients, doctors and health professionals, providing care-coordination, education and assistance to help you to stay as well as possible

Social Workers provide support during times of stress and change e.g. grief, adjustment to illness, and personal difficulties. They provide counselling and can help with matters such as Enduring Power of Attorney and Advance Health Directives, community services, and Centrelink payments.

Specialists: Geriatrician, Neurologist, Neuropsychologist, Psychiatrist, Older Persons Mental Health Service:

Specialists assist in the dementia diagnosis and management of uncharacteristic behaviours and mood.

Speech Pathologists assess, monitor and provide advice on ways to retain and improve speech, language, communication and swallowing abilities. Assistance in this way may increase independence, function and engagement

Operation 'raise awareness'

- YOD page featured enablement approach with posts by PWD, Health Professionals & others during September.
- I hoped this would encourage people to be proactive and 'go after' support. I also hoped it would inform HPs using the page
- Reactions around the world showed people like the idea of the guide, and getting help

Let's see enablement in action...

Enablement in action

Alan

- 78, married 55 years. Referred to Memory Clinic
- Mixed Alzheimer's & Vascular dementia
- Supportive family
- Referred to me because of:
 - **Apathy**
 - **Carer stress**
 - **Dementia education.**



Psychologist

- Alan was spending his days sitting – resisting activity, not helping with housework, wife tired & frustrated
- Resisting social engagement but talkative when out
- Alan resisting certain foods (e.g. salads).
- Resisting medications – misleading wife. Wife checking mouth and finding tablets in toilet, sink, lounge chair.
- Relationship strain & lack of understanding of Alan's difficulties
- Wife wanted day respite – Alan resistant 'It's for sick old people' & he was once a respite bus driver
- Daughter telling Mum about nutrition & encouraging her to give Dad more gluten free, superfoods, coconut oil & green smoothies. This added pressure to wife.

Psychologist

- Dementia Education
- Screened for depression and anxiety. Alan seemed depressed.
- Supportive counselling - adjustment to diagnosis, and ongoing support
- Information about, and access to, support services
- Couples social support group
- Encouraged lifestyle changes – so he took up walking and swimming
- Discussed Advance Care plan options
- Drug study information (at their request)
- Continence advisor for ‘accidents’ when they went out
- Wife reported all aged care workers were ‘marvellous’, however Alan misleads HPs when being assessed. She complained their life had become ‘all about dementia’
- Wife adamant ‘*We’ve always eaten salad for lunch, he’s just being difficult*’
- I offered onward referral for more support

Allied Health Referrals

- **Drive Ax** – Alan withdrew voluntarily prior to ax
- **OT for advice** - Alan declined.
- **Pharmacy** review of meds re which tablets could be crushed. This was helpful.
- **Dietetics** – recommendations
 - Diet adequate & weight stable.
 - ‘Just not hungry’ at lunch
 - Minor adjustments suggested (↑ calcium)
 - Wife was asked to adjust some meals, monitor meds
 - Follow up review scheduled

Speech Pathologist

- (For difficulty swallowing).
- **Impression**
Alan had difficulty swallowing some things because of changes in his fine motor control & timing of the muscles involved in swallowing. Reduced awareness was a factor.
- His tongue had reduced ability & food residue remained in his mouth after a swallow.
- He had trouble controlling fluids in his mouth.
- Alan's throat muscles were weakened and he had genuine difficulty swallowing tablets.

Speech Pathologist's Recommendations

1. Continue to eat his usual diet & drink regular fluids. **Tucking his chin down when swallowing** may help.
2. Try **taking medications with cold water** instead of room temperature. Use thicker fluids (like custard) as needed to compensate for reduced tongue control.
3. **Avoid using a straw to drink.**
4. **Rinse his mouth with water after meals** to reduce food and bacteria that could end up in his airway.
5. **Maintain very good oral hygiene.** Eg. rinse mouth and brush teeth after every meal.
6. **Use the following strategies** when eating:
 - Reduce or avoid environmental distractions
 - Maintain a calm environment.
 - Gentle verbal prompts.
 - Offer favourite foods & enhance flavours with sauces and/or spices if needed.
 - Allow time for AC to eat to his capability.
7. Alan's **wife was asked to monitor** his swallowing behaviour & request re-assessment with the Speech Pathologist if she notices further avoidance around eating or tablet taking.
8. Monitor for signs of breathing in fluids & developing pneumonia & **consult GP immediately if concerned**

At follow-up

Alan's daughter had encouraged drinking 'room temperature drinks' & once **cold** water used, tablet taking was easier

Wife started seeing Carer's Qld for her own counselling
She felt 'Everything had become about dementia' and this got worse the more support he was offered because there were more app'ts to manage)

Speech pathology, dietitian & psychology monitoring until Alan and his wife are back on track again

So: Alan and his wife received support and guidance from specialists because he was **not 'just being difficult'** – his dementia symptoms were misunderstood. Without this support they would have remained frustrated by changes in his ability to swallow. GP may have said 'What can YOU do, he has dementia'.

More to life than health professionals!

Facebook user:

- Dementia, chronic pain, depression, anxiety, suicidal....
- Low income, socially isolated
- Saw a psychologist – 2 sessions – he did not enjoy this at all
- Bowen therapy provided the best support. Gentle touch, nurturing, caring.

And another...

- Mr W – spent his life savings flying to Europe, alone, on the basis of wild claims for treatment
- Lived in & attended daily sessions 1 month
- Returned philosophical about lack of cure. He DID achieve meaningful support through *group therapy, meditation, new friends, good diet, strengthened religiosity and peace*
- However: another gentleman, confused on landing in the USA, was returned immediately to Australia
- Good help is often from peers who are going through the same types of things – DAI chats!
- *Enablement is anything that assists/empowers you to live your life as best you can despite the challenges.*

Take home messages, I hope...

- Ask your GP for help. Talk about the things you struggle with and ask what help is available in your area. Keep notes about things you want to mention to the GP.
- Health Professionals can often help you to work out ways of managing changes. Ask for advice to be written down or photographed so you can review it later
- Be proactive – seek help, even if this challenges your health professionals
- Know that you are worth the effort!

Feedback

- Has this webinar been useful to you?
- Are you more likely to ask your GP to refer you to someone who could help?
- Is there anything else you would like to tell me?

Thank you so much.



Thank you for attending

- This webinar does not provide professionals with credits for learning, but we will provide a Certificate of Attendance as requested
- We are still an unfunded non for profit charity, and sincerely appreciate your support
- Donations are always appreciated
- Thank you for your interest



**DEMENTIA
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Support and Advocacy: Of, by and for people with dementia