Post-diagnostic support for people with dementia and their care partners

Henry Brodaty on behalf of the COGNISANCE team
The diagnosis

• Diagnosis occurs 2-3 years after symptoms start

• Multiple reasons
  • PLWD fearful, family fearful, stigma
  • GPs - lack awareness, skills or time
    • attitude of nihilism
    • ‘being kind’ to patient, fearful of effect on pt.

• Multiple guidelines for dementia diagnosis exist, eg
  • UK (NICE), USA (NIA), Canada, Australia, Germany
Diagnosing dementia

Nearly all guidelines cover:

- History – patient and informant
- Medical and psychiatric differential diagnosis
- Cognitive testing
- Physical examination, investigations
- Medications
- Legal – Enduring Power of Attorney, Guardianship, work, driving, financial management
Diagnosing dementia

*Not all guidelines discuss the process:*

- Whether to see patient & family member separately
- How to break the news, truth-telling
- Using the ‘D’ or ‘A’ word
- Whether to tell others about the diagnosis
- Discussing management and prognosis
- Giving written information to patient & family
- How to avoid…..
“Prescribed disengagement”

- Get your affairs in order and stop driving
- Family embarrassment
- Stigma → withdrawal

Kate Swaffer
Or ... post-diagnosis

• How to help PLWD and Care partners (CP) deal with the news
• How to live positively with dementia
• Alternative is disability model → rehabilitation (cf stroke)
• How to compensate for handicaps of dementia
  • Disability can be arrested for some time or even improved with appropriate intervention

Post-diagnostic support

• Manage medication, other chronic diseases, BP (General Practitioner)
• Support everyday living activities (keep on living their lives, doing ‘ordinary stuff’ … at home, work, driving etc. (Occupational Therapist)
• Supporting mobility and physical function (moving around their home and communities) (Physiotherapist, OT)
Post-diagnostic support

- Support cognition and communication, remain connected *(Psychologist, Speech therapist)*
- Support PLWD emotionally *(Peer/buddy, Psychologist, S/W)*
- Support PLWD cognitively *(Psychologist, Brain training)*
- Support primary care partner: ‘dementia is more than one person’s disease’ *(Social worker)*
Post-diagnostic support

- Peer support (buddy program, cf Breast Cancer)
- Virtual peer support (DAI)
- Dementia navigator, key worker
- Occupational Therapy (TAP, COPE¹)
  - Improved function and engagement for PLWD
- Day centres → Alzheimer Cafés; PALZ

Care partner supports: Alzheimer Associations
Reablement

Supporting everyday living activities through:
1. an occupational therapy program
2. an exercise program
3. a cognitive program

Supporting mobility and physical function through:
4. a falls prevention program
5. an exercise program

Supporting cognition and communication through:
6. an exercise program
7. a cognitive program
8. a communication program

O’Connor CM et al. *Supporting independence and function in people living with dementia* (2nd Ed) Sydney: HammondCare, 2019
Interventions: Person living with dementia

- Multi-domain
- Physical activity
- Cognitive training
- Cognitive Rehabilitation
- Cognitive stimulation
- Reminiscence

Cognitive behavioural interventions

Livingston G et al. 2014; McDermott O et al. 2018; Samus QM et al. 2018; Moniz-Cook E et al. 2011
Definitions

- **Reminiscence therapy** - discussion of past activities, events and experiences, aided by memory triggers

- **Cognitive stimulation** - engagement in range of activities & discussions aimed at general enhancement of cognitive and social function

- **Cognitive training** - guided practice on set of standard tasks designed to reflect particular cognitive functions

- **Cognitive rehabilitation** - individualised approach where personally relevant goals are identified & addressed

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1 Subramaniam and Woods (2012, p. 545); 2 Woods R et al, 2012
Summary: Cognitive & Behavioural Interventions

- **Reminiscence** – Small benefits in QoL, cognition, communication
- **Cog Stimulation** – S/T benefits cognition (> ChEI), QoL, socialisation, communication\(^1\text{-}^4\)
- **Cog Rehab** - ↓ CG burden, ↓ functional disability & ? delay in institutionalisation \(^6\text{-}^7\)
  - No cog benefit (xpt ?\(^\uparrow\) w. computer cog training) \(^8\text{-}^9\)

\(^1\)Woods B et al. *Cochrane Sys Rev* 2012; \(^2\)Orrell M et al. 2014; \(^3\)Mkenda S et al. 2016; \(^4\)Paddick SM et al. 2017; \(^5\)Clare L et al.; \(^6\)Bahar-Fuchs A 2013; \(^7\)Clare L 2017; \(^8\)Amieva H et al. 2016; \(^9\)Garcia-Casal et al. 2017
Summary: Cognitive & Behavioural Interventions

- **Physical training** – physical & cognitive benefits\(^1\)
- **Cog training** – benefits for healthy older & MCI, limited evidence for people with dementia
- **Multi-domain** – ? greater benefit \(^2\)

\(^1\)McDermott et al. 2018; \(^2\)Maffei L et al. *Nature Sci Rep.* 2017
Care partner support: training

• Sydney Carers Training Pgm\(^1-3\)
• Going to Stay at Home\(^4\)
  Residential respite care + 5-day Sydney Carers’ program
  • CGs’ unmet needs ↓ & BPSD ↓
  • ↓ nursing home admission

Brodaty & Gresham BMJ 1989; Brodaty et al Int Psychoger 1991; Brodaty et al IJGP 1997; Gresham M et al, Int Psychogeriatr 2018
Care partner supports: counselling 
(Manchester, NY, Sydney)

Control group

Counselling group

BDI II Score

5 sessions of counselling

Months

Mittelman MS, Brodaty H, Wallen AS, Burns A. Am J Geriatr Psychiatry 2008
Innovative environments

- Multi-generational living\(^3\); Dementia villages\(^4,5\)
- Systematic review (\(N = 19\) articles, 27 studies)\(^6,7\)
- Diverse outcomes precluded strong conclusions

\(^1\)de Boer B, Hamers JPH, Zwakhalen SMG, et al. 2017; \(^2\)de Boer B…Tan FES, Verbeek H 2017; \(^3\)Harris J 2016; \(^4\)Chrysikou E, Tziraki C, Buhalis D 2018; \(^5\)Haeusermann T 2018; \(^6,7\)Petrewsky 2016a, 2016b)
Post diagnostic support options

• Menu of support strategies for PWLD & for care partners
• Selection depends on person, context, availability, access, stage of dementia
• Variable evidence for their efficacy, because …
• Research expensive and difficult

Q: how to package this into program that best suits the person, the care partner and the context
• Co-designing Dementia Diagnosis And Post Diagnostic Care = COGNISANCE
• JPND awarded grant
• Australia, Canada, Poland, Netherlands, UK
• Co-design with PLWD, care partners, primary care practitioners, specialists in area
• Build on the work of PriDem\(^1\) Newcastle University

https://research.ncl.ac.uk/pridem/
How effective are models of post-diagnostic dementia care delivered by primary care? A systematic review

- PriDem review
  23 papers/ 10 studies/ 9 interventions
- … a primary care provider-case management partnership model currently offers the most promise

Frost R .. Robinson L.... Rait G, *British J General Practice*, In press

[https://research.ncl.ac.uk/pridem/](https://research.ncl.ac.uk/pridem/)
1. Surveys & focus groups in areas of each country to determine experience of people diagnosed with dementia in previous 12 months, CPs and PCPs (NL)

2. Co-design post-diagnostic support package (UK)

3. Implement marketing campaign for PCPs & older people (Aus)

4. 12 months later: repeat #1. Evaluate surveys (Canada)

5. Develop package that can be adapted worldwide especially in developing countries (Poland)

https://cheba.unsw.edu.au/consortia/cognisance

See Poster 6.3
Thank you

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