

# 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”



Kate Swaffer

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



# 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<sup>1</sup>



# 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, COPE<sup>1</sup>)
  - Improved function and engagement for PLWD
- Day centres → Alzheimer Cafés; PALZ



<sup>1</sup> Gitlin LN et al, (2010). A biobehavioral home-based intervention and the well-being of patients with dementia and their caregivers: The COPE randomized trial. *JAMA* 304:983-91

# Care partner supports: Alzheimer Associations



## Stop dementie

1 op de 5 mensen krijgt dementie. Daar moeten we iets aan doen. En daar kunnen we iets aan doen. Met meer onderzoek komen we dichtbij een toekomst zonder dementie voor onze kinderen en kleinkinderen. Helpt u mee?

[Doneer nu](#)



## TV-show 'Herinneringen voor het leven'

Op 2 oktober zond AVROTROS op NPO 1 ons avondvullende live tv-programma *Herinneringen voor het leven* uit. Toine van Peperstraten en Roos van der Wal gingen in gesprek met mensen met dementie en hun naasten. Over de impact van het leven en de impact van deze ingrijpende hersenziekte, die 1 op de 5 mensen in Nederland treft.

[Over de TV-show](#)

[Kijk online terug](#)



# Alzheimer's Society

Leading the  
fight against  
dementia

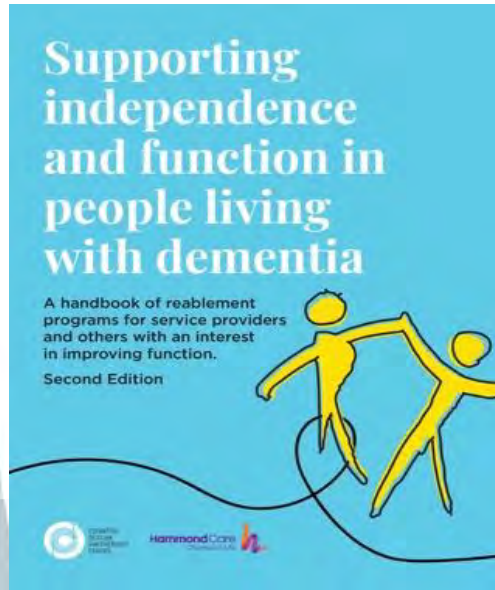


# alzheimer's association





# Reablement



Consultation process  
betw. project team and  
PWD, family carers) →  
selection of studies for  
8 reablement  
programs that met 3  
“essential areas of  
support” as described  
by consumers

**Supporting everyday living activities through:**

1. an occupational therapy program
2. an exercise program
3. a cognitive program

**Supporting mobility and physical function through:**

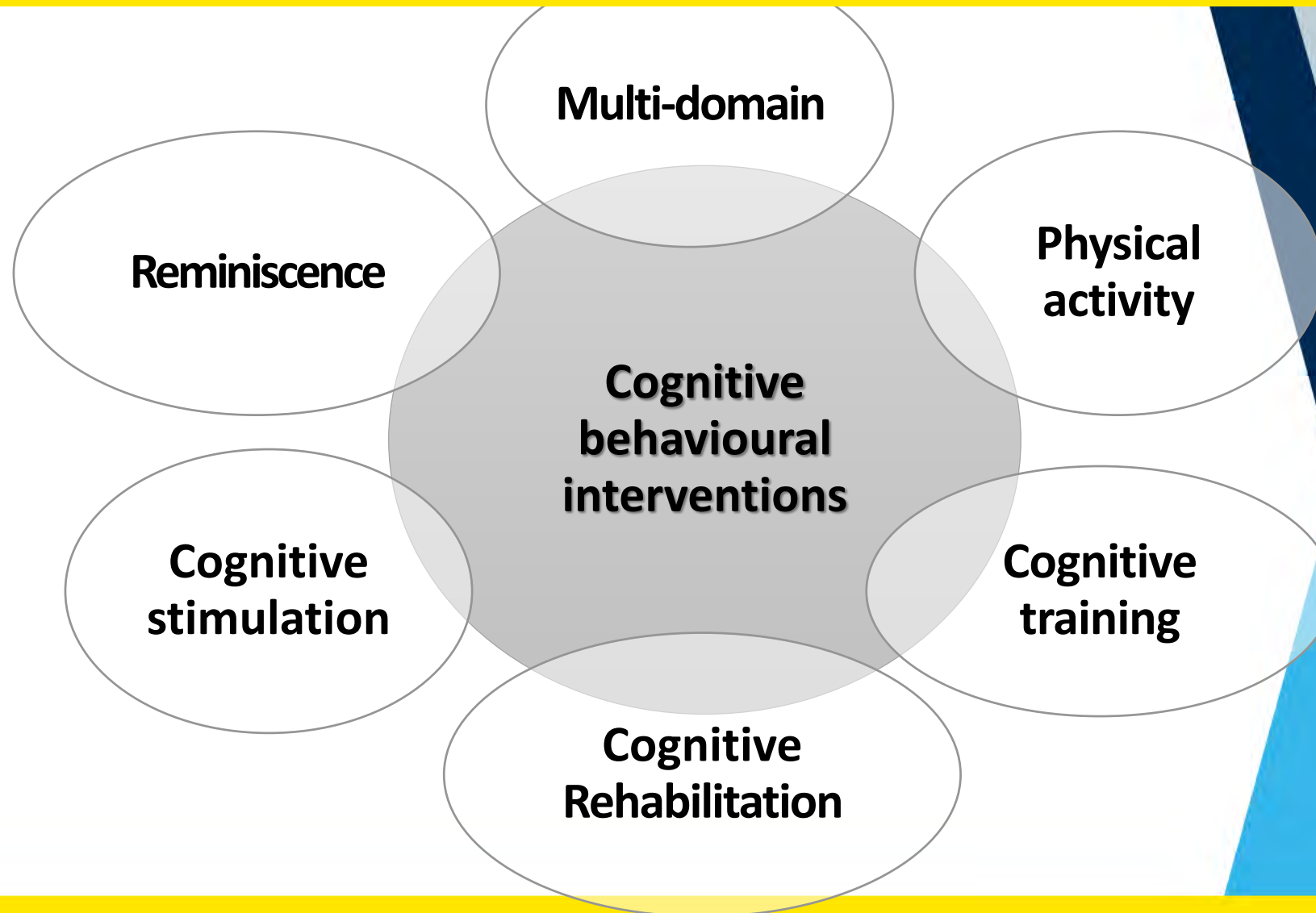
4. a falls prevention program
5. an exercise program

**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



# Definitions

- ***Reminiscence therapy*** - discussion of past activities, events and experiences, aided by .. memory triggers<sup>1</sup>
- ***Cognitive stimulation*** - engagement in range of activities & discussions aimed at general enhancement of cognitive and social function<sup>2</sup>
- ***Cognitive training*** - guided practice on set of standard tasks designed to reflect particular cognitive functions<sup>2</sup>
- ***Cognitive rehabilitation*** - individualised approach where personally relevant goals are identified & addressed<sup>2</sup>



# Summary: Cognitive & Behavioural Interventions

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

<sup>1</sup>Woods B et al. *Cochrane Sys Rev* 2012; <sup>2</sup>Orrell M et al. 2014; <sup>3</sup>Mkenda S et al. 2016; <sup>4</sup>Paddick SM et al. 2017; <sup>5</sup>Clare L et al.; <sup>6</sup>Bahar-Fuchs A 2013; <sup>7</sup>Clare L 2017; <sup>8</sup>Amieva H et al. 2016; <sup>9</sup>Garcia-Casal et al. 2017

# Summary: Cognitive & Behavioural Interventions

- Physical training – physical & cognitive benefits<sup>1</sup>
- Cog training – benefits for healthy older & MCI, limited evidence for people with dementia
- Multi-domain – ? greater benefit <sup>2</sup>



Photos: "Boxing Grannies" FP / Gulshan Khan. South Africa; G Coronas aged 99 / Australian Dolphins Swim Team; Virtual reality cognitive therapy / France; Friends, Muslim Aged Care Australia

<sup>1</sup>McDermott et al. 2018; <sup>2</sup>Maffei L et al. *Nature Sci Rep.* 2017

# Care partner support: training

- Sydney Carers Training Pgm<sup>1-3</sup>
- **Going to Stay at Home**<sup>4</sup>  
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

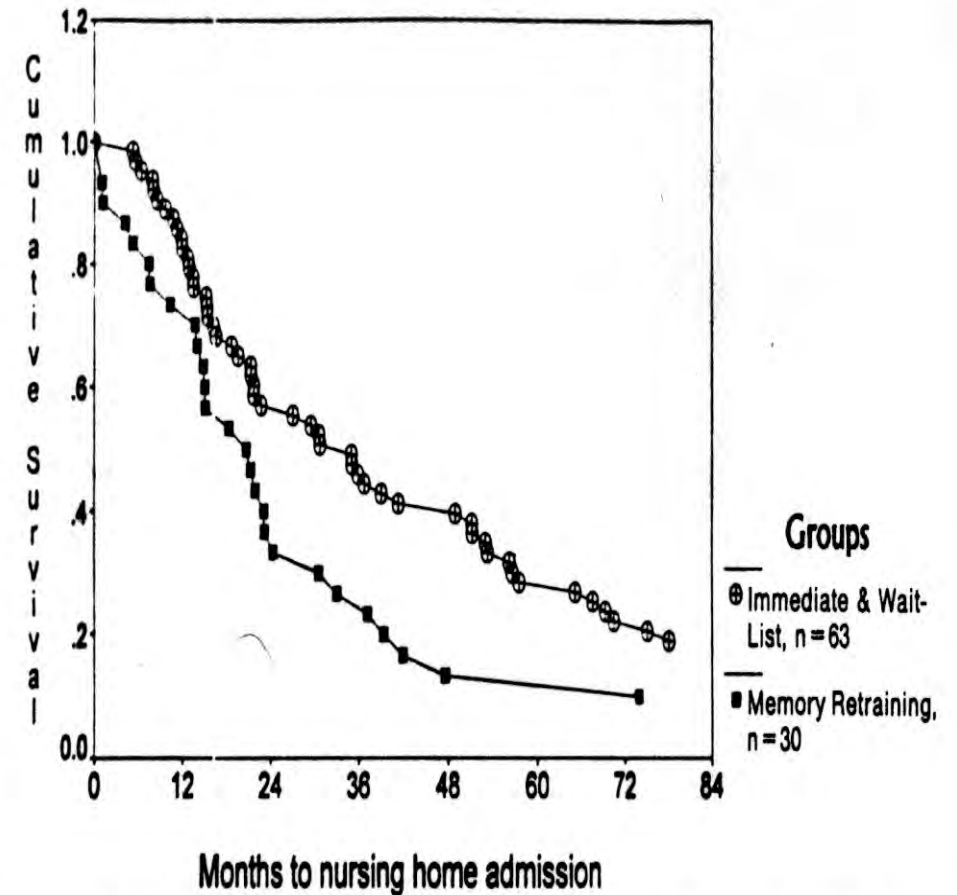
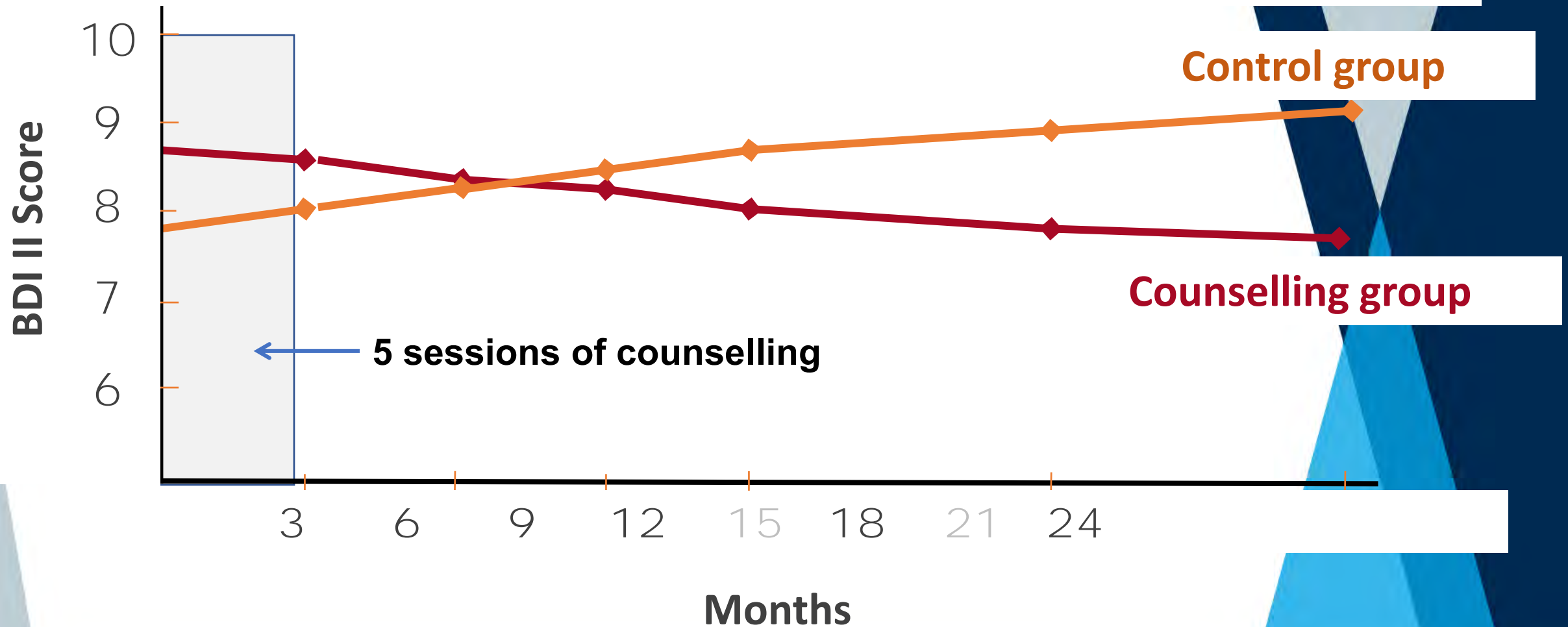


Figure 2. Kaplan-Meier survival functions for nursing home admission comparing the combined training groups with the memory retraining group

# Care partner supports: counselling (Manchester, NY, Sydney)





# Innovative environments



De Hogewyk village



Eden Alternative



Green Care Farms<sup>1,2</sup>

- **Multi-generational living<sup>3</sup> ; Dementia villages<sup>4,5</sup>**
- **Systematic review ( $N = 19$  articles, 27 studies)<sup>6,7</sup>**
- **Diverse outcomes precluded strong conclusions**

<sup>1</sup>de Boer B, Hamers JPH, Zwakhalen SMG, et al. 2017; <sup>2</sup>de Boer B...Tan FES, Verbeek H 2017; <sup>3</sup>Harris J 2016; <sup>4</sup>Chrysikou E, Tziraki C, Buhalis D 2018; <sup>5</sup>Haeusermann T 2018; <sup>6,7</sup>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<sup>1</sup> Newcastle University**

**<https://research.ncl.ac.uk/pridem/>**

# How effective are models of post-diagnostic dementia care delivered by primary care? A systematic review



- World Alzheimer Report 2016 proposed: task-shifted model of post-diagnostic dementia care, moving towards primary and community-based care
- 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

- 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

- **Henry Brodaty (UNSW), Frans Verhey (Maastricht Uni) Greta Rait (UCL), Isabelle Vedel (McGill Uni), Joanna Rymaszewska (Wroclaw Medical Uni), Lee-Fay Low (Uni of Sydney), Lyn Phillipson (Uni of Wollongong), Louise Robinson (Uni of Newcastle)**
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