Dementia as a Cognitive disAbility

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brainXchange

DEMENTIA ALLIANCE INTERNATIONAL

The global voice of dementia

Root causes of stigma

Dementia
50 million
Approximately 50 million people worldwide have dementia.
One new diagnosis every 3 seconds.

Dementia cost
$818 billion
The majority of care is provided by family carers.

Mortality
7th
Dementia is now the 7th leading cause of death.

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World Health Organization, 2018 - http://www.who.int/mental_health/neurology/dementia/en/
Alzheimer's Disease International, World Alzheimer Report 2015 https://www.alz.co.uk/research/world-report-2015

Advocating for rehabilitation

REHABILITATION 2030 a call for action

- Diagnosed with younger onset dementia in 2008, aged 49
- Advocating for rehabilitation for dementia since 2009
- Attended the WHO mhGAP Forum in 2016
- Dementia comes under Mental Health at the WHO: intellectual disabilities, psychosocial disabilities and mental illness
- Advocated for a fourth category for dementia – cognitive disabilities
- Attended the WHO Rehabilitation: 2030 Forum in 2017

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Support and Advocacy, of, by and for people with dementia

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Current post diagnostic pathway

- Difficult diagnosis to make and receive
- Prescribed Disengagement®
- Lack of ‘common sense’
- Ignoring the evidence for rehabilitation and dementia
- Post diagnostic pathway still based on the medical model of care
- Based on deficits, not remaining abilities
- Still stuck in the 70’s, and based on ‘late’ stage dementia

Current Clinical Guidelines

- Inadequate as they do not include rehabilitation
- Still Prescribing Disengagement® (from pre-diagnosis life)
- Prescribing ‘non pharmacological interventions’, rather than proactive disability support to continue living well
- Referrals to community services, day programs, respite centres still too focused on a deficits based medical model of care
- No proactive disability assessment & support, except ADL’s

World Health Organisation

"Dementia is one of the major causes of disability and dependency among older persons worldwide."

World Health Organisation, (2017) *Dementia: Key Facts*, http://www.who.int/news-room/fact-sheets/detail/dementia

The U.N. Convention

The **1948** United Nations Convention is meant to protect every single member of civil society in the world… Including people diagnosed with any type of a dementia, and who have dis**Abilitie**s caused by the symptoms of their **dementia.**

67 years later…

The Organisation for Economic Co-operation and Development (OECD) report ***Addressing Dementia: The OECD Response*** concluded (2015):

"Dementia receives the worst care in the developed world."

Rehabilitation

This OECD report also confirmed why it was necessary to demand a human rights based approach to dementia at the WHO in 2015, which includes **equal access to the CRPD** as all others, including **acquired brain injury style rehabilitation for our cognitive disabilities**.

The WHO First Ministerial Conference on Dementia

- DAI has always advocated for human rights
- Other organisations and individuals agreed, but only ever ‘in principle’; no action followed
- Keynote speaker at the WHO First Ministerial Conference on dementia, March 2015

My three demands:

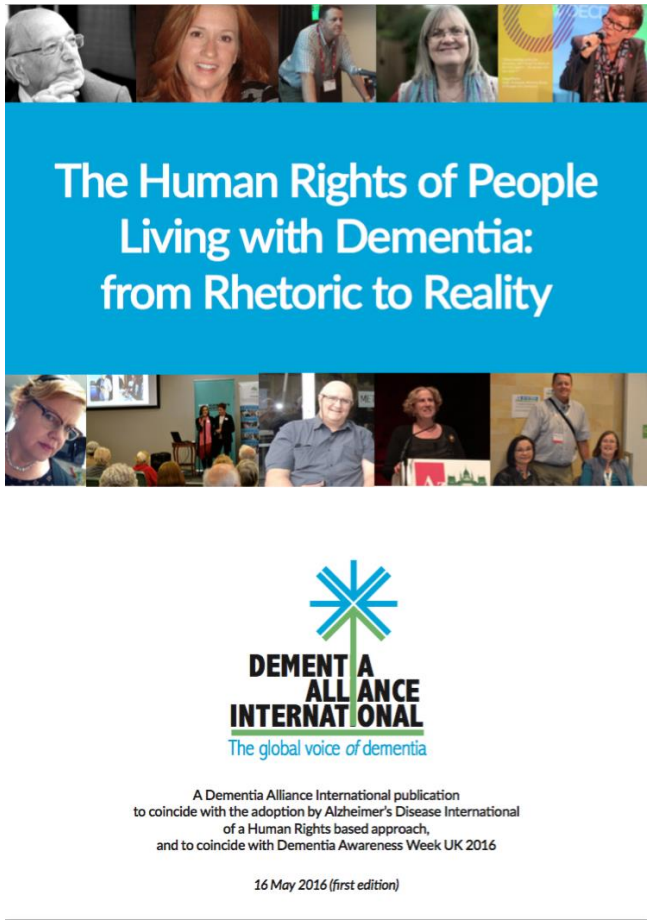
1. We have human right to a more ethical pathway of care
2. Being treated with the same rights as all others, under the Disability Discrimination Acts and UN Convention on the Rights of Persons with Disabilities
3. That research does not only focus on a cure, but on our pre and post-diagnostic care, and on pre and post vention including rehabilitation.

The need for Human Rights

"It is widely recognized that people living with dementia are frequently denied their human rights both in the community and in care homes. In many countries people living with dementia are often physically and chemically restrained, even when regulations are in place to uphold their rights. Furthermore, people living with dementia can also be victims of abuse…

This reflects the ethical challenges inherent in the support and protection of people living with dementia, and legislation alone will not be sufficient to ensure the protection of their rights." (WHO 2015)

From Rhetoric to Reality



DAI launched this landmark publication, as a direct result of our advocacy, and demand for a human rights based approach including access to the CRPD, now adopted by ADI and in the WHO Global Dementia Action Plan.

What matters to us now is that people living with dementia should be empowered to use their undisputed right of access to this and to other relevant UN Human Rights Conventions, including the CRPD and a future Convention on the Rights of Older Persons.

REHABILITATION 2030 (WHO 2017)

Article 26 of the Convention on the Rights of Persons with Disabilities (CRPD): **Habilitation and Rehabilitation**

The goal of rehabilitation is not to cure a person, nor necessarily to return a person with injuries or a condition causing chronic disabilities to ‘full’ functional capacity. It is to support independence and quality of life, support to live, and to promote well being.

The WHO Global Disability Action Plan 2014-2021

- This plan is fully based on CRPD Principles and Articles
- It has good indicators for assessing progress
- Therefore CRPD and Community Based Rehabilitation (CBR) must be reflected in Regional and National Dementia Strategies and Plans, and be included in
- Post diagnostic pathway for people with dementia

Community Based Rehabilitation (CBR)

The aim of **community-based rehabilitation** is to help people with disabilities, by establishing **community-based** programs for social integration, equalization of opportunities, and **physical therapy rehabilitation** programs for people with any type of disability.

Dementia Alliance International

- DAI began with eight people with dementia from 3 countries on January 1, 2014, now with members in 48 countries
- DAI is a registered charity, and is **the global voice of dementia**
- We empower others to live more positively with dementia, thereby improving the quality of life of people with dementia
- DAI provides weekly peer to peer support groups and other online supports, services and education
- We advocate for rehabilitation disability support

People with dementia want:

- A Timely diagnosis
- Disability assessment and support, including referral to rehabilitation, speech pathology, neuroplasticity approaches, OT, positive approach to dementia
- Therefore, clinical guidelines and services that support living with, not only dying from dementia, & INCLUDE REHABILITATION
- Recommending lifestyle changes (as we would with e.g. heart disease)
- Loss and grief counseling and peer to peer support
- Palliative care plans, at the time of diagnosis

Finally, for the last 20+ years…

- Advocates have been asking for full and equal inclusion (Article 19)
- Proactive disability support based on maintaining independence, to remain employed if working, or volunteer or remain engaged with our usual pre diagnosis activities
- Respectful language, and dignified person-centred care
- No discrimination or stigma
- **For the last 10 years, we have also been asking for Rehabilitation** (physical and cognitive) and access to the CRPD

Thank you

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https://www.linkedin.com/in/dementia-alliance-international
https://www.facebook.com/DementiaAllianceInternational/

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Stuck in the 'too hard' basket: Health professional perspectives on the delivery of multidisciplinary rehabilitation to people with dementia

Dr Monica Cations

Department of Rehabilitation, Aged and Extended Care

Flinders University

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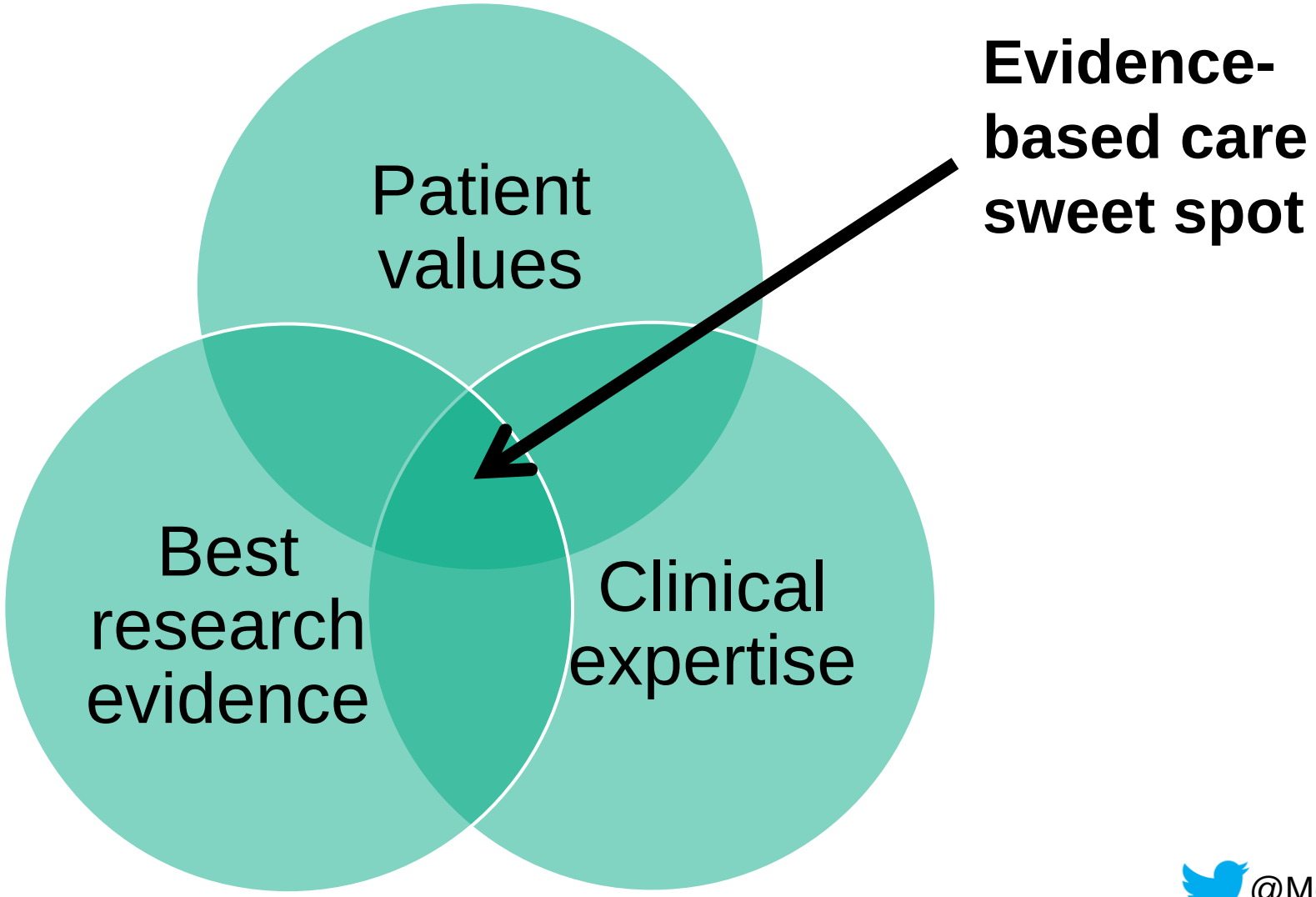
Evidence-based care



Dementia care

- Dementia is a complex condition, experience varies
- Needs change over time
- Needs can (and often do) exceed support available
- Traditional models: deficit-focussed, task-oriented
- Now: focus on *re-ablement*, promoting independence, meaningful engagement, and person-centred care

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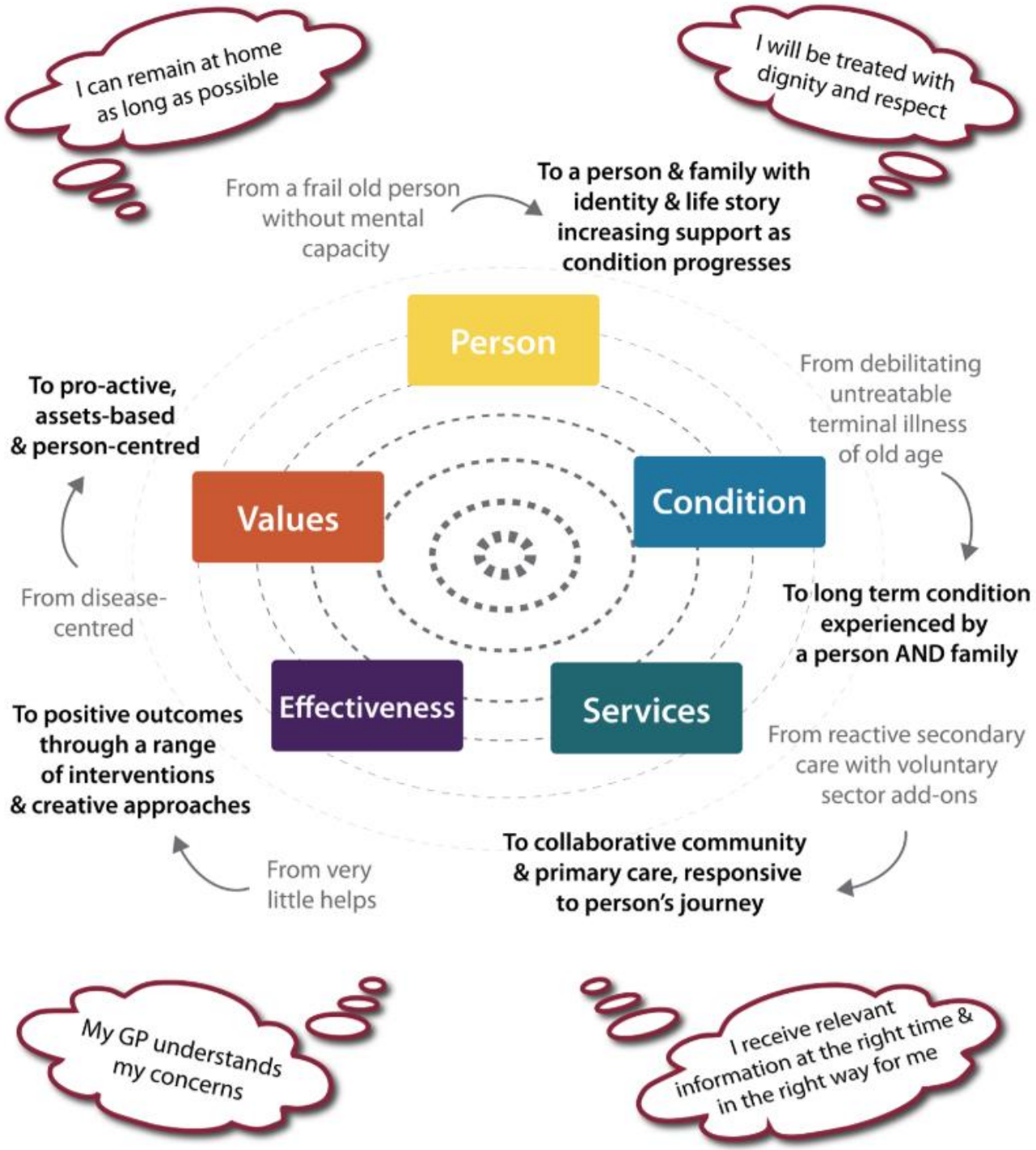
- Dementi es
- Needs ch
- Needs ca le
- Tradition
- Now: foc ence, meaningful engagem



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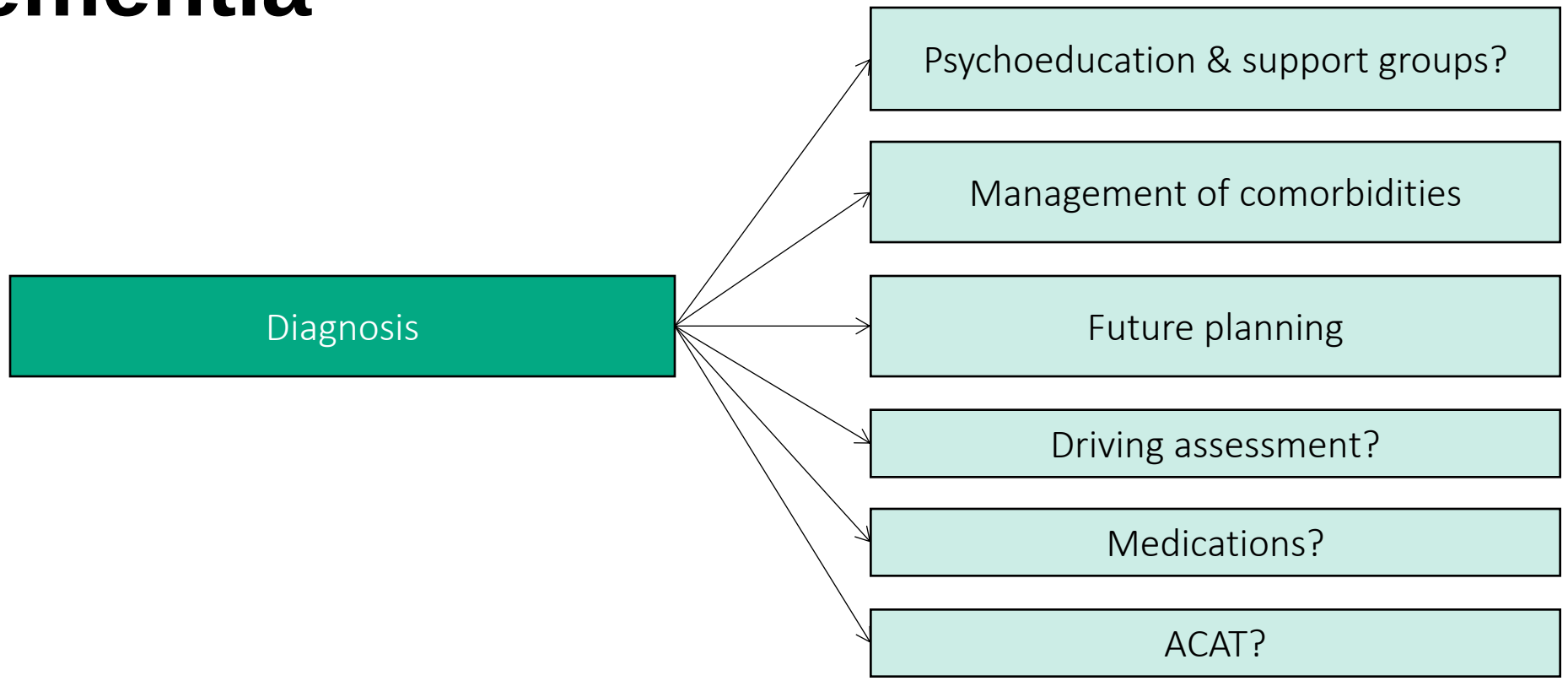
Current post-diagnosis pathways for dementia



"Prescribed disengagement" (Swaffer, 2015)

What does evidence-based dementia care look like?

- What do people with dementia want?
  - Individualised (i.e. person-centred)
  - Tailored and timely
  - Maximises abilities; compensates for difficulties
  - “Reinvesting in life” – Kate Swaffer

Non-pharmacological treatments

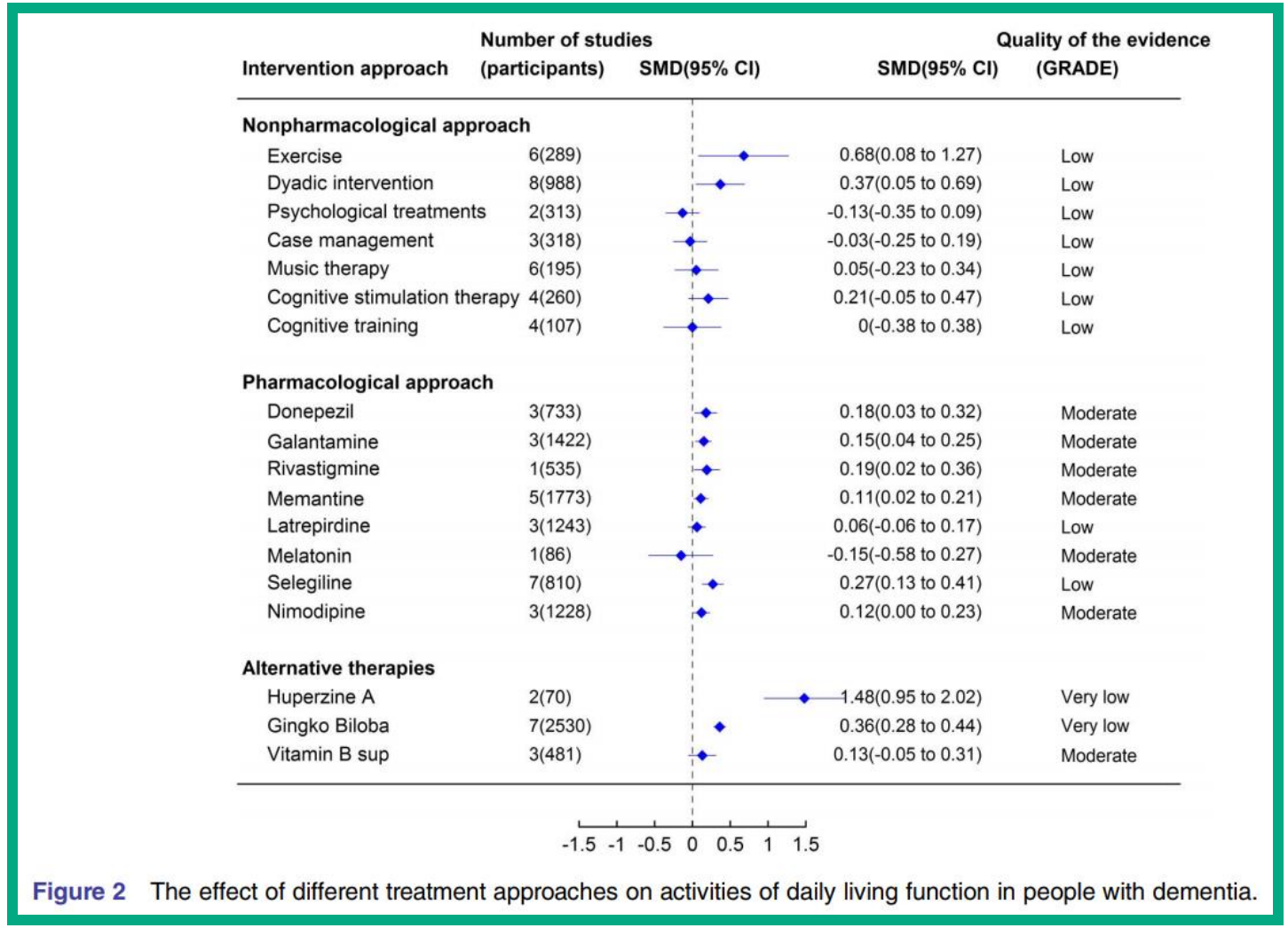


Figure 2 The effect of different treatment approaches on activities of daily living function in people with dementia.

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Cognitive-oriented treatments

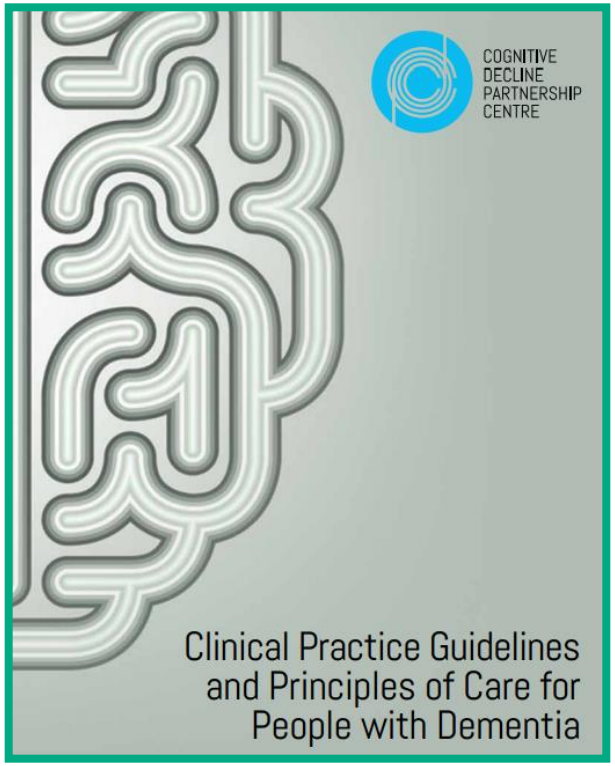
Table 1. Selected characteristics of cognitive training, stimulation, and rehabilitation

	Cognitive training	Cognitive rehabilitation	Cognitive stimulation
Target	Impairment	Participation restriction	Participation restriction
Context	Structured tasks and environments	In the person's natural environment	Usually in a clinic/residential care, or daycare setting
Focus of intervention	Specific cognitive abilities and processes. Psychoeducation and strategy training sometimes included	Groups of cognitive abilities and processes required to perform individually-relevant everyday tasks. Behaviour, environment and everyday activity. Psychoeducation and strategy training sometimes included	Orientation, Global cognitive status
Format	Individualised or group	Individualised	Typically group
Proposed mechanism of action	Mainly restorative; mechanisms related to neuroplasticity	A combination of restorative and compensatory approaches; reduction of 'excess disability'	Improved orientation, general activation
Goals	Improved or maintained ability in specific cognitive domains	Performance and functioning in relation to collaboratively set behavioural or functional goals	Improve overall orientation and engagement in pleasant abilities

Guidelines for clinical practice

Clinical Practice Guidelines and Principles of Care for People with Dementia in Australia

"Health and aged care staff should aim to promote and maintain functional and social independence of people with dementia in community and residential care settings. Interventions should address activities of daily living that maximise independence, function and engagement." (Laver et al., 2016)



Guidelines for clinical practice

Canada CPG Infobase

"Consider referral to specialty services to address specific concerns that might arise in the care of patients with dementia ."

"Strive to maintain an optimal level of functioning with use of non-pharmacological (e.g., memory aids) and pharmacological interventions"

"Enlist support from family, friends and community resources (e.g., home care, day programs, respite) to maximize functioning and ease caregive

Everyone is catching on!

“The future of psychosocial treatment for dementia will be combination (that is, physical + cognitive), goal-directed, and continuous”

– Professor Henry Brodaty, July 2018

Eyes on rehabilitation

"Rehabilitation is a set of measures that assist individuals, who experience or are likely to experience disability, to achieve and maintain optimum functioning in interaction with their environments. Rehabilitation should be a holistic approach to management for ***all chronic diseases."***
– World Health Organization 'Rehabilitation 2030' Campaign (2017)

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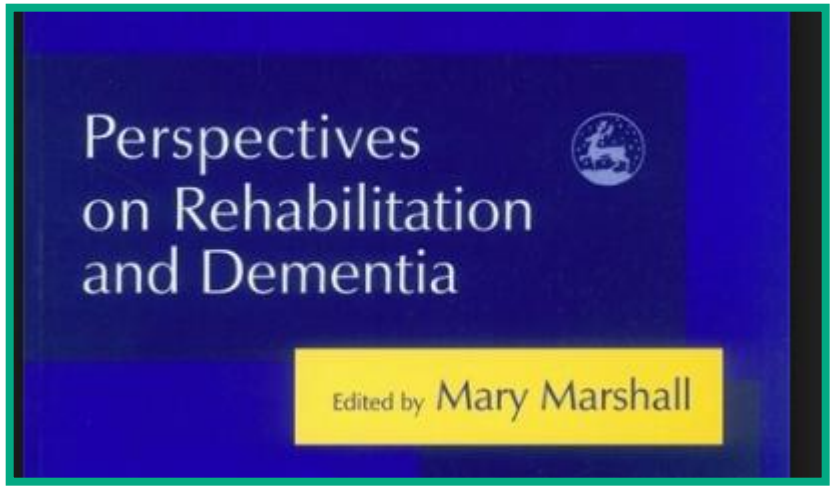
Eyes on rehabilitation



Eyes on rehabilitation

Perspectives on Rehabilitation

Editorial

Dementia and Prescribed Disengagement™

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Dementia
2015, Vol. 14(1) 3–6

DOI: 10.1177/1471301214548136
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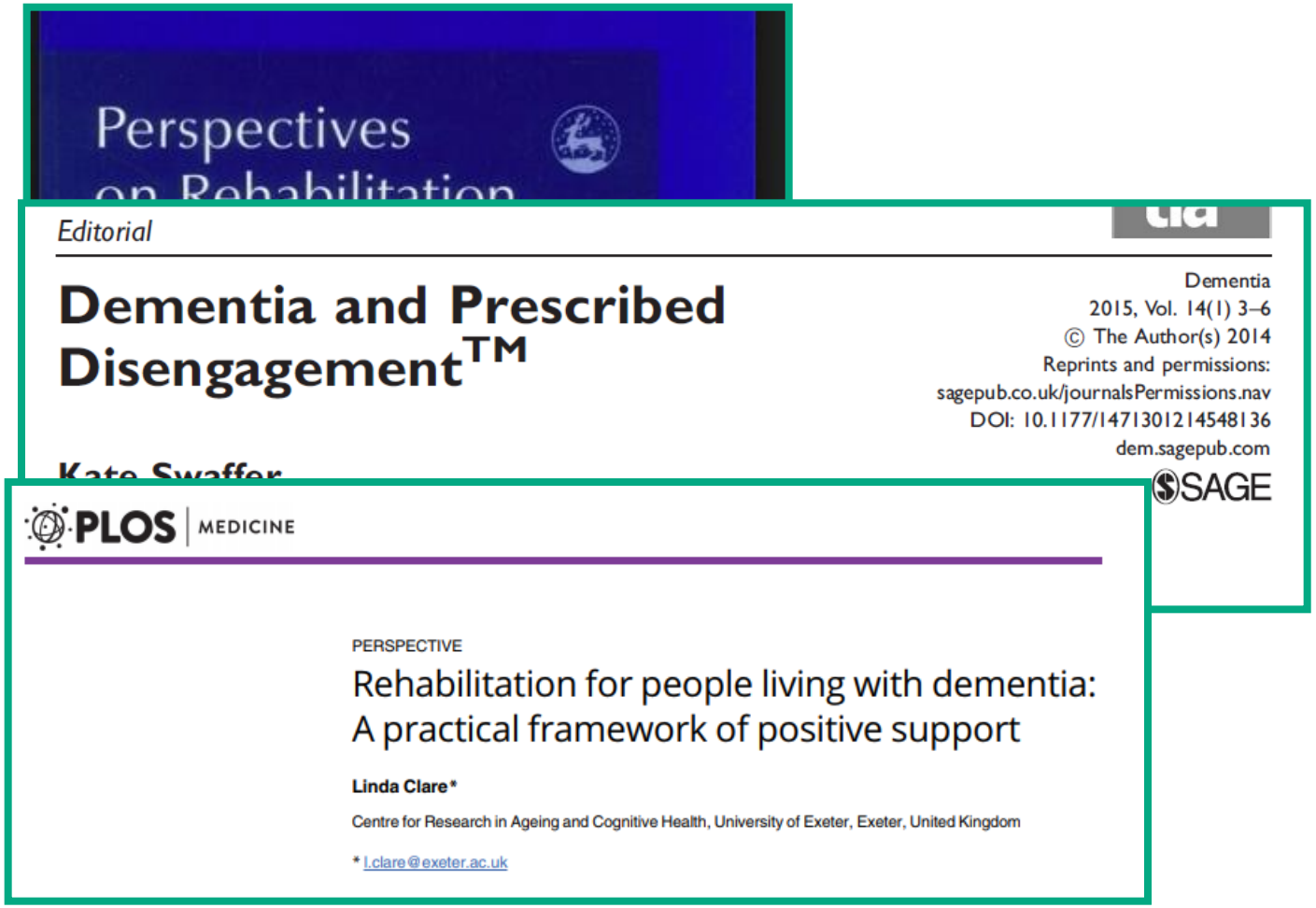
Eyes on rehabilitation



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But

- No structured rehabilitation programs available for people with dementia
- People with dementia are sometimes (often?) excluded from rehab for acute conditions

The Rehab-D Study

1. What do people with dementia and their supporters want from a rehab program?

2. How do the broader population of people with dementia feel about it?

3. How do health professionals view the value and feasibility of rehabilitation for people with dementia?

The Rehab-D Study

1. What do people with dementia and their supporters want from a rehab program?

2. How do the broader population of people with dementia feel about it?

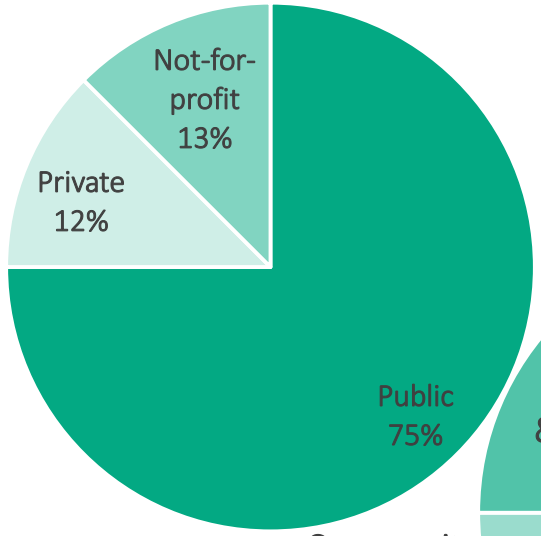
3. **How do health professionals view the value and feasibility of rehabilitation for people with dementia?**

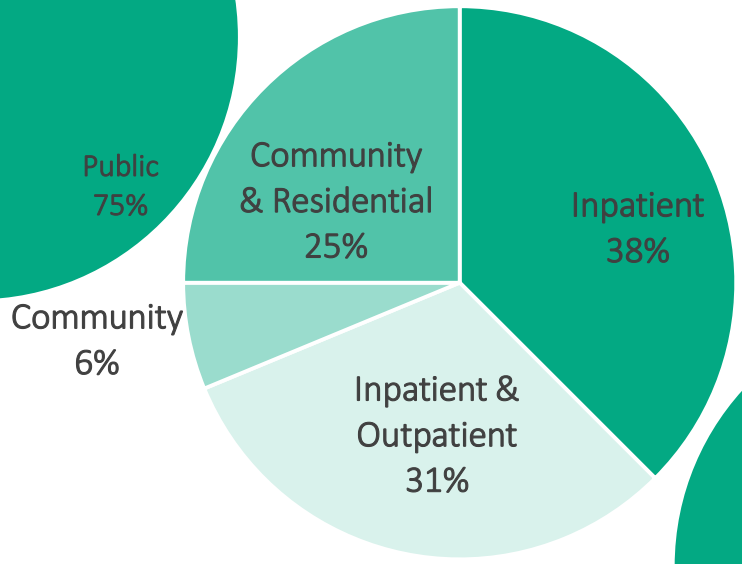
Our participants

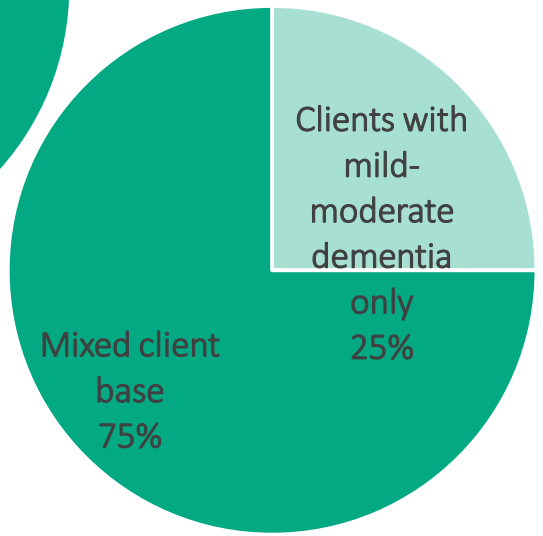
16 health professionals

- Geriatric specialists = 3
- Rehab specialists = 2
- Primary care physicians = 2
- Nurses = 2
- Physiotherapists = 2
- Occupational Therapists = 1
- Exercise physiologists = 1
- Dieticians = 1
- Neuropsychologists = 1
- Social workers = 1

Mostly South Australia based







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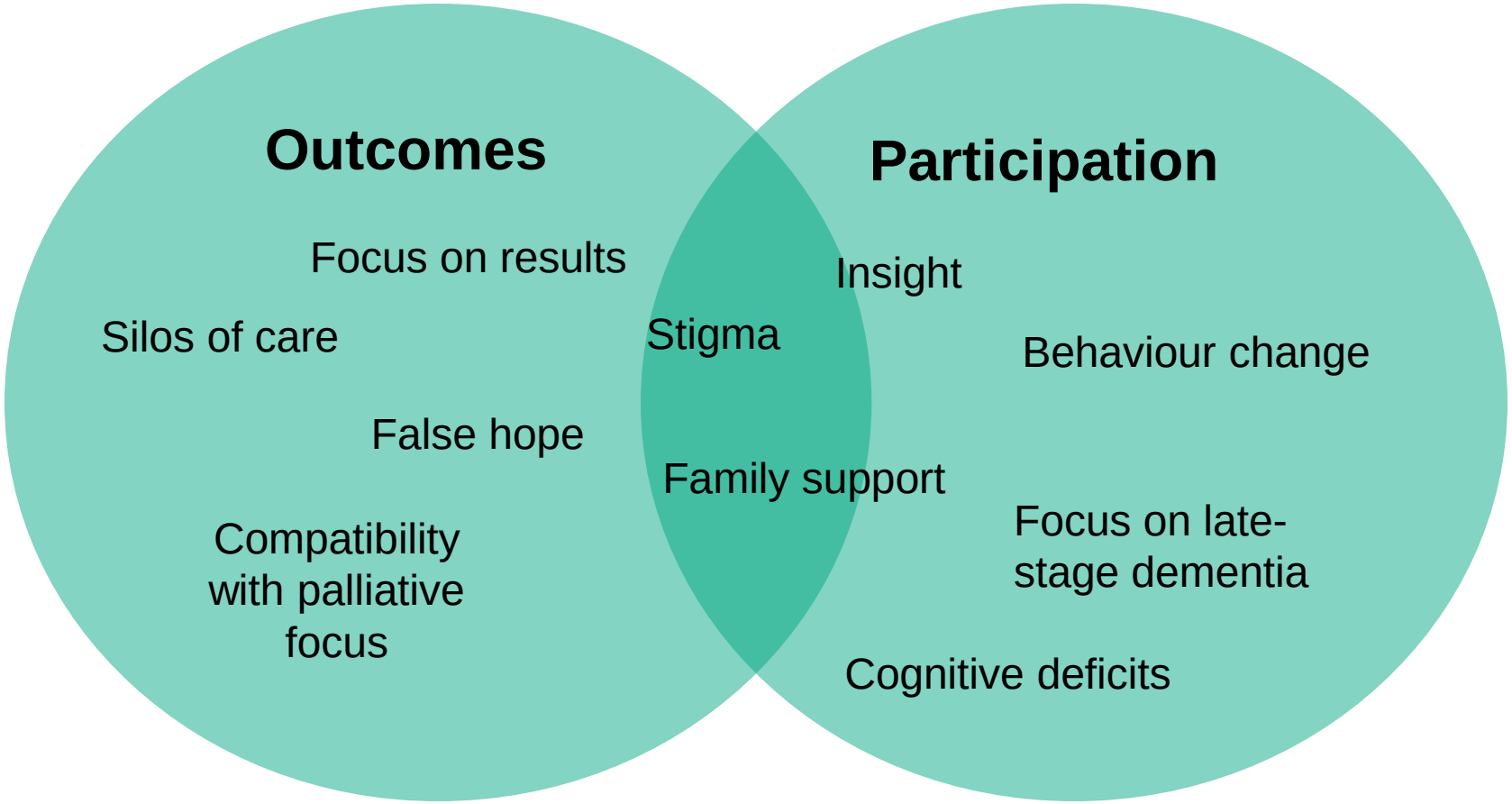
Themes


Outcomes
Focus on results
Silos of care
False hope
Compatibility with palliative focus
Stigma
Family support
Participation
Insight
Behaviour change
Focus on late-stage dementia
Cognitive deficits

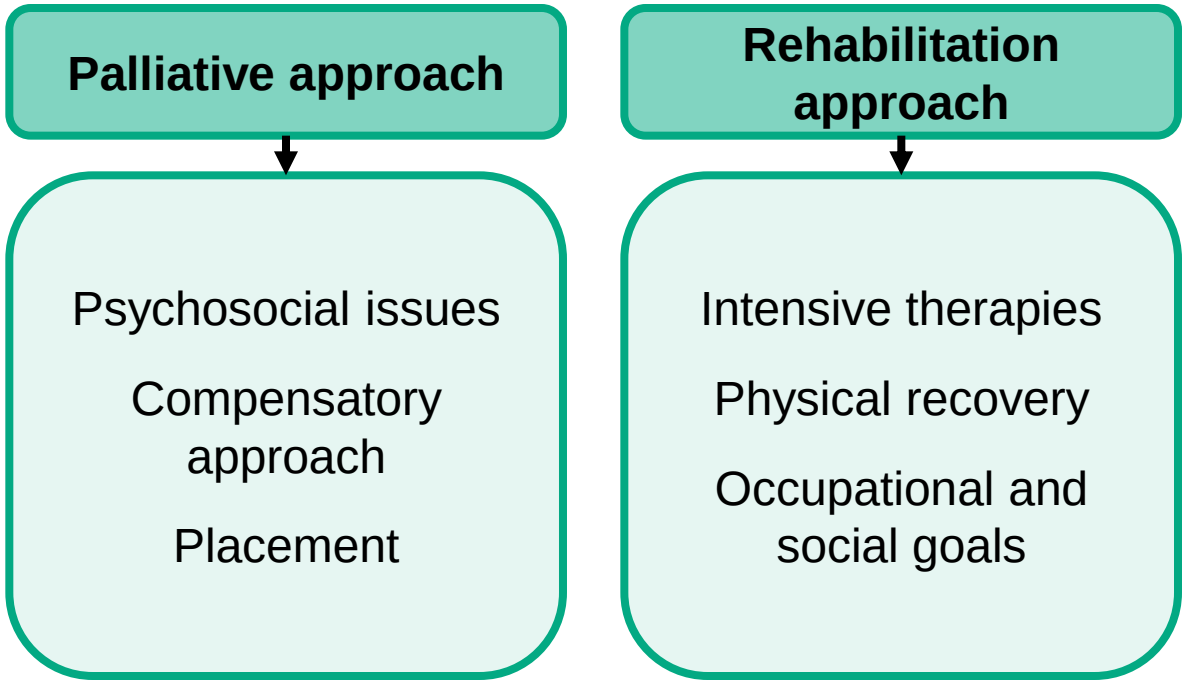
Outcomes

> *"If we make goals that people with dementia can't reach then it is not possible to demonstrate the worth of the program. It's not like when someone's had a stroke and you get them from being bed-bound to walking again." (HP01)*

- Health professionals gain professional fulfilment from seeing their patients reach higher participation goals
- If goals are not achieved or 'meaningful', what's in it for me? How can I demonstrate the benefit to maintain funding?
- Definitional issues

Outcomes

- Can palliative and rehabilitative approaches overlap?
- General tendency to speak of dementia in severe terms
- Worries about false hope
- Some acknowledged benefits regardless of goal attainment



Participation

“Seeing the benefits for themselves [is a problem] because if they’re going to go ‘there’s nothing wrong with me’ then they’re not going to want to participate. From a service provider point of view, I’m not entirely sure how we move ahead with that.” (HP12)

- Insight and carer support considered essential to successful participation
- Some could acknowledge benefits even without between-session adherence

Participation

> *"A lot of [professionals] that I've come across have said, 'The patient is not going to remember how to do any of this so why are we doing it?'" (HP17)*

- Memory loss and cognitive decline perceived as insurmountable → therapeutic nihilism
- Behaviour change a major challenge in all contexts

Making sense of it for a clinician

- Dementia will be (or already is!) everyone's business
- Broader valuing of people with dementia and their right to live a good life is the first step
- Reframing our understanding of rehabilitation takes dementia out of the 'too hard' basket
- You can be an agent of innovative chang

Where to next?

- Interviews with people with dementia – what exactly is missing from the post-diagnosis care pathway?
- Survey of wider population of people with dementia
- Expanding evidence base
- Providing a frame of reference – what might it actually look like?

Thank you!

Questions?

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"Excuse me, is this the Society for Asking Stupid Questions?"