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Brain health, dementia care, support and rehabilitation

Georgina Chelberg PhD

Nathan M D'Cunha PhD

17th April 2024

COTA ACT Midweek Matters

The University of Canberra acknowledges the Ngunnawal people, traditional custodians of the lands where Bruce Campus is situated. We wish to acknowledge and respect their continuing culture and the contribution they make to the life of Canberra and the region. We also acknowledge all other First Nations Peoples on whose lands we gather.

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Introduction

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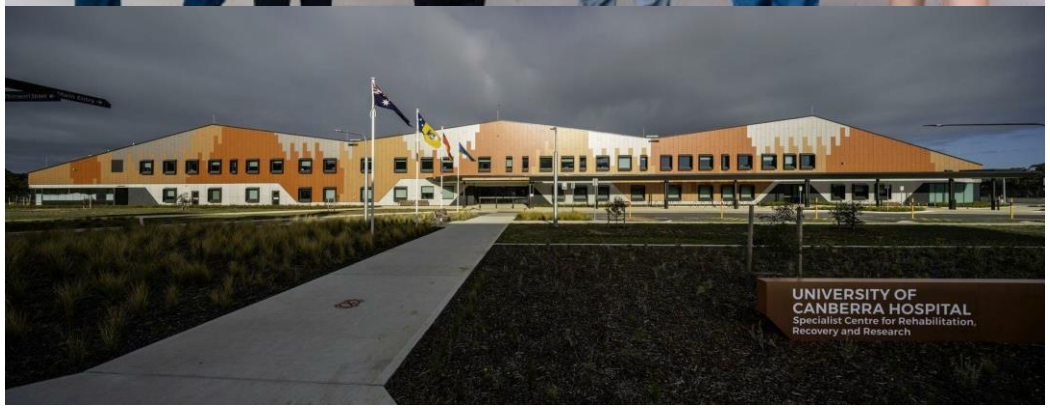

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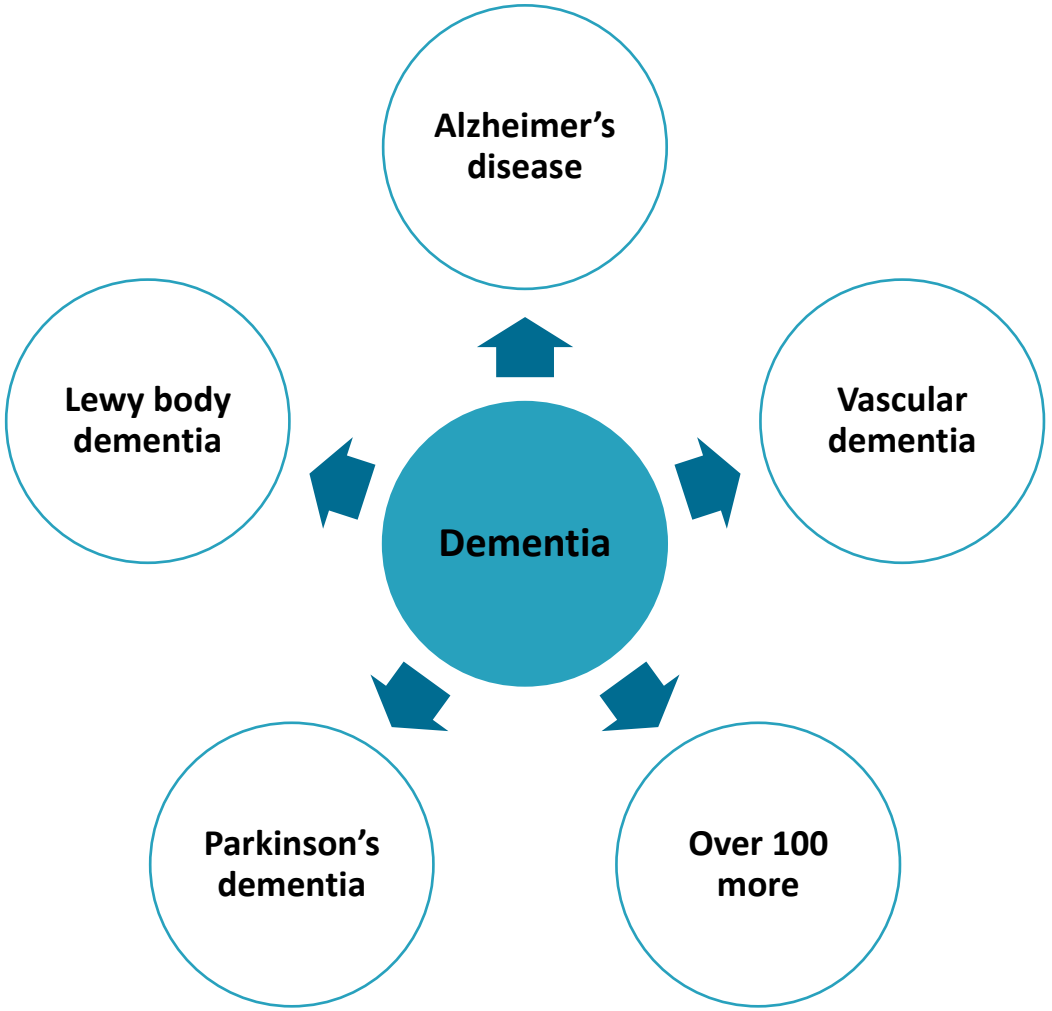
Why talk about dementia?

- Understanding is helpful
- Connect with support if needed
- Support people with dementia and care partners to reduce community stigma

What is dementia?

- **Dementia is a collective term**
  - A syndrome (group of symptoms)
  - Variety of underlying causes
- **Dementia affects brain function:**
  - Thinking, memory, attention
  - Ability to do everyday tasks
  - Interferes with social or work life
  - There is currently no cure, but some treatments can offer positive effects



Dementia Australia., 2024; Livingstone G, et al., 2017

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What is dementia ?

- **Dementia is diverse**
  - Medical cause and prognosis
  - Context, treatment, experience
  - Humans are individual and incredible!

Dementia Australia., 2024; Sabat 2018.

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Person with **DEMENTIA**

PERSON with Dementia

Dementia Australia., 2020.

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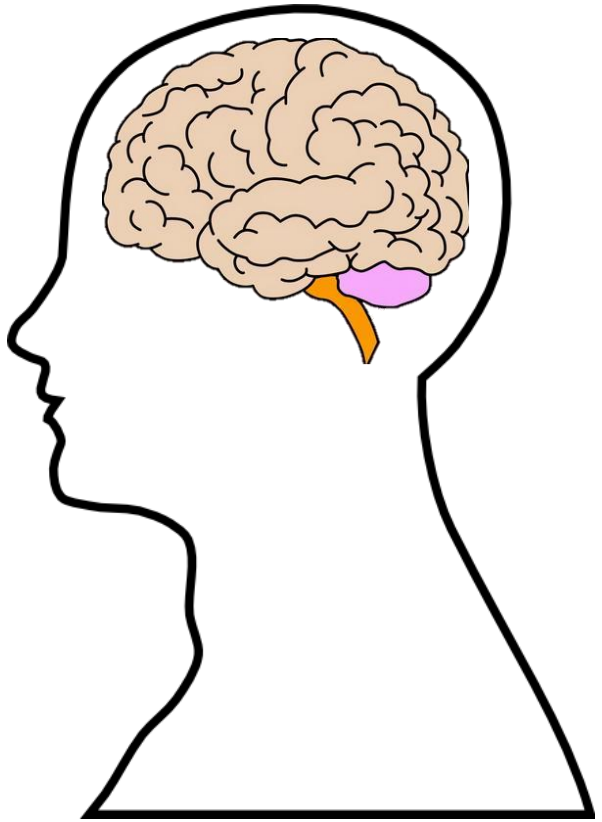
Dementia causes

Physiology:

- Neurofibrillary tangles
- β-Amyloid cascade
- Genetics
- Brain insulin resistance
- Infectious agents
- Blood-brain barrier dysfunction
- Chronic stress/trauma
- Systemic low-grade inflammation

Modifiable risk factors:

- Western dietary patterns
- Physical inactivity
- Cognitive inactivity
- Smoking
- Depression
- Hypertension
- Social isolation
- Circadian rhythm disruption, sleep patterns and apnoea
- Hearing loss?



Research seeks to better understand contributors to causes, potential cures, and how we can live well with dementia

Livingston G et al., 2017, 2020; D'Cunha, 2017

HiClipArt.com; illustAC.com

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Health and wellbeing … positive steps

"What's healthy for your heart is healthy for your brain"

- **Physical activity:** movement, strength, balance, connection
- **Variety nutritious food:** vegetables, fruit, wholegrains, quality protein
- **Water** (limit alcohol)
- **Social connection**
- **Mental health**
- **Meaningful occupation**
- **Quality sleep**

Dementia Australia., 2024.

Water

Physical activity

Meaningful occupation

Variety of nutritious food

Sleep

Social connection

Water

Physical activity

Meaningful occupation

Variety of nutritious food

Sleep

Social connection

Health and wellbeing … positive steps

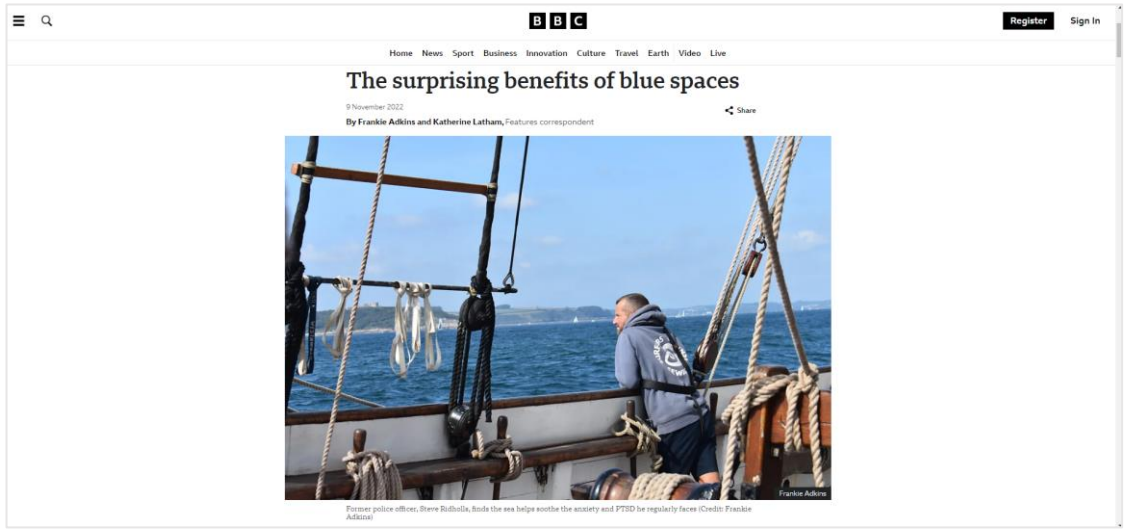
- Blue therapy
- Shinrin Yoku
- GPs - activity prescription, ParkRun

- Music therapy
- Sensory immersion
- Chair yoga or chair dancing

@ehdlou TripAdvisor.com

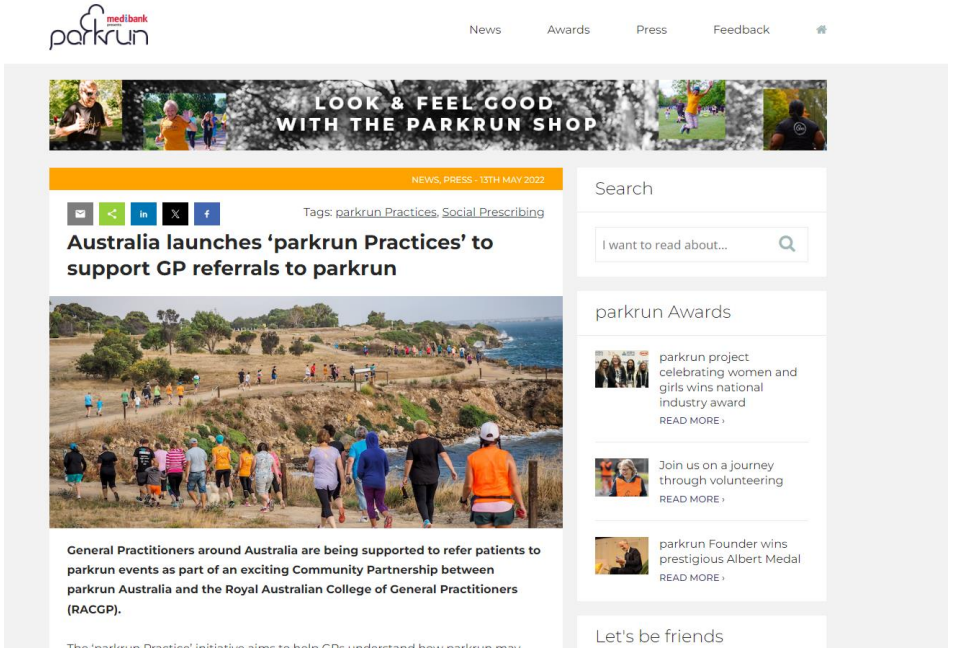
https://alchemychorus.com/

Dementia Australia., 2020.

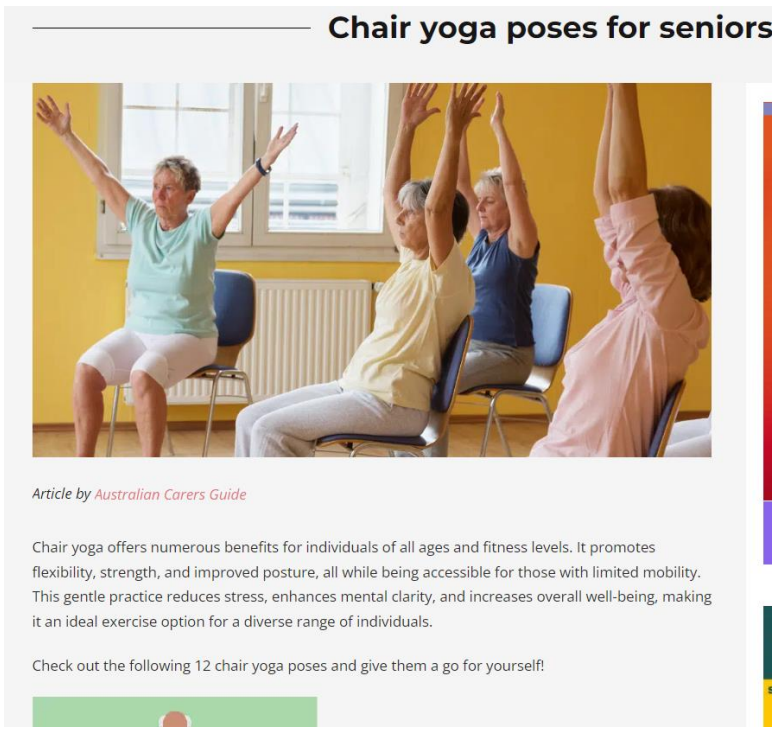


https://www.bbc.com/future/article/20221108-the-doctors-prescribing-blue-therapy

https://www.scientificwellness.com/blog-view/benefits-of-shinrin-yoku-or-forest-bathing-426



https://blog.parkrun.com/au/2022/05/13/parkrunpracticesaulaunch/



https://australiancarersguide.com.au/chair-yoga-poses-for-seniors/

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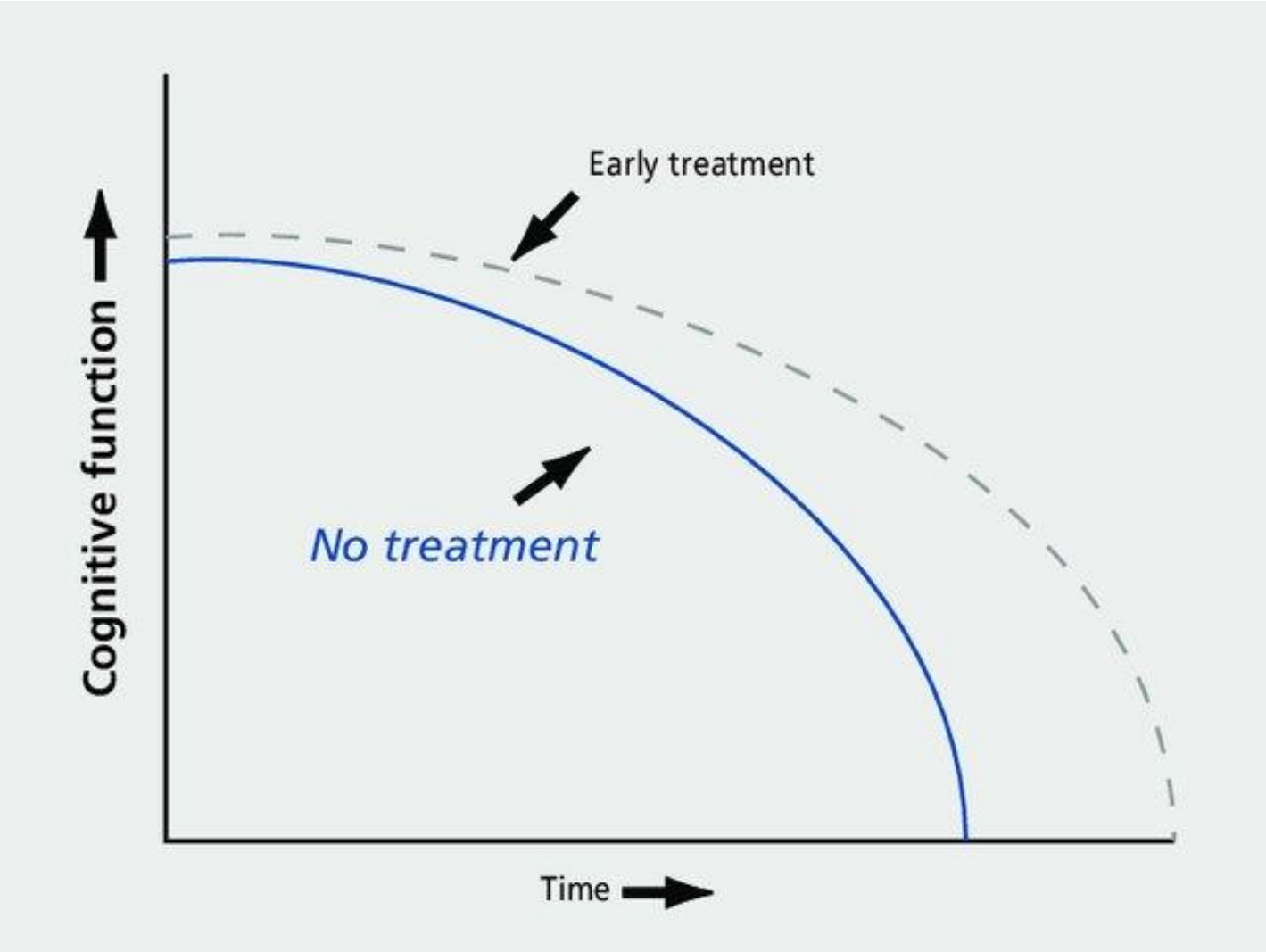
What happens when someone is diagnosed with dementia?



Small, 2000. *Dialogues in Clinical Neuroscience*.

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Rehabilitation in dementia

- Dementia is an acquired disability
- Each person will experience symptoms in their own way
- People with dementia should have access to support and treatments such as rehabilitation, like with other health conditions

- Rehabilitation:
  - Maintaining activities, independence and quality of life
  - Some interventions may slow the progression of dementia
  - Treatments and approaches should be tailored to the needs of the individual and focussed towards what is meaningful and important to them

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Access to dementia rehabilitation

- Most treatments offered are pharmacological
- Supports are often aimed towards doing things for the person
    - This can lead to increased disability, further loss in function, depression and lower quality of life

- People with dementia are best supported by maximising the opportunity for the person to continue to do things for themselves
- Involving care partners and family is important

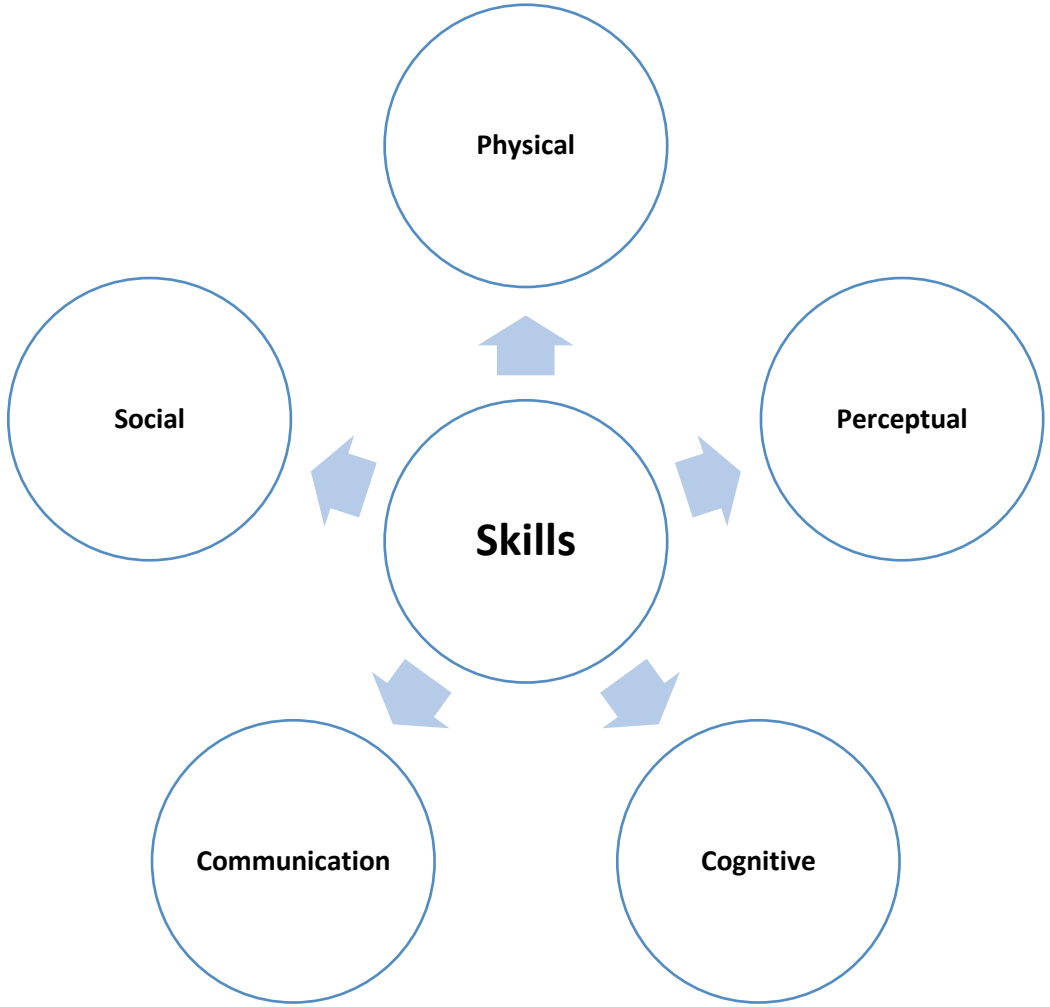
Why are meaningful activities important?

- Loneliness and social isolation are predictive of cognitive decline
- Engagement in activities beyond normal care is an indicator of quality of life
- Can be tailored to the person's choices, strengths, needs or preferences
- Group activities provide opportunity for social interaction

Photo: Community Home Australia

Why are meaningful activities important?

- It's not just about the ability to do a particular activity
- There are benefits from:
  - Being in a supportive environment
  - Having the opportunity and choice to perform the activity
  - Having a reason to do the activity when it is linked to the person's needs, roles, routines, interests or values



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Dementia in the ACT

- ~6,000 people diagnosed with dementia
- Second highest death rate in Australia, leading cause of death in women
- Disproportionate number of referrals to Dementia Support Australia
- ~20% of people with dementia live in residential aged care compared with national rate of ~35%

Photo: Community Home Australia

What are the gaps in the ACT?

Interviews with 29 clinicians and care and service providers in 2022-23:

1. A lack of dementia-specific services
    - Not enough day or respite services
    - Poor care options for people with dementia who have unmet needs (e.g. aggression, agitation, depression)
2. Concern with the quality of existing dementia care
    - Staff training for people with dementia who have unmet needs
    - Poor availability of staff with dementia-specific skills
3. Insufficient funding for dementia services
4. Poor public awareness of dementia
    - Poor knowledge of dementia and stigma contributing to a delay in timely diagnosis and access to support

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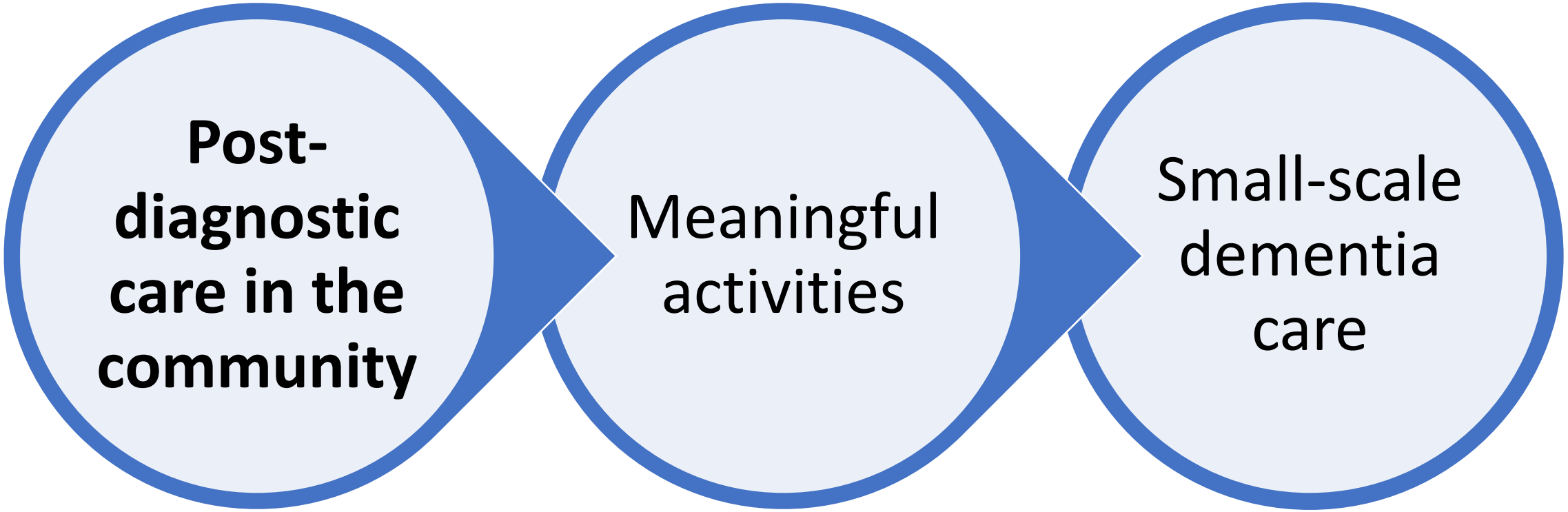
Dementia care and support research



Multicomponent lifestyle interventions

Dementia prevention, intervention, and care: 2020 report of the *Lancet* Commission

Gill Livingston, Jonathan Huntley, Andrew Sommerlad, David Ames, Clive Ballard, Sube Banerjee, Carol Brayne, Alistair Burns, Jiska Cohen-Mansfield, Claudia Cooper, Sergi G Costafreda, Amit Dias, Nick Fox, Laura N Gitlin, Robert Howard, Helen C Kales, Mika Kivimäki, Eric B Larson, Adesola Ogunniyi, Vasiliki Orgeta, Karen Ritchie, Kenneth Rockwood, Elizabeth L Sampson, Quincy Samus, Lon S Schneider, Geir Selbæk, Linda Teri, Naaheed Mukadam

- "Post-diagnostic care for people with dementia should address physical and mental health, social care, and support."
- "Specific multicomponent interventions decrease symptoms and are the treatment of choice."
- "Specific interventions for family carers have long-lasting effects."

Sustainable **P**ersonalised **I**nterventions for **C**ognition, Care, and **E**ngagement (SPICE) Program

ACT Government | Canberra Health Services

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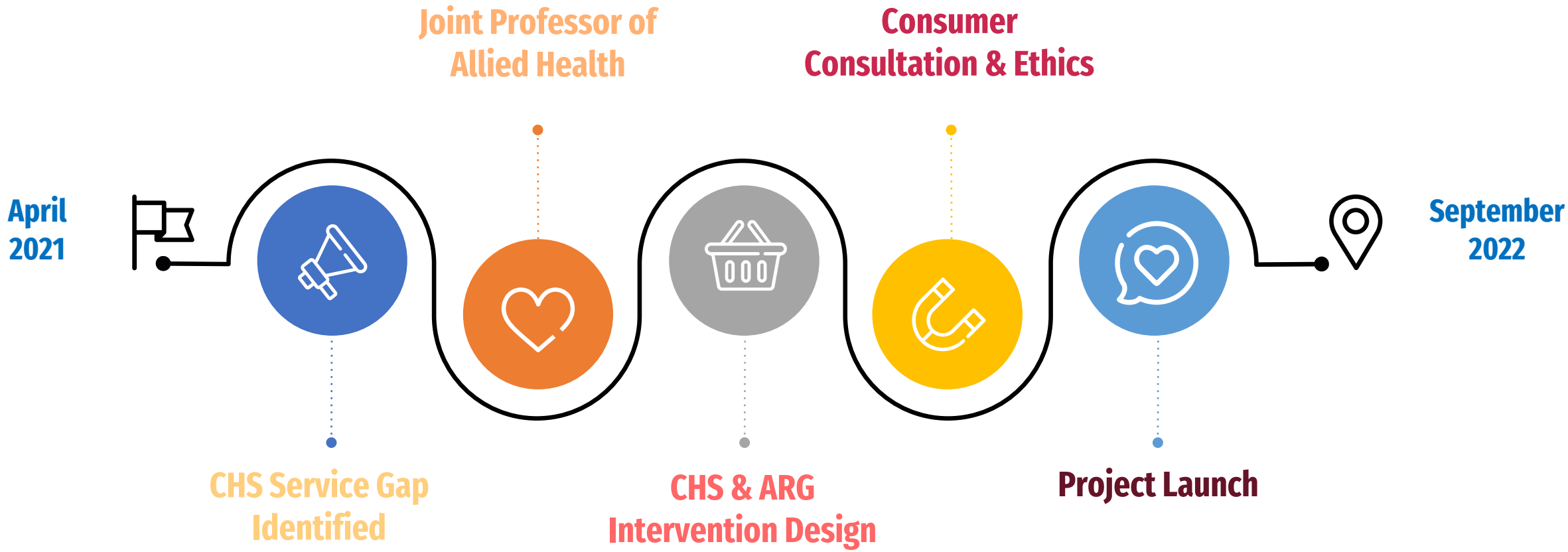
SPICE program development



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Multidisciplinary approach

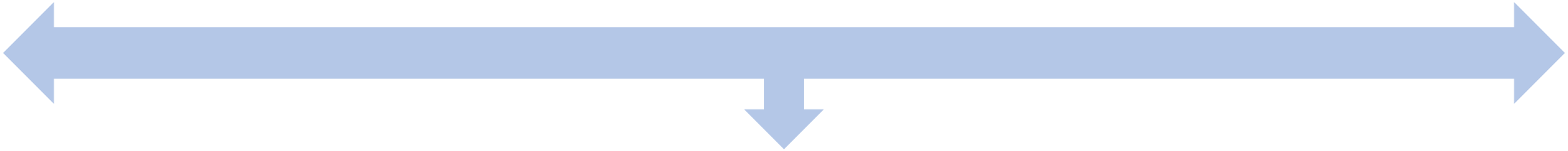
Canberra Health Services
- Occupational Therapy
- Physiotherapy
- Neuropsychology
- Clinical Psychology
- Social Work
- Speech Pathology
- Allied Health Assistants

University of Canberra
- Nutrition & Dietetics
- Pharmacy
- Occupational Therapy
- Physiotherapy
- Nursing
- Health policy
- Gerontology

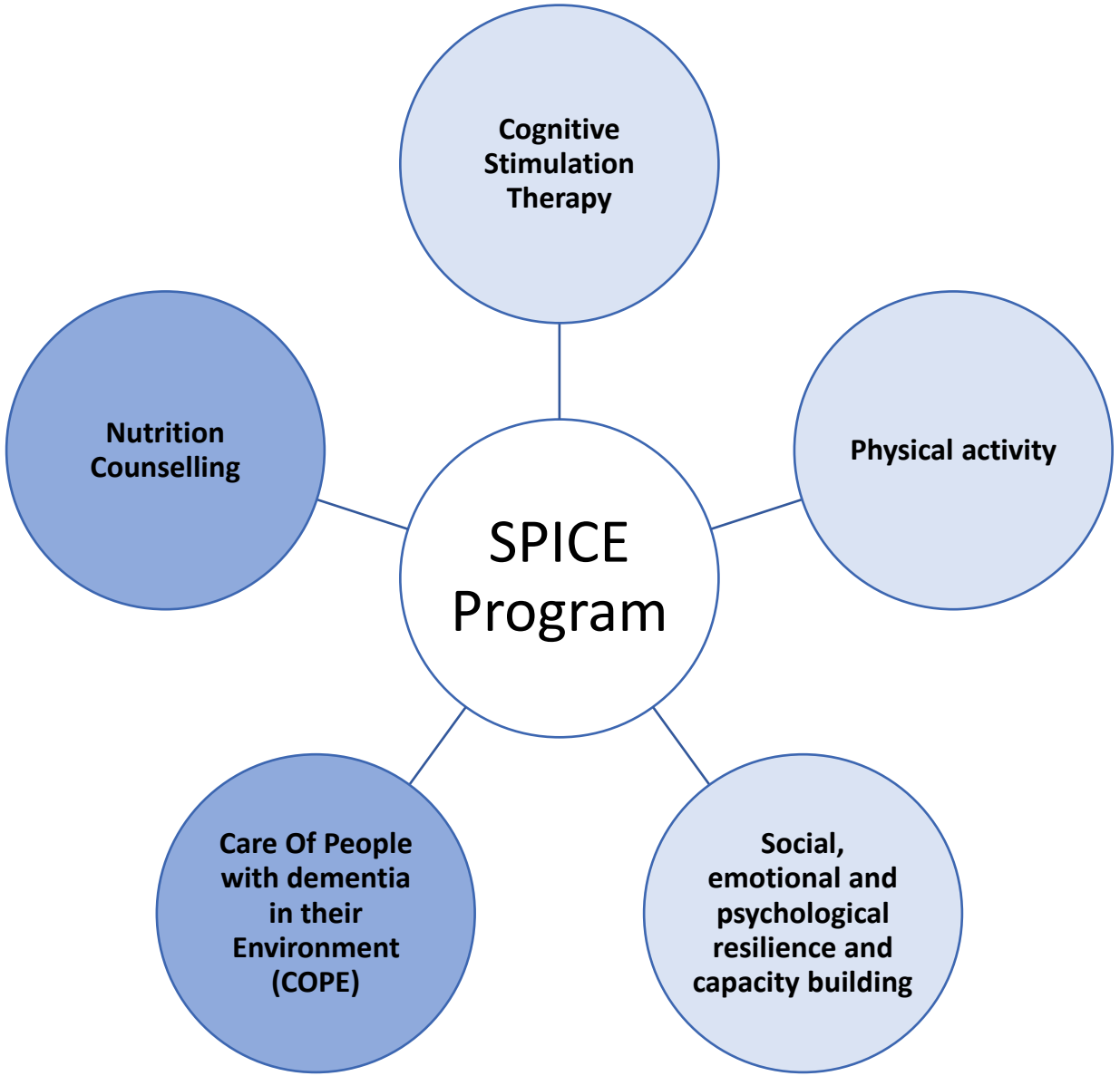
Dementia Australia
ACT Health

Joint CHS/UC Steering Group

External Advisory Committee



Working towards a more comprehensive post-diagnostic pathway for people with dementia and their carer partners in the ACT



12 week multicomponent program

Participants receive:

- Group activities twice per week for 2.5 hours
  - Cognitive Stimulation Therapy
  - Physical activity
  - Carer capacity building
- By appointment:
  - Ten in-home sessions with an occupational therapist
  - Three appointments with a dietitian

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Social engagement

- Participants have afternoon tea together each session
- Spend ~60 hours with each other (and SPICE staff)
- Group activities built into exercise program

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Preliminary results

- Program satisfaction ratings are very high
- Attendance rates over 93%

Person with dementia	Carer
↑ Carer-rated quality of life	↑ Self-efficacy
↓ Neuropsychiatric symptoms	↓ Distress related to neuropsychiatric symptoms
↓ Alternating step test	↓ Alternating step test
	↓ Timed up and go

Twelve weeks after the program:

- Benefits maintained for quality of life (self-reported & carer-rated)
- Reduction in neuropsychiatric symptoms and carer distress

Keys to success

1. Social connection, engagement and interaction were key drivers of the success of the program
2. Clinicians fostered a positive and respectful culture
3. Carers were supported with strategies and skills to reframe dementia
4. Reablement can be fun

D'Cunha et al., 2023 (Health & Social Care in the Community)


WINNEWS

Staying connected

- WhatsApp group
- Lunches & dinners
- Social gatherings outside of SPICE
- Impromptu peer support
- Day trips
- DA Memory Cafes
- Self-organised exercise groups

Next steps for SPICE

- Funded through end of 2024
- Collaborative work towards program sustainability
- Respond to identified gaps:
  - Dementia-specific at-home rehab program
  - SPICE Step Down program
- Multi-site trial
  - Grant proposal to evaluate SPICE in Sydney, Wollongong, Melbourne and Perth

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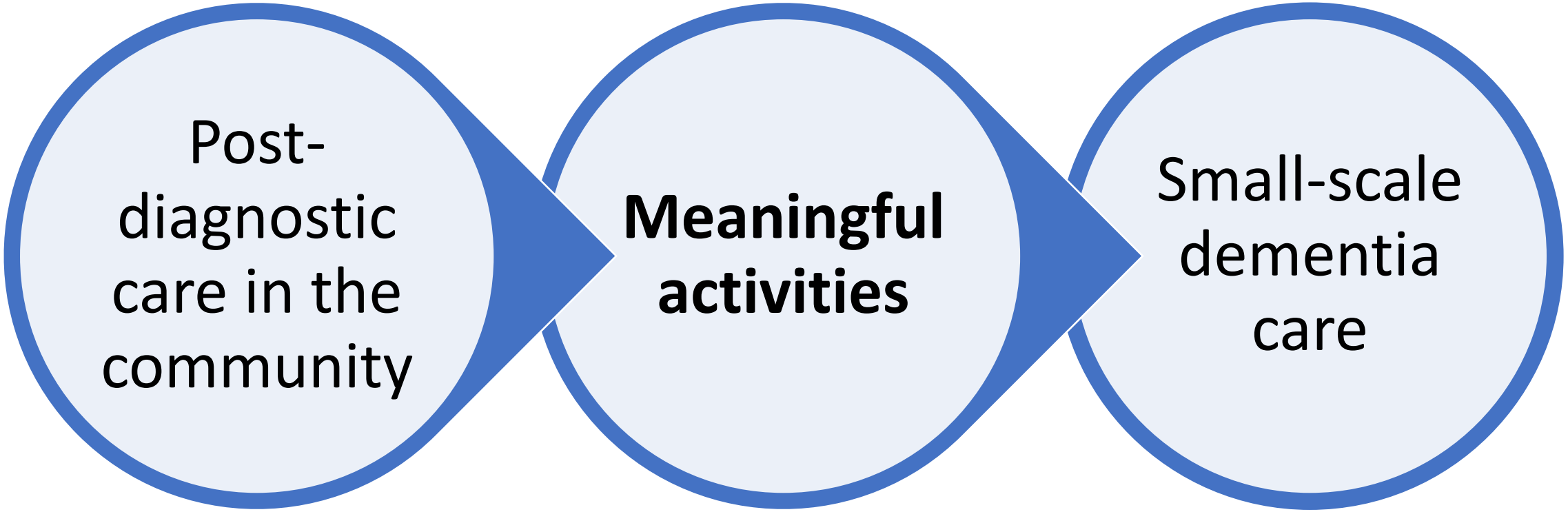
Dementia care and support research



National Gallery of Australia Art and Dementia Program

- One of the most successful and long running programs in the world
- Arts-based discussion groups benefitted people with dementia living in residential aged care in a six-week program (*n*=25)
  - Change in diurnal salivary cortisol ratio
  - Improvements in QoL, cognition
  - Twelve participants recalled specific parts of the program six weeks later

D'Cunha et al., 2019 Journal of Alzheimer's Disease

Intergenerational programs in aged care

- National Survey during COVID-19 (*n*=572)
- Only 80 respondents had never ran a program
- Many programs were paused due to COVID risk (44.2%)
- Most common activities included:
  - Singing (67.8%), games (56.8%), reading (51.1%) and craft (41.5%)

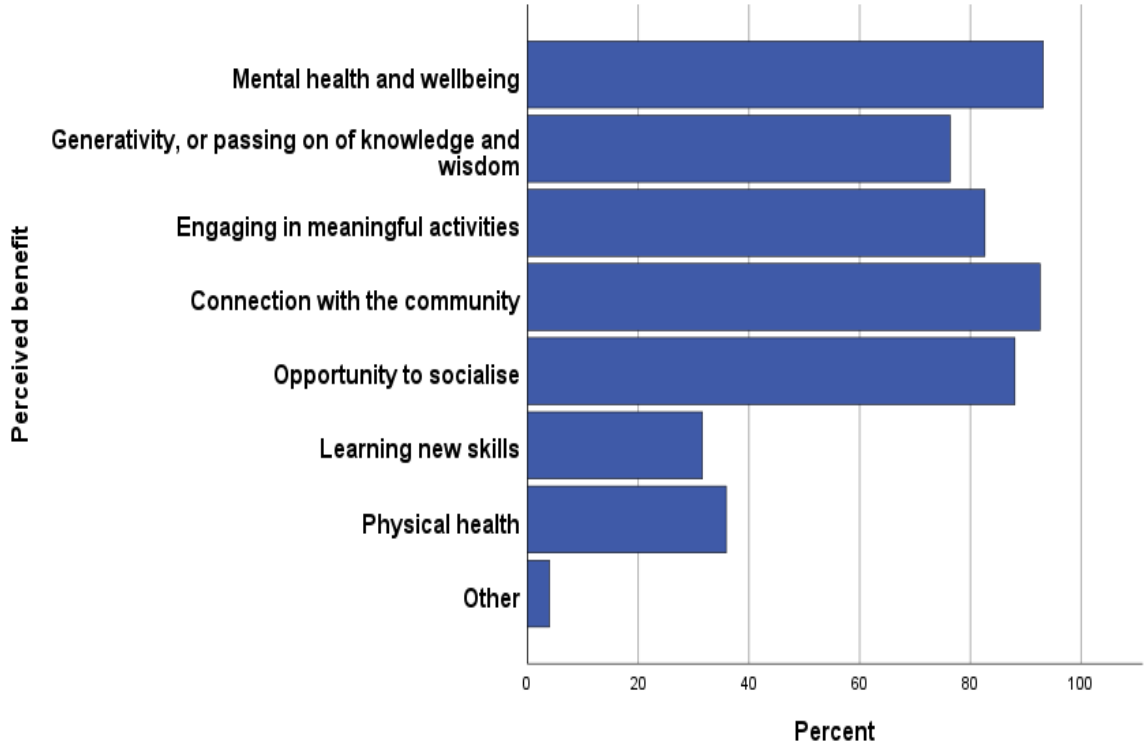


Figure. Perceived program benefits

D'Cunha et al., 2023 Journal of Intergenerational Relationships

Co-located intergenerational program

- Nine week semi-structured weekly program facilitated by OT's
  - Interrupted by COVID-19
- Activities were based on pre-study profiles of all participants
  - Included music, arts & crafts, obstacle course, dress-ups
- Participants:
  - Older people w/cognitive impairment (n=9; Mean age=91.7 years)
  - Children (n=13; Mean age=4.38 years)
- No change in loneliness or neuropsychiatric symptoms

D'Cunha et al., 2023 Dementia

Co-located intergenerational program

"[It] was maybe after the third session when I started noticing the children becoming a bit physical with the residents. And basically, in a good way. **They were more emotional and sensitive about touching the residents, holding their hands.** … I thought, there was no one encouraging them to do that. And it was just the **conversation flowing** away. And they just, it happened. So, I think there was when I said, the **connection** is there." (Staff)

Virtual reality experiences in aged care

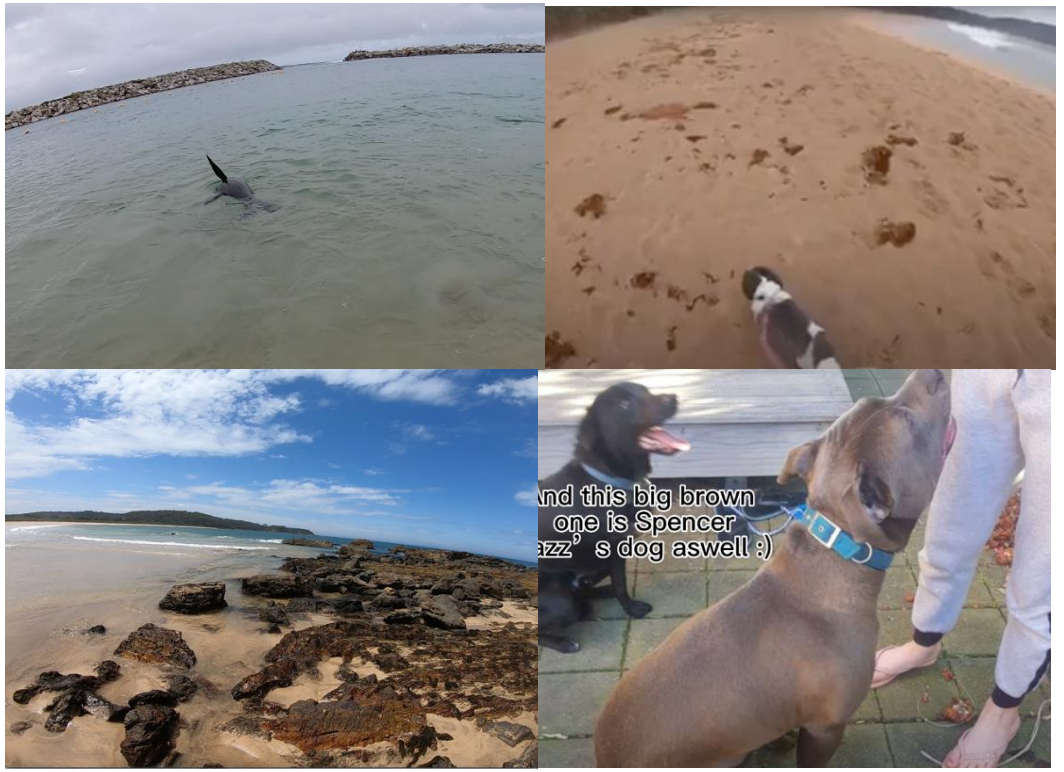
- Warrigal Care
  - Using virtual reality to do upper limb exercise
  - High acceptance and benefits to physiotherapy staff

- Southern Cross Care
  - Group cycling to familiar locations around Canberra
    - Films developed using a GoPro
  - Authentic and immersive experience
  - Opportunities for reminiscence
  - Some residents met each other for the first time

"I was looking quite a bit at the kilometres I was doing, and I would push myself a bit harder. When I came to turns, I found myself turning to slow down a little, so to turn more easily which is possibly what I really did when I used to ride bikes."

Take a Cycle with Me

- Year 11 students (*n*=25) co-created virtual cycling experiences with aged care residents (*n*=18) in Broulee, NSW
- Two-week structured program across four visits
- Mean increase in quality of life scores and adolescent attitudes towards dementia



"I was a bit hesitant at first, but then when I went and met them and saw how nice they were, I warmed up to them and they just got better from there." (Student)

Isbel et al., 2023 (In review: Journal of Intergenerational Relationships)

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Intergenerational live-in program

- Based on the University of Sydney Gold Soul Companionship program
- Allied Health students will live in an independent living unit for free, in exchange for 35 hours volunteer time in the residential aged care home
- Tasks: Assist staff with delivering and developing activities, help at mealtimes, and organising social events
- Commencing in mid-2024

Photo: Australian Journal of Dementia Care

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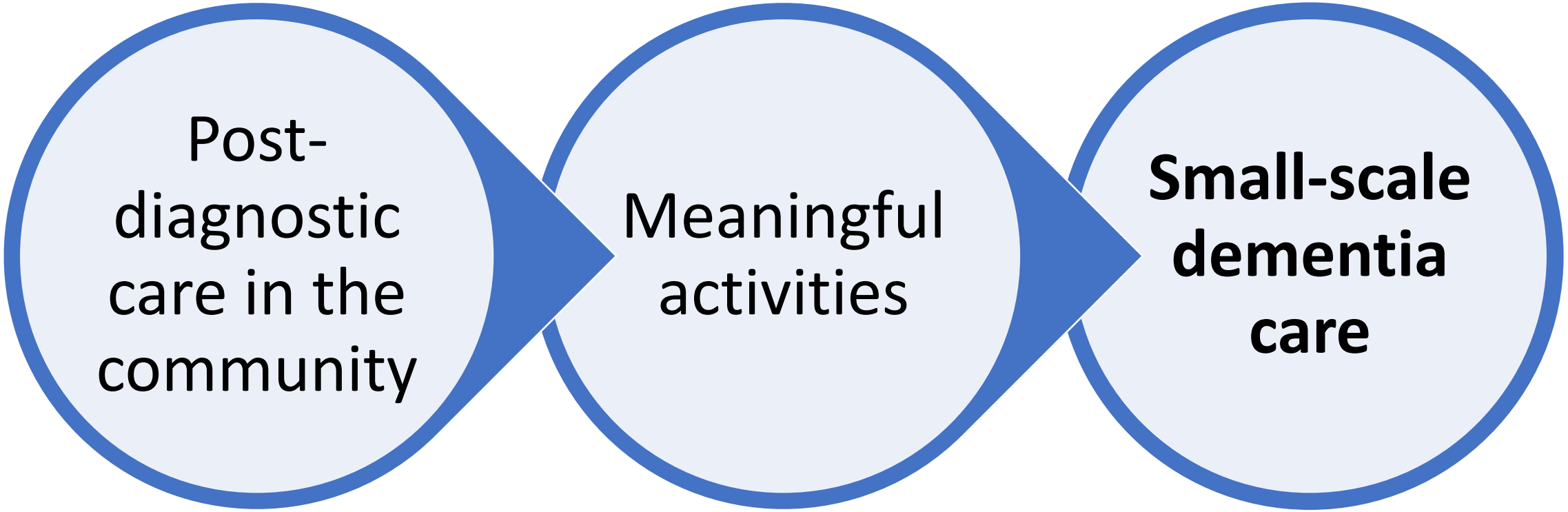
Dementia care and support research



Small-scale dementia care

- The Royal Commission recommended aged care providers:

  "provide small-scale congregate living which facilitates the small household model of care".

- Evidence suggests small-scale care may:
  - Increase meaningful engagement, access to the outdoors, quality of life, staff satisfaction, and reduce hospitalisation and emergency department presentations
- We need aged care models that embrace 'dignity of risk' – seeking a balance between enabling people with dementia to make choices and safety
- However, the cost is a barrier to greater implementation

Community Home Australia
Best Practice Dementia Support

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Kambera House

Community Home Australia
Best Practice Dementia Support

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Findings on Kambera House

1. Care-orientated and smart-sensing technology supported guests, family, and staff
2. Free, everyday technology connected the home with families and supported care
3. A community and not an institution
4. Conditions of work are the conditions of care
5. Responsiveness, change, and flexibility

“Every time you come here, you're welcomed here. It's like coming into your own home. ‘It's basically like not being a visitor, but being in your own home, and everyone else is basically visiting you, even though there's the carers here.’ I find, it's like home.” (Family)

Photo: Community Home Australia

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The Neighbourhood Canberra

Vision: To create thriving communities for people living with dementia.

Mission: To establish, for people living with dementia needing residential care, home-like clustered care homes in a village setting connected with the surrounding community and where intergenerational connections are fostered.

THE SNOW FOUNDATION

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Principles for success

1. A surrounding community invested in the village
2. Education of all people at every level of the village and community
3. The organisational mission, vision and values promote an inclusive culture
4. Care staff who promote an enabling person-centred care environment
5. Meaningful activities should meet the needs of all living in the village
6. The built environment is designed to enable maximum engagement and safety

"I think the local community is going to require some preparation, and I think this will require quite a lot of investment of time and resources.

But, what we have not yet done anywhere … is really get the surrounding community to fully embrace and accept and almost rejoice in the fact that within the community, there are a group of people who happen to have dementia.

I think that's where that's where the real challenge lies. And that's what I find inspiring about this project." (R8).

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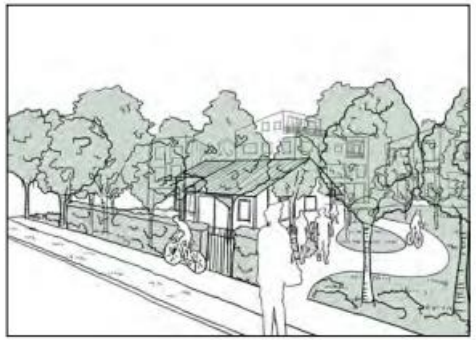
Curtin dementia village



Possible view of Village from Storey Street

Possible view of Village shared uses from Carruthers Street

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Other projects in CARAT

- Storytiling
- Allied Health in Residential Aged Care
  - GP-led multidisciplinary teams including physiotherapy, dietetics, optometry, speech pathology, and occupational therapy
- Nutrition education for carers of people with dementia
- Evaluation of a digital alert system to support aged care staff
- Research to inform the ACT Health framework for responsive behaviours in dementia

Bringing it all together…

Overall, we have come to realise:

- Socialisation is a key outcome of our work
- Person-centred and relationship-centred meaningful activities can lead to success in maintaining physical, cognitive, and psychosocial function

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CHS Team

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Sarah Jack
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Sarah Whitting
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