

Australian Journal of DementiaCare

For all who work with people with dementia

Vol 13 No 3 Jul/Aug/Sep 2024

Diversity in Care + Early Diagnostics

**A New Era of
Aged Care**

**Dementia
Diagnosis
Pathways**

**LGBTQIA+
Australians**

**Trauma-
informed
Care**

**Working with
Interpreters**



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The *Australian Journal of Dementia Care* is published by the University of Wollongong and managed by *Dementia Training Australia*.

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ISSN 2049-6839 (Print)

ISSN 2981-9040 (Online)

Printing and Distribution

Print & Distribution Services,
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Website

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Subscriptions

12 months \$99

4 issues per year:

January/April/July/October

To subscribe, visit:

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Writing for AJDC:

Do you have a project or survey to report, or a change in practice organisation or structure which has worked well (or not), and would you like to share this experience with others? We welcome contributions of this kind, as well as bright ideas for improving the environment or wellbeing of people with dementia, and letters to the editor responding to articles in *AJDC*.

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COMMENT



We are All on the Rainbow

Recently, I have been learning more than I ever thought I would need to know about rainbows and unicorns (or noonicornms, as I'm assured it is correctly pronounced). Delilah, my granddaughter and chief instructor, has taught me many extraordinary and precious life lessons, but her wisdom about people is something I hold in my heart and seek to apply every day – the thing about people, she says, is “we are all on the rainbow”.

At DTA, we aspire to create and encourage inclusivity and tolerance, and they underpin our ideas about person-centred care and training to support that. This issue is about diversity – how do we support all humans on their journey with dementia; how do we support workers and carers, who are on journeys of their own; and how do we support different ways of learning, because no two journeys, no two people are necessarily the same and that's OK.

It remains a challenge to ensure consistency of quality learning and access to quality care, but as this issue shows, accommodating diversity can enrich quality of life for those living with dementia, and it can create opportunities for connection and compassion, and enhance the development and application of technical knowledge.

Data on the impact of not acknowledging cultural, social, neuro and sexual diversity suggests that a failure to accommodate diversity is profound and negative. We need to do better. It is a privilege to work with those who are pioneering tools and approaches that will move us forward to more inclusive models of care and tools to support that. I know that in part this is a broader socio-cultural reformation not limited to dementia care but why wait? We don't stop being who we are just because of a dementia diagnosis and being able to safely express that and where we “fit” on the rainbow ought to be supported to be part of our dementia care experience.

I do not want to diminish the complexity of this, but surely acceptance, tolerance and inclusion must be at the heart of any model of care and establishing and maintaining any caring relationship – we already know that such relationships (however fleeting or temporary) are central to positive outcomes in any care setting.

I live in the hope that in my granddaughter's lifetime, we see a cure/preventative vaccine/continuously improving care for those living with dementia. We all have a part to play in the latter and that starts now. For the people featured in this issue, it has been their mission for a while now and it is a privilege to share their stories and their work. According to Delilah, “Everybody has a colour, they just have to find it. And they are allowed to be whatever colour they want.” I'm told that sometimes, if you are lucky, you can have a unicorn to help, but you would be just as lucky to be inspired by one of the amazing professionals committed to diversity and inclusion featured herein.

I hope we all find our colour.

Isabelle Meyer, Executive Director, Dementia Training Australia

The **Australian Journal of Dementia Care** is a multidisciplinary journal for all professional staff working with people with dementia, in hospitals, nursing and aged-care homes, day units, and the community. The journal is committed to improving the quality of care provided for people with dementia, by keeping readers abreast of news and views, research, developments, practice and training issues. The *AJDC* is grounded firmly in practice and provides a lively forum for ideas and opinions.

Australian Journal of DementiaCare

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Acknowledgement of Country

The *Australian Journal of Dementia Care* would like to show our respect and acknowledge the traditional custodians of the lands on which this journal was produced and published. We extend this respect to elders past, present and emerging, and to all Aboriginal and Torres Strait Islander Peoples. We also pay respect to Aboriginal and Torres Strait Islander Peoples living with dementia and their carers.

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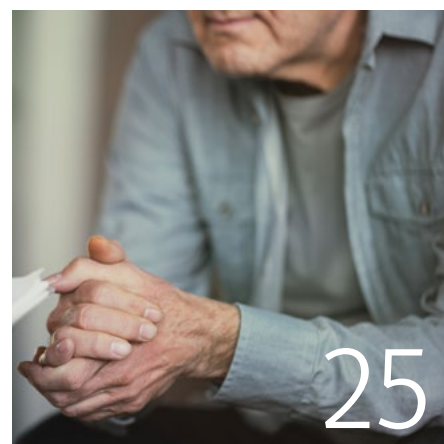


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Navigating Diversity in Dementia Care: lessons from the LGBT+ community

By Keira Donegan, editor of the *Australian Journal of Dementia Care*



Sitting down with Dr Louisa Smith, senior lecturer in disability and inclusion at Deakin University and a passionate advocate for inclusive dementia care, I was struck by her dedication to transforming how we support the diverse experiences of those living with dementia, especially within the LGBT+ community. Our discussion delved into the challenges and essential shifts needed in dementia care to foster an environment that genuinely respects and supports the LGBT+ community. Louisa's insights were both eye-opening and inspiring, revealing how understanding diversity, addressing misconceptions, and implementing specialised care models can create a more inclusive and supportive system for everyone as they age.

Moving beyond assumptions

Louisa emphasises the importance of moving beyond assumptions based on appearances or initial impressions. "A person who appears to be a white cisgender man may, in reality, use different pronouns or have a long history with a same-sex partner," she says. This principle extends beyond LGBT+ identities to encompass cultural and linguistic diversity.

For Louisa, the heart of inclusive dementia care is about understanding and honouring each individual's unique life experiences and identities without preconceived notions.

"Not making assumptions about people is an important starting point [for diversity]. And I think many people assume that is taken care of in person-centred care, but it's not," she says. "Often, in the intake processes or in meeting people, they might be hesitant about disclosing various kinds of diversity for fear that they may not be treated fairly or be discriminated against. And that's based on histories of discrimination throughout people's lives. So I think that the ideas of person-centred care, while meaningful, don't necessarily get captured in the ways we need to build a diverse understanding of someone as a whole."

Louisa related her experiences advocating for LGBT+ inclusivity within dementia care, highlighting the resistance and misunderstandings she often encounters. She recounted a memorable presentation on diversity in dementia where she faced questions that revealed deep-seated misconceptions about both the condition and LGBT+ identities.

"Some people asked why it matters

to know an individual's LGBT+ status in advanced dementia stages, but they are assuming that cognitive decline erases personal histories and identities." These assumptions, she noted, reflect a fundamental misunderstanding of both dementia and the enduring nature of gender and sexual identities.

"The questions indicated a lack of understanding around LGBT+ issues, but also a problematic conceptualisation of dementia," she says. "What often happens is when we overlay diversity with dementia, we get amplified cognitivism as well. This is where people's misconceptions of dementia become more apparent and compounded by this other area [of diversity]."

The intersection of dementia and LGBT+ identities often amplifies existing biases and misconceptions. Louisa shared poignant stories of trans individuals in aged-care facilities being pressured to conform to binary gender expressions, highlighting societal discomfort with transgender, non-binary and fluid gender identities. Additionally, the stigma surrounding LGBT+ identities can lead to increased isolation and reluctance to seek care, resulting in delayed diagnoses and inadequate support.

Explains Louisa, “We often expect people to embody their gender in stable and binary ways.[...] And I’ve heard quite a few people say, but they’re a trans woman, so I have to shave them. I have to maintain their gender expression. However, we know that that’s not the way that a lot of older women generally embody their gender identity and that sometimes trans women (and women generally) may want to express gender differently. Dementia sometimes comes with greater sensitivity around the skin, and maybe they don’t want to be shaved. [It’s OK not to shave them], it’s okay to have a trans woman with a beard if that’s what she wants.”

Demand for targeted solutions

Louisa passionately argues for developing specialised care models tailored to diverse populations, including the LGBT+ community.

“Contrary to the argument that ‘we are all just humans’ and thus don’t need tailored approaches, the unique challenges faced by LGBT+ individuals demand targeted solutions,” she insists. Ensuring equitable and effective care means mainstream services must understand and accommodate these needs.

Says Louisa, “We need approaches that understand [the histories of health care] and support people to engage [with services] earlier so that they can do more preventative rehabilitation and ensure that people aren’t staying in the closet [forcibly] because I think when people are engaging in services, they’re often not coming out or not feeling safe to come out which is in itself, okay. But as we’ve seen, once dementia progresses, not being out can have a really huge impact.”

One promising approach she highlighted is the integration of peer support models. These models leverage the strength of the LGBT+ community to provide support and create intergenerational connections, precious for those who may lack traditional family support networks. By fostering a sense of community and belonging, peer support can significantly mitigate the isolation often experienced by older LGBT+ individuals.

“So where the LGBT+ community has been taking these kinds of approaches forever, where peers support peers such as what we saw with HIV, we’re seeing that if we bring that over into aging, [peer

mentoring] can be powerful because it can reconnect people with the community,” she says. “It also provides some intergenerational connections that older LGBT+ folks may not have if they don’t have children.”

Education and training are fundamental to creating inclusive environments in dementia care. Louisa stressed the importance of understanding LGBT+ histories and applying trauma-informed and healing-informed care.

“This awareness helps caregivers appreciate the unique experiences and potential traumas faced by LGBT+ individuals,” she explains. However, she cautioned against viewing education and training as a cure-all solution, noting significant challenges such as changing attitudes, addressing diverse backgrounds, and overcoming institutional barriers.

Says Louisa, “We need to have much more community awareness, and by that, I also mean LGBT+ community awareness, where queer communities become aware that there are elders who have paved the way for them to be who they are and to realise they need to do some work to support them, either as peer workers or as people who just drop in. That’s probably one of the significant things. We need to be thinking really broadly and about education and training.”

Louisa acknowledged the aged care workforce’s diverse and often transient nature as a significant challenge. Many caregivers work casually, come from varied cultural and religious backgrounds, and face immense time pressures. “Placing the burden of fostering inclusivity in these overworked and underpaid individuals is problematic,” she notes. Additionally, some aged-care facilities operate within religious frameworks that may not support LGBT+ inclusivity, further complicating the implementation of training programs.

“To place all the responsibility on the people who are on the ground is problematic because we know that people who are working in aged care are already incredibly stressed, and they already want to be doing way more than they are to support people to live their best lives and to have dignity and respect,” she says. “They also encounter people from a huge variety of cultural backgrounds, including religious ones, and there are whole aged-care facilities dominated by religious beliefs that don’t believe LGBT+ people should

exist. There are also potential institutional challenges in implementing education and training in areas like that. We have to be creative around how we think about education and training.”

Reforms essential for change

Policy and systemic reforms are essential for lasting change. Louisa acknowledges that while some policies are in place to prevent discrimination and promote appropriate care, there needs to be more evidence of what quality care for LGBT+ individuals looks like. More research is required to develop a solid understanding of effective care practices. She says that the upcoming census will better count LGBT+ individuals and provide valuable data for future policies and care models.

“We don’t know what good care looks like for this group. No one’s done actual research into what quality care would look like. There’s quite a lot about what it doesn’t look like, and about attitudes being problematic, and that’s huge. However, there’s a need for significant clinical understandings, which are broadly absent in geriatricians and aged-care facilities. We don’t have evidence of what it should look like on the ground. Things are in place at that kind of policy and advocacy level.”

Programs such as the Australian Visiting Volunteers Scheme are crucial in supporting isolated LGBT+ individuals. These programs connect socially isolated elders with volunteers who provide companionship and gender-affirming care. Notes Louisa, “These interactions can be life-changing, often providing the only opportunity for these individuals to express their true identities in a supportive environment.”

As our conversation shifts to the global stage, Louisa says that the diversity within older adult communities becomes increasingly pronounced as the global population ages. This diversity, spanning various cultural, ethnic and identity dimensions, poses unique challenges and opportunities for the aged-care sector. She suggests that the Visiting Volunteers Scheme provides insightful strategies that can be adapted to other countries to address these complexities.

Louisa stresses the importance of recognising the nuanced differences within the LGBT+ community. “This group, often viewed monolithically, consists of individuals

INTERVIEW

with vastly different experiences and needs,” she says. The experiences of trans and non-binary individuals, for example, can be starkly different from those of lesbian, gay or bisexual individuals. This understanding is crucial for creating nuanced care strategies that respect each person’s unique identity and experiences.

Embracing aging and death

A central theme in our talk is embracing aging and death as natural parts of life. This involves creating care models that support individuals living authentically and with dignity as they age. For LGBT+ individuals, this means recognising and respecting their identities in all aspects of care, including dementia care.

“The visitors scheme emphasises relational care models, which are essential for affirming individuals’ identities and experiences,” Louisa says. This approach can be adapted globally to ensure that aging populations receive care that respects their dignity and supports their authentic selves.

“Rather than avoiding the idea of aging and death, we need as a society to be thinking about how we support people and not something we avoid but something we embrace and work towards,” says Louisa. [...] “How do we create the intimacy that supports authenticity through aging and death?”

Louisa discusses the importance of allyship within the healthcare community to advance LGBT+ inclusivity. True allyship, she argued, involves taking on the responsibility of supporting and advocating for LGBT+ individuals rather than placing the burden on them. This means that non-LGBT+ staff should actively engage with LGBT+ communities and take steps to create inclusive environments. For instance, aged-care facilities could implement policies encouraging staff to become allies, such as attending LGBT+ events, connecting with LGBT+ organisations, and promoting inclusive practices. “This proactive approach can help create a safe and welcoming environment for LGBT+ residents,” she notes.

Despite the potential for progress, Louisa acknowledges the significant structural barriers hindering advancements in aged care, including inadequate staffing ratios, insufficient training and a lack of resources. Addressing these issues requires systemic changes, such as increased funding for aged care, better wages for care workers, and comprehensive training programs that include diversity and inclusivity components. The recent Royal Commission into Aged Care in Australia highlighted these challenges, emphasising

higher staff-to-resident ratios to provide person-centred care. All countries can learn from these findings and invest in their aged care systems to ensure all individuals receive the care and respect they deserve.

Important insights

Louisa’s insights give me a profound sense of the importance of inclusive dementia care, the future of which must evolve to meet the diverse needs of an aging global population, including the LGBT+ community. By acknowledging and addressing the unique challenges faced by LGBT+ individuals, we can develop care models that honour their identities and experiences. Integrating peer support, comprehensive education, and policy reforms are crucial to achieving this goal. Louisa’s words are a reminder that true allyship involves active engagement and shared responsibility and that systemic changes are essential for creating inclusive environments. As we move forward, it is imperative to embrace aging and death with dignity, ensuring that all individuals can live authentically and receive the respectful care they deserve.



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Embracing Cultural and Linguistic Diversity

By Grace Wei and Fiona Kumfor, School of Psychology and the Brain and Mind Centre, The University of Sydney

Dementia is a global issue, affecting people across all cultures and backgrounds. In Australia, with nearly a third of the population born overseas (ABS, 2023), it is crucial for dementia care to be culturally inclusive. Despite this need, notable gaps exist in the understanding, care and support provided to people living with dementia from culturally and linguistically diverse (CALD) backgrounds.

People from CALD backgrounds often face unique challenges in the diagnosis and management of dementia, including a lack of service accessibility, cultural and language barriers to inclusivity, and stigma, which can negatively impact the quality of care they receive (Shatnawi et al., 2023). These populations are also often underrepresented in both research and clinical settings, resulting in care that is not always informed by evidence specific to their needs.

Differences in clinical presentation

The current diagnostic criteria for dementia are largely based on studies of Western populations. Whether these are valid in non-Western populations is not clear. A recent study found that English-speaking Australians with behavioural-variant frontotemporal dementia presented with high levels of apathy and loss of empathy (Skeggs et al., 2023), which closely align with existing diagnostic criteria (Rascovsky et al., 2011), but Australians from CALD backgrounds who spoke a language other than English, presented with disinhibition and hyperorality.

The role of cognitive reserve

Such research raises the question of why people from CALD backgrounds may present differently. Possibly, people from CALD backgrounds may have higher “cognitive reserve”, which refers to the brain’s ability to adapt and maintain function despite aging, disease or injury (Stern et al., 2020). It is a kind of resilience that is developed through an active lifetime and is influenced by factors such as speaking multiple languages, higher education, varied life experiences and engagement in complex professions.

For individuals from CALD backgrounds, especially those who are multi- or bilingual,

the cognitive flexibility required to manage multiple languages may enhance their cognitive reserve. Research has shown that people with frontotemporal dementia born overseas and spoke a first language other than English, had higher cognitive reserve (Skeggs et al., 2023). They also performed better on non-verbal tasks than verbal ones, whereas monolingual individuals showed similar impairment across both task types.

Interestingly, those with higher cognitive reserve also had greater disease-related brain atrophy so by the time symptoms do appear, the underlying brain changes may be more advanced. While cognitive reserve and bilingualism can delay the onset of noticeable symptoms (Alladi et al., 2013), this can also complicate timely diagnosis and treatment. As a result, individuals with higher cognitive reserve, such as those from CALD backgrounds, may be diagnosed at a later disease stage.

Addressing the gaps

Improving dementia care for CALD communities requires a multi-faceted approach. This includes:

- **Developing inclusive diagnostic tools:** Current standard dementia assessments in Australia often have cultural biases and can disadvantage non-English speakers, leading to under- or misdiagnosis. While interpreters can mitigate this risk to some extent, the development and selection of tests that are less culturally and linguistically biased is important.
- **Promoting inclusive research:** Research practices need to be more inclusive, with increased opportunities for CALD populations to participate in studies. Researchers should also consider addressing questions relevant to CALD communities and promoting recruitment efforts that focus on ensuring diverse participation.
- **Enhancing cultural competence:** Healthcare professionals should receive training in cultural competence to better understand and support people from CALD backgrounds and their families.
- **Improving accessibility:** Services should provide information in multiple languages

and ensure the availability of interpreters. Implementing culturally appropriate practices and care decisions is essential for making services more accessible for people from CALD backgrounds.

- **Tailoring programs:** Education programs and interventions should be designed to increase awareness of dementia, reduce stigma, and to bridge the gap between CALD communities and healthcare services by using culturally relevant materials and offering information in multiple languages.

Towards inclusive care

Embracing cultural and linguistic diversity in research and clinical practice is key to providing more effective support for everyone affected by dementia in Australia. Clinicians should recognise that people from CALD backgrounds may present differently and consider the role of cognitive reserve during diagnosis. To ensure accurate and timely identification of dementia, it is crucial to develop and use diagnostic tools that are culturally and linguistically appropriate.

As a multicultural society, we must strive to address the gaps and inequities faced by all those living with dementia, particularly those from CALD communities who are often underrepresented and underserved. Prioritising cultural sensitivity in clinical practice alongside continued research and education is essential to ensuring that all people living with dementia and their families receive the support and care they need.

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Improving Interpreting for Dementia Assessments – MINDSET study

By Marina G. Cavuoto, Bianca Brijnath, Simona Markusevska, Nyssa Clarke and Erika Gonzalez

Australia's multicultural population is increasingly ageing, with significant growth in the prevalence of dementia predicted in culturally and linguistically diverse (CALD) Australians in coming decades (Wilson et al., 2020). Dementia assessment and diagnosis are fundamental to ensuring access to health care for those developing or living with dementia (Phillips et al., 2011). However, CALD Australians face barriers to accurate assessment and often receive delayed diagnoses, leading to health inequities (LoGiudice et al., 2001). Such barriers can include limited and diminishing English proficiency, which may be related to aphasia (i.e., worsening ability to speak or understand speech), a common symptom that usually begins in the non-primary language (i.e., for CALD Australians that may include English) (Tipping & Whiteside, 2015).

Australian health guidelines state that independent and qualified interpreters should be present during cognitive assessments to assist people who do not use English as their primary language (Department of Health, 2021; NHMRC, 2016).

However, many interpreters report finding this a challenging area of practice. They have variable knowledge of dementia and cognitive assessment techniques which may lead to inconsistencies in the assessment process and communication errors that can negatively impact the assessment's validity (Plejert et al., 2015). Many interpreters may not be familiar with the appropriate term for dementia in the non-English language and may fall back on colloquial expressions that can be highly offensive and inaccurate. This may hamper building rapport with the patient and negatively impact the assessment.

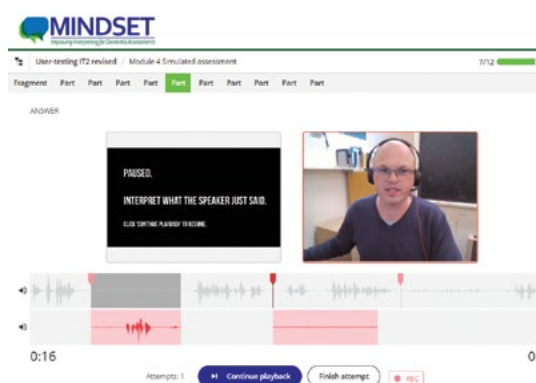
Also, interpreting cognitive assessments is linguistically intense and attentionally demanding (Haralambous et al., 2018). When a patient has a cognitive impairment, low health literacy or anxiety about the assessment process, interpreters face challenges in knowing how to negotiate these demands. A lack of specific training

in dementia means they may not have the skills for effectively communicating with cognitively impaired patients, knowledge of cognitive assessments and understanding their role in cognitive assessments (Plejert et al., 2015).

MINDSET training package

In response, we developed the Improving Interpreting for Dementia Assessments (MINDSET) training¹, a codesigned training package for interpreters mediating cognitive assessments for dementia (Brijnath et al., 2022; Gilbert et al., 2023). The MINDSET study aims to improve the quality of interpreter communication during a cognitive assessment. Our training was codesigned with input from interpreters, clinicians and CALD family members of a person with dementia to ensure it reflected diverse stakeholder perspectives. The training was user-tested and trialled by interpreters to ensure it met their needs.

The training is online, self-paced and modulated, so interpreters can take it when they choose and in "chunks" that fit in with their schedule. It covers topics such as dementia and the Australian aged-care sector, culture and dementia, briefings, introductions and debriefings, interpreting cognitive assessments, the interpreter code of ethics and how this may apply in dementia settings. The MINDSET study has been evaluated in a national randomised controlled trial (RCT) with 127 interpreters of the six most common languages spoken by older CALD Australians, including Arabic, Cantonese, Greek, Italian, Mandarin, and Vietnamese (analyses currently underway). A novel aspect of the trial used online video-simulated interpretation to evaluate interpreting quality. It involved a pre-recorded cognitive assessment between a clinician and patient, with pauses throughout to allow the interpreter to video record their interpretation of the interaction (see image).



The MINDSET Study is being rolled out nationally, providing free training to all interpreters regardless of language, qualification or experience level. The goal is to reach 2405 interpreters, representing approximately 10 per cent of the active workforce. To date, 1414 people have registered their interest in the training, 1053 interpreters have enrolled, and 385 interpreters have completed the training. Preliminary analyses suggest that interpreters in over 92 languages have completed the training!

In future, increased dementia assessments will be required to facilitate timely diagnosis, optimal post-diagnostic support and good-quality care. Clinicians conducting dementia assessments will need to rely on interpreters when assessing CALD patients with non-English language preferences.

Upskilling interpreters is one piece of the puzzle; another is training clinicians who may not be trained to work with interpreters. Many clinician training programs spend limited time on cultural competence, which may not touch on working with interpreters. Additionally, while many clinicians find working with professional interpreters challenging they must work effectively with them to better support and achieve the best quality of care for their CALD patients. This is the next step in the research program to improve dementia assessment and diagnosis for

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Working with Interpreters: practice tips and tricks

Always use qualified and NAATI certified professional interpreters during clinical care, rather than family members or unqualified staff as ad hoc mediators. For more about interpreters, see: www.naati.com.au/wp-content/uploads/2023/12/Flyer-A-guide-to-finding-a-translator-or-interpreter-English_Digital.pdf

- Even if bilingual, ad hoc mediators may not be adequately proficient in either language to interpret content and terms in a health setting accurately. Interpreting requires solid competence in both working languages, interpreting techniques and modes, professional code of ethics, interaction management skills, and in-depth knowledge of the clinical environment/health system.
- Ad hoc mediators can intentionally or unintentionally omit or add information given to or by the person being assessed due to their own interpretation of what was said.
- Family members may feel ethically compromised if they are the ones to deliver bad news or ask sensitive questions of another family member.

Find the right interpreter.

- Having the right interpreter is essential for ensuring patient trust in them.
- Check the patient's dialect because these can differ substantially and may not be understood by speakers of other dialects of the same language.
- Check if the patient has preferences regarding the interpreter's gender or religion.
- For health interpreting aim to find those with higher skill levels. In descending order, the skill level includes Certified Specialist Health Interpreters, Certified Interpreters, Certified Provisional Interpreters, and Recognised Practising Interpreters. For more, see the NAATI website: www.naati.com.au/certification/

Allow extra time when working with interpreters.

- Schedule double the time for an interpreted interaction, as everything

needs to be said at least twice.

Phone interpreting should only be used for brief information (e.g., confirming appointments).

- Video interpreting can be a viable alternative, provided a good audiovisual setup exists.

Provide a separate waiting area for interpreters and patients.

- Interpreters should not meet with patients without the clinician present as this can compromise their ability to remain impartial during clinical interactions.

Provide a briefing to the interpreter before you both meet the patient.

- Provide the interpreter with a summary of your approach and what will happen. Show them any materials you might use, and give them time to look up any terms they may need to use.
- Ask if there is anything about the patient's cultural background that you should consider when interacting with them.
- Provide information about the general cognitive status, expected severity of cognitive impairment, and the patient's wellbeing.

During the healthcare interaction.

- Introduce yourself and the interpreter and allow them to introduce themselves.
- Allow the interpreter to explain the rules of the interaction and how interpreted interviews work.
- Speak directly to the patient, e.g., my name is... I will ask you some questions about your health today, rather than "tell the patient that my name is... and I will be asking them some questions today".
- Be aware that interpreters will provide a direct interpretation of the speaker ("my name is..." and not "she said her name is").
- Provide information in chunks, then allow a pause for the interpreter

to speak. Do not overload the interpreter with large amounts of information that may be difficult to recall accurately.



Interpreters are required to keep everyone in the interaction "linguistically present".

This means the interpreter's role involves interpreting everything said by patients, family members and clinicians, even if they do not want it interpreted in the other language. If a conversation occurs between a clinician and family member, the interpreter may switch to whispered simultaneous interpreting or chuchotage (in which they interpret immediately and don't wait for a pause, in a low volume to the patient). This may be appropriate for interactions at the bedside.

Allow time for a debriefing.

- Ask the interpreter if there were any cultural or linguistic factors that you should know about.
- Ask the interpreter if they have questions or provide feedback if any issues occur during the session.
- Interpreters can experience vicarious trauma due to traumatic, upsetting or confrontational patient material or behaviour. Address anything that occurred that may have been distressing for the interpreter as they may have no other opportunity to debrief (e.g., dealing with an aggressive patient or disclosure of traumatic life events by the patient) (Lai & Heydon, 2015).

Continued from page 8

CALD patients.

Always remember that the quality of an interaction is a shared responsibility. It is paramount that clinicians and interpreters work as a team to achieve optimal communication outcomes.

¹ This work was funded by the National Health and Medical Research Council (NHMRC) through the Partnerships Projects scheme, with partners including National Accreditation Authority for Translators and Interpreters (NAATI), Dementia Australia, Australian Institute of Interpreters & Translators (AUSIT), the Migrant and Refugee Health Partnership, the NSW Health Interpreting Service, All Graduates Interpreting and Translating Service, Translating & Interpreting Service (TIS National), and the Commonwealth Department of Health and Aged Care.

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Breaking the Silence: a carer's experience with rare dementias

By Julane M Bowen

Early on in our journey with dementia, I grasped a fundamental truth that has since coloured my perception: no two cases are alike. Each person's experience with dementia is as unique as the spots on a dalmatian dog.

The diagnosis

The journey to diagnose my husband Jeff's condition, suspected to be behavioural variant frontotemporal dementia (bvFTD), was fraught with challenges that have left lasting scars. Jeff's decline began shortly after retiring from his beloved job as an airline captain. Initially dismissed by his GP as mild depression, Jeff's health rapidly deteriorated with my concerns ignored. Friends questioned my actions, and even our children accused me of worsening his state. But I knew it was more than that and I was terrified.

The turning point came when Jeff, now frail and weak, tried to lift me off the floor at home but instead accidentally dropped me, causing me to hit my head. It was a moment of truth. I decided to call an ambulance for my mild whiplash, hoping they would recognise Jeff's urgent need for intervention. The paramedics were quick to discern Jeff's grave condition and promptly scheduled him for assessment. Unfortunately, Jeff resisted their attempts to take me away for my own evaluation, leading to a distressing ordeal involving law enforcement.

Jeff was admitted to a public hospital emergency ward, then spent the next four months in the mental health ward. Despite my insistence, the medical staff neglected to diagnose him, instead pressuring me to consider permanent residential care. Refusing to succumb to this direction, I persisted in seeking proper diagnosis and care for Jeff.

Fortunately, my persistence paid off when an associate facilitated the necessary tests, including organising structural and functional brain imaging. Jeff's working

diagnosis by his medical team was revised to suspected FTD, and he was transferred to a geriatric psychiatric hospital. At the same time, I had also dedicated myself to researching medical conditions and discovered bvFTD as a potential diagnosis. My husband ticked every single box bar one.

Jeff's new treating psychiatrist at the geriatric unit became our saviour. I found the FRONTIER Research Group at the University of Sydney, a specialist FTD research centre through my late-night research. I requested a referral, and our new psychiatrist provided it. The psychiatrist followed up a few weeks later to ensure we were accepted into the research program.

That was seven years ago. Jeff began to improve with the support of his compassionate psychiatrist and a structured routine, including medication adjustments, dietary changes and physiotherapy. He stabilised enough to be brought home, where he continued improving a little in his own surroundings. I could never thank that psychiatrist enough for the past seven years he has given our family.

Navigating dementia care services and finding help for carers

Getting Jeff home brought on an entirely new set of challenges. A hospital social worker had been assigned to help me navigate support and apply for an aged-care assessment to receive My Aged Care benefits. Unfortunately, everything to do with government assistance is very time-consuming and Jeff was discharged long before we had completed the necessary documentation. I also found that many dementia service providers are not actually structured to accommodate the rare dementias. They focus on Alzheimer's disease, and my husband's dementia does not fit into that box. Finding appropriate services for rare dementias, such as Jeff's FTD, proved especially challenging. I was fortunate to have a strong educational background, good research skills, and a



supportive family and friend network to help me navigate the system, but I deeply sympathise with those less fortunate who face these same challenges.

Something that helped me immensely, especially in the early years, was meeting other carers of people living with FTD. This was a blessing because it helps to know you are not alone in sharing things that others understand because they too are living it. I know this isn't the case for everyone. I consider support networks crucial for carers or close loved ones who are suffering the long, slow decline of their loved ones. The isolation that so many carers experience is heartbreaking. Dementia has a tragic reputation of seeing carers abandoned by other family members and friends because, in my experience, people not living it find it too confronting.

Hopes for a better future

In the seven years since Jeff's diagnosis, I have become a vocal advocate for dementia awareness, particularly for rare dementias. Most people equate dementia with Alzheimer's disease, but there are dozens of different dementias that do not present like that. Jeff has never experienced memory issues and might never do so; he passes every dementia memory test

administered to him. His needs, and mine as his carer, are vastly different from that of those living with Alzheimer's disease.

The lack of awareness and understanding of rare and/or younger-onset dementia is deeply frustrating. Realistically, there are very few supports available for those of us caring for someone with a rare dementia. I did not want others to suffer as we had, so I went back to university, obtained an honours law degree and am now working towards practising in dementia law. Living with dementia does not mean a person loses their capacity entirely. They may have fluctuating capacities that can be accommodated while respecting their autonomy and self-determination. People living with dementia deserve to retain their human rights, and I have had to fight continuously for Jeff's right to home support, enabling him to live his final years surrounded by the people and animals he loves.

If I had one wish, it would be that a breakthrough in diagnostic tools happens in my lifetime. Families need certainty. Uncertainty is a common story for those living with rare dementias because diagnoses are only ever 'suspected' until confirmation at autopsy. If we had a

LIVED EXPERIENCE

reliable diagnostic tool and doctors willing to consider the possibilities, our reality would have been dramatically different. It would have enabled us to put in place early interventions, home support and a targeted pharmaceutical program to manage his symptoms and behaviours.

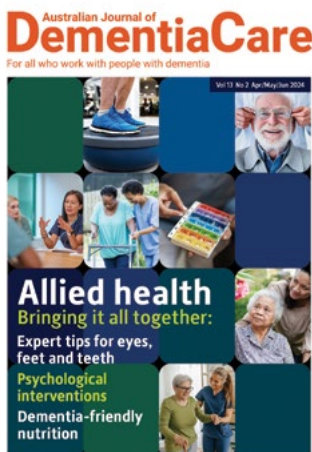
Enhancing patient care today: a new resource to assist Australian clinicians and patients

Recently, I was privileged to work with the team at FRONTIER to put together an article for clinicians and patients. This is a comprehensive guide for Australian primary and tertiary healthcare clinicians involved in dementia diagnostics and post-diagnosis care. Importantly, it considers all types of dementias, including rare and younger onset dementias. It provides up-to-date practical information, including relevant websites and services in Australia and internationally. Additionally, it features a Dementia Resources Guide booklet (Appendix S2) for clinicians to share with patients.

Article: onlinelibrary.wiley.com/doi/full/10.1111/ajag.13291

Conclusion

Navigating the world of dementia care is a daunting task filled with emotional, physical and psychological challenges. My journey with Jeff has taught me the importance of persistence, the value of support networks, and the critical need for better awareness and understanding of rare dementias. I hope our story inspires and assists others facing similar battles, as I remain committed to advocating for improved care and support for all individuals living with dementia, their carers and their loved ones.



Stay informed about the latest developments in dementia care practice, clinical updates, training, technology, research, resources and news. Subscribe to receive the journal delivered to your inbox or your door.

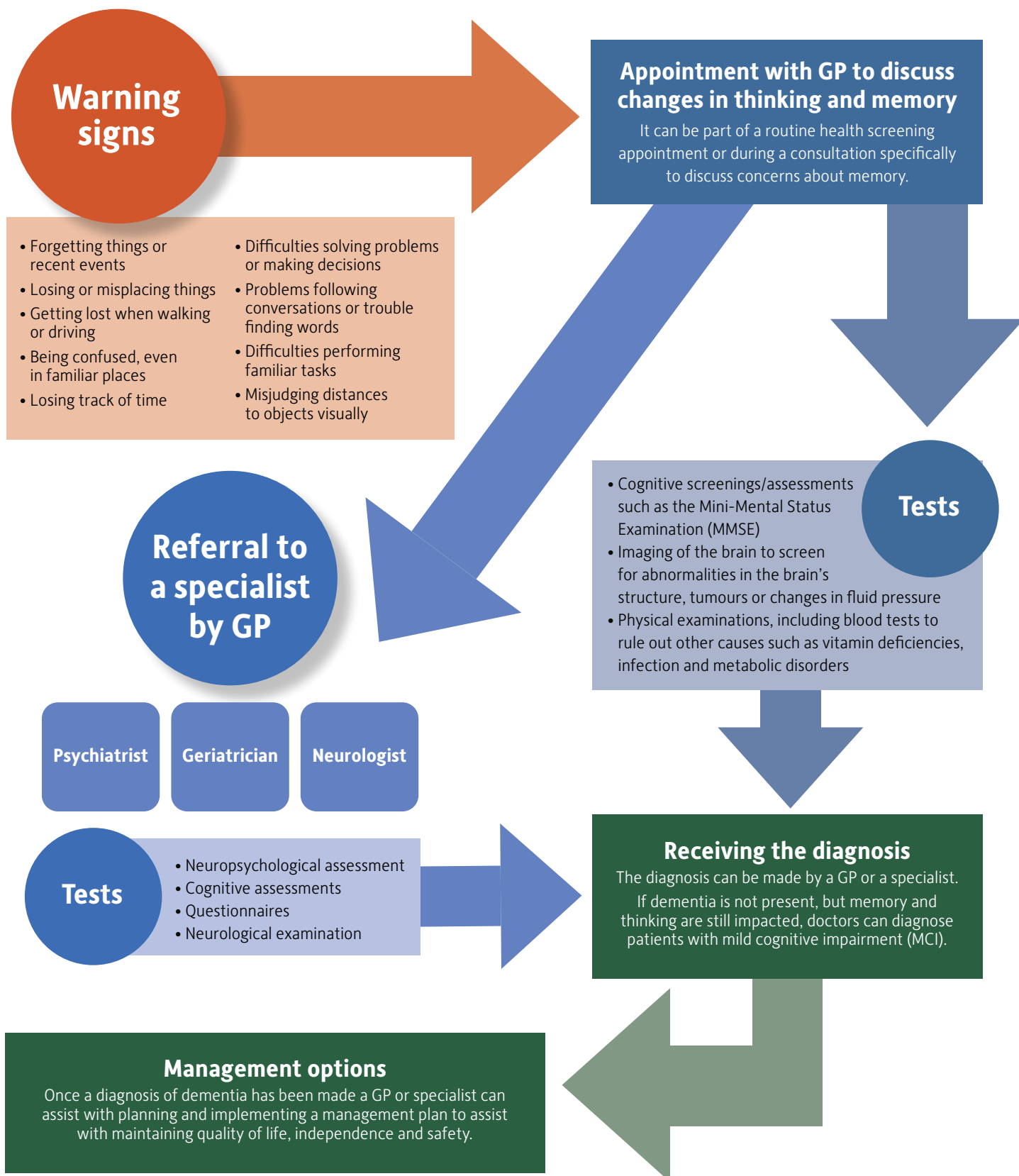
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Dementia Diagnosis Pathways

Recognising warning signs like forgetfulness or getting lost can be worrying. However, it's crucial to remember that seeking help from a GP at the onset of these changes is not just important; it's urgent. In Australia, receiving a dementia diagnosis is a pivotal moment for individuals and their families. Understanding the various pathways to diagnosis is essential for navigating the healthcare system effectively. From initial screenings by general practitioners to comprehensive assessments by specialists, diverse avenues are available.



Dementia Toolbox: seven assessment tools

Kimberley Indigenous Cognitive Assessment (KICA)

KICA is a culturally appropriate dementia screening tool for Aboriginal and Torres Strait Islander people in Australia, developed collaboratively by various stakeholders. Initially validated in the Kimberley region of Western Australia, KICA has been revalidated in multiple areas and adapted for urban and regional use, including a shorter version called KICA Screen. It has also been adapted for Indigenous communities in other countries. Research confirms KICA's effectiveness in assessing dementia in Indigenous populations, with results comparable to mainstream cognitive screening tools. For more information and access to KICA, visit: www.dementiaresearch.org.au/wp-content/uploads/2016/03/05_KICA_Form.pdf

Addenbrooke's Cognitive Examination-III (ACE-III)

ACE-III is a widely used cognitive screening tool for detecting and monitoring dementia. Recent research indicates its potential to distinguish between the three primary progressive aphasia (PPA) variants based on their unique profiles on the test's five subdomain scores. For more information and access to ACE-III, visit: www.sydney.edu.au/brain-mind/resources-for-clinicians/dementia-test.html

Mini-Mental State Examination (MMSE)

MMSE, a standard cognitive screening tool comprising 11 questions, is widely employed by healthcare professionals to assess cognitive function, including memory, communication, understanding and thinking abilities. Doctors often administer MMSE when there's a suspicion of cognitive impairment, such as following a head injury or during sudden illness episodes like infections. It serves as a crucial component in diagnosing conditions like dementia. In Australia, healthcare professionals employ

a version called the Standardised MMSE which ensures consistent administration and scoring procedures, facilitating accurate cognitive assessment. To find out more and access MMSE, visit: www.ihacpa.gov.au/health-care/classification/subacute-and-non-acute-care/standardised-mini-mental-state-examination

Rowland Universal Dementia Assessment Scale (RUDAS)

RUDAS is a comprehensive tool for evaluating cognitive impairment across diverse educational, cultural and linguistic backgrounds. Developed in 2004 by Rowland, Storey and colleagues, each component of the RUDAS underwent rigorous review by a cultural advisory group to ensure relevance and ease of translation. This scale has been validated in multicultural populations in Australia, making it particularly useful in diverse healthcare settings. One of its primary advantages is its reduced cultural and educational bias, making it suitable for individuals from culturally and linguistically diverse (CALD) backgrounds. Administering RUDAS typically takes approximately 10 minutes. For more information and access to RUDAS, visit: www.dementia.org.au/sites/default/files/2023-12/RUDAS-admin-scoring-guide.pdf

General Practitioner Assessment of Cognition (GPCOG)

GPCOG serves as a screening tool for cognitive impairment, tailored explicitly for GPs, primary care physicians and family doctors. Unlike a diagnostic test, the GPCOG is designed to quickly and sensitively identify potential cognitive issues rather than provide a definitive diagnosis. While GPCOG is notably brief, its sensitivity to cognitive impairment is high. But like any screening instrument, it's not infallible. There's a possibility of false negatives where it may miss detecting impairment, and false positives indicating impairment when there

isn't. The likelihood of these occurrences is minimal and often influenced by the prevalence of cognitive impairment within a particular population. For more information and access to GPCOG, visit: gpcog.com.au/

Montreal Cognitive Assessment (MOCA)

MoCA is a widely utilised screening tool for efficiently detecting cognitive impairment. Typically completed within 10 minutes, MoCA assesses various cognitive domains, including visuospatial skills, attention, language, abstract reasoning, delayed recall, executive function and orientation. Compared to MMSE, MoCA covers a broader range of cognitive areas, resulting in higher sensitivity and specificity. This expanded assessment makes it particularly effective in identifying mild cognitive impairment. Dr Ziad S. Nasreddine and colleagues developed MoCA as a rapid screening measure for evaluating individuals' cognitive function. Its ease of use and comprehensive evaluation make it invaluable in diagnosing, monitoring progress, and managing various forms of cognitive impairment. For more information and access to MoCA, visit: mocacognition.com/

Clock Drawing Task (CDT)

The CDT is a nonverbal screening tool assessing cognitive abilities by prompting patients to draw a clock and set it to '10 minutes past 11 o'clock'. It evaluates skills such as visual-spatial reasoning, numerical sequencing, attention, memory and motor function. CDT is widely applicable due to its absence of language and cultural biases. Studies suggest it may be more effective than MMSE in detecting cognitive impairment, especially in conditions such as heart failure. Combining it with the Mini-Cog test (a rapid screening tool) adds a memory component, enhancing diagnostic capabilities. For more information about administering CDT, visit: www.cgakit.com/_files/ugd/2a1cfa_824ff7874c-8c48888a7a0cb99ca24.pdf



BrainTrack App Promotes Timely Diagnosis of Dementia

By Dr David Sykes, director, Centre for Dementia Learning, Dementia Australia, and director, Dementia Training Australia

People living with dementia often report how difficult it was to receive their diagnosis. On average in Australia, a diagnosis takes three years and up to seven years for younger onset dementia. Many are not diagnosed at all.

Australian and international studies show that stigma and discrimination associated with dementia can discourage people from seeking health care, including a diagnosis, and can also reduce social engagement with family, friends and the broader community. This can have serious consequences for the physical, cognitive and psychosocial health of the person living with dementia.

An early diagnosis can help a person take control and plan ahead. It also means vital support and resources can be accessed sooner, to maximise quality of life and plan for the future.

In 2022 Dementia Australia launched BrainTrack, a free mobile app for individuals interested in understanding more about their brain health to effectively monitor and better understand potential changes in their cognition over time. Individuals with concerns about changes to their cognition can track these through a series of games. A report of their results can be produced and confidentially shared with their GP or healthcare professional as a conversation starter to assess the underlying possible causes of cognition changes.

BrainTrack can be used by anyone of any age, including individuals who simply want to know more about brain health and healthy ageing or reduce their risk of dementia. The app incorporates fun, travel-themed games adapted from validated cognitive tests, where users are prompted each month to play and monitor their results. Games focus on specific cognitive domains covering executive function, visuospatial function, language, visual recognition and memory.

There are specific resources for GPs,

diagnosticians and other healthcare professionals, including interpreting a patient's results, what it might mean, and tests that can be used to validate them. There is also information about modifiable risk factors and guidance on having a conversation with a patient.

Users can opt to share the report privately with their GP or other health professionals to promote open conversations about cognitive health and early diagnosis. Since launch, there have been nearly 96,000 downloads of BrainTrack and more than 35,000 participants have opted in to share their data for research anonymously.

While not intended to replace a formal cognitive assessment, BrainTrack supports the early identification of cognitive changes over time that may warrant investigation. A conversation with their GP early when a person has concerns about cognition may lead to timely diagnosis. With more than 421,000 Australians living with dementia in 2022 – projected to increase to more than 812,500 by 2054¹ – improving timely diagnosis must be a priority.

Once diagnosed, health and allied professionals play an essential role in helping people living with dementia to live well for longer. By assessing physical and cognitive issues they can provide interventions to support the maintenance of current strengths and capabilities, improve skill acquisition and promote recovery, enablement and rehabilitation.

The right support at the right time can enable people with dementia to maintain their independence and functional capacity for as long as possible. Research indicates that the use of allied health services can slow the progression of cognitive and functional decline, improve quality of life, and delay or prevent residential aged-care admission.

The more healthcare professionals know and understand about dementia and how Dementia Australia's support and services can support their patient as part of the multidisciplinary care, the better the system and healthcare experience will be for all.

A resource for GPs when treating patients with dementia diagnoses or general

cognition concerns is Dementia Australia's GP referrer pack (www.dementia.org.au/resources/health-professionals/order-your-gp-pack). This includes a dementia service guide, information on the BrainTrack app and a GP referral script pad which provides further support, information and resources by directing patients to Dementia Australia. Dementia Australia offers an outreach service for people newly diagnosed with mild cognitive impairment and dementia. This means any healthcare professional, with a patient or client's consent, can ask Dementia Australia to reach out with suggestions of appropriate support.

Anyone who works in the aged care industry, GPs and other health professionals can call the National Dementia Helpline on 1800 100 500 at any time for information on how to best support patients and clients.

BrainTrack was developed by Dementia Australia with the Applied Artificial Intelligence Institute (A²I²) of Deakin University and funded by the Australian Government. It is a free download and is available to everyone through the Apple App Store and Google Play. For more, visit www.dementia.org.au/braintrack

Since launch, BrainTrack has:

- Won the 2023 Google Play Award for 'Best app for good' and received an Honourable Mention for 'Best hidden gem' (Singapore)
- Won the Community/Not-for-Profit category at the 2023 Australian Information Industry Association, National iAwards which led to being a Finalist in the 2023 Asia-Pacific Information Communications Technology Alliance Awards (Hong Kong)
- Shortlisted in the 2023 Future of Ageing Awards, Technology – Health and Wellbeing category

Privacy information: Providing data to assist with research and to continue to enhance the app is optional and anonymous. Data is de-identified and only collected with a user's consent. Data is for research purposes and securely held by and accessible to Deakin University only. Dementia Australia and Deakin University do not collect any personal information through BrainTrack. Visit 'Learn more about our research' in the Information section in the BrainTrack app.

¹ Australian Institute of Health and Welfare (2022) Dementia in Australia, AIHW, Australian Government.

Timely Diagnosis

Is Timely Dementia Diagnosis Happening in Australia?

By Meredith Gresham Research Fellow, University of Wollongong and Visiting Fellow, UNSW Sydney.

In September 2021, AJDC posed this question to a panel of five experts. Diverging views were expressed, but echoed throughout each response was the need for the general population to understand the signs of cognitive impairment better and have access to assistance in seeking assessment so that appropriate support and treatment be made available to people living with dementia, their families and carers. In addition, extended waiting times for diagnosis were singled out as a barrier to early intervention and hampered future planning.

What is 'timely diagnosis'?

This rather ill-defined term is sometimes used synonymously with 'early diagnosis', but is also used to indicate that a diagnosis occurs at the 'right' time for the person and their family. What is considered 'right' varies for each individual and their circumstances.

Five criteria that help define what a 'timely' diagnosis is:

- A diagnosis provided with time for the person and their family to adjust and adapt to it
 - Scope to prepare for the future, including legal, financial and future care and support, and accommodation needs
 - Access to appropriate medical intervention, including disease-modifying medications given at a point in the disease that the person will derive the most benefit
 - Time to make lifestyle modifications to slow disease progression and improve quality of life
 - Access to post-diagnostic support for the person living with dementia and their families and devising disease management strategies.
- Timely assessment may also mean that

reversible causes, such as depression, medication side effects or nutritional deficiencies, can be addressed.

Where are we now?

We know that the majority of Australians recognise at least some of the early symptoms of dementia (Nagel et al., 2021). However, a nearly two-year gap remains between first noticing symptoms and seeking a doctor's appointment and 3.1 years until full diagnosis (Mansfield et al., 2022). The gap is even greater in people from culturally and linguistically diverse backgrounds (Low et al., 2019). Reasons for delay in help-seeking are numerous and include the stigma, pervasive misconceptions – both in the community and even from health professionals – that 'nothing can be done' for people with dementia, and suboptimal detection and diagnosis in primary care (Dobson et al., 2023; Ng & Ward, 2019)

An even more insidious problem is the lack of diagnosis. It is conservatively estimated that around half of Australians living with dementia remain undiagnosed (Lang et al., 2017). The 2021 *Dementia in Australia Report* highlights the lack of robust data on how many people in Australia are diagnosed by GPs or specialist services (Dobson et al., 2021).

Timely diagnosis (and even diagnosis in itself) remains an issue in 2024, just as in 2021. A new project, **Face Dementia** (www.facedementia.au), aims to address and improve diagnosis rates and timeliness through a public awareness campaign focusing on Western Sydney and Adelaide. Devised by researchers from seven Australian universities, the year-long campaign includes online resources, community events, and awareness-raising activities working with local primary health

and community organisations as well as Dementia Australia.

The project chief investigator, Professor Lee-Fay Low from the University of Sydney, said, "We want Australians to recognise early signs of dementia and understand the benefits of a timely diagnosis. The resources shared as part of the campaign can help families start a conversation about concerns and ask their GP for an assessment."

Online resources include a checklist that helps people with concerns identify symptoms and provide advice on how to have difficult conversations with family and talk with a GP.

The program resources were developed by leading researchers from the University of Sydney, the University of Wollongong, Flinders University, Deakin University, UNSW Sydney, the University of Queensland, and the University of Tasmania.

We are still far from the ideal of timely diagnosis, but it's time we made a concerted effort to make it so.

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Dementia and LGBTQIA+ Australians: challenges, gaps and paths forward

By Keira Donegan, Editor of the Australian Journal of Dementia Care

Dementia, a progressive neurodegenerative condition, poses significant challenges to individuals and their communities worldwide, including in Australia (Australian Institute of Health and Welfare [AIHW], 2024). As our understanding of dementia grows, researchers and healthcare professionals have increasingly recognised the importance of considering how various social identities intersect with the experience of dementia (Shippee et al., 2024). Among these identities, sexual orientation and gender identity play crucial roles in shaping an individual's experiences, access to care, and quality of life (Shippee et al., 2024). However, the intersection of dementia and the LGBTQ+ community remains relatively underexplored in both research and clinical practice within the Australian context.

The historical context of Australia's LGBTQ+ community is deeply rooted in a legacy of discrimination, marginalisation and invisibility. Throughout much of the 20th century, LGBTQ+ individuals faced pervasive societal stigma, legal persecution and medical pathologisation of their identities (Bull et al., 1991). The legal landscape reflected deeply entrenched homophobia and transphobia, with laws criminalising same-sex relationships and activities (Mazel, 2022). Until the late 20th century, consensual sexual activity between people of the same sex was criminalised in various states and territories (Bull et al., 1991). This legal persecution created a climate of fear and secrecy among LGBTQ+ individuals, compelling many to conceal their identities and live in the shadows.

LGBTQ+ individuals faced social ostracisation, employment discrimination and violence, further marginalising them within society. The pathologising of homosexuality and transgender identities also contributed to this, viewing LGBTQ+ people as mentally disordered and in need of treatment or to be "cured" (Grey, 2022). The lack of legal recognition for LGBTQ+ relationships also contributed to systemic inequalities and vulnerabilities (Mazel, 2022). LGBTQ+ individuals were denied fundamental rights and protections, including the ability to marry or enter into legal partnerships, access to spousal benefits, and inheritance rights (Mazel, 2022).

This lack of legal recognition exacerbated social and economic disparities, leaving LGBTQ+ elders particularly vulnerable in later life (Fredriksen-Goldsen, 2019). As a result, LGBTQ+ elders in Australia today may carry a lifetime of trauma, discrimination and invisibility, which can manifest in unique ways in the context of dementia (Fredriksen-Goldsen, 2019). Many LGBTQ+ individuals have lived through decades of systemic oppression, leading to a deep mistrust of institutions and healthcare systems. The mistrusting historical context shapes their experiences of aging, access to care, and support networks, contributing to distinct challenges and disparities in dementia (Shippee, 2024). Understanding this is crucial for healthcare providers, policymakers and researchers seeking to address the unique needs of LGBTQ+ individuals living with dementia. By acknowledging and addressing the legacy of discrimination and marginalisation, we

can work towards creating more equitable and inclusive systems of care that respect the dignity and autonomy of all individuals, regardless of sexual orientation or gender identity.

The intersection of dementia and LGBTQ+ identities presents numerous challenges and disparities that impact access to care, quality of life, and health outcomes. These include:

- **Healthcare discrimination and lack of cultural competency:**

LGBTQ+ elders may face discrimination and insensitivity from healthcare providers who are not trained to address their unique needs, leading to reluctance to seek care or disclose their sexual orientation or gender identity (Ayhan et al., 2020). Discriminatory attitudes, lack of understanding, and heteronormative assumptions can create barriers to accessing appropriate care, leading to delayed diagnosis, misdiagnosis or inadequate treatment.

- **Intersectional identities:** The experiences of LGBTQ+ individuals living with dementia are further shaped by intersecting identities such as race, ethnicity, disability and socioeconomic status (Fredriksen-Goldsen et al., 2018). LGBTQ+ elders from marginalised communities may face compounded discrimination and barriers to care, exacerbating health inequities and disparities (Fredriksen-Goldsen et al., 2018).

- **Unique care dynamics:** LGBTQ+ caregivers may experience unique challenges in providing care for a loved one with dementia, including navigating

healthcare systems that may not be inclusive or understanding of their family dynamics (Fredrick-Goldsen et al., 2018). Ignorance of family dynamics can lead to increased stress, burnout and compromised wellbeing for both the caregiver and person living with dementia.

• Erosion of support networks:

LGBT+ individuals with dementia may experience the erosion of their support networks as their cognitive abilities decline, particularly if they have relied on chosen family or community connections for care and companionship (Shippee, 2024; Henning-Smith, 2015). This loss of support can impact their emotional wellbeing and contribute to feelings of loneliness and isolation.

Addressing these challenges and disparities requires a comprehensive approach prioritising cultural competency, inclusive care practices and policy reform. By acknowledging the historical context of discrimination and trauma, healthcare providers and policymakers can work towards creating more equitable and inclusive systems of care that respect the dignity and autonomy of all individuals, regardless of sexual orientation or gender identity.

Ensuring equitable access to healthcare and fostering inclusive practices is paramount for addressing the needs of LGBT+ individuals living with dementia. Healthcare organisations and providers must actively work to create safe, welcoming environments where LGBT+ elders feel respected and supported (Shippee, 2024). Several strategies can facilitate this goal within the Australian healthcare system:

• Cultural competency training:

Healthcare providers should undergo comprehensive cultural competency training to understand better and address the unique needs and concerns of LGBT+ individuals (Seelman, 2019). Training programs should cover topics such as LGBT+ terminology, inclusive language and the impact of discrimination and stigma on health outcomes (Pereira et al., 2020; Price, 2012). By enhancing provider awareness and sensitivity, cultural competency training can help reduce barriers to care and improve patient-provider communication (Simpson et al., 2017).

• Affirming intake processes:

Healthcare intake processes should be designed to collect accurate and inclusive demographic information, including sexual orientation and gender identity (Willis et al., 2016). Collecting this data allows healthcare providers in Australia to understand their patients' diverse identities and experiences and tailor care accordingly. Electronic health record systems must also accommodate diverse gender identities and pronouns, ensuring patient information is accurately documented and respected.

• Community partnerships and engagement:

Healthcare organisations can enhance their capacity to serve LGBT+ elders by forging partnerships with local LGBT+ community organisations and advocacy groups. Collaborating with community stakeholders can help providers better understand the needs and priorities of LGBT+ individuals and facilitate outreach and education initiatives (Fredriksen et al., 2019). By actively engaging with LGBT+ communities, healthcare organisations can build trust, foster collaboration, and ensure that services are responsive to community needs (Fredriksen-Goldsen et al., 2019).

By prioritising cultural competency, adopting inclusive policies and fostering meaningful engagement with LGBT+ communities, healthcare providers and organisations can create environments where LGBT+ elders living with dementia feel affirmed, respected and empowered to seek the care and support they deserve. These efforts are essential for promoting health equity and reducing disparities within the healthcare system.

The intersection of dementia and the Australian LGBT+ community represents a complex and underexplored area of research and practice. Addressing the unique challenges faced by LGBT+ individuals living with dementia requires a concerted effort from healthcare providers, researchers, policymakers and community stakeholders. By fostering inclusive care practices, conducting targeted research, and advocating for policy changes within the Australian context, we can work towards ensuring that all individuals, regardless of sexual orientation or gender identity, receive the support and dignity they deserve in the face of dementia.

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Disclaimer: In this article, LGBT+ refers to the diverse community of individuals who identify as lesbian, gay, bisexual, transgender, and other sexual orientations and gender identities. We acknowledge that this acronym may not encompass all identities and experiences within the community and aim to use inclusive language while respecting each person's individuality.

Dementia in Aboriginal and Torres Strait Islander Communities: current evidence, gaps and need for culturally safe, community-led programs

Image by Gumbaynggirr artist Alison Williams, taken from the Ngarraanga Giinganay program

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In line with global population projections, Aboriginal and Torres Strait Islander people in Australia are reaching older age in increasing numbers (Temple et al., 2020). Older Aboriginal and Torres Strait Islander people are central to communities, carrying out important cultural roles such as Eldership and passing on knowledge to younger generations. These roles are couched in immense strength and resilience, fulfilled in the face of the ongoing trauma and health disparities stemming from colonisation and past policies, including the Stolen Generations (Griffiths et al., 2016; Menzies, 2019).

This pervasive exposure to racism and discrimination affects the holistic social, emotional, physical and cultural wellbeing of Aboriginal and Torres Strait Islander people (Kairuz et al., 2021). There is also a higher proportion of older Aboriginal and Torres Strait Islander people who develop dementia compared to the broader Australian population (Radford et al., 2015; Russell et al., 2021; Smith et al., 2008). This is despite the majority of older people not developing dementia in their lifetime.

Better understanding

Research conducted in partnership with Aboriginal and Torres Strait Islander

communities is leading to a better understanding of dementia and the factors that may be contributing to these disproportionately higher rates. We now know that the most common diagnosis of dementia for Aboriginal people is Alzheimer's disease (Radford et al., 2015), following a similar pattern to non-Indigenous people.

Our work with Aboriginal communities in urban and regional New South Wales, through the Koori Growing Old Well Study (KGOWS), has identified various factors across the lifespan that are related to all-cause dementia, including age, childhood stress and adversity, unskilled work in midlife, and cerebrovascular disease and head injury in later life (Radford et al., 2017; 2019).

Longitudinally, we have found that age, male sex, unskilled work and polypharmacy increase the risk of incident dementia and mild cognitive impairment over six years (Lavrencic et al., 2022). Similar studies in other Aboriginal and Torres Strait Islander communities have identified overlapping risk factors in terms of dementia prevalence, as well as additional factors such as education, current smoking, epilepsy and chronic kidney disease (Russell et al., 2021; Smith et al., 2010).

Major gaps

Although the importance of addressing dementia-related needs and preferences for Aboriginal and Torres Strait Islander people is being increasingly recognised, there are still major gaps in our understanding of many aspects of dementia and dementia care. The current focus on modifiable biomedical risk factors at the individual level fails to address the dementia and brain health landscape as it does not recognise the “dynamic interconnectedness” between culture and spirituality, family and community, historical, social and economic factors, nor recognise community strengths (Gehlert et al., 2008; Henderson et al., 2024).

Yet research has shown that quality of life for older Aboriginal peoples encompasses aspects outside of individual biomedical risk factors. Instead, living “a good life” is influenced by factors such as culture, Country, spirituality, the Elder role and community, in addition to other more commonly considered aspects, including health and basic needs (Smith et al., 2021).

The ongoing impact of broader factors is also alluded to through our KGOWS findings linking childhood trauma and adversity to dementia. Notably, 10 per cent of participants indicated they had been

Survivors of the Stolen Generations are now all aged 50 years and older, meaning that it is increasingly important to focus on factors outside of the individual in the context of dementia and aged care for Aboriginal and Torres Strait Islander older people.

removed from their family and more than 40 per cent of participants had family who had been separated (Radford et al., 2015; 2017). This highlights the undoubted long-term impact of such historical factors and their contemporary ripple effects across communities.

Survivors of the Stolen Generations are now all aged 50 years and older (AIHW, 2021), meaning that it is increasingly important to focus on factors outside of the individual in the context of dementia and aged care for Aboriginal and Torres Strait Islander older people, in line with the Social and Emotional Wellbeing model (Gee et al., 2014). Understanding the health of the whole community is essential for understanding and supporting the health of older people, including community strengths and resources.

Despite gaps in our knowledge of dementia risk and protective factors, the mounting evidence does support the need for dementia prevention programs that target modifiable factors. However, mainstream programs and resources are often inappropriate, unrelatable, and culturally insecure. Genuine co-design with Aboriginal and Torres Strait Islander people and communities is required from the outset to ensure they feel safe, welcomed and culturally respected. Tailored programs specific to the local context and participant group will likely be most effective.

One example of program co-design with Aboriginal communities comes from our research group. We identified the need for a tailored program to address psychosocial wellbeing for older Aboriginal people based on two factors: (1) the KGOWS findings that identified links between dementia and life course trauma and stress and (2) further consultation with the KGOWS Aboriginal and Torres Strait Islander Steering Committee that highlighted gaps in culturally safe programs aimed at reducing rates of cognitive decline (Lavrencic et al., 2021).

This led to us developing the Ngarranga Giinganay program (meaning 'thinking peacefully' in Gumbaynggirr language). Ngarranga Giinganay is a culturally grounded, mindfulness-based program developed for Aboriginal people living on Gumbaynggirr Country in New South Wales (Lavrencic et al., 2021). An idea for

the program was decided on among the lead researchers (including an Aboriginal Elder), and we collaboratively developed an eight-week group-based program that encompasses information about mindfulness ('teachings'), mindfulness exercises, poems, local artwork and discussion.

It was decided that the program should be facilitated by two Aboriginal people, including a local Elder, to ensure cultural information could be included and discussed appropriately. This program draws on Aboriginal ways of knowing, being and doing – connection – which reflect but are not necessarily labelled as mindfulness techniques.

After initial development, we conducted a pilot trial of the program. We found that Ngarranga Giinganay was feasible and acceptable for older Aboriginal people, with preliminary effectiveness established through both positive qualitative participant feedback as well as trends in reductions for psychological symptoms and blood pressure (Lavrencic et al., 2021).

At all stages, including piloting, we were committed to genuine co-design and refined the program through workshops (including Aboriginal and non-Indigenous experts), collaborative yarning groups with local Aboriginal Elders, ongoing community feedback and integration of suggested program changes throughout and after piloting (Lavrencic et al., 2021). One example outcome of this process is that the program now also includes poems and other content in Gumbaynggirr language, which helps to strengthen cultural connection and ownership over the program.

Success with close collaboration

The pilot success of Ngarranga Giinganay was undoubtedly due to the close collaboration with Aboriginal people and Elders throughout all stages of the research. This program has been created with and for community. Although some of the leading researchers of this work are non-Indigenous, everyone who has driven this work forward has a genuine commitment to focusing on community priorities and ensuring that the community has ownership over the program. In addition, it is led by Aboriginal people with strong ties to the local community. This has been critical to the program's success, providing cultural understanding and safety

that would not have been achieved even with non-Indigenous staff well-known and accepted by the community.

Given the support of the community to keep the program going, we continue to trial the Ngarranga Giinganay program not only on Gumbaynggirr Country but through adaptation to other Aboriginal communities as part of a larger trial called the Standing Tall with Our Mob Project (STOMP!). This adaptation involves an Elders yarning group held on Country to discuss the existing program, including going through some of the mindfulness exercises as examples.

Work in progress

To date, we have carried out this adaptation process with one community and implemented their suggestions, including removing Gumbaynggirr language (with the intention of including local language instead) and following up with local artists and writers to incorporate more relevant artwork, poems and quotes. This continues to be a work in progress, helped by the fact that the Ngarranga Giinganay program was developed to be responsive to the needs of local communities and participants.

Overall, our experience of co-designing programs with older Aboriginal people has been a valuable learning experience for the research team. We have needed to be flexible and adaptable, which can sometimes be difficult when working within strict funding guides and timelines. However, we have strived to listen and act based on community feedback, which has led to overwhelmingly positive results regarding participant feedback and engagement with the research. We continue to evaluate the effectiveness of Ngarranga Giinganay and other programs as part of our commitment to listening and driving forward priorities set by partnering Aboriginal communities.

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Diverse Perspectives: incorporating cultural values in dementia care

By Sally Day, occupational therapist, The University of Sydney

Our culture shapes who we are and creates a sense of belonging. Culture incorporates our beliefs, values, lifestyles, traditions, and experiences. Understanding people with dementia's culture is vital to providing culturally inclusive and acceptable care.

Know the individual living with dementia

- **Find out about their culture and demonstrate your understanding. This can make people living with dementia feel known and valued.**
 - However, don't make assumptions.
- **Ask the right questions in the right way; people's cultural needs may not fit into a standard checklist.**
 - Ask, "What is important and meaningful to you?"
 - Draw on family insights; they are the experts of their family member with dementia
- **Examples of culturally inclusive care include:**
 - Building relationships by spending time talking before starting the care
 - Asking permission before entering

someone's room or home: asking if you should remove your shoes before entering

- Accepting refreshments when offered

Engage the person living with dementia and their family

- **Consider your communication:**
 - Use interpreters, simple language or pictures
 - Make sure the person with dementia and their family all understand the exact meaning of what is being said. For example, are they saying "yes" because they agree with you or are they being polite?
 - Draw on cultural advocates to help you understand the person with dementia
- **Consider how you offer support; culture can influence people's perception of care. Engaging the family in discussions about how care should be provided is essential. In some cultures:**
 - It is the family's job to provide care for an older person, and they may be reluctant to accept outside "care" but may accept company or other forms of support
 - There is stigma around dementia, and they may prefer you use different

terminology.

Support people with dementia to engage in culturally meaningful activities to make them feel part of their community

- Even if they can't do all of an activity, they can participate in some of it
- Make sure activities are still important and culturally relevant to them now.

Embed culture into the everyday

- **Culture and cultural practices are not just for special occasions. Work to ensure cultural inclusivity is part of the everyday life for the person living with dementia, for example, through food choices, activities and routines.**

Consider your own role in culturally inclusive care

- **We all have a 'cultural lens'. This describes how our experiences, beliefs and values influence our perception of situations, and we make judgements and assumptions based on our own cultural lens.**
 - Realise your cultural lens is not the same as another's. Be aware that you don't know what is culturally acceptable to an individual.

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Trauma-informed care for people living with dementia

By Lenore de la Perrelle, PhD, Research Fellow, College of Nursing and Health Services, Flinders University, Adelaide

It's not surprising that people living with dementia may also be affected by past traumatic events. Up to 70 per cent of older adults have experienced a psychologically traumatic event in their life (Reynolds et al., 2016). While most people recover, traumatic events can have lasting effects, including increasing the risk of dementia (Severs et al., 2023). Traumatic life experiences can include war-related trauma, sexual assault, domestic violence, adverse childhood events, and racial or religious persecution. Staff supporting war veterans, Holocaust survivors or refugees will recognise symptoms such as heightened fear and anxiety, high sensitivity to care practices, intense emotions and anger, mood disturbances and hyperarousal. Trauma symptoms can re-emerge in older age and affect behaviour and the experience of care (Cations et al., 2020).

Impact of traumatic experiences

How do traumatic experiences impact a person living with dementia? Distinguishing between symptoms of dementia and post-traumatic stress disorder (PTSD) is complex and they may overlap each other. What may be considered symptoms of dementia, such as agitation, aggression, fear and anxiety or withdrawal, may also be symptoms of PTSD. Using aged care requires older people to accept their limitations and lose control of their privacy, their own home or safe place, sharing spaces with strangers, accepting intimate personal care from strangers, closed or locked doors, noise, and the monitoring of their movements and physical state. Even in pleasant care environments, these changes and routines can overwhelm older people, who grieve losses and privacy.

For people living with dementia, in addition, many aged-care experiences don't make sense as they may not recognise their own needs or may not recall why they have a stranger providing care or are in a place other than home. They may want to go home, and resent or refuse strangers interfering with their lives.

When you add previous traumatic life experiences to the experience of dementia and losses of ageing, reactions to routine aged-care practices may trigger memories of past trauma and responses such as explosive anger or aggression, reliving the event, refusing care, and a need to escape. Sometimes, an opposite reaction occurs, such as a sense of hopelessness, dependence and withdrawal, which affects the person's wellbeing (Couzner et al., 2022).

People living with dementia may not be able to express their fears and past traumatic life experiences verbally or adapt to the care environment. The impact of dementia reduces their ability to regulate the intense emotions triggered by reliving a traumatic event (Craftman et al., 2020). Family members may not know of past traumatic experiences or only have a limited understanding of a person's history and feel unprepared to respond to out-of-character behaviour.

Trauma-informed care

What is trauma-informed care and how does it differ from regular practices? It can improve the quality of aged and dementia care (de la Perrelle et al., 2022). In contrast to trauma-specific treatment services, trauma-informed care does not require specialised clinical skills. Trauma-informed care can be applied to any service and involves understanding and being responsive to service users' trauma experiences at all service levels. Trauma-informed care originated in mental health services where mental illness and trauma symptoms are common. It is used across many human services to respond to the needs of trauma survivors for safety, a sense of control and avoidance of triggering reactions within any service.

The fundamental principles of trauma-informed care include maximising the availability of safety, trustworthiness, choice, collaboration, empowerment (Fallot & Harris, 2008) and respect for diversity and inclusion. In aged care, if we recognise

Tips for dementia-care staff

- Always screen the person's life history at entry to aged care, as they may have experienced traumatic life experiences
- Add a question to admission protocols to ask directly if the person has had previous traumatic life experiences
- Always ask the person or family to identify examples of sensitive or upset behaviour, such as not trusting strangers, a need to see exits, fear or distrust of places, sleep disturbances or nightmares, a need for privacy, distress on anniversaries of events, discomfort with changes, inconsistency, or sudden noise
- Always use the person's name and explain what you are doing before you do it. Offer choices to allow control
- Always maintain a calm approach, do not hurry or raise your voice, and do what you promise, such as returning in a few minutes.

that many people have experienced trauma and that symptoms can resurface in older age and with dementia, we can make services safer for staff and older people by modifying service level practices to minimise re-traumatisation. For example, suppose we know the person's history. In that case, we can plan care to recognise sensitivities, such as consistency for privacy, not wanting certain care staff, always offering choices and being transparent by not using an authoritarian approach.

While person-centred care is the basis of good dementia care, the added perspective on the role of trauma in how survivors experience care is needed. This includes a whole-of-service approach to recognise the possibility of trauma affecting all service users, a commitment to minimising re-traumatising effects of service routines and practices, routine screening of a person's

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A New Era of Aged Care: insights from an expert

By Keira Donegan, Editor of the Australian Journal of Dementia Care



Let's journey into the changing landscape of aged care, guided by the wisdom of Ian Yates AM, who spent 20 years as CEO of the Council on the Ageing (COTA), the national peak consumer body for older Australians. Ian also served as interim inspector-general of aged care and is currently acting inspector-general of aged care. Ian sheds light on how aged-care practices have shifted gears, touching on transparency, governance, dementia care, diversity and technology.

Australia's aged-care system is rapidly growing and evolving, and it can appear complex and secretive to outsiders. But, on reflection and comparing the past and present of aged care, Ian shines a light of hope on the sector and how it opens up more to the public eye. Things are becoming clearer thanks to initiatives such as the Serious Incident Response Scheme (SIRS).

"The aged-care system has been in significant evolution for years. [The Royal Commission has] shone a powerful spotlight regarding some significant issues and the lack of priority aged care has been getting in public policy," says Ian. "We have a way to go in terms of what I would regard as the centrality of dementia care to aged care. People are realising the great significance of home care in terms of dementia care. We're early on the journey, but transparency in the aged-care system has changed because of the Royal Commission's recommendations

and the government's regulatory response."

Ian underscores the significance of transparency in fostering an environment where discussions about aged care and dementia can thrive. He acknowledges the strides made but highlights the ongoing need to evolve. "The aged-care system is more transparent to the world than it was, not to say that it couldn't be more transparent. But there's only so far you can go with regulation. My message is that transparency remains an absolute bedrock for positive engagement with the community so they can accept when you say, 'Well, this is what we're trying to do; we got it right here. We're trying to do this, and we can engage in that.' But if you're doing it all behind closed doors, the community doesn't know what's happening."

Dementia is getting more attention now, with advocates stepping up and the public starting to talk about it more openly. Says Ian, "Aged care is a funny beast

because people don't want to discuss it. So, the Royal Commission says, for example, that we want more people to think about their aged-care plans ahead of time. That's a significant challenge; [people] won't do it. It is very much the same with dementia. While

some things have changed over the last decade, we are seeing the emergence within the sector of people with dementia speaking as advocates. Dementia is being discussed as a major public policy issue rather than something we didn't talk about. There is a recognition of dementia being an umbrella [rather than a single] disease."

Ian acknowledges there's still work to be done in reducing stigma and spreading awareness about dementia and its

challenges. "You hear the stories such as 'I got a diagnosis of dementia, and from that day on, my doctor started talking to my spouse/child as if I wasn't there and I couldn't understand what they were saying.' There are issues about general awareness in the community that go hand in hand with the focus on the sector. It's about how we as a community live with the

fact that people continue to live even with a dementia diagnosis. There is a lot of feeling still that if you get dementia, you're headed to residential aged care. Most people with dementia are not living in residential aged care. They're in the community."

Ian stresses the importance of treating

"I got a diagnosis of dementia, and from that day on, my doctor started talking to my spouse/child as if I wasn't there and couldn't understand what they were saying."

everyone in aged care with respect and understanding their individual needs. He wants to see a shift away from a one-size-fits-all approach to one that embraces diversity and cultural sensitivity. “The aged-care sector needs to become much more aware, and this is a leadership issue for government and management levels, but also at the sector-wide level. It needs to become much more aware that you need to be engaged with your consumers about who they are and what they want out of support and care. One of the issues is about what we will do in aged care, and then we talk about diversity, which is a given.

“I get annoyed with people talking about mainstream aged care. It should just be aged care focused on how you support an individual. Certainly, there are groups of individuals with certain characteristics that you might learn how to deal with next time. For example, one Italian person is not necessarily the same as another. It is about understanding that diversity is at the core of your mission – that is, how do we support each person to live the best life they can.”

Technology can be a game-changer in aged care, but Ian thinks overall the sector is still far from fully using it to its full potential. From streamlining operations to offering remote-care solutions, there’s a lot we

can do. However, he reminds us that we must ensure everyone can access and use these technologies.

“It is critical regarding your basic operations as an organisation,” he says. “For example, are you using tech which enables you to record everything that’s going on with a particular resident so it’s there in the system for the next shift? Do all the components of your systems talk to each other? There have been research studies that show huge increases (some by 20 to 25 per cent) in productivity for staff if they have the right IT setup.”

Ian envisions a more holistic and inclusive aged-care system with early intervention, better rehabilitation services, and a workforce trained to meet the diverse needs of older adults. Ultimately, he believes we can create a future where aged care is transparent, eclectic and centred around the individual.

“Firstly, the Royal Commission pointed to the need for a new aged care system that wasn’t divided into different buckets and structures. Now, we haven’t seen that yet. “Let’s think about a support and aged-

care system that is oblivious to location and doesn’t have defaults. Conceptually, we have to think about that because it brings in all sorts of other senior living environments where you can perhaps insert different types of support. Secondly, we need a much more diverse system because we still have a cookie-cutter approach. Why should we have an aged care system? Why shouldn’t we have a care system for people who need support? Also we have to build the offering around the customer and the person

and embed it as a culture in aged care. That’s fundamental. We are doing much more consulting, or the sector is doing much more. These are things we’re doing and planning to do.”

Ian’s insights are a reminder that aged care is evolving but has room for improvement. By embracing transparency, valuing diversity, harnessing technology and prioritising individual needs, we can build a brighter future for aged care in Australia and beyond.

“There shouldn’t be any mainstream aged care; it should just be aged care focused on how you support an individual.”

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life history to identify if there have been any traumatic events, and the delivery of care in a way for the person to feel safe and respected. Staff should be trained to recognise trauma-related needs and how to modify their approach to reduce distress and offer comfort.

Trauma-informed care in dementia

People who have experienced trauma earlier in life are more likely to experience a decline in mental health, physical health and cognition. As we are living longer, we now see the effects of past trauma on older people. For trauma survivors who develop dementia, their emotional memories persist, and they may re-experience traumatic events as if they are occurring in the present moment, even though they cannot verbally explain what they are going through (Craftman et al., 2020). Aged-care staff have identified that caring for people with dementia and behavioural disturbance is complex, and that behaviour appears

unrelated or out of the blue. The lack of awareness of the impact of trauma may result in causing distress, and compromise the safety of staff and the person living with dementia. Dementia care services need to use a trauma lens to understand the person, their behaviour and causes of distress. Aged-care staff need to know the person’s history and their individual needs to put in place care plans that are trauma-informed, respectful and safe.

Trauma-informed care extends person-centred care. By recognising that traumatic life events can impact the care experience, services and staff can plan care practices that respect needs and respond to individuals’ sensitivities. By ensuring safe, consistent and calm approaches to care, staff can minimise reactions and improve safety for staff and the person living with dementia.

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Early Diagnosis in Primary Care

By Dr Marita Long, Lecturer in Dept of General Practice and Primary Care at the University of Melbourne and Honorary Medical Advisor for Dementia Australia

Currently, 421,000 people live with dementia in Australia, and this is projected to double by 2050 (Dementia Australia, 2024). Over 50 per cent of people with dementia remain undiagnosed, limiting their access to treatments that could slow disease progression and improve their quality of life (Tierney et al., 2019).

Barriers challenge GPs

Some 84 per cent of individuals seek an initial consultation with a GP to discuss their dementia symptoms (Tierney et al., 2019). While primary care settings can often lead to an accurate diagnosis, several barriers hinder GPs from feeling confident in identifying dementia such as the lack of a specific diagnostic test; educational gaps; and perceived limited treatment options. The lack of specific diagnostic tests that may not give a definitive result for dementia can seriously challenge the GP. Insufficient education can impact a GP's ability to recognise early signs (Tierney 2019; Mason 2020). Sadly, many still assume that dementia is a normal part of ageing which can delay their presentation to a GP for assessment (AIHW, 2024). There is also a significant level of fear and stigma that accompanies a diagnosis (Mason, 2020). People with dementia may have comorbidities, such as high blood pressure and diabetes, which also impact the process of receiving a diagnosis, subsequent management and overall quality of life (Bergman et al., 2023).

While it might be tempting to label a dementia diagnosis as "too challenging" for GPs, unnecessary referrals to other specialists can lead to delays in diagnosis and fragmented care – especially when long waitlists exist for memory clinics, geriatricians and old age psychiatrists. People with comorbidities, who are already engaging with a range of specialists and health professionals, may feel as if they are trapped in a referral rabbit hole.

Growing resources

There are just not enough geriatricians, psychiatrists, neurologists or memory clinics available to cater for the growing number of people who will be living with dementia over the next 30 years, particularly in remote areas (Evashwick, 2023). The good news is that there is a growing number of resources, educational opportunities and decision-making tools to support GPs in feeling more confident about diagnosing dementia and initiating care (Evashwick, 2023). Hopefully, by improving interprofessional collaboration and coordination of care between GPs, specialists and allied health providers, some of these challenges will be minimised.

An initial step toward improving the quality of care for people living with dementia is to raise awareness. By introducing patients (and carers) to the concept of brain 'health' akin to how we approach other chronic diseases, we can make a major impact (Chong et al., 2021). Some key points to consider are:

Understanding dementia as a chronic disease: Dementia is not an isolated event; it is a chronic, neurodegenerative condition. Notably, abnormal changes begin about 20-30 years before symptoms.

Modifiable risk factors: Certain modifiable risk factors contribute to dementia development. About 40 per cent of cases globally could be prevented or delayed by addressing these (Livingston et al., 2020).

Midlife as a critical period: Midlife is a critical time for individuals to be aware of their dementia risks and take proactive steps to mitigate them.

Medicare-funded assessments: Australians aged between 45 and 49 are eligible for a midlife health assessment which is an excellent opportunity to raise the idea of brain health and risk modification (Chong et al., 2021).

Additional resources:

- CogDrisk is a free, online evidence-based tool to assess an individual's risk of dementia and offer strategies to reduce it. It generates a report that can be downloaded and shared with the GP.
- Clinical guidelines synthesise current evidence in dementia care and emphasise timely diagnosis, encouraging the person with dementia to exercise, eat well and keep doing as much for themselves as possible; supporting and training carers; and reducing the prescription of potentially harmful medications.
- Dementia Australia National Help Line on 1800 100 500 offers GPs 24-hour access to free and confidential expert support and guidance, as well as their GP Dementia Referral Pack (www.dementia.org.au/professionals/gps-and-other-referrers/refer-someone-your-care).

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Validation Meets Mindfulness: beating burnout

By Helena de Klerk & Vicki de Klerk-Rubin

What is burnout?

Burnout occurs when mental, emotional and physical exhaustion takes over (van Dam, 2021; Maslach & Leiter, 2016; Maslach et al., 2001). More than feeling stressed, it is a mind and body state of 'I have overstepped my limits'. It often includes key aspects of emotional exhaustion, depersonalisation and reduced personal accomplishment (Maslach et al., 1996). Burnout is usually a result of unrealistic external expectations blended with internal pressures that push us to this state of collapse and so affect not only individuals but also whole systems (National Academy of Medicine, 2019). Burnout is most often referenced within work stress or work-related conflict. But it can also occur in stressful situations such as being a caregiver.

What is validation?

Validation is a method for connecting and communicating with older adults, especially with cognitive decline. It encompasses a theory of ageing, a fundamental attitude and techniques that help a validator communicate with the person. Since its creation by Naomi Feil in the 1970s, the method has been implemented worldwide in professional and home-care settings by physicians, nurses, social workers, direct caregivers, and family care partners.

Since Feil first presented her research at the Gerontological Society of America in 1972, studies globally have reported increased satisfaction and reduced stress symptoms; positive changes in the qualitative nature of relationships between staff and residents; reduced physical and verbally aggressive behaviour by the

residents; and improved work climate (Oliveira & Sousa, 2021). A literature review by Sanchez-Martinez et al. (2020) reiterated those results. For more information, visit: vvalidation.org/

What is mindfulness?

Mindfulness is a process by which we foster non-judgmental awareness of the present moment (Kabat-Zinn, 2003). Its origins are in Buddhism, where it is often cultivated through meditation. Any activity that encourages us to slow down and become more aware of what is going on internally can promote mindful attention. And any activity that helps us become more aware of our reactivity, thoughts, feelings or behaviour helps us cultivate a more mindful attitude.

Mindfulness has been researched in numerous sectors and is practised in therapy forms in Mindfulness-Based Stress Reduction (MBSR) and Mindfulness-Based Cognitive Therapy (MBCT). While research has shown that mindfulness reduces burnout and stress and improves wellbeing and self-compassion, it is essential to remember that it is not a cure-all and it does not automatically make us calmer and less stressed (Gerada, C. (2019); Goodman & Schorling, 2012; Green & Kinchen, 2021). It is a process of paying attention to whatever arises and helps us respond rather than react to what arises. It focuses just as much on challenging experiences as on nice ones and not only helps us identify when we might be burned out, but it can also help us notice signs of burnout and support us in preventing it from developing by giving us

space to respond instead than react, helping us make informed choices rather than reacting to external circumstances and personal impulses.

Where do they meet?

There is currently no research available comparing these two approaches. However, both processes involve similar qualities and processes, although they differ in fundamental ways. We propose that they start from a similar place. Both cultivate an awareness of the present moment (i.e., centering in validation) and an ability to step back to see what's going on (i.e., observation in validation). However, they diverge at the point of taking action; at its core, validation is a method for communicating with others, whereas mindfulness is not. In Buddhist practice, mindfulness is often viewed as a way of being fully conscious that lays the groundwork for actions of the mind and body, such as loving, kindness and compassion. This comparison between them is captured below.

Clinician validate thyself

There are several areas where validation and mindfulness overlap and several skills can help clinicians and caregivers prevent burnout. For example:

1. Centering or awareness

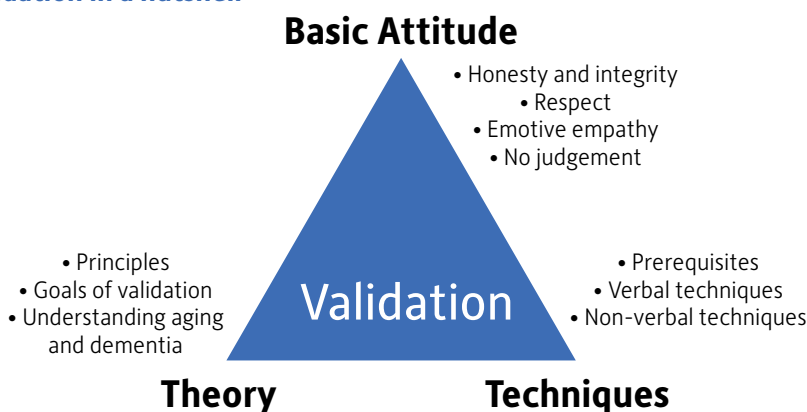
An older adult, filled with sadness about her life, comes into my office and says, 'It's just not worth it anymore'. But I feel rather wonderful because my oldest daughter is graduating with honours, and I'm looking forward to it.

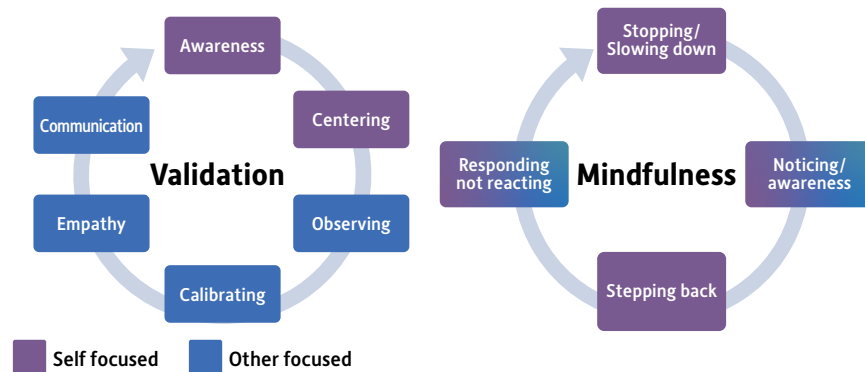
Response A) I smile at the woman, ignoring her sadness, and say, 'It's going to be OK'.

Response B) I quickly put aside my happiness and thoughts of the future to be in the present situation with my patient. I can pick up my thoughts and feelings and clear out the other person's emotions at the end of the visit.

Mindfulness – A key focus is noticing what is arising. I might check in with myself, which might help me see that I am feeling good but that this other person is feeling very differently. In slowing down and checking in, I notice an impulse to avoid

Validation in a nutshell





Note. This diagram simplifies the nuances and complexity of validation and mindfulness to capture their similarities and differences. These authors believe that while both incorporate elements of self and other focus, the other focus is more explicit and central in validation, especially concerning the skills needed to engage in the validation method.

engaging with feelings of sadness expressed by the person by saying something like, “It’s going to be OK”. It becomes more apparent that there is some conflict in me about whose needs I need to prioritise.

Validation – ‘Centering’ is used to clear away our thoughts and feelings so that we can be open to the thoughts and feelings of the other. If I am filled with my emotions or thoughts, I can’t be available to others and what comes up for them.

2. Breaking through automatic reactions

A 78-year-old man blames you for making him incontinent.

Response A) I say, “No, sir. That’s just your age.”

Response B) I recognise that he is not accepting the losses that come with age. I take a breath and rephrase, using a voice that matches his: “You notice that you’re incontinent!” Then, I would follow up with open questions that explore his experience.

Mindfulness – I would pause to notice what this interaction is bringing up in me, which might include several different thoughts, feelings, physical sensations or impulses. By slowing down and noticing this, I am allowing myself to choose how I want to respond based on what I’ve noticed about the situation and myself, which allows me to broaden my awareness of the older man.

Validation – Centring is a way of giving oneself time to enter the other person’s world, using empathy. Instead of responding to others from our perspective, we respond from their perspective. There is a reason behind the behaviour of older adults living with cognitive decline, which is usually anchored in a basic human need. I explore what the older adult is expressing.

3. Accept the other as they are
Mary Williams, 82 years old, eyes wide with fear, approaches the doctor,

saying, “I have cancer. I’m going to die.”

Response A) I think she’s perfectly healthy; she’s overly dramatic, and I dismiss her concerns by saying, “You’re perfectly well, Mary. You’re not going to die.”

Response B) Instead of contradicting her, I recognise that this is an expression of fear.

Doctor: “Where do you feel the cancer and is it sharp or dull?”

Mary: “It’s in my stomach and feels dull.”

Doctor: “How long have you had it?”

Mary: “It’s been at least three months from when Fred died.”

Doctor: “The pain started after your husband died?”

Mary: “Is there a connection?”

Doctor: “Do you think so?”

Mary: [after a pause] “Maybe.”

By now Mary is looking less fearful and breathing more slowly. Exploring her fear helps her express it. By accepting Mary as she was, the doctor built a trusting connection.

Mindfulness – Another key element is being nonjudgmental. This often focuses on not judging ourselves (e.g., it’s OK if our minds wander) but also expands to not judging others. We do not know what motivates other people. This nonjudgmental stance can affect how we engage with ourselves and others.

Validation – The principle that applies to this concept is that ‘older adults should be accepted as they are; we should not try to change them’. A validator accepts the individual, recognising that they are trying to fulfil a basic human need.

Top tips from mindfulness

- Check in with yourself, especially after a difficult interaction. How are you feeling? If you’re struggling to notice, it can help to see what’s happening in your body
- Check in with yourself at the start and end of the day. Noticing what’s arising

bookends the day and helps you transition from one thing to the next

- Slow down and ask what you need to minimise the risk of reacting rather than responding
- Notice if you crave or avoid anything specific and how this might affect you.

Top tips from validation

- Develop a daily ‘centering’ practice. Use breathing, images, touch or sounds to anchor a sense of being at peace and open.
- Take time before each interaction to closely observe the person with dementia, including voice tone, facial expression, posture and emotions.
- Try to match their emotional tenor and find empathy.
- Let go of what you want to accomplish now and be with them.

These techniques can be used in any circumstance, not just in stressful interactions. Avoiding burnout is better than dealing with it once it’s taken hold.

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