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Memory, Motivation and the Self: Recommendations for the Delivery of Personalised Dementia Care

White Paper

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Irish Photo

Professor Muireann Irish is Professor of Cognitive Neuroscience in the School of Psychology and Brain and Mind Centre at the University of Sydney. Originally from Ireland, Muireann completed her PhD at Trinity College Dublin, before relocating to Australia in 2010 and establishing the MIND research team. Muireann's research program explores how memory and motivation are affected in people living with dementia. Through her research, Muireann aims to refine the early and accurate diagnosis of dementia and to develop novel interventions to improve quality of life for those affected. To date, Muireann has produced over 150 publications and her work has been recognised by major awards from almost every society in her field. Highlights include the 2020 Gottschalk Medal from the Australian Academy of Science and the 2020 Elizabeth Warrington Prize from the British Neuropsychological Society for outstanding contributions to the field.

BUILDING CAPABILITY IN THE AGED CARE WORKFORCE

Australia is a leader in many areas of dementia research and care; however, community feedback and findings from the 2020 Royal Commission into Aged Care Quality and Safety indicate that there is room for improvement. More recently, the National Dementia Plan consultation paper argued for a critical need to build dementia capability in the workforce.¹ The consultation paper emphasises that high-quality care should focus on optimising quality of life, while being person-centred and sensitive to cultural differences or past traumas.

In practice, this means that aged care workers need to understand the unique circumstances of the individual, and to provide care that is sensitive to their specific needs. A key part of this process is understanding how changes in memory, due to dementia, shape the person's sense of self and identity and impact their engagement and interactions with others. Provision of targeted training is needed to give aged care workers appropriate insight into drivers of different behaviours, to recognise unmet needs, and to empower staff in creating enabling environments for the person living with dementia.

MEMORY AND THE SELF IN DEMENTIA

Our memories provide us with a sense of who we are as individuals, connecting us to our past and enabling us to envisage how our future might unfold. Recall of the past provides us with a sense of continuity and a central storyline or narrative of who we are. For example, a person may fondly reminisce about memories of their children, which in turn reinforces their sense of self as a parent or carer. Memories also provide an important means of communicating and sharing our stories with others, enabling us to form and maintain social bonds.

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As will be emphasised, understanding memory changes and identity in dementia is fundamental to the delivery of person-centred care.
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Regrettably, dementia is often viewed through a pejorative lens, with phrases such as “loss of self”, “Mum is gone” and “living death” being used. These descriptors fail to reflect the fact that a wealth of information, skills, preferences and functions are preserved in dementia, and these ‘islands’ of sparing contribute to the person's sense of self.² Indeed, while memory impairments are a hallmark feature of many dementia syndromes,³ not all information is lost, and not all time periods are affected equally.

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Best practice care needs to be informed by relevant, up-to-date scientific research that is delivered in an empathetic, person-centred manner.
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INTRODUCTION

Current estimates suggest that over 400,000 Australians are living with dementia. As the third leading cause of disease burden in Australia, dementia costs the Australian Government more than \$3 billion per year, and, in the absence of a cure, these figures are projected to rise dramatically in the coming decades.¹ To support people living with dementia, it is essential to integrate advances in scientific research to ensure that the needs of people living with dementia are being met.

THE SELF IN ALZHEIMER'S DISEASE

Alzheimer's disease is the most common form of dementia, associated with progressive changes in memory, spatial orientation, and activities of daily living. Research on memory and identity in Alzheimer's disease suggests that the person's sense of self becomes increasingly grounded in the time period where memory is least affected. Intuitively, this change in identity makes sense, as we tend to define ourselves in line with the experiences that we can recall from our past. In Alzheimer's disease, difficulties encoding recent events can result in the person gravitating towards older memories that remain relatively well preserved. These memories typically include self-defining and emotional experiences from childhood and early adulthood years.

“ **Understanding the incongruence between the person's expectations and their immediate surroundings is crucial to validate their subjective experience and approach their care in a way that embraces these connections to the past.** ”

Events from the person's young adult life become the foundation for their identity, providing a sense of stability and an anchor point for initiating conversations. In the care setting, this may manifest in seemingly cyclical conversations or repeated questioning, as encoding difficulties impair the ability to keep track of recent interactions or to monitor which stories have recently been shared.

'THEN' VERSUS 'NOW'

As recent memories begin to fade, the person with Alzheimer's disease may increasingly rely on events from the past to inform who they are. Essentially, the past becomes their present.

This mismatch between the identity of the person (constructed in the past) and the current environment (an unfamiliar care setting) can produce disorientation and confusion. Many aspects of the current surroundings — layout, furnishings, and décor of their room; the people they meet on the corridors; the meals they are being served in a shared dining room — may feel unfamiliar or unsafe as they depart significantly from the person's prior expectations. With such incongruencies between the current environment and their internal template of what should be happening, it is not surprising that people with dementia frequently express a desire to “go home”. They are simply looking for familiarity and comfort based on their past experiences.

A note of caution: People with Alzheimer's disease display an intact capacity to form emotional memories, particularly for negative or emotionally arousing experiences. As such, attempts to correct or reorient the person with dementia are not advised. For example, informing the person that their parents are no longer alive or that the family home has been sold can be highly distressing and destabilising. Our research shows that while the details of



these interactions may fade, the person with Alzheimer's disease encodes and retains the emotional distress. As such, they may feel deeply agitated or distressed many hours later but may be unable to articulate why.

UNLOCKING THE PAST THROUGH MUSIC

Music offers a powerful way to access memories from the past and to connect with someone living with dementia. Many of our most enjoyable and pivotal memories are connected to music (such as a favourite song or a wedding dance). Music encountered during adolescence and early adulthood has the greatest impact on individuals throughout their lives and can be used to cue or access memories from these time periods.

Importantly, many of the brain regions involved in musical memory encoding are strikingly well preserved in Alzheimer's disease. Mounting evidence suggests that music can be effectively used to access self-defining memories from the past, even in later stages of the disease. Again, it is important to remember that the music must be personalised to the individual — a one-size-fits-all approach will not work in this instance. Certain types of music might evoke negative associations with the past and this must be dealt with in a sensitive and empathetic manner.

“ **Understanding the musical preferences of the individual, particularly during their early adulthood years, provides a unique access point to promote wellbeing through recollection.** ”

MOTIVATION AND PURPOSE

Apathy or loss of motivation is highly prevalent in dementia and can lead to a loss of engagement or goal-directed activity.⁴ In parallel, new evidence suggests that the capacity for pleasure may be dampened in some types of younger-onset dementia (dementia that occurs under the age of 65 years) with negative consequences for functional independence, quality of relationships and overall wellbeing.

A lack of motivation can have widespread implications for everyday functioning. Carers often note that disinterest or withdrawal is very difficult to manage. The person with dementia may seem unwilling to engage in new activities or inflexible or set in their ways. They may engage in stereotypical or repetitive behaviours and may display narrowed or restricted interests which they compulsively pursue. Deviation from an established routine may cause agitation or, in some cases, aggression. It is important to understand the origin of these behaviours and to respond in an empathetic manner. Simple strategies can foster engagement and overcome some of the barriers that a loss of motivation in dementia can bring.⁵

RECOMMENDATIONS FOR PERSON-CENTRED DEMENTIA CARE

Drawing on the latest scientific research, we propose the following recommendations to improve engagement and quality of life for the person living with dementia. We preface these recommendations by recognising that not all strategies will work for all people with dementia, and it may take trial and error to find what works best in any given circumstance.

1. Remember the person

Every person with dementia is an individual with their own unique memories, talents, skills, and preferences. While medical and physical needs are important, too often the personhood of the individual is neglected. A comprehensive inventory of the person is needed in the care setting, providing the staff member with an overview of personal traits, preferences, values, defining moments and places, as well as any cultural sensitivities or past trauma. Essentially, the equivalent of a medical chart is needed for dementia care settings, in which the self/personhood of the person is emphasised.

2. Using personalised cues

Care providers might also consider working with families to create a repository of physical objects with personal significance at intake. This “memory box” could contain photographs, postcards from defining places in the person’s past, childhood toys, fabrics, ornaments and favoured fragrances or scents. A personalised playlist and reasons behind the song choices is essential. Such items provide a powerful way to cultivate nostalgia, strengthen

identity, and promote social connection. These items can be added to over time and may prompt other memories to emerge.

3. Cultivate a sense of purpose

We all want to feel included in society and to participate meaningfully in life. For people living with dementia, we can encourage their meaningful engagement by cultivating a sense of purpose. People with dementia retain a strong sense of personhood and values, often related to their past roles or achievements, for example, their career, hobbies, sporting endeavours or caring roles. Remember the strengths of the person and help them to retain independence through positively reinforcing their inclusion and participation, for example assigning a meaningful task or role and acknowledging their involvement and contributions.

4. Understand motivational changes

Motivational changes in dementia may cause the individual to appear disinterested or socially withdrawn. It is important to remember that these behaviours are not under the control of the person but reflect biological changes in the brain caused by dementia. Personality changes in some types of dementia (e.g., frontotemporal dementia) can lead to new skills and interests. Finding appropriate triggers to stimulate interest can help to motivate and energise the person with apathy. Our research also shows that many people living with dementia are unable to envisage future events or to imagine pleasurable experiences.⁶ We can overcome these challenges by using visualisation techniques to set the scene for the person and help them to look ahead to future activities.

5. Optimise the environment

Finally, given the possible mismatch between a person’s expectations and their current surroundings, it is essential to organise the environment by removing clutter. Personally meaningful items which trigger positive associations and interest should be made visible and easily accessible to encourage engagement. Structure can also be promoted through schedules or activity checklists; however, this may not always work for everyone. Again, trial and error is important to understand how best to enable the person with dementia to make sense of their surroundings and to feel in control of their activities.

CONCLUSION

Caring for someone with dementia requires us to understand their identity and current sense of self, all of which is shaped by the stage and type of dementia, and their past experiences. For carers and people who are interacting with someone living with dementia, it is important to understand that although some memories fade, the person’s core sense of self is preserved and often has its foundations in their early adulthood memories.

Developing a thorough understanding of the person with dementia is essential to deliver sensitive, empathic care that emphasises their intact memories and cultivates a sense of purpose. Personalised music offers a powerful way to reconnect with memories from the past and to promote recollection in dementia. Best practice will deliver person-centred care informed by the latest research on how memory interacts with the self in dementia.

Catholic Healthcare will incorporate this research as it reviews its Model of Care and plans the Catholic Connected Communities of the future, as part of a new strategic approach.

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