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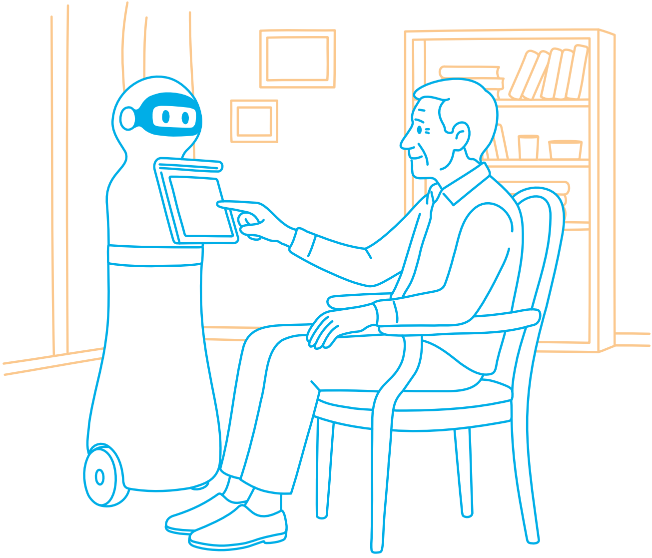
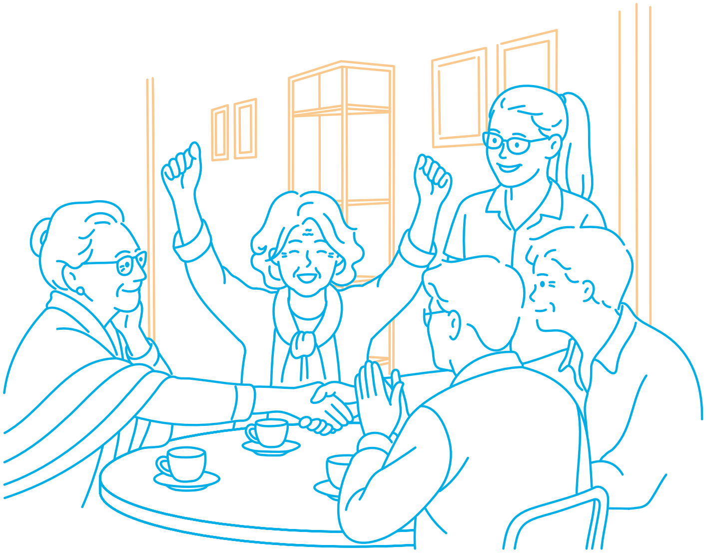
Dementia and the Human Rights of Older Persons





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Dementia and the Human Rights of Older Persons

ASEM Global Ageing Center

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We would like to express our gratitude to the AGAC Issue Focus Advisory Group—Jung-Hwa Ha at Seoul National University; Sabine Henning at the United Nations Economic and Social Commission for Asia and the Pacific; Mijin Lee at Konkuk University; Silvia Perel-Levin at the NGO Committee on Ageing in Geneva; and Margaret Young at the Global Alliance for the Rights of Older People and Age Knowble. They provided general guidance on the outline and theme of this report.

Valuable insight and input were provided by the contributors to this issue—Carol Ma Hok Ka at the Singapore University of Social Sciences; Debanjan Banerjee at Apollo Multispecialty Hospitals; Theresa Flavin at the Older Persons Advocacy Network and University of New South Wales' School of Psychology; and Magda Kaczmarska at DanceStream Projects and the Global Brain Health Institute.

We hope that this edition will inspire advocates for the human rights of older persons all around the world and contribute to improving older people's quality of life, particularly with respect to dementia. We are both awed and elated by the admirable accomplishments of persons living with dementia and those who work with them, as our audience will discover in this issue. We are optimistic about a world in which dementia is no longer a barrier to enjoying and realizing one's full potential, whether it comes later or sooner.

HyeKyung Lee

HyeKyung Lee
Executive Director, ASEM Global Ageing Center (AGAC)

AGAC ISSUE FOCUS ADVISORY GROUP

The AGAC Issue Focus Advisory Group is a group of experts focused on ageing and the human rights of older persons. They advise on the themes and topics of Issue Focus publications and provide feedback on the volumes. The advisors share their insights and views, bringing to bear expertise from around the world. Issue Focus addresses issues and agendas of ageing that are relevant to all ASEM partners.

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Theresa Flavin is an advocate and activist for the human rights and dignity of all persons living with dementia, including herself, and their care partners. She serves on the Sexual Assault and Dementia Special Interest Group of the Older Persons Advocacy Network (OPAN). She also works as a research assistant and lived experience consultant at the University of New South Wales' School of Psychology. Having been critical of the exclusion of people living with dementia from decision-making in relation to the development and implementation of research and advocacy, policy, and services, Flavin is actively involved in promoting equitable inclusion of people living with dementia in all aspects of community life and the design of care policy, products, and services. In connection with this, she is interested in supported decision-making, reablement strategies, and the recognition and prevention of sexual assault against older people and people living with dementia. Flavin has contributed to papers and reports on these topics, provided consultations to entities such as the Dementia Centre for Research Collaboration in Australia, HammondCare's Dementia Centre, Dementia Australia, Dementia Alliance International, and the Australian Government, and spoken at numerous outlets, including the Thirteenth Session of the UN Open-Ended Working Group on Ageing. She has professional expertise in risk management and finance, and is based in Sydney, Australia.

Magda Kaczmarska, MFA & ACE-CPT, is a dance artist, researcher, and advocate for dance as a catalyst for brain health. Kaczmarska is an Atlantic Fellow for Equity in Brain Health at the Global Brain Health Institute (GBHI), University of California San Francisco (UCSF). The GBHI, based out of UCSF and Trinity College Dublin, takes an equity-based approach to promoting education, effecting policy change, and developing evidence-based interventions to reduce the scale and impact of dementia worldwide. Atlantic Fellows for Equity in Brain Health benefit from innovative training and networking opportunities, and work as emerging global leaders in brain health, leadership, and dementia prevention. Kaczmarska brings 20 years of experience as a dance artist and ten years of preclinical neuropharmacology research to inform arts and health intervention innovation, design, and implementation, specifically within the areas of Alzheimer's disease and related dementias, brain health, and creative aging. Kaczmarska founded and currently serves as the executive director of DanceStream Projects, a New York City-based arts and health non-profit with a mission to promote brain health and build creative community through dance and movement. Through DanceStream Projects, she has created several award-winning programs, including the Stories in the Moment dance program for people living with dementia; all these programs employ evidence-informed approaches to extend brain health for older adults and people living with dementia through co-creative dance.

Dementia and the Human Rights of Older Persons

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INTRODUCTION

Eunsun Lee | *ASEM Global Ageing Center*

Dementia is a general term for the loss of cognitive functions, such as remembering and reasoning, to the point where the losses interfere with daily life. Currently, no cure is available for dementia (National Institute on Ageing, n.d.; World Health Organization [WHO], 2025). Dementia is believed to be the result of abnormal brain changes induced by injury or certain diseases, including Alzheimer's disease or vascular, Lewy body, frontotemporal, or mixed dementia (Alzheimer's Association, n.d.). It is common for some brain cells to degenerate—progressively decline in their function, lose connectivity with other brain cells, or even die—as people age. Indeed, age is a risk factor for dementia. However, dementia is not a normal part of ageing (National Institute on Ageing, n.d.).

The number of dementia cases and the associated costs are expected to rise. Globally, it is predicted that the number of people living with dementia will increase from 57.4 million in 2019 to 152.8 million in 2050 (Nichols et al., 2022). In 2019, 3.4% of people living with dementia were estimated to be in Africa, 18.7% in the Americas, 11.8% in Southeast Asia, 25.5% in Europe, 4.2% in the Eastern Mediterranean, and 36.4% in the Western Pacific region (WHO, 2021), and, based on 2021 data, more than 60% of them reside in low- and middle-income countries (WHO, 2025). Due to relatively higher population growth and population ageing in certain regions, the largest projected increase in dementia rates between 2019 and 2050 is in North Africa and the Middle East (367%) and Eastern Sub-Saharan Africa (357%), with the smallest in high-income Asia Pacific (53%) and Western Europe (74%; Nichols et al., 2022).

The estimated cost of dementia to the global economy was U.S. $1.3 trillion in 2019; however, this will grow to U.S. $1.7 trillion—or U.S. $2.8 trillion if adjusted for the forecasted increased costs of care—by 2030 (WHO, 2021). Nations, particularly those anticipating a surge in the prevalence of dementia, need to prepare for the interventions and care that will facilitate efficient prevention, timely diagnoses, and the provision of quality treatment, in addition to accelerated acquisition of dementia knowledge.

Dementia and the Tangles

Responding adequately to dementia is complicated by the fact that scientific information and people's beliefs about dementia may not always correspond. The number of people living with dementia could be almost halved if the risk factors were removed. These risk factors include a low level of education, hearing impairment, high low-density lipoprotein cholesterol, depression, traumatic brain injury, physical inactivity, diabetes, smoking, hypertension, obesity, excessive alcohol consumption, social isolation, air pollution, and visual impairment (Livingston et al., 2024). However, the results of a global survey showed that, in 2024, 80% of the general public and 65% of health and care professionals had the misconception that dementia is a normal part of becoming older (up from 66% and 62% in 2019, respectively; Alzheimer's Disease International, 2019, 2024). More than 25% of the respondents reported that there was nothing they could do to prevent dementia. A particularly large increase in the prevalence of this belief—from 20% in 2019 to 37% in 2024—was noted among respondents in low- and middle-income countries (Alzheimer's Disease International, 2019, 2024), where the number of dementia cases is expected to rise.

Around one-third of the respondents thought that people living with dementia are often dangerous, with two-thirds believing that they are impulsive and unpredictable (Alzheimer's Disease International, 2024). More than a quarter stated that a care home may be the best option for those living with dementia, even if such a move were against their will. Meanwhile, nine out of ten people living with dementia confirmed that they faced discrimination in different areas of their lives, such as housing; their family, personal, and social lives; safety and security; and health and care. They and their care partners also reported higher levels of loneliness than the general public (Alzheimer's Disease International, 2024).

These misunderstandings and the discrimination against people living with dementia (e.g., Nwakasi et al., 2021), in addition to factors such as a lack of public health education, awareness, resources, accessibility, and cultural and literacy considerations (e.g., Magklara et al., 2019), may slow the timely diagnoses that are essential for adequate treatment and future planning. Such issues are more pronounced in low- and middle-income than high-income countries (Livingston et al., 2024).

Within a given country, minority groups have a greater incidence and prevalence of dementia than their counterparts (e.g., Mayeda et al., 2016; Mukadam et al., 2023). Furthermore, disparities are present globally in the treatment of dementia. For example, cholinesterase inhibitors and memantine, which are recommended for treating Alzheimer's disease and Lewy body dementia because of their reasonable effects and affordability, are less available in low- and middle-income countries than in most high-income countries (Livingston et al., 2024). In addition, lecanemab, a recently introduced disease-modifying drug for treating Alzheimer's disease (which thus carries some risks), is reported to cost ₩20–30 million (U.S. $14,431–21,646) per patient per year in the Republic of Korea (Heo, 2024). This sets a high barrier for financially disadvantaged groups in a country where the average annual pension is less than half the drug price (Statistics Korea, 2024), and the poverty rate among older people is the highest among Organization for Economic Co-operation and Development (OECD) countries (OECD, 2023).

New Ways to Untangle

How can the current status of dementia prevention, intervention, and care be improved? What needs to be done to meet the future challenges associated with this condition at local, national, and international levels? How can society reach a place where everyone, regardless of their condition, including dementia, can live with dignity? To tackle these imperatives, experts were invited to submit diverse perspectives regarding and approaches to dementia for this edition. First, Carol Ma Hok Ka proposes the use of emerging technologies in dementia care, as they may be of value in boosting the autonomy and well-being of people who live with dementia while relieving some of the strain on their care partners. Ma argues that for technology to be meaningfully integrated into their lives, a person-centered and participatory approach to technology development and deployment is necessary. Accordingly, Ma advocates for an evaluative framework to be put in place that includes availability, accessibility, affordability, acceptability, appropriateness, and adaptability (the 6As Framework). Ma further calls for cross-sectoral collaboration and inclusive research and policy development and cites innovative products and initiatives.

Debanjan Banerjee raises an important yet rarely discussed topic in the dementia discourse: inappropriate sexual behavior (ISB). Banerjee points out that ISB has been stigmatized, underreported, and overlooked in clinical, caregiving, and overall societal settings, which has led to violations of the human rights and dignity of people living with dementia as well as distress among their care partners and family members. His comprehensive overview, which serves as an anchor point, covers information on ISB, ethical issues, assessments and management, care partners, policy and legal considerations, and future directions, such as global guideline development, research priorities, and legislative and policy reforms.

In her article, Theresa Flavin alternates her dementia experience with dementia facts, leading readers into an encounter with a person experiencing dementia that will undoubtedly correct misconceptions. This insider account is laced with wit and courage, and debunks the myth of the person with dementia as an empty shell or a vulnerable monster. Flavin argues that for people living with dementia, ageing in place may be a better option than mass institutionalization. She suggests adjustments to social security, taxation, pensions, and other related systems to make this a reality. Her ideas about the advance social directive and advance identity directive may appeal to those concerned about the will and preferences of people living with dementia.

Magda Kaczmarska proposes dance as an efficient way to enhance physical and brain health and social connections. Her approach is based on both academic literature and her extensive career as a researcher in the field, whose work has brought her into contact with different people, many of whom were older, living with dementia, or their care partners. Kaczmarska argues from her experience that dance may help people strengthen their life purpose by empowering them with agency and creativity and assist them in overcoming unfounded, negative views toward people living with dementia on intrapersonal, interpersonal, and social levels. Degraded communication, which is commonly expected of those living with dementia, may not apply in the case of dance, which offers new modes of communication; Kaczmarska thus offers a fresh and transformative approach to living with dementia.

It is unfortunate that a magic elixir to cure dementia has not yet been developed, but what readers may understand as they turn the final page of this edition is that the path to a cure may be care: care for the people living with dementia and their care partners—us, in its ultimate translation. *Seiltänzer*, the dancer who treads a tightrope stretched above an abyss, is due our allegiance to easing their path, every step of the way.

References

Alzheimer's Association. (n.d.). *What is dementia?* https://www.alz.org/alzheimers-dementia/what-is-dementia

Alzheimer's Disease International. (2019). *World Alzheimer Report 2019: Attitudes to dementia*. https://www.alzint.org/resource/world-alzheimer-report-2019/

Alzheimer's Disease International. (2024). *World Alzheimer Report 2024: Global changes in attitudes to dementia*. https://www.alzint.org/resource/world-alzheimer-report-2024/

Heo, J. (2024, November 28). *Eisai introduces Alzheimer's disease drug lecanemab in Korea.* Chosun Media. https://www.chosun.com/economy/science/2024/11/28/KZYGGHYC4T3L7GWLFJLHHLHBQM/

Livingston, G., Huntley, J., Liu, K. Y., Costafreda, S. G., Selbæk, G., Alladi, S., Ames, D., Banerjee, S., Burns, A., Brayne, C., Fox, N. C., Ferri, C. P., Gitlin, L. N., Howard, R., Kales, H. C., Kivimäki, M., Larson, E. B., Nakasujja, N., Rockwood, K., … Mukadam, N. (2024). Dementia prevention, intervention, and care: 2024 report of the Lancet Standing Commission. *The Lancet*, *404*(10452), 572–628. https://doi.org/10.1016/S0140-6736(24)01296-0

Magklara, E., Stephan, B. C. M., & Robinson, L. (2019). Current approaches to dementia screening and case finding in low- and middle-income countries: Research update and recommendations. *International Journal of Geriatric Psychiatry*, *34*(1), 3–7. https://doi.org/10.1002/gps.4969

Mayeda, E. R., Glymour, M. M., Quesenberry, C. P., & Whitmer, R. A. (2016). Inequalities in dementia incidence between six racial and ethnic groups over 14 years. *Alzheimer's & Dementia*, *12*(3), 216–224. https://doi.org/10.1016/j.jalz.2015.12.007

Mukadam, N., Marston, L., Lewis, G., Mathur, R., Rait, G., & Livingston, G. (2023). Incidence, age at diagnosis, and survival with dementia across ethnic groups in England: A longitudinal study using electronic health records. *Alzheimer's & Dementia*, *19*(4), 1300–1307. https://doi.org/10.1002/alz.12774

National Institute on Ageing. (n.d.). *What is dementia? Symptoms, types, and diagnosis.* https://www.nia.nih.gov/health/alzheimers-and-dementia/what-dementia-symptoms-types-and-diagnosis

Nichols, E., Steinmetz, J. D., Vollset, S. E., Fukutaki, K., Chalek, J., Abd-Allah, F., Abdoli, A., Abualhasan, A., Abu-Gharbieh, E., Akram, T. T., Al Hamad, H., Alahdab, F., Alanezi, F. M., Alipour, V., Almustanyir, S., Amu, H., Ansari, I., Arabloo, J., Ashraf, T., … Vos, T. (2022). Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: An analysis for the Global Burden of Disease Study 2019. *The Lancet Public Health*, *7*(2), e105–e125. https://doi.org/10.1016/S2468-2667(21)00249-8

Nwakasi, C. C., de Medeiros, K., & Bosun-Arije, F. S. (2021). "We are doing these things so that people will not laugh at us": Caregivers' attitudes about dementia and caregiving in Nigeria. *Qualitative Health Research*, *31*(8), 1448–1458. https://doi.org/10.1177/10497323211004105

OECD. (2023). *Pensions at a glance 2023: OECD and G20 indicators.* https://www.oecd-ilibrary.org/finance-and-investment/oecd-pensions-at-a-glance_19991363

Statistics Korea. (2024). *2024 Statistics on the aged.* https://kostat.go.kr/synap/skin/doc.html?fn=19b52057130280d69d34e24adcc2d43b4d94fef82851f2eea819da0a71def847&rs=/synap/preview/board/11759/

WHO. (2021). *Global status report on the public health response to dementia*. https://www.who.int/publications/i/item/9789240033245

WHO. (2025). *Dementia*. https://www.who.int/news-room/fact-sheets/detail/dementia

Embracing Technology Alongside People Living With Dementia and Care Partners

Carol Ma Hok Ka | *Singapore University of Social Sciences*

Dementia represents one of the most pressing global public health challenges of the 21st century, profoundly impacting quality of life for people living with dementia (PLWD) and their care partners. The evolving field of assistive technology and artificial intelligence presents significant opportunities to support autonomy, enhance well-being, and reduce care partner burden. However, technology adoption in dementia care often falls short due to issues related to accessibility, appropriateness, and ethical considerations. This paper advocates for a participatory and inclusive approach to technology development, centring the voices and experiences of PLWD and their care partners. By integrating the 6As Framework (Availability, Accessibility, Affordability, Acceptability, Appropriateness, and Adaptability) developed by the Age+ Living Lab, and drawing on the principles of person-centred care and co-design, the paper outlines how technology can be meaningfully embedded in daily life. Real-world examples are discussed to illustrate best practices in fostering engagement and cognitive and emotional well-being. The paper concludes with a call for cross-sectoral collaboration, inclusive research, and policy development that ensures digital innovations truly serve the diverse needs of the dementia community.

Dementia is one of the most significant global health and social care challenges, affecting over 55 million people worldwide in 2019 (World Health Organization [WHO], 2021a). This number is projected to rise to 139 million by 2050. The Western Pacific Region has the largest population of people living with dementia (20.1 million), followed by the European Region (14.1 million), the Americas (10.3 million), Southeast Asia (6.5 million), the Eastern Mediterranean (2.3 million), and the African Region (1.9 million; WHO, 2021a).

People living with dementia (PLWD) and their care partners face multifaceted challenges, including memory loss, communication difficulties, safety risks, social isolation, and considerable care partner stress and burnout. Beyond the direct impact on individuals with dementia, dementia imposes substantial socio-economic burdens and emotional strain on care partners, who often provide extensive, unpaid support (Brodaty & Donkin, 2009; Schulz & Beach, 1999). In response, assistive technologies have emerged as promising tools to promote independence, improve quality of life, and provide support to care partners.

Despite technological advancements, many assistive technology solutions fail to align with the real-world needs and contexts of PLWD and their care partners. Barriers such as limited digital literacy, high costs, lack of personalisation, and inadequate user involvement in the design phase impede widespread adoption. Ethical concerns around surveillance and consent further complicate implementation. Addressing these issues requires a paradigm shift toward person-centred, co-designed technology solutions.

A Dementia-Friendly Ecosystem for Enabling Technology: Integrating Person-Centred Innovation, Care Partner Support, and Policy

Addressing the complex and evolving challenges of dementia requires a holistic, interdisciplinary approach that places PLWD at the centre of care. This includes amplifying their voices, supporting care partners, adapting physical environments, fostering community inclusion, and enacting enabling policies.

Person-centred care, as articulated by Kitwood (1997), shifts the paradigm from focusing solely on cognitive deficits to recognising an individual's identity, strengths, preferences, and life history. This principle should also guide the development of technologies and interventions aimed at enhancing autonomy and well-being.

Support for care partners is equally vital. As they often experience high levels of stress, tailored interventions—such as care partner education, respite services, and peer support networks—can strengthen resilience and caregiving capabilities (Nemcikova et al., 2023). Since caregiving evolves over time, assistive living technologies must support care partners throughout the different stages of the dementia journey.

Environmental adaptations also play a critical role in enhancing daily functioning and reducing confusion. Evidence-based modifications—such as improved lighting, clear signage, and safer bathroom design—can significantly enhance the independence and safety of PLWD (Calkins, 1988).

Community integration is essential for reducing the stigma and isolation associated with dementia. Inclusive programming and accessible social networks can greatly enhance quality of life and foster a sense of belonging.

Finally, policy support must align with technological innovation to create a supportive and affordable ecosystem. When selected and implemented with empathy and ethical consideration, assistive technologies can help bridge cognitive and functional gaps by supporting navigation, communication, and therapeutic engagement.

By integrating person-centred principles, care partner empowerment, adaptive environments, social inclusion, and innovative technologies and policies, we can shape dementia-friendly societies that prioritise dignity, autonomy, and collective well-being.

Best Practices for Employing Technology: Centring Human Needs Through the 6As Framework and Participatory Innovation

Effectively employing technology to support PLWD and their care partners requires more than product availability. It demands a deep understanding of their lived experiences and everyday challenges.

The 6As Framework: A Guiding Lens for Gerontechnology

To operationalise a person-centred and inclusive approach to technology, the 6As Framework offers a comprehensive evaluative lens. Developed by the Singapore University of Social Sciences and SG Assist (a social enterprise in Singapore that focuses both on care utilising technology and care support) through the Age+ Living Lab (Ma, 2023), this framework outlines six key dimensions and has been modified to be used to address the needs of PLWD and care partners as follows:

- availability—where can I get it? Is the technology readily available to those who have cognitive issues?
- accessibility—is it accessible to me, and is it easy to use? Can individuals with cognitive, sensory, or physical impairments use it?
- affordability—can I afford it? Are there available subsidies? Is the cost manageable for the average user or care partner?
- acceptability—do I feel comfortable and confident to use it? Does the design respect users' dignity, preferences, and cultural norms?
- appropriateness—does it meet my needs and preferences? Is the technology suitable for its intended context (e.g., home, community, or institution)?
- adaptability—can it meet my changing needs and goals? Can the technology be modified or personalised as the PLWD's condition progresses?

This framework is best applied through participatory design, engaging people with lived experience of dementia and care partners at every stage—from ideation to implementation. Such co-design processes ensure technologies are contextually relevant, empowering, and ethically sound. When PLWD are treated as co-creators rather than passive recipients, or at least consulted in the process of developing products that can support their daily living, the results could be more impactful, since PLWD are more likely to use those products (Moyle et al., 2025; O'Sullivan et al., 2023).

Thus, centring user voices and needs is paramount. Recognising the progressive nature of dementia, a one-size-fits-all approach is impossible (Alzheimer Society of Ireland, 2019; Moyle et al., 2025; Niedderer et al., 2024). Technologies must be tailored to an individual's cognitive stage, life history, and evolving needs. Additionally, designers should avoid stigmatising features or intrusive monitoring. Technologies should be discreet, supportive, and transparent in purpose to build user trust.

Enhancing Ageing in Place for People Living With Dementia Through Assistive Technology

Ageing in place has become an essential objective in dementia care, aiming to support individuals to remain in familiar home environments for as long as possible. To effectively support ageing in place, technology should:

- promote independence and autonomy by enabling PLWD to maintain their routines, engage in meaningful activities, and exercise choice in their daily lives
- enhance safety and security, reducing the risk of falls, wandering, and other accidents, thereby providing peace of mind for both PLWD and care partners
- facilitate social connection, allowing individuals to communicate with loved ones and reducing feelings of isolation

The following sections examine how emerging and existing assistive technology solutions fulfil these purposes, and assess their effectiveness across various use cases.

Promoting Independence and Autonomy. Maintaining a sense of independence is integral to the dignity and well-being of PLWD. Assistive technologies that support memory, orientation, and routine adherence play a critical role in preserving autonomy and enabling PLWD to remain engaged in daily life.

Calendar and reminder systems are among the most widely used technologies to assist with temporal orientation and appointment recall. These tools can be either digital or physical, and their effectiveness largely depends on simplicity of design and user familiarity. The ENABLE study conducted in Ireland demonstrated that such tools not only aid PLWD in managing their schedules but also provide reassurance to care partners (Cahill et al., 2007). However, the effectiveness of these systems is highly dependent on consistent prompting from care partners and the reliability of the systems themselves. Simpler, familiar-looking tools with intuitive and recognisable interfaces have been shown to be particularly successful in achieving broader adoption among users with cognitive impairments.

Automatic medication dispensers are another important innovation for promoting medication adherence. These devices are especially beneficial in ensuring that medications are taken at the correct times, thereby improving treatment efficacy and reducing health risks (ENABLE partners, 2004). However, research has shown mixed outcomes regarding direct use by PLWD. Significant dropout rates are often attributed to technical or usability issues, such as complex interfaces or device malfunction. Consequently, these dispensers tend to be more helpful for care partners, who benefit from reduced anxiety about missed or incorrect doses and who can monitor adherence more effectively.

In recent years, advances in artificial intelligence (AI) have become increasingly evident in the realm of dementia care. AI-powered GPS geofencing systems, for instance, can alert care partners when a person with dementia leaves a designated safe zone, thus enhancing safety without restricting movement. Conversational AI interfaces provide spoken assistance for tasks such as navigation or reminders, allowing for more natural interaction. Predictive wayfinding technologies are capable of detecting abnormal movement patterns that may indicate confusion or distress, while visual recognition tools help orient users by matching images to familiar places or tasks. While these developments show considerable promise in promoting autonomy, their success depends heavily on user-centred design, which must take into account the cognitive and sensory limitations of the end-users.

Enhancing Safety and Security. Physical safety is a major concern for PLWD, primarily due to the increased risk of falls, wandering, and emergency incidents. To address these challenges, a wide range of sensor-based and location-monitoring technologies has been developed to support both users and their care partners.

Telecare and sensor-based monitoring systems—such as pressure-sensitive mats, fall detectors, and bed or door exit alarms—are effective in enhancing safety while still supporting limited autonomy. These tools not only safeguard PLWD but also offer peace of mind to their care partners. Boyle (2022) identified four key factors that influence the successful adoption of such systems: personalised training, co-design with users and care partners, ease of use, and cultural relevance. Nevertheless, many systems rely heavily on care partners for both initial setup and ongoing operation, presenting challenges in long-term usability. Additional barriers include unintended adverse consequences (e.g., false alarms), challenges linked to disease progression, technology-related anxiety, system failures, the digital divide, and a general lack of awareness of or access to appropriate assistive technologies.

GPS trackers and location devices are particularly effective in reducing care partners' anxiety and supporting the independence of individuals prone to wandering (Carswell et al., 2009; Doyle et al., 2024). However, their long-term adoption is conditional on several factors, including the device's simplicity, operational reliability, and the willingness of PLWD to engage with them and wear them consistently. Common obstacles to sustained use include forgetfulness, difficulty adjusting to new routines, sensory discomfort, and concerns about privacy or perceived surveillance.

Facilitating Social Connection. Social isolation remains a significant concern for PLWD, often contributing to accelerated cognitive decline and emotional distress. Communication tools, such as simplified smartphones and video call platforms, have been shown to play a valuable role in preserving social ties and promoting cognitive and emotional well-being.

Visual-button phones, which feature easily recognisable images for initiating calls, are generally perceived by PLWD as easy to use and less intimidating compared to traditional devices. Care partners, in turn, appreciate the reliability and simplicity of these communication aids (Pappadà et al., 2021). Video-calling platforms and telehealth services further enhance engagement (Poon et al., 2005), with many PLWD expressing a preference for face-to-face interaction over voice-only phone calls. These technologies also enable healthcare providers to monitor symptoms remotely and deliver psychosocial interventions, extending access to care and reducing travel burdens.

Moreover, therapeutic platforms that integrate music therapy, storytelling, and reminiscence activities offer additional pathways for enhancing social and emotional connection (Anderson et al., 2022; Carswell et al., 2009). For example, there is a program called Computer Interactive Reminiscence and Conversation Aid (CIRCA) that promotes social interaction, meaningful conversation, and reminiscences for PLWD. The application is designed with multimedia content and a touchscreen interface, and allows for care partner support. Results show that it improves social interaction for PLWD, increases cognitive stimulation, enhances quality of life, and strengthens caregiving relationships (Alm et al., 2004; Astell et al., 2010, 2018).

Assistive Technologies for Different Levels of Dementia: International and Regional Efforts

Various products can support PLWD, but there are also key considerations to take into account. Table 1 shows a summary of different assistive technologies tailored to various stages of dementia, along with important considerations for their use (Ancoli-Israel et al., 2003; Baker et al., 2001; Boyle et al., 2022; Carswell et al., 2009; Doyle et al., 2024; ENABLE partners, 2004; Fleming & Sum, 2014; Garland et al., 2007; Gibson et al., 2015; Lancioni et al., 2010, 2012; Libin & Cohen-Mansfield, 2004; Oriani et al., 2003; Sloane et al., 2007).

Table 1

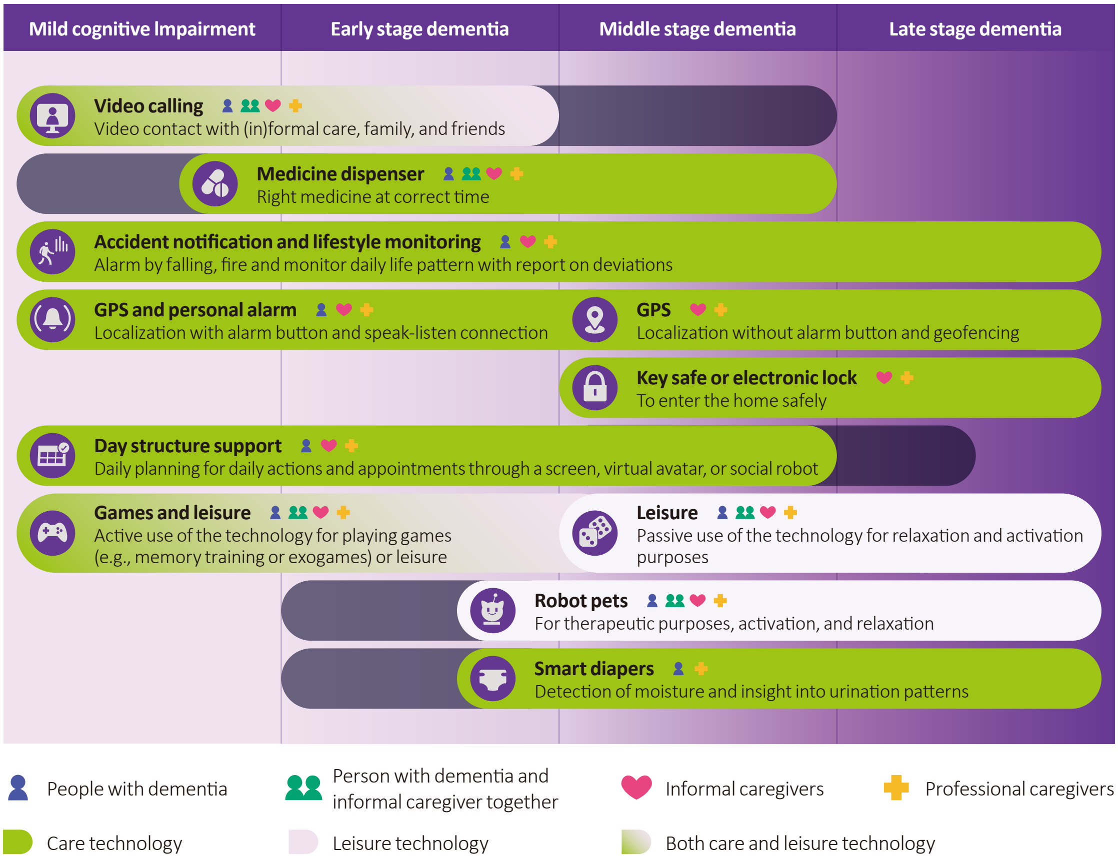
Assistive Technologies for Different Levels of Dementia

Dementia level	Products	Benefits	Considerations
Mild to moderate	Electronic Memory Aids (EMA; Oriani et al., 2003)	Improves prospective memory and task management	Requires training and familiarity with technology
	Verbal-Instruction Technologies (Lancioni et al., 2010)	Supports daily activities like table setting and grooming	May need care partner assistance for initial setup and use
	Bright Light Therapy (Sloane et al., 2007)	Improves sleep and reduces behavioural disturbances	Needs consistent exposure; effectiveness varies by individual
Moderate to severe	Technology-Aided Pictorial Cues (Lancioni et al., 2012)	Enhances activity performance with visual and verbal instructions	Requires ability to follow cues; effectiveness decreases with cognitive decline
	Multi-Sensory Environments (Snoezelen Rooms; Baker et al., 2001)	Improves mood and activity levels	Benefits are short-lived unless integrated into broader care strategies
	Robotic Pets (Libin & Cohen-Mansfield, 2004)	Provides emotional stimulation and reduces agitation	May not appeal to all individuals; some prefer plush toys over robotic versions
	Tracking Devices (Carswell et al., 2009; Doyle et al., 2024)	Ensures safety by monitoring location, especially for wandering	User compliance (e.g., wearing the device) can be challenging
Severe	High-Intensity Lighting (Ancoli-Israel et al., 2003)	Improves sleep and reduces agitation in institutional settings	May not be effective for visually impaired individuals
	Simulated Presence Therapy (SPT) (Garland et al., 2007)	Reduces anxiety and agitation with audio recordings of family members	Acceptance varies; effects are modest and short-lived
General use across different levels	Telecare and Telehealth (Boyle et al., 2022)	Provides remote monitoring, medication reminders, and cognitive interventions	Requires reliable internet and care partner involvement for setup and monitoring
	Assistive Devices for Daily Living (ENABLE partners, 2004)	Includes calendars, medicine reminders, and automatic lighting systems	Effectiveness depends on user familiarity and device reliability

To illustrate the suitability of supportive technologies across different stages of dementia, Vilans—the Dutch expertise centre for long-term care—developed a visual chart (see Figure 1) that indicates the recommended timing for introducing various care technologies (Ipakchian Askari et al., 2024). Additionally, the international HAAL project (HeAlthy Ageing eco-system for peopLe with dementia) brought together a multidisciplinary consortium to co-design and assess technologies that help care partners monitor the health and well-being of PLWD (Nap et al., 2024).

Figure 1

Supportive Technologies by the Level of Dementia



Note. The grey block indicates the possibility of extended use or early implementation. Figure 1 is intended to serve simply as a guideline for the implementation of care technology for people living with dementia; it does not claim to be applicable to every individual with dementia, or to be consistently effective, since the effectiveness of care technology implementation is determined by a variety of contextual factors, including personal characteristics, background, and technical experience. It should be noted that technologies could be implemented in other stages depending on the person living with dementia and their preferences and characteristics; thus, communication with them is critical. Adapted from "Mapping Dementia Care Technology: Tailored Digital Solutions Across Stages," by S. Ipakchian Askari, D. Vasseur, B. Hofstede, P. Koowattanataworn, and H. H. Nap, 2024, *International Medical Education*, *3*(2), p. 142 (https://doi.org/10.3390/ime3020012). CC BY 4.0.

Many organisations are also promoting how technologies can support PLWD. WHO has demonstrated a strong commitment to a holistic, person-centred approach when leveraging technology to support people living with dementia and their care partners. One notable initiative is the *iSupport* digital care partner training program, which provides accessible, evidence-based education and emotional support for informal care partners of individuals with dementia (Global Dementia Observatory, n.d.). Additionally, WHO, in collaboration with the International Telecommunication Union (ITU), published the *mDementia Handbook* in 2021, offering a comprehensive guide for implementing mobile health interventions focused on dementia risk reduction and care partner support (WHO, 2021b).

Beyond global efforts, national and regional organisations also contribute significantly to the technological landscape of dementia care. In Singapore, Dementia Singapore curates a comprehensive list of assistive technologies designed to support PLWD in their daily lives (Dementia Singapore, 2020). In Ireland, the Alzheimer Society of Ireland (2019), building on the ENABLE study mentioned in the previous section, developed a practical guide outlining steps to enhance independence among PLWD through assistive technology. Similarly, Dementia Australia has pioneered a suite of innovative tools, including mobile applications, online platforms, and virtual reality experiences, to promote cognitive engagement and support caregiving (Dementia Australia, n.d.). The Australian government also maintains a resource hub listing assistive technologies that support older adults experiencing declines in intrinsic capacity, including cognitive function.

In the United Kingdom, the Alzheimer's Society has established an educational website to inform individuals about the benefits of assistive technologies in supporting various aspects of daily life. This site also acts as a one-stop service for purchasing dementia-supportive products online (Alzheimer's Society, n.d.). Collectively, these initiatives demonstrate a growing international movement to integrate technology into dementia care, enhancing autonomy, safety, and quality of life for both PLWD and their care partners.

Empathy Meets Innovation: Human-Centred Technologies for People Living With Dementia

While many countries are promoting the adoption of technologies to support PLWD, the effective deployment of such tools must adhere to the principles of ethical co-design and rigorous user testing. As innovative solutions become increasingly integrated into dementia care, it is essential that their development be grounded in empathy, human dignity, and cognitive and emotional well-being. Design must extend beyond functional utility to reflect the lived experiences, identities, and emotional needs of users.

An empathy-first approach prioritises collaboration with PLWD and their care partners to ensure that solutions foster comfort, trust, and familiarity. Ethical innovation is critical—technologies must uphold autonomy, informed consent, and emotional safety. Transparent data governance and consent protocols are especially vital, given the changing cognitive capacities of users. Interfaces should be designed to accommodate cognitive and sensory impairments, using voice-first commands, simplified visuals, and intuitive navigation.

When thoughtfully implemented, technology can enhance—not replace—human connection. For example, integrating location tracking with personal photo archives can provide meaningful memory cues, supporting both navigation and identity. A case in point is *Memory Lane* in Singapore (https://memorylane.co/), which creates personalised, interactive memory banks using photographs and audio narratives. The platform promotes cognitive stimulation and emotional continuity, and is being co-designed in collaboration with older adults, care workers, and care partners to ensure its relevance and accessibility in aged care settings.

Ultimately, the success of dementia-focused innovations hinges on human-centred design, ethical responsibility, and community participation. These elements ensure that technology becomes a compassionate tool for inclusive and dignified care. As societies respond to the rising impact of dementia, there is an urgent need to reimagine how technology is developed and deployed. A person-centred, co-designed approach—anchored in ethical practice and grounded in real-world usability—holds the key to harnessing technology's full potential.

By adopting frameworks such as the 6As (Availability, Accessibility, Affordability, Acceptability, Appropriateness, and Adaptability) and promoting cross-sectoral collaboration, we can build technological ecosystems that genuinely support the well-being, dignity, and autonomy of PLWD and their care partners.

Conclusion

Dementia presents a formidable global challenge, yet the strategic integration of assistive technology offers a promising avenue to improve the lives of PLWD and reduce the burden on care partners. This paper outlines the critical issues faced by this population and underscores a comprehensive, person-centred approach that integrates technological interventions.

Crucially, success in dementia care requires best practice that prioritises the voices and needs of PLWD and their care partners. Co-design, user involvement, and ease of use are paramount. Technologies must be reliable, non-stigmatising, and tailored to individual contexts to effectively support ageing in place—promoting independence, enhancing safety, and fostering social connections. While tools such as reminder systems, communication devices, and safety monitors show consistent effectiveness, implementation must also consider the role of care partners and address barriers such as cost and lack of support.

Looking ahead, ongoing research and development are needed to refine existing technologies, create new solutions, and ensure equitable access and sustained support for both PLWD and their care partners. By truly embracing technology together with those it aims to serve, we can work toward a future where PLWD live with greater autonomy and dignity, and better quality of life, within their communities.

References

Alm, N., Astell, A., Ellis, M., Dye, R., Gowans, G., & Campbell, J. (2004). A cognitive prosthesis and communication support for people with dementia. *Neuropsychological Rehabilitation*, *14*(1–2), 117–134. https://doi.org/10.1080/09602010343000147

Alzheimer Society of Ireland. (2019). *Practical steps to support your independence*. https://alzheimer.ie/wp-content/uploads/2018/11/ASI-Assistive-Technologies-Brochure-Nov-2019-website.pdf

Alzheimer's Society. (n.d.). *How technology can help*. https://www.alzheimers.org.uk/get-support/staying-independent/how-technology-can-help

Ancoli-Israel, S., Gehrman, P., Martin, J. L., Shochat, T., Marler, M., Corey-Bloom, J., & Levi, L. (2003). Increased light exposure consolidates sleep and strengthens circadian rhythms in severe Alzheimer's disease patients. *Behavioral Sleep Medicine*, *1*(1), 22–36. https://doi.org/10.1207/S15402010BSM0101_4

Anderson, M., Menon, R., Oak, K., & Allan, L. (2022). The use of technology for social interaction by people with dementia: A scoping review. *PLOS Digital Health*, *1*(6), e0000053. https://doi.org/10.1371/journal.pdig.0000053

Astell, A. J., Ellis, M. P., Bernardi, L., Alm, N., Dye, R., Gowans, G., & Campbell, J. (2010). Using a touch screen computer to support relationships between people with dementia and caregivers. *Interacting With Computers*, *22*(4), 267–275. https://doi.org/10.1016/j.intcom.2010.03.003

Astell, A. J., Smith, S. K., Potter, S., & Preston-Jones, E. (2018). Computer interactive reminiscence and conversation aid groups—Delivering cognitive stimulation with technology. *Alzheimer's and Dementia: Translational Research and Clinical Interventions*, *4*, 481–487. https://doi.org/10.1016/j.trci.2018.08.003

Baker, R., Bell, S., Baker, E., Holloway, J., Pearce, R., Dowling, Z., Thomas, P., Assey, J., & Wareing, L.-A. (2001). A randomized controlled trial of the effects of multi-sensory stimulation (MSS) for people with dementia. *British Journal of Clinical Psychology*, *40*(1), 81–96. https://doi.org/10.1348/014466501163508

Boyle, L. D., Husebo, B. S., & Vislapuu, M. (2022). Promotors and barriers to the implementation and adoption of assistive technology and telecare for people with dementia and their caregivers: A systematic review of the literature. *BMC Health Services Research*, *22*, 1573. https://doi.org/10.1186/s12913-022-08968-2

Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience*, *11*(2), 217–228. https://doi.org/10.31887/DCNS.2009.11.2/hbrodaty

Cahill, S., Begley, E., Faulkner, J. P., & Hagen, I. (2007). "It gives me a sense of independence"—Findings from Ireland on the use and usefulness of assistive technology for people with dementia. *Technology and Disability*, *19*(2–3), 133–142. https://doi.org/10.3233/TAD-2007-192-310

Calkins, M. P. (1988). *Design for dementia: Planning environments for the elderly and the confused*. University of Minnesota Press. http://archive.org/details/designfordementi00calk

Carswell, W., McCullagh, P. J., Augusto, J. C., Martin, S., Mulvenna, M. D., Zheng, H., Wang, H. Y., Wallace, J. G., McSorley, K., Taylor, B., & Jeffers, W. P. (2009). A review of the role of assistive technology for people with dementia in the hours of darkness. *Technology and Health Care*, *17*(4), 281–304. https://doi.org/10.3233/THC-2009-0553

Dementia Australia. (n.d.). *Technology*. https://www.dementia.org.au/get-support/technology

Dementia Singapore. (2020, April 9). *Technology to help with dementia care*. https://dementia.org.sg/2020/04/09/technology-dementia-care/

Doyle, M., Nwofe, E. S., Rooke, C., Seelam, K., Porter, J., & Bishop, D. (2024). Implementing global positioning system trackers for people with dementia who are at risk of wandering. *Dementia*, *23*(6), 964–980. https://doi.org/10.1177/14713012241248556

ENABLE partners. (2004). *Enabling technologies for people with dementia: Cross-national analysis report*. https://citeseerx.ist.psu.edu/document?repid=rep1&type=pdf&doi=545b14cadbd9d469ea55cd5a256718537579f87e

Fleming, R., & Sum, S. (2014). Empirical studies on the effectiveness of assistive technology in the care of people with dementia: A systematic review. *Journal of Assistive Technologies*, *8*(1), 14–34. https://doi.org/10.1108/JAT-09-2012-0021

Garland, K., Beer, E., Eppingstall, B., & O'Connor, D. W. (2007). A comparison of two treatments of agitated behavior in nursing home residents with dementia: Simulated family presence and preferred music. *The American Journal of Geriatric Psychiatry*, *15*(6), 514–521. https://doi.org/10.1097/01.JGP.0000249388.37080.b4

Gibson, G., Dickinson, C., Brittain, K., & Robinson, L. (2015). The everyday use of assistive technology by people with dementia and their family carers: A qualitative study. *BMC Geriatrics*, *15*, 89. https://doi.org/10.1186/s12877-015-0091-3

Global Dementia Observatory. (n.d.). *iSupport network*. https://globaldementia.org/en/iSupportNetwork

Ipakchian Askari, S., Vasseur, D., Hofstede, B., Koowattanataworn, P., & Nap, H. H. (2024). Mapping dementia care technology: Tailored digital solutions across stages. *International Medical Education*, *3*(2), Article 2. https://doi.org/10.3390/ime3020012

Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Open University Press.

Lancioni, G., Singh, N., O'Reilly, M., Zonno, N., Cassano, G., De Vanna, F., Laura De Bari, A., Pinto, K., & Minervini, M. (2010). Persons with Alzheimer's disease perform daily activities using verbal-instruction technology: A maintenance assessment. *Developmental Neurorehabilitation*, *13*(2), 103–113. https://doi.org/10.3109/17518420903468480

Lancioni, G., Perilli, V., Singh, N. N., O'Reilly, M. F., Sigafoos, J., Cassano, G., Pinto, K., Minervini, M. G., & Oliva, D. (2012). Technology-aided pictorial cues to support the performance of daily activities by persons with moderate Alzheimer's disease. *Research in Developmental Disabilities*, *33*(1), 265–273. https://doi.org/10.1016/j.ridd.2011.09.017

Libin, A., & Cohen-Mansfield, J. (2004). Therapeutic robocat for nursing home residents with dementia: Preliminary inquiry. *American Journal of Alzheimer's Disease and Other Dementias*, *19*(2), 111–116. https://doi.org/10.1177/153331750401900209

Ma, H. K. C. (2023). Promoting access to assistive technology for healthy ageing in Singapore. In *Case studies on promoting the rights of older persons through expansion of public accessibility of assistive/welfare technology*. ASEM Global Ageing Center. https://asemgac.org/board/view?bd_id=pb02&wr_id=44

Moyle, W., Sriram, D., Murfield, J., Pu, L., & Lion, K. (2025). Co-designed technologies and people living with dementia: A qualitative systematic review. *Contemporary Nurse*, 1–18. https://doi.org/10.1080/10376178.2025.2500377

Nap, H. H., Stolwijk, N. E., Ipakchian Askari, S., Lukkien, D. R. M., Hofstede, B. M., Morresi, N., Casaccia, S., Amabili, G., Bevilacqua, R., Margaritini, A., Barbarossa, F., Lin, C.-J., Chieh, H.-F., Su, F.-C., Revel, G. M., Tesfay, E., Bai, D., Wirtjes, C., & Hsu, Y.-L. (2024). The evaluation of a decision support system integrating assistive technology for people with dementia at home. *Frontiers in Dementia*, *3*. https://doi.org/10.3389/frdem.2024.1400624

Nemcikova, M., Katreniakova, Z., & Nagyova, I. (2023). Social support, positive caregiving experience, and caregiver burden in informal caregivers of older adults with dementia. *Frontiers in Public Health*, *11*. https://doi.org/10.3389/fpubh.2023.1104250

Niedderer, K., Ludden, G., Dening, T., & Holthoff-Detto, V. (Eds.). (2024). *Design for dementia, mental health, and wellbeing: Co-design, interventions and policy*. Routledge. https://doi.org/10.4324/9781003318262

Oriani, M., Moniz-Cook, E., Binetti, G., Zanieri, G., Frisoni, G. B., Geroldi, C., De Vreese, L. P., & Zanetti, O. (2003). An electronic memory aid to support prospective memory in patients in the early stages of Alzheimer's disease: A pilot study. *Aging & Mental Health*, *7*(1), 22–27. https://doi.org/10.1080/1360786021000045863

O'Sullivan, D., Turner, J., O'Neill, S., Wilson, M., & Doyle, J. (2023, April). Co-designing assistive technology with and for persons living with dementia. *eTELEMED 2023: The Fifteenth International Conference on eHealth, Telemedicine, and Social Medicine*. https://doi.org/10.21427/6C0N-NA96

Pappadà, A., Chattat, R., Chirico, I., Valente, M., & Ottoboni, G. (2021). Assistive technologies in dementia care: An updated analysis of the literature. *Frontiers in Psychology*, *12*. https://doi.org/10.3389/fpsyg.2021.644587

Poon, P., Hui, E., Dai, D., Kwok, T., & Woo, J. (2005). Cognitive intervention for community-dwelling older persons with memory problems: Telemedicine versus face-to-face treatment. *International Journal of Geriatric Psychiatry*, *20*(3), 285–286. https://doi.org/10.1002/gps.1282

Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *JAMA*, *282*(23), 2215–2219. https://doi.org/10.1001/jama.282.23.2215

Sloane, P. D., Williams, C. S., Mitchell, C. M., Preisser, J. S., Wood, W., Barrick, A. L., Hickman, S. E., Gill, K. S., Connell, B. R., Edinger, J., & Zimmerman, S. (2007). High-intensity environmental light in dementia: Effect on sleep and activity. *Journal of the American Geriatrics Society*, *55*(10), 1524–1533. https://doi.org/10.1111/j.1532-5415.2007.01358.x

WHO. (2021a). *Global status report on the public health response to dementia*. https://www.who.int/publications/i/item/9789240033245

WHO. (2021b). *WHO and ITU launch new guide on introduction of dementia risk reduction and carer support programmes using mobile technology*. https://www.who.int/news/item/26-02-2021-who-and-itu-launch-new-guide-on-introduction-of-dementia-risk-reduction-and-carer-support-programmes-using-mobile-technology

Managing Inappropriate Sexual Behavior in Dementia With Dignity: Clinical Realities, Caregiver Support, and Policy Imperatives

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As the global population ages, the prevalence of dementia is rising rapidly, posing complex challenges not only to healthcare systems but also to societal attitudes, caregiving approaches, and public policy. According to the World Health Organization (WHO; 2025), over 55 million people worldwide live with dementia, and this number is expected to double every 20 years, reaching 139 million by 2050. Amid this growing burden, certain manifestations of dementia—such as inappropriate sexual behavior (ISB)—remain deeply stigmatized, underreported, and poorly addressed in both clinical and caregiving contexts.

ISB in dementia, though often marginalized in public discourse, is neither rare nor inconsequential. Estimates suggest that between 7% and 25% of individuals with dementia may exhibit some form of ISB, including sexually suggestive comments, public masturbation, inappropriate touching, or delusional misidentification of others as romantic partners (Alagiakrishnan et al., 2005; Guay, 2008). These behaviors, often rooted in neurobiological changes such as frontal lobe disinhibition or temporal lobe pathology, are frequently interpreted through a moral or disciplinary lens, leading to stigmatization, punitive responses, or inappropriate pharmacological restraint.

The issue is further complicated by sociocultural taboos surrounding sexuality in older adults. Sexuality among older persons is frequently viewed as irrelevant, inappropriate, or even pathological—responses that derive from deeply ingrained ageism (Kuhn, 2002). When such biases intersect with the behavioral symptoms of dementia, it can result in a potent combination of shame, neglect, and violation of fundamental human rights. In institutional settings, responses to ISB often oscillate between two extremes: overreaction (e.g., involuntary sedation, seclusion) and complete avoidance (e.g., ignoring or dismissing behaviors); both fail to address the underlying needs and dignity of the person.

The crux of the challenge lies in reconciling the preservation of individual rights—especially the right to sexual expression and identity—with the imperative to ensure safety, comfort, and boundaries for coresidents, caregivers, and staff. This dilemma raises critical ethical questions around autonomy, consent, capacity, and the duty of care (Mahieu et al., 2017). It also calls for the integration of human rights frameworks into dementia care, guided by the principles of the United Nations Convention on the Rights of Persons With Disabilities (CRPD) and the Madrid International Plan of Action on Ageing (MIPAA).

Moreover, caregivers—both familial and professional—are often ill-equipped to handle ISB, lacking training in both clinical interpretation and compassionate response. The emotional toll of such behaviors can be significant, frequently contributing to caregiver burnout, institutionalization decisions, and strained interpersonal relationships (Hayward et al., 2013). Without adequate support and guidance, caregivers may resort to suppressive measures or harbor feelings of guilt, fear, or helplessness.

This article aims to explore ISB in individuals living with dementia through a multidimensional lens—clinical, psychosocial, ethical, and legal—while advocating for a shift towards person-centered, dignity-affirming approaches. I will examine typologies and neurobiological underpinnings of ISB, discuss the ethical considerations in managing such behaviors, and present evidence-based assessment and treatment strategies. Additionally, the article will highlight the importance of caregiver training, institutional protocols, and policy frameworks that uphold the rights and dignity of older adults, particularly those living with dementia. Through this lens, I underscore the urgency of developing global best practices for ISB management that are inclusive, empathetic, and rooted in human rights.

Understanding Inappropriate Sexual Behavior in Dementia

Inappropriate sexual behavior (ISB) in dementia is a deeply sensitive and often neglected aspect of neurocognitive disorders. It challenges care professionals, distresses families, and tests the limits of institutional policies around dignity, consent, and safety. Although sexuality is a basic human right across the lifespan, in dementia, it is often either pathologized or completely ignored. The lack of clinical training and societal comfort in dealing with sexual expression among older adults—especially those with cognitive decline—contributes to poor management, rights violations, and inadequate care. Table 1 shows the various clinical presentations of ISB in dementia.

Table 1

Typology of Inappropriate Sexual Behavior (ISB) in Dementia

Category of ISB	Clinical examples	Neurobiological or trigger mechanism	When it occurs
Verbal sexual innuendo	Sexual jokes, comments about body parts, flirtatious language	Frontal disinhibition, temporal lobe dysfunction	More common in FTD than AD
Inappropriate touching	Groping, fondling of others, grabbing caregivers	Loss of social inhibition, impaired perception of boundaries	FTD, advanced AD
Public masturbation	Masturbation in communal spaces, inability to suppress sexual urges	Orbitofrontal dysfunction, boredom, anxiety, loss of inhibition	AD, FTD, Lewy body dementia
Disrobing or exhibitionism	Undressing in public, exposing genitals	Parietal lobe dysfunction, confusion, discomfort (e.g., heat)	Moderate-to-severe AD
Delusional misidentification	Believing spouse is someone else, confusing caregiver with romantic partner	Temporal lobe dysfunction, Capgras-type delusions	AD with psychosis
Sexual aggression	Forcible advances, attempts at intercourse without consent	Frontal lobe injury, hypersexuality, psychiatric comorbidity	Rare but possible in FTD and mixed types of dementia

Note. AD = Alzheimer's dementia; FTD = frontotemporal dementia.

Definition and Typology

ISB is broadly defined as "a verbal or physical act of an explicit or perceived sexual nature, which is unacceptable within the social context in which it is carried out" (Johnson et al., 2006, as cited in De Giorgi & Series, 2016, Definition). It can be verbal (e.g., inappropriate comments), physical (e.g., groping, grabbing), behavioral (e.g., disrobing), or delusional (e.g., misidentifying someone as a romantic partner). These behaviors may not necessarily reflect actual sexual intent. In many cases, they stem from unmet emotional needs, confusion about context, or sensory misinterpretations.

For example, a patient who disrobes in a common area may not be engaging in exhibitionism but may be too warm, uncomfortable, or misperceiving their location as a private space. Such incidents, however, are often misread as sexually aggressive, leading to overreactions such as chemical restraints, seclusion, or punishment—all of which compromise dignity and ethical care (Mahieu et al., 2017).

Clinical Differentiation and Diagnostic Relevance

Differentiating ISB from other behavioral and psychological symptoms of dementia (BPSD) is critical. While BPSD includes a broad spectrum—agitation, hallucinations, aggression—ISB specifically pertains to socially inappropriate sexual behaviors. It is crucial to rule out other conditions that may mimic ISB, such as the following:

- delirium—sudden-onset sexual disinhibition can occur in hyperactive delirium
- medication-induced behavior—dopaminergic agents used in Parkinson's or mixed dementia may cause hypersexuality
- hypomania or mania—it may occur in older adults with late-onset bipolar disorder
- frontal lobe syndromes—behavioral disinhibition is a hallmark
- psychiatric comorbidities—for example, someone with schizophrenia may also suffer disinhibited behavior

Thorough medical, neurological, and psychiatric assessments help determine whether ISB is a core symptom of the dementia process or secondary to another modifiable condition.

Neuroanatomical and Pathophysiological Insights

ISB is often linked to degeneration in the frontal and temporal lobes, especially in frontotemporal dementia (FTD), where loss of inhibitory control and social filter is prominent (Mendez & Shapira, 2013). In Alzheimer's disease (AD), ISB may be more sporadic, and associated with late-stage cognitive decline. Some individuals may have exaggerated libido (hypersexuality), while others misinterpret intimacy cues due to memory and perceptual deficits. Furthermore, damage to the hypothalamus or pituitary-adrenal axis in neurodegenerative conditions can disrupt sexual behavior regulation.

Another dimension is the loss of social cognition—particularly theory of mind—which makes patients less aware of the discomfort or reactions of others. They may not recognize that their actions are socially inappropriate or distressing.

Triggers and Environmental Influences

Environmental factors can also trigger or exacerbate ISB. Overcrowded living spaces, lack of privacy, poor lighting, sensory overstimulation, or understimulating environments can all contribute. Inadequate staff ratios or gender mismatches during caregiving tasks (e.g., a male patient being bathed by a female staff member) can trigger confused or sexually charged responses from individuals with dementia, especially if they have residual awareness of gender norms alongside impaired impulse control.

Unmet needs—such as for affection, touch, or companionship—can also manifest as sexualized behavior. Dementia reduces a person's ability to articulate these needs appropriately, and thus they may act them out behaviorally.

Cultural and Societal Stigma

In society at large, sexuality in older adults remains fraught with taboos. ISB in dementia is often met with shame, denial, or concealment by families and care institutions. In many collectivist societies in particular, such behaviors may be treated as signs of "moral decay" or family disgrace, leading to concealment and delayed medical attention. Staff and caregivers may be ill-equipped or emotionally overwhelmed, further compounding the problem.

This stigma can compromise the quality of care, as ISB often becomes an unspoken issue. Nursing homes or residential facilities may not have formal guidelines or training modules to help staff respond with empathy and structure. Moreover, cultural reluctance to discuss sexuality makes caregiver education on this topic both essential and difficult.

Clinical and Ethical Implications

The challenge lies not only in identifying and managing ISB but also in maintaining a delicate balance between upholding the rights of the person living with dementia and ensuring the safety and comfort of others. ISB requires a nuanced, nonjudgmental, and person-centered approach. Addressing it solely through pharmacological suppression ignores its psychological, emotional, and environmental underpinnings.

Ethical and Human Rights Considerations

Managing inappropriate sexual behavior (ISB) in individuals with dementia presents not only a clinical challenge but also a profound ethical and human rights dilemma. Balancing the dignity, autonomy, and rights of the person living with dementia with the need to protect others in their environment—caregivers, coresidents, and family members—requires sensitive, case-by-case deliberation. Unfortunately, many systems of care tend to either pathologize or suppress these behaviors without considering the deeper ethical implications or the basic human rights of older individuals.

Preserving Dignity and Personhood

Central to dementia care is the concept of preserving dignity—a moral principle that recognizes the inherent worth of every person, regardless of cognitive ability (McMillan, 2005). When ISB is managed through restrictive means such as chemical restraints, physical isolation, or public shaming, the person's dignity is often violated. These approaches reinforce the view that individuals with dementia are disruptive or deviant rather than people experiencing vulnerability whose behaviors may be symptomatic of illness or unmet needs.

A person-centered approach, grounded in the work of Thomas Kitwood (1997), emphasizes that every behavior—even those that are challenging—has meaning and arises from an individual's life history, environment, and emotional needs. Understanding ISB in this framework allows caregivers and professionals to respond with empathy and respect rather than control or punishment.

Autonomy, Consent, and Sexual Expression

Sexuality remains a core component of human identity across the lifespan. Yet the sexual rights of older adults, particularly those with cognitive impairment, are frequently overlooked. The challenge of assessing capacity for consent in dementia complicates the ethical landscape. Individuals in the early stages of dementia may retain the ability to form intimate relationships and express sexual desire, but in more advanced stages, this capacity may be compromised. However, the presumption should not automatically be that a diagnosis of dementia nullifies sexual autonomy.

Ethical frameworks suggest a nuanced, functional approach to assessing sexual consent, focusing on the individual's ability to understand the nature of the relationship, the voluntary nature of the act, and the potential consequences (Mahieu et al., 2017). This assessment must be individualized, culturally sensitive, and frequently revisited. The tendency to adopt overly paternalistic attitudes—where decisions about intimacy are made without involving the person living with dementia—must be resisted.

In institutional settings, there is often discomfort among staff regarding expressions of sexuality. This may result in hasty interventions or denial of privacy. Policies that prohibit consensual sexual activity between residents may infringe on personal freedoms and violate ethical principles of autonomy and self-expression. Facilities must navigate these situations with discretion, risk mitigation, and resident-focused care planning.

Human Rights Frameworks and Global Obligations

From a rights-based perspective, the management of ISB must align with international declarations and conventions. The United Nations Principles for Older Persons (1991) affirm the rights of older people to dignity, care, and self-fulfillment. Similarly, the Convention on the Rights of Persons With Disabilities (CRPD; 2006) affirms that persons with disabilities, including cognitive impairment, have the right to autonomy, non-discrimination, and participation in all areas of life.

The Madrid International Plan of Action on Ageing (MIPAA; 2002) further underscores the need to protect older persons from abuse—including neglect and over-restriction—and to respect their sexual and emotional needs. However, implementation remains inconsistent. Many countries lack specific legislation or guidelines addressing ISB in dementia care. In this vacuum, responses are often driven by fear of litigation, media scandal, or bureaucratic reluctance to engage with complex ethical issues, rather than the individual's will and preferences.

Ethical Responsibilities of Care Institutions

Care facilities bear a dual obligation: to protect all residents from harm and to honor the dignity and rights of the person exhibiting ISB. Staff training, ethical leadership, and policy development are key. Institutions must have clear protocols on how to assess capacity for sexual expression, how to respond to ISB ethically, and how to ensure that interventions are the least restrictive necessary to ensure safety and dignity.

Moreover, ethical care involves understanding the emotional toll on caregivers. Repeated exposure to ISB without adequate support can result in moral distress, burnout, and compassion fatigue (Hayward et al., 2013). Ethically grounded supervision and training are essential to empower caregivers to act with integrity, confidence, and compassion.

Assessment and Management Approaches

Approaching inappropriate sexual behavior (ISB) in dementia requires a structured, empathetic, and interdisciplinary process. Management must be both individualized and evidence-informed, addressing underlying causes, safeguarding dignity, and ensuring the well-being of all involved. Despite its prevalence, ISB is often mismanaged—either minimized or harshly penalized—due to lack of clear protocols, training gaps, and discomfort with the topic.

Comprehensive Assessment

A thorough clinical evaluation is foundational. ISB should never be interpreted in isolation. Rather, it should be examined in the context of the person's neurological, medical, psychiatric, psychosocial, and environmental status, as further discussed below.

History and Behavior Analysis. A detailed description of the behavior, including its frequency, triggers, setting, and targets, helps identify patterns. Caregivers can provide crucial insight into antecedents and emotional states. It is important to distinguish between isolated incidents and repetitive, escalating behaviors.

Cognitive and Functional Assessment. Use of tools such as the Mini-Mental State Examination (MMSE) or the Montreal Cognitive Assessment (MoCA) helps estimate the stage of dementia, while neuropsychiatric instruments like the Neuropsychiatric Inventory (NPI) or the Behavioral Pathology in Alzheimer's Disease (BEHAVE-AD) rating scale can quantify BPSD, including ISB (Cummings et al., 1994).

Medical Review. Pain, urinary tract infections, constipation, delirium, or sleep disturbances can exacerbate behavioral symptoms. Additionally, some medications—including dopaminergic drugs, benzodiazepines, or anticholinergics—can provoke disinhibition or hallucination. A comprehensive medication review is thus critical.

Psychiatric Comorbidities. Late-onset bipolar disorder, schizophrenia, impulse control disorders, or prior history of sexual trauma should be explored. These may interact with neurodegeneration and complicate the behavioral picture.

Environmental Context. Crowded spaces, absence of privacy, lack of structure, or gender mismatches in caregiving may contribute to ISB. Environmental modifications can sometimes preclude the need for pharmacological interventions altogether (Alagiakrishnan et al., 2005).

Non-Pharmacological Management

Non-drug interventions form the cornerstone of ISB management and should always precede pharmacological options unless there is immediate risk or severe distress. Below are several methods for this.

Behavioral Therapy. Applied Behavior Analysis (ABA), redirection, and distraction techniques can help modify responses over time. Some success has been seen with habit reversal and reinforcement strategies.

Environmental Adjustments. Simple changes—such as more private spaces, structured routines, or assigning same-gender caregivers—can significantly reduce triggering situations.

Meaningful Engagement. Loneliness and sensory deprivation may manifest as sexually inappropriate behavior. Music therapy, pet therapy, art, or reminiscence activities can help redirect energy positively.

Education and Communication. Training caregivers to recognize ISB as a medical symptom rather than willful misconduct can reduce moral distress and improve response efficacy. Language that avoids judgment ("someone is touching others inappropriately" vs. "someone is being a pervert") is crucial.

Pharmacological Strategies

When ISB causes distress, disrupts care, or risks safety, pharmacological options may be considered with caution. Medications are typically off-label and should be used at the lowest effective dose, with close monitoring. Some considerations are listed below.

Selective Serotonin Reuptake Inhibitors (SSRIs). Drugs like citalopram or sertraline may help reduce impulsivity and sexual preoccupation, particularly in frontotemporal dementia (Mendez & Shapira, 2013).

Antipsychotics. Atypical antipsychotics (e.g., risperidone, quetiapine) may be used for aggression or delusions but carry risks including falls, sedation-related problems such as nausea or somnolence, and increased mortality in older adults with dementia (Ballard et al., 2006).

Hormonal Agents. In extreme cases of hypersexuality, medications such as anti-androgens (e.g., medroxyprogesterone) or GnRH analogs have been used, but because of ethical and legal implications, these are usually seen as a last resort and only appropriate if the behaviors are dangerous and refractory. Use of hormonal treatments is often considered akin to “chemical castration” and hence is a potentially serious human rights violation (Guay, 2008).

Mood Stabilizers. Valproate or carbamazepine may be considered for comorbid agitation or mood dysregulation but have limited evidence specific to ISB.

All pharmacologic decisions must be made collaboratively (see the section on Interdisciplinary Collaboration below), documented carefully, and accompanied by consent from the patient themselves, as well as their family or legal guardians if the patient has decision-making concerns. However, suffering from dementia is not in itself sufficient to assume that an individual cannot consent to their treatment decisions. The consent-making capacity is fluid and is retained in most individuals in the mild cognitive impairment and mild dementia stages. Consent-making capacity is context-specific and may not be the same in all aspects. For example, someone may not be able to comprehend the extent of their property but may understand the treatment processes they are undergoing. Table 2 highlights the basic tenets of ISB assessment and management.

Table 2

Clinical Management Algorithm for ISB in Dementia

Step order	**Algorithm description**	
Step 1	Observe and document	Describe frequency, triggers, setting, and response by others
Step 2	Rule out medical and psychiatric causes	Screen for infections, pain, sleep issues, medication side effects; assess for delirium, psychosis, mania
Step 3	Cognitive and functional assessment	Use MMSE, NPI, MoCA, ADLs/IADLs
Step 4	Environmental and psychosocial review	Evaluate privacy, routines, boredom, unmet needs
Step 5	Implement non-pharmacological interventions	Behavioral strategies, caregiver training
Step 6	Consider pharmacological options	Start with SSRIs or low-dose atypicals and monitor closely
Step 7	Ethical oversight and consent	Involve patient, family, and legal guardian; prioritize least-restrictive measures (if patient retains capacity to understand the treatment process—their consent is enough)
Step 8	Review and reassess	Monitor behavior, side effects, and care goals continuously

Note. MMSE = Mini-Mental State Examination; NPI = Neuropsychiatric Inventory; MoCA = Montreal Cognitive Assessment; ADL = Activities of Daily Living; IADL = Instrumental Activities of Daily Living; SSRI = Selective Serotonin Reuptake Inhibitor

Interdisciplinary Collaboration

Effective management of ISB requires a coordinated approach involving:

- geriatricians or primary care physicians to address comorbidities
- psychiatrists for behavior planning and medication oversight
- nurses and social workers to monitor responses and deliver daily care
- occupational therapists to suggest environmental modifications
- family caregivers for historical context and continuity

Team meetings and behavioral case reviews help maintain alignment and ensure interventions are person-centered.

Caregiver Training and Support

Caregivers—both familial and professional—play a pivotal role in recognizing, interpreting, and responding to inappropriate sexual behavior (ISB) in dementia. Despite the critical nature of their role, most caregivers report feeling ill-equipped, unsupported, and emotionally distressed when faced with ISB. The combination of stigma, lack of formal training, and the personal discomfort surrounding sexual expression in older adults contributes to significant gaps in quality care and emotional well-being for all parties involved (Hayward et al., 2013).

Understanding the Emotional Burden

ISB can be emotionally taxing, especially for family caregivers. When a loved one engages in unfamiliar or seemingly "shameful" behaviors, caregivers may experience a mixture of embarrassment, guilt, fear, and sadness. These reactions are compounded by cultural taboos, especially in more conservative societies where sexuality in older adults is a sensitive topic (Mahieu et al., 2017). Spouses may interpret ISB as rejection or infidelity; children may find such behaviors disturbing or morally wrong. Without appropriate psychological support or reframing, these reactions can lead to caregiver burnout, strained family dynamics, and premature institutionalization.

Professional caregivers, including nursing staff and aides, often lack formal training in behavioral symptom management. Encounters with ISB may result in personal discomfort, avoidance, or punitive interventions. Staff turnover, especially in under-resourced care homes, further reduces the continuity and confidence of care provision. In the absence of structured protocols, staff may adopt inconsistent or judgmental responses that escalate behavioral incidents rather than de-escalate them. Table 3 outlines the essential (core) competencies needed for caregivers to manage and deal with inappropriate sexual behavior in dementia.

Table 3

Core Competencies for Caregivers in Responding to ISB

Competency area	Skill description
Recognition	Ability to identify and document ISB accurately, avoiding judgmental language
Empathic interpretation	Understanding that ISB is a symptom of disease, not intentional behavior
De-escalation techniques	Use of redirection, distraction, and non-verbal cues to defuse situations
Communication skills	Clear, respectful, and non-stigmatizing responses to ISB, and education of others
Cultural sensitivity	Acknowledging cultural and religious factors in shaping response and behavior
Emotional regulation	Managing personal reactions, avoiding shame, guilt, or retaliatory behavior
Reporting and documentation	Accurate incident logging and knowledge of protocols
Ethical awareness	Understanding consent, dignity, and rights-safety balance
Collaboration	Working with interdisciplinary teams and families for person-centered care

Importance of Caregiver Education

Training caregivers to understand the neurobiological basis of ISB is critical. Recognizing that such behaviors are not intentional misconduct but expressions of disinhibition, confusion, or unmet needs helps reduce stigma and fosters compassionate care. Education should focus on empathy, emotional regulation, and non-confrontational communication techniques.

Simulation-based training, behavioral rehearsal, and case-based learning can enhance caregiver preparedness. Modules should include real-world scenarios with emphasis on the following:

- interpreting behavioral cues
- using redirection and distraction
- responding to coresident distress
- documenting and reporting incidents appropriately
- knowing when to raise concerns to clinical staff

Cultural sensitivity must be integrated into all training initiatives. For example, a caregiver in India or the Middle East may face different ethical and interpersonal dilemmas than one in Europe or North America. Respecting religious values, gender dynamics, and language norms while upholding the personhood of the dementia patient is essential.

Emotional and Psychological Support for Caregivers

In addition to skill-building, caregivers must have access to emotional support systems. Family caregivers benefit from psychoeducation, counselling, and peer support groups where they can share experiences without fear of judgment. Professional caregivers need regular debriefing sessions, supervision, and mental health check-ins to avoid compassion fatigue and moral distress. Administrators of care facilities have a responsibility to create an environment where ISB can be openly discussed, ethically addressed, and recorded without fear of blame. Establishing a culture of transparency, support, and non-punitive accountability not only improves care but also protects the rights and safety of both patients and staff.

Institutional Framework and Policy Support

Training should be embedded in broader institutional frameworks. Policies must define what constitutes ISB, delineate roles and responsibilities, and ensure incident review systems are in place. Staff should be protected under whistleblower policies if they report inappropriate practices related to resident management. Equally, families must be involved in care planning and consent processes from the outset, particularly when ISB is a known or anticipated risk. Ultimately, caregiver training is not just about behavioral management. It is about restoring dignity to care, ensuring safety, and maintaining empathy in complex human situations.

Policy, Legal, and Institutional Implications

While inappropriate sexual behavior (ISB) in dementia is clinically recognized and ethically significant, policy frameworks across most countries remain underdeveloped or inconsistent. There is a pressing need to integrate human rights principles, clinical standards, and cultural considerations into national and institutional dementia care policies. Failing to do so not only compromises care but also violates the dignity and autonomy of older adults.

Policy and Governance Gaps

Despite the increasing prevalence of dementia worldwide, very few national ageing or mental health policies directly address ISB. Most policies focus on physical safety, abuse prevention, and institutional regulation, but the right to sexual expression, nuanced understanding of ISB, and its management in long-term care are rarely discussed. In many countries, care institutions are left to define and manage ISB independently, often without ethical guidance, clinical protocols, or legal support. As a result, responses to ISB are reactive, erratic, and heavily dependent on the values of individual caregivers or administrators. This inconsistency may result in overuse of restraints, inappropriate medication, violation of privacy, or underreporting of incidents due to fear of liability (Bauer et al., 2014).

Legal and Ethical Ambiguities

The legal landscape surrounding ISB in dementia care is marked by ambiguity. There is limited clarity on how to assess and operationalize consent in people with cognitive decline. In many jurisdictions, capacity laws are designed for financial or medical decisions, not intimate or sexual behavior. The absence of clear legal definitions often leads to zero-tolerance approaches or unnecessary restrictions, denying individuals the right to meaningful relationships.

Additionally, staff in nursing homes or assisted living facilities may hesitate to intervene appropriately due to fear of litigation. Conversely, they may overreact—removing individuals from social environments, enforcing blanket restrictions, or administering unnecessary medication—to avoid institutional risk. Both extremes undermine the individual’s autonomy and may inadvertently foster abuse. There is also an urgent need to protect staff from false accusations and ensure that reporting systems are robust, confidential, and supportive.

Institutional Protocols and Accountability

Institutions must adopt standard operating procedures (SOPs) for ISB, rooted in ethical care and supported by training. This includes establishing multidisciplinary behavior management teams, using individualized care plans, and setting up clear documentation and review mechanisms. These protocols should delineate when certain behaviors raise medical concerns, when they require redirection, and when they may necessitate ethical or legal intervention.

Quality assurance audits, incident reporting, and family involvement must be integrated into institutional practice. Accreditation bodies and elder care regulators should evaluate whether such systems are in place and functioning. Institutions should also ensure privacy and dignity for residents who engage in consensual relationships. This may require offering private spaces, discussing preferences during intake assessments, and fostering a sex-positive, age-inclusive care philosophy.

Global Best Practices and Recommendations

Several countries have initiated promising steps in addressing sexuality and dementia care:

- Australia has incorporated sexual rights into aged care standards, supporting consensual relationships and requiring staff education on ISB.
- Canada promotes harm-reduction and dignity-conserving approaches through national dementia strategies.
- The Netherlands emphasizes resident autonomy and intimacy in long-term care, with guidelines on private space, staff response, and family involvement.

These models underscore the feasibility and benefits of structured ISB policy frameworks rooted in rights-based care. Table 4 summarizes the best international policy guidelines for managing ISB.

Table 4

International Best Practice and Policy Models for ISB Management

Country	Policy/Program	Key features
Australia	Aged Care Quality Standards (introduced in 2019)	Recognizes sexual rights; mandates staff training (Aged Care Quality and Safety Commission of the Australian Government, n.d.)
Canada	National Dementia Strategy	Promotes ethical ISB management and education (Public Health Agency of Canada, 2019)
Netherlands	Dutch Long-Term Care Guidelines	Supports sexual autonomy and private spaces (Lichtenberg, 2014)
United Kingdom	Care Quality Commission (CQC) Elder Care Guidelines	Emphasizes documentation and respectful care (Care Quality Commission, n.d.)
United States	Centers for Medicare and Medicaid Services (CMS) Regulations on Abuse Prevention	Requires incident reporting; lacks guidance on consensual intimacy (Centers for Medicare and Medicaid Services, n.d.)
South Africa	Older Persons Act (assented in 2006)	Addresses elder abuse; limited mention of sexual rights

Future Directions and Recommendations

The effective management of inappropriate sexual behavior (ISB) in dementia is not only a clinical priority but also a human rights imperative. As the global burden of dementia rises, systems of care must evolve to accommodate the behavioral complexities of the condition without compromising dignity and autonomy. ISB represents a challenging intersection of neurodegeneration, sexuality, stigma, and care ethics, which demands a coordinated, compassionate response from individuals, institutions, and nations alike.

Development of Global Guidelines

One of the most pressing needs is the creation of standardized, evidence-based international guidelines for managing ISB in dementia. It will be practical if these are headed by global organizations such as the WHO or Alzheimer's Disease International. Guidelines must integrate medical, psychological, legal, and cultural dimensions, and promote human-rights-centered approaches over risk-averse or punitive measures. Such frameworks should include the following:

- define ISB clearly and classify its subtypes
- outline ethical principles of assessment and intervention
- recommend standards for staff training and institutional protocols
- address consent, capacity, and safeguarding in culturally sensitive ways

These global standards should serve as templates for national policy adaptation.

Research Priorities

There remains a dearth of robust research into the prevalence, typology, and management outcomes of ISB. Future studies should prioritize the following:

- epidemiological mapping across different dementia subtypes and cultural contexts
- neuroimaging studies to link structural dysfunction to behavior patterns
- intervention trials comparing pharmacological and non-pharmacological strategies
- qualitative studies capturing caregiver, staff, and patient perspectives

Additionally, economic analyses are warranted to explore the cost-effectiveness of early training interventions versus the downstream consequences of unaddressed ISB (e.g., caregiver burnout, hospitalization, litigation).

Integration With WHO Healthy Ageing Framework

The WHO's work on the United Nations Decade of Healthy Ageing 2021–2030 emphasizes creating age-friendly environments, combating ageism, and integrated care for older adults. ISB management aligns closely with these goals. Sexual health and expression are often ignored in healthy ageing discourse, yet are intrinsic to well-being and identity. Future dementia care strategies must include behavioral training, intimacy-preserving design in care homes, and age-positive communication campaigns.

Education and Professional Development

Mandatory inclusion of ISB management in medical, nursing, social work, and allied health curricula is essential. Continuous professional development programs should cover the following:

- recognition and assessment of ISB
- ethical and legal implications
- communication and de-escalation skills
- cultural competence in dementia care

International exchange of training models and best practices could promote harmonization of care standards, especially in low- and middle-income countries where formal elder care structures are still developing.

Strengthening Caregiver Advocacy and Support

Families caring for persons living with dementia must be empowered through the following:

- accessible educational material (print, audio-visual, online)
- support groups focused on behavioral challenges
- legal counselling on guardianship and consent issues
- integration of family feedback into institutional policies

Promoting caregiver voices through advocacy coalitions can shape more responsive care environments and reduce the isolation that often accompanies ISB-related distress.

Legislative and Policy Reform

Governments must revise outdated or absent eldercare policies to include the following:

- recognition of older adults' sexual rights
- provision for consensual intimacy in care facilities
- legal definition of sexual consent in cognitive impairment
- training and oversight requirements for institutions
- support for interdisciplinary behavioral response teams

Policymakers should collaborate with legal experts, dementia clinicians, ethicists, and human rights bodies to ensure that such reforms are inclusive, enforceable, and culturally adaptable.

These future directions underscore a critical shift from reaction to preparation, from stigma to understanding, and from control to care. By investing in evidence, training, rights-based policies, and cross-sectoral collaboration, we can move toward a global dementia care paradigm that is not only competent but truly compassionate.

Conclusion

Inappropriate sexual behavior (ISB) in dementia remains one of the least understood, most stigmatized, and most poorly addressed aspects of neurocognitive disorders. While it may represent only a subset of behavioral and psychological symptoms, its ethical, emotional, and legal reverberations are disproportionately intense—affecting individuals, families, caregivers, and institutions. The historical tendency to either pathologize or suppress such behaviors has often led to interventions that violate the dignity and rights of those living with dementia.

This article underscores the importance of approaching ISB not as a moral failing or isolated symptom but as a complex behavioral expression rooted in neurobiology, context, unmet needs, and identity. Whether it manifests as verbal innuendo, inappropriate touching, or disinhibited behavior, each instance calls for interpretation through the lens of personhood. Respect for the older adult's humanity must remain at the core of all responses.

Management must begin with a comprehensive assessment, and prioritize non-pharmacological, individualized strategies. Where pharmacologic treatments are necessary, they must be used judiciously and ethically. Training and supporting caregivers—both formal and informal—is indispensable, not only to mitigate burnout and distress but also to foster empathetic, informed responses that center on the person living with dementia, not the symptom.

At the broader level, legislative clarity, institutional protocols, and national policies must be developed to uphold sexual rights, safeguard all stakeholders, and provide consistent standards of care. Cross-national learning and integration with global ageing frameworks, such as the WHO's Healthy Ageing Agenda and the United Nations Decade of Healthy Ageing, can propel this agenda forward.

Ultimately, managing ISB in dementia is a litmus test of how far our systems have come in delivering person-centered, rights-based, and age-inclusive care. In rising to meet this challenge, we affirm the core value of eldercare: that even in cognitive decline, every person deserves respect, autonomy, and dignity.

References

Aged Care Quality and Safety Commission of the Australian Government. (n.d.). *Quality standards*. https://www.agedcarequality.gov.au/providers/quality-standards

Alagiakrishnan, K., Lim, D., Brahim, A., Wong, A., Wood, A., Senthilselvan, A., Chimich, W. T., & Kagan, L. (2005). Sexually inappropriate behaviour in demented elderly people. *Postgraduate Medical Journal*, *81*(957), 463–466. https://doi.org/10.1136/pgmj.2004.028043

Ballard, C. G., Waite, J., & Birks, J. (2006). Atypical antipsychotics for aggression and psychosis in Alzheimer's disease. *Cochrane Database of Systematic Reviews*, *1*, Article CD003476. https://doi.org/10.1002/14651858.CD003476.pub2

Bauer, M., Fetherstonhaugh, D., Tarzia, L., Nay, R., & Beattie, E. (2014). Supporting residents' expression of sexuality: The initial construction of a sexuality assessment tool for residential aged care facilities. *BMC Geriatrics*, *14*(1), Article 82. https://doi.org/10.1186/1471-2318-14-82

Care Quality Commission. (n.d.). *Adult social care: Information for providers*. https://www.cqc.org.uk/guidance-regulation/providers/adult-social-care

Centers for Medicare and Medicaid Services. (n.d.). *State operations manual—Appendix pp: Guidance to surveyors for long-term care facilities*. https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/downloads/som107ap_pp_guidelines_ltcf.pdf

Convention on the Rights of Persons With Disabilities (CRPD), 2006, https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd

Cummings, J. L., Mega, M., Gray, K., Rosenberg-Thompson, S., Carusi, D. A., & Gornbein, J. (1994). The neuropsychiatric inventory: Comprehensive assessment of psychopathology in dementia. *Neurology*, *44*(12). https://doi.org/10.1212/WNL.44.12.2308

De Giorgi, R., & Series, H. (2016). Treatment of inappropriate sexual behavior in dementia. *Current Treatment Options in Neurology*, *18*, Article 41. https://doi.org/10.1007/s11940-016-0425-2

Guay, D. R. P. (2008). Inappropriate sexual behaviors in cognitively impaired older individuals. *The American Journal of Geriatric Pharmacotherapy*, *6*(5), 269–288. https://doi.org/10.1016/j.amjopharm.2008.12.004

Hayward, L. E., Robertson, N., & Knight, C. (2013). Inappropriate sexual behaviour and dementia: An exploration of staff experiences. *Dementia*, *12*(4), 463–480. https://doi.org/10.1177/1471301211434673

Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Open University Press.

Kuhn, D. (2002). Intimacy, sexuality, and residents with dementia. *Alzheimer's Care Quarterly*, *3*(2), 165–176.

Lichtenberg, P. A. (2014). Sexuality and physical intimacy in long-term care. *Occupational Therapy in Health Care*, *28*(1), 42–50. https://doi.org/10.3109/07380577.2013.865858

Madrid International Plan of Action on Ageing (MIPAA), 2002, https://social.desa.un.org/issues/ageing/madrid-plan-of-action-and-its-implementation-main/madrid-plan-of-action-and-its

Mahieu, L., Anckaert, L., & Gastmans, C. (2017). Intimacy and sexuality in institutionalized dementia care: Clinical-ethical considerations. *Health Care Analysis*, *25*, 52–71. https://doi.org/10.1007/s10728-014-0287-2

McMillan, J. (2005). Identity, self, and dementia. In J. Hughes, S. Louw, & S. R. Sabat (Eds.), *Dementia: Mind, meaning, and the person*. Oxford University Press. https://doi.org/10.1093/med/9780198566151.003.0004

Mendez, M. F., & Shapira, J. S. (2013). Hypersexual behavior in frontotemporal dementia: A comparison with early-onset Alzheimer's disease. *Archives of Sexual Behavior*, *42*(3), 501–509. https://doi.org/10.1007/s10508-012-0042-4

Public Health Agency of Canada. (2019). *A dementia strategy for Canada: Together we aspire*. https://www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia-strategy.html

South African Government. (2006). *Older Persons Act 13 of 2006*. https://www.gov.za/documents/older-persons-act

United Nations Principles for Older Persons, 1991, https://www.ohchr.org/en/instruments-mechanisms/instruments/united-nations-principles-older-persons

WHO. (2025). *Dementia*. https://www.who.int/news-room/fact-sheets/detail/dementia

Will and Preferences in the Context of Dementia: Retaining Personhood in a Changing World With a Changing Brain

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It was around 2012 when I was diagnosed with younger-onset dementia (any kind of dementia developed before the age of 65). At first, I pretended it was all a big mistake, but as time passed and symptoms became even more problematic, I had to accept that the life I had built and the future I had planned for were going to change. Gradually, I came to see that special look in people's eyes—a mixture of fear and pity. Everyone wanted to swoop in and fix me so that life would return to *normal*.

I came to understand that dementia is not what I expected. I have seen older people in my family and community live and die with dementia. I thought the person was disappearing and their body was becoming an *empty shell*. These people seemed to change personalities; they were unpredictable and difficult to help. I said to myself, "Thank goodness, there is an institution to take care of them." Now that I am living with dementia, I find that I am not disappearing at all. I still feel present inside and outside. I am slowly changing from a thinking woman with feelings into a feeling woman with thoughts. My intellect is intact, but my ability to organise, remember, and function in a world with clocks, timeframes, responsibilities, and obligations is diminishing fast. As these abilities reduce, my sensory perception increases. I suspect that functionality is being replaced by emotion. I sense everything around me—every nuance, every sigh, and every smile—but I do not always understand the meaning of the words spoken. I feel as if I live in two worlds—the internal world, that can be described as numinous, spiritual, pleasant, and calm, and the external world, that I describe as the mundane. In my internal, numinous world, I am worthy and enough. In my external mundane world, I am neither. I know that on the outside, I am getting that *vacant* look. I see the pain and fear in the eyes of my loved ones when this happens. However, as dementia progresses, it becomes easier to retreat from the outside world.

While I understand that to the outside world, I may look like an empty shell, I maintain an awareness of the mundane world and its activities, and my body responds to that sometimes. I do not feel that I am fading away; I feel as though I am merging into everything. Many professionals describe these quiet hours as *apathy*. However, the use of this term implies giving up, giving in, or being unconcerned, as if I deliberately choose to be this way. I propose that *rêverie* (a pleasant state where, in French, one is lost in thought) may be a better description. In fact, I would argue that this may be an outward sign of acceptance of a changed future.

As I continue to try to function and interact with systems and services, I realize that, despite terminology like *person-centred care*, I do not fit easily into established categories. I am not old enough for dementia, do not look to have dementia, and therefore just appear not to be trying as hard as I should. Based on numerous conversations with persons impacted by dementia, as well as my own experiences, I have identified common difficulties:

- ostracised—we can no longer function in the way that society expects; we are encouraged to stay out of sight to avoid embarrassment, or placed in a facility (such as an institution) far from family and community.
- homogenised—it is untenable to deliver individualised person-centred care in an environment where economy of scale and efficiency are dominant. That is, there is little room for individuality or diversity in a communal living arrangement, for instance.
- dehumanised—we are different, and we cannot always behave in the way that others want. We are considered difficult and unpredictable. When the features that society associates with humanity are not obvious in us, we are quickly reduced to a commodity, a physical entity to be managed, as Chelberg (2023) discussed.
- commoditised—the discussion seems to revolve around questions such as how much it costs to keep our body alive, what our asset base is, what income stream can be generated from care and support services and for how long, and how and by whom the assets can be released.
- institutionalised—when family members cannot afford to leave their jobs to care for us, the government will only pay for 20 hours of support per week. When social services decide that we are incapable of caring for ourselves, our families will become terrified and guilty. Then we will have no choice but to leave home and go to an institution.

Spectre of Institutionalisation

I was born at a Mother and Baby Home in Northern Ireland. There was intense pressure on my mother to give me away to a family with greater resources, which led to my foster care and eventual adoption. There was no structural support in place for my mother to survive and raise me independently. Now, in my own later years, I find myself facing institutionalisation all over again for exactly the same reasons. There are few structural supports for my family to care for me in my decline, so they have no real choice aside from placing me in an institution. Given the circumstances, I feel that I live in a world where there is no room for me. That was my birth, and that will be my death; the circle of life is complete, life's irony. The implementation of human rights treaties, and the gradual but powerful changes to quality of life and broader awareness of human rights across the globe, stand in stark contrast to the institutionalisation and commoditisation of older people. It seems that human rights are only as valuable as your ability to claim them.

Prior to the adoption of the Convention on the Rights of Persons With Disabilities (CRPD) in 2006, any human of any age who did not communicate or behave to the satisfaction of society was deemed incompetent to make meaningful choices about their lives and bodies, and was routinely institutionalised (e.g., Royal Commission of Australia, 2021). Similarly, before the Convention on the Elimination of All Forms of Discrimination Against Women in 1979, the Convention on the Rights of the Child in 1989, and the UN Declaration on the Rights of Indigenous Peoples in 2007, socially undesirable women and children were often separated from their families and communities and placed in institutions, as if for their own benefit (e.g., Lucey, 2015; Parliament of Australia, 2004). Children of these women were deposited across countries and continents in new and seemingly suitable families, robbed of any connection to their birthplace culture or community.

Countries across the world are struggling to come to terms with the repercussions of mass institutionalisation of persons placed in vulnerable situations in the past (e.g., Chavez, 2024; Irish Commission of Investigation Into Mother and Baby Homes, 2020; Yoo, 2022). Redress plans, apology schemes, and truth-telling are becoming more prevalent as we grapple to understand and move past earlier misjudgments. However, older people consigned to institutionalised care are largely excluded from these redress processes. Routine institutionalisation is broadly gone from most of the world, except for older people. Institutionalisation remains the ultimate destination of many older people, particularly those of us who live with disabilities.

Institutionalisation is compounded by ageism, which is deeply ingrained not only in interpersonal relationships but also in systems and advocacy models that were built and adopted in days gone by. In Australia, for example, the National Disability Insurance Scheme funds disability support for people who acquire disability prior to the age of 65, based on need, with no funding restrictions and no personal contributions required. In contrast, if disability is acquired after the age of 65, no disability-specific funding is available, and in-home support is capped at approximately 4 hours per day, 5 days per week; older persons, with the exception of those who qualify for hardship provisions (a challenging process for an older person to navigate), have to contribute up to 80% of the cost of these supports.

If an older person needs more than 20 hours of assistance a week to live safely in the community, the expectation in Australia is that they will move into residential aged care, which includes accommodation, 24-hour personal care, and access to nursing and general health care services (Australian Government, 2025); Australia is among the countries that use residential aged care the most (Dyer et al., 2020). Failure to address this gap (weekly support of 20 hours at home vs. full-time residential care, for instance) through provision of disability-specific support for older people may result in an older person being denied a meaningful choice to live at home and in their community. This may be interpreted as a violation of CRPD, and may lead older people to wonder if the government is preserving this gap to benefit the residential care industry (dressed up as an attempt to provide continuity of service) rather than to serve the will and preferences of older people. In a perfect world, all humans would be treated equally and equitably regardless of their chronological age; until that time, we need a Convention on the Rights of Older People, to elevate older people to a position of equality.

Current Landscape of the Human Rights of Older Persons

The UN, on April 3, 2025, adopted a resolution to establish a working group to begin drafting an international treaty on the human rights of older people (Human Rights Council, 2025). This welcome step is undeniably the fruit of years of work by many individuals and local and international entities emphasising how the current international human rights mechanisms have failed older people. For example, when I was given the opportunity to directly address the UN Open-Ended Working Group on Ageing in New York in 2023, bringing the voice of a person living with dementia to the conversation for the first time, it was through the support of the Global Alliance for the Rights of Older People, the Older Persons Advocacy Network, and Dementia Alliance International. I considered this was one of the most important first steps towards restoring the rights of older people and people living with dementia to parity with people of all ages.

However, while human rights instruments should be interpreted and applied in accordance with a life course approach, this does not seem to be the case in practice. For example, Articles 1 (dignity), 3 (security), and 25 (health and living standards) of the Universal Declaration of Human Rights (UDHR) apply broadly but do not specifically address institutionalised or cognitively impaired older people. According to Australian Institute of Health and Welfare (AIHW) statistics (2024), in general, disability increases with age (e.g., approximately 80% of those over the age of 85 live with disability); despite this, older people are often actively and passively excluded from the human rights protections of CRPD by factors such as the artificial segregation of older people in places where others "make decisions about the person's care, including their placement in segregated locked wards" (Devandas-Aguilar, 2019, p. 12).

Current Issues of Core Human Rights for Older People

Right to Health

All humans have the right to health care regardless of age. However, the COVID-19 years revealed the ageism embedded in our healthcare services (e.g., triage decisions based on age). Hundreds of accounts have been published by bereaved families across the world who lost their elders due to inadequate decision-making and resource allocation policies, with details of egregious and systematic breaches of the human rights of older people throughout this period (e.g., Australian Human Rights Commission, 2025). It is clear that the tension between a human rights-based approach and the need for restrictions on personal freedom and autonomy in times of pandemic should be reviewed and remedied, particularly in relation to older people, many of whom already live in severely restricted circumstances with little or no control over their personal environment or bodily autonomy. For example, it was reported that older persons living with dementia faced isolation and loneliness during the pandemic more severely than others because of a lack of comprehension of lockdown rules (Australian Human Rights Commission, 2025, p. 49).

Right to Freedom From (Inflicting or Receiving) Torture, Abuse, and Discrimination

The Australian Aged Care Quality and Safety Commission collects self-identified serious incident reports across residential aged care facilities (RACFs), where residents tend to be older and more likely to be living with dementia than in community settings (Lumos, n.d.). From July to September 2024, 200,019 older people lived in RACFs (Australian Aged Care Quality and Safety Commission, 2024). 15,017 of these people experienced a serious incident during this time period (approximately 7.5% per quarter); this can be roughly translated as 30% of older persons in RACFs experiencing a serious incident in a single year. Specifically, there were reports of unreasonable use of force (7,936 incidents), neglect (3,950), psychological or emotional abuse (1,380), unlawful sexual contact or inappropriate sexual conduct (613), unexplained absence from care (440), unexpected death (269), inappropriate use of restrictive practices (221), and stealing or financial coercion by a staff member (208; Australian Aged Care Quality and Safety Commission, 2024). Despite an extensive Royal Commission investigation, serious incidents in RACFs continue to happen. It is also worth noting that, over a five-year period from July 2016 to June 2021, older people in RACFs had more preventable hospital admissions than those living in the community (12% vs. 7%; Lumos, n.d.).

These figures make it difficult to justify putting an older person into this environment in the apparent interests of their safety. Further, personal communications with hundreds of people who have worked in these institutions have led me to consider a possibility that the very nature of institutionalisation may foster a culture of fear and resentment between residents and staff. Working in even the best institution may feel wrong to staff members; they may sense the inherent wrongness of the system, which can negatively impact their mental health. This can express itself in two general ways. First, the discord between the internal ethics of the worker and the work required to pay their bills becomes intolerable and develops into resentment. This resentment is directed not only at other workers and management but also at the residents. The second outcome is where the worker experiences the discord, recognises it, and leaves the industry. Either way, the older person is the ultimate victim.

The moral injury to workers has only recently been recognised in academic literature (e.g., Reynolds et al., 2022), although it has been well known and understood in the community for many years. Cheerful team meetings and other self-care activities will not address the deep moral injustice that society expects these workers to enact. In my opinion, this is a form of passive torture for aged care workers, again with the ultimate victim being the older person, who does not typically have recourse to a wellness program or an employee assistance program.

This situation may be exacerbated by a considerable gap in dementia training for workers and informal carers. While training exists, it is usually developed from the perspective of an interested observer, and the disappointing lack of co-creation of training with older people and people living with dementia inevitably reinforces unhelpful stereotypes and outdated terminology such as “absconding,” “wandering,” and “attention seeking.” Ultimately, society is pushing residential aged care workers to implement *crowd control* without the benefit of appropriate training or support. This invariably results in the excessive deployment of restrictive practices, further jeopardising the safety, dignity, and consequently human rights of an older person who is potentially trapped in a locked ward.

Right to Autonomy and Self-Determination

The legal construct of *capacity* is regularly leveraged as a means to overturn the decisions and choices of older people on the grounds of serving their best interests; the matter of informed consent is impeded and often superseded by this best interests model of substitute decision-making and guardianship. For example, Australian legislation expects an older person in an RACF to co-design a behaviour support plan (a document outlining strategies to address the individual's concerning behaviours) and consent to any restrictive practice offered by the provider (Australian Aged Care Quality and Safety Commission, n.d.). However, it is my observation and experience that, while the legislation requires *consent*, in practice this is often conflated with *permission*. The CRPD has greatly influenced the ability of many people to emerge from the outdated *substitute decision-making* construct and begin making their own decisions, large and small, often with *support*. While the disability community is making progress in regaining agency and autonomy, older people are at the beginning of this journey of change.

Ageing, Disability, and Dementia—Incarceration and Crowd Control

One of the greatest challenges in a world where many of us are older and living with dementia is safety, physical and emotional. Medical and care professionals use the term *behavioural and psychological symptoms of dementia* (BPSD) to describe unpredictable and occasionally unpleasant aspects of dementia, non-cognitive and behavioural, such as agitation, aberrant motor behaviour, anxiety, elation, irritability, depression, delusions, hallucinations, and sleep or appetite changes (Cerejeira et al., 2012). From a living experience perspective, as I described in the previous section, the individual living with dementia may be responding to a situation or event in a way that is logical to them. A person who finds themselves in an RACF, for instance, may yearn for, and attempt to return to, their home, because home means more than a property; it signifies a time in the past when they felt safe and in control of their lives and surroundings. Unthoughtful use of terms such as "wandering" deeply minimises the extraordinary levels of fear and pain that the individual is experiencing in that moment as they seek solace. A simple increase in understanding of what it may actually feel like to live with dementia fosters empathy and compassion, whereas reductionist language conventions such as describing a possible expression of fear and pain as “calling out” reinforce the view of people with dementia as “vulnerable monsters” (Chelberg, 2023, p. 1), normalising the conclusion that they need to be controlled for the protection of themselves and their neighbours. We need to move beyond this view.

I would suggest use of the term *responsiveness* rather than the BPSD categorisation to describe the manifestation of inconsistent reactions in some people living with dementia as the disease progresses. Dementia can be unpredictable, since we can switch between a heightened state of responsivity, periods of reverie, and our former self (as recognised by others). When we feel deeply afraid and are at our lowest point, it is sadly true that that is the moment when society demands our exclusion. Institutionalisation at this point might appear to be a safe option, but this is only a superficial judgement. The prospect of being removed from our family and community may make us more fearful, and may further fuel responsive and fear-based expression. What is often overlooked is that the very nature of dementia is progressive, and while many of us will experience a period of hyper-responsiveness, the symptoms vary and may be temporary (van der Linde et al., 2016). However, while the responsiveness period may not persist, the institutional placement is invariably permanent.

Neither personal experience nor academic literature has convinced me that BPSD accurately represents dementia; rather, it describes a mismatch between the natural human emotional response to extremely difficult circumstances and the moderating facility that allows for the expression of pain in a socially acceptable manner, which is impaired in people living with dementia. It is hard to accept that you are terminally ill, that in the future you will not always be in control of your thoughts, words, and deeds, while simultaneously discovering that the mechanisms you have used all your life to regulate intense emotions have vanished. The body will naturally compensate in order to achieve emotional release.

During this period I describe as *responsive*, onlookers, caregivers, and institutional managers who try to help will frequently implement various means to suppress unwanted or unsociable expressions of distress, including restraint. However, there is evidence that high-quality short-term specialised care results in relatively few instances of responsiveness in even the most activated individuals (Buckley, 2022; Healy, 2022). It is difficult to argue that mass institutionalisation in a generic facility, with the only option for responsive individuals being consignment to a locked ward, is a more effective and humane way to care for older people in compliance with the CRPD than a short-term specialised facility. It is my opinion that our leaders deliberately choose the mass institutional pathway because of their resistance to change, fear of increased costs, and pressure from industry lobby groups. Older people are not offered the opportunity to counter such pressure, and the consequent indifference to their situation, as the direct voice of older people and people living with dementia is usually absent in advocacy and decision-making processes. I do believe there is a place for RACFs as part of a range of support mechanisms offered to older people. However, when it is the only available option, it becomes a human rights matter.

While the UN conducts inspections of places of detention, under the Optional Protocol to the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (OPCAT), which technically includes RACFs, there are instances where access has been denied or avoided (e.g., Australian Human Rights Commission, 2023; Hitch, 2023). This is a matter that requires urgent attention. As society grapples with the institutional harms caused by forced removal from communities in the past, we must take this opportunity to learn from history and avoid perpetuating more suffering. It is worth noting, however, that while redress programs are in place for a great deal of institutional harm, institutional aged care redress programs are ignored, possibly as a result of passive and systemic ageism.

Advocacy—Direct and Indirect

There are numerous NGOs across the globe that receive funding from governments and communities to focus on the human rights of older people and those living with dementia. These organisations are staffed by professional, well-meaning individuals working for these people's best interests. This is undoubtedly helpful; such NGOs have made terrific progress in the international human rights space, yet the message implicit in these organisations' activities is often the following: We work for them, but not with them. Despite disability action plans and a variety of other mechanisms, older people and people living with dementia are rarely embedded in or employed by these organisations. We are placed on arm's-length committees with no decision-making power, which is completely counterproductive. Why would anyone value the opinion of a person living with dementia in the community or an institution when the peak disability advocacy organisations do not? I believe that we will see change only when the major NGOs make space for us to speak for ourselves. Direct voices based on lived experience will be more powerful than proxies.

The Future of Aged Care and the Right to Community

It is my opinion that the mass institutionalisation of older people as a convenient means for society to maintain the cycle of production (i.e., those who might slow the cycle are eliminated from society) will one day be seen as inhumane. Indefinite residential aged care can and must be a voluntary, engaged, and informed choice made by the older person themselves. Respite services, specialist behaviour support units, palliative care, and hospice services will continue to comprise a significant part of the care and support of older people. Artificial withholding of support at home for older people with higher support needs removes the possibility of choice, leaving us with systemic coercion. As research shows that people of all ages prefer to live at home with adequate support (Egan, 2020), the development of well-formed, long-term deinstitutionalisation policies that move away from the convenience and efficiency of institutions and towards the wants and needs of individual older persons and those who support them is inevitable.

Solutions

Multi-Agency Policy Shift Towards Care and Support in the Community. Ageing in place is the term commonly used to describe when an individual wishes to live and die in their own home and community. Combined with a life course approach to social support, it represents an ideal model for older people. However, this lifestyle is not always achievable—in fact, it is impossible—without collective societal effort. Adequate alterations to taxation, pensions, and social security can support willing family members to take career breaks in order to actively participate in the care and support of their older relatives and friends. Employment legislation can be modified to allow carers to take phone calls from geriatricians during work hours. Modest grant and loan schemes to promote applications for small homes and extensions to house older people closer to their families would produce the additional benefit of freeing up housing stock. Providing carer payments and allowances to more than one family member can help to better support the older person, letting them remain in the community and maintain family bonds. Standardisation of inter-family property transfer could greatly simplify and support intergenerational care while not compromising the economic viability of younger family members, with the value of the property serving as compensation for foregone earnings and superannuation. These are basic ideas, crafted by ordinary people based on their desires and needs. I believe that each of these options is financially, socially, and morally superior to the present institutionalisation model.

Socio-Legal Solutions: Enhanced Advance Care Planning and the Right to Personal Autonomy Through the Idea of an Advance Social Directive. Advance care planning has been long established, but with persistently low uptake, particularly among older people. In the context of dementia, after being advised to make an advance care directive, I was demoralised to discover that the principles-based template only allowed me to rate scenarios as acceptable or unacceptable. Unfortunately for me, the situations presented were all stages of dementia progression. For example, the checklist included questions such as "If I can no longer recognise my family and loved ones, I would find life…" with tick boxes for "bearable," "unbearable," or "unsure" (NSW Government of Australia, n.d., p. 2). Whatever I wrote on the directive would be irrelevant because these events and situations would happen regardless, and my directions would have no obvious impact on my clinical care. In fact, upon requesting further information to help me draft an *informed* directive, I was denied it on the grounds of *capacity* and redirected to fill out a so-called *do not resuscitate* section (NSW Government of Australia, n.d., p. 4) with my doctor.

However, after we receive a dementia diagnosis, we're urged by many people to get our affairs in order. Typically, this refers to making legal instruments that specify preferences for asset distribution and advance directions for end-of-life care. In my experience, these instruments do not seem adaptable to cognitive changes over an extended period of time. That is, they do not readily offer me a means to make advance directions for the period during which I will still be alive but significantly changed. It is as if I am meant to plan for the future of a different person, who will inhabit my body but may be unrecognisable, even to me as I live today. As a way of helping myself to feel some small element of control over my future with cognitive impairment, I came up with the idea of an *advance social directive* whereby I could specify matters that are essential to my well-being and provide background information and support to the people around me in the future, giving them certainty about my wishes.

For example, I have spoken with many older men whose deepest fear is that they may become violent, or sexual assault perpetrators, in their later years should they develop dementia. They are concerned that there will be no way for them to secure access to appropriate support for chemical restraint, as providers will be reluctant to offer or prescribe it in order to avoid breaching their human rights. When the matter becomes a problem, it is often too late for the older person to collect enough thoughts to the point of asking for such medication or even remembering that such an option exists (and in any case, such a request is unlikely to be respected due to capacity concerns). The consent required for this type of restraint can only be expressed by the individual concerned. On the other hand, many older people look forward to the freedom to express their sexuality in their later years and would welcome consensual, respectful, and safe sexual activity, as well as support for this activity. Were this man afforded the opportunity to prepare an advance social directive, where he could set out his wishes for matters essential to his personal well-being, he could look at the future with a little more certainty of personal safety and dignity.

Right to Personhood—The Idea of an Advance Identity Directive. From the lived experience of older persons, the most common lever used in their financial coercion is the threat of institutionalisation. Across the world, older persons are told, "I will put you into a home if you do not do what I want." At first glance, this does not seem to pose a significant threat, because the individual must consent to entering residential care. However, the *best interests* paradigm is still stronger than that of *will and preferences* in health and aged care settings (decision-making by others based on what is regarded to be objectively the best interest of the individual concerned vs. decision-making based on the person's own will and preferences). When combined with the human tendency to avoid risk, and people's fear of litigation, decision-making by substitutes becomes a major barrier for anyone wishing to express their own will and preferences. I believe, however, that there are steps we can take to reinforce and backstop the wishes we make in essential matters and avoid a great deal of predatory litigation and coercion, even in the early to mid-stages of dementia.

My thought experiment begins where a *pre-dementia self* and a *post-dementia self* are legally separable, each with its own set of rights, responsibilities, and decision-making status. In this experiment, the will and preferences paradigm may turn out to be useful to link the living experience of dementia with existing legal frameworks. Pre-dementia identity refers to an individual's autonomous, competent self before significant cognitive decline, when they have full control over their decisions in finances, medical treatment, and property. This identity can be the one that holds the will, "that person's long-term vision for their life" (Flynn, 2018, p. 164). Post-dementia identity refers to the individual after moderate to severe cognitive decline, when the ability to connect with past experiences as a basis for choice and decision-making is limited. This version of the self expresses the preferences of that moment in time. Since this experiment treats them as distinct legal persons or agents, the pre-dementia self's intentions are not trumped by the post-dementia self's incapacity, or by third-party assumptions. That is, the pre-dementia self may have a legally enshrined *right to permanence*, which binds the post-dementia self beyond what current advance directives allow.

However, the principle of autonomy sometimes conflicts with the level of capacity (e.g., English Court of Appeal, 1992). That is, the pre-dementia self's autonomy may be erased when the post-dementia self's incapacity triggers guardianship, creating two misaligned persons. In corporate law, a company's legal identity persists despite changes in leadership; in line with this, I believe the pre-dementia self could retain a distinct legal status despite cognitive shifts. For the continuity of dignity and identity, I argue that the pre-dementia self's values (e.g., a desire to avoid institutional care) should not be superseded by a post-dementia self's preferences that the individual would not recognise as theirs. The right to self-determination should extend across cognitive stages, not dissolving with dementia.

An advance identity directive, amongst other things, would have the effect of *an irrevocable living will,* thus reinforcing personal and individual choices in self-identified material and essential matters that cannot be overridden by well-meaning outsiders, allegedly on the basis of the person's best interests. Furthermore, this could help to prevent the financial abuse of older people through coercion or other manipulative means, giving those of us living with dementia the certainty that our advance wishes would always take precedence. In practical terms, this will be difficult because people living with dementia tend to express their preferences in the moment. However, any potential disconnect could and should be managed with care, dignity, and compassion through supported decision-making processes.

Moving Towards Sustainable Equality and Safety of Older People

In 2025, we are at a critical juncture as we await the development and implementation of a UN Convention on the Rights of Older People. It is a significant opportunity in our lifetimes to review aged care policy at the international level, with the goal of safe, measured, planned, and supported processes to move from the systemic institutionalisation of older people to a model of choice and self-determination. This will most certainly bring challenges as well as possibilities. From my perspective, it will provide an important impetus for the reorganisation of an obsolete system, an opportunity to free older people from the spectre of unwanted and often indefinite institutionalisation through the reorganisation of social security, taxation, and other systems to facilitate direct participation by family and community in the care of older persons. Increased understanding of older people's human rights will result in higher expectations of equal and equitable treatment, both in society and in the law.

Legal mechanisms such as legal recognition of supported decision-making processes that accept that capacity is not a binary state, as well as the advance social directive and the advance identity directive that I proposed in the previous section, will empower older people to plan their own lives with the assurance that their wishes will not be challenged arbitrarily or coercively, freeing up legal and advocacy resources for other matters. Standardisation of contracts, including inter-family transfers of property and assets in recognition of care rendered, could improve the likelihood that families have the means to participate in the care and support of ageing family members.

I look forward to a day where people living with dementia are not written off or excluded upon diagnosis but instead are offered reablement therapy and supported, along with their families and people of choice, to live as well as they can as long as they can. I look forward to the day when ageism is no longer a barrier to our humanity and when we choose to see the person, not the age or the disease manifestation. There is much we can do to better the lives of older people, especially those living with dementia, but it will take courage and, most importantly, leadership. Work with us, not for us. Recognise, and listen directly and carefully to, those with lived experience. We know what we need and how it might be paid for. We are not asking for more. We are asking for something new and different.

References

Australian Aged Care Quality and Safety Commission. (2024). *Aged Care Quality and Safety Commission: Sector performance report*. https://www.agedcarequality.gov.au/sites/default/files/media/sector-performance-report-for-quarter-1-july-september-2024.pdf

Australian Aged Care Quality and Safety Commission. (n.d.). *Overview of restrictive practices*. https://www.agedcarequality.gov.au/sites/default/files/media/overview-of-restrictive-practices_0.pdf

Australian Government. (2025). *About residential aged care*. https://www.health.gov.au/our-work/residential-aged-care/about-residential-aged-care

Australian Human Rights Commission. (2023). *Urgent action needed following termination of UN inspection*. https://humanrights.gov.au/about/news/urgent-action-needed-following-termination-un-inspection

Australian Human Rights Commission. (2025). *Collateral damage: What the untold stories from the COVID-19 pandemic expose about human rights in Australia*. https://humanrights.gov.au/about/news/opinions/covid-report-provides-reality-check-human-rights-during-pandemic

Australian Institute of Health and Welfare. (2024). *People with disability in Australia 2024*. https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/people-with-disability/prevalence-of-disability

Buckley, G. (2022). Reflections of uniting eabrai on delivering the SDCP. *Australian Journal of Dementia Care*, *11*(1), 31.

Cerejeira, J., Lagarto, L., & Mukaetova-Ladinska, E. (2012). Behavioral and psychological symptoms of dementia. *Frontiers in Neurology*, *3*. https://doi.org/10.3389/fneur.2012.00073

Chavez, N. (2024, June 14). *US Catholic bishops formally apologizes for 'trauma' inflicted on Native American communities*. CNN. https://www.cnn.com/2024/06/14/us/catholic-bishops-indigenous-apology-reaj

Chelberg, K. (2023). 'Vulnerable monsters': Constructions of dementia in the Australian Royal Commission into aged care. *International Journal for the Semiotics of Law—Revue Internationale de Sémiotique Juridique*, *36*(4), 1557–1580. https://doi.org/10.1007/s11196-023-09979-w

Devandas-Aguilar, C. (2019). *Rights of persons with disabilities* (A/74/186). Independent Expert on the enjoyment of all human rights by older persons.

Dyer, S. M., Valeri, M., Arora, N., Tilden, D., & Crotty, M. (2020). Is Australia over-reliant on residential aged care to support our older population? *Medical Journal of Australia*, *213*(4). https://www.mja.com.au/journal/2020/213/4/australia-over-reliant-residential-aged-care-support-our-older-population

Egan, N. (2020, July 12). *Perceptions about aged care residents' welfare "very negative."* Australian Ageing Agenda. https://www.australianageingagenda.com.au/royal-commission/perceptions-about-aged-care-residents-welfare-very-negative/

English Court of Appeal. (1992). Re T (adult: refusal of medical treatment). *The All England Law Reports*, *1992*, 649–670.

Flynn, E. (2018). Legal capacity for people with dementia: A human rights approach. In S. Cahill (Ed.), *Dementia and human rights* (pp. 157–174). Bristol University Press. https://doi.org/10.46692/9781447331384.008

Healy, M. (2022). A clinician's perspective. *Australian Journal of Dementia Care*, *11*(1), 32.

Hitch, G. (2023, February 20). *UN torture prevention body cancels Australia trip after refused access to detention, mental health centres*. ABC News. https://www.abc.net.au/news/2023-02-21/united-nations-torture-prevention-cancel-australia-trip-jails/102001760

Human Rights Council. (2025). *Open-ended intergovernmental working group for the elaboration of a legally binding instrument on the promotion and protection of the human rights of older persons* (A/HRC/RES/58/13). https://primarysources.brillonline.com/browse/human-rights-documents-online/promotion-and-protection-of-all-human-rights-civil-political-economic-social-and-cultural-rights-including-the-right-to-development;hrdhrd99702016149

Irish Commission of Investigation Into Mother and Baby Homes. (2020). *Final report of the Commission of Investigation Into Mother and Baby Homes*. https://gov.ie/en/department-of-children-disability-and-equality/publications/final-report-of-the-commission-of-investigation-into-mother-and-baby-homes/

Lucey, D. S. (2015). Single mothers and institutionalisation. In *The end of the Irish poor law?: Welfare and healthcare reform in revolutionary and independent Ireland* (pp. 82–118). Manchester University Press. https://doi.org/10.7228/manchester/9780719087578.003.0003

Lumos. (n.d.). *Health care usage for older people*. https://www.health.nsw.gov.au/lumos/Factsheets/health-care-usage-for-older-people.pdf

NSW Government of Australia. (n.d.). *NSW health advance care directive (ACD)*. https://www.health.nsw.gov.au/patients/acp/Publications/advance-care-directive-form-bw.pdf

Parliament of Australia. (2004). *Forgotten Australians: A report on Australians who experienced institutional or out-of-home care as children*. https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Completed_inquiries/2004-07/inst_care/report/index

Reynolds, K. A., Pankratz, L., Jain, B., Grocott, B., Bonin, L., King, G., Sommer, J. L., El-Gabalawy, R., Giuliano, R. J., Kredentser, M., Mota, N., & Roos, L. E. (2022). Moral injury among frontline long-term care staff and management during the COVID-19 pandemic. *Frontiers in Health Services*, *2*. https://doi.org/10.3389/frhs.2022.841244

Royal Commission of Australia. (2021). *Disability in Australia: Shadows, struggles, and successes*.

van der Linde, R. M., Dening, T., Stephan, B. C. M., Prina, A. M., Evans, E., & Brayne, C. (2016). Longitudinal course of behavioural and psychological symptoms of dementia: Systematic review. *The British Journal of Psychiatry*, *209*(5), 366–377. https://doi.org/10.1192/bjp.bp.114.148403

Yoo, C. (2022, June 9). *State panel to uncover truth about detention camp set up by military junta in 1980s*. Yonhap News Agency. https://en.yna.co.kr/view/AEN20220609005300315

Belonging Through Action: Dance for Brain Health and Connection Among People Living With Dementia

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Dementia is experienced by over 55 million people globally, with projections of growth in the next 25 years disproportionately affecting the global south. Despite dedicated and extensive advocacy led by people living with dementia, policy experts, and civil society representatives, along with decades of clinical and academic research, widespread, efficacious, accessible, and cost-effective treatment is still lacking, especially for those in the global south. There is a need for alternative, widely accessible, and scalable approaches that can address this need.

As global epidemiological and public health experts increasingly favor monitoring brain health over the life course, and early detection, people diagnosed with cognitive change relatively early in life can expect to live for longer with dementia. In recognition of the centrality of lived experience, approaches that do not view dementia only as a biomedical phenomenon but also honor the human rights of people living with dementia are of paramount importance.

In this connection, non-pharmacological approaches offer promising benefits. Arts-based interventions, dance and music in particular, are increasingly recognized not only as vehicles for promoting brain health and mitigating risk; they also cultivate social cohesion, model horizontal participation among diverse stakeholders, and enhance the agency of those affected by dementia.

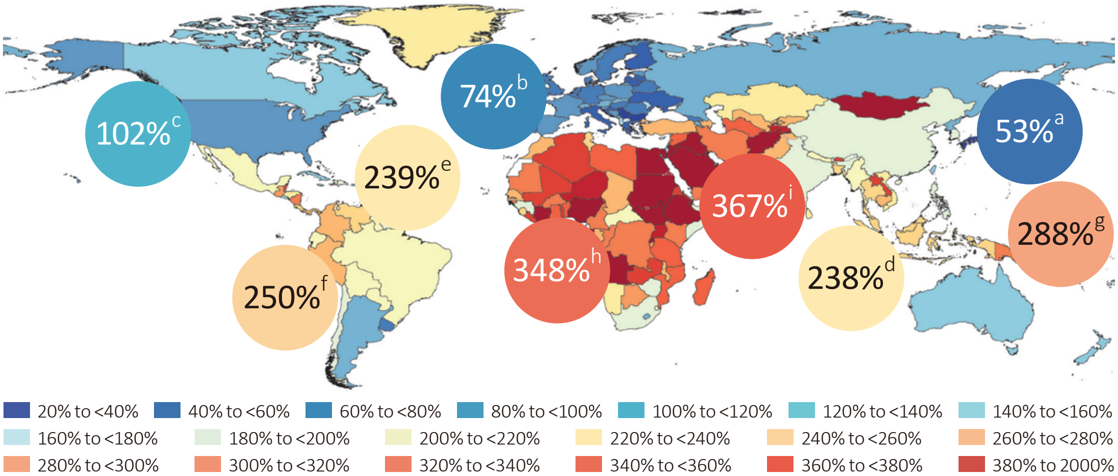
Dementia Around the World: Leaning Into a Global Challenge

Dementia is an umbrella term that defines a decline in brain function caused by a number of underlying pathologies such as Alzheimer's disease, frontotemporal dementia, Lewy body dementia, and vascular dementia (WHO, 2025). Dementias are projected to affect nearly 153 million people globally (Nichols et al., 2022), with total costs (e.g., medical and long-term care, forgone earnings for care partners) surpassing $9.12 trillion in U.S. dollars by 2050 (Alzheimer's Disease International, n.d.a). Informal, unpaid care accounts for about half of these costs, with an estimated 133 billion hours provided each year

(Alzheimer's Disease International, n.d.a). The impact of dementia is expected to grow rapidly as the population ages, especially in low- and middle-income countries, over the next few decades (Nandi et al., 2022; Rodriguez et al., 2008; Stephan et al., 2020). Figure 1 depicts the projected increase in dementia incidence from 2019 to 2050 by country and region.

Figure 1

Projected Increase in Incidence of Dementia Between 2019 and 2050 by Country and Region



Note. The projected increase in incidence of dementia between 2019 and 2050 by region from lowest to highest is as follows: high-income Asia Pacific (53%), Western Europe (74%), Central Europe (82%), Eastern Europe (92%), high-income North America (102%), Australasia (128%), Southern Latin America (131%), the Caribbean (155%), Southern Sub-Saharan Africa (185%), East Asia (200%), tropical Latin America (207%), South Asia (209%), Southeast Asia (238%), Central Latin America (239%), Central Asia (244%), Andean Latin America (250%), Oceania (288%), Central Sub-Saharan Africa (332%), Western Sub-Saharan Africa (348%), Eastern Sub-Saharan Africa (357%), and North Africa and the Middle East (367%; Nichols et al., 2022). Adapted from "Estimation of the Global Prevalence of Dementia in 2019 and Forecasted Prevalence in 2050: An Analysis for the Global Burden of Disease Study 2019," by E. Nichols, J. D. Steinmetz, S. E. Vollset, K. Fukutaki, J. Chalek, F. Abd-Allah, A. Abdoli, A. Abualhasan, E. Abu-Gharbieh, T. T. Akram, H. Al Hamad, F. Alahdab, F. M. Alanezi, V. Alipour, S. Almustanyir, H. Amu, I. Ansari, J. Arabloo, T. Ashraf, ... T. Vos, 2022, *Lancet Public Health*, *7*(2), p. e117 (https://doi.org/10.1016/S2468-2667(21)00249-8). CC BY 4.0.

[a] High-income Asia Pacific
[b] Western Europe
[c] High-income North America
[d] Southeast Asia
[e] Central Latin America
[f] Andean Latin America
[g] Oceania
[h] Western Sub-Saharan Africa
[i] North Africa and the Middle East.

Despite the existing and projected influence of dementia on global economies and people's health and quality of life, current disease-modifying treatments for dementia have limited efficacy and access. To date, several drugs have been approved to treat Alzheimer's disease (Alzheimer's Association, 2023). Those most recently approved, aducanumab and lecanemab, target the underlying biology of Alzheimer's disease by reducing beta-amyloid plaques in the brain. While these drugs represent medical advancement, they are specifically indicated for people with mild cognitive impairment (MCI) or mild dementia caused by Alzheimer's disease; they are not as effective for those with other types of dementia or who have more cognitive or functional change due to these conditions (Alzheimer's Association, 2023; Korczyn & Grinberg, 2024; van Dyck et al., 2023; Woloshin & Kesselheim, 2022). As such, only 8%–17% of people diagnosed with Alzheimer's disease are eligible to participate in existing clinical trials (Pittock et al., 2023). Moreover, there are risks associated with taking these medications, including amyloid-related imaging abnormalities (ARIA; Alzheimer's Association, 2023; Korczyn & Grinberg, 2024; van Dyck et al., 2023; Woloshin & Kesselheim, 2022), and the long-term effects are unknown. Importantly, ethnoracially diverse people remain underrepresented in clinical trials addressing dementia (Franzen et al., 2022). A recent study that reviewed the global distribution of disease-modifying therapies for various dementias over a 21-year study period identified a total of 3,467 clinical trials tested in 74 countries. 88.4% of them were conducted in high-income countries, with 11.6% in emerging economies (Llibre-Guerra et al., 2023). While researchers worldwide work to increase access to and diversify disease-modifying research, non-pharmacological interventions that address prevention over the life course, delay disease progression, and increase quality of life are critical for supporting global communities in dealing with dementia.

Non-Pharmacological and Lifestyle Interventions Serve as Lifelong Sources of Brain Health

Much of the latest research on brain health and aging has emphasized our brains' potential to be malleable and plastic throughout life. The actions we take or do not take, our social and physical environments, and our biology influence our brain health trajectory.

A life-course brain health focus through a preventative lens (WHO, 2022) and non-pharmacological interventions are increasingly recognized as crucial to meeting the growing needs of communities living with dementia. The third Lancet Commission on dementia prevention, intervention, and care, led by University College London researcher Gill Livingston, reported in 2024 that nearly half (45%) of all dementia cases could be prevented by engaging with 14 risk factors over one's life (Livingston et al., 2024). These 14 modifiable risk factors involve education, managing hearing loss, managing depression, preventing traumatic brain injury, quitting smoking, managing cholesterol, engaging in physical activity, managing diabetes, managing hypertension, reducing obesity, avoiding excessive alcohol consumption, mitigating social isolation, avoiding air pollution, and addressing vision loss. Out of these 14, two non-pharmacological approaches, social interaction and physical activity, account for significant reduction in dementia risk.

Physical Activity Is One of the Most Influential Non-Pharmacological Interventions We Can Implement to Prevent Dementia, yet Most Older Adults Are Not Sufficiently Active

On average, 30% of the global population of adults do not meet the minimum recommendations for physical activity (WHO, 2024), with rates of inactivity reaching 48% in high-income Asia (comprising Japan, Republic of Korea, and Singapore) and approaching 45% in South Asia (comprising Afghanistan, Bangladesh, Bhutan, India, Nepal, Pakistan, and Sri Lanka). Among people over the age of 60, physical inactivity increases astronomically as they age. In the United States, according to a 2023 report, only 7% of adults aged 80 years and older met the recommendations for multi-component exercise (both aerobic and muscle-strengthening components) during leisure-time physical activity, compared to 17% of adults aged 65 to 69 years (U.S. Department of Health and Human Services, 2023).

Meanwhile, social isolation and loneliness constitute a growing public health crisis, to the extent that former U.S. Surgeon General Vivek Murthy declared loneliness an epidemic in the United States, highlighting its severe impact on public health (Office of the U.S. Surgeon General, 2023). About 43% of adults aged 60 and older in the United States have reported experiencing loneliness (National Academies of Sciences, Engineering, and Medicine, 2020).

Identifying interventions and engagements that promote physical activity and social connection is critical to addressing these population trends. Fortunately, researchers are demonstrating how even relatively light levels of physical activity and social connection can have a significant impact on brain health trajectories, even when implemented in later life. Kaitlin Casaletto and her team at the University of California San Francisco have investigated the function of late-life physical activity in promoting cognitive reserve (Casaletto et al., 2022). In a recent study, they discovered that individuals who engaged in physical activity in later life presented higher levels of synaptic proteins, which are a biologic correlate of cognition. Post-mortem analysis of brain tissue from participants in this study who had engaged in late-life physical activity revealed that exercise was related to higher levels of synaptic proteins. Particularly, among those with pathology in their brains consistent with neurodegenerative conditions, performance on functional cognition tests appeared to be unaffected, which implies that physical activity may maintain or build brain resilience while offsetting existing pathological changes in the brain (Casaletto et al., 2022).

Another study offered promising news for older persons who are concerned about their lack of physical activity. A 2025 study by Johns Hopkins University researchers analyzed a dataset of nearly 90,000 adults living in the United Kingdom who wore smartwatch-type activity trackers, and found that engaging in as little as 35 minutes of moderate to vigorous physical activity per week, compared to zero minutes per week, was associated with a 41% lower risk of developing dementia over an average four-year follow-up period (Wanigatunga et al., 2025). The researchers found that increased physical activity reduced the risk of dementia. Importantly, this study focused on older adults who would be identified as “frail” due to their physical strength and mobility; it demonstrated that even for those individuals, any exercise is significantly better than no exercise when it comes to long-term brain health outcomes (Wanigatunga et al., 2025).

Social Connection, Physical Activity, and Cognitive Health Are Closely Interconnected, Providing Opportunities for Interventions That Extend Brain Health

Studies suggest that feeling lonely increases the risk of all-cause dementia by around 31% (Luchetti et al., 2024). Although the results are inconsistent regarding the exact impact of social isolation on dementia risk, with estimates ranging from 27% to 60% increased risk (A. R. Huang et al., 2023), the detrimental impact is undeniable. Social connection is not linked only to risk of dementia, however. Helena Blumen of Stony Brook Medicine is shedding light on the direct correlation between social connection and the functioning of numerous cognitive domains. Specifically, Blumen’s research shows the mutual reinforcement and interconnection of social, cognitive, and motor domains for brain health.

Importantly, Blumen’s research illuminates a correlation between a lack of social connection and a decrease in physical activity and mobility. In a 2024 study published in *Frontiers in Public Health*, Blumen analyzed data from 1,931 older adults from the Rush Memory and Aging Project from baseline to a mean follow-up of 4.8 years, and discovered associations between loneliness and physical activity that differed by marital status (Pollak et al., 2024a). Widowed older adults who expressed a sense of loneliness had a decrease in physical activity, which grew annually (Pollak et al., 2024a). Another study by this team identified an association between older adults with robust tangible support (a measure of social connection) and gait preservation (a measure of functional mobility that includes walking speed, consistency and symmetry, and balance and step size), both in simple walking and complex walking (multi-tasking while walking, which better replicates walking outside of a laboratory environment; Pollak et al., 2024b). Robust social connection networks appear to have a direct impact on ambulatory mobility, which is associated with a variety of positive health outcomes and independence.

Furthermore, it appears that the level of social connection as we age is directly correlated with combined motoric and cognitive decline. Blumen's team has been studying a condition known as motoric cognitive risk syndrome (MCR), which is characterized by slow gait and subjective cognitive complaint (Felix et al., 2022). This syndrome affects almost 10% of community-dwelling older adults around the world, and it consistently predicts Alzheimer's disease and vascular dementia to the extent of almost doubling the risk of dementia. In a 2022 study published in *Innovation in Aging*, Blumen's team identified that enhanced overall social support reduced the incidence of MCR by 33% among community-dwelling older adults (Felix et al., 2022).

Collectively, these studies emphasize the interconnectedness and mutual reinforcement of social connection, physical activity, and cognitive health. Social isolation and loneliness are common among those with cognitive change, such as MCI or dementia. In a 2025 meta-analysis and systematic review, researchers discovered that 38.6% of people living with MCI and 42.7% of those living with dementia experience loneliness (Hajek & König, 2025). This finding is highly concerning, particularly when considering the strong linkages between social connection, mobility, and cognitive health. In light of this, it is imperative to identify programs that enhance existing social connection and cultivate novel social connection as we age.

Dance Is Uniquely Positioned to Balance Aesthetic, Physical, and Social Benefits to Extend and Promote Positive Brain Health

Dance is a unique activity that engages artistic, aesthetic, and physical exercise domains and possesses a cultural meaning for diverse communities around the globe. As a multimodal activity, dance combines multiple cognitive tasks with aerobic exercise and social engagement; it is increasingly lauded as a vehicle for social engagement by older adults (Podolski et al., 2023), people with MCI (Chan et al., 2020; C. Huang et al., 2023), and those living with dementia (Kaczmarska, 2023; Schroeder et al., 2023).

Dance can positively impact seven of the 14 modifiable dementia risk factors discussed in the previous section: physical activity (Hwang & Braun, 2015), social connection (Hansen et al., 2021), managing depression and anxiety (Jaldin et al., 2025), maintaining cardiovascular health (Rodrigues-Krause et al., 2016), controlling cholesterol levels (Li et al., 2024), managing diabetes (Mangeri et al., 2014; Rodziewicz-Flis et al., 2023), and maintaining a healthy weight (Murrock & Gary, 2010; Stillman et al., 2018).

A growing body of research shows that dance has the potential to impact brain health positively in a variety of ways, including engaging motor control and function on multiple levels, supporting individual and social well-being, offsetting depression, and offering ameliorative cognitive effects through aerobic fitness and creative engagement (Bisbe et al., 2020; Hackney et al., 2015; Joung & Lee, 2019; Müller et al., 2017; Murrock & Graor, 2014; Patterson et al., 2018; Rehfeld et al., 2018; Vankova et al., 2014; Verghese et al., 2003; Zhu et al., 2018).

Dance promotes cardiovascular health. A 2016 cohort study that pooled data from independent population surveys of 48,390 adults over 12 years identified that moderate-intensity dancing was associated with a significantly lower risk of cardiovascular disease than walking (Merom et al., 2016). Given that our brains are highly vascularized (despite weighing only 2% of our body, the brain consumes 20% of our blood supply; Cipolla, 2009) and that vascular dementia is the second most common type of dementia worldwide (Alzheimer's Disease International, n.d.b), dance may be a beneficial activity for promoting cerebrovascular and circulatory health.

Dance helps keep our minds sharp. Older adults who engage in moderate aerobic dance have networks that fire more in memory-supporting areas of their brain when compared to age-matched non-dancing counterparts. In a 2021 Rutgers University study analyzing the impact of a 20-week aerobic dance intervention, participants presented dynamic changes in connectivity within the medial temporal lobe network (regions of the brain that are among the first to be impacted by Alzheimer's disease), as visualized via fMRI scanning (Sinha et al., 2021). Participants also reported functional changes as a result of the dance intervention, including improved verbal recall, and application of previously learned information to new tasks (Sinha et al., 2021). Marta Bisbe's study in Spain found that choreographed dance among people with MCI improved verbal memory performance more than multimodal physical therapy (Bisbe et al., 2020).

Dance boosts mood and neural synchrony. Older adults who participated in three months of dance classes at a nursing-home community in the Czech Republic experienced such significant improvements in their mood that they either reduced or stopped their need for depression medication (Vankova et al., 2014). Dance leads to mirroring, which results in synchronous involvement of brain areas linked to empathy (Ellingsen et al., 2020).

Dance helps increase coordination and agility. Joe Verghese's 2006 study on the mobility of older leisure social dancers discovered that older adults who dance have a better gait (faster and more consistent walking speeds, larger step sizes, and longer single-legged balance) than their non-dancing counterparts, even when their muscle strength was matched (Verghese, 2006).

In collaboration with our community partner programs, I and my colleagues at DanceStream Projects (a New York City-based arts and health non-profit) and the University of California San Francisco have been applying evidence-based research to develop programs that encourage brain-healthy habits among diverse older adults. Figure 2 illustrates older adult participants in *Every Body Moves*, a dance and fitness program that uses dance elements to support brain health and build confidence, connection, and creative expression among community-dwelling older adults. Every Body Moves used the latest research on the ways dance promotes multiple domains of brain health to shape the program's exercises and curriculum. This collaboration, delivered as part of Creative Minds, a community arts in health program based at the University of California San Francisco's Memory and Aging Center Community Outreach Program, aims to build brain health literacy and foster engagement between older adults at higher risk of developing dementia and local clinicians and researchers.

Figure 2

Participants in Every Body Moves

Note. Every Body Moves is a dance program designed by Magda Kaczmarska to boost the brain health of older adults. This photograph illustrates a class hosted at the Healthy Aging and Disability Services (HADS) Department of MNC Inspiring Success in San Francisco, United States, in 2023. By Gloria A. Aguirre.

These interventions have a significant impact on the health of older adults. During 20 years of working with diverse communities of older adults, I have come to the conclusion that dance motivates older people to be physically active. This is corroborated by empirical evidence. Whereas almost 85% of older adults do not meet the minimum physical activity recommendations (U.S. Department of Health and Human Services, 2023), dance, which encourages community participation while also providing physical fitness, is often cited as the preferred physical activity among diverse community-residing older adults (Harrison et al., 2020). In the dance and educational programs offered by DanceStream Projects, we often witness older adults and people living with dementia engage willingly in dance even when motivation for other physical activities is low, and this observation is consistent among participants, directors of older adult centers, adult day centers, and assisted living centers, and care partners.

The multifaceted benefits of dance were well depicted by Simon Long, editor at large for The Economist and lead author of Alzheimer's Disease International's 2023 World Alzheimer Report:

> I've been struck by how powerful music and dance are in helping cognition and memory...If you had to design from scratch an activity to reduce the risk of dementia, it might involve socializing, communicating, using the brain, and engaging in aerobic exercise. In other words, it might look a lot like dancing. (Alzheimer's Disease International, 2023, 21:31)

The Arts Offer a Cost-Effective, Accessible, and Promising Approach to Mitigating Adverse Brain Health While Nurturing Agency and Enhancing Motivation for Other Beneficial Activities

Recognition of the promising efficacy of non-pharmacological approaches in addressing the various needs of people living with dementia and their care partners has fueled an upsurge in empirical research into the impact of the arts on the structure and function of the brain (Magsamen & Ross, 2023; Sun et al., 2022). This has translated into influencing public health guidelines and feeding further research into the role of the arts in preventing dementia and improving quality of life for older persons and people living with dementia. As highlighted by Gill Livingston in the pivotal 2017 Lancet Commission article, "engaging in meaningful and pleasurable activities is hypothesized to improve health and well-being" (Livingston et al., 2017, p. 2702) for people living with dementia. The benefits of these social engagements include "reconnecting individuals to their physical and social environment; supporting self-esteem; building neural connections through complex interactions; and promoting a sense of role continuity, purpose, personhood, self-identity, and meaning[-making]" (Livingston et al., 2017, pp. 2702–2703).

Arts-based approaches to health have existed since the dawn of human civilization (Fancourt, 2017). Recently, recognition of the convergence and reciprocity of these fields in impacting human well-being has reached global dimensions. For example, the WHO began investigations into the role of arts in health in 2019 (Fancourt & Finn, 2019), and is collaborating with the Jameel Arts and Health Lab on a Lancet Global Series to investigate and report on the different impacts of the arts on multiple domains of health (WHO, 2023).

The role of the arts in extending healthy aging and well-being for older adults and individuals living with dementia is increasingly reported in prominent academic and public journals. Notable examples include a focus on the role of choral singing, such as that of Community of Voices, led and studied by Julene Johnson at the University of California San Francisco's School of Nursing (Johnson et al., 2020), and that of The Unforgettables (Mittelman & Papayannopoulou, 2018), a dementia-inclusive choir coordinated by Mary Mittelman at New York University's School of Medicine; also on the role of collaborative theatre, such as Ann Basting's TimeSlips program (Vigliotti et al., 2019) and the Memory Ensemble (Dunford et al., 2017).

What distinguishes these approaches is an emphasis on health that goes beyond disease mitigation and encompasses a holistic perspective, both on the individual and the individual's place in the fabric of society. Importantly, all of these programs utilize collaborative and interactive techniques, which challenge people to learn a new skill set while also engaging socially. Dance is an art form that adroitly balances collaborative creativity, community, and brain health-boosting activity.

Dance Shifts Perspectives From a Lens of Deficit to One of Agency, Curiosity, and Purpose

Dance improves multiple aspects of brain health, as discussed in previous sections, but it also helps to strengthen one's life purpose. A strong sense of purpose and meaning is increasingly recognized as having health benefits, such as a lower risk of dementia. A recent systematic review and meta-analysis from the United Kingdom followed individuals over five years to assess their sense of purpose and meaning in life. Every one-point increase in feeling of meaning was associated with a 35% decreased risk of all-cause dementia (Sutin et al., 2023). Other studies have found a correlation between a sense of purpose and better outcomes after a stroke, even among people with cardiovascular disease (Kim et al., 2019; Koizumi et al., 2008).

In addition to the symptoms of a progressive chronic illness, which can manifest as shifts in modes and capacities for expression, people living with dementia face stigma and multi-layered marginalization, which can impair their ability to express themselves and feel connected to the communities around them. People living with dementia are frequently excluded from participating in public discourse. Too many dementia narratives paint the experience as one-note, characterized solely as tragedy; the person living with dementia is removed from speaking their own story and is relegated to a silent subject, observed only through the lens of loss and deficit. These pervasive narratives around dementia inadvertently influence how people who receive a dementia diagnosis perceive their own agency and sense of purpose.

Mark Timmons, an artist and leading dementia advocate, has spoken about this from his own lived experience, both as someone diagnosed with early-onset dementia in his late 40s and through his ongoing advocacy work with people newly diagnosed with dementia. He acknowledges the stigma that people living with dementia perceive in their communities and internalize, allowing deficit-driven narratives to limit their belief in their own ability and agency. He goes on to say:

> What getting involved in the arts gives people living with dementia is an opportunity to prove to themselves that they still have a purpose; they still can contribute to society and the world, rather than listen to the doomsayer messages. These arts programs help people living with dementia realize the potential they still possess. I can relate, as I never realized the extent of my own creative talents before my diagnosis of dementia…So many grieve over a sense of a lack of purpose after a diagnosis of a neurocognitive condition. The arts help people turn that page in life, find a new purpose, and begin to write the new chapter of their story. (personal communication, January 19, 2025)

Our experience at DanceStream Projects in the last five years of direct collaboration with people living with dementia, as well as with older adults through our community dance and education programs, has led us to develop a diametrically different perspective from deficit-driven narratives of dementia. Our perspective embraces a multifaceted view of the dementia experience that does not deny its challenges but believes that navigating this experience can often coexist with the discovery, creation, and rich expression of ideas in a community of people who can have much to say, and deserve a platform to do so. Figure 3 shows some of our work in the United States and Poland.

Figure 3

Participants in the Stories in the Moment Program

(a) (b)

Note. Magda Kaczmarska created the dance program Stories in the Moment to boost brain health and meaningful connection for people living with dementia. (a) A class that took place in Queens, New York, United States, in 2023. By Nuria Rius for DanceStream Projects; (b) a class held in collaboration with Muzeum Śląsk and Dom Pomocy Społecznej "Przystań" in Katowice, Poland, in 2024. By Dom Pomocy Społecznej "Przystań."

Stories in the Moment is a program that combines dance, improvisation, and collaborative dance-making to enhance brain health, well-being, connection, and expression among people living with dementia (DanceStream Projects, n.d.; Kaczmarska, 2022). The approach uses movement-based improvisation, narrative, and gesture-based choreography to collaborate with people living with dementia to tell their stories and build new connections within their communities. Participants work together, alongside resident dance artists, to discover their abilities as movement-based storytellers and cultivate a sense of confidence.

Operating both in person and, since 2020, virtually, the program has received regional, national, and international acclaim (Being Patient, 2023; Eyewitness News ABC7NY, 2023; Noyale & Stamp, 2025), reaching more than 400 people living with dementia around the globe. From the beginning of our time collaborating with communities of people living with dementia, they and care partners have spoken about the ways in which the program helps them not only navigate anxiety, shift their mood, and build connections, but also discover new creative tools.

One participant in the Stories in the Moment program, Yvonne, remarked that co-creative dance is helping her identify an embodied approach to communication and is bolstering her awareness of and agency in a vocabulary based on movement. She recognizes that her specific diagnosis will eventually impair her ability to communicate verbally, and so, aside from engaging in speech therapy, she has joined the dance program and is finding it provides her both with tools to communicate and an increased sense of confidence that she will be able to communicate even as her verbal acuity begins to change. In (re)connecting with her own embodied selfhood, and honing tools of movement-based expression, she sees dance as a means of social connection, agency, participation, and, ultimately, purpose.

Pia Kontos and Alisa Grigorovich alluded to this in a seminal 2018 paper in which they discussed dance as a source of what they call relational citizenship. According to them, "relational citizenship...furnishes citizenship with a human rights ontology that recognizes corporeality and relationality as fundamental to self-expression, interdependence, and reciprocal engagement" (p. 718). Our cognitive abilities do not exist in isolation or separation from our bodies; our brains are of course embodied. Kontos and Grigorovich argue that instead of focusing solely on the cognitive and neural benefits of dance, we should recognize that "sentient and tacit forms of knowledge and expression" (p. 720) are central to our existence as embodied individuals within shared corporeality frameworks. Dance takes on new meaning in the lives of people with dementia, who may have limited access to and engagement with verbal communication. It has the potential to be an important source of interconnection, meaning-making, and conversation. Kontos and Grigorovich conclude as follows:

> In the context of cognitive impairment, dance takes on even greater significance given that corporeality becomes the primary means of engaging with the world and with others. Dance provides a unique medium for non-verbal communication, affect, and reciprocal engagement which profoundly enables the relational citizenship of persons living with dementia. (2018, p. 720)

Working Together With People Living With Dementia Through Dance to Write New Narratives, Shift Perspectives, and Promote Social Change

Dancing is a highly social activity, increasingly recommended for people of all ages to promote their overall health and well-being. In our work with people living with dementia and older adults, we frequently hear that dancing with peers provides them with a sense of belonging and the opportunity to make meaningful connections with others. The ability to uncover new skill sets in oneself while building new connections with others can produce a fertile and welcoming environment for nurturing self-confidence, agency, and relational community.

In a recent mixed-methods study conducted by our team at DanceStream Projects, we investigated the impact of engaging virtually in the Stories in the Moment dance program on the sense of belonging and well-being of people living with dementia (aged 50 or older) and care partners (providing care at least eight hours a week; Kaczmarska et al., 2025). After three months of weekly engagement, participants reported increased general well-being, less anxiety and loneliness, and a stronger sense of belonging.

In focus groups following the dance intervention, one participant described experiencing less anxiety after participating in the program, having had to face their fear and anxiety in order to interact with others in the group:

> It was important for me to come out of my fear. I get anxious, and I tend to go off things, but I didn't let myself or my anxiety get to me in this class. I tried to overcome [it] so I could be able to help with the different dances. And I tried to come up with ideas.

Participants reported a sense of discovering new abilities in themselves. A participant said, "It really brought out a lot of different feelings, movement, and things that I didn't know that I had in me. Like I wasn't embarrassed to try to come up with a dance move." Others mentioned the importance of connecting with other people living with dementia and learning about one another through the program. One participant said, "In getting together and learning about each other, there's an exhilarating experience…It's like I walk away with something very special."

Care partners as well were surprised at how much they also benefited from the program. One care partner mentioned that they joined for their parent (living with dementia) but stayed for themselves, adding that "the greatest impact was emotional. It opened us up…[Life with dementia] can get heavy…[But] this was the opposite. It's joyful, and that carries…It lasts throughout the week."

This shift in perspective, from one of decline to one of continued growth and self-actualization, is arguably one of the most powerful advantages of co-creative dance. By adjusting viewpoints to ones of possibility and curiosity, a new sense of purpose can be found, generating even greater motivation and reinforcing an emphasis on health, well-being, and thriving. Even though the condition is still there, this change in attitude has a major influence. One participant noted about themselves after three months of collaborative dance: "I came in heavy, weighted down by the diagnosis. I'm in a far better place than I was when I first started. The condition hasn't lightened, but our attitude toward it has."

This transformation in perspective is in itself an important reason for investing in dance for people living with dementia. When we create shared spaces for collaborative dance among people living with dementia, we instill hope, agency, self-confidence, a renewed sense of interdependence, and trust in community. That resonates; as one participant shared, "The oneness we created was very special" (Kaczmarska et al., 2025).

But much as co-creative dance fosters collaborative space that benefits individuals living with dementia, this approach also has ramifications for wider societal transformation, since it promotes a narrative change and ultimately (and hopefully) the global embrace of measures that recognize and protect the human rights of people living with dementia. When we realize that dance is something we do "with" one another rather than "to" or "for" people living with dementia, we embrace a perspective that is vital not only for people living with dementia but for all of us. Together, we can build a future informed by the voices of people living with dementia, transform narratives that falsely portray the experiences of people living with dementia as one-note and deficit-driven, and cultivate a community where everyone living with dementia does so with dignity, agency, and a sense of purpose, while being deeply integrated into the fabric of society.

References

Alzheimer's Association. (2023). 2023 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, *19*(4), 1598–1695. https://doi.org/10.1002/alz.13016

Alzheimer's Disease International. (2023, September 21). *World Alzheimer report 2023 webinar launch* [Video]. YouTube. https://www.youtube.com/watch?v=e8dBV-Rk_rA

Alzheimer's Disease International. (n.d.a). *Dementia fact sheet*. https://www.alzint.org/u/Dementia-fact-sheet-English.pdf

Alzheimer's Disease International. (n.d.b). *Vascular dementia*. https://www.alzint.org/about/dementia-facts-figures/types-of-dementia/vascular-dementia/

Being Patient. (2023, September 4). *What could more dance research mean for dementia? Being patient live talk with Magda Kaczmarska* [Video]. YouTube. https://www.youtube.com/watch?v=KK45Bt0j55w

Bisbe, M., Fuente-Vidal, A., López, E., Moreno, M., Naya, M., de Benetti, C., Milà, R., Bruna, O., Boada, M., & Alegret, M. (2020). Comparative cognitive effects of choreographed exercise and multimodal physical therapy in older adults with amnestic mild cognitive impairment: Randomized clinical trial. *Journal of Alzheimer's Disease*, *73*(2), 769–783. https://doi.org/10.3233/JAD-190552

Casaletto, K., Ramos-Miguel, A., VandeBunte, A., Memel, M., Buchman, A., Bennett, D., & Honer, W. (2022). Late-life physical activity relates to brain tissue synaptic integrity markers in older adults. *Alzheimer's & Dementia*, *18*(11), 2023–2035. https://doi.org/10.1002/alz.12530

Chan, J. S. Y., Wu, J., Deng, K., & Yan, J. H. (2020). The effectiveness of dance interventions on cognition in patients with mild cognitive impairment: A meta-analysis of randomized controlled trials. *Neuroscience & Biobehavioral Reviews*, *118*, 80–88. https://doi.org/10.1016/j.neubiorev.2020.07.017

Cipolla, M. J. (2009). Introduction. In *The cerebral circulation*. Morgan & Claypool Life Sciences. https://www.ncbi.nlm.nih.gov/books/NBK53083/

DanceStream Projects. (n.d.). *Stories in the Moment*. https://dancestreamprojects.org/stories-in-the-moment

Dunford, C. M., Yoshizaki-Gibbons, H. M., & Morhardt, D. (2017). The memory ensemble: Improvising connections among performance, disability, and ageing. *Research in Drama Education*, *22*(3), 420–426. https://doi.org/10.1080/13569783.2017.1326806

Ellingsen, D.-M., Isenburg, K., Jung, C., Lee, J., Gerber, J., Mawla, I., Sclocco, R., Jensen, K. B., Edwards, R. R., Kelley, J. M., Kirsch, I., Kaptchuk, T. J., & Napadow, V. (2020). Dynamic brain-to-brain concordance and behavioral mirroring as a mechanism of the patient-clinician interaction. *Science Advances*, *6*(43). https://doi.org/10.1126/sciadv.abc1304

Eyewitness News ABC7NY. (2023, October 20). *Dance class helps adults with dementia exercise short-term memory* [Video]. YouTube. https://www.youtube.com/watch?v=71Y8rOtJXLk

Fancourt, D. (2017). A history of the use of arts in health. In *Arts in health: Designing and researching interventions*. Oxford University Press. https://doi.org/10.1093/oso/9780198792079.003.0001

Fancourt, D., & Finn, S. (2019). *What is the evidence on the role of the arts in improving health and well-being? A scoping review.* WHO Regional Office for Europe. http://www.ncbi.nlm.nih.gov/books/NBK553773/

Felix, N., Ayers, E., Verghese, J., & Blumen, H. M. (2022). Increased social support reduces the incidence of motoric cognitive risk syndrome. *Innovation in Aging*, *6*(5). https://doi.org/10.1093/geroni/igac048

Franzen, S., Smith, J. E., van den Berg, E., Rivera Mindt, M., van Bruchem-Visser, R. L., Abner, E. L., Schneider, L. S., Prins, N. D., Babulal, G. M., & Papma, J. M. (2022). Diversity in Alzheimer's disease drug trials: The importance of eligibility criteria. *Alzheimer's & Dementia*, *18*(4), 810–823. https://doi.org/10.1002/alz.12433

Hackney, M. E., Byers, C., Butler, G., Sweeney, M., Rossbach, L., & Bozzorg, A. (2015). Adapted tango improves mobility, motor–cognitive function, and gait but not cognition in older adults in independent living. *Journal of the American Geriatrics Society*, *63*(10), 2105–2113. https://doi.org/10.1111/jgs.13650

Hajek, A., & König, H.-H. (2025). Prevalence of loneliness and social isolation among individuals with mild cognitive impairment or dementia: Systematic review and meta-analysis. *BJPsych Open*, *11*(2). https://doi.org/10.1192/bjo.2024.865

Hansen, P., Main, C., & Hartling, L. (2021). Dance intervention affects social connections and body appreciation among older adults in the long term despite COVID-19 social isolation: A mixed methods pilot study. *Frontiers in Psychology*, *12*. https://doi.org/10.3389/fpsyg.2021.635938

Harrison, E. A., Lord, L. M., Asongwed, E., Jackson, P., Johnson-Largent, T., Jean Baptiste, A. M., Harris, B. M., & Jeffery, T. (2020). Perceptions, opinions, beliefs, and attitudes about physical activity and exercise in urban-community-residing older adults. *Journal of Primary Care & Community Health*, *11*. https://doi.org/10.1177/2150132720924137

Huang, A. R., Roth, D. L., Cidav, T., Chung, S.-E., Amjad, H., Thorpe Jr., R. J., Boyd, C. M., & Cudjoe, T. K. M. (2023). Social isolation and 9-year dementia risk in community-dwelling Medicare beneficiaries in the United States. *Journal of the American Geriatrics Society*, *71*(3), 765–773. https://doi.org/10.1111/jgs.18140

Huang, C., Yan, Y., Luo, Y., Lin, R., & Li, H. (2023). Effects of dance therapy on cognitive and mental health in adults aged 55 years and older with mild cognitive impairment: A systematic review and meta-analysis. *BMC Geriatrics*, *23*. https://doi.org/10.1186/s12877-023-04406-y

Hwang, P. W.-N., & Braun, K. L. (2015). The effectiveness of dance interventions to improve older adults' health: A systematic literature review. *Alternative Therapies in Health and Medicine*, *21*(5), 64–70.

Jaldin, M. A., Balbim, G. M., Pinto, J., Negrete, M., Motl, R. W., Bustamante, E. E., Aguiñaga, S., Kaushal, N., Castillo, C., Khanna, S., Brunskill, A., & Marquez, D. X. (2025). Systematic review and meta-analysis of the effects of dance on cognition and depression in healthy older adults. *Medicine & Science in Sports & Exercise*, *57*(3), 490–500. https://doi.org/10.1249/MSS.0000000000003585

Johnson, J. K., Stewart, A. L., Acree, M., Nápoles, A. M., Flatt, J. D., Max, W. B., & Gregorich, S. E. (2020). A Community choir intervention to promote well-being among diverse older adults: Results from the community of voices trial. *The Journals of Gerontology: Series B*, *75*(3), 549–559. https://doi.org/10.1093/geronb/gby132

Joung, H. J., & Lee, Y. (2019). Effect of creative dance on fitness, functional balance, and mobility control in the elderly. *Gerontology*, *65*(5), 537–546. https://doi.org/10.1159/000499402

Kaczmarska, M. (2022, June 27). *Stories in the moment: Creating shared spaces of belonging for and with people living with dementia*. Dancers Group. https://dancersgroup.org/2022/06/stories-in-the-moment/

Kaczmarska, M. (2023). Valuing embodiment: Insights from dance practice among people living with dementia. *Frontiers in Neurology*, *14*. https://doi.org/10.3389/fneur.2023.1174157

Kaczmarska, M., McDonagh, M., Theofanopoulou, C., Brown-Istrefi, H., Fallon, G., Galvin, M., & Allen, I. (2025). *Nurturing community, overcoming anxiety: Mixed-method analysis of online dance program for people living with dementia* [Manuscript in preparation].

Kim, E. S., Delaney, S. W., & Kubzansky, L. D. (2019). Sense of purpose in life and cardiovascular disease: Underlying mechanisms and future directions. *Current Cardiology Reports*, *21*(11), Article 135. https://doi.org/10.1007/s11886-019-1222-9

Koizumi, M., Ito, H., Kaneko, Y., & Motohashi, Y. (2008). Effect of having a sense of purpose in life on the risk of death from cardiovascular diseases. *Journal of Epidemiology*, *18*(5), 191–196. https://doi.org/10.2188/jea.je2007388

Kontos, P., & Grigorovich, A. (2018). Integrating citizenship, embodiment, and relationality: Towards a reconceptualization of dance and dementia in long-term care. *The Journal of Law, Medicine & Ethics*, *46*(3), 717–723. https://doi.org/10.1177/1073110518804233

Korczyn, A. D., & Grinberg, L. T. (2024). Is Alzheimer disease a disease? *Nature Reviews Neurology*, *20*(4), 245–251. https://doi.org/10.1038/s41582-024-00940-4

Li, Y., Zhai, Q., Li, G., & Peng, W. (2024). Effects of different aerobic exercises on blood lipid levels in middle-aged and elderly people: A systematic review and Bayesian network meta-analysis based on randomized controlled trials. *Healthcare*, *12*(13). https://doi.org/10.3390/healthcare12131309

Livingston, G., Huntley, J., Liu, K. Y., Costafreda, S. G., Selbæk, G., Alladi, S., Ames, D., Banerjee, S., Burns, A., Brayne, C., Fox, N. C., Ferri, C. P., Gitlin, L. N., Howard, R., Kales, H. C., Kivimäki, M., Larson, E. B., Nakasujja, N., Rockwood, K., … Mukadam, N. (2024). Dementia prevention, intervention, and care: 2024 report of the Lancet Standing Commission. *The Lancet*, *404*(10452), 572–628. https://doi.org/10.1016/S0140-6736(24)01296-0

Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S. G., Huntley, J., Ames, D., Ballard, C., Banerjee, S., Burns, A., Cohen-Mansfield, J., Cooper, C., Fox, N., Gitlin, L. N., Howard, R., Kales, H. C., Larson, E. B., Ritchie, K., Rockwood, K., Sampson, E. L., … Mukadam, N. (2017). Dementia prevention, intervention, and care. *The Lancet*, *390*(10113), 2673–2734. https://doi.org/10.1016/S0140-6736(17)31363-6

Llibre-Guerra, J. J., Heavener, A., Brucki, S. M. D., Marante, J. P. D., Pintado-Caipa, M., Chen, Y., Behrens, M. I., Hardi, A., Admirall-Sanchez, A., Akinyemi, R., Alladi, S., Dorsman, K. A., Rodriguez-Salgado, A. M., Solorzano, J., & Babulal, G. M. (2023). A call for clinical trial globalization in Alzheimer's disease and related dementia. *Alzheimer's & Dementia*, *19*(7), 3210–3221. https://doi.org/10.1002/alz.12995

Luchetti, M., Aschwanden, D., Sesker, A. A., Zhu, X., O'Súilleabháin, P. S., Stephan, Y., Terracciano, A., & Sutin, A. R. (2024). A meta-analysis of loneliness and risk of dementia using longitudinal data from >600,000 individuals. *Nature Mental Health*, *2*(11), 1350–1361. https://doi.org/10.1038/s44220-024-00328-9

Magsamen, S., & Ross, I. (2023). *Your brain on art: How the arts transform us*. Random House Publishing Group. https://www.randomhousebooks.com/books/

Mangeri, F., Montesi, L., Forlani, G., Dalle Grave, R., & Marchesini, G. (2014). A standard ballroom and Latin dance program to improve fitness and adherence to physical activity in individuals with type 2 diabetes and in obesity. *Diabetology & Metabolic Syndrome*, *6*, Article 74. https://doi.org/10.1186/1758-5996-6-74

Merom, D., Ding, D., & Stamatakis, E. (2016). Dancing participation and cardiovascular disease mortality: A pooled analysis of 11 population-based British cohorts. *American Journal of Preventive Medicine*, *50*(6), 756–760. https://doi.org/10.1016/j.amepre.2016.01.004

Mittelman, M. S., & Papayannopoulou, P. M. (2018). The unforgettables: A chorus for people with dementia with their family members and friends. *International Psychogeriatrics*, *30*(6), 779–789. https://doi.org/10.1017/S1041610217001867

Müller, P., Rehfeld, K., Schmicker, M., Hökelmann, A., Dordevic, M., Lessmann, V., Brigadski, T., Kaufmann, J., & Müller, N. G. (2017). Evolution of neuroplasticity in response to physical activity in old age: The case for dancing. *Frontiers in Aging Neuroscience*, *9*. https://doi.org/10.3389/fnagi.2017.00056

Murrock, C. J., & Gary, F. A. (2010). Culturally specific dance to reduce obesity in African American women. *Health Promotion Practice*, *11*(4), 465–473. https://doi.org/10.1177/1524839908323520

Murrock, C. J., & Graor, C. H. (2014). Effects of dance on depression, physical function, and disability in underserved adults. *Journal of Aging and Physical Activity*, *22*(3), 380–385. https://doi.org/10.1123/JAPA.2013-0003

Nandi, A., Counts, N., Chen, S., Seligman, B., Tortorice, D., Vigo, D., & Bloom, D. E. (2022). Global and regional projections of the economic burden of Alzheimer's disease and related dementias from 2019 to 2050: A value of statistical life approach. *eClinicalMedicine*, *51*. https://doi.org/10.1016/j.eclinm.2022.101580

National Academies of Sciences, Engineering, and Medicine. (2020). *Social isolation and loneliness in older adults: Opportunities for the health care system*. National Academies Press. https://doi.org/10.17226/25663

Nichols, E., Steinmetz, J. D., Vollset, S. E., Fukutaki, K., Chalek, J., Abd-Allah, F., Abdoli, A., Abualhasan, A., Abu-Gharbieh, E., Akram, T. T., Al Hamad, H., Alahdab, F., Alanezi, F. M., Alipour, V., Almustanyir, S., Amu, H., Ansari, I., Arabloo, J., Ashraf, T., … Vos, T. (2022). Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: An analysis for the Global Burden of Disease Study 2019. *The Lancet Public Health*, *7*(2), e105–e125. https://doi.org/10.1016/S2468-2667(21)00249-8

Noyale, C., & Stamp, K. (2025). *Arts for health: Dancing*. Emerald Publishing Limited. https://bookstore.emerald.com/dancing-pb-9781837539154.html

Office of the U.S. Surgeon General. (2023). *Our epidemic of loneliness and isolation*. https://www.hhs.gov/sites/default/files/surgeon-general-social-connection-advisory.pdf

Patterson, K. K., Wong, J. S., Prout, E. C., & Brooks, D. (2018). Dance for the rehabilitation of balance and gait in adults with neurological conditions other than Parkinson's disease: A systematic review. *Heliyon*, *4*(3). https://doi.org/10.1016/j.heliyon.2018.e00584

Pittock, R. R., Aakre, J. A., Castillo, A. M., Ramanan, V. K., Kremers, W. K., Jack, C. R., Vemuri, P., Lowe, V. J., Knopman, D. S., Petersen, R. C., Graff-Radford, J., & Vassilaki, M. (2023). Eligibility for anti-amyloid treatment in a population-based study of cognitive aging. *Neurology*, *101*(19), e1837–e1849. https://doi.org/10.1212/WNL.0000000000207770

Podolski, O. S., Whitfield, T., Schaaf, L., Cornaro, C., Köbe, T., Koch, S., & Wirth, M. (2023). The Impact of dance movement interventions on psychological health in older adults without dementia: A systematic review and meta-analysis. *Brain Sciences*, *13*(7). https://doi.org/10.3390/brainsci13070981

Pollak, C., Verghese, J., & Blumen, H. M. (2024a). Loneliness predicts decreased physical activity in widowed but not married or unmarried individuals. *Frontiers in Public Health*, *12*. https://doi.org/10.3389/fpubh.2024.1295128

Pollak, C., Verghese, J., & Blumen, H. M. (2024b). Longitudinal associations of social support and gait speed decline in aging. *The Journals of Gerontology: Series A*, *79*(3). https://doi.org/10.1093/gerona/glad250

Rehfeld, K., Lüders, A., Hökelmann, A., Lessmann, V., Kaufmann, J., Brigadski, T., Müller, P., & Müller, N. G. (2018). Dance training is superior to repetitive physical exercise in inducing brain plasticity in the elderly. *PLoS ONE*, *13*(7), Article e0196636. https://doi.org/10.1371/journal.pone.0196636

Rodrigues-Krause, J., Farinha, J. B., Krause, M., & Reischak-Oliveira, Á. (2016). Effects of dance interventions on cardiovascular risk with ageing: Systematic review and meta-analysis. *Complementary Therapies in Medicine*, *29*, 16–28. https://doi.org/10.1016/j.ctim.2016.09.004

Rodriguez, J. J. L., Ferri, C. P., Acosta, D., Guerra, M., Huang, Y., Jacob, K. S., Krishnamoorthy, E. S., Salas, A., Sosa, A. L., Acosta, I., Dewey, M. E., Gaona, C., Jotheeswaran, A. T., Li, S., Rodriguez, D., Rodriguez, G., Kumar, P. S., Valhuerdi, A., & Prince, M. (2008). Prevalence of dementia in Latin America, India, and China: A population-based cross-sectional survey. *The Lancet*, *372*(9637), 464–474. https://doi.org/10.1016/S0140-6736(08)61002-8

Rodziewicz-Flis, E. A., Kawa, M., Kaczor, J. J., Szaro-Truchan, M., Flis, D. J., Lombardi, G., & Ziemann, E. (2023). Changes in selected exerkines concentration post folk-dance training are accompanied by glucose homeostasis and physical performance improvement in older adults. *Scientific Reports*, *13*, Article 8596. https://doi.org/10.1038/s41598-023-35583-w

Schroeder, H., Haussermann, P., & Fleiner, T. (2023). Dance-specific activity in people living with dementia: A conceptual framework and systematic review of its effects on neuropsychiatric symptoms. *Journal of Geriatric Psychiatry and Neurology*, *36*(3), 175–184. https://doi.org/10.1177/08919887221130268

Sinha, N., Berg, C. N., Yassa, M. A., & Gluck, M. A. (2021). Increased dynamic flexibility in the medial temporal lobe network following an exercise intervention mediates generalization of prior learning. *Neurobiology of Learning and Memory*, *177*, Article 107340. https://doi.org/10.1016/j.nlm.2020.107340

Stephan, B. C. M., Pakpahan, E., Siervo, M., Licher, S., Muniz-Terrera, G., Mohan, D., Acosta, D., Pichardo, G. R., Sosa, A. L., Acosta, I., Llibre-Rodriguez, J. J., Prince, M., Robinson, L., & Prina, M. (2020). Prediction of dementia risk in low-income and middle-income countries (the 10/66 Study): An independent external validation of existing models. *The Lancet Global Health*, *8*(4), e524–e535. https://doi.org/10.1016/S2214-109X(20)30062-0

Stillman, C. M., Donahue, P. T., Williams, M. F., Callas, M., Lwanga, C., Brown, C., Wollam, M. E., Jedrziewski, M. K., Kang, C., & Erickson, K. I. (2018). Weight-loss outcomes from a pilot study of African dance in older African Americans. *Obesity*, *26*(12), 1893–1897. https://doi.org/10.1002/oby.22331

Sun, Y., Ji, M., Leng, M., Li, X., Zhang, X., & Wang, Z. (2022). Comparative efficacy of 11 non-pharmacological interventions on depression, anxiety, quality of life, and caregiver burden for informal caregivers of people with dementia: A systematic review and network meta-analysis. *International Journal of Nursing Studies*, *129*, Article 104204. https://doi.org/10.1016/j.ijnurstu.2022.104204

Sutin, A. R., Luchetti, M., Aschwanden, D., Stephan, Y., Sesker, A. A., & Terracciano, A. (2023). Sense of meaning and purpose in life and risk of incident dementia: New data and meta-analysis. *Archives of Gerontology and Geriatrics*, *105*, Article 104847. https://doi.org/10.1016/j.archger.2022.104847

U.S. Department of Health and Human Services. (2023). *Physical activity guidelines for Americans midcourse report: Implementation strategies for older adults*. https://odphp.health.gov/sites/default/files/2023-08/PAG_MidcourseReport_508c_08-10.pdf

van Dyck, C. H., Swanson, C. J., Aisen, P., Bateman, R. J., Chen, C., Gee, M., Kanekiyo, M., Li, D., Reyderman, L., Cohen, S., Froelich, L., Katayama, S., Sabbagh, M., Vellas, B., Watson, D., Dhadda, S., Irizarry, M., Kramer, L. D., & Iwatsubo, T. (2023). Lecanemab in early Alzheimer's disease. *New England Journal of Medicine*, *388*(1), 9–21. https://doi.org/10.1056/NEJMoa2212948

Vankova, H., Holmerova, I., Machacova, K., Volicer, L., Veleta, P., & Celko, A. M. (2014). The effect of dance on depressive symptoms in nursing home residents. *Journal of the American Medical Directors Association*, *15*(8), 582–587. https://doi.org/10.1016/j.jamda.2014.04.013

Verghese, J. (2006). Cognitive and mobility profile of older social dancers. *Journal of the American Geriatrics Society*, *54*(8), 1241–1244. https://doi.org/10.1111/j.1532-5415.2006.00808.x

Verghese, J., Lipton, R. B., Katz, M. J., Hall, C. B., Derby, C. A., Kuslansky, G., Ambrose, A. F., Sliwinski, M., & Buschke, H. (2003). Leisure activities and the risk of dementia in the elderly. *New England Journal of Medicine*, *348*(25), 2508–2516. https://doi.org/10.1056/NEJMoa022252

Vigliotti, A. A., Chinchilli, V. M., & George, D. R. (2019). Evaluating the benefits of the TimeSlips creative storytelling program for persons with varying degrees of dementia severity. *American Journal of Alzheimer's Disease & Other Dementias*, *34*(3), 163–170. https://doi.org/10.1177/1533317518802427

Wanigatunga, A. A., Dong, Y., Jin, M., Leroux, A., Cui, E., Zhou, X., Zhao, A., Schrack, J. A., Bandeen-Roche, K., Walston, J. D., Xue, Q.-L., Lindquist, M. A., & Crainiceanu, C. M. (2025). Moderate-to-vigorous physical activity at any dose reduces all-cause dementia risk regardless of frailty status. *Journal of the American Medical Directors Association*, *26*(3). https://doi.org/10.1016/j.jamda.2024.105456

WHO. (2022). *Optimizing brain health across the life course: WHO position paper*. https://www.who.int/publications/i/item/9789240054561

WHO. (2023). *Ground-breaking research series on health benefits of the arts*. https://www.who.int/news/item/25-09-2023-ground-breaking-research-series-on-health-benefits-of-the-arts

WHO. (2024). *Global levels of physical inactivity in adults: Off track for 2030*. https://www.who.int/publications/i/item/9789240096905

WHO. (2025). *Dementia*. https://www.who.int/news-room/fact-sheets/detail/dementia

Woloshin, S., & Kesselheim, A. S. (2022). What to know about the Alzheimer drug aducanumab (Aduhelm). *JAMA Internal Medicine*, *182*(8), 892. https://doi.org/10.1001/jamainternmed.2022.1039

Zhu, Y., Wu, H., Qi, M., Wang, S., Zhang, Q., Zhou, L., Wang, S., Wang, W., Wu, T., Xiao, M., Yang, S., Chen, H., Zhang, L., Zhang, K. C., Ma, J., & Wang, T. (2018). Effects of a specially designed aerobic dance routine on mild cognitive impairment. *Clinical Interventions in Aging*, *13*, 1691–1700. https://doi.org/10.2147/CIA.S163067

Asia-Europe Meeting

ASEM

The Asia-Europe Meeting (ASEM) is an intergovernmental process established in 1996 to foster dialogue and cooperation between Asia and Europe.

ASEM addresses political, economic, financial, social, cultural, and educational issues of common interest in a spirit of mutual respect and equal partnership. Its foremost event, the ASEM summit, is a biennial meeting between the heads of state and government, the president of the European Council, the president of the European Commission, and the secretary-general of ASEAN. In addition, ASEM ministers and senior officials also meet in their respective sectoral dialogues.

The initial ASEM partnership in 1996 consisted of 15 EU member states, 7 ASEAN member states, China, Japan, Korea, and the European Commission. Today, ASEM comprises 53 partners: 30 European and 21 Asian countries, the European Union, and the ASEAN secretariat.

Through its informal process based on equal partnership and enhancing mutual understanding, ASEM facilitates and stimulates progress but does not seek to duplicate bilateral and other multilateral relationships between Asia and Europe.

For more information, visit the ASEM Info Board website (www.aseminfoboard.org).

ASEM PARTNERS

Partner Organisations

ASEAN Secretariat
Joined 2008

European Union
Joined 1996

Partner Countries

Australia
Joined 2010

Austria
Joined 1996

Bangladesh
Joined 2012

Belgium
Joined 1996

Brunei Darussalam
Joined 1996

Bulgaria
Joined 2008

Cambodia
Joined 2004

China
Joined 1996

Croatia
Joined 2014

Cyprus
Joined 2004

Czech Republic
Joined 2004

Denmark
Joined 1996

Estonia
Joined 2004

Finland
Joined 1996

France
Joined 1996

Germany
Joined 1996

Greece
Joined 1996

Hungary
Joined 2004

India
Joined 2008

Indonesia
Joined 1996

Ireland
Joined 1996

Italy
Joined 1996

Japan
Joined 1996

Kazakhstan
Joined 2014

Korea
Joined 1996

Lao PDR
Joined 2004

Latvia
Joined 2004

Lithuania
Joined 2004

Luxembourg
Joined 1996

Malaysia
Joined 1996

Malta
Joined 2004

Mongolia
Joined 2008

Myanmar
Joined 2004

Netherlands
Joined 1996

New Zealand
Joined 2010

Norway
Joined 2012

Pakistan
Joined 2008

Philippines
Joined 1996

Poland
Joined 2004

Portugal
Joined 1996

Romania
Joined 2008

Russian Federation
Joined 2010

Singapore
Joined 1996

Slovakia
Joined 2004

Slovenia
Joined 2004

Spain
Joined 1996

Sweden
Joined 1996

Switzerland
Joined 2012

Thailand
Joined 1996

United Kingdom
Joined 1996

Viet Nam
Joined 1996

ASEM GLOBAL AGEING CENTER (AGAC)

ASEM Global Ageing Center (AGAC) is a specialized international institution based in Seoul that operates as a global hub for coordinating a wide variety of agendas surrounding the human rights of older persons for ASEM partners. The center aims to address various issues confronted by ASEM partners regarding the human rights of older persons and ultimately contribute to the promotion and protection of human rights of older persons through policy research, cooperation, awareness raising and education, and information sharing.

ASEM Global Ageing Center

INTRODUCTION

Carol Ma Hok Ka

Embracing Technology Alongside People Living With Dementia and Care Partners

Debanjan Banerjee

Managing Inappropriate Sexual Behavior in Dementia With Dignity: Clinical Realities, Caregiver Support, and Policy Imperatives

Theresa Flavin

Will and Preferences in the Context of Dementia: Retaining Personhood in a Changing World With a Changing Brain

Magda Kaczmarska

Belonging Through Action: Dance for Brain Health and Connection Among People Living With Dementia

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AGAC ISSUE FOCUS

AGAC Issue Focus is a biannual periodical that aims to address ageing and human rights issues in a timely fashion. The publication introduces relevant ASEM partner policies and responses to a wider audience in order to promote information sharing and awareness raising and ultimately enhance ASEM partner cooperation. Each report focuses on a distinct theme that highlights current major concerns to do with ageing and the human rights of older persons in Asia and Europe.

For more information, visit the AGAC website (www.asemgac.org).

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