Special Issue: Citizenship and Dementia

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Dementia Citizenship Revisited: New Directions in Theory, Practice, and Lived Experience

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Abstract

Over the past two decades, citizenship discourse has become an important framework within dementia studies, shifting attention from individualised and deficit-oriented understandings of dementia toward the socio-political, legal, institutional, cultural and relational conditions that shape everyday life. This editorial introduces a 2026 special issue on dementia citizenship that explores the growth of this important field of dementia studies since the landmark 2016 special issue on citizenship was published in Dementia: The International Journal of Social Research and Practice. Highlighted in the 2026 special issue are contributions that extend scholarship on agency, participation, embodiment, rights, collaboration and social justice for persons living with dementia across long-term care, community care-collectives, and volunteering among persons living with dementia. Together, the articles demonstrate how citizenship is enacted, constrained, and supported, and how institutional routines, professional practices, interdependence, and recognition shape opportunities for participation and flourishing. Finally, the editorial emphasizes the importance of experiential knowledge in the development and review of this special issue, and in the co-authorship of one of the contributions. Collectively this editorial and the special issue that it introduces aims to stimulate further critical inquiry and practice development to ensure that persons living with dementia have equal opportunities to participate in social life and to flourish.

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The past two decades have seen an important turn in the dementia field to citizenship discourse. This has brought attention to the importance of embedding understandings of dementia within socio-political practices and discourses. A citizenship lens focuses on how experiences are shaped by cultural norms, economic conditions, legal provisions, political decisions, institutional practices and other systemic factors such as the relations between welfare state and its citizens and relations among/between the citizens (Bartlett & O'Connor, 2007; Nedlund et al., 2019; Nedlund & Nordh, 2015, 2018; Nordh & Nedlund, 2017; Örulv, 2012). This is a key distinction from other influential paradigms and approaches in dementia studies. For example, biomedical approaches draw on use pathophysiological developments as sources of explanation for the lived experience of dementia (Bartlett, 2014b; Behuniak, 2010; Grigorovich et al., 2019; Kontos, Grigorovich, Dupuis, et al., 2020; Mitchell et al., 2020). Person-centred dementia care, in contrast, recognises the intrinsic value and uniqueness of the individual living with dementia and their relationships with care partners as being decisive in determining how they experience dementia (Kitwood, 1997). In contrast, and due to its focus on power differentials, agency and issues relating to societal structure, the citizenship lens highlights systemic inequalities that are often overlooked in biomedical or person-centered models, emphasizing the importance of sociopolitical dynamics and how these enable or constrain access to, and experience with, health and social care institutions, and social life more broadly.

The growth of dementia citizenship studies as a subfield is evidenced by a recent review of the literature that included 49 empirical and conceptual contributions (O'Connor et al., 2022). Within this research field, transdisciplinarity—understood as involving close partnerships among academics across disciplines and experts by lived experience (Grigorovich et al., 2019)—has increasingly positioned researchers at the forefront of such collaborative approaches and has significantly advanced understandings of dementia and citizenship entitlements for individuals living with dementia. Dementia citizenship studies has contributed to shifting the discourse on dementia from being a predominantly deficit-oriented one to one that focuses on agency and participation, recognizing persons living with dementia as active agents rather than passive care recipients (Bartlett, 2014a; Gilmour & Brannelly, 2010; Grigorovich & Kontos, 2018; Marsh et al., 2018; Nedlund et al., 2019; Russell, 2020) and acknowledging the presence of active, everyday agency of people with dementia (Nedlund et al., 2019; Nygard et al., 2025). It has challenged the reduction of agency to cognition by centering body-self and body-world relations in explorations of how dementia is represented and/or experienced (Baldwin, 2008; Baldwin & Greason, 2016; Birt et al., 2017; Grigorovich et al., 2019; Grigorovich & Kontos, 2018; Kontos et al., 2017; Kontos, Grigorovich, & Colobong, 2020). Likewise, this scholarship has widened the scope of liberal justice by more inclusively granting citizenship entitlements to persons living with dementia in long-term residential care, and interrogating violations of those entitlements (Bartlett & O'Connor, 2007; Boyle, 2008; Kelly & Innes, 2013); this importantly emphasizes the rights of persons living with dementia to flourish across multiple settings and activities, including long-term care, leisure and recreation, political engagement, workplace participation, and everyday activities and affairs, however mundane and sometimes trivial they might seem (Bartlett & O'Connor, 2007; Fischer, 2022; Nedlund et al., 2019; Nygard et al., 2023; Nygård et al., 2025; Phinney et al., 2016; Russell, 2023; Russell et al., 2023).

In 2016, a cutting edge special issue on dementia citizenship was published in *Dementia: The International Journal of Social Research and Practice* (O'Connor & Nedlund, 2016). The special

issue included contributions that advanced dementia citizenship studies by conceptually introducing and empirically applying models of micro citizenship (Baldwin & Greason, 2016), democratic citizenship (Sonnicksen, 2016), relational citizenship (Kontos et al., 2016), social citizenship (Phinney et al., 2016), narrative citizenship (Clarke & Bailey, 2016), and active citizenship (Wiersma et al., 2016). The 2016 special issue broadened the field by publishing pieces that connected the citizenship lens to other discourses, such as dementia-friendly communities (Bartlett, 2016) and the ethics of care (Brannelly, 2016). It also included a study on an arts-based approach to promoting citizenship (Dupuis et al., 2016), (2) another on how persons living with dementia exercise resistance and agency in the context of hairdressing (Ward et al., 2016), and still another on how legal constructions, norms, and practices complicate the reclamation of citizenship (Nedlund & Taghizadeh Larsson, 2016).

Ten years later, we are excited to present a second special issue, albeit smaller in scope. Continuing the tradition of the 2016 edition, this special issue also embraces the diversity of dementia citizenship studies characteristic of the field. In early 2025, a call for abstract submissions was issued, inviting contributions from across the field. Following a review of fourteen submitted abstracts, a number of authors were invited to submit full manuscripts that offered important new directions in dementia citizenship theory, practice and lived experience.

In their article, Mac Tavish et al. (2026) explore how experiences and perceptions of leisure are both supported and constrained by the institutional, cultural, and structural environment of a long-term care home. Drawing on both social and relational citizenship frameworks, and using an ethnographic approach to explore everyday leisure experiences, the authors discuss how interdependence, reciprocity, and embodied selfhood can be constrained by routine, risk management, and ableist assumptions that privilege verbal communication over embodied forms of expression. Their analysis further highlights how leisure activities have the potential to support interdependence, dignity, and diverse ways of being and relating.

The article by Van Keulen et al. (2026) explores how social citizenship is enacted in community care-collectives. Drawing on an ethnographic case study of a clustered social housing model for older adults in the Netherlands, the authors focus on recurring interprofessional meetings that bring together housing, care, and social welfare professionals. These meetings serve to identify early changes in residents' participation and wellbeing and to proactively coordinate tailored support, enabling persons living with dementia to remain actively engaged in community life. The study sheds light on the ethical and practical challenges that emerge from professionals' active role in fostering social citizenship, particularly in navigating boundaries of responsibility and collaboration across domains.

Finally, the contribution by Vincent et al. (2026) focuses on exploring volunteering by persons living with young onset dementia in the UK, including a consideration of the benefits gained through volunteering, barriers people may encounter in accessing opportunities, and what is needed to improve access to volunteering for persons living with dementia. The article helps us to consider a novel example of everyday citizenship (cf. Nedlund & Bartlett, 2018; Nedlund et al., 2019), whereby lives are led by persons living with dementia and relationships forged in ways that highlight how agency can be expressed in circumstances that might appear ordinary. Persons living with dementia, through action taken as volunteers manifesting this as 'citizenship as a practice', whilst those living without dementia having opportunity to enable people to realise their 'citizenship in practice'. The article offers recommendations for how to strengthen social citizenship beginning with recognising and valuing the contributions of that persons living with young onset dementia can make to social life. Finally, that co-authorship of the article is inclusive of people with lived experience, and that they assumed a leadership role in the research itself, is further

contribution in that it models a citizenship approach by challenging the dominant deficit-focused model of dementia with recognition and support of agency and expertise through active partnership.

Just as the 2016 edition, the 2026 special issue was shaped and guided by an international network of researchers, the Citizenship and Dementia International Research Network (CDIRN). The network aims to promote and engage in dementia citizenship studies. It seeks to encourage scholarly work, both conceptual and empirical in nature, to foster international comparisons on the meanings, practices, and socio-legal and political contexts of citizenship within and across nations, and to stimulate academic, public, and policy debates about fostering meaningful citizenship. The network has expanded with members from more than 15 countries across the globe and includes academics from a wide breadth of disciplines as well as persons with lived experience; the network is inclusive of academic and experiential knowledges.

Drawing on experiential knowledge was central to the development of this special issue. From the outset, our editorial team was enriched by the contribution of a guest editor living with dementia, Julie Hayden. Her perspective helped to shape the direction and scope of the collection. In addition, two reviewers with lived experience played a crucial role in the peer review process, ensuring that every manuscript was considered not only through academic lenses but also in relation to the realities of everyday life with dementia. Each article was thus not only reviewed by two academics but also by a person living with dementia, who contributed their own ideas and understandings of citizenship and offered critical reflections grounded in experiential expertise. We wish to express our sincere gratitude to the reviewers with lived experience who generously volunteered their time and knowledge.

We would also like to thank the authors of the articles included within this special issue. We believe that their articles will capture the attention and interest of individuals both familiar and new to citizenship discourse in the context of dementia. It is our hope that our special issue offers vital stimuli for critical investigation and practice development to ensure that persons living with dementia experience freedom from discrimination and have equal opportunities to participate in social life and to flourish.

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Ethical Considerations

This editorial does not contain any studies with human or animal participants. There are no human participants in this article and informed consent is not required.

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References

Baldwin, C. (2008). Narrative(,) citizenship and dementia: The personal and the political. *Journal of Aging Studies*, *22*(3), 222–228. https://doi.org/10.1016/j.jaging.2007.04.002

Baldwin, C., & Greason, M. (2016). Micro-citizenship, dementia and long-term care. *Dementia*, *15*(3), 289–303. https://doi.org/10.1177/1471301216638762

Bartlett, R. (2014a). Citizenship in action: The lived experiences of citizens with dementia who campaign for social change. *Disability & Society*, *29*(8), 1291–1304. https://doi.org/10.1080/09687599.2014.924905

Bartlett, R. (2014b). The emergent modes of dementia activism. *Ageing and Society*, *34*(4), 623–644. https://doi.org/10.1017/S0144686X12001158

Bartlett, R. (2016). Scanning the conceptual horizons of citizenship. *Dementia*, *15*(3), 453–461. https://doi.org/10.1177/1471301216644114

Bartlett, R., & O'Connor, D. (2007). From personhood to citizenship: Broadening the lens for dementia practice and research. *Journal of Aging Studies*, *21*(2), 107–118. https://doi.org/10.1016/j.jaging.2006.09.002

Behuniak, S. M. (2010). Toward a political model of dementia: Power as compassionate care. *Journal of Aging Studies*, *24*(4), 231–240. https://doi.org/10.1016/j.jaging.2010.05.003

Birt, L., Poland, F., Csipke, E., & Charlesworth, G. (2017). Shifting dementia discourses from deficit to active citizenship. *Sociology of Health & Illness*, *39*(2), 199–211. https://doi.org/10.1111/1467-9566.12530

Boyle, G. (2008). The *Mental Capacity Act 2005*: Promoting the citizenship of people with dementia? *Health and Social Care in the Community*, *16*(5), 529–537. https://doi.org/10.1111/j.1365-2524.2008.00775.x

Brannelly, T. (2016). Citizenship and people living with dementia: A case for the ethics of care. *Dementia*, *15*(3), 304–314. https://doi.org/10.1177/1471301216639463

Clarke, C. L., & Bailey, C. (2016). Narrative citizenship, resilience and inclusion with dementia: On the inside or on the outside of physical and social places. *Dementia*, *15*(3), 434–452. https://doi.org/10.1177/1471301216639736

Dupuis, S. L., Kontos, P., Mitchell, G., Jonas-Simpson, C., & Gray, J. (2016). Re-claiming citizenship through the arts. *Dementia*, *15*(3), 358–380. https://doi.org/10.1177/1471301216637206

Fischer, J. (2022). The political presence of persons living with dementia in parliament. A qualitative study into the dementia representation work of German parliamentarians. *Journal of Aging Studies*, *61*, Article 101026. https://doi.org/10.1016/j.jaging.2022.101026

Gilmour, J. A., & Brannelly, T. (2010). Representations of people with dementia – subaltern, person, citizen. *Nursing Inquiry*, *17*(3), 240–247. https://doi.org/10.1111/j.1440-1800.2009.00475.x

Grigorovich, A., & Kontos, P. (2018). Advancing an ethic of embodied relational sexuality to guide decision-making in dementia care. *The Gerontologist*, *58*(2), 219–225. https://doi.org/10.1093/geront/gnw137

Grigorovich, A., Kontos, P., & Kontos, A. P. (2019). The "violent resident": A critical exploration of the ethics of resident-to-resident aggression. *Journal of bioethical inquiry*, *16*(2), 173–183. https://doi.org/10.1007/s11673-019-09898-1

Kelly, F., & Innes, A. (2013). Human rights, citizenship and dementia care nursing. *International Journal of Older People Nursing*, *8*(1), 61–70. https://doi.org/10.1111/j.1748-3743.2011.00308.x

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

Kontos, P., Grigorovich, A., & Colobong, R. (2020). Towards a critical understanding of creativity and dementia: New directions for practice change. *International Practice Development Journal*, *10*(Suppl), 1–13. https://doi.org/10.19043/ipdj.10Suppl.003

Kontos, P., Grigorovich, A., Dupuis, S., Jonas-Simpson, C., Mitchell, G., & Gray, J. (2020). Raising the curtain on stigma associated with dementia: Fostering a new cultural imaginary for a more inclusive society. *Critical Public Health*, *30*(1), 91–102. https://doi.org/10.1080/09581596.2018.1508822

Kontos, P., Grigorovich, A., Kontos, A. P., & Miller, K.-L. (2016). Citizenship, human rights, and dementia: Towards a new embodied relational ethic of sexuality. *Dementia*, *15*(3), 315–329. https://doi.org/10.1177/1471301216636258

Kontos, P., Miller, K., & Kontos, A. P. (2017). Relational citizenship: Supporting embodied selfhood and relationality in dementia care. *Sociology of Health & Illness*, *39*(2), 182–198. https://doi.org/10.1111/1467-9566.12453

Marsh, P., Courtney-Pratt, H., & Campbell, M. (2018). The landscape of dementia inclusivity. *Health & Place*, *52*, 174–179. https://doi.org/10.1016/j.healthplace.2018.05.013

Mitchell, G., Dupuis, S. L., Kontos, P., Jonas-Simpson, C., & Gray, J. (2020). Disrupting dehumanising and intersecting patterns of modernity with a relational ethic of caring. *International Practice Development Journal*, *10*(1), 1–15. https://doi.org/10.19043/ipdj.101.002

Nedlund, A.-C., & Bartlett, R. (2018). Citizenship-in-and-as-Practice: A framework for improving life with dementia. In L.-C. Hydén (Hrsg.), *Living with dementia* (S. 49–67). Macmillan Education UK. https://doi.org/10.1057/978-1-137-59375-7_4

Nedlund, A.-C., Bartlett, R., & Clarke, C. L. (Hrsg.). (2019). *Everyday citizenship and people with dementia*. Liverpool University Press. https://doi.org/10.2307/jj.12638998

Nedlund, A.-C., & Nordh, J. (2015). Crafting citizen(ship) for people with dementia: How policy narratives at national level in Sweden informed politics of time from 1975 to 2013. *Journal of Aging Studies*, *34*, 123–133. https://doi.org/10.1016/j.jaging.2015.06.003

Nedlund, A.-C., & Nordh, J. (2018). Constructing citizens: A matter of labeling, imaging and underlying rationales in the case of people with dementia. *Critical Policy Studies*, *12*(3), 253–272. https://doi.org/10.1080/19460171.2017.1297730

Nedlund, A.-C., & Taghizadeh Larsson, A. (2016). To protect and to support: How citizenship and self-determination are legally constructed and managed in practice for people living with dementia in Sweden. *Dementia*, *15*(3), 343–357. https://doi.org/10.1177/1471301216638966

Nordh, J., & Nedlund, A.-C. (2017). To coordinate information in practice: Dilemmas and strategies in care management for citizens with dementia. *Journal of Social Service Research*, *43*(3), 319–335. https://doi.org/10.1080/01488376.2016.1217580

Nygård, L., Nedlund, A.-C., Issakainen, M., Astell, A., Boger, J., Mäki-Petäjä-Leinonen, A., Engvall, A.-L., Heuchemer, B., Rosenberg, L., & Ryd, C. (2025). Coming to terms with a changing everyday life with dementia: What can we learn from people who are diagnosed while still working? *Dementia*, *24*(6), 1040–1058. https://doi.org/10.1177/14713012251323939

Nygard, L., Nedlund, A.-C., Mäki Petäjä Leinonen, A., Astell, A., Boger, J., Issakainen, M., Engvall, A.-L., Heuchemer, B., Rosenberg, L., & Ryd, C. (2023). What happens when people develop dementia whilst working? An exploratory multiple case study. *International Journal of Qualitative Studies on Health and Well-Being*, *18*(1), Article 2176278. https://doi.org/10.1080/17482631.2023.2176278

O'Connor, D., & Nedlund, A-C. (2016). Editorial introduction: Special issue on Citizenship and Dementia. *Dementia*, *15*(3), 285–288. https://doi.org/10.1177/1471301216647150

O'Connor, D., Sakamoto, M., Seetharaman, K., Chaudhury, H., Phinney, A., et al. (2022). Conceptualizing citizenship in dementia: A scoping review of the literature. *Dementia*, *21*(7), 2310–2350. https://doi.org/10.1177/14713012221111014

Örulv, L. (2012). Reframing dementia in Swedish self-help group conversations: Constructing citizenship. *International Journal of Self Help and Self Care*, *6*(1), 9–41. https://doi.org/10.2190/SH.6.1.c

Phinney, A., Kelson, E., Baumbusch, J., O'Connor, D., & Purves, B. (2016). Walking in the neighbourhood: Performing social citizenship in dementia. *Dementia*, *15*(3), 381–394. https://doi.org/10.1177/1471301216638180

Russell, C. (2020). People with dementia, contributing to learning and teaching in higher education: Innovative practice. *Dementia*, *19*(2), 447–452. https://doi.org/10.1177/1471301216685460

Russell, C. (2023). "We can Do this!": The role of physical activity in what comes next for dementia. *International Journal of Environmental Research and Public Health*, *20*(15), 6503. https://doi.org/10.3390/ijerph20156503

Russell, C., Kohe, G. Z., Evans, S. B., & Brooker, D. (2023). Rethinking spaces of leisure: How people living with dementia use the opportunities leisure centres provide to promote their identity and place in the world. *International Journal of the Sociology of Leisure*, *6*(2), 135–166. https://doi.org/10.1007/s41978-022-00121-x

Sonnicksen, J. (2016). Dementia and representative democracy: Exploring challenges and implications for democratic citizenship. *Dementia*, *15*(3), 330–342. https://doi.org/10.1177/1471301216638998

Ward, R., Campbell, S., & Keady, J. (2016). 'Gonna make yer gorgeous': Everyday transformation, resistance and belonging in the care-based hair salon. *Dementia*, *15*(3), 395–413. https://doi.org/10.1177/1471301216638969

Wiersma, E. C., O'Connor, D. L., Loiselle, L., Hickman, K., Heibein, B., Hounam, B., & Mann, J. (2016). Creating space for citizenship: The impact of group structure on validating the voices of people with dementia. *Dementia*, *15*(3), 414–433. https://doi.org/10.1177/1471301216642339

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