

## Separate and Unequal: A Time to Reimagine Dementia

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### **Abstract:**

The rapid emergence of COVID-19 has had far-reaching effects across all sectors of health and social care, but none more so than for residential long-term care homes. Mortality rates of older people with dementia in residential long-term care homes have been exponentially higher than the general public. Morbidity rates are also higher in these homes with the effects of government-imposed COVID-19 public health directives (e.g., strict social distancing), which have led most residential long-term care homes to adopt strict ‘no visitor’ and lockdown policies out of concern for their residents’ physical safety. This tragic toll of the COVID-19 pandemic highlights profound stigma-related inequities. Societal assumptions that people living with dementia have no purpose or meaning and perpetuate a deep pernicious fear of, and disregard for, persons with dementia. This has enabled discriminatory practices such as segregation and confinement to residential long-term care settings that are sorely understaffed and lack a supportive, relational, and enriching environment. With a sense of moral urgency to address this crisis, we forged alliances across the globe to form Reimagining Dementia: A Creative Coalition for Justice. We are committed to shifting the culture of dementia care from centralized control, safety, isolation, and punitive interventions to a culture of inclusion, creativity, justice, and respect. Drawing on the emancipatory power of the imagination with the arts (e.g., theatre, improvisation, music), and grounded in authentic partnerships with persons living with dementia, we aim to advance this culture shift through education, advocacy, and innovation at every level of society.

**Keywords:** arts | coalition | covid-19 | culture change | relational caring | residential long-term care | social justice

### **Article:**

When COVID-19 first spread across Europe and North America, the mortality rate of older people living with dementia in residential long-term care homes was exponentially higher than the general public [1, 2]. Long-term care residents accounted for 81% of all reported COVID-19 deaths in

Canada, compared with an average of 38% in other OECD (Organisation for Economic Co-operation and Development) countries [1]. Data from Canada and the United States suggest further disparities for people from Black, Indigenous, and people of color (BIPOC) communities due to longstanding structural inequities that leave them “more exposed and less protected” from COVID-19 [3–5]. For example, BIPOC are more likely to lack health benefits, which along with greater exposure to environmental toxins and discrimination lead to increased risk of underlying health conditions and thus greater risk of infection and death from the virus. Further, given that in the United States, Black and Hispanic people may be more likely to be diagnosed with dementia and to live in substandard quality residential long-term care homes as compared with white Americans, they have been particularly negatively impacted by COVID-19 [6].

Morbidity rates were also higher in residential long-term care settings, particularly with the effects of physical distancing to limit the spread of the virus [2]. Government-imposed COVID-19 public health directives, such as strict social distancing, led most residential long-term care homes to adopt strict ‘no visitor’ and lockdown policies out of concern for their residents’ physical safety. This resulted in residents being placed in solitary confinement for extended periods of time, cut off from family and friends, and with no enriching activities, exacerbating a competing public health crisis of “diseases of despair” [7, 8] and increased frailty. In the context of residential long-term care, many residents have experienced increases in depression, anxiety, withdrawal from care (e.g., refusal to eat, take medication, engage in self-care), and increased use of psychotropic medications and physical restraints [9–11]. In Canada, Spain, and Italy, military troops were deployed in a number of the hardest hit public and private residential long-term care homes that were overrun by COVID-19 outbreaks, and because of a dramatic shortage of workers, residents were found lacking the most basic care. The military reported undeniable evidence of separate and substandard living conditions for society’s most vulnerable citizens. For example, in Canada, many people living with dementia were found unbathed for weeks, in soiled linens, with choking hazards, left to fend for themselves, and some long dead in their beds [12]. Global overview of the second wave of the pandemic suggests that in some countries there has been a reduction in case fatality ratios [13]. However, with countries easing social distancing restrictions, the number, size, geographic dispersion, and severity of outbreaks have been increasing dramatically [14]. A report published in October 2020 that is based on data from twenty-one countries indicates that the current average of the share of all COVID-19 deaths that are residents from long-term residential care settings is 46% [15].

This tragic toll of the COVID-19 pandemic has profoundly reinforced what many dementia researchers, health care practitioners, clinicians, and advocates have long known—the segregation and unilateral sequestering of people living with dementia away from their familiar communities highlights profound stigma-related inequities that undermine the principles of a just, caring, and inclusive society [16–20]. Though conditions in some residential long-term care homes have improved over the decades with the thrust of the person-centered care culture change movement, such institutions are for the most part sites that reveal neoliberal-driven structural conditions including for-profit care delivery and the associated reliance on a temporary and casual workforce, low staffing levels, and inadequate care supplies. There is as well as the intensification of care work and the resulting reduction of care to basic physical tasks such as eating, toileting, and bathing, and the reliance on clinical outcome measures that inadequately reflect resident experiences that support life quality [16, 17, 21]. These structural conditions and their exploitation by COVID-19 have featured prominently in analyses of the impact of the pandemic on the long-term care sector [18]. Further, in long-term residential care settings opportunities for people living

with dementia to pursue life-enhancing relationships and activities are often not offered, and physical and pharmaceutical restraints are still considered acceptable for use on residents [22]. So much work needs to be done in these settings to better support staff, strengthen care relationships, and to ensure that residents' humanity and life quality is fully supported.

Since communicating verbally often becomes difficult for people with cognitive challenges, many have been unable to speak up for their citizen rights to access equal standards of living, participate in decisions involving them, their community, culture, recreation, privacy, and other aspects of their well being, in ways other disability groups have historically done. Left unchallenged are societal assumptions that the neuropathology associated with dementia 'eradicates the essence of the person'. This is evident in the metaphors and images in policy and popular culture that represent dementia as "the funeral without end", "the loss of self", "the zombie", and "a living death", which perpetuate a deep and pernicious fear of, and disregard for, persons living with dementia [20, 23, 24]. This has enabled discriminatory practices such as segregation and confinement to residential long-term care settings that are sorely understaffed and lack a supportive, relational, and enriching environment. We know that deeply caring health care practitioners do exist, but often despite a culture and system that devalues them, not because of it.

With a sense of moral urgency to address what can only be described as a humanitarian crisis—the COVID-19 toll on residential long-term care settings and the stigma-related inequities that it high-lights—we began forging alliances across the globe to form Reimagining Dementia: A Creative Coalition for Justice. We circulated a 'call to action' [25] on the social media pages (e.g., Facebook, LinkedIn, Twitter, Instagram) of the founding members and by email to members' contacts, which allowed us to reach across a vast breadth of sectors (e.g., science/academia, industry, policy, community). We are also extending our targeted outreach to organizations such as Leaders Engaged on Alzheimer's Disease, Alzheimer's Disease International, and Dementia Friendly America, to disability rights movements, organizations involved in provincial and national dementia strategies, and to other relevant social justice movements. Forging alliances in this intentional way is consistent with the solidarity network concept and the utility of such networks as an enabling force to influence social change [26]. What started as a relatively small group of founding members has quickly grown to four hundred members. We are a diverse group: health care practitioners, people living with dementia (young and old), care partners, advocates, artists, academics, legal experts, human rights activists, and others committed to culture change related to aging and dementia. For us this includes drawing on the transformative potential of creativity [27, 28] as we identify, mobilize, and disseminate best practices and political processes to treat people living with dementia as full members of a society that needs them to flourish and evolve. It also includes drawing on citizenship and human rights discourses, and a relational caring philosophy as these have all contributed to recent advancements in the dementia field [17, 28–30].

Major transformation will be required to shift the culture of dementia care from centralized control, safety, isolation, and punitive interventions toward a culture of inclusion, creativity, justice, respect, and love, for both residents and the formal care partners working in these settings. So 'reimagining dementia' will require, by definition, the human imagination, an ability perhaps even more significant than memory (the often-cited measure of dementia). We believe in the interactive, educational, and emancipatory power of the imagination with the arts to help redress inequities. Referred to broadly as "social justice art" [31] (also known as 'liberation arts' [32]), this involves the use of literary forms (creative non-fiction, storytelling), performance (e.g., applied theatre, dance, movement), visual arts (e.g., painting, photography), and new media (e.g., video, webinars) for challenging entrenched and oppressive attitudes, perceptions, institutions, and

social relations, and to imagine and effect more equitable solutions. A powerful example of social justice art is the use of storytelling by activists across the globe to organize, express, and enact claims to recognition, rights, and justice, and to define and implement tactics for achieving a more just society [33]. In the specific context of dementia, theatre is another example of social justice art that has been successfully used as a public health strategy to reduce stigma across community and residential long-term care settings [20, 34]. From a policy perspective, based on an extensive review of the state of evidence concerning the impacts of the arts on health and wellbeing, the All-Party Parliamentary Group on Arts, Health and Wellbeing in the UK has enlisted the arts to address a number of policy challenges such as mitigating social isolation and loneliness, ensuring more equitable access to the arts for people who are living with dementia, strengthening local services, and promoting more cohesive communities [27]. Our coalition also includes members who have drawn on the evidence of the impact of the arts on persons living with dementia in long-term care homes to effect policy change, specifically in terms of supporting the Alzheimer's Society of Canada's submission to the House of Commons' Standing Committee on Health [35] and more recently making a submission to Ontario's Long-Term Care COVID-19 Commission [36]. With the above cited evidence linking arts engagement to health and wellbeing, and the political endorsement of the transformative power of arts, our growing coalition is committed to advancing culture change together through arts-based education, advocacy, and innovation at every level of society (i.e., micro, meso, macro) to disrupt and change individual perceptions, inhumane patterns of relating, and dominant oppressive discourses, institutional structures, and policies. Our strategies for radical change will always be firmly rooted in the science and practice that supports the effectiveness of the arts to discursively change attitudes and perceptions, practices, and institutional structures and policies.

Genuine inclusion is at the core of this coalition. We actively solicit and facilitate the contributions of persons living with dementia and their care partners, including citizens from marginalized communities. Their perspectives, interests, and identified goals should be at the forefront of any social action plan aimed at bettering the world for them. We share our personal knowledge and professional resources, expertise, and maintain open discussions on innovative culture change using social justice art to rethink the values and commitments of our society. This collective and inclusive approach, grounded in authentic partnerships [37], is essential because many people living with dementia unfortunately remain excluded, segregated, isolated, silenced, and unable to access resources, services, and opportunities they need to participate in collective action. In these early days of the Coalition there is an expected degree of indeterminacy regarding specific goals and implementation strategies since the task ahead of us is to engage all of our members to collectively create a plan for radical change.

Our international coalition members are already inspiring reforms to policy and practice to support people to live well with dementia using theatre, film, and visual art; we will importantly leverage these and other collective initiatives, resources, expertise, and passion to create environments in which everyone is supported to grow and to thrive. This includes rethinking, revisioning, and actually reconstructing diverse living environments and health care approaches if we are to ever achieve a more just, caring, and inclusive society—not only for people living with dementia, but for us all.

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