

**A roadmap of noninstitutional living options for people with dementia:
“Don’t fence me in.”**

by

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Summary

Canadians overwhelmingly do not want to live in long-term-care facilities (nursing homes) when they age; however, many end up there for lack of homecare, because family care partners burn out, or because they and their professional advisors are unaware of alternatives to institutions. Not only is institutional dementia care riven with problems, it segregates disabled people, thereby abrogating human rights. Because systemic ageism and ableism cloud seniors’ care, institutions remain the default option for Canadians with dementia. Yet, decades of deinstitutionalization enabled younger disabled Canadians to live in the community with supports. Why not seniors?

We present a roadmap for considering all relevant care options in service plans, one that incorporates supported decision-making by people with dementia. We then describe a plethora of noninstitutional dementia-care alternatives. We propose a paradigm shift in how Canada serves its senior citizens—not just the current generation but those to come, including ourselves.

Understanding institutional living

There is little dignity in institutional life. Residents with dementia live behind locked doors and pace sanitized corridors to the distant sound of televisions furnishing minimalist common spaces, void of personal touches and designed for easy maintenance. Yet, although 97% of Canadians over 65 polled in 2021 did not want to reside in long-term care institutions (LTCIs) (NIA, 2021), little has been done to challenge the institutional model of dementia/seniors’ care. Still today, LTCI residents are merely considered objects of costly medical and domestic care tainted by the stigma of sickness and death (Hummel & Tettamanti, 2009). This is even truer for residents living with dementia, who are disabled by social attitudes (Shakespeare et al., 2017).

It is paradoxical that, even following media coverage of high death rates in LTCIs during COVID-19’s first and second waves (Carette, 2021), politicians still support the institutional model as Canada’s default option for dementia care. Burnt-out family care partners often resign themselves to the seeming absence of other viable options. For people with dementia, the disadvantages and dangers of institutions are many. They may (a) receive only physical care, with quality depending on staffing levels, (b) contract easily transmitted infections, such as COVID-19 and influenza, (c) lack privacy, (d) lose autonomy and dignity, (e) wear diapers instead of being helped to the toilet, resulting in frequent urinary-tract infections, (f) very likely be depressed, (g) endure physical and psychological abuse, (h) deteriorate mentally and physically, (i) likely develop dental problems, leading to malnutrition, weight loss, and frailty,

and (j) suffer during influenza-outbreak lockdowns, preventing families from monitoring their care. (For references, see our full article.)

Given the dangers of institutional dementia/seniors' care and Canadians' rejection of it, why do our governments keep funding institutions? Compared with other OECD countries, Canada drastically underfunds home care for seniors. Canada's spending on geriatric institutions is over five times higher than its spending on home care (Drummond et al., 2020).

Canadian governments should replace the institutional model of care with community-based alternatives. To understand why, we look at what drives seniors' institutionalization. Systemic ageism (discrimination based on age) clouds much of Canadian social policy and practices regarding end-of-life services and care-partner supports. Healthcare-quality decline with age is well reported (Nemiroff, 2022). Seniors often encounter paternalistic physician attitudes (Fernández-Ballesteros et al., 2019); stigma; higher rates of under- and overtreatment (Mistry, 2021); barriers to timely, effective care (Nemiroff, 2022); and, in the face of functional decline, few alternatives to barren, segregated institutions (Herron, Kelly & Aubrecht, 2021).

Systemic ageism is bolstered by systemic ableism (discrimination based on ability). Through confinement to LTCIs, people with dementia experience epistemic and humanitarian injustices. Indeed, institutional management of residents with dementia contradicts the United Nations Convention on Rights of Persons with Disabilities (UNCRPD), a treaty that Canada signed. As Steele and colleagues (2020) point out, "care homes commonly employ a wide range of physical and environmental barriers to movement, including locked doors, lap sashes and belts, bed rails, and segregated wards" (p. 9). These physical constraints compound the widespread use of drugs to control residents with dementia, clearly violating their rights to non-discrimination and equality as disabled people (Minkowitz, 2006).

In view of the above, the need for LTCI alternatives is not only undeniable but an urgent human-rights remedy (Steele et al., 2020) and cost saver for taxpayers. Nonetheless, professionals, people with dementia, and their families lack tools and knowledge to find other care avenues. To address these needs, we (a) provide a nonexhaustive roadmap (see Figure 1) that professionals can use to guide decision-making by clients with dementia and their families, (b) discuss supported decision-making, which empowers people with dementia, rather than substitute decision-making, which dominates the eldercare landscape, and (c) describe current and potential alternatives to institutional living (see Table 1). All alternative options should be discussed jointly with people with dementia and based on their preferences, care needs, social and financial resources.

Figure 1
Roadmap of alternatives to institutional care for someone with dementia

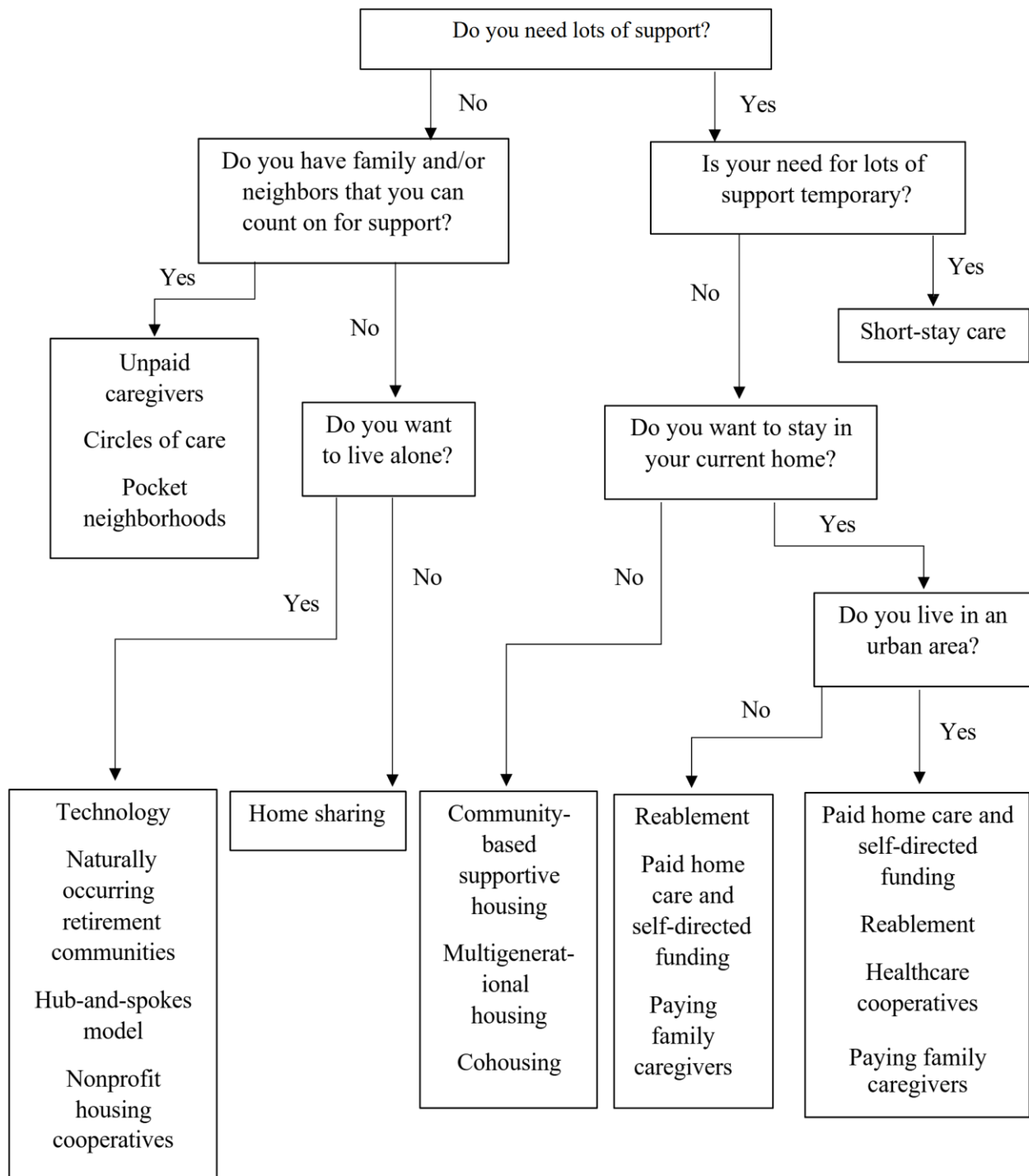


Table 1

Noninstitutional Options for Supporting People with Dementia

Minimal in-home supports	Extensive domestic and medical in-home supports	Out-of-home options
Unpaid caregiving	Paid home care and self-directed funding	Community-based supportive housing
Circles of support	Reablement	Multigenerational housing
Technology	Healthcare cooperatives	Cohousing
Home sharing	Public community-based-care insurance plans ^a	Nonprofit housing cooperatives
Naturally occurring retirement communities (NORCs)	Short-stay care	Pocket neighborhoods
Hub-and-spokes model	Paying family caregivers	

Note. ^aNot currently available in Canada.

Our roadmap's foundation is supported decision-making (SuDM). This approach recognizes the right of disabled people under the UNCRPD to make decisions about their lives, with support if needed (Alzheimer Europe, 2017). SuDM is addressed by legislation in at least 6 Canadian provinces. British Columbia was the first to legally recognize SuDM directly in 1996 and New Brunswick the most recent in 2022. Four other provinces and territories, Manitoba, Yukon, Alberta, and Saskatchewan have different models of supported decision-making (CCEL, 2014). Notably, Ontario does not have SuDM legislation. Although SuDM legislation and other models of decision-making have younger people with intellectual disabilities in mind, there is no reason why it cannot benefit people with dementia (personal communication, B. Pooran, Pooran Law, Chair, Microboards Ontario, Annual Family Networking Forum, April 20, 2024).

SuDM involves listening to the preferences and self-identified needs of people with dementia. To listen, professionals can build relationships with people with dementia and their families well before discussing decisions; allow time for decision-making and multiple discussions; look to nonverbal cues like facial and other bodily expressions; watch out for verbal

and nonverbal signs of anxiety and disagreement; and use pictures to explain abstract concepts (Oldfield, 2021).

Non-Institutional Options for Supporting People with Dementia

We now describe noninstitutional options currently available in Canada, along with those in other countries. We group the options into (a) minimal in-home supports, (b) extensive domestic and medical in-home supports, and (c) out-of-home supports.

Minimal In-Home Supports

Although dementia eventually causes ability losses, diagnosis does not mean immediate need for substantial support or institutionalization. Initially, minimal supports are best to avoid disrupting people's lives.

Unpaid care partners provide physical and emotional support to parents, partners, friends, or neighbors. They may also organize and monitor paid care. Unpaid care partners, therefore, save governments substantially in health-care costs. However, unpaid care can require a lot from the women who mostly do it. Middle-aged family care partners juggle caring for parents and children living at home. To accommodate care, they may switch to part-time employment or leave their jobs, leading to increased dependence on their partners, reduced family income, more stress, and worsening mental and physical health. These negative impacts are largely tied to insufficient government compensation and workplace accommodation, and to the structural ageism and ableism that shape insufficient seniors' supports (Lévesque, 2022). However, when unpaid care is coupled with appropriate supports (described below), not only is care-partner burnout reduced but risk of institutionalization drops.

Circles of support bring together groups of friends or community members who weave a personal safety net around a disabled person, who is then empowered through supported decision-making in jurisdictions that legally recognize it. Because Ontario does not, circles of support there have incorporated as nonprofit organizations called Microboards. They are neither guardians nor substitute decision-makers (microboardsontario.com). In contrast, Quebec has formalized the importance of ally groups for people under protection mandates, who must be consulted in legally implementing a protection mandate (Curateur public du Québec, 2022).

Protective technology can allow people with dementia to remain at home without compromising safety. Wearable alerts summon help from a service operator and generally use global-positioning-system and/or fall-detection technology. Devices can link to cellphones and other smart devices. Simpler technology, such as carrying a card or wearing a lanyard or bracelet with one's name, address, and emergency-contact information, can facilitate a return home if lost. Similarly, medic-alert bracelets tell emergency personnel about someone's medical conditions, allergies, etc. without the person being articulate or even conscious.

Home sharing programs match seniors who have unused bedrooms in their homes with housemates (e.g., students) looking for low or free rent in exchange for housework or home maintenance. Other benefits for both parties include companionship, security, and mutual caring. Although home sharing can postpone institutionalization, home sharing has some drawbacks. First, it may not meet seniors' complex or intensive needs; however, housemates may organize and monitor paid care. Second, housemates may turn out to be incompatible. Nonetheless, some home-sharing programs safeguard against this outcome through a thorough acquaintance process. Third, because municipal zoning may prohibit sharing one's home with unrelated people, potential home sharers should seek advice about relevant bylaws before proceeding.

Naturally occurring retirement communities (NORCs) are apartment buildings not intended for seniors when built where at least a third of residents are now seniors. Residents may partner with senior-serving agencies to provide in-home supports at reduced or no cost (Benzie et al., 2020). The Ontario Ministry of Health and Long-Term Care funds several City-of-Toronto-owned seniors' buildings (www.toronto.ca/community-people/children-parenting/seniors-services/seniors-housing-services/supportive-housing-program/) to provide eligible tenants with the following services: personal care, navigating the healthcare system, light housekeeping and laundry, medication reminders, safety checks, light meal preparation, health promotion activities and education, and referral to community resources. In addition, the NORC Innovation Centre, OASIS (oasis-aging-in-place.com), and Women's College Hospital are helping seniors set up NORCs in their buildings.

The **hub-and-spokes model** extends health and social services based in buildings housing mostly seniors, the hubs, to seniors in the surrounding community, the spokes (SSAO, November 28, 2022). This model (a) serves seniors in various housing arrangements (e.g., houses, multigenerational homes, apartment buildings with few seniors), (b) reduces costs by not requiring new infrastructure to expand clientele, (c) delivers services more efficiently by serving co-located groups, not widespread individuals. (See our full article for an example.)

Extensive Domestic and Medical In-Home Supports

Eventually, people with dementia will likely need more extensive daily support. There are in-home options that address most needs of people with dementia.

Community-based geriatric assessment, rather than hospital-based assessment, reduces the likelihood of Canadians with dementia being institutionalized by 6 times (CIHI, 2022). Hospital administrators, under pressure to control costs and free up beds, in turn pressure discharge planners to quickly discharge patients no longer needing acute care. Having little time to get to know these patients or their community-care options and aware that community-services waiting lists are long, discharge planners ask families to choose LTCIs from a list. To facilitate return home from hospital, senior patients and their families need integrated continuing-care plans that start with community-based geriatric assessment in coordination with patients' family physicians, who know their situations well.

Paid home care and self-directed funding are key initiatives preventing people with dementia being institutionalized. Despite paid home care being far cheaper at \$45/day/person than LTCI beds at \$142/day, Canadian governments drastically underfund home care. Consequently, the proportion of Canadians over 65 remaining at home is far lower than seniors in Europe and New Zealand (Drummond et al., 2020), where home care funding takes priority over institutions. In America, Medicaid's Money Follows the Person directly funds seniors to choose where to spend the money: on institutions, home care, or other non-institutional alternatives (SSAO, February 23, 2021). Canada already has a model for self-directed seniors'-care funding: younger people with physical disabilities (but not intellectual or psychiatric disabilities) can receive provincial funds to independently hire and manage their own personal attendants (Kelly et al., 2020). Except for Saskatchewan, none of this funding specifically includes people with dementia. There, seniors are expected to hire and manage their own attendants, limiting the program's usefulness for people with dementia (personal communication, K. Ottley, Canadian Association on Gerontology conference, October 26, 2023).

Reablement, or restorative care, aims to increase independence. Practitioners focus on building strength and confidence in abilities, promoting self-care, regaining skills, preventing

hospital readmission, and, crucially, postponing institutionalization (Rostgaard, Parsons, & Tuntland, 2023). Reablement also dispels the assumption that people with dementia will only decline (Lévesque, 2022) and has been shown to reduce healthcare and support use (Aspinal et al., 2016). Encouraging seniors to regain some independence is more fruitful than helping unpaid care partners cope with their distress at watching seniors struggle (Poulos et al., 2017).

Healthcare cooperatives are community initiatives that fill gaps in government-funded senior home care. One type, worker cooperatives, is owned by personal support workers. A second type of cooperative is owned by its consumers, a group of seniors or families who want better home care. Each member contributes a certain amount per month to jointly hire a personal support worker (SSAO, December 5, 2022). Quebec has integrated healthcare cooperatives into its social economy as a relief valve for government-funded home-care services. Cooperatives are regarded more favorably than for-profit agencies, known to cut corners on services or underpay workers to maximize their profit (Craddock & Vayid, 2004). Although healthcare-cooperative services are not usually free, fees are kept reasonable with supplemental government funding.

Public community-based-care insurance plans have been implemented in East Asia and Europe, among other world regions. They cover not only institutional care but home and nursing care. Japan's plan, an international model of best practice, emphasizes community-based supports while facilitating familial care (Chen, Zhang & Xu, 2020). Long-term-care-insurance plans can be financed by employer and employee contributions, income taxes, and pension deductions. Public community-based insurance plans are not yet available to Canadians. However, when Réjean Hébert was Quebec's Minister of Health, he proposed such a plan (Hébert, 2016). Community-based-care-insurance plans show great promise for allowing seniors to choose where and how to receive care.

Short-stay care allows family care partners who live with people with dementia to take breaks or vacations while care recipients occupy bedrooms in group homes, supported apartments, or LTCIs. Short-stay care can also provide regular respite when care partners feel burned out, have limited resources at home, or need more community support. Crucially, short-stay care can, together with other interventions, significantly reduce negative care experiences and delay the institutionalization of people with dementia (Etters et al., 2008). More broadly, respite care frees up alternate level of care (ALC) beds (Drummond et al., 2020). Conversely, short-stay care can facilitate hospital-to-home transition, while seniors recover and in-home services are arranged.

Paying family care partners can reduce the likelihood of institutionalization. When seniors need extensive healthcare and/or domestic services, care partners may find care difficult to juggle with full-time employment. Raising children, being poor, living far from elder parents, and lacking community support make unpaid care impossible. Accessing paid leave from employers and/or being paid to care are two ways to solve this problem. Some federal programs pay family care partners: under employment insurance, the family-caregiver-for-adults benefit and compassionate-care benefit; and the caregiver tax credit. However, only care partners below certain incomes are eligible for these payments, which are too low to replace employment earnings. (For details and the two provinces that pay family care partners, see our full article.)

Out-of-Home Supports

When all options that enable the person with dementia to remain at home have been exhausted, if the person does not want to live alone, it is time to look for community-based housing that provides more supports.

Community-based supportive housing (CBSH) is an option for seniors who do not want to live alone or with family, or who do not have unpaid care partners such as adult children. Replacing LTCIs with community-based alternatives echoes a movement that began in the 1960s called deinstitutionalization. CBSH enabled non-senior people with disabilities to leave or avoid institutions.

CBSH for people with developmental disabilities, inconspicuously located within neighborhoods, is generally owned and run by non-profit agencies. The first type is group homes modelled on family homes not hospitals, which house 4-10 residents who have 24-hour staff support. The mostly private bedrooms are decorated to residents' tastes with their own belongings. Staff and residents may cook meals together, do laundry, and clean. Staff accompany residents on outings of their choosing, help with personal care, and provide emotional support. In the second type of CBSH, supported-apartment living, several people share an apartment and staff rotate among apartments (Oldfield, 2019). Since CBSH is small, institutional time does not predominate, with more time for relational care and routines that follow residents time (Oldfield, 2019). Although in Canada, the CBSH model has been applied on a small scale to serve people with dementia, it has been applied more widely in the United States (Green House model), Sweden, Germany, and Japan (SSAO, March 31, 2021). (For more about deinstitutionalization and CBSH's advantages over eldercare institutions, including lower cost and greater safety, see our full article.)

Multigenerational housing can enable seniors with dementia to not only remain in the community but close to their families. Existing family homes can be expanded into multigenerational dwellings in two ways. Homeowners can construct small houses in their backyards or replace garages. When grandparents no longer need the accessory dwellings, they can be rented out for income. Homeowners with smaller lots can construct in-law suites in their basements. Although increasingly common across Canada, retrofitting houses into multigenerational homes may face restrictive zoning bylaws and building regulations requiring separate electrical hookups to the power grid. However, many cities have loosened these restrictions (Benzie et al., 2020), enabling accessory dwellings and encouraging developers to construct large multigenerational houses to serve immigrant families in which senior parents customarily live with their adult children.

Cohousing is a type of communal living comprising single houses, apartments or townhouse clusters. Units can be owned privately or rented out by an organization. Occupants agree to support each other socially and instrumentally, may share operating and maintenance costs, and pool their resources through bulk purchasing. Another form of cohousing is where ageing people purchase a home together. They care for each other and, when they no longer can, jointly hire personal support workers. This form of cohousing can be managed by family or friends as owners age.

Nonprofit housing cooperatives are apartment buildings or townhouses collectively owned by all resident members. Member volunteers democratically run each cooperative, and large cooperatives often have paid staff. Rents remain affordable since they only increase with the cooperative's budget, which members must approve collectively. To facilitate aging in place, members can budget co-operative funds to retrofit units, apply for grants as nonprofit organizations, and neighbors may become unpaid care partners. Given cooperatives' collective

structure, services arranged by individual members (e.g., homecare) can be coordinated to improve service-delivery efficiency.

Pocket neighborhoods are small car-free neighborhoods comprising 6-12 dwellings clustered around an open area. Entrances face each other, fostering interaction among neighbors. The dwellings may include bedrooms for paid caregivers (Benzie et al., 2020). When people with dementia live in small neighborhoods well connected with community services, they are less likely to “fall between the cracks” when their needs surpass available services. For seniors whose dementia progresses slowly, is well managed, and/or who are frequently visited by unpaid care partners, pocket neighborhoods maintain meaningful community engagement and minimize isolation.

Conclusion

The institutional model of dementia care—locked wards in long-term-care institutions—is not only rife with problems but unanimously repudiated as a last resort and unimaginable end of life (Lévesque, 2022). Segregating disabled people, including those with dementia, in institutions is against the United Nations Convention on Rights of Persons with Disabilities, a treaty that Canada signed. Yet Canada’s dementia care remains clouded by systemic ageism and ableism, with institutions as the default option irrespective of senior Canadians’ overwhelming preference for ageing in place. Decades of deinstitutionalization enabled younger disabled people to live in the community with supports. Do seniors with dementia not deserve the same?

Given the strong evidence supporting community-based alternatives for dementia care presented above, we argue that politicians’ continued funding of institutions and reluctance to fund noninstitutional alternatives—which are cheaper and safer—is inexcusable.

You can advance change. Spread the word about the plethora of noninstitutional alternatives to your colleagues, family, and friends. Write your MP and your provincial politician and lobby them in person. Tell them to shift funding from institutional care to home care and community-based options. Look for guidance from Seniors for Social Action Ontario (www.seniorsactionontario.com) or a similar organization in your province or territory. Encourage your colleagues, family, and friends to lobby their local politicians, too. If you belong to a professional association, encourage members to add the paradigm shift to the organization’s advocacy agenda. As we have shown throughout this article, shifting the paradigm away from institutional care is possible.

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