



# Towards a Community-Based Dementia Care Strategy: How do We Get There from Here?

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## Abstract

As recent policy reports in Ontario and elsewhere have emphasized, most older persons would prefer to age at home. This desire does not diminish for the growing numbers of persons living with dementia (PLWD). Nevertheless, many PLWD end up in residential long-term care (LTC) or in hospital beds. While LTC is valuable for PLWD with highly progressed cognitive and functional impairment requiring high-intensity care, it can be a costly and avoidable option for those who could remain at home if given early access to a coordinated mix of community-based supports. In this lead paper, we begin by exploring the “state of the art” in community-based care for PLWD, highlighting the importance of early and ongoing intervention. We then offer a brief history of dementia care policy in Ontario as an illustrative case study of the challenges faced by policy makers in all jurisdictions as they aim to re-direct healthcare systems focused on “after-the-fact” curative care towards “before-the-fact” prevention and maintenance in the community. Drawing on results from a “balance of care” study, which we conducted in South West Ontario, we examine how, in the absence of viable community-based care options, PLWD can quickly “default” to institutional care. In the final section, we draw from national and international experience to identify the following three key strategic pillars to guide action towards a community-based dementia care strategy: engage PLWD to the extent possible in decisions around their own care; acknowledge and support informal caregivers in their pivotal roles supporting PLWD and consequently the formal care; and enable “ground-up” change through policies and funding mechanisms designed to ensure early intervention across a continuum of care with the aim of maintaining PLWD and their caregivers as independently as possible, for as long as possible, “closer to home.”

## Introduction

As recent policy reports at provincial and national levels have emphasized, most older Canadians would prefer to age in their own homes (Sinha 2012; Walker 2011; Van Hoof et al. 2013). This desire does not diminish for the growing numbers of older persons living with dementia (PLWD). Nevertheless, many PLWD still end up in residential long-term care (LTC) or in hospital alternative level of care (ALC) beds waiting for residential placement (CIHI 2010; Drummond 2012; Walker 2011). In part, this reflects the complex, chronic and progressive nature of dementia often leading to or associated with neurocognitive and physical decline. However, it also reflects the

fact that episodic acute-focused and bed-based healthcare systems are poorly equipped to support persons with chronic health and social needs, safely and appropriately, “closer to home.”

In this paper, we make the case that although the onset of dementia is often portrayed as a catastrophic event, leading almost inevitably to loss of independence and institutionalization, a majority of PLWD can continue to live relatively independently for most or all of their lives if diagnosed at an early stage and can be provided with coordinated access to needed home and community care (H&CC). Such care spans health services such as nursing and physical therapy provided by professionals, as well as

community supports such as homemaking, personal care and transportation provided by care workers and volunteers.

Moreover, improved access to “before-the-fact” community-based care can do much to support and sustain informal caregivers. The international evidence shows that it is family, friends and neighbors that do most of the heavy lifting in the community; they provide an estimated 70% to 90% of the everyday personal, instrumental and emotional care required by older persons to maintain their well-being and independence (Mittleman et al. 2006, 2004; Williams et al. 2016; Williams et al. 2015a). Not only are informal caregivers the main reason why many older persons can continue to age at home, without informal caregivers, formal care systems would not be sustainable (Donner 2015; Sinha 2012).

We are not the first to make this case.

Over the past decade, there have been numerous calls locally, nationally and internationally to meet the needs of older persons, including growing numbers of PLWD and their informal caregivers, closer to home (WHO and ADI, 2012; ASC, 2010). Nevertheless, policy has lagged. As news headlines in national media have recently reminded us, Canada remains one of only two G7 countries – the other being Germany – that have no national dementia care strategy (OMNI Health Care 2015).

In the first section of this paper, we begin by briefly reviewing what we know about dementia and approaches to caring for PLWD and their informal caregivers in community settings.

In the second section, we offer a brief history of dementia care policy in Ontario as an illustrative case study of the challenges faced by policy makers in all jurisdictions as they aim to re-direct healthcare systems focused on “after-the-fact” curative care towards “before-the-fact” prevention and maintenance in the community. Drawing on results from a “balance of care” study, which we conducted in South West Ontario, we

examine how, in the absence of viable community-based care options, PLWD can quickly “default” to institutional care.

In the final section, we consider the way forward. While transformational or “big bang” change seems unlikely, we think that progressive improvements in dementia care still offer value, particularly if enabled and channeled by a guiding strategy. Ontario, like other jurisdictions across Canada and beyond, is now actively considering the essential elements of such a strategy. To that end, we draw from national and international experience to identify three key strategic pillars to guide action: first, engage PLWD early and to the extent possible as active participants in their own care; second, acknowledge and support informal caregivers who play a pivotal role in supporting persons who cannot manage on their own and sustaining formal healthcare systems; and third, enable “ground-up” change through policies and funding mechanisms designed to ensure early intervention across a continuum of care with the aim of maintaining PLWD and their caregivers as independently as possible, for as long as possible, “closer to home.”

### **Part 1: What We Know About Dementia and Dementia Care**

There is a vast and growing literature about dementia and the needs of those affected by it. Contrary to popular belief, dementia is not a normal part of aging; only a minority of older Canadians, estimated at about 15% of those over the age of 65 years, will experience its effects (ASC 2016a). In fact, dementia rates across the developed countries seem to be trending downward, particularly among women and those with higher levels of education (Alzheimer’s Association 2014). Nevertheless, because age is a principal risk factor for dementia, an aging population augurs continued growth in numbers of PLWD (Chertkow 2008; Volicer 2001). Improvements in diagnosis,

medical care and symptom management are contributing to PLWD living longer post-diagnosis and requiring care over more extended periods of time – on average approximately 8.5 years (Keene et al. 2001).

Dementia is complex. It encompasses a broad class of neurocognitive disorders associated with cognitive and physical decline (American Psychiatric Association DSM-V 2013). Dementia is associated with more years of disability than many other chronic illnesses (ASC 2010; WHO and ADI 2012), and it accounts for a higher burden of illness overall (Alzheimer Society of Ontario 2007). Issues with perception, judgement and memory loss can inhibit PLWD's ability to manage routine tasks and personal care on a daily basis, to interpret their environment, to recognize when help is needed and to access formal health and social care in a timely fashion. When neurocognitive changes are combined with age-related declines in vision, hearing and mobility, and/or the lack of an informal caregiver, dementia becomes a “game changer.”

Moreover, because dementia often advances subtly and is concurrent with other chronic conditions, family members and healthcare providers alike can have trouble recognizing early warning signs and symptoms. Missed or delayed diagnosis and poor care management can result in poor quality care, with PLWD often interacting with the healthcare system (e.g., in the emergency room of a hospital) only at a point of crisis in their own health or that of their caregiver (Aminzadeh et al. 2012; Lee et al. 2014, 2010; McAiney et al. 2008; Weber et al. 2011; Woods et al. 2003).

The impact on informal caregivers can be severe (Williams et al. 2015a; MAS 2008; Mittleman et al. 2006, 2004). Although there are many positive aspects related to informal caregiving of PLWD (e.g., reciprocity of care, personal satisfaction), the experience can be difficult, leading to physical, emotional and financial strain and to caregiver fatigue, ill

health and burnout (Fast 2015; Smale and Dupuis 2004a, 2004b, 2004c, 2004d). The literature shows that particularly when intensive and sustained, caregiving can limit social engagement while increasing the risks of physical and mental health problems including stress and depression (Keefe 2011; MAS 2008). Caregivers of PLWD can also experience considerable economic costs related to employment restrictions, out-of-pocket expenses and time spent in caregiving activities (Fast 2015; Keating and Fast 2015).

System costs are also high. Dementia has been identified as “a significant economic burden on the Canadian healthcare system” (MAS 2008: p. 23). Compared with older adults without dementia, PLWD are two to five times more likely to use a range of services, including home care, hospital emergency departments (EDs), in-patient hospital beds, hospital ALC beds and LTC, and they experience more negative clinical outcomes (Aminzadeh et al. 2012; Weber et al. 2011). When in the hospital, PLWD can require ongoing and high-intensity care owing to confusion, anxiety, agitation and delirium (Phelan et al. 2012; Weber et al. 2011). PLWD typically stay longer in the hospital than their peers (Cahill et al. 2012; Timmons et al. 2015), and they are more commonly discharged to residential LTC (Morrison and Siu 2000 in Timmons et al. 2015).

Nevertheless, international evidence and local experience point to a range of community-based supports that can help PLWD and informal caregivers maintain their well-being and independence while minimizing use of costly bed-based care. These include clinical and non-clinical services such as memory clinics, interdisciplinary primary care team approaches, respite care, homemaking, meal programs, early and ongoing case management and care navigation; fulsome dementia curricula, including training and bridging programs for

providers; knowledge exchange platforms, which highlight and communicate the “state of the art”; community support services such as supportive housing, adult day programs and MedicAlert® Safely Home®; and home adaptations such as accessibility and orientation aids, monitoring technology and adequate lighting (Morton-Chang 2015).

In this connection, early diagnosis, intervention and ongoing support are consistently identified as best practices in dementia care, with primary care being the accessible “first contact” to set this process in motion (Aminzadeh et al., 2012; Alzheimer’s Disease International 2011; ASC 2015b; Iliffe et al.

2002; McAiney et al. 2008; Ministry of Health 2012; Prince et al. 2011; Vernooij-Dassen et al. 2005; Woods et al. 2003). Team-based comprehensive interdisciplinary primary care organizations such as Family Medicine Groups in Quebec and Family Health Teams in Ontario and Alberta appear particularly well positioned to provide early and ongoing care and individualized care plans, which adapt to the changing needs of PLWD and caregivers (Bergman and Vedel 2015; Grant 2015).

A complementary community program that collaborates with primary care to connect PLWD and caregivers to a range of community-based services and supports at the point of diagnosis is the Alzheimer Society’s First Link® program. First Link® has been evaluated in Ontario and Saskatchewan as being a successful intervention to enhance health professionals’ understanding of managing dementia and link more people to information and support sooner than without the program (McAiney et al. 2014).

While proactive community-based care is highly important to help maintain the independence of frail and vulnerable older adults, it is not always easily accessible, with access varying considerably within and

across jurisdictions and becoming particularly problematic outside of urban centres (Kuluski et al. 2012a, 2012b; Morton-Chang 2015; Morton 2010).

In Ontario, for example, different community-based programs and providers have different entry points, eligibility requirements, service offerings and user fees (MortonChang 2015; Morton 2010; Peckham 2016). Moreover, while many providers collaborate effectively to coordinate care for older persons with multiple chronic needs and caregivers, there are few formal mechanisms beyond information and referral, to accomplish this, or to follow an individual’s progress as they move between different community-based care providers, or between community, hospitals and LTC (Peckham 2016; Kuluski 2012; Peckham 2014a; Williams et al. 2009a, 2009b; 2016; 2014a, 2014b). Other challenges can include a general lack of awareness among providers and caregivers of dementia-specific services; limited access to key services like respite care that may not be available on evenings and overnight; and lack of ethnically/culturally/linguistically appropriate care (Caplan 2005; Denton et al. 2006; Morton 2010).

Such supply-side challenges can help explain why many PLWD and informal caregivers do not access needed care until they are at the point of crisis (McAiney et al. 2008; MAS 2008; Tootab et al. 2013; Pratt et al. 2006; Smale and Dupuis 2004a, 2004b, 2004c, 2004d). In addition to impacting negatively on the well-being of PLWD themselves, delayed access can limit opportunities for informal caregivers to develop proactive coping strategies, and the ability of formal providers to help them to do so, increasing the likelihood of physical and mental health problems, lost income, isolation, stress and burnout (Fast 2015; Peckham 2016, 2014b; Warrick et al. 2014; Williams et al. 2015a).

## Part 2: Where We Are Now

In addition to impacting negatively on the well-being of PLWD and caregivers, challenges in accessing appropriate community-based care can also increase the likelihood of “default” to costly hospital and institutional bed-based care, placing additional pressures on already-stretched healthcare systems. Ontario provides an illustrative case study of these dynamics.

In 2011, Walker analyzed the roots of Ontario’s persistent hospital ALC bed problem; ALC beds are those occupied by individuals, including significant numbers of PLWD, who no longer require costly hospital care but cannot be discharged because of a lack of community-based discharge options. Rather than concluding that hospitalization and referral to LTC are normal and unavoidable consequences of needs, he concluded that older persons, most of whom wish to age at home, too often “default” to hospital EDs and then to in-patient hospital beds because of a lack of proactive community-based care. Moreover, because acute care hospitals are not designed to meet “restorative, supportive and rehabilitation needs” and have been shown to advance functional deterioration and pose risks of “hospital-related infections, falls and other adverse events,” hospitalization can itself increase the likelihood of permanent placement in LTC, “an outcome which could have been avoided” (Walker 2011).

Sinha’s 2012 review of care for older persons, while not focused specifically on dementia, similarly emphasized the need for an integrated seniors’ strategy aimed at building an integrated community-based continuum of care. Because the needs of an aging population are increasingly complex and chronic, this strategy would begin by promoting health and wellness and strengthening access to primary care and community supports. When community care would no longer suffice, it would encourage the evolution of “senior-friendly” hospitals with

timely discharge to home and community, and improve capacity within residential LTC to support short-stay and restorative options, as well as discharge back to the community. Informal caregivers would also be recognized and supported (Sinha 2012).

Donner’s more recent provincially commissioned expert panel highlights the costs and consequences of current fragmented and under-resourced community care systems (Donner 2015). While acknowledging that there are many individual examples of excellent H&CC programs and services in Ontario, she concluded that a general lack of proactive community-based care not only fails “to meet the needs of clients and families” but also misses opportunities to “reduce the use of less appropriate and more expensive healthcare services such as emergency rooms, hospitals and long-term care homes” (Donner 2015: 1). This report again highlights the crucial role of informal caregivers who provide the bulk of the everyday support required by communitydwelling older persons, and who should be included in an expanded “unit of care.”

Of course, such observations are not limited to Ontario. They apply, in varying degrees, to jurisdictions across the industrialized world as they struggle to meet the rise of increasingly complex chronic health and social needs, including dementia, associated with aging populations. For example, the INTERLINKS project, funded by the European Commission and conducted across 13 European Union countries (Austria, Denmark, Finland, France, Germany, Greece, Italy, The Netherlands, Slovakia, Spain, Sweden, UK and Switzerland), clarifies that all countries are now engaged in efforts to span two deeply embedded divides: the first between health-care and social care and the second between formal and informal care (INTERLINKS 2013). Even relatively modest projects to establish interdisciplinary care teams, almost universally considered to be a best practice in



the care of persons with multiple health and social needs including dementia, can confront layers of professional legislation, regulations and funding mechanisms that establish strict hierarchies and limit collaboration, even among regulated healthcare providers (Billings 2013).

The importance of system-level strategies to meet these challenges is by now well recognized internationally (Butler 2016). As noted, most G7 countries – with the exceptions of Canada and Germany – now have a national dementia care strategy.

However, such strategies may be more or less comprehensive, and they can be difficult to achieve and sustain politically, particularly in the face of competing demands from dominant bed-based systems of care. This has clearly been the case in Ontario (MortonChang 2015; Williams et al. 2016).

More than two decades ago, it was already well recognized in Ontario that an aging population and the associated rise of dementia and other chronic needs, if left unaddressed, could result in inappropriate care for individuals and potentially unsustainable pressures on healthcare systems. In 1996, Ontario initiated a broad-based consultation with diverse consumers and providers (MOHLTC 1999) to consider how best to meet the needs of growing numbers of PLWD. In 1999, it introduced a four-year, \$68.4 million Strategy for Alzheimer Disease and Related Dementias, a wide-ranging plan, which proposed a series of initiatives spanning community and institutional settings. These included education for healthcare providers, caregivers and the public (e.g., staff training, physician training, increased public awareness); service enhancements and expansion (e.g., planning for appropriate, safe and secure environments, respite services for caregivers, psychogeriatric consulting resources and intergenerational volunteer initiatives); and research activities and knowledge exchange (e.g., research on

caregiver needs, and the creation of research coalitions) (McAiney 2005).

While other provinces and territories had also begun developing dementia care policies, Ontario's Alzheimer's Strategy was identified by the National Advisory Council on Aging (NACA) as a benchmark for future policy development (NACA 2004). Nevertheless, Ontario's strategy soon came up against new political realities as the Progressive Conservative Government of the day announced that its main response to an aging population would be to build or retrofit 20,000 LTC beds. Although there was little evidence that this number of beds was justified (Coyte et al. 2002; MOHLTC, 2002) and expert advice had argued instead for the creation of new community-based care "spaces" (including home care, supportive housing and day programs), once built, the new beds needed to be filled (Morton-Chang 2015). In 2001, the government capped provincial home care budgets (thus limiting the availability of community care options) and introduced regulations "to ensure existing beds in LTC homes are fully utilized" (Williams et al. 2016).

The succeeding Liberal Government took power in 2003 as the provincial dementia care strategy was winding down. Rather than renewing the strategy, the government provided limited funding for a transition period running to March 2007 during which various "legacy projects," including a virtual repository of knowledge and information gained through the strategy (the Alzheimer Knowledge Exchange) hosted at the Alzheimer Society of Ontario (ASO 2004), were expected to seek alternative funding sources.

In part, a lack of enthusiasm for a dementia-specific strategy reflected legitimate concerns that "disease-specific" policies had the potential to exacerbate the fragmentation of an already "siloed" healthcare system, pitting one disease group against another.<sup>1</sup> However, as it turned out, such concerns took

a back seat to the more intractable politics of community-based versus bed-based care.

In 2007, the Liberal Government introduced a four-year, \$1.1-billion Aging at Home Strategy (AAH) which promised to expand community living options for all older persons (including PLWD) to enable them “to continue leading healthy and independent lives in their own homes.” Included were nonprofessional community-based supports for activities of daily living, such as meal preparation, transportation, shopping, friendly visiting, snow shoveling, adult day programs and caregiver relief and respite (MOHLTC 2010). However innovative and promising, this strategy was soon overtaken by the needs of acute care hospitals that were finding it increasingly difficult to cope with rising numbers of ALC patients, including significant numbers of PLWD, who no longer required hospital care but had no viable community discharge options. Although, as observed by Walker (2011), ALC beds may be seen to result from a lack of before-the-fact community-based care, policy makers were persuaded that after-the-fact solutions to improve hospital “flow through” were preferable (Boyle and Welsh 2011). In 2009–2010, less than a year after the Strategy’s rollout, the province redirected 50% of AAH monies to the discharge of ALC patients; in 2010–2011, 25% of the AAH money was held back by the ministry for its own provincial-level ALC initiatives, with the remaining 75% to be used to address ALC problems at the regional level (Government of Ontario 2010).

This preoccupation with beds also impacted Ontario’s next, albeit more limited, foray into dementia-specific policy. In 2010, the provincial government initiated its Behavioural Supports Ontario (BSO) program to enhance services for older persons with responsive behaviors (e.g., agitation, wandering, physical resistance and aggression) associated with complex and challenging mental health, dementia or other

neurological conditions living in LTC homes or in independent living settings (ASO 2010). Although originally intended to build capacity across the entire continuum (e.g., prevention and early detection for those with cognitive impairments, those at risk of the same, and their caregivers, those in need of community multiple agency support, high-risk individuals in need of LTC specialty services) (Dudgeon and Reed 2010), the implementation of this project mainly focused on people already in LTC beds with relatively limited community focus (Morton-Chang 2015).

We observed the costs and consequences of these policy choices in a “balance of care” (BoC) research project conducted in South West Ontario in 2009 (Morton-Chang 2015). This project, one of a series conducted by our team between 2005 and 2015 in 12 of Ontario’s 14 healthcare regions, brought together an “expert panel” of experienced front-line care managers and decision-makers from across the care continuum (including home care, community supports, hospitals and LTC) to construct ideal community-based care packages required to “divert” LTC waitlisted home care clients at different levels of assessed need back to community settings.

BoC projects conducted in other parts of the Province had estimated divert rates ranging from 10% to 50%, meaning that, in the view of experienced local experts, up to half of individuals waiting for residential LTC could potentially be supported in community “places” rather than in institutional beds (Williams et al. 2016). Higher-range estimates were typically associated with more integrated and cost-effective delivery models such as supportive housing, where needed services could be coordinated around older persons living in the same building.

For example, BoC projects conducted in the North East and North West Local Health Integration Networks (LHINs) concluded



that if scaled up and spread, supported housing models already present in those regions could potentially redirect up to two-thirds of individuals waiting for LTC back to the community (Williams et al. 2010).

In South West Ontario, however, the BoC expert panel estimated a zero divert rate for wait-listed PLWD. Panelists concluded that although, in principle, PLWD and their caregivers could and often were supported in the community to advanced levels of need, there was not, at that time, sufficient community-based capacity to guarantee it on more than an exceptional basis. Panelists noted, for example, that while supportive housing had great potential owing to the flexible, integrated, case-managed care it could provide, most available supportive housing places had not been designed or staffed to meet the needs of persons experiencing cognitive challenges (Morton-Chang 2015). Moreover, even when supportive housing providers could accept PLWD, they could not normally accept them later in the disease progression when more difficult, resource-intensive transitions were required. By contrast, earlier transitions to housing were seen as more manageable, as they would allow PLWD and caregivers to become familiar with staff and setting, while allowing staff to learn about client preferences, establish routines and develop proactive care strategies which balanced client safety and care needs with available resources (Morton-Chang 2015).

The South West project also provided insight into what could be done to support PLWD and caregivers in their own homes. While it is commonly assumed that cognition and difficulties with activities of daily living (ADLs) such as bathing and dressing are key drivers of loss of independence, the home care assessment data revealed – and the expert panelists confirmed – that difficulties with instrumental activities of daily living (IADLs) were just as often the trigger for LTC

placement; this corroborated the findings from previous and subsequent BoC projects across the Province (Kuluski, 2012a, 2012b; Williams et al. 2016, 2010, 2009a). Panelists pointed to the critical importance of everyday community supports for IADLs including transportation (e.g., to access medical appointments, attend Alzheimer day programs, maintain social connections); medication and nutrition monitoring (e.g., including reminders and help with grocery shopping and meal preparation); housekeeping (e.g., especially for those with mobility issues or risk of falls); and respite (e.g., to allow caregivers a break). While not health-care per se, a failure to access these “low-level” community-based supports in a timely manner could lead to “default” to hospital and LTC beds (Kuluski 2012a, 2012b; Morton-Chang 2015; Williams et al. 2010; 2009a).

Expert panelists also emphasized that H&CC packages had to acknowledge and support a broader “unit of care” including PLWD and caregivers. Without such essential caregiver contributions as 24/7 monitoring and coordination of multiple providers in the home, H&CC would not be safe or economically viable.

### **Part 3: Where We Go From Here**

Political theory suggests that “big bang” policy change is unlikely, and that policy development usually occurs in small steps. And, in fact, Canadian policy makers are responding to population aging and the rise of dementia, albeit slowly and often in a piecemeal fashion, relying as much on the relatively weak policy tools of information and persuasion as on the more robust tools of legislation and funding.

At this point, the chances for a unified national dementia strategy in Canada seem modest. In October 2014, the former Conservative Minister of Health, Rona Ambrose, hosted a meeting of provincial and territorial health ministers where a national

plan to help reduce the personal, societal and economic impact of dementia was discussed, although with few concrete commitments (Canadian News Wire 2014). In February 2016, following the election of a Liberal majority government, a private member's Bill promoting a national dementia strategy (C-233: An Act respecting a national strategy for Alzheimer's disease and other dementias) was introduced by an opposition Member of Parliament (MP) with support from a government MP; however, such bills are largely symbolic.

Nevertheless, the Senate Standing Committee on Social Affairs, Science and Technology has now undertaken a study on the issue of dementia in Canadian society; it is currently hearing from witnesses as to what the federal role should be. Witnesses at the hearings, comprising both individuals and organizations, have provided detailed accounts on the societal effects of dementia, with many advocating for the development of a Canadian Alzheimer's Disease and Dementia Partnership (CADDP) (ASC 2015a; Parliament of Canada 2016). The proposed CADDP would bring together dementia experts, governments, researchers, healthcare providers, industry and consumer groups, as well as PLWD and their families to inform, coordinate and facilitate the development and implementation of an integrated, comprehensive national dementia strategy (ASC 2015a).<sup>2</sup>

As well, there are other actions, short of a full-scale national strategy, that the federal government could take. For example, the federal government could use its spending power, possibly through a renewed health accord, to encourage provincial/territorial action in the area of dementia care. It might also use targeted funding to spur the emergence of panCanadian organizations (such as the former Health Council of Canada) to conduct research, disseminate information

and build consensus around best practices and standards of care (ASTP 2006; Parliament of Canada 2016).

In addition, the federal government has scope to act in areas outside of healthcare. For example, it might consider extending its current enthusiasm for infrastructure renewal by reinvigorating its historical role in social housing, a key area of need for PLWD and others with chronic needs. Examples of dementia-friendly housing models have been elaborated by the Canada Mortgage and Housing Corporation (CMHC) in their recent series "Housing Options for Persons Living with Dementia" (CMHC 2015a, 2015b, 2015c).

Of course, even in the absence of federal action, Canadian provinces and territories are fully capable of developing their own dementia care strategies. As shown in Table 1, a number of Canadian provinces already have, or are in the process of doing so, although these vary considerably. While Table 1 does not provide an exhaustive review – much of the information is derived from a special session of the 2015 Canadian Association of Gerontology (CAG) Conference in which not all provinces/territories were represented – it does offer an instructive snapshot of recurrent themes (CAG 2015).

A first key theme relates to enhanced awareness, information, education and research. In addition to initiatives aimed at connecting older persons, caregivers and providers to existing knowledge, all aim to generate new knowledge, leading hopefully to improved prevention and care.

A second theme speaks to the need to improve and coordinate "person-centred" care. As presented in these provincial initiatives, such care should follow PLWD through the dementia journey, beginning with prevention, early intervention, primary care and home care; moving to acute care

and crisis management; and finally to end-of-life care that respects people's wishes, dignity and comfort.

A third, albeit less consistent, theme concerns family and informal caregivers. In addition to acknowledging caregivers as essential partners in care planning and delivery, caregivers are increasingly seen to merit support in their own right. If not revolutionary, this increasingly common perspective in provincial initiatives and in the international literature highlights an evolution from conventional models of

provider-centred care (where providers determine what patients receive); to “client- or patient-centred” care (where the focus now shifts to what's best from the perspective of the care recipient); to an expanded “unit of care” (including both the care recipient and informal caregiver); and to the creation of supportive neighborhoods and communities (Peckham 2016, 2014a).

Internationally, three countries, England, Japan and Germany, have emerged as frontrunners in promoting such broader visions of dementia care.

**Table 1. Dementia strategy responses for six provinces**

Province	Initiative	Key foci/priority areas
British Columbia (Zaharia 2015)	2007 Dementia Framework < <a href="http://www.alzheimer.ca/bc/-/media/Files/bc/Advocacy-and-education/Other-files/2007-09-01%20BC%20Dementia%20Service%20Framework.pdf">www.alzheimer.ca/bc/-/media/Files/bc/Advocacy-and-education/Other-files/2007-09-01%20BC%20Dementia%20Service%20Framework.pdf</a> >	<ol style="list-style-type: none"> <li>1. Collaborative work among stakeholders</li> <li>2. System gaps in dementia care identified</li> </ol>
	2012 Provincial Dementia Action Plan < <a href="http://www.health.gov.bc.ca/library/publications/year/2012/dementia-actionplan.pdf">www.health.gov.bc.ca/library/publications/year/2012/dementia-actionplan.pdf</a> >	<ol style="list-style-type: none"> <li>1. Support prevention and early intervention</li> <li>2. Ensure quality person-centred dementia care</li> <li>3. Strengthen system capacity and accountability</li> </ol>
	2015 Three-Year Dementia Action Plan (not available online)	<ol style="list-style-type: none"> <li>1. Wandering</li> <li>2. Increase public awareness</li> <li>3. Dementia training across the system</li> <li>4. Commitment to patient and healthcare worker safety</li> </ol>
	2016 Provincial Guide to Dementia Care in British Columbia: Achievements and Next Steps < <a href="http://www.health.gov.bc.ca/library/publications/year/2016/bc-dementiacare-guide.pdf">http://www.health.gov.bc.ca/library/publications/year/2016/bc-dementiacare-guide.pdf</a> >	<ol style="list-style-type: none"> <li>1. Public awareness and early recognition</li> <li>2. Improve community supports for persons with dementia and informal caregivers</li> <li>3. Improve quality of residential dementia care</li> </ol>
Alberta (Schalm 2015)	2002 Alzheimer Disease and other Dementias: Strategic Directions in Healthy Aging and Continuing Care in Alberta < <a href="http://www.health.alberta.ca/documents/Strategic-Alzheimer-Report-2002.pdf">www.health.alberta.ca/documents/Strategic-Alzheimer-Report-2002.pdf</a> >	<ol style="list-style-type: none"> <li>1. Public awareness</li> <li>2. Education and training</li> <li>3. Support for informal caregivers</li> <li>4. Service delivery across the continuum of care</li> <li>5. Supportive environments and</li> <li>6. Ethical issues</li> </ol>
	2015 Alberta Dementia Strategy and Action Plan < <a href="http://www.ascha.com/PDF_files/rollout/2015/InfoHandoutDRAFTADSAP18Mar2015.pdf">www.ascha.com/PDF_files/rollout/2015/InfoHandoutDRAFTADSAP18Mar2015.pdf</a> >	<ol style="list-style-type: none"> <li>1. Acute care and crisis management</li> <li>2. Caregiver support</li> <li>3. Dementia journey</li> <li>4. Primary care</li> <li>5. Public awareness</li> <li>6. Research and innovation</li> </ol>
Manitoba (Weihs 2015)	2002 Strategy for Alzheimer Disease and Related Dementias in Manitoba < <a href="http://www.alzheimer.mb.ca/election/Strategy%20Backgrounder.pdf">www.alzheimer.mb.ca/election/Strategy%20Backgrounder.pdf</a> >	<ol style="list-style-type: none"> <li>1. Education</li> <li>2. Guidelines for diagnosis and treatment</li> <li>3. Standards across all programs and services</li> <li>4. Family and individual support</li> <li>5. Programs and services changes</li> <li>6. Case management and collaboration</li> <li>7. Equitable access to diagnostic and support services</li> <li>8. Human and financial concerns</li> <li>9. Research and evaluation</li> </ol>

Province	Initiative	Key foci/priority areas
Manitoba (Weihls 2015) (continued)	2014 Manitoba's Framework for Alzheimer's Disease & Other Dementias < <a href="http://www.gov.mb.ca/health/alzframework.html">www.gov.mb.ca/health/alzframework.html</a> >.	<ol style="list-style-type: none"> <li>1. Developing a health workforce strategy</li> <li>2. Reviewing and enhancing dementia and cognitive impairment</li> <li>3. Education in health provider education programs</li> <li>4. Promoting family/caregiver involvement in care</li> <li>5. Enhancing ongoing delivery of dementia education for staff</li> <li>6. Reviewing personal care home standards related to dementia education</li> <li>7. Developing a coordinated approach to dementia research.</li> </ol>
Ontario (Morton-Chang 2015; ASO 2016)	1999–2004 Ontario's Strategy for Alzheimer Disease and Related Dementias < <a href="http://brainxchange.ca/Public/Resource-Centre-Topics-A-to-Z/Ontario%E2%80%99s-Strategy-for-Alzheimer-Disease-and-Relat.aspx">http://brainxchange.ca/Public/Resource-Centre-Topics-A-to-Z/Ontario%E2%80%99s-Strategy-for-Alzheimer-Disease-and-Relat.aspx</a> >	<ol style="list-style-type: none"> <li>1. Staff education and training</li> <li>2. Physician training (Mentor Programs)</li> <li>3. Increasing public awareness, information and education</li> <li>4. Planning for appropriate, safe and secure environments</li> <li>5. Respite services for caregivers</li> <li>6. Research on caregiver needs</li> <li>7. Advance directives on care choices (Education)</li> <li>8. Psychogeriatric consulting resources</li> <li>9. Coordinated specialized diagnosis and support</li> <li>10. Intergenerational volunteer Initiative</li> </ol>
	2004 Three-year Alzheimer Strategy Transition Project (not available online)	<ol style="list-style-type: none"> <li>1. Web-based repository and sharing platform (Alzheimer Knowledge Exchange)</li> <li>2. Regional dementia networks</li> <li>3. Roundtable on future planning for people with Alzheimer's Disease and related dementia</li> <li>4. Provincial Alzheimer Group (was convened and has since concluded)</li> </ol>
	2010 Older Adults Behavioural Support System < <a href="http://brainxchange.ca/Public/Files/BSO/Older-Adults-Behavioural-SupportSystem.aspx">http://brainxchange.ca/Public/Files/BSO/Older-Adults-Behavioural-SupportSystem.aspx</a> >	Building on investments from the 1999 strategy, this initiative provides support for older Ontarians whose cognitive impairment is accompanied by responsive behaviours living at home, in acute care facilities or in long-term care homes
	2016 Developing Ontario's Dementia Strategy: A Discussion Paper < <a href="https://www.ontario.ca/page/developing-ontarios-dementia-strategydiscussion-paper">https://www.ontario.ca/page/developing-ontarios-dementia-strategydiscussion-paper</a> >	The Ontario Government has committed to developing another provincial dementia strategy with expected implementation in 2017
Québec (Bergman and Vedel 2015)	2009 "Meeting the Challenges of Alzheimer's Disease and Related Disorders" < <a href="http://www.alzheimer.ca/en/montreal/About-us/~media/D6DF412C089F4C1995014784D532BAD7.ashx">www.alzheimer.ca/en/montreal/About-us/~media/D6DF412C089F4C1995014784D532BAD7.ashx</a> >	<ol style="list-style-type: none"> <li>1. Raise awareness, inform and mobilize</li> <li>2. Provide access to personalized, coordinated assessment and treatment services for PLWD and their informal caregivers</li> <li>3. Promote quality of life and provide access to home-support services and a choice of high quality alternative living facilities</li> <li>4. Promote high-quality, therapeutically appropriate end-of-life care that respects people's wishes, dignity and comfort</li> <li>5. Treat family/informal caregivers as partners who need support</li> <li>6. Develop and support training programs</li> <li>7. Mobilize an unprecedented research effort</li> </ol> <p>Note: Quebec's Primary Care Report established family medicine groups which are seen as the cornerstone of the Alzheimer strategy</p>
Nova Scotia (Knowles 2015)	2015 "Towards Understanding: A Dementia Strategy for Nova Scotia" < <a href="http://novascotia.ca/dhw/dementia/Dementia-Report-2015.pdf">http://novascotia.ca/dhw/dementia/Dementia-Report-2015.pdf</a> > 2015–2018 "Dementia Strategy Action Plan" < <a href="http://novascotia.ca/dhw/dementia/Dementia-ActionPlan-2015.pdf">http://novascotia.ca/dhw/dementia/Dementia-ActionPlan-2015.pdf</a> >	<ol style="list-style-type: none"> <li>1. Facilitate early diagnosis, treatment, care and support</li> <li>2. Enhance health system capacity to provide coordinated care and support that is person-centred and culturally specific</li> <li>3. Enhance awareness and understanding about dementia</li> </ol>

Note: This high-level table has been shaped based on presentation slides at the Canadian Association on Gerontology Supporting Canadians Living with Dementia Symposium 23 October 2015 for five provincial dementia strategies: British Columbia, Alberta, Manitoba, Québec and Nova Scotia. No presentation was made for Ontario at this symposium; however, material for this province has been added by the authors in addition to links for all referenced documents where possible.

England's 2009 dementia care plan, titled *Living Well With Dementia: a national dementia strategy*, captured the attention of former Prime Minister David Cameron, who is said to have had a personal connection to a PLWD. It established a strategic framework for improvements to local services to address health inequalities related to dementia; provide advice, guidance and support for the planning, development and monitoring of services; and provide a guide to the content of high-quality dementia care services (Department of Health 2009). In 2012, the Prime Minister issued a national challenge on dementia care, committing his government to deliver major improvements in dementia care and research by 2015. Three champion groups were set up to drive improvements in health and care; improve dementia research; and create dementia-friendly communities. England's national Dementia Friendly Campaign, backed by over £1.8 billion in 2012–2013, has spurred the emergence of such community-focused actions as the UK Dementia Friendly Initiative, which encourages ordinary people to learn more about dementia and finds ways of supporting PLWD (Alzheimer Society United Kingdom (ASUK) 2016b).

Japan's 2015 New Orange Plan for dementia care, championed by Prime Minister Shinzo Abe himself, identifies seven pillars or principles to guide the creation of dementia-friendly communities, support family caregivers, encourage cooperation and remove institutional barriers within government and between providers, incent intergenerational projects and give people with dementia a greater voice. This plan has stimulated an array of grass-roots innovations, such as dementia training for front-line bank tellers, grocery clerks and garbage collectors who interact with PLWD and their caregivers on a daily basis. It has also spurred the emergence of dementia open houses in private homes where PLWD, informal caregivers and care workers can congregate,

share meals and experiences, socialize, provide mutual support and learn about dementia and best practices; open house hosts have access to professional training and a 24/7 hotline (Hayashi 2015a; Whitehouse 2015). The establishment of professional-free zones where medical care is not provided likewise validates and mobilizes informal social networks, including healthy older persons who can help their peers as well as school children who learn to assist older persons who appear to be lost or in need of assistance (Canadian Research Network for Care in the Community (CRNCC) 2015; Williams et al. 2016).

Germany, as we noted, does not currently have a national dementia care strategy. Nevertheless, it does have a growing country-wide, community-based infrastructure to support PLWD and their caregivers, supported and funded by the national government. By the end of 2016, Germany aims to have in place over 500 "local alliances for persons with dementia" (lokale allianzen für menschen mit demenz), involving municipalities, healthcare and social care authorities, citizens, businesses and educational institutions aimed at developing comprehensive community-based approaches for improving the lives of people with dementia and their families permanently. This approach affirms that local solutions are the way to go, as the municipality is the place where PLWD normally live and where neighbours, decisionmakers employers and other actors in the civil society, can take direct action to influence the design of living conditions (Federal Ministry of Family Affairs 2016; Federal Ministry for Family Affairs, Senior Citizens, Family and Youth 2014).

We believe that these international examples, combined with experiences in Ontario and across Canada, point not only to the importance of developing a robust dementia care policy framework (whether starting from the local level and building up

or vice versa), but also to key principles or pillars to guide the development of such a framework. Here, we are less concerned about resolving jurisdictional issues, as it is clear that all levels of the government need to be involved, but are more concerned about how to improve the lives of PLWD and their caregivers, and, in the process, sustain increasingly stretched healthcare systems. Although focused on dementia care, we suggest that these same principles can improve care for a growing number of persons of every age who face the daily challenges of multiple, ongoing health and social needs.

### **Pillar One: Put People First**

This most important and basic principle is embedded in virtually all dementia care initiatives across Canada and internationally. It affirms both the dignity and worth of PLWD, and also, to echo the motto of the UK dementia strategy, the goal of “living well,” as dementia, at least for the foreseeable future, is not open to cure. Nevertheless, PLWD, and those around them, can and should be able to look forward to fulfilling lives.

As a series of expert reports and commissions in Canada have emphasized, for the majority of older Canadians, including PLWD, living well means living as independently as possible, for as long as possible “closer to home.” In turn, this requires Canadian policy makers, while considering genuine issues of risk and safety, to avoid overprotective responses and to reject the notion that the onset of dementia leads almost inevitably to residential care beds. Instead, they, like their counterparts in countries including Japan, England and Germany, should now aim to find ways to strengthen the physical, social and emotional environments where people normally live.

Nor is this merely a matter of preference; it constitutes good care. A growing body of evidence suggests that aging in familiar

surroundings and routines can enhance the PLWD’s ability to rely on their procedural (unconscious) and emotional memory systems and help compensate for progressive losses. Particularly for PLWD, living in familiar settings may also provide a large measure of comfort and a sense of security and belonging (CMHC, 2015a, 2015b), enhancing quality of life.

Of course, it needs to be recognized that this idea of “person-centred” care goes further than simply providing better care to PLWD as passive care recipients. It also implies that PLWD, to the extent possible, should be active participants in decisions around their own care. At a personal level, even when PLWD progress to a point where they cannot manage routine tasks independently (e.g., finances, cooking, travelling, self-care) most can still express preferences around where and how they live and how care is provided. At the policy level, the Ontario Dementia Advisory Group (ODAG) – a group of PLWD in Ontario, which was formed in 2014 with the purpose of influencing policies, practices and people to ensure that people living with dementia are included in every decision that affects their lives – shows that ways can be found to facilitate meaningful and continuing engagement by PLWD and caregivers in the design of dementia care strategies (ODAG 2016).

Moreover, particularly during dementia’s early stages, PLWD may also wish to continue to help others. As experience in countries such as Japan shows, more capable older persons can assist those less capable as volunteers and peer supporters. Not only does this help to keep people more active, maintain self-worth and live longer in their own community, it can do much to normalize dementia and combat the perception that PLWD are simply a burden on the rest of society (CRNCC 2015).

Of course, even if self-evident, “putting people first,” in principle, can still be hard to achieve in practice, particularly to the extent



that it is seen to imply a decline in provider control and the redistribution of resources away from bed-based towards community-based care. In our case study of Ontario, for example, successive attempts to bolster community-based care for PLWD and older persons with ongoing needs were hollowed out by the competing political imperatives of building institutional beds and solving problems in the acute care sector. Ironically, as our Balance of Care in South West Ontario observed, and as recent expert reports have confirmed, outcomes have been largely perverse. Not only do many older persons, including PLWD, now “default” to costly hospital and residential beds because of a lack of before-the-fact community-based care, hospital ALC rates have shown little improvement in over a decade (Williams et al. 2016).

### **Pillar Two: Support Informal Caregiving**

This second pillar highlights the crucial role of informal caregivers, the family, friends and neighbors who provide an estimated 70–90% of the everyday care required to maintain persons of all ages with ongoing health and social needs safely and appropriately in community settings. As recent expert reports in Ontario and elsewhere have observed, it is the contributions of informal caregivers that allow many older persons, including PLWD, to continue to live at home; without these contributions, formal care systems would not be sustainable (Williams et al. 2016, 2015a, 2015b).

Yet, paralleling the current state of dementia care policy, Canada does not currently have a national caregiver strategy, and caregiver support initiatives at the provincial/territorial levels remain uneven (Peckham, 2016: 140). Although provinces like Nova Scotia provide tangible supports in the form of monthly caregiver allowances and labour code amendments, which extend compassionate care leave to 28 weeks

(Government of Nova Scotia 2015a, 2015b), other provinces like Manitoba concentrate on affirming the informal caregiver role through largely symbolic measures such as its Caregiver Recognition Act (Government of Manitoba 2016).

This compares to dementia care strategies in other jurisdictions internationally where caregivers, families and extended social support networks are now recognized as essential partners in care qualifying for a range of formal supports in their own right. In the UK, for example, the principle of “living well” is extended to people caring for someone with dementia. This includes having access to support services provided by knowledgeable professionals; having access to respite care and time to go out and keep up activities you enjoy; having support to manage your own health; and having support to maintain social relationships and build up peer support networks (Isden 2016). England’s recent Carers Strategy likewise aims to improve caregiver access to a wide range of tangible resources including healthcare and social care but also extends to education, pensions and income support (Department of Health 2014).

In acknowledging and supporting informal caregivers, policy makers need to guard against simply “load shifting” onto individual family members (the majority of whom continue to be women) who may themselves experience a range of physical, emotional and mental health challenges because of caregiving activities. Rather than building informal caregiver capacity and resilience, this could produce the opposite outcome of increased caregiver burden and stress, leading to caregiver burnout and withdrawal and a decline of caregiver capacity (Health Quality Ontario 2016; Williams et al. 2015a, 2015b).

As well, international experience and practice suggests that the idea of caregiving should now be broadened to look beyond

family caregivers, particularly, as traditional nuclear families are in decline across the industrialized nations (McNeil and Hunter 2014). In Canada, for example, the numbers of older persons (those 65 years of age and older) exceeded numbers of younger persons (those under the age of 14) for the first time in 2016, reflecting demographic trends in other countries (McNeil and Hunter 2014) and auguring a progressive erosion of the traditional family caregiver base (Williams et al. 2015a).

Instead, countries like the UK, Germany and Japan are now redefining caregiving as a shared social responsibility and emphasizing the importance of bolstering broader support networks including building “dementia-friendly” communities (ASUK 2016a; Peckham 2016). In such communities, PLWD “are supported to live a high quality of life with meaning, purpose and value” by “policies, services and physical spaces” designed to enable people of all ages “to live in a secure and accessible physical and social environment” (Webster 2016). In the UK and Japan, this includes training and equipping tens of thousands of volunteers – “dementia friends” – to provide essential everyday supports to PLWD, including telephone calls, companionship, peer support and help to attend medical appointments and social activities (ASUK 2016a; CRNCC 2015; Isden 2016).

There are local Canadian examples as well. In Ontario, for instance, the small town of Bobcageon recently initiated a “Blue Umbrella Program,” which brings together multiple stakeholders (e.g., local businesses, professionals, bus drivers, volunteers) to build and strengthen communities by raising awareness about dementia and creating safe places for PLWD to continue to interact in their community (Webster 2016). Age- and dementia-friendly communities, which encourage broader preventative and maintenance efforts and the creation of supportive environments for not only PLWD but also

persons of all ages with multiple chronic needs, seem a logical next step (MortonChang 2015).

### **Pillar Three: Enable “Ground-Up” Innovation and Change**

Which brings us to the key policy question: How best to achieve needed change.

The value of a comprehensive dementia care strategy at national and/or provincial/territorial levels seems clear. Such strategies can establish dementia as a public policy priority at a time when dementia numbers are rising. They can also set clear goals for concerted action, a crucial consideration given that good dementia care for PLWD and caregivers is increasingly seen to span not only a continuum of programs, services and providers within healthcare but also programs, services and providers within diverse fields such as social care, housing, education and income support. As we have seen, dementia care strategies internationally also aim to bolster informal support networks and build stronger neighborhoods.

However, it is less clear that such strategies need to be “top down” or heavily prescriptive. As we have seen, many promising initiatives gain traction at the local community level, where people normally live. Given that communities vary considerably in terms of their needs and capacity, “one size fits all” solutions are unlikely to work. In Ontario, and across Canada, the most rapidly aging communities are in rural and remote areas characterized by sparse formal care infrastructures, and by overall population decline as younger persons (and potential caregivers) pursue education and jobs in cities. Rather than requiring that a pre-specified “basket of services” be present in every community – an essentially “provider-centric” view – as this is unlikely to happen, it might be better to ask how formal and informal resources, including but not limited to healthcare, can be organized around people’s needs where they live.

In the UK, for example, its national dementia care strategy has encouraged local non-governmental organizations (NGO's) such as Enfield Age UK to train dementia care “navigators” in hospitals, as well as dementia care well-being coordinators in communities, to work with caregivers and existing care teams and providers, help access available services and supports and identify and fill care gaps (Enfield Age UK n.d.).

In Japan, the New Orange Plan supports the establishment of an Intensive Support Team in every municipality by 2018; an increase in the number of dementia care community promoters from 175 in 2012 to 700 in 2017; and the mobilization of up to 8 million dementia care “friends” by 2017, including bank staff, grocery clerks, school children and younger older persons (Hayashi 2015b; Wake 2016).

In Germany, its emerging country-wide network of community dementia alliances is mandated to take action in the following four fields: science and research; social responsibility; support for people with dementia and their families; and (re)structuring of support and healthcare systems (Federal Ministry for Family Affairs, Senior Citizens, Family and Youth 2014).

Such approaches do not let senior levels of government off the hook. Rather, they commit them to enabling the development of “ground-up” innovations through the establishment of clear goals, the reduction of bureaucratic hurdles and the infusion of needed resources. In doing so, they also galvanize political support. Instead of starting with a national dementia strategy, Germany is now enabling local communities to build one “from the ground up.”

### Conclusions

While focusing on dementia, we do not see it as the only challenge now facing older Canadians, caregivers, communities and health systems. And we certainly do not advocate action that would see limited

resources stripped away from other needs groups, or pit disease-specific organizations one against the other.

However, dementia is a “game changer” to the extent that it complicates other health and social needs and erodes the capacity of individuals to manage on their own.

Moreover, even if rates of dementia are nudging downward and most older persons are living longer and healthier lives, which is where any dementia strategy should start, an aging population means that more people will be touched by dementia, a reality that has prompted leaders nationally and internationally to establish dementia care a policy priority. Moreover, because PLWD are among those most likely to experience the effects of multiple chronic health and social needs, their needs can usefully and appropriately drive the development of more comprehensive and integrated community-based approaches to care for Canadians of all ages who cannot manage on their own. As our work in Ontario suggests, the option of “business as usual” is not a good one: in addition to the negative impact on the well-being and independence of PLWD, the likelihood of caregiver burden and burnout can be expected to increase, with “default” to bed-based care eroding the sustainability of healthcare systems.

Although a Canadian dementia strategy may be desirable, to the extent it applies equally to all Canadians, provinces and territories are fully capable of developing their own strategies, as many provinces have already done, and as Ontario is once again in the process of doing. Nor should provincial strategies preclude federal action, as the federal government can establish national bodies to support knowledge generation and translation, and it can act with considerable freedom in such areas as housing which are key to dementia care.

Moreover, rather than being top-down and prescriptive, we suggest that strategies should aim to enable and set clear goals for

local action against which policy makers at all levels can be held accountable.

We think three overriding goals are essential. The first, “person-centred care,” reflects a growing national and international consensus that care should focus on what PLWD need, and that this in turn means “living well” in familiar settings. The second, “support informal caregivers,” recognizes not only that family, friends and neighbors do most of the heavy lifting in the community, but that they often require help in their own right to “live well” and continue to care. The third, “enable ground-up innovation and change,” emphasizes the need for senior levels of government to create the conditions, and provide tangible support for local innovations, which build capacity within and beyond healthcare to maintain PLWD as independently as possible, for as long as possible, “closer to home.”

In conclusion, we want to extend our thanks to the editors of this journal for giving us the opportunity to contribute to, and hopefully stimulate, ongoing discussion nationally and internationally about the future of dementia care. We look forward to hearing the ideas from an excellent group of commentators.

## Notes

1. Interestingly however, another more generic strategy developed during this time frame designed to provide a common policy framework to guide efforts toward effective prevention and management of chronic diseases, with risk factors common to many diseases (Lee, 2006), was also eventually allowed to lapse.
2. Three national strategic objectives have been highlighted by ASC for CADDP: expanded funding and scope of dementia research; evidence-based strategies for dementia prevention and health promotion; and ensuring those who have dementia are living well with their condition (ASC 2015a).

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