NAO
North American Observatory
on Health Systems and Policies

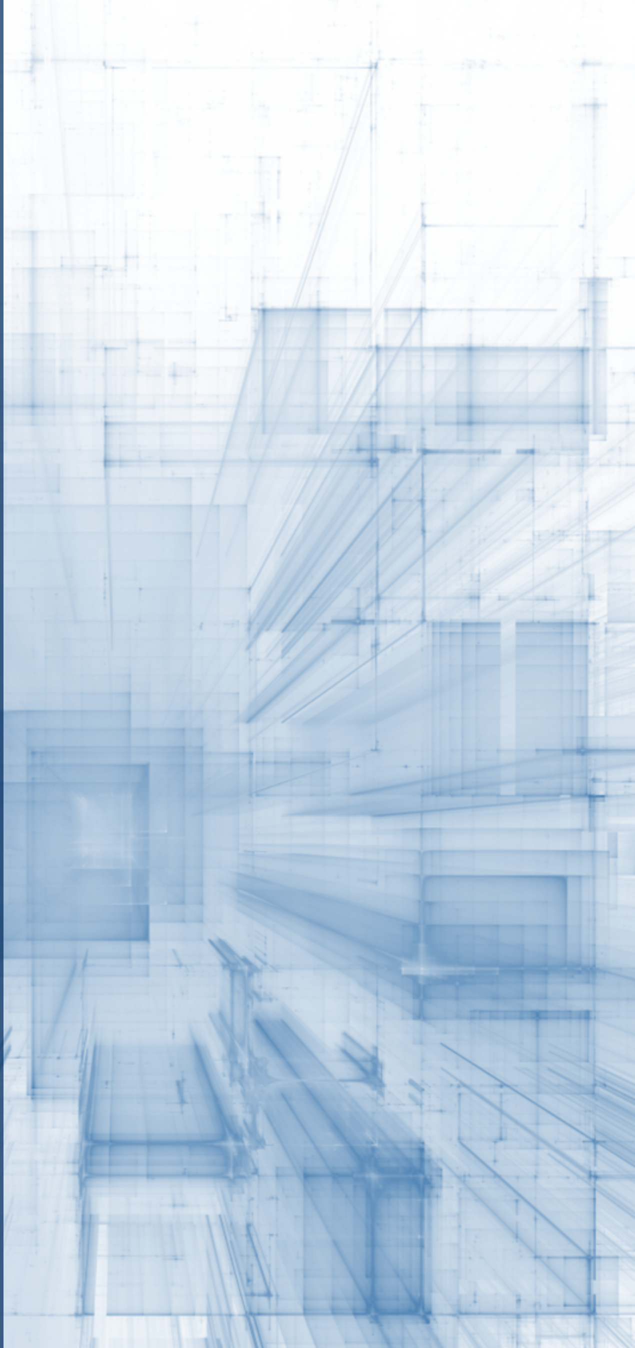
Rapid Review

Community-based supports for people living with Alzheimer's disease and related dementias and care partners

Prepared for The Rossy Foundation

Peckham, A., Sadow, S., Schmid, L.,
Roerig, M., Budhiraja, M., Chau, R.,
Monsey, K., Schuchardt-Vogt, C.,
Skon, C., Morton-Chang, F.,
& Allin, S.

October 2025



Acknowledgements

Funding support for this work was generously provided by the Rossy Foundation.

We are grateful to experts in Canada for their review and feedback of earlier versions of this report, including Dr. Saskia Sivananthan, Phyllis Fehr, Ron Beleno, and Dr. Sharon Anderson.

We also thank Patrick Farrell for copyediting and Melaine Seabrook for support with translation.

Suggested citation

Peckham, A., Sadow, S., Schmid, L., Roerig, M., Budhiraja, M., Chau, R., Monsey, K., Schuchardt-Vogt, C., Skon, C., Morton-Chang, F., & Allin, S. (2025). Community-based supports for people living with Alzheimer's Disease and related dementias and care partners. Toronto: North American Observatory on Health Systems and Policies. *Rapid Review* (No. 47).

About NAO

The North American Observatory on Health Systems and Policies (NAO) is a collaborative partnership of interested researchers, research organizations, governments, and health organizations promoting evidence-informed health system policy decision-making.

Contact Information

North American Observatory on Health Systems and Policies
155 College Street, Suite 425
Toronto, ON M5T 3M6

www.naohealthobservatory.ca

naobservatory@utoronto.ca

nao_health

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List of Abbreviations

2SLGBTQI	Two-Spirit, Lesbian, Gay, Bisexual, Transgender, Queer, Intersex
ADRD	Alzheimer’s disease and related dementias
CBT	Cognitive behavioural therapy
NFP	Not-for-profit
NGO	Non-government organization
PHAC	Public Health Agency of Canada
PLWD	People or persons living with dementia
UK	United Kingdom

Executive Summary

Alzheimer’s disease and related dementias (ADRD) affect millions worldwide and pose a significant public health challenge. In Canada, the prevalence of ADRD is increasing, yet there are major gaps in the health and social supports available to meet the diverse needs of people living with dementia (PLWD) and their care partners.

As a foundational step toward addressing this gap, we conducted a rapid review to uncover and learn from promising community-based solutions for PLWD and their care partners. We explored innovative and impactful approaches from Canada and other countries with well-developed public healthcare systems and established dementia strategies, including Denmark, the United Kingdom (UK), and the Netherlands. Exploring approaches from other countries offers valuable insights and best practices that can inform improvements in Canada.

Our rapid review included two steps. First, we conducted a rapid literature review to identify peer-reviewed community-based interventions or programs that have been evaluated, and to uncover the key programmatic factors contributing to positive outcomes for PLWD and/or their care partners. Second, we conducted a rapid jurisdictional review to identify promising innovations in Canada, Denmark, the UK, and the Netherlands. Promising innovations were included if they met multiple programmatic elements of success identified from the literature review.

Based on this review, we developed a framework tailored to the Canadian context to guide the design and implementation of successful community-based interventions for PLWD and their care partners. This framework is grounded in core principles and values: addressing stigma, ensuring accessibility, promoting equity and intersectionality, and prioritizing sustainability. It highlights critical programmatic factors of success, including the need for early intervention, triadic involvement in care planning, individualized and person-centred approaches, multi-component interventions, and community building and social engagement. Additionally, it outlines key considerations for design and implementation, including factors such as target population, delivery, co-design and engagement strategies, costs, resources and system incentives, impacts and outcomes, and geography and local context.

Our review highlights a range of Canadian initiatives that embody several of these factors and considerations, with each showcasing potential for additional learning and evaluation, expansion, and opportunities for further investment. Findings also provide globally transferable lessons learned that may be useful to other communities and organizations to implement or invest in the maintenance, scaling, and spread of these innovative approaches for maximum impact.

Introduction & Background

Globally, it is estimated that approximately 50 million individuals are currently affected by Alzheimer's disease and related dementias (ADRD), with this number projected to triple by 2050 (1). Over 700,000 Canadians are currently living with ADRD, with this number projected to approach 1 million by 2030 (2), and over the next 30 years, the number of people living with ADRD in Canada is anticipated to grow by 187% (3). The terms "Alzheimer's disease" and "dementia" are often used interchangeably; however, dementia is an umbrella term for a set of neurocognitive symptoms caused by physical disorders affecting the brain. Alzheimer's disease is the most common cause of dementia, accounting for 60–80% of all diagnoses (4).

As the prevalence of dementia escalates, the care burden increasingly shifts to unpaid caregivers[1]—predominantly family members—who provide up to 80% of the care for individuals with neurocognitive disorders (5). Caregivers are instrumental in preserving the health, wellbeing, and functional independence of people living with dementia (PLWD) (6). However, the essential nature of this care comes at considerable personal cost, underscoring the critical need to support unpaid caregivers to ensure not only their own wellbeing, but also the sustainability of the care partnership and the broader health system (7).

The impact of the rising prevalence of dementia is felt across borders, sectors, and cultures (3); this has prompted the global community to acknowledge it as an urgent public health crisis, leading to concerted efforts to enhance support for both PLWD and their caregivers (8,9). A national Canadian dementia strategy was developed in 2019 to guide actions by all levels of government, non-government organizations (NGOs), communities, families, and individuals to address dementia in Canada. The vision of the strategy, *A Dementia Strategy for Canada: Together We Aspire* is: "A Canada in which all PLWD and caregivers are valued and supported, quality of life is optimized, and dementia is prevented, well understood, and effectively treated" (9). This is Canada's first national dementia strategy with a five-year $50 million funding commitment that outlines the country's priorities for dementia, including national objectives to prevent dementia, advance therapies, and improve the quality of life of PLWD and their caregivers. While some progress has been made through this national strategy and provincial strategies (where applicable), provincial gaps remain when addressing the diverse needs of PLWD, those partnering in their care, and the health and social systems supporting them.

A significant area of focus has been the promotion of aging in place—the ability to remain in one's home and community for as long as possible while aging (10)—which aligns with the preferences of many older adults including PLWD (11). Aging in place is associated with numerous benefits, including improved quality of life, strengthened social connections, and overall wellbeing (12). The desirability of aging in place compared to facility-based long-term care is driven by the benefits of remaining in familiar settings, and long waitlists to enter institutional care, even when suitable. However, significant options and barriers exist in effectively supporting the health and wellbeing of individuals and their caregivers within community settings (e.g., appropriate housing for needs, accessible programs, and services) (11). The increasing

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[1] The Alzheimer Society of Canada has developed *Person-Centred Language Guidelines* for anyone who lives with, supports, or works with a PLWD or caregiver/partner in care. The use of person-centred/dementia-friendly language is important to reduce stigma. In some Canadian jurisdictions, the term "care partner(s)" is used and preferred over "caregiver" to respect PLWD who feel they do not need "caregivings" but rather people who will support them or caregivers who may not identify themselves in a caregiving role but as a partner (e.g., "I am his wife, not his caregiver"). In this report we use the terms interchangeably, but it is best practice to ask the person what they prefer.

number of PLWD, combined with a widely held desire to age in place and the reliance on unpaid caregivers, necessitates the integration of innovative community-based supports. These supports are vital for addressing the multifaceted needs of both PLWD and their caregivers, ensuring they receive the comprehensive care and assistance required to maintain independence, resilience, and quality of life. Canada's vast geography, along with its rich ethnocultural and linguistic diversity, adds critical layers of consideration in the design and implementation of these services.

In recent years, we have seen an influx in efforts to support PLWD in their local communities as part of a shift away from institutionalization (11). However, there remains limited evidence to inform the design and implementation of these innovations. Additionally, there is limited knowledge of what features these innovations should include to sufficiently support the health and wellbeing of PLWD and their caregivers in their local communities (13).

This rapid review aims to: 1) identify key factors of success and best practices of innovative approaches to support community-dwelling PLWD and their caregivers; and 2) present and describe innovative and impactful community-based approaches nationally and internationally (Canada, Denmark, the United Kingdom [UK], and the Netherlands) that support the needs of PLWD and their caregivers. Findings reveal transferable lessons learned that may be useful to other jurisdictions or organizations seeking to implement these innovative approaches.

Methods

Literature Review

A comprehensive search strategy was used to determine community-based interventions or programs for PLWD and their care partners. A combination of search terms was used across four databases (Scopus, Medline, Cinahl, and PsychINFO) with articles filtered for availability in English. The results were imported into Rayyan, a systematic review software, for screening. Articles were included if they were in English, peer-reviewed primary research or reviews, included an intervention or approach for PLWD and/or their care partners, assessed the impact or outcome of a program, assessed the care partner and recipient needs for community-based care, and included patient and care partner outcomes. See **Appendix A** for a detailed methodology, including search strategy terms.

Articles that met inclusion after title/abstract and full-text screening underwent data extraction to detail each paper's key characteristics (author, year published, year the study was conducted, country in which the study was conducted), the study design and methods, the population of interest or disease stage (if specified), the intervention (including outcome(s) of interest, measured, and evaluation), results, and lessons learned. Results were then reviewed and lessons learned compiled, with a focus on barriers and enablers to implementation, and programmatic factors observed to be connected to positive outcomes for PLWD and/or their care partners.

Jurisdictional Review

The rapid literature review was supplemented by a rapid jurisdictional review of four jurisdictions of interest—Canada, Denmark, the UK, the Netherlands—to further identify promising innovations and compare promising features and lessons learned in offering supportive community-based care to PLWD and their caregivers. Grey literature, including government and other relevant organizational websites, was analyzed to identify promising practices. Promising programs and interventions were included if they met multiple programmatic elements of success identified in the rapid academic literature review. The programmatic factors explicitly targeted by each intervention are documented, though certain interventions may indirectly influence additional factors.

Limitations

This rapid review offers a snapshot of promising programs and interventions for community-dwelling PLWD and their care partners; it does not provide a comprehensive inventory of all relevant innovations in the included jurisdictions and excludes interventions occurring mainly in residential care settings. Academic sources were limited by English. Among the grey literature, sources that were not in English (excluding those from Canada in French) were translated using Google Translate. The jurisdictions included were selected to ensure a narrow and targeted focus, offering a diverse range of approaches from countries comparable to Canada.

Analytic Overview

A total of 23 articles from 19 countries were included from the rapid literature review. All were from high-income countries, except for one from China, which is classified as a high-middle-income economy according to the World Bank (14). Among the academic literature, five articles were systematic reviews (15–18). The academic literature and examples from our international review included various types of innovations, including technology-based programs (15–17,19–22); direct caregiver supports (23); case managed co-located interventions (24–29); day programs (30–32); dementia inclusive educational interventions (17,18,20,21,33,34); community building and arts based connections (35–42); home visits/respite (43,44); counselling interventions (45–48); and transportation and mobility assistance.

Descriptions and examples of these program types are described in **Table 1.** These categories and components were not always mutually exclusive, and many innovations included multiple components. For example, both counselling and education may be offered together in a single program.[2] Moreover, some interventions focus on direct care delivery, while others offer supportive services and resources, and some integrate both.

Table 1. Definitions and examples of innovations

Innovation	Definition & Examples
Technology-based programs	Using technology to deliver various types of interventions to PLWD and care partners and to make life easier. *e.g., webinars, internet forums, web-based psychoeducational programs, support groups, online messaging, videoconferencing, mobile applications, assistive technology, etc.*
Direct caregiver supports	Programs or supports specifically for caregivers, which may include consultations, system navigation, support groups, workshops focusing on caregiver wellness, and other training.
Case managed co-located interventions	The use of protocols for assessment, diagnosis and planning, support with managing the care plan and coordinating services. *e.g., memory clinics.*
Day programs	Attending an out-of-home program, typically at an organization or community centre. *e.g., visiting a farm for horticultural therapy, art and music-based programs and therapy, visiting a museum, exercise classes, etc.*
Dementia inclusive educational interventions	Educational resources and training to help create communities that are inclusive and accessible for PLWD. *e.g., online training, tip sheets, public service announcements, videos, etc.*
Community building and arts-based connections	Programs that bring people together to build connections and social supports, including many arts-based programs that promote socialization. *e.g., art/music therapy, dance therapy, podcasts, etc.*
Home visits/respite	Support provided in one's home.
Counselling	"Talk therapy" where feelings, emotions, and challenges are discussed with a professional.
Transportation and mobility assistance	Supports to transport PLWD to programs and appointments. *e.g., a van/bus to transport program participants for day programs or to appointments.*

Based on our analyses of the academic and jurisdictional reviews, we developed a framework that includes core principles and values, programmatic factors of success, and considerations for design and implementation. Our report concludes with considerations for Canada, identifying possible areas for future attention and investment.

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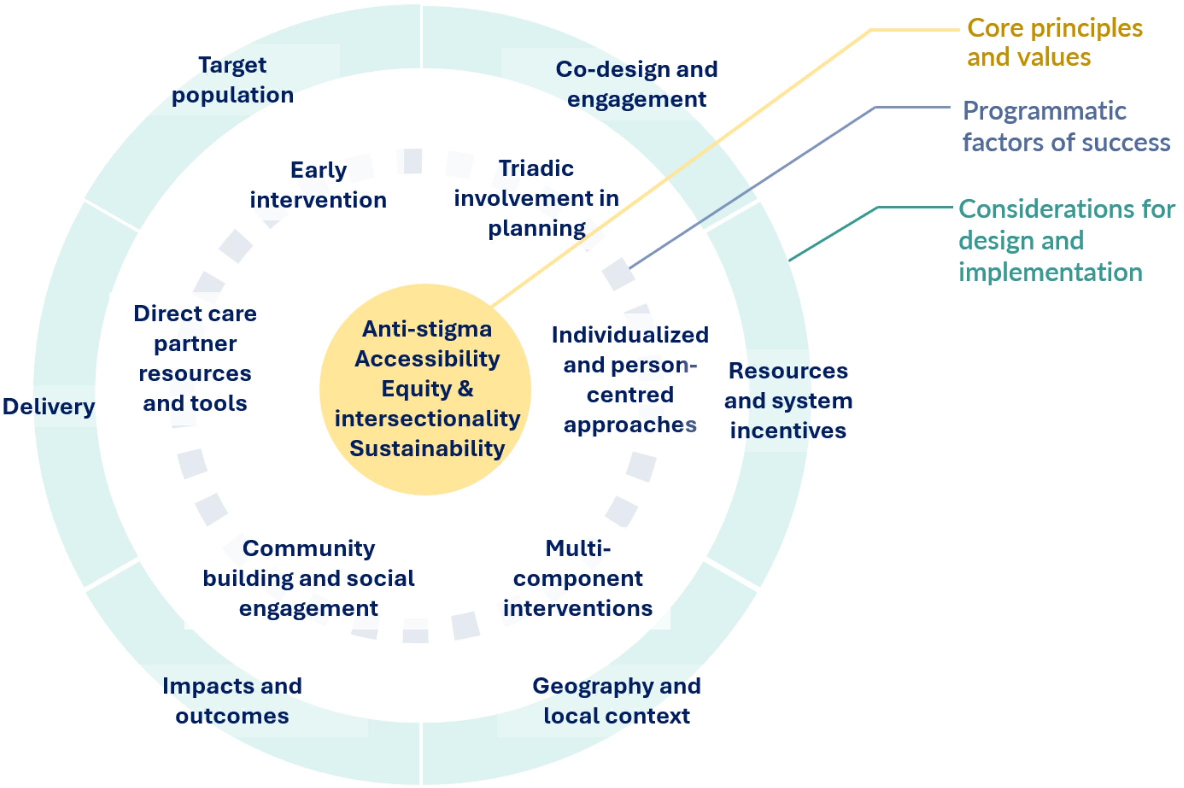
[2] The terms "intervention" and "program" may be used interchangeably to refer to any action taken that has the purpose of lessening the effects of a disease or improving health/wellbeing (British Psychology Society, 2014).

Framework for Successful Interventions for Community-Dwelling PLWD and their Care Partners

The interventions revealed from the rapid literature review and international jurisdiction review provide important education and connections to helpful programs and services to support the greatest health, safety, independence, and quality of life possible as well as proactive opportunities to build resilience over time. We identified six programmatic factors that contributed to positive care recipient and partner outcomes, and five opportunities for consideration when designing and implementing these community-based supports. We developed a framework (**Figure 1**) building on these findings to ensure their relevance to the Canadian context, including core principles and values.

This framework can help identify current gaps in support for PLWD and care partners, and ground future focus of innovations and/or scaling current interventions.

Figure 1. Framework for successful interventions for community-dwelling PLWD and their care partners



Core Principles and Values

In this framework, anti-stigma, accessibility, equity and intersectionality, and sustainability are considered as core principles and values that are foundational to community-based programs and supports for PLWD and their care partners.

Anti-stigma

Stigma around dementia "encompasses any negative attitude or discriminatory behaviour against people living with dementia, just on the basis of having the disease" (49). Such stigma can result from uninformed beliefs about dementia, incorrect language, or assumptions about the capabilities of PLWD, which can pose as barriers to their participation in their communities, limiting access to services and support, and reducing their quality of life (50). Canada's *National Dementia Strategy* recognizes eliminating stigma as a key challenge to its successful implementation (8,9).

According to the 2024 *World Alzheimer Report* (51), dementia is still wrongly stereotyped as a normal part of aging by both the public and health practitioners, contributing to less than 1 in 4 people with dementia receiving a diagnosis worldwide, and impacting the ability to intervene proactively. Stigma reduction is a key factor in enabling dementia-inclusive communities (50). PLWD are often reluctant to disclose their concerns, which can lead to more hidden and isolated lives because of shame, fear of negative reactions, lack of acceptance from others, and in some cases, a lack of awareness of their condition (52). Conversely, timely proactive interventions have been shown to improve knowledge and understanding about dementia, improve social connection and engagement, increase caregiver resilience, and avoid premature/ unnecessary admission to institutional care settings for PLWD.

Additionally, anti-stigma considerations like the use of empowering language are essential when engaging and undertaking programs and initiatives with PLWD and caregivers, including cultural and linguistic understandings. For example, the term dementia does not translate well into French and does not carry positive connotations. Terms used by the Quebec Alzheimer Society are "maladie d' Alzheimer" or "un autre trouble neurocognitive," ensuring more person-centred and non-offensive language and terminology that makes sense to those seeking support and offering it (50).

Accessibility

Access can be defined as "the opportunity to reach and obtain appropriate services" (53). We adopt the five dimensions of accessibility of services described by Levesque and colleagues (2013), including approachability, acceptability, availability and accommodation, affordability, and appropriateness (defined in **Table 2**).

Table 2. Definitions of access (53)

Dimension of Access	Definition
Approachability	People facing health needs can identify that some form of services exist, can be reached, and have an impact on the health of the individual.
Acceptability	Cultural and social factors determining the possibility for people to accept the aspects of the service and the judged appropriateness for the persons to seek care.
Availability and accommodation	Services that can be reached both physically and in a timely manner.
Affordability	The economic capacity for people to spend resources and time to use appropriate services.
Appropriateness	The fit between services and client need, its timeliness, the amount of care spent in assessing health problems and determining the correct treatment plan, and the technical and interpersonal quality of the service provided.

Equity and intersectionality

Canada's 2019 five-year *National Dementia Strategy* (9) aligns with existing national strategies from all other G7 countries (8) and points to important considerations facing women care partners, and the social isolation and loneliness that both PLWD and care partners can face in the dementia journey. It also highlights the importance of information about and navigation of helpful programs and challenges in accessing them, from stigma to barriers faced by specific equity-deserving groups (e.g., Indigenous and 2SLGBTQI communities).

Studies have found that racially diverse communities have a higher prevalence of dementia and face disproportionate challenges to accessing and receiving care and supports (54,55). Lacking culturally safe and appropriate care may result in seeking help at later stages of dementia (25). It is also important to acknowledge that different cultural norms around accessing formal services may exist, particularly among Indigenous communities where traditional healers do not fit well within Western medicine practices (25). Women are also disproportionately affected by dementia, accounting for two-thirds of all older Canadians living with dementia and for most of the unpaid family and friend caregivers (9). When designing, implementing, and delivering interventions, it is crucial to consider how various characteristics or forms of inequality may compound and intersect to shape a person's experience (56), and where remaining gaps may exist in services to better target interventions. Intersectionality experienced by PLWD and care partners can encompass and extend beyond gender and race, including socioeconomic status, disability, geographic location, and language barriers, all of which influence access to dementia care and support.

Sustainability

In Canada, there remain gaps across the broader dementia continuum for all involved. Canada is often referred to as "the land of pilot projects" with much seed funding, yet there is limited-to-no sustainable baseline operational funding, regardless of program success and impact.

Many promising, powerful, and innovative pilot/proof-of-concept projects directly support PLWD and help care partners provide longer, more effective care. These include interest-based initiatives like dementia cafes and arts-based programs. Such programs offer safe environments for sharing information and building connections. With long-term investment, these programs can be sustained, scaled, and expanded to be accessed by more individuals and include other wrap-around supports.

Long-term investments are needed to build awareness of, distribute and update information about initiatives and supports available to PLWD and caregivers. Additionally, sustainable funding is required to find related forums/platforms, support their authentic co-design with experts with lived experience, and foster community building and social engagement. Future considerations could look toward cross-pollination of different levels of government and other vested stakeholders with the possibility of shared funding where appropriate to avoid concerns of duplication across responsibilities of other jurisdictions or provider types.

Programmatic Factors Contributing to Positive Outcomes

Our analysis of the literature review identified six programmatic factors that contributed to positive outcomes, including:

- **Early intervention**: *early identification of condition, education, and connection to resources*.
- **Triadic involvement in collaborative care planning:** *care planning that is developed collaboratively with the PLWD, care partner, and health provider*.
- **Individualized and person-centred approaches**: *tailoring care and interventions to the preferences and contexts of individual PLWD and care partners*.
- **Multicomponent interventions**: *having different components to an intervention to address the multi-faceted and evolving needs of PLWD and their care partners*.
- **Direct resources and tools for care partners**: *providing care partners with resources, tools, and support directly for their own wellbeing and resilience*.
- **Community building and social engagement**: *providing regular opportunities for PLWD and/or care partners to connect with others, build friendships, and develop a sense of community*.

These programmatic factors directly influence key desired outcomes, including improved symptom management, delayed institutionalization, reduced caregiver burden, and enhanced social engagement. Applying these factors to international examples reveals programmatic gaps that may limit their reach and impact. **Table 2** highlights examples that included three or more of the six factors. Note that all the selected interventions included at least one programmatic factor, but few featured triadic involvement in collaborative care planning (24,27).

Below we further describe each of the factors with examples. Associated outcomes of each are presented in **Appendix B**.

Table 2. Examples of interventions with 3+ programmatic factors

	Intervention	Programmatic Factors					
		Early intervention	Triadic involvement in care planning	Individualized & person-centred approaches	Multi-component	Direct resources & tools for care partners	Community building & social engagement
Denmark	Dementia Line	✓	✗	✗	✗	✓	✓
	Football Club Dementia	✓	✗	✗	✓	✗	✓
	Demensalliancen (The Dementia Alliance)*	✗	✗	✓	✓	✓	✓
	The forget-me-not bus	✗	✗	✓	✗	✓	✓
	Dementia-friendly parking at cultural sites	✗	✗	✓	✗	✓	✓
Netherland	Reighershove*	✗	✗	✓	✓	✓	✓
UK	Dementia Helpline	✓	✗	✓	✗	✓	✗
	Young Dementia Network*	✓	✗	✓	✗	✓	✗
	Together in Dementia Everyday (TIDE)	✗	✗	✓	✗	✓	✓
Canada	CARE-RATE	✗	✗	✓	✓	✓	✗
	First Link	✓	✓	✗	✓	✓	✗
	Together for Fun!	✗	✗	✓		✓	✓
	From the Inside Out	✗	✗	✓	✓	✓	✓
	Using therapeutic and culture-based approaches to support the wellbeing of care partners of red river Metis living with dementia	✓	✗	✓	✗	✓	✗
	What Connects Us – Ce qui nous lie	✗	✗	✓	✓	✓	✓
	Apprendre à aider sans s'oublier	✓	✗	✓	✗	✓	✗
	Caregiver Project for Seniors & Alzheimer Counselling and Financial Support	✓	✓	✓	✗	✓	✓
	Coaching à domicile pour les aidants	✓	✗	✓	✗	✓	✗
	Dementia Dialogue	✓	✗	✓	✗	✗	✓
	Finding your way/Trouvez votre chemin	✓	✓	✓	✓	✗	✗

✓ intervention includes programmatic factor; ✗ intervention does not include programmatic factor

* Box 1 provides more information on these selected innovations

Early intervention

Early identification, education, and connection to resources facilitates timely intervention and support. Early education is essential for PLWD as well as care partners, who play a critical role in the diagnosis, care planning, and management/ adherence of care plans (26). Providing timely information about available community resources and treatment options in earlier stages of the disease (25) can empower care partners to navigate the care process and manage symptoms for PLWD, including pain (28). While foundational, information and resource lists are not knowledge or navigation in and of themselves and PLWD and care partners benefit from ongoing assessment for resources and supports tailored to their needs throughout the full disease trajectory. Finally, ongoing and early connection to resources also helps care partners develop coping and management strategies, which mitigates potential negative outcomes associated with the caregiving role, such as increased stress, burden, and guilt, and decreased wellbeing and quality of life (43,57).

For example, the Young Dementia Network in the UK (**Box 1**) works to raise awareness and improve knowledge of the signs and symptoms of young-onset dementia among health professionals and the general public to reduce the time it takes to receive a diagnosis and help individuals connect to appropriate care and support sooner (58).

Interventions that included this programmatic factor were found to have positive effects on caregiver wellbeing, service use, and aging in place for PLWD, and increased quality of life and satisfaction with the intervention and quality of care for both PLWD and caregivers. Moreover, early intervention was associated with reducing institutionalization, hospitalization and emergency department visits among PLWD.

Box 1. Key International Examples of Early Interventions

Young Dementia Network, UK: The Young Dementia Network (founded in 2016) is an online community and resource hub for people living with young-onset dementia and their families, as well as professionals across health, social care, and volunteer sectors. It aims to improve the experience of individuals living with young-onset dementia and their families, expand access to lifelong support, and foster knowledge, connection, and hope. The Network collaborates with individuals with lived experience, advocates for policy and practice improvements, and offers a variety of educational and social events.

Demensalliancen ("The Dementia Alliance"), Denmark: Demensalliancen was established in 2014 to improve the everyday lives of PLWD and their families and work towards a more dementia-friendly Denmark. Through free, tailored strategy workshops ("Dementia Camps"), they assist municipalities in identifying actionable steps to become more dementia-friendly at the community and policy levels. Each year, they conduct an impact study to evaluate changes and pinpoint areas for improvement. Additionally, they host an annual Dementia Summit, which provides researchers, experts, politicians, and PLWD and their families an opportunity to come together to build connections and share knowledge. The Alliance also offers "Dementia Schools" and other training events, as well as transportation programs such as the "forget-me-not bus."

Reigershoeve, Netherlands: Initiated in 2013, Reigershoeve is a residential care farm for PLWD that prioritizes small-scale community living, while centering individuals' independence, preferences, habits, and lifestyles. There are a variety of activities for PLWD to choose from, such as spending time with animals in the meadow, harvesting vegetables from the garden, and working on projects in the workshop or art studio, supporting independence. In addition to residents who stay long-term (maximum 27 residents), community-dwelling PLWD may also visit the farm through day programs and can stay at the farm on a short-term basis for respite care.

Triadic involvement in collaborative care planning

Care planning is vital for PLWD across all disease stages, with the most effective plans accounting for evolving needs in achievable, measured, and sustainable ways (26). While caregiving is considered a dyadic process, in which “the responses of both the caregiver and the care recipient can impact on the wellbeing of one another,” care plans (including advance care plans) should be developed collaboratively with the PLWD, care partner, and health provider (25,26,28). Plans should also consider the preferences, social location (i.e., sociodemographics, context, culture, etc.), and needs of both PLWD and care partners (16,29,47), including the end-of-life wishes of the PLWD (28).

Triadic involvement in collaborative care planning was shown to positively impact satisfaction with support among care partners and quality of life for both PLWD and care partners, and reduce family conflict, institutionalization, and hospitalization.

Individualized and person-centred approaches

Individualized and person-centred approaches involve co-designing and tailoring interventions from the outset with, and based on the preferences and contexts of, PLWD and caregivers (16). This includes tailoring interventions to care partners’ differing levels of knowledge of dementia and care options, experience with providing care and navigating systems, and capacity (17); offering a variety of activities to PLWD for varying levels of cognitive functioning (32); and ensuring that approaches are culturally sensitive (25) and considerate of sociodemographics (16). Examples include flexible, self-paced eHealth interventions to meet the specific needs of caregivers (17,20,21) and offering access to healthcare workers outside of regular hours, (25,32,59).

Similar to care planning above, involving both care partners and PLWD in the design of care models and programs, particularly technological solutions, has been found to enhance their effectiveness (16). The Young Dementia Network (UK) and similar programs in Canada, such as YouQuest (60), promote age-appropriate support by tailoring resources to the unique needs of individuals living with young-onset dementia (e.g., guidance notes targeting topics such as setting up support groups and considerations for dementia support/care workers) (58,61).

Early-stage dementia is often difficult to detect, and families and professionals may not recognize changes until well into its progression. People often do not demonstrate noticeable or physical signs of decline in the earliest stages, and decreases in cognitive function may be misunderstood as inattentional behaviour or intentionally concealed to the best of the individual’s ability. Understanding the needs of PLWD can be facilitated through family counselling, which has also been found to reduce conflict and caregiver stress (47). Finally, effective communication across disciplines, along with active engagement with PLWD and caregivers, supports interventions to remain person-centered and responsive to individual needs (59).

Individualized, person-centred approaches were shown to have numerous positive impacts for PLWD and care partners. For care partners, these include greater satisfaction with support, increased empathy, and improved perspective-taking. For PLWD, they support better service use, and general and cognitive functioning. Both groups were found to have improved mood, quality of life, social engagement, and satisfaction with the intervention and quality of care, social engagement, and social, emotional, and instrumental support for both PLWD and caregivers; and have a positive impact on the relationship between the PLWD and caregiver. Moreover, this programmatic factor demonstrated a decreased impact on depression symptoms, anxiety among caregivers, and hospitalizations and emergency department visits among PLWD.

Multicomponent interventions

To address the multifaceted and evolving needs of PLWD and their care partners, interventions should be multifaceted and include, at minimum, psychoeducation, social support, and reliable access to healthcare professionals (15). Pharmacological interventions (26) and addressing sensory impairments to vision and hearing can remove additional barriers to communication and facilitate social engagement (44). Integrative approaches should consider the built environment, psychosocial support, healthcare resources, and caregiver support, with a strong emphasis on collaborative team-based approaches (25,59). eHealth interventions, combining psychoeducation, counselling, and advocacy, can improve care access (21), and caregiver training on digital tools is crucial (16). Incorporating acute care into long-term care services can further support aging in place (25).

The Dementia Alliance (Demensalliancen) in Denmark offers a range of programs to address the multifaceted needs of PLWD and their families. These include the Dementia School, which provides cognitive stimulation, conversational support, and compensatory teaching for PLWD; educational opportunities to increase knowledge of dementia and target specific issues, such as sexuality and intimacy; a temporary respite program that also offers round-the-clock assistance to caregivers; recommendations to improve comfort and accessibility of dental care; and transportation-related interventions, such as reserved parking spots, priority seats at community venues, and training for community bus drivers (62).

Positive effects associated with multicomponent interventions for care partners included wellbeing, competence, mastery, and self-efficacy, and social, emotional, and instrumental support; and for PLWD included social engagement, quality of life, service use, and satisfaction with the intervention and quality of care. Interventions with this programmatic factor were also associated with negative (decreased) impact on caregiver wellbeing, and institutionalization and hospitalization among PLWD.

Direct care partner resources and tools

Providing care partners with direct support through respite care, resources, and tools is essential for their wellbeing and resilience. For example, day programs can reduce caregiver burden, but vary in effectiveness based on flexibility (i.e., programs at different times and days), accessibility (i.e., transportation), and appropriateness for disease stages (32,40,43). For example, Reigershoeve in the Netherlands offers a flexible adult day service for community-dwelling PLWD with options to stay for up to three weeks, providing caregivers with opportunities for respite.

It has been well-established that care for PLWD should be consistent, with minimal staff turnover, reliable attendance, and mitigation of the number of times caregivers need to repeat important care information (43). However, often this is not possible in Canada’s fragmented, siloed, and strained system, which is also facing unprecedented care worker shortages across all care settings (63). Assisted Living, Supportive Housing, and Adult Day programs with consistent teams and schedules are good examples of optimizing location and people to support the best possible care for PLWD and caregivers (11,64).

Skills training and perspective reappraisal help caregivers manage stress and emotional triggers (45,48). Supporting caregivers to develop communication strategies and approaches to managing responsive behaviours can prevent frustration and manage challenging behaviours (34), while social and family support, along with addressing caregivers’ individual concerns, is crucial (48). Caregivers should be regularly checked in on for common stressors like guilt, satisfaction with new placements, and interactions with paid staff (65). Ongoing support should include accessible psychosocial resources in practice settings (18). Telehealth/eHealth interventions can also help, particularly in rural areas and during stressful periods like transitions or changes in disease stage (16,21,25).

Effective dementia education and skills training is also vital for the health and social care workforce to best support PLWD and care partners. Collaboration through knowledge exchange across disciplinary sectors, geographical areas, and involvement of those with lived experience is desirable to reach the maximum potential for practice enhancement and assist in developing a deeper understanding of the dementia journey for all involved, including the types of programs and services available to provide the right care at the right time (66,67).

Interventions that included direct resources and tools for care partners had positive outcomes for both care partners and recipients. For care partners, this included positive impacts on empathy, perspective-taking, attitudes toward dementia, knowledge of resources, and relationships with nursing staff. For PLWD, this included positive impacts on their general functioning, service use, and satisfaction with life and/or circumstances. For both PLWD and care partners, this included positive outcomes on wellbeing, quality of life, social, emotional and instrumental support, social engagement, satisfaction with intervention and quality of care, and relationship between the PLWD and care partner. Negative (decreased) effects included caregiver distress and guilt, as well as decreased institutionalization, hospitalization, and emergency department visits among PLWD.

Community building and social engagement

Interventions should offer regular opportunities for PLWD and care partners to connect, build friendships, and foster a sense of community (32), both in person and online (21). Creative activities involving music and art, such as music circles and attending art galleries, designing personalized playlists, and participating in singing groups, can reduce stress and strengthen relationships between care partners and PLWD (36,39,41). One example is Football Club Dementia, offered by FC Demens in Denmark, which provides a safe environment for PLWD to play football while increasing mental health, physical activity, and social interaction (35).

Inclusion in programs and in the broader community can be supported by building dementia-friendly communities and environments. Modifications such as navigational aids can improve accessibility and mitigate common losses (e.g., sensory, mobility, relational, etc.) in later stages of the disease (59). Community centres can also train staff to promote acceptance and inclusivity of neurodivergence in community settings (e.g., local events and activities) (59).

Interventions that incorporated community building and social engagement showed positive effects. These included improved social engagement and quality of life among caregivers; wellbeing, satisfaction with life and/or circumstances, and general functioning among PLWD; and subjective mood, stress, and burden, and emotional and instrumental support among both PLWD and caregivers, as well as their interpersonal relationships. Finally, this programmatic factor was associated with negative (decreased) effects on anxiety among PLWD.

Considerations for Design and Implementation

Target population

Considering the target population or populations is important for program design and implementation, as different populations may have differing needs. For example, interventions may aim to target PLWD, care partners, or both; sub-populations, such as those based on dementia stage, culture, language, and other characteristics; and individuals or groups. Interventions that are specifically designed to target sub-populations can enhance comfort and utilization for both caregivers and PLWD.

Notably, the needs of PLWD and care partners may be different. For example, providing care partners with information and educational materials for different disease stages has been reported as essential to support their evolving informational needs as the dementia progresses (18). Ensuring caregiver wellbeing is also regarded as equally important to prevent burn out—"a sense of fatigue, frequently being overwhelmed, and losing interest in [things] previously enjoyed" (68). Personalized goal setting within interventions helps support tailored outcomes, while psychosocial, educational, and social support groups enable caregivers to adapt as care needs evolve (18,44). Group dynamics and group activities have also been found to be effective in meeting social needs, though they can also influence caregiving decisions, as caregivers in groups supportive of long-term care placement may be more likely to utilize such services compared to those in groups advocating for home care (57).

Delivery

Delivering interventions to support PLWD and their care partners require flexibility and personalization to address their evolving needs. It is also important to recognize that care partners may also have their own distinct care needs. Supporting a PLWD or providing respite care does not necessarily fully address the holistic needs of someone partnering in their care.

Technology-based programs can enhance access, cost-effectiveness, and flexibility but are only effective for individuals with access to the necessary devices, software, and reliable internet—barriers that persist for some caregivers and PLWD (15,20,21,28,39). Individuals with mid-to-late-stage dementia often require additional support to engage with technology, which, if formally provided, can place added stress on caregivers (16,17,40). The inclusion of technology may require training for PLWD, care partners (paid and unpaid), and other individuals providing health and social care. For example, paid professionals may also need training to offer supportive counselling using an online platform as opposed to face-to-face (15,34,40). Providing care partners with 24/7 access to online programming and care staff enhances accessibility by allowing support whenever needed, without requiring video conference availability (17). Furthermore, the ability to call care staff and speak with them, regardless of support groups, boosts care partners' confidence and helps them manage caregiving responsibilities more effectively (32,48).

While eHealth interventions are often sought after and deemed acceptable by care partners, they may not replicate the social health benefits of in-person programs that promote direct meaningful engagement (16,21). Offering hybrid formats—combining in-person, telephone, and online supports—can improve accessibility, while 24/7 access to online programming and care staff provides flexibility and boosts confidence (17,32). For example, direct access to care staff via phone can help them manage responsibilities more effectively, fostering better outcomes for themselves and the care recipient (32,48).

Co-design and engagement strategies

Programs that foster inclusive communities of place and promote long-term engagement of care partners and PLWD are essential for positive outcomes. As discussed above, they must seek to address stigma and other barriers to participation (e.g., person-centred language and culturally specific approaches) and consider how to sustain engagement over time.

Interventions should be co-designed with PLWD and/or care partners to ensure that the interventions are relevant and effective in meeting their needs (21,26,69). The importance of involving both in the development of these programs has been highlighted by the World Health Organization and in the *National Dementia Strategy in Canada* (8,9). Five enabling factors identified for authentic and synergistic co-design partnerships with PLWD and care partners and intervention providers and/or researchers include the need for: a diverse group of individuals and identifying and supporting the personal strengths and resources of all partners; creating a safe space where partners feel comfortable expressing their views openly; establishing, valuing, and including diverse perspectives; establishing and maintaining open communication with accessible language considerations in mind; and regular personal and group reflection and communication within the partnership to assess what is working well or needs to be strengthened (70).

Strategies for engagement may include regular follow-ups/check-ins during the intervention (21,26,28) and ensuring that programs are co-designed with the above enabling factors in mind to ensure interventions are meaningful and relevant to all participants (71). For example, addressing caregivers' emotional, financial, and practical needs, such as transportation, can improve access to essential resources and services, such as day programs (32,41). Similarly, community-based interventions that encourage communities of place can play a key role in reducing stigma by fostering social inclusion and enhancing wellbeing. For example, engaging with cultural and social activities in museums or galleries has been shown to reduce stigma and encourage participation (36). Resources are more likely to be utilized by care partners and PLWD if they are focused on reducing dementia-associated stigma (45). Reducing stigma around dementia, including the double stigma of ageism and dementia-related discrimination, can encourage more care partners to engage in support programs (45).

Resources and system incentives

Implementing programs to support PLWD and their care partners also requires consideration of costs and resources to the individual, organizations, and the system. For example, online platforms can lower costs for providers and program recipients alike (20). Virtual remote services also offer practical benefits, such as reducing travel costs, maintaining routines for PLWD, addressing mobility or caregiving constraints, and improving around the clock-access to care (16,17,32,48). Expanding access to reliable internet and devices in rural and remote areas is essential to ensure equitable participation in these programs.

Limited health system incentives to support seamless transitions between care models can hinder the integration of such programs (25), underscoring the need for systemic changes, such as partnerships across local programs or cross-sector interventions that include reimbursement strategies (25,26).

Impacts and outcomes

Measuring the impact of interventions for PLWD and their care partners is essential to ensure they effectively address evolving needs and achieve meaningful outcomes. When care partners are made aware of necessary resources, they are more likely to utilise these services, enhancing their ability to provide care (29). Personalized goal setting, tailored to individual circumstances, can support outcomes that are both achievable and relevant to care partners and recipients, ensuring interventions remain responsive as care needs change (44). Clear and measurable impact and outcome goals should be established during program implementation to assess effectiveness and guide future improvements. This should also be considered when engaging in co-design efforts.

Monitoring reduction in caregiver stress and burden, such as through the Kingston Caregiver Stress Scale (KCSS), can track improvements in caregiver wellbeing (72). Measuring participation in social activities can provide insight into a program's success in fostering social inclusion and reducing isolation. Utilizing tools like BSO's Dementia Observation Scale (73) can help track changes in PLWD cognitive function, behaviour, and overall mood. Regular assessments of both PLWD and caregiver quality of life—using tools such as the UK's person-centred Dementia Care Mapping™ tool (74,75)—can provide insight into the effectiveness of interventions. Assessment of caregiver knowledge on dementia care, resources, and their self-efficacy in managing care tasks can serve as additional key outcome indicators.

Qualitative methods such as impact narratives can capture the personal experiences of care partners and PLWD. The Dementia Observation Scale and Dementia Care Mapping offer both quantitative and qualitative measures of care outcomes, helping assess the effectiveness of interventions, and provide insights into wellbeing and social engagement.

Geography and local context

In a country as vast and diverse as Canada, contextual factors are critical to successful design and implementation of dementia-focused interventions. Canadians are diverse and PLWD are not homogeneous, requiring individualized and person-centered approaches. Geographic considerations when serving people in and across urban, rural, remote, and northern communities pose unique challenges for jurisdictional context, scalability and equity considerations, including accessibility. For example, rural settings often face the challenge of lacking health and social resources. As a result, integration efforts in these contexts often focused on strategies to overcome resource scarcity (25).

Promising Canadian Examples

Numerous Canadian interventions to support PLWD and their care partners successfully incorporate several of the key programmatic factors identified in the framework above. We present a preliminary selection of Canadian initiatives identified as among the most impactful, based on their demonstrated effectiveness in improving key outcomes such as symptom management, caregiver burden reduction, delayed institutionalization, and increased social engagement. Further investigation and consideration of additional interventions were incorporated via expert review. Similarities to established international programs with demonstrated effectiveness may inform viability and success in the community from a Canadian context. We acknowledge that there are several other intervention types and noteworthy “points of light”; future research could for example, explore small-scale design residential-based programs (e.g., Green House Project) to apply to the community and/or mixed-setting housing (e.g., seniors’ campuses) to leverage community connections along a broader continuum of care.

Technology-Based Programs

Digital Tools for Integrated Dementia Care is a project led by Dr. Olivier Beauchet at the Centre de Recherche de l’Institut Universitaire de Gériatrie de Montréal, aiming to enhance care continuity, autonomy, and quality of life for patients while reducing caregiver burden and healthcare costs. Initiated in 2021 with support from a grant from the Ministère de la Santé et des Services sociaux du Québecin partnership with the Unité de soutien au système de santé apprenant du Québec and the Fonds de recherche du Québec – Santé, this participatory action research project integrates two digital health applications, CARE© and ESOGER©, into conventional care pathways to improve access to first-line services for PLWD and their caregivers. CARE© identifies health vulnerabilities, while ESOGER© addresses detected care needs, tracks interventions, and facilitates collaboration among care networks (76,77).

Tech-Empowered Healthy Living for Seniors Living with Dementia is an initiative by Human Endeavour, a community-based non-profit multi-service organization, committed to innovation in health, economic, and social solutions, including education and training programs to settlement support and a seniors active living centre. The dementia tablet project builds on a seniors focused technology project and aims to enhance quality of life, safety, and social engagement of PLWD and peace of mind for caregivers (19). In this program, seniors with dementia are equipped with individually personalized and accessible pre-programmed smart tablets (available in 15 languages) with tools for daily living support, socialization, and health monitoring. The smart tablets receive voice commands and send voice reminders and prompts for important activities of daily living (socializing, bedtime, medication, meals, etc.). The tablet also interacts with caregivers when tasks are not completed to prompt for potential intervention. A multilingual helpline and remote access to reprogram, debug, or fix tablets are also provided (50). This initiative was recently launched in 2023 with support from the Public Health Agency of Canada (PHAC) (78) and intervention research is being carried out by York University; findings will be shared on how to reach and successfully engage people living with dementia and caregivers with this technology (50).

CARE-RATE was initiated in 2015 through AGE-WELL[3] collaborative research, and leverages natural language processing and artificial intelligence to help caregivers search for and find relevant information and resources more quickly. Its approach differs from search engines that require knowledge of what a caregiver is looking for before searching it, allowing users to describe the situation one is facing rather than a solution and rate usefulness of the information provided to leverage machine learning to make better recommendations over time (22,79,80).

Direct Support for Care Partners

Caregiver Project for Seniors is led by the Alzheimer Society of Toronto and offers personalized consultations, system navigation, support groups, and workshops focused on caregiver wellness, dementia management, and self-care skills, as well as physical resources to enhance care (23). This project is supported by donations and grants and intended to offer flexibility to address needs that may include more traditional supports (e.g., respite care) to non-traditional (e.g., supplies). Outcomes include reduced caregiver stress and burnout, which enhances the ability to care for loved ones (81).

Coming Together to Support 2SLGBTQI People Living with Dementia and their Unpaid Primary Carers is multi-phase research, education, and bilingual awareness-raising project that responds to gaps in knowledge and a growing need for shared understanding, resources, and critical inquiry to support the wellbeing of PLWD who are also members of Two Spirit, lesbian, gay, bisexual, transgender, queer, and intersex (2SLGBTQI) communities and public awareness for those partnering in their context of dementia (50,82). The research and resources explore the lived experiences and perceptions of 2SLGBTQI PLWD and their primary unpaid caregivers (82). During Alzheimer's Awareness Month in January 2024, Egale, a national Canadian 2SLGBTQI organization, launched the *Help Us Remain* public awareness campaign to urge Canadians to take a closer look at the hidden issues and concerns facing this community through the use of bus shelter ads, social media content, an award winning short film (2024 Clio Health Awards), and audio stories to raise awareness of the need for tailored, inclusive healthcare support to preserve the identities and dignity of 2SLGBTQI PLWD. Over 4.1 million individuals were reached by this campaign (50).

Using Therapeutic and Culture-Based Approaches to Support the Well-Being of Care Partners of Red River Métis Living With Dementia is spearheaded by the Manitoba Métis Federation and Government of the Red River Métis, alongside the University of Manitoba, and offers a Métis-specific approach of culturally adapted cognitive behavioural therapy (CBT) in community-based counselling sessions, cultural engagement days, educational resources, sharing circles to support caregivers of Red River Métis PLWD and a wellness communication campaign (50,83). Initiated in 2023 with support from PHAC, the program aims to improve quality of life and wellbeing of Red River Métis PLWD and caregivers to reduce stress, enhance cultural connection, and raise dementia awareness (e.g., risks and protective factors associated with dementia) (50).

Other notable culturally specific programs that have been implemented in other jurisdictions with high success, include Jewish Care's Memory Way Cafes (84) and Singing for Memory programs in the UK (85).

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[3] AGE-WELL is a Canadian network aimed at advancing technology and innovation to support healthy aging. Its initiatives include research, innovation, and entrepreneurship, with projects focusing on assistive technologies, healthcare tools, and social inclusion.

Case Managed Collocated Interventions

These interventions offer resources similar to those included in the UK's Together in Dementia Everyday (TIDE) and Dementia Carers Count programs.

First Link® was first developed and implemented by the Alzheimer Society of Ontario in 2007 as a demonstration (pilot) project (86). The program aims to support consenting individuals upon diagnosis of dementia with a direct referral to their local Alzheimer Society. Over time the program has expanded to other provinces and offers a proactive referral process, with early access to counselling, support, education, information, referrals, and follow-up (24). It allows primary care providers to refer patients with memory or cognitive concerns for comprehensive assessments and individualized multi-component care plans through innovative partnerships between primary care, community agencies, and other providers across the dementia journey. The Canadian Age Well at Home federal grants and contributions program recently funded an initiative *Scaling Up Support Services for Seniors Living with Dementia and their Caregivers project*, allowing the Alzheimer Society of Canada to expand this program so more older adults living with dementia and caregivers across Canada can access to vital services. Expansion will focus on bringing in new staff to support new clients through several promotional campaigns, development of engagement strategies with different equity-seeking communities across the country, and scaling up internal resources for First Link® staff (50).

Multispecialty Interprofessional Team (MINT) Memory Clinics are an interprofessional team-based care model that promotes collaboration with primary care physicians and community partners. MINT clinics work with a patient's own family physician to receive comprehensive assessments and individualized care plans when experiencing memory or cognitive concerns (27). This model serves as a single access point for timely care and navigational supports to enhance quality of life for both patients and caregivers. It has also been shown to positively impact health professionals' perceptions of the challenges and attitudes associated with providing dementia care and interest in continued collaboration among health providers (87). MINT staff also train primary care providers in conducting standardized holistic assessments and other important educational offerings. In the past decade this not-for-profit organization that has spread to 100+ communities in Ontario with the support of numerous organizations (88). The model differs from other specialist-led memory clinic care models operating in tertiary care settings, hospital-based specialized geriatric services or specialized psychiatry services, and geriatric research centres that operate at arm's length from primary care and that focus on providing a consultation service with minimal provision of ongoing patient care (Ibid.). Recent funding has been provided through the federal Dementia Guidelines and Best Practices initiative for cultural adaptations of these clinics to improve equitable access to high-quality dementia guidance for older Canadians (50).

Day Programs

Green Care Farms Inc. is modelled after Dutch Care Farming approaches in the Netherlands. Like Reigershoeve residential care farm for PLWD (31) Green Care Farms offers immersive sensory and horticultural therapy for PLWD in Milton, Ontario (89). Participants engage in meaningful farm activities designed around the needs and abilities of members, including social engagement, physical activity and skill building opportunities with staff support, helping reduce stress, loneliness, and cognitive decline while improving mood, energy, and independence, and providing caregivers daytime respite opportunities

(30). Green Care Farms Inc. has recently offered training for community leaders interested with the desire to either open a care farm of their own or be directly involved in opening one (e.g. working with a farmer).

YouQuest is a daytime community-based support program in Calgary, Aberta designed to support the nonmedical needs of people living with young-onset dementia (YOD) also known as early onset dementia (60). YOD refers to people diagnosed with dementia before age 65 or those who show symptoms before that age and are in the process of receiving a diagnosis. YouQuest is offered in a public recreation setting where participants experience an inviting place to engage in meaningful activities co-planned by participants with recreation therapists and volunteers where participants define their needs and decide how to spend their day. This intervention is supportive of care partners ability to maintain work, family life, and their own health.

Dementia Inclusive Educational Interventions

Dementia Friendly Canada is a bilingual initiative hosted by the Alzheimer Society of Canada in partnership with several provincial and local Alzheimer Societies, with online training, tip sheets, and public service announcements to help create dementia-friendly communities (Alzheimer Society of Canada, 2024). With financial support from the Public Health Agency of Canada to support scale up and expansion of reach to new populations/jurisdictions/sectors, the initiative aims to increase awareness and accessibility, empowering confident, inclusive interaction with PLWD (50). Resources are provided in both English and French and align with other local and provincial dementia friendly initiatives.

Dementia Resources for Eating, Activity, and Meaningful Inclusion (DREAM) project created a toolkit with resources to promote the health and wellbeing of PLWD and caregivers. Founded on the principles of authentic co-design, the project team included PLWD, caregivers, community organizations, and researchers from the University of Waterloo and University of Northern British Columbia. The team created and adapted physical activity and nutrition training resources aimed at building community capacity by creating inclusive wellness services across Canada (50). These include educational modules, videos, handouts, and wallet cards in English, French, and other languages (including select key resources in Arabic, Simplified Chinese, Portuguese, and Punjabi) to support the integration of dementia-inclusive practices within organizations, supporting the inclusion, empowerment, and wellbeing through a variety of physical activities (including exercise and non-exercise), healthy eating, and mealtime programs and services (33).

Community Building and Arts-Based Connections

Together for Fun! was pioneered by the Alzheimer Society of Granby and region (Quebec), offering caregivers in nine different community settings in Quebec and Nova Scotia guidance on using simple activities to create meaningful shared moments. This initiative, followed by a support group for care partners, aims to boost caregiver skills, knowledge, and wellbeing while enhancing social inclusion and quality of life for caregivers and PLWD (37). A virtual adaptation of the program was also developed in response to the COVID-19 pandemic. The program received pilot funding from PHAC between 2019–2023.

What Connects Us – Ce qui nous lie is a Montreal-based project supported by the Public Health Agency of Canada[4] (2019–2023) that engages PLWD and their caregivers to create a sense of interconnectedness and support through storytelling, shared activities, and events, across partnerships with community organizations and institutions, including the Montreal Museum of Fine Arts and Les Grands Ballets (42). Community engagement through these collaborative offerings helped promote a positive public perception of dementia. Although several international initiatives provide social engagement activities, What Connects Us – Ce qui nous lie is innovative in its multi-modal and culturally rich participatory and community-centred approach to destigmatize dementia (50).

Dementia Dialogue is a community-based podcast that has partnered with Lakehead University, the Alzheimer Society of Ontario, and other community partners/sponsors to share the lived experiences of PLWD, their care partners, and supporters from across Canada (38). Interviews are often (co)moderated by people with lived experience and demonstrate their capacity to live fully and enable peer listeners to gain insight and strengthen their adaptive skills (90). The podcast began as an English offering and has expanded to also feature French-speaking PLWD and caregivers. The platform for storytelling fosters understanding, emotional validation, community engagement, and calls to action in support of PLWD and caregivers. Recently, learning guides contained within the podcast website have been developed to increase understanding of podcast content and maximize the potential to decrease stigma with accompanying PHAC research on how to best utilize the guides to assist those with lived experience.

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[4] Support from PHAC was evidenced between 2019-2023. What Connects Us – Ce qui nous lie appears to still be in operation at the time of writing.

Conclusion

The identification and support of community-dwelling PLWD and their care partners is complex, often involving layered supports and services that go beyond the health system to optimize outcomes for both (91). Proactive and tailored interventions can help to manage and accommodate for the impact of dementia and increasing limitations on daily activities, and related effects of offering care including stress/burnout, increased financial impacts and/or social isolation (92). Based on the application of internationally derived programmatic success factors and design and implementation considerations to a Canadian context, we highlight a range of community-based initiatives that embody three or more of these factors. Each offers unique opportunities as a case example to learn from and potential merit for maintenance support or opportunities for scale and/or spread to increase and sustain positive impacts on health, wellbeing, quality of life, relationships, and social engagement.

From our analyses, we developed a framework building on the literature review findings to outline the different factors and considerations for successful community-based interventions that are relevant to the Canadian context. The framework includes core principles and values, programmatic factors of success, and considerations for the design and implementation of interventions.

Core principles and values:
- ✓ anti-stigma
- ✓ accessibility
- ✓ equity and intersectionality
- ✓ sustainability.

Programmatic factors of success:
- ✓ early intervention
- ✓ triadic involvement in care planning
- ✓ individualized and person-centred approaches
- ✓ multi-component interventions
- ✓ direct care partner resources and tools
- ✓ community building and social engagement.

Considerations for design and implementation:
- ✓ identifying the target population
- ✓ delivery of the program/intervention
- ✓ costs, resources, and system incentives
- ✓ the measurement of success in its process, impacts, and outcomes
- ✓ geography and local context.

It is important to support care partners with their caregiving responsibilities and build their capacity to continue caring, especially when caregivers have their own health and social care needs. This includes increasing awareness and understanding of important programs and services, supporting system navigation and at different stages of progression and across different geographies, diverse backgrounds and unique needs and circumstances (e.g., ethno/cultural/linguistic offerings, young caregivers, working) (17,29,32,41,45,47,48). Ensuring caregivers, both local and remote, remain engaged throughout interventions is also crucial to achieving successful outcomes (21,26,28,36).

Many of the interventions described are developed and delivered by community-based not-for-profit organizations and NGOs using a patchwork of funding. Reducing costs for programs, offering system incentives like reimbursements and baseline funding can improve accessibility to needed programs and promote better more sustainable care (16,20,25,26). In considering best options for support, scope, and reach, it is important to achieve a balance between cost efficiencies, economies of scale, and opportunities for social inclusion and individually tailored interventions. For example, while group interventions/sessions provide valuable support, they may not always offer the personalized care that some care partners need, highlighting the importance of individualized approaches (18,43,44,47,57).

The COVID-19 pandemic was particularly hard for many isolated older adults and taught many valuable lessons on the viability of supporting the wellbeing and social connections of PLWD and care partners virtually—particularly when in-person programs and services were restricted. Virtual programs were found to enhance opportunities for social engagement, and in some cases led to continued involvement in programs and social gatherings for many whose needs became too complex to continue to attend or actively participate in-person (e.g., day program eligibility criteria) or able to travel to the program). Beyond virtual programing, expanding current day program offerings to support tangible supports (e.g., enhanced personal care, foot care, health and behaviour monitoring, etc.) would provide opportunities for more consistent and reliable health and social care across PLWD's progressing needs in a familiar setting and by familiar staff. Such expansion would benefit PLWD and care partners affected by program discharge due to heightened personal care needs, while also addressing challenges in accessing required home care given global care worker shortages. Community-dwelling PLWD and their care partners require a range of support that extends beyond the health system as they adapt to the progressive changes of dementia. Based on our review of the academic literature and promising programs internationally and in Canada, to achieve positive impacts on various aspects of health, wellbeing, and quality of life for PLWD and their caregivers, investment in the creation of new interventions or scaling existing ones should incorporate at least three of the five programmatic factors of success, while also considering the other elements of the framework.

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Appendix A. Detailed Methodology

Literature Search

Box A1. Search Terms

(dementia OR alzheimer OR neurocognitive disorder OR neurodegenerative disorder)
AND (unpaid caregivers OR carers OR informal caregivers OR family caregivers OR caretaker OR care partner)
AND (home and community care OR community-based care OR home care services OR home-based care)
AND (caregiver support OR dementia support)
AND (quality of life)
AND (satisfaction)
AND (quality of care)

The rapid academic review was focused on identifying community interventions for PLWD and/or their caregivers, while also assessing the outcomes. A search strategy was developed using search terms and keywords related to the main concepts: AD/ADRD, caregivers, home and/or community-based supports, and individual-level outcomes (see **Box A1**).

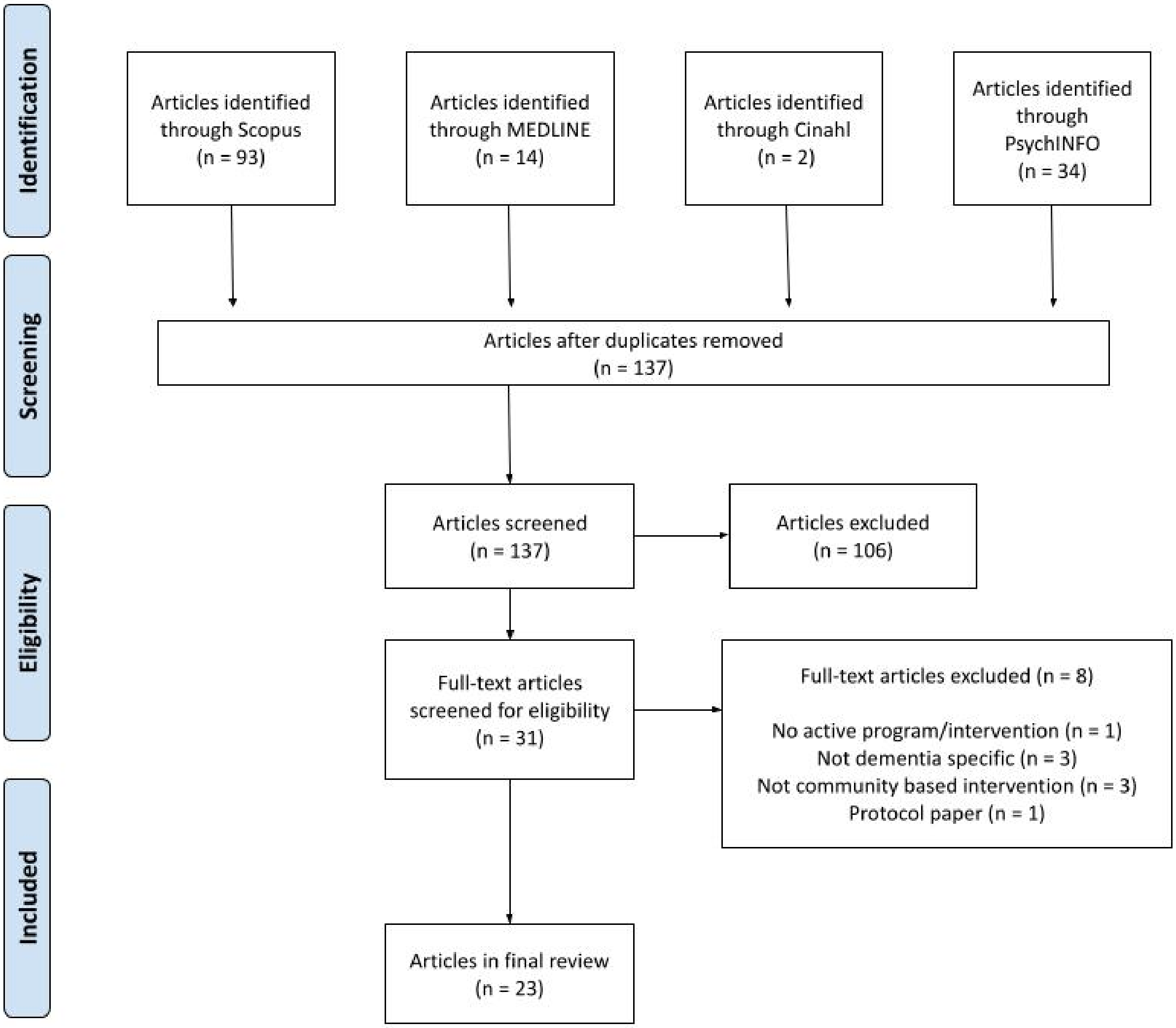
The search was executed in four databases (Scopus, Medline, CINHAL, and PsychInfo) and results were imported to Rayyan, a systematic review software, for screening. Screening occurred in two stages: 1) title/abstract and 2) full-text. Articles were included or excluded based on the criteria in **Table A1**.

Articles that met inclusion after title/abstract and full-text screening (see **Figure A1**) underwent data extraction to detail key characteristics of the paper (author, year published, year the study was conducted, country in which the study was conducted), the study design and methods, the population of interest or disease stage (if specified), the intervention (including outcome(s) of interest, measured, and evaluation), results, and lessons learned. Three research assistants (CS, SS, KM) read through the articles and completed the data extraction table; the results were then reviewed and lessons learned compiled, focusing specifically on barriers and enablers to implementation, and programmatic factors seen to be connected to positive outcomes for PLWD and/or their caregivers.

Table A1. Inclusion and Exclusion Criteria

Included	Excluded
- Language: English - Type: peer-reviewed articles, reviews - Program, intervention or approach for people living with dementia and their caregivers; assesses the impact or outcomes of the community-based program; assesses the caregiver and care recipient needs for community-based care; included the patient and caregiver outcome.	- Language: Non-English - Type: Not peer-reviewed, protocol papers, books - Program is not intended for those living with dementia or their caregivers - Is not measuring a program or intervention - Program is in a different setting other than the community - There are no measures of the patient or caregiver outcomes being assessed.

Figure A1. PRISMA Diagram



Jurisdictional Review

The rapid literature review was supplemented by a rapid jurisdictional review of four jurisdictions of interest—Canada, Denmark, the United Kingdom (UK), and the Netherlands—to further identify promising innovations and compare promising features and lessons learned in offering supportive community-based care to PLWD and their caregivers. We searched grey literature, including government and other relevant organizational websites (e.g., Public Health Agency of Canada, Age-Well, Alzheimer's Society Canada and UK, Scotland's National Dementia Strategy 2023 – *Everyone's Story*, Alzheimer Nederland, and The Dementia Alliance in Denmark) to identify promising practices in these jurisdictions. The Canadian search in particular targeted key governmental (e.g., Public Health Agency of Canada [PHAC], Health Canada), non-governmental (e.g., Alzheimer Society of Canada, Canadian Dementia Learning & Resource Network), and sector-specific websites (e.g., AgeWell, Baycrest Centre for Aging and Brain Health Innovation) to streamline the search process (RC, FMC).

Due to the vast number of potential interventions available and the need to efficiently identify relevant examples, Canadian interventions were pre-screened based on funding sources, geographic spread, accessibility, and comprehensiveness in regard to programmatic factors and populations served. Additional information was obtained through further searches of the intervention/programs' websites and associated publications. To ensure inclusivity and address any gaps, a French-language search using the same methodology was conducted to complement the findings of the English-language search (RC). Findings were reviewed by various team members (RC, FMC, MR, SA) to confirm suitability and mitigate bias.

A data extraction template was created to systematically characterize key details about all of the included interventions, including intervention/sub-intervention name, organizational lead(s), partners, initiation/time-limitation, goals, target population(s), geographic focus, direct/anticipated outcomes, practices to achieve outcomes, funding source(s), and associated policies/strategies.

Appendix B. Programmatic Factors and Associated Outcomes

	Early Intervention	Individualized & Person Centered Approaches	Triadic Involvement in Collaborative Care Planning	Multicomponent Interventions	Direct Resources & Tools for Care Partners	Community Building & Social Engagement
Psychological						
Distress *(Caregivers)*		-			-	
Emotional disruption *(Caregivers)*		-				
Well-being	+ (CG)	+ (Both)		+ (CG)	+ (Both)	+ (PLWD) 0 (CG)
Subjective mood		+ (Both)			+ (Both)	+ (Both)
Satisfaction with life and/or circumstances		+ (Both)			+ (PLWD) 0 (CG)	+ (PLWD) 0 (CG)
Happiness						+ (Both)
Stress & burden *(Caregivers)*		0		0	0	0
Anxiety	0 (CG)	- (CG)		- (CG)	0 (CG)	- (PLWD)
Competence, mastery, & self-efficacy *(Caregivers)*		0		+	+	
Cognitive functioning *(PLWD)*		+			0	
Depression symptoms *(Caregivers)*	0	-	0		0	0
Social/interpersonal						
Relationship between caregivers & PLWD		+ (Both)			+ (Both)	+ (Both)
Family fonflict *(Caregivers)*		-	-			
Satisfaction with support *(Caregivers)*		+	+			
Empathy *(Caregivers)*		+			+	
Perspective-taking *(Caregivers)*		+			+	
Attitudes towards dementia *(Caregivers)*					+	
Social, emotional, & instrumental support		+ (Both)		+ (CG)	+ (Both)	+ (Both)
Social engagement		+ (Both)		+ (PLWD)	+ (Both)	+ (PLWD)
Health, quality of life, & service use						
Aging in place *(PLWD)*	+					
Quality of life	+ (Both)	+ (Both)	+ (Both)	+ (PLWD) 0 (CG)	+ (Both)	+ (CG) 0 (PLWD)
Service use	+ (PLWD)	+ (PLWD)		+ (PLWD)	+ (PLWD) 0 (CG)	
Institutionalization *(PLWD)*	-				-	
Hospitalization *(PLWD)*	-	-	-	-	-	
Emergency department visits *(PLWD)*	-	-	-	-	-	
General functioning *(PLWD)*	0	+	0	0	+	+
Knowledge of resources *(Caregivers)*					+	
Knowledge of disease *(Caregivers)*		0				
Satisfaction with intervention & quality of care[1]	+ (Both)	+ (Both)		+ (PLWD)	+ (Both)	

Notes. *PLWD = People Living with Dementia; CG = Caregiver. To compute each of the cells, the positive, negative, and null effects observed across all studies exhibiting a given programmatic factor and measuring a given outcome were summed: + = more evidence to suggest a positive effect, - = more evidence to suggest a negative effect, and 0 = evidence is inconclusive.*

[1] Encapsulates the following outcome variables: "Satisfaction with pain control", "Satisfaction with end-of-life care", "Satisfaction with intervention", "Satisfaction with quality of care", and "Satisfaction with nursing care"

www.NAOhealthobservatory.com

naobservatory@utoronto.ca

nao_health