

RESEARCH ARTICLE

# CCCDTD5: Individual and community-based psychosocial and other non-pharmacological interventions to support persons living with dementia and their caregivers

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## Abstract

**Introduction:** Current pharmacological therapies for dementia have limited efficacy. Thus it is important to provide recommendations on individual and community-based psychosocial and non-pharmacological interventions for persons living with dementia (PLWDs) and their caregivers.

**Methods:** Phase 1: A systematic review for developing recommendations on psychosocial and non-pharmacological interventions at the individual and community level for PLWDs and their caregivers. Phase 2: Rating of recommendations using the Grading of Recommendations Assessment, Development and Evaluation (GRADE) guidelines. Phase 3: Delphi process (>50 dementia experts) for approving recommendations by the 5<sup>th</sup> Canadian Consensus Conference on the Diagnosis and Treatment of Dementia (CCCDTD5).

**Results:** The CCCDTD5 approved the following recommendations: Exercise (1B) and group cognitive stimulation for PLWDs (2B), psychosocial and psychoeducational interventions for caregivers (2C), development of dementia friendly organization and communities (2C), and case management for PLWDs (2B).

**Discussion:** The CCCDTD5 provides for the first time, evidence-based recommendations on psychosocial and non-pharmacological interventions for PLWDs and their caregivers that can inform evidence-based policies for PLWDs in Canada.

## KEYWORDS

dementia, non-pharmacological interventions, psychosocial interventions

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## 1 | INTRODUCTION

Dementia is a chronic disorder characterized by a decline in cognition.<sup>1-2</sup> Affecting >50 million people around the globe,<sup>3</sup> it is one of the most significant causes of disability among people 65 years and older, greater than other diseases such as stroke, musculoskeletal disorders, and cardiovascular diseases.<sup>4</sup> Different neurological diseases can cause dementia. The most common conditions are Alzheimer's disease, vascular dementia, dementia with Lewy bodies, and frontotemporal dementia.<sup>5</sup>

Persons living with dementia have symptoms in various domains such as memory, learning, language, executive function, attention, and social cognition.<sup>1,6</sup> The symptomatology associated with dementia can vary depending on the severity of the disease and from person to person. The National Dementia Strategy for Canada aims to promote the best quality of life for PLWDs and their caregivers, by providing access to quality of care and support services for dementia, and by promoting supportive communities.<sup>7</sup> The American Psychiatric Association recommends the use of individualized and multimodal management for PLWDs.<sup>6</sup> Given that dementia impacts more than health, affecting almost all activities of daily living and the ability to manage finances,<sup>8</sup> transportation,<sup>9</sup> and socializing,<sup>10</sup> an individualized approach to supporting PLWDs is paramount. A diagnosis of dementia not only affects the PLWDs, but also impacts the physical, psychological, and economic health of family and caregivers.<sup>2,6,11</sup> For instance, caregivers of PLWDs report higher rates of depression and anxiety compared to their counterparts caring for physically impaired older adults.<sup>12</sup>

The World Health Organization (WHO) in 2012<sup>2</sup>, followed by a Global Dementia Action Plan in 2017,<sup>13</sup> recommended that countries consider dementia as a high priority. Countries were encouraged to actively consider the needs and preferences of PLWDs, community supports, and to move beyond just pharmacological management.<sup>13</sup> Current medications for dementia aim to manage symptomatology (eg, sleep disorders and behavioral problems such as depression, anxiety, aggression, and psychosis) and to slow down the progression of the disease with varying levels of success.<sup>14-15</sup>

There are many reasons that psychosocial and other non-pharmacological management strategies should be prioritized. Current medications have limited efficacy,<sup>16</sup> numerous side effects, and due to the age of the patient, altered absorption, metabolism, and distribution.<sup>6</sup> PLWDs and their caregivers have many different needs that need to be considered holistically and individually.<sup>2</sup> It is important to note that psychosocial and other non-pharmacological interventions can have a positive effect on outcomes for PLWDs.<sup>16-17</sup> For instance, evidence suggests that cognitive stimulation therapy improves cognition and self-reported quality of life. Exercise interventions have positive effects on functional status for PLWDs, in addition to the other health benefits of physical activity (cardiovascular and cerebrovascular health, reduction of obesity, increase of strength, and protection against frailty).<sup>17</sup> Finally, psychosocial and other non-pharmacological interventions are non-invasive, safe, and have few side effects.<sup>16,18</sup>

### HIGHLIGHTS

- We recommend exercise for persons living with dementia (PLWDs). 1B (93%).
- We recommend group cognitive stimulation therapy for PLWDs. 2B (96%).
- We recommend psychosocial and psychoeducational interventions for caregivers of PLWDs. 2C (96%).
- We recommend the development of dementia-friendly organizations/communities for PLWDs. 2C (91%).
- We recommend the use of case management for PLWDs. 2B (93%).

### RESEARCH IN CONTEXT

1. Systematic review of reviews and Delphi: A systematic review of reviews describing individual and community-based psychosocial and other non-pharmacological interventions for persons living with dementia (PLWDs). Study results were shared with a group of dementia experts for grading to inform recommendations as part of the 5<sup>th</sup> Canadian Consensus Conference on the Diagnosis and Treatment of Dementia (CCCDTD5).
2. Interpretation: We provide evidence-based recommendations on psychosocial and non-pharmacological interventions for PLWDs and their caregivers.
3. Future directions: The recommendations of the present study can be useful to guide the development of policies and clinical guidelines for PLWDs and their caregivers in Canada, with the possibility of informing other jurisdictions as well. Other non-pharmacological interventions for dementia not covered by the review and the CCCDTD5 discussion (eg, cognitive rehabilitation, cognitive training) will be reviewed and discussed in future CCCDTD events.

## 2 | INDIVIDUAL AND COMMUNITY-BASED PSYCHOSOCIAL AND OTHER NON-PHARMACOLOGICAL INTERVENTIONS

Individual and community-based psychosocial and other non-pharmacological interventions aim to improve health, functioning, and well-being.<sup>19</sup> In this article we consider interventions that aim to improve symptoms, reduce caregiver stress (which in turn has been shown to improve care for PLWDs), or adapt organizations and communities to the needs of PLWDs and their caregivers.<sup>16</sup> Their goal is usually to enhance the quality of life and well-being; hence support is required at the individual and community level.

At the individual level, psychosocial and non-pharmacological interventions often involve a philosophy of “person-centered care,” which means that the values and preferences of individuals are elicited and, once expressed, guide all aspects of their health and social care, supporting their health and life goals as best as possible.<sup>20–21</sup> This philosophy focuses on the holistic health and resources of the person, and not only the disease and its consequent limitations.<sup>20</sup> Person-centered care is achieved through a dynamic relationship among PLWDs, others who are important to them, and relevant providers.<sup>20</sup> Furthermore, person-centered care seeks to ensure that people maintain their functional status as expressed by them, regardless of the disease they are facing.<sup>11</sup> Based on this philosophy, clinicians are expected to look beyond the medical treatment of a disease, as they should listen to the story told by their patient, trying to understand how the disease affects the person's daily life.<sup>20</sup> Person-centered care seeks a shared agreement of care provided between the person living with the condition, their caregivers, and the clinician.<sup>20</sup> At the community level, these interventions aim to support PLWDs and their caregivers in their day-to-day lives, as well to reduce stigma and increase community awareness. Dementia-friendly communities, for instance, aim to preserve the safety and well-being of people living with dementia, empowering all the members of the community so that they value the capabilities and of PLWDs in the place where they reside.<sup>22–23</sup>

It is essential to identify psychosocial and other non-pharmacological interventions that improve the symptoms of PLWDs and reduce stress for their caregivers and family members, and that organizations and communities can adopt to give support to PLWDs.

Our objective was to develop Canadian recommendations on psychosocial and other non-pharmacological interventions, at individual and community levels, for community-dwelling PLWDs.

### 3 | METHODS

Since 1989, the CCCDTD has convened five times to provide evidence-based dementia diagnostic and treatment guidelines for clinicians and researchers in Canada. This work is done as part of the fifth iteration of the CCCDTD.<sup>24</sup> This paper provides details on the recommendations developed for individual and community-based psychosocial and other non-pharmacological interventions for PLWDs and their caregivers.

To develop the present recommendations, we used a three-phase process:

- Phase 1: A preliminary review was conducted to determine the scope of the review questions. The findings of this preliminary review were shared and discussed with a panel of experts (described below) to determine the feasibility and the scope of the review of reviews. After reaching consensus, we conducted a systematic review of reviews to develop preliminary recommendations on the five selected areas under consideration. A systematic review of reviews allows the inclusion of reviews already conducted on various psychosocial and other non-pharmacological interventions for

dementia, thus rapidly obtaining the evidence available while minimizing errors in data extraction.<sup>25</sup>

- Phase 2: A working group of 11 experts who were members of the CCCDTD5 Working Group 7 graded the recommendations (see Appendix A). The members of the panel were from various backgrounds, representing PLWDs, clinicians, and researchers. The results of this review of reviews were shared with the working group with the aim of developing recommendations based on the identified interventions by using the Grading of Recommendations Assessment, Development and Evaluation (GRADE) system.<sup>26</sup>
- Phase 3: The full CCCDTD5 panel of experts, involving >50 Canadian experts on dementia, voted on the recommendations and their rationale. This process was based on the Delphi consensus method. Members of the CCCDTD5 expert group were from various backgrounds representing PLWDs, caregivers, family physicians, other geriatric specialists, allied health care professionals, researchers, and policymakers.

### 3.1 | Systematic review of reviews

This systematic review of reviews<sup>27</sup> was carried out on psychosocial and other non-pharmacological interventions at individual and community levels for PLWDs with the support of an academic librarian with expertise in conducting systematic reviews of reviews. The study was conducted following the preferred reporting items for systematic reviews and meta-analyses (PRISMA) checklist for systematic reviews.<sup>28</sup>

#### 3.1.1 | Search strategy

The search of the scientific and gray literature was carried out in the following databases and websites between September 3, 2019 and September 11, 2019: PubMed/Medline plus, Google Scholar, Medscape, UpToDate, DynaMed, Primo Tri-Universities Group of Libraries (Wilfrid Laurier University, University of Waterloo, and University of Guelph), National Library of Medicine Health Services Research Information Central, WORLDCAT, EBSCO database for academic libraries, Cochrane database of systematic reviews, Agency of Health Research and Quality—National Guideline Clearinghouse, NICE, American Geriatrics Society, British Geriatrics Society, National Institute of Health / National Institute on Aging, Sagelink, Taylor and Francis (not indexed in PubMed).

To be included, the reviews needed to meet the following criteria: (1) interventions with robust systematic, meta-analysis, or scoping reviews that allow for more immediate recommendations; (2) involving community-dwelling populations (eg, excluding reviews of interventions in long-term care only); (3) individual and community level psychosocial and non-pharmacological interventions; and (4) interventions aimed at PLWDs and their caregivers. Reviews of interventions for persons with mild cognitive impairment (MCI) or for persons living in a long-term care facility were excluded.

Given the abundance of the literature and the time constraints (the working group was required to gather the information and provide recommendations within 2 months), and based on the preliminary analysis of the literature, we included interventions for which the expert panel concluded there was a sufficient body of evidence. Members of the working group agreed that other interventions such as cognitive rehabilitation, computerized training, virtual reality, art therapy, music, aromatherapy, and reminiscence therapy and professional support for caregivers (eg, cognitive behavioral therapy, psychotherapy) require a different approach and will be reviewed for recommendation in the next iteration of the CCCDTD.

Medical Subject Headings (MeSH) terms and text words were used for searching the literature and were tailored to meet the characteristics of the databases used. Because the topic of psychosocial and non-pharmacological interventions is broad, we conducted five different searches on each database. A complete search strategy for Medline is presented in Appendix B.

Individual level interventions:

- The effect of physical activity (including reviews on fitness and daily physical activity such as gardening/vacuuming) for PLWDs
- The effect of cognitive stimulation for PLWDs
- The effect of psychosocial education (support groups, respite care may be considered within this category) for caregivers for PLWDs
- Community level interventions:
  - The impact of dementia friendly organizations/communities for PLWDs
  - The impact of case management for PLWDs

Given the rapid evolution of psychosocial and other non-pharmacological interventions and the need to provide results in a limited timeframe as requested by the CCCDTD5 leadership, we limited our search to studies published from September 2014 to September 2019, representing the last 3 years of available literature on the topic. However, with the help of the librarian, we conducted backward citation tracking to identify companion articles that were published before 2014. Thus relevant reviews published before 2014 were included in the present study. No language limitation was applied. Duplicates were removed from each individual search. Abstracts and full texts were extracted for the remaining articles.

Study selection was carried out by two reviewers in parallel (SS, IV). Disagreements were resolved by the consensus approach. A similar process was used for data extraction. Both authors independently extracted information from each article on the first author, year, country, review method, type of interventions, target population, number of included articles, and total population, when the information was available (see Table 1). Any outcomes (patient-level outcomes, caregiver-level outcomes, system-level outcomes) were extracted. We did not contact the authors of the article to obtain missing or incomplete information regarding data or methods.

### 3.1.2 | Synthesis method

Based on the type of intervention, articles were organized in five groups (exercise, cognitive stimulation therapy, psychoeducational interventions, dementia friendly organizations and communities, and case management). For each type of intervention, we synthesized the outcome by carrying out a qualitative synthesis.<sup>29-31</sup> Results were integrated at the level of extracted data.

### 3.2 | Develop recommendations with the working group

This systematic review was informed by a working group including persons with lived experiences. The members of the working group convened as many times as was necessary to complete the following objectives to discuss and reach consensus for general methods and search strategy, determine inclusion and exclusion criteria, review of results, and reach consensus on recommendations.

Based on the Grading of Recommendations Assessment, Development and Evaluation (GRADE),<sup>26</sup> experts rated the quality of evidence from the systematic review of reviews and meta-analyses, assigning the grade of recommendation and the level of evidence. Any disagreement was resolved by consensus during the working group meetings.

### 3.3 | Validation of recommendations by the CCCDTD5 panel of experts

A semi-structured consensus building methodology was used, based on the Delphi consensus method,<sup>32</sup> to generate the final recommendations of the working group. The CCCDTD5 panel of experts, involving >50 Canadian participants, decided whether the recommendations were accepted or not, following specific guidelines. According to these guidelines:

- The recommendation was accepted if 80% or more of the group agreed with the recommendation.
- The recommendation was accepted upon revision and re-voting at an in-person meeting with a minimum of two delegates per working group in attendance if 60% to 80% agreed with the recommendation.
- The recommendation was not accepted if <60% agreed with the recommendation.

## 4 | RESULTS

We identified 169 systematic reviews, meta-analyses, and scoping reviews. After removing duplicates, evaluating title and abstracts, and reading full texts, 22 articles were included in our review.

**TABLE 1** Characteristics of included studies

Authors and year of publication	Countries	Method	Type of intervention(s)	Outcome of interest	Target population	Number of included articles	Total population
Sanders LMJ, et al (2019) <sup>35</sup>	Not reported	Systematic review and metaanalysis	Exercise defined as "aerobic, anaerobic, multicomponent or psychomotor exercise of any intensity or frequency, and a duration of $\geq 4$ weeks"	All outcomes reported in the primary studies	People 50 years and older with and without cognitive impairment (MCI, VCI or dementia)	36	2007 participants.
Jia et al (2019) <sup>34</sup>	China (7), Brazil (2), Italy (1), Australia (1), Germany (1), Denmark (1).	Systematic review	Exercise-only intervention.	All outcomes reported in the primary studies	Diagnosed with dementia	13	673
Forbes D et al. (2015) <sup>33</sup>	United States (4), Sweden (1), France (2), Australia (2), Netherlands (3), Belgium (1), Brazil (1), Italy (1), South Korea (1), Spain (1).	Systematic review	Exercise programs offered over any length of time. Any combination between aerobic-, strength-, or balance-training. Duration: From two weeks to 18 months.	Effects of exercise on cognition, activities of daily living, neuropsychiatric symptoms, and depression. Secondary outcomes: Effects on caregiver burden and adverse effects of exercise.	Older people with Alzheimer's disease.	17	1067 participants
Zuchella Cet al. (2018) <sup>16</sup>		Systematic review	Exercise and motor rehabilitation	All outcomes reported in the primary studies	persons living with dementia.	49	Not reported
Clarkson et al. (2017) <sup>39</sup>	No information provided	Overview of systematic reviews with narrative summary	Cognitive intervention classified as cognitive stimulation, cognitive training and cognitive rehabilitation.	All outcomes reported in the primary studies	persons living with dementia.	18	Not reported
Huntley et al. (2015) <sup>37</sup>	No information provided	Systematic review, metaanalysis and meta-regression	Cognitive stimulation therapy	Impact on persons living with dementia and/or their caregivers.	Persons living with dementia and their caregivers.	36	Not reported
			Cognitive interventions classified as cognitive stimulation, cognitive training and cognitive rehabilitation.	Impact on cognitive measures (eg, MMSE, ADAS-Cog)	Persons living with dementia, >60 years old,	33	Not reported

(Continues)

TABLE 1 (Continued)

Authors and year of publication	Countries	Method	Type of intervention(s)	Outcome of interest	Target population	Number of included articles	Total population
Woods et al (2012) <sup>36</sup>	France, United Kingdom, Italy, Spain, Brazil.	Systematic review	Cognitive stimulation as an intervention with a range of enjoyable activities providing general stimulation for thinking, concentration, and memory, usually in a social setting, such as a small group	Outcomes: persons living with dementia: performance on test on cognitive functioning, mood, well-being, ADLs, behaviour, neuropsychiatric symptoms and behaviour problems, social engagement.	Persons living with dementia (Alzheimer's disease, vascular dementia, mixed of both). No age restriction.	15	718
Dickinson et al (2017) <sup>44</sup>	No information	Systematic review of systematic reviews and metaanalyses	Psychosocial interventions including cognitive behavioral therapy, psychotherapy, family therapy, counseling, anxiety and depression management, stress management, education and psychoeducation, health education and social support.	caregivers': well-being, depression, anxiety, burden, strain, coping, satisfaction with intervention. Psychological outcomes such as depression or anxiety, healthcare use and quality of life.	Informal caregivers of persons living with dementia. Community dwelling.	31 (seven studies on intervention of interest- psychoeducational interventions)	Not reported
Gilhooly et al (2016) <sup>41</sup>	No information provided	Meta-review of systematic reviews and metaanalyses.	Psychoeducational interventions	Psychological wellbeing and knowledge/coping strategies	Persons living with dementia and/or their caregivers	45 (seven on psychoeducational interventions)	Not reported
Huis in het Veld et al. (2015) <sup>40</sup>	Netherlands (3), Australia (1), Brazil (1), Canada (1), Germany (1), Taiwan (1), United Kingdom (1).	Systematic meta review	Professional self-management support interventions, provided by a professional, focused on helping the informal caregiver to deal with the relative's dementia and its consequence on daily living.	Effects on caregiver	Informal caregivers of persons living with dementia.	10	Not reported

(Continues)

TABLE 1 (Continued)

Authors and year of publication	Countries	Method	Type of intervention(s)	Outcome of interest	Target population	Number of included articles	Total population
Laver et al (2017) <sup>45</sup>	United States, Taiwan, Netherlands, Hong Kong, Canada, Italy, Brazil, Finland, Denmark.	Systematic review and metaanalysis	Interventions focussed on "education, counseling, information regarding services, enhancing caregiver skills to provide care, problem solving and strategy, development, and increasing resilience and coping skills in the caregiver"	Direct impact on the caregiver (depression, quality of life, caregiver burden, and caregiver upset in relation to behavioral and psychological symptoms of dementia), Persons with dementia (ADL function, behavioral and psychological symptoms of dementia)	Caregivers of persons living with dementia, or dyad.	40	6157
Vandepitte et al (2016-1) <sup>43</sup>	No information provided	Systematic review		Impact of intervention on caregiver, care recipient or on health care resource utilization.	Caregivers, persons living with dementia	17	4000
Vandepitte et al (2016-2) <sup>42</sup>	United Kingdom (4), Netherlands (4), United States (22), Germany (4), Canada (3), Russia (1), Australia (1), Sweden (3), France (1), Spain (3), Norway (1), Finland (1), Denmark (1), Italy (3), Southern Europe (no mention of specific countries - 1)	Systematic review	Psychoeducational interventions	Effect of the intervention on the wellbeing of caregivers or persons living with dementia	Caregivers and persons living with dementia	53	Not reported
Buckner et al (2019) <sup>48</sup>	England	Scoping review of lay literature	Dementia friendly communities	Impact of dementia friendly communities on persons living with dementia and their caregivers	PLW and caregivers	100 dementia friendly communities in England	Not applicable

(Continues)

TABLE 1 (Continued)

Authors and year of publication	Countries	Method	Type of intervention(s)	Outcome of interest	Target population	Number of included articles	Total population
Hebert et al (2019) <sup>23</sup>	Europe (mainly UK), Australia, Canada, New Zealand, United States	Quantitative, qualitative, and conceptual/theoretical peer reviewed research literature	Dementia-friendly initiatives in care, long term care, and community settings.	Achieving dementia friendly spaces	persons living with dementia	20 empirical articles and 12 conceptual or theoretical articles.	Not reported
Parke et al (2017) <sup>47</sup>	No provided	Scoping review	Dementia-friendly hospital design for acute care	Impact on hospitalized older persons with dementia for acute care	Persons living with dementia	28 studies	Not reported
Lin et al (2017) <sup>46</sup>	Not applicable	Concept exploration	Dementia friendly communities	Concept of dementia friendly communities	Persons living with dementia	Not applicable	Not applicable
Reilly et al (2015) <sup>51</sup>	United States, Hong-Kong, Canada, India, Finland, United Kingdom, Netherlands,	Systematic review of RCTs	Case management	Effects on persons living with dementia admission to nursing home, on period before entering long-term care, behaviour disturbance, depression, functional abilities and cognition. Care burden, depression, well-being, social support. Healthcare costs.	Persons living with dementia and their caregivers	13	9615
Bunn et al (2016) <sup>52</sup>	Not provided	Evidence synthesis-systematic review (both terms are used)	Case management -Admiral nurses	Scope and effectiveness of admiral nurses	persons living with dementia and caregivers	33 items (10 classified as research)	Not reported
Khanassov et al (2016) <sup>53</sup>	United States, United Kingdom, Netherlands, Sweden, Belgium	Systematic mixed studies review	Case management	persons living with dementia and caregivers needs.	persons living with dementia and caregivers	Eight studies on case management	Not reported
Khanassov et al (2014) <sup>50</sup>	United States, Belgium, Netherlands, India, China, United Kingdom, Australia,	Systematic mixed studies review	Case management	Factors associated with Case Management	persons living with dementia	23	Not reported
Somme et al (2012) <sup>49</sup>	United States, Sweden	Systematic literature review	Case management	Effects on clinical outcomes and use of services of persons living with dementia	persons living with dementia	6 RCTs	Not reported



## 4.1 | Individual level interventions

### 4.1.1 | Exercise

For this intervention, four reviews were identified.<sup>16,33–35</sup> Exercise was found to have effects on global cognition,<sup>34–35</sup> activities of daily living,<sup>33</sup> caregiver burden,<sup>33</sup> physical health, and well-being for PLWDs,<sup>16</sup> as well as reducing behavioral and psychological symptoms of dementia.<sup>16</sup> There are heterogeneous findings regarding the characteristics of exercise recommended. Exercise programs with short session duration and high frequency were found to be associated with higher effect sizes<sup>35</sup>; however, other authors found that there was no difference between high or low intensity exercise sessions in their effects on cognition in PLWDs.<sup>34</sup>

The varied evidence on the characteristics of exercise sessions recommended is explained by the variety of exercise methods explored for PLWDs. These methods include aerobic exercise, resistance training, weightlifting, balance, and flexibility, and the measuring method for its intensity and effect varies between studies.<sup>16</sup> Exercise programs should be tailored by the health care professional to each individual's needs and characteristics, to maximize adherence to exercise recommendations and to ensure long-lasting effects.<sup>35</sup>

### 4.1.2 | Cognitive stimulation therapy

For this intervention, we included four systematic reviews.<sup>16,36–39</sup> Cognitive stimulation therapy is an intervention for PLWDs that offers a range of enjoyable activities providing general stimulation of thinking, concentration, and memory usually in a social setting, such as a small group.

Cognitive stimulation therapy was found to have positive effect on the PLWDs<sup>16,37</sup> with evidence of improved cognition,<sup>16,39</sup> quality of life,<sup>36,39</sup> memory,<sup>36</sup> thinking test scores,<sup>36</sup> such as Mini Mental State Examination (MMSE) and the Alzheimer's Disease Assessment Scale-cognitive subscale,<sup>16</sup> and communication and interaction skills with others.<sup>36</sup> Studies did not show improvements in the mood of PLWDs, in their behavior, or in their independence and ability to care for themselves.<sup>36</sup> Most of the papers that evaluated this intervention included PLWDs in the mild to moderate stages of the disease and did not find benefits for persons with advanced stages of dementia.

### 4.1.3 | Psychoeducational interventions

For this intervention, six systematic reviews were selected.<sup>40–45</sup> This intervention, tailored for caregivers of PLWDs, has the aim of developing problem-focused coping strategies while psychosocial interventions address the development of emotion-focussed coping strategies.<sup>40,42,44–45</sup> Coping strategies include education, counseling, information regarding services, enhancing caregivers' skills to provide care, problem solving, and strategy development to address the problems that the caregivers identified.

Psychoeducational interventions demonstrated benefit for PLWDs in terms of behavioral and psychological symptoms<sup>41,45</sup> and coping with the disease.<sup>41</sup> For caregivers, these interventions improved their well-being,<sup>41</sup> knowledge about dementia,<sup>41</sup> skills to provide care for the PLWDs,<sup>45</sup> resilience,<sup>45</sup> psychological health,<sup>44</sup> and coping with the disease.<sup>40–41,45</sup> Delays in accessing these services may affect the benefits obtained from this intervention.<sup>41</sup> Psychoeducational interventions reduce depressive symptoms, improve quality of life, and reduce the impact on the caregiver.<sup>45</sup> However, other authors found that psychosocial interventions had no effect on depressive symptoms or on caregiver burden.<sup>42</sup>

## 4.2 | Community level interventions

### 4.2.1 | .Dementia-friendly organizations and communities

For this intervention, four reviews were selected<sup>23,46–48</sup>; two focused on dementia-friendly care organizations, one focused on dementia-friendly communities, and one focused on both types of interventions. This intervention is defined as the practice and organization of care and communities that are aware of the impact dementia has on a person's ability to engage with services and manage their health, promoting inclusion of PLWDs and their caregiver in decisions and discussions with the aim of improving outcomes for the PLWDs and their caregiver.

The concept of dementia-friendly organizations has been used in different contexts. It can be applied, for example, to hospitals and clinics,<sup>47</sup> housing organizations, religious institutions, banks, and fire departments.<sup>48</sup> As a result, the information available is variable in terms of type, financial resources available, and activities between different organizations.<sup>23,46–48</sup> The characteristics of the organizations, their priorities, and how they operate also vary depending on the time they have been functioning and the people who lead them.<sup>48</sup>

Several concepts have been used for describing dementia-friendly organizations. For instance, one definition is more focused on the "personhood" of the PLWDs (focusing on empowerment, aspiration, self-confidence, contribution, participation, and meaningful activities), another adds the human rights domain, and a third focuses more on the way-finding ability, sense of safety, accessibility to local facilities, social acceptance, and understanding of dementia of PLWDs.<sup>46</sup>

In the context of health care settings, dementia-friendly can refer to the physical design of settings (or units/services) within these settings,<sup>46–47</sup> and/or the engagement of PLWDs in decision-making related to their care.<sup>46</sup> Dementia-friendly health care services should be tailored and be appropriate to the needs of PLWDs, and be of an equivalent standard to that expected for any person without dementia.<sup>46,48</sup> Hospitals should aim to introduce changes on every level, including the provision of health care services (access to services, diagnosis, treatment and follow-up, hospitalization and access to long-term care, implementing case management, and post-diagnostic support), infrastructure changes (including colors, lighting, walkways

and wayfinding, room components, and art), and care pathways.<sup>23,46,48</sup> The evaluation of physical settings often involves assessing compliance with dementia-friendly design standards using audit tools<sup>46</sup>; there is little evidence to support the impact of dementia-friendly physical design features on improving the functioning of PLWDs.<sup>47</sup> Relative to other health care settings, there is a larger body of evidence for dementia-friendly design in long-term care homes; however, more robust studies are needed to understand the impacts of these designs on PLWDs.<sup>23</sup>

In non-health care settings (eg, businesses), much of the research is qualitative in nature, with limited information on the impacts of dementia-friendly initiatives within these settings. More research with stronger designs is needed.<sup>23</sup>

Some dementia-friendly organizations and communities can also lead awareness and educational campaigns for their populations with the aim of improving relationships among their members and enhancing the well-being of both PLWDs and those who do not have the disease.<sup>23</sup> In addition, several models, toolkits, and evaluation processes are described in the literature for the implementation and monitoring of dementia-friendly organizations.<sup>41,46,48</sup>

Despite the overall benefits and preliminary positive results of dementia-friendly organizations and communities for PLWDs and their caregivers, there is a lack of intervention studies to understand how, and under what conditions, dementia-friendly organizations and communities have an impact on PLWDs.<sup>46–47</sup> Evaluation of dementia-friendly communities and data on the impacts these communities may have are also limited.<sup>46,48</sup> Much of the research has focused on process (eg, the number of organizations participating or trained in being dementia-friendly, the number of dementia-friendly initiatives undertaken, and the number and type of changes made to organizations based on feedback from PLWDs).

#### 4.2.2 | Case management

For this intervention, we selected four systematic reviews.<sup>49–53</sup> Case management consists of the introduction, modification, or removal of strategies to improve the coordination and continuity of delivery of services, which includes the social aspects of care.<sup>49–53</sup> It involves the assessment, planning, facilitation, care coordination, and advocacy for options and services for the PLWDs and their caregivers and families.<sup>53</sup>

Case management is effective in improving access and uptake of services, caregiver mood and caregiver self-efficacy, and the quality of life of the PLWDs.<sup>53</sup> The latter is particularly the case where other health care services are integrated into the overall care of the PLWDs.<sup>49</sup> In addition, case management has shown effects in reducing institutionalization and behavior disturbances,<sup>51</sup> and improving the well-being of the caregiver and the social support that he receives.<sup>51</sup>

There are contradictory results regarding the effect of case management on caregiver depression. One review concluded that it diminished caregiver depression,<sup>51</sup> whereas another found no effect of case

management in reducing depression in caregivers.<sup>52</sup> Uncertain results were also found in relation to PLWD depression, functional abilities, and cognition, as well as delay in institutionalization.<sup>51</sup>

## 5 | RECOMMENDATIONS

The results of the review were shared, discussed, and analyzed with the 11 experts in the working group, resulting in the development of five recommendations and the consequent approval by the CCCDTD5 Panel of Experts. For each recommendation, practical tips for health care providers were developed (see Tables 2 to 6). These practical tips contained information regarding the definition of the intervention, sources to obtain evidence-based information, actions to implement the recommendations in their practice/daily life, and other consideration pertinent to each intervention.

### 5.1 | Individual level

We recommend exercise, either group or individual physical exercise, for PLWDs. We cannot recommend any specific exercise duration or intensity at this time<sup>16,33–35</sup> (GRADE: 1B–strong recommendation, moderate quality of evidence–consensus of 93%).

We recommend considering group cognitive stimulation therapy for persons living with mild to moderate dementia<sup>36–39</sup> (GRADE 2B–weak recommendation, moderate quality of evidence–consensus of 96%).

We recommend considering psychosocial and psychoeducational interventions for caregivers of PLWDs<sup>40–45</sup> (GRADE 2C–weak recommendation, moderate quality of evidence–consensus of 96%).

### 5.2 | Community level

We recommend considering the development of dementia-friendly organizations and communities for PLWDs<sup>23,46–48</sup> (GRADE 2C–weak recommendation, low quality of evidence–consensus of 91%).

We recommend considering the use of case management for PLWDs<sup>49–53</sup> (GRADE 2B–weak recommendation, moderate quality of evidence–consensus of 93%).

## 6 | DISCUSSION

Psychosocial and other non-pharmacological interventions play an important role. We found evidence-based interventions at individual and community levels, such as exercise, group cognitive stimulation therapy, psychosocial and psychoeducational interventions, dementia-friendly organizations/communities, and case management are beneficial for PLWDs and their caregivers.

At the individual level, we found evidence that exercise and cognitive stimulation therapy are beneficial for PLWDs. Future research

**TABLE 2** Practical tips—exercise

What is the definition of the intervention?	Physical activity refers to any bodily movement produced by skeletal muscles that requires energy expenditure. Physical activity in daily life can be categorized into occupational, sports, conditioning, household, or other activities. <sup>54</sup> Exercise is a subset of physical activity that is planned, structured, and repetitive and has as a final or an intermediate objective to improve or maintain physical fitness. <sup>54</sup> Broadly, there are two main types of exercise: (1) aerobic exercise training (eg, running), aimed at improving cardiovascular health, and (2) resistance training (eg, lifting weights), aimed at improving muscle mass and strength. Each type of exercise training has its own distinct physiology and benefits. <sup>55</sup> Exercise to improve one's balance and coordination (ie, balance exercises) are highly beneficial to reduce the risk of falls.
Where would you get evidence-based information on this recommendation?	Community centers and local Alzheimer Society are good sources of information. Physical therapists will also be able to provide individualized exercise programs that can be done at home.
How would you implement this recommendation in your practice or daily life?	To increase overall physical activity: Take regular walks around the neighbourhood or in local public buildings, such as the mall Take up active hobbies such as gardening Do most basic types of house work Take up active play with grandchildren, if you have any
	To increase your fitness levels: Join community-based programs such as dance classes or walking groups. Most people find it easier to keep exercising when they are doing it with others. For example, Minds in Motion offered by the Alzheimer Society. Work with an exercise professional (eg, physical therapist, kinesiologist) to develop a simple program you can do at home to increase your muscle strength and balance. Make sure you ask for written instructions and pictures to guide you at home.
Other considerations	If you have a chronic condition such as high blood pressure or type 2 diabetes, it is important to speak with your doctor before you start an exercise program. Exercise is safe, as long as it is done in consideration of one's health. It is important that as you increase your physical activity level that you ensure you are properly hydrated and eating foods that provide you with good sources of energy. As sleep disruptions are common in those living with dementia, it may be beneficial to engage in outdoor physical activity or exercise in the morning and early afternoon.

**TABLE 3** Practical tips: cognitive stimulation

What is the definition of the intervention?	Cognitive stimulation refers to engaging people (typically in group settings) in a range of activities with the goal to enhance general cognitive and social functioning
Where would you get evidence-based information on this recommendation?	Check with your local Alzheimer Society, day programs, or any community organization in your area.
How would you implement this recommendation in your practice or daily life?	Offer group activities such as reminiscence therapy, reality orientation, sensorimotor activities, and games that promote remembering the past, evoking knowledge (eg, naming animals or songs), or problem solving Ensure the activities target multiple cognitive domains (eg, attention, memory, problem solving) Aim to conduct the activities in group settings to enhance social functioning Read your clients: If they seem uninterested or frustrated by one activity, switch to a new activity

should focus on comparing the different modalities of exercise to make it possible to recommend a specific types of training for PLWDs (eg, aerobic and/or strength training, and balance training) and on factors such as intensity, frequency, and duration.

Caregivers play a key role in the management and well-being of the PLWDs. However, caregivers are usually overworked and is common that they experience emotional exhaustion and burnout.<sup>56</sup> At an individual level, psychoeducational interventions are beneficial for caregivers of PLWDs for improving their role as a caregiver as well as their well-being.

At the community level, we found evidence to recommend two interventions: dementia-friendly communities and organizations, and case management.

Dementia-friendly organizations and communities are promising for PLWDs. However, there is a lack of intervention studies that explore the impact this intervention may have on this population, or indicate what specific characteristics may be useful to take into account when implementing this intervention,<sup>46-47</sup> especially given the variety of terms, organizations, and evaluations recommended for dementia-friendly organizations and communities.

**TABLE 4** Practical tips—psychosocial and psychoeducational interventions

What is the definition of the intervention?	This refers to a broad range of interventions that can include: education (about dementia, services, etc.), cognitive behavioral therapy, counseling, skill building, problem solving, coping strategies, and social support.  Interventions may include one strategy (single interventions) or multiple strategies (multicomponent interventions).
Where would you get evidence-based information on this recommendation?	Local Alzheimer Society, community support service organizations
How would you implement this recommendation in your practice or daily life?	When advising on which intervention(s) to recommend to caregivers:  <ul style="list-style-type: none"> <li>• Consider interventions that may have greater impacts, namely: <ul style="list-style-type: none"> <li>Interventions that include both education and therapeutic components</li> <li>Interventions that are longer and of greater intensity</li> <li>Multicomponent interventions</li> </ul> </li> </ul> <p>*Recommend interventions that best match the needs of the caregiver</p>

**TABLE 5** Practical tips—dementia friendly organizations and communities

What is the definition of the intervention?	A dementia-friendly community is where persons living with dementia, their caregivers, friends, and families are welcomed, acknowledged and included, and where those who work alongside and support them have access to practical education and training.
Where would you get evidence-based information on this recommendation?	Alzheimer Societies have education, awareness programs and support services ( <a href="https://alzheimer.ca">https://alzheimer.ca</a> )  Information on dementia friendly communities can be found at the Alzheimer Disease International ( <a href="https://www.alz.co.uk/dementia-friendly-communities">https://www.alz.co.uk/dementia-friendly-communities</a> )  Information on how to make your organization more dementia-friendly can be found here: <a href="https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities/make-your-organisation-more-dementia-friendly">https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities/make-your-organisation-more-dementia-friendly</a>
How would you implement this recommendation in your practice or daily life?	Know and understand dementia (both medical and quality-of-life aspects) for the benefit of your patients, and appreciate the impact of stigma of dementia on the patient and caregiver ( <a href="https://alzheimer.ca/en/Home/About-dementia/What-is-dementia/Stigma">https://alzheimer.ca/en/Home/About-dementia/What-is-dementia/Stigma</a> ).  Inform and inspire—there is life after a diagnosis of dementia and "dementia doesn't make you stupid" (View Person-Centered Matters: <a href="https://daanow.org/an-extraordinary-video-about-dementia/">https://daanow.org/an-extraordinary-video-about-dementia/</a> ).  Encourage your persons living with dementia and caregivers to live life to the fullest. Maybe they would like to volunteer? Assist them in seeking a purpose—a reason to get out of bed in the morning.  Be empathetic. A diagnosis for many will be a surprise, like a punch in the stomach. Time will be needed to help them adjust to the "journey" of dementia.  Introduce them to the Alzheimer Society's First Link program.  Be aware of local and provincial support services available for persons living with dementia and caregivers.  Acquaint patients with the Canadian Charter of Rights for People with Dementia ( <a href="https://alzheimer.ca/en/Home/Get-involved/The-Charter">https://alzheimer.ca/en/Home/Get-involved/The-Charter</a> ) and the UN Convention on the Rights of Persons with Disabilities.  Engaging persons living with dementia in planning and implementing these initiatives is key.  Involving the local Alzheimer Society is important.  Identify resources that can assist in planning for a DFC/org. Here's an example of a toolkit: <a href="https://alzheimer.ca/sites/default/files/files/bc/advocacy-and-education/dfc/dfc_toolkit_vjan2016.pdf">https://alzheimer.ca/sites/default/files/files/bc/advocacy-and-education/dfc/dfc_toolkit_vjan2016.pdf</a>  Other resources: <a href="https://www.alz.co.uk/dementia-friendly-communities/principles">https://www.alz.co.uk/dementia-friendly-communities/principles</a>  <a href="https://www.dementia.org.au/files/NATIONAL/documents/Dementia-friendly-communities-toolkit-for-local-government.pdf">https://www.dementia.org.au/files/NATIONAL/documents/Dementia-friendly-communities-toolkit-for-local-government.pdf</a>

**TABLE 6** Practical tips—case management

What is the definition of the intervention?	Case management consists of the introduction, modification, or removal of strategies to improve the coordination and continuity of delivery of services, which includes the social aspects of care.
Where would you get evidence-based information on this recommendation?	Ask health and social care organizations with whom you work closely if case managers are available (eg, home care services in your area)
How would you implement this recommendation in your practice or daily life?	<u>Key implementation factors at the organisational level:</u> Collaboration between the family physician, case manager, persons living with dementia and caregiver Interdisciplinary teams where the roles and responsibilities are clearly delineated Acknowledge the value of every team member, including persons living with dementia and caregivers <u>Key implementation factors at the clinical level:</u> Pro-active follow-up to ensure that the persons living with dementia are coming to their appointment (continuity with a family physician). Regular contact with the persons living with dementia and caregiver to address questions and concerns, and to ensure their full engagement in care and care decisions. Pay specific attention during healthcare transitions.

## 7 | STRENGTHS AND LIMITATIONS

This is the first time that the CCCDTD has reviewed and provided recommendations for individual and community-based psychosocial and other non-pharmacological interventions for PLWDs and their caregivers.

Our study had some limitations. Given the broad scope of the topic, our review was limited to only five interventions, three at the individual level and two at the community level. The recommendations developed by CCCDTD5 are therefore limited only to these areas. This does not mean that other types of non-pharmacological interventions are not recommended for PLWDs and their caregivers, but simply that they will be reviewed and analyzed during future meetings of the CCCDTD.

Given the need for recommendations by December 2019, the literature search conducted in September 2019 was limited to 3 years of literature. However, with the help of the librarian, we actively searched for companion papers of included studies that date back to 2012. In addition, the topic of individual and community-based psychosocial and other non-pharmacological interventions is constantly evolving, so despite not including more years in our review, we believe that the included literature represents the most up-to-date information available for these interventions.

## 8 | CONCLUSIONS

For the first time on the CCCDTD, recommendations on individual and community-based psychosocial and other non-pharmacological interventions have been provided for PLWDs and their caregivers. There is evidence that these interventions such as exercise, group cognitive stimulation therapy, psychoeducational interventions, dementia-friendly organizations and communities, and case management have

positive effects on the PLWDs and on their caregivers.<sup>16,23,33–37,39–53</sup> Implementing these interventions will allow health care practitioners to provide holistic care to their patients based on the principles of person-centered care, to decrease stigma and increase engagement of PLWDs in their community and health care organizations.<sup>11,20–21,57</sup>

More detailed information is needed about the interventions themselves (eg, frequency, who is provided by, measurement tools). Some of the intervention studies lacked rigour. There is also a limited use of outcomes that are identified as meaningful for PLWDs and caregivers.

Psychosocial interventions are rarely considered in discussions at the clinical and policy level. And are usually not considered when developing recommendations for PLWDs and their caregivers. This is why our working group was formed by CCCDTD. The present recommendations have the potential to inform ongoing and future initiatives and policies to include psychosocial and other non-pharmacological interventions for persons with dementia in Canada more broadly. These results may also be useful in other jurisdictions as well.

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## LIMITATIONS

"Interventions with robust systematic, meta-analysis and scoping reviews that allow for more immediate recommendations. Individual level interventions."

## FILTERS

Date range: last 3 years. Language: English, Species: Humans, Age: older adults, Article type: as outlined in "Limitations."

## CONFLICTS OF INTEREST

HB is a member of the advisory board for Nutricia Australia. The other authors report no conflicts of interest.

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### SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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