

Evidence *in* Context

Issue: Supporting the Independence of
Persons with Dementia
Released : October 2015

Health research — synthesized and contextualized for use in Newfoundland & Labrador

Supporting the Independence of Persons with Dementia *in* Newfoundland and Labrador

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Newfoundland & Labrador Centre for

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Cite as: Chappell, N., Bornstein, S., Goodyear, R., Kean, R., Speed, D. (2015). Supporting the Independence of Persons with Dementia in Newfoundland and Labrador. St. John's, NL: Newfoundland & Labrador Centre for Applied Health Research, Memorial University

ISBN: 978-0-88901-467-1

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About This Report

About NLCAHR

The Newfoundland and Labrador Centre for Applied Health Research, established in 1999, contributes to the effectiveness of the health and community services system of the province and the physical, social, and psychological well-being of the population. NLCAHR accomplishes this mandate by building capacity in applied health research, supporting high quality research, and fostering more effective use of research evidence by decision makers and policy makers in the province's health system.

About the Contextualized Health Research Synthesis Program

In 2007, NLCAHR launched the Contextualized Health Research Synthesis Program (CHRSP) to provide research evidence that would help guide decision makers in the provincial health system on issues of pressing interest to Newfoundland and Labrador.

CHRSP analyzes findings from high-level research already conducted in the subject area, such as systematic reviews, meta-analyses and health technology assessments. Findings are then synthesized and subjected to a systematic process of contextualization: they are analyzed in terms of their applicability to the conditions and capacities of the unique context of Newfoundland and Labrador. Our contextual analysis includes assessing the specific forms an issue may take in this province as well as the applicability of any proposed solutions and methods to locally available resources, infrastructure, human

resources, cultural conditions and financial capacities. CHRSP uses a combination of external experts and local networks to carry out and contextualize the research synthesis and to facilitate the uptake of the results by research users. CHRSP focuses on three types of projects: health services/ health policy projects, health technology assessment (HTA) projects, and projects that combine the two to examine processes for the organization or delivery of care involving a health technology.

Who Should Read This Report?

This report provides a synthesis of the relevant research-based evidence on preventing or delaying the admission of persons with dementia to long-term care in Newfoundland and Labrador. This report is intended to inform and assist decision makers in Newfoundland and Labrador's four Regional Health Authorities and its Departments of Health and Community Services, and Seniors, Wellness and Social Development. The findings of our synthesis are based on an international search of the literature and may also be applicable to other countries, but are specifically interpreted for the context of Newfoundland and Labrador.

Decision makers from other jurisdictions, especially those with similar potential clients, geography and resources, may also find the content helpful. The report includes explanations of research terms and technical language; as such, there is no need to have a specialized medical or health background in order to understand its content.

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Acronyms

ADL	Activities of Daily Living
AMSTAR	Assessment of Multiple Systematic Reviews
CHRSP	Contextualized Health Research Synthesis Program
CI	Confidence Interval
CIHI	Canadian Institute for Health Information
DHCS	Department of Health and Community Services (Government of Newfoundland and Labrador)
HSP	Home Support Program
LTC	Long-Term Care
LUFOA	Life Unlimited for Older Adults
RCT	Randomized Controlled Trial
PwD	Persons with Dementia
RHA	Regional Health Authority
SAP	Special Assistance Program
SRC	Seniors' Resource Centre

Glossary

AMSTAR	Assessment of Multiple Systematic Reviews: an 11-item instrument used to assess the methodological rigor of systematic reviews
Long-Term Care	Facilities that provide living accommodation for people who require on-site delivery of 24-hour, seven-day-a-week supervised care, including professional health services; personal care services; and services such as meals, laundry, and housekeeping
Primary Research	Research that involves the collection and analysis of data from actual participants, as opposed to the combination of such research (i.e., higher level studies) or secondary analyses of previously-collected data
Randomized Controlled Trial	A type of primary research in which participants are randomized with regard to treatment, with the objective of eliminating confounding factors that may exist among the participants
Systematic Review	A literature review that tries to identify, select, appraise, and synthesize published and unpublished research evidence relevant to a specific research question

The Research Question

“What interventions are most effective in preventing or delaying the admission of people with dementia to long-term care?”



Background

In 2014, the Newfoundland and Labrador Department of Health and Community Services (DHCS) and the four Regional Health Authorities (RHAs) asked the Contextualized Health Research Synthesis Program (CHRSP) to identify and review the best available research-based evidence on care options for people with mild to moderate levels of dementia (at the time this topic was selected for study, the Department of Seniors, Wellness, and Social Development of the Government of Newfoundland and Labrador had not yet been created). Although this subject area was initially suggested by officials at Central Health, consultations with the province's other Regional Health Authorities and with the Department of Health and Community Services revealed that supporting the independence of persons with dementia was a high-priority issue across the province.

CHRSP personnel assembled a project team that included officials from the four RHAs and the DHCS, the Executive Director of the Seniors' Resource Centre of Newfoundland and Labrador, and a faculty member from the Western Regional School of Nursing. Dr. Neena Chappell, Canada Research Chair in Social Gerontology and Professor of Sociology at the University of Victoria, agreed to serve as Subject Expert for the project.

At the first project meeting, team members decided that the requested synthesis should focus on interventions that could potentially help people with dementia to stay out of long-term care (LTC). In this report the term “LTC” refers to any facility that provides living accommodation for people who require on-site delivery of 24-hour, seven-day-a-week supervised care. In Newfoundland and Labrador, admission to LTC is restricted to people requiring what is known as “level three” care or higher. Level three care is defined as care “that [is] required by a person who is chronically ill and/or has a functional

disability (physical or mental)” and who “therefore requires a range of therapeutic services, medical management, and skilled nursing care plus provision for psychosocial needs” for months or years (1). The team also identified a set of outcomes that would be used in the synthesis to assess the various interventions described in the research literature. Preliminary literature searches indicated that, when assessing interventions designed to maximize the independence of people with dementia and reduce their reliance on LTC, researchers often evaluate an intervention’s effectiveness according to ‘proximate’ outcomes such as institutionalization or delayed institutionalization, as well as a set of more ‘distal’ outcomes such as performance of activities of daily living (ADL) and caregiver burden. Through subsequent discussions, the team resolved that the synthesis would only include articles that measured:

- a ‘proximate’ outcome such as delayed institutionalization, and/or
- *at least one* of the following ‘distal’ outcomes:
 - ADL performance
 - caregiver burden or distress, and
 - safety of the care recipient

Project team members, each of whom has a professional and/or scholarly background in care for persons with dementia, felt strongly that these particular distal outcomes were important because they are often determinants of admissions to LTC.

Synthesis of the Evidence

Our synthesis is based primarily on evidence from systematic literature reviews. We restricted our search to reviews published between January 2010 and January 2015 because we wanted to select only those reviews that included the most recent primary research available at that time. In the end, we selected 27 reviews. To supplement this review evidence, we also conducted a search for randomized controlled trials (RCTs) published too recently to have been eligible for inclusion in any of our selected reviews. On this basis, we retrieved 12 RCTs published between March 2014 and March 2015. Detailed descriptions of our inclusion criteria, search strategy, article selection, and critical appraisal of selected articles are contained in the online companion document:

<http://www.nlcahr.mun.ca/CHRSP/PwDOnlineCD.pdf> This companion document also includes a table containing details about all selected articles.

Our critical appraisal methodology for systematic reviews employed the Assessment of Multiple Systematic Reviews (AMSTAR) tool, a validated measurement tool for evaluating the methodological quality of systematic reviews (2). A high AMSTAR score can be taken as an indicator that the various stages of the review were conducted appropriately. A low AMSTAR score does not necessarily mean that the review should be discarded, but that less confidence can be placed in its findings and that the review must be examined closely to take its limitations into consideration.

In Table 1 below, we provide the AMSTAR scores for the reviews included in the synthesis, ranked from the highest score to the lowest.

Table 1: AMSTAR scores for systematic reviews synthesized in this report

Review Year	AMSTAR Score
Lins 2014 (3)	90%
Jensen 2014 (4)	80%
Maayan 2014 (5)	80%
Vernooij-Dassen 2011 (6)	64%
Orgeta 2014 (7)	60%
Carrion 2013 (8)	56%
Tam-Tham 2013 (9)	55%
Burton 2015 (10)	50%
Somme 2012 (11)	50%
Drennan 2012 (12)	44%
Boots 2014 (13)	40%
McKechnie 2014 (14)	40%
Meyer 2013 (15)	40%
Pitkala 2013a (16)	40%
Van't Leven 2013 (17)	40%
Zabalegui 2014 (18)	40%
Corbett 2012 (19)	36%
Olazarán 2010 (20)	36%
Hurley 2014 (21)	33%
Marim 2013 (22)	30%
McLaren 2013 (23)	30%
Schoenmakers 2010 (24)	27%
Godwin 2013 (25)	22%
Buettner 2010 (26)	20%
Goy 2010 (27)	20%
de Werd 2013 (28)	18%
Martin-Carrasco 2014 (29)	18%

As this table indicates, not all reviews were deemed equal in terms of methodological quality; we took this variability into account when formulating our conclusions. We also took into account the number of primary studies each review covered. In general, we assigned greater weight to higher-quality and more comprehensive systematic reviews.

The twelve included RCTs were appraised using the Cochrane Risk of Bias Tool (30). We found that the inability to blind personnel and participants inevitably placed these trials at risk of performance bias, but this is generally true of most research into interventions of this nature. Additionally, most of the included RCTs assessed subjective outcomes that were reported by the (un-blinded) study participants

themselves, placing them at risk of detection bias. The four trials that assessed objective outcomes (e.g., cognitive performance or time-to-transfer out of home) used blind raters, and we judged these studies to be at low risk of detection bias. Random sequence generation procedures were sufficiently well-described to permit a judgment of low risk in just over half of the included studies, but only two studies clearly demonstrated that they had taken steps to conceal the allocation sequence. Explanations of the flow of participants through these studies were generally ambiguous and confusing, though we judged the risk of attrition bias to be low in four cases. Previously-published study protocols were generally inaccessible, so the risk of reporting bias was unclear in all cases. Our Risk of Bias assessments are consistent with those conducted by the authors of the Cochrane reviews included in our synthesis (3,5), suggesting that the methodological strengths and weaknesses of these twelve RCTs are fairly common within this area of research.

This synthesis evaluates the available research evidence on healthcare interventions for persons with dementia who are not already residing in LTC. We are specifically interested in evidence that might enable us to ascertain an intervention's effectiveness in improving one or more of the targeted outcomes listed earlier: institutionalization, activities of daily living, functional decline, caregiver burden or distress, and/or safety of the care recipient. In the pages below, we present the evidence gathered by various researchers to determine the effectiveness of given interventions, and we categorize it as:

- promising,
- suggestive, or
- insufficient at present.

When considering these designations, readers should not necessarily conclude that an intervention is generally ineffective or harmful simply because we have stated that there is, at present, insufficient evidence to demonstrate its effectiveness. In the first place, this synthesis focuses narrowly on the outcomes described above. An intervention that fails to have a measurable impact on these outcomes might nonetheless have a positive effect on other important outcomes, such as quality of life. Furthermore, some of the interventions described below may not demonstrate effectiveness when they are evaluated as stand-alone measures, but they might yield different results if they were to be tested in combination with other interventions. Finally, researchers are continually adding new findings and insights to the existing body of knowledge on this subject, and interventions that are not presently supported by a great deal of research may very well demonstrate their effectiveness in future research efforts.

To clarify these categories even further:

- Where we have characterized the evidence for the effectiveness of a given intervention as **promising**, we feel decision makers can be reasonably confident in the effectiveness of that intervention as a means for producing positive change in one or more of the following outcomes: institutionalization, activities of daily living, functional decline, caregiver burden, and/or safety of the care recipient.

- If the evidence for the effectiveness of an intervention is described as **suggestive**, then it may be worth trying, though planners and decision-makers would be well-advised to carefully evaluate its effect on targeted outcomes.
- Finally, if the evidence for the effectiveness of an intervention is deemed to be **insufficient at present**, then readers should be cautioned against developing an expectation that this intervention will, by itself, yield significant benefits with respect to targeted outcomes.

Table 2 below outlines the evidence categories we used in this report and the criteria for each. The reader should note that we tailored these criteria to this particular subject, with the aim of developing a ranking system that clearly distinguishes the *relative* strength of the evidence for particular interventions within the overall body of research on the subject. Therefore, these criteria would not necessarily be applicable to other questions or bodies of research.

Table 2: Evidence categories for the effectiveness of interventions and their criteria

Evidence Category	Criteria
PROMISING	Evidence for the effectiveness of the intervention is provided in one or more high-quality reviews (i.e., AMSTAR score $\geq 67\%$), encompassing 5 or more different primary studies
SUGGESTIVE	There is partial or qualified evidence to demonstrate the effectiveness of the intervention, derived from one or more moderate-to-high quality reviews (i.e., AMSTAR score $>33\%$) encompassing more than one primary study
INSUFFICIENT AT PRESENT	Either there is no moderate-to-high quality review evidence to demonstrate the effectiveness of the intervention, or the combined reviews include only one primary study, or no primary studies on this intervention.

Interventions with promising evidence

Psychoeducational support interventions for caregivers

There were two high-quality reviews in our synthesis, Jensen 2014 and Lins 2014, and seven moderate-quality reviews, Boots 2014, Corbett 2012, McKechnie 2014, Olazarán 2010, Van't Leven 2013, Vernooij-Dassen 2011, Zabalegui 2014, that evaluated the effectiveness of psychoeducational caregiver support interventions on caregiver burden or distress. These interventions vary in their mode of delivery (i.e., face-to-face or internet or telephone delivery) and in the balance they sought to strike between educational and psychosocial components. Overall, there is considerable moderate-quality review evidence to support psychoeducational caregiver-targeted interventions of all types, and the high-quality review by Jensen et al. finds that “educational programmes for carers of community

dwelling patients with dementia have a protective effect on caregiver burden” (4, p. 11). This finding is supported by a meta-analysis of five primary studies, each with low-to-moderate risk of bias (31-35), that showed a moderate effect (standardized mean difference = -0.52; 95% confidence interval [CI] -0.79 to -0.26, $p < 0.0001$). These five studies all evaluated structured, face-to-face education programs designed to address topics relevant to dementia caregiving and the caregiver role. For this reason, we describe the evidence for the effectiveness of psychoeducational caregiver-targeted support interventions as promising, particularly when these interventions are delivered face-to-face and incorporate a strong focus on practical caregiving skills and strategies. Three of the five trials evaluated interventions delivered in a one-on-one format and two evaluated group-based programs. The total duration of educational sessions ranged from 2.5 to 24 hours with an average duration of eleven hours spread over a period of nine weeks. Interventions in all five trials were delivered by health professionals. It should be noted, however, that there was one study in the review by Jensen et al. that reported on transitions to LTC, and it found no effect of psychoeducational caregiver-targeted interventions on this outcome at 15-month follow-up (36).

Evidence demonstrating the effectiveness of web- or telephone-based interventions is somewhat more muted, though the existing research suggests that the still-developing field of computer-mediated psychoeducational support holds promise. A moderate-quality review by McKechnie et al. of computer-mediated interventions that were focused primarily on education reported statistically significant positive effects on caregiver burden in five studies of medium and high quality (37-41), but not in four others (42-45). The reviewers state that additional research is needed to determine the efficacy of individual intervention components as well as the optimal intensity and duration of exposure to interventions. Nevertheless, they conclude that:

*There is **promising** evidence for the effectiveness of psychoeducational support interventions as a means of relieving caregiver burden, particularly when these interventions are delivered face-to-face by health professionals and incorporate a strong focus on practical caregiving skills and strategies.*

[C]omputer-mediated intervention[s] for informal carers of PwD... offer a range of potential benefits. This review found that their effectiveness is mixed, but generally positive. This suggests that it would be beneficial to carers, and also to services—in terms of reaching more carers as well as potential cost saving implications—for this medium of intervention to be developed so that more individuals can benefit (14, p. 1634).

In much the same vein, a moderate-quality review (13) of web-based modes of support found that caregiver burden decreased significantly in two studies (37, 46) but not in two others (44, 47). These reviewers note, however, that one of the latter two studies did detect a significant difference in caregiver burden between non-users and frequent users of the website. By contrast, interventions delivered exclusively over the telephone seem to have less support. The highest-quality review in our synthesis evaluated telephone counselling for caregivers, which was described as “eliciting a person’s

concerns, listening, and providing support, information, or teaching in response to a person's stated concerns, over the telephone" (3, p. 2). These reviewers' meta-analysis of four studies (48-51) revealed no clear positive effect of this intervention on caregiver burden.

The other five moderate-quality reviews combined studies of face-to-face interventions with interventions delivered via telephone or web. A Cochrane review by Vernooij-Dassen et al., which fell just short of our threshold for a high-quality rating, evaluated "cognitive reframing interventions" designed to recalibrate caregivers' understanding of their responsibilities, needs, and loved ones' behaviour. Combined results from the four studies in their review that measured caregiver burden showed no significant benefit; however, a separate meta-analysis of studies that measured caregiver distress (38, 52-54) *did* indicate significant though modest benefit (standardized mean difference = -0.24; 95% CI -0.40 to -0.07, $p=0.006$). On this basis, these reviewers conclude that "[I]n clinical practice, cognitive reframing could be a useful additional tool in individualised support for carers of people with dementia" (6, p. 11).

Corbett 2012, Olazarán 2010, Van't Leven 2013, and Zabalegui 2014 each included studies on a range of interventions that varied greatly in their length, their mode of delivery, their precise mix of instructional and psychosocial components, and their intended targets (i.e., caregivers, care recipients, or both). For example, both Corbett 2012 and Olazarán 2010 mix studies of caregiver-targeted psychoeducational support together with studies of interventions that are perhaps best understood as forms of dementia case management; therefore, these reviews do not enable the reader to draw conclusions specific to either type of intervention. Fortunately, Van't Leven 2013 distinguishes more clearly between the two. This review included eight studies that assessed the effect on caregiver burden of multi-component interventions involving psychoeducational support delivered over six to 10 home visits or group sessions during a period of five weeks to six months. Six of these studies showed a significant positive effect (53, 55-59) and two did not (60, 61). These reviewers describe the strength of this evidence as "moderate" ($p. 1597$), but they do not state which program components are most effective. On the basis of a very small number of studies ($n=3$), including two that were also reviewed in Van't Leven 2013 (57, 58), Zabalegui 2014 concludes that psychoeducational interventions for informal caregivers can improve caregiver burden symptoms.

Similar findings are reported by two of the three lower-quality reviews in our synthesis that looked specifically at psychoeducational interventions for caregivers (22, 29); the third (24) found that such interventions produced non-significant decreases in caregiver burden. Furthermore, our search of RCTs published after March 2014 revealed six studies of psychoeducational support interventions for caregivers; of these, four (62-65) reported significant improvement in caregiver burden scores and two (66, 67) did not. Significantly, the four successful interventions involved regular face-to-face contact with health professionals, whereas the remaining two assessed the effectiveness of a 20-page picture book and of telephone support, respectively.

To summarize, though the benefits of face-to-face educational programs for caregivers stand out most clearly, there is also considerable evidence to demonstrate the effectiveness of interventions involving different blends of educational and psychosocial components and different modes of delivery.

Interventions with suggestive evidence

Case Management

Dementia case management may be defined as “a collaborative intervention that involves assessment, planning, and advocacy for people with dementia and their caregivers” (68). One of the primary aims of case management is facilitating timely access to essential services, and its chief components are:

- standardized multidimensional assessment by health care professionals,
- individually-tailored care planning, and
- ongoing monitoring of plan implementation (9, 11).

There is suggestive evidence for the effectiveness of professionally-delivered dementia case management as a means for achieving short-term reductions in LTC placement.

Case management targets both the care recipient and the family caregiver and can last for several years. The largest and highest-quality review in our synthesis on case management interventions, Tam-Tham 2013, included studies of 16 separate trials that assessed the effect of this intervention on LTC placement (69-84). Case managers in these studies were drawn from a variety of professional backgrounds, such as nursing, social work, psychology, and occupational therapy, and sometimes worked as members of a multidisciplinary team. Modes of delivery included home visits, telephone calls, or a combination of both. The reviewers found that

[T]here appeared to be a short-term effect in that dementia [case management] was associated with a significant reduction in LTC placement within the first 18 months following the intervention (9 p. 900).

This finding is based on a meta-analysis of the five included studies with a follow-up duration of less than 18 months (70, 77, 79, 83, 84; pooled risk ratio = 0.61, 95% CI 0.41 to 0.91, $p=0.015$). The reviewers offer alternative explanations for the apparently time-limited effect of case management interventions. They suggest that the benefits of case management may accrue mainly to the family caregiver, whereas the long-term effects on the care recipient’s symptoms are minimal. Therefore, the lack of effect past 18 months may simply be attributable to the natural progression of the disease; that is to say that unchecked functional decline will at some point nullify the effects of any intervention for helping persons with dementia to avoid LTC. Alternatively, it may be that these interventions are

effective only while they are being offered, and post-intervention effects diminish rapidly. In the reviewers' judgment, the short-term effectiveness of case management indicates a need for "repeated dementia [case management] interventions that address the progression of symptoms in care receivers and the fading effect of a single-time intervention" (9, p. 901).

There were five other moderate-quality reviews (11, 17-20) in our synthesis and one lower-quality review (27) that evaluated the effect of case management on LTC placement. None of them reviewed as many case management studies or scored as high on the AMSTAR instrument as Tam-Tham 2012 and none included any relevant studies that were not found in Tam-Tham 2012. Our synthesis also included two RCTs of case management published after March 2014. Samus 2014 analyzed data on 188 persons with dementia and concluded that participants who received 18-month home-based coordination of their dementia care overseen by geriatric clinicians "had a significant delay in time to all-cause transition from home and the adjusted hazard of leaving the home was decreased by 37% (hazard ratio: 0.63, 95% Confidence Interval: 0.42 – 0.94) compared with control participants" (85, p. 398). Chodosh 2015 compared two modes of case management delivery: home visits supplemented with telephone calls as compared with telephone calls and mailings. These researchers did not observe any additional benefit from an approach that included in-person interactions (86).

In summary, there is suggestive evidence for the effectiveness of dementia case management as a means for achieving short-term delays in LTC placement.

Physical exercise

There were four systematic reviews of moderate quality that assessed the effect of physical exercise interventions, Burton 2015, Meyer 2013, Orgeta 2014, Pitkälä 2013a, though each used a different set of outcomes. We have grouped these reviews according to the outcomes they measured.

Physical function – Pitkälä 2013a examined ten randomized controlled studies of exercise interventions targeting home-dwelling adults with dementia. The studies covered a wide range of exercise interventions, including Tai-chi, stationary cycling, strength and balance training, and various forms of aerobic exercise. According to the reviewers, two studies were of high quality (78, 87), five were of moderate quality (88-92) and three were of poor quality (93-95). Though the heterogeneity in intervention duration, intensity, and type of exercise performed precluded meta-analysis, the reviewers found that "there is moderate grade of evidence that intense exercise (at least twice per week) for at least three months entailing several types of exercises may improve at least some dimensions of mobility or functional limitations among patients with dementia" (16, p. 92). This finding was corroborated by both of the high-quality studies they reviewed, as well as four of the five moderate-quality studies. Successful interventions involved exercise twice weekly for at least 30 minutes, usually with a progressive increase in intensity. Both individual and group exercise interventions yielded improvements in mobility and/or functionality.

Falls – Burton et al. reviewed four studies that examined home- and community-delivered exercise interventions designed to reduce falls or the risk of falls. The intervention group in the largest study, Pitkälä 2003b, received individually-tailored home-based exercise training provided by a physiotherapist with specialized dementia training. Exercises increased in intensity and dosage over time, and included stair-climbing, balance and transfer training, walking, dual tasking, and outdoor activities. Of the remaining studies, Mackintosh 2005 evaluated a multi-element intervention involving exercise, medication management, vision assessment, and walking aids; Wesson 2013 evaluated complex exercise programs focused on different muscle groups; and Suttanon 2013 examined the Otago exercise program, which includes strengthening exercises, standing balance exercises, and a walking program. The duration of interventions ranged from one session a week to five, for a duration of three to twelve months. Only Pitkälä 2013b and Wesson 2013 supplied falls data that could be pooled. Pooled results from these two studies of home-based interventions showed that mean falls were significantly lower in the exercise group compared to the control group at the completion of the intervention, (standardized mean difference= -1.07, 95% CI = -1.78 to -0.36, $p = .003$), and participants' risk of falling was reduced by 32% (risk ratio = 0.68, 95% CI 0.55 to 0.85, $p=0.01$). With respect to the two studies whose results were not pooled, Suttanon 2013 found that risk of falling improved significantly among participants in the exercise intervention group, while Mackintosh (2005) reported no differences between groups at the pre-test and post-test assessments. Burton et al. note that the three RCTs included in the review (Pitkälä 2013b, Wesson 2013, Suttanon 2013) were of high quality, though Wesson 2013 and Suttanon 2013 were underpowered and had relatively short follow-up periods (\leq six months). Overall, Burton et al. conclude that exercise programs incorporating strength, balance, endurance, and progressively increasing intensity over time are likely to reduce falls among older people with dementia living in the community, although “there may need to be some modifications, such as those utilized by Suttanon et al. and Wesson et al. including engagement of carers, regular contact by physiotherapist, more detailed exercise history in order to tailor the exercises to participant preferences, and a greater choice of exercises” (10, p. 431). By contrast, an older and lower-quality review by Meyer et al. noted a “consistent nonsignificant trend toward a reduction in falls rates in intervention groups” (15, p. 14). However, only six of the eleven studies included in Meyer 2013 assessed exercise-based interventions, making it difficult to draw clear conclusions about the effectiveness of exercise in particular.

There is suggestive evidence for the effectiveness of exercise interventions as a means of reducing functional limitations, mobility problems, and falls among people with dementia; however, the effects of caregiver-targeted exercise programs on caregiver burden is, as yet, uncertain.

Caregiver Burden – Orgeta 2014 reviewed three studies that examined the impact of caregiver-targeted physical exercise programs on caregiver burden (96-98). All three evaluated low-to-moderate-intensity endurance training which consisted primarily of three to four 30-minute brisk walking sessions every week for a period of four to twelve months. Study authors used a variety of instruments to measure subjective caregiver burden, and the pooled results from these studies varied according to the

instrument used. Data gathered by Castro 2002 and King 1997 using the Screen for Caregiver Burden scale suggested a significant reduction in caregiver burden (standardized mean difference = -0.43, 95% CI -0.81 to -0.04, $p=.03$), whereas data gathered by Castro 2002 and Connell 2009 using separate instruments did not.¹ Based on these equivocal results, Orgeta et al. concluded that “physical activity may be of some benefit in terms of reducing caregiver burden for carers of people with dementia; however, further high-quality evidence is needed to reach a definitive conclusion,” (7) p. 778).

In summary, there is suggestive evidence for the effectiveness of exercise interventions as a means of reducing functional limitations, mobility problems, and falls among people with dementia; however, the effects of caregiver-targeted exercise programs on caregiver burden are, as yet, uncertain. This finding is shared by McClaren 2013, a lower-quality review that included many of the same studies as Pitkälä 2013a; and by Holthoff 2015, the lone RCT in our synthesis published after March 2014 that examined an exercise intervention. Holthoff et al. conducted a small study ($n = 27$) of a home-based twelve-week physical activity training intervention and observed “transfer benefits to ADL, cognitive and physical skill in patients with AD” (99, p. 2).

Interventions targeting ADL performance

There were three moderate-quality reviews in our synthesis that evaluated the effect of interventions designed specifically to improve or preserve the ability of persons with dementia to perform Activities of Daily Living (ADL) – Carrion 2013, Olazarán 2010, and Van’t Leven 2013. Each of these publications reviewed a different set of studies and interventions. Van’t Leven et al. reviewed seven studies of short-term (i.e., one to six months) multi-component programs designed to encourage the independence of

There is suggestive evidence for the effectiveness of interventions targeting ADL performance, particularly when they involve face-to-face contact with health professionals.

persons with dementia and their engagement in ADL. All interventions involved face-to-face contact between a care professional and the person with dementia. Five of these studies showed statistically significant positive effects on instrumental ADL performance (60, 61, 100-102) and two did not (58, 103). Of the five studies that demonstrated positive effects, four assessed programs that incorporated daily activity training for the person with dementia, personalized activity schedules, and environmental adaptations. According to these reviewers, “programs with intervention components that are related to... targeted functional

domains are promising, especially for the outcomes of ADL/IADL dependency and competence, adding to better quality of life for both [the caregiver and the care recipient]” (17) p. 1598). It should be noted, however, that Van’t Leven et al. identified short follow-up periods as a limitation common to many of the studies in their review.

¹ As stated, Castro 2002 used the Screen for Caregiver Burden, and Connell 2009 used a modified version of the Revised Memory and Behavior Problem Checklist.

The other two moderate-quality reviews were inconclusive. Carrion 2013 examined a range of training exercises requiring the person with dementia to perform basic daily activities or other memory and perceptual tasks. Their review included four studies that measured ADL but none of them observed statistically significant effects. Olazarán et al. reviewed three studies of multicomponent interventions involving various forms of cognitive stimulation, and though these reviewers performed a meta-analysis that “indicated positive results” (20) p. 168) with respect to ADL, they unfortunately do not state whether they performed a test of significance. There were, in addition, two lower-quality reviews that assessed interventions targeted at ADL performance. McLaren 2013 reviewed seven RCTs of occupational therapy interventions, most of which were included in the review by Van’t Leven et al., and likewise found that these interventions produced positive, significant increases in the abilities of care recipients. De Werd 2013 reviewed interventions based on “errorless learning,” which the reviewers define as an instructional method involving “any combination of graded tasks where the task at hand is broken down into small steps, immediate error correction, encouraging participants not to guess, modeling the task steps, fading cues and prompts when steps are successfully performed (vanishing cues), or rehearsal of the retrieval of information that is taught with increasing time intervals (spaced retrieval)” (28, p. 1178). They report that 17 of the 26 studies in their review demonstrated statistically significant positive effects on task performance that persisted beyond one week and in some cases for several months.

Our search of RCTs published after March 2014 identified three studies of interventions targeting ADL performance. Brunelle-Hamann 2014 found that interventions that incorporate errorless learning had no significant effect on caregiver burden (104), though these researchers did note a significant difference in ADL performance between the treatment ($n = 9$) and control ($n = 8$) groups (105). Dopp 2014 did not observe any effect from a training package for community-based occupational therapists on ADL performance in persons with dementia (106). Muniz 2014 found that a three-year cognitive-motor stimulation program offered to non-institutionalized persons with dementia produced significant benefits in basic ADL at the second- and third-year assessments, and in instrumental ADL at the second-year assessment (107). Data from 68 participants were analyzed for this study.

In summary there is suggestive evidence for the effectiveness of interventions targeting ADL performance, particularly when they involve face-to-face contact with health professionals.

Interventions with insufficient evidence

Respite care

Respite care generally involves providing support or companionship to a care recipient so that the primary caregiver can have a break from her/his caregiving responsibilities. There was only one high quality systematic review in our synthesis on the effects of respite care, Maayan 2014, and it included four studies. Three of these studies involved a series of home visits of two to six hours in duration, staggered over a period of two to eight weeks. According to these reviewers:

Current evidence does not demonstrate any benefits or adverse effects from the use of respite care for people with dementia or their caregivers. These results should be treated with caution, however, as they may reflect the lack of high quality research in this area rather than an actual lack of benefit (5, p. 2).

The low-quality systematic review by Schoenmakers et al. pooled results from two studies on respite care, including one reviewed by Mayaan et al., and found that respite care was associated with *increased burden*:

Caregivers of patients, who were temporarily admitted to or scheduled for a day or night care center, reported an increase in burden.... Handing over a relative with dementia is not well accepted by family caregivers. Besides the concerns about the nursing quality, caregivers feel rather uncomfortable about the suddenly generated time off (24, p. 53).

Meditation

A low-quality systematic review by Hurley et al. addressed meditation for caregivers as a possible intervention for reducing their burden. Of the five studies included in this review, only three found that meditation significantly reduced burden. Though these reviewers offered cautious support for meditation as a potential intervention, they recognized that sampling bias may have affected results and that the overall literature on the topic was poor.

Interventions that Target Urinary Incontinence

A moderate quality review by Drennan et al. evaluated interventions that targeted urinary incontinence. Unfortunately, only three studies were included in this review and each used markedly different approaches to reducing urinary incontinence. Results from these studies were found to be largely non-significant.

Summary of Review Evidence

Our synthesis indicates that evidence for the effectiveness of psychoeducational support interventions is promising, particularly when delivered in face-to-face formats. In addition, there is suggestive evidence for the effectiveness of case management, physical exercise, and interventions targeting ADL performance. By contrast, there is as yet insufficient evidence to support the effectiveness of respite care, meditation for caregivers, and interventions for preventing urinary incontinence (Table 3). In the next section, we examine the implications of these findings for healthcare in Newfoundland and Labrador.

Table 3: Evidence Categories, Criteria and Interventions in Each Category

Evidence for effectiveness	Criteria	Interventions in this category
PROMISING	Evidence for the effectiveness of the intervention is provided in one or more high-quality reviews (i.e., AMSTAR score $\geq 66.7\%$) encompassing 5 or more different primary studies	<ul style="list-style-type: none"> • Psychoeducational support interventions for caregivers
SUGGESTIVE	There is partial or qualified evidence to demonstrate the effectiveness of the intervention, derived from one or more moderate-to-high quality reviews (i.e., AMSTAR score $\geq 33.3\%$) encompassing more than 1 primary study	<ul style="list-style-type: none"> • Case management • Physical exercise • Interventions targeting ADL performance
INSUFFICIENT AT PRESENT	Either there is no moderate-to-high quality review evidence to demonstrate the effectiveness of the intervention, or the combined reviews include only one primary study, or no primary studies on this intervention.	<ul style="list-style-type: none"> • Respite care • Meditation (for caregivers) • Interventions for preventing urinary incontinence

The Newfoundland and Labrador Context



Throughout the course of this project, we have tried to identify contextual factors unique to Newfoundland and Labrador that may influence the relevance and applicability of the research-based evidence. This section of the report addresses those contextual factors and is based primarily on consultations with key informants.

Contextualization Approach

Our contextual analysis relied heavily on the input of our project team members. In assembling the team, we deliberately sought out persons with both extensive professional experience in this subject area and practical knowledge of the province's healthcare system. Team members helped us to identify key informants, participated in interviews themselves, and/or supplied relevant documents and sources of data. Our group of key informants included director-level and front-line personnel from a range of organizations that provide services to seniors and others with dementia. In total, we interviewed nine people, including at least one representative from each of the province's four RHAs. We decided to stop the interviews at nine because new interviews were yielding little in the way of additional information.

Client Base

Population aging is now a defining demographic trend throughout Canada and most other industrialized countries, but it is especially pronounced in Newfoundland and Labrador. This province already has the highest median age in the country (44.2) and the fourth highest proportion of residents aged ≥ 65 years (17.1). Moreover, according to all of the various population projection scenarios developed by Statistics Canada, the median age in Newfoundland and Labrador is projected to increase to between 50.7 years and 54.5 years in 2038, at which time it will be the highest in the country (108). Likewise, the proportion of the population aged ≥ 65 years will reach between 31.6% and 35.9%, still higher than any other province or territory. As the proportion of older persons rises, so too will the incidence and prevalence of dementia. In a landmark report entitled *Rising Tide: The Impact of Dementia on Canadian Society*, the Alzheimer Society of Canada estimated that in 2038 there will be 257,811 new cases of dementia among Canadians aged ≥ 65 years, 2.5 times the number of new cases in 2008 and "the number of Canadians (of all ages) with dementia will increase to 2.3 times the 2008 level, i.e., to 1.1 million people, representing 2.8% of the Canadian population" (109, pp. 16-7). Though the Alzheimer Society does not have precise province-level data for Newfoundland and Labrador, the executive director of the Society's provincial chapter has recently stated in a CBC news article that "there are currently over 8,600 people affected by the disease in the province [and] we are looking at double the number in 15 years" (110).

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In many of the rural areas of the province, the effects of population aging have been compounded by outmigration of working-age residents. Between 1991 and 2007, the population of the St. John's Census Metropolitan Area grew by about 8,600 while the population of the rest of the province declined by around 82,000. Population decline has been particularly marked on the island in rural outport communities (111). A 2010 qualitative case study of one rural community on the southern part of the Avalon Peninsula gives some indication as to how rural seniors have been affected by this shrinking of the working-age population. Outmigration had indeed removed from this community a number of people who might otherwise have provided informal care to elderly relatives. Nevertheless, many of the older residents who remained were confident in their ability to age in place, and insisted that there was a strong culture of helping in the community. Younger seniors, in particular, have increasingly taken on the responsibility of looking after older family members, friends, and neighbours. However, even these younger seniors described their ability to age in place as tenuous and dependent on the continued availability of local services. Furthermore, the more isolated older residents, those who, for one reason or another, had fewer sources of support, were particularly vulnerable. Overall, the study seems to suggest that the effects of outmigration are quite complex and will vary from community to community and from person to person; some older adults will fill the gaps by drawing on the support of friends and neighbours, and some will prove more vulnerable to the loss of informal sources of support (112).

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Labrador constitutes something of an exception to these trends. According to the Community Accounts Unit of the Newfoundland and Labrador Statistics Agency, roughly 8% of Labrador residents were aged ≥ 65 years in 2011 compared to 16% in the province as a whole (113). As well, the total birth rate² for Labrador in 2013 was significantly higher than that of the province as a whole, 14.9 compared to 8.9 (114). The relative youthfulness of Labrador's population is partly attributable to the presence of major resource and construction projects, which tend to attract working-age persons and young families in search of high-paying jobs, and partly attributable to its high concentration

of aboriginal peoples, who generally have higher fertility levels than the rest of the population. Roughly one quarter of the total population of Labrador is Innu or Inuit. In addition to the services provided by the Labrador-Grenfell Regional Health Authority, both groups receive additional health benefits from the organizations that represent them: the Innu Nation and the Nunatsiavut government. In fact, participants in a 2012 qualitative study of health services in Happy Valley-Goose Bay and the Nunatsiavut region suggested that "Labradorians limited to Medical Care Plan coverage faced the most significant financial barriers to accessing provincially insured and uninsured health care services" (115, p. 12). Moreover, one of our key informants suggested to us that Innu and Inuit Labradorians with

² Total birth rate is the ratio of live births to the population expressed per 1,000.

dementia may benefit from the extended family structures that are common among many aboriginal groups. A recent Statistics Canada report revealed that aboriginal Canadians aged ≥ 45 years were almost three times more likely than their non-aboriginal counterparts to live in shared homes with their grandchildren, and two-thirds of these co-resident aboriginal grandparents also shared a household with middle-generation parents (116). These extended family structures may represent a source of informal caregiving support for persons with dementia – though they may also entail unique forms of stress for the other household residents.

Service Landscape

Community-dwellers with dementia in Newfoundland and Labrador can avail themselves of a network of provincial and regional-level services designed to support their independence. These services are crucial to the success of any interventions for helping people with dementia to improve or maintain their quality of life, physical functioning, mobility, and ADL performance. In order to engage in these interventions safely and effectively, people with dementia must have access to safe, functional built environments; timely assistance with basic personal care; appropriate professional guidance; and, in some cases, supportive aids and equipment. Services are also needed by family caregivers who, as the evidence demonstrates, report significantly lower levels of burden when they can draw upon different types of practical and psychological support. Below we examine the provincial and regional services available to people with dementia and their caregivers.

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Provincial Home Support Program and Special Assistance Program

The DHCS-funded Home Support Program (HSP) subsidizes the purchase of home support services from provincially regulated private-sector agencies or from individual workers hired directly by clients. To access publicly-funded home support services, persons with dementia must first be assessed by RHA personnel to determine whether they:

- a) require long-term assistance with daily living,
- b) live in their own private residence, and
- c) have liquid assets below the allowable level for the program – \$10,000 for single people and \$20,000 for couples (117).

Services provided through the home support program typically include assistance with personal care, household management, and caregiver respite. In addition, workers can also be trained by community health nurses to perform selected nursing tasks. The purpose of the program is to “supplement, not replace, service provided by the individual’s family and/or support network” (118), with the overall aim of helping people to remain living in their own homes.

The DHCS also funds the Special Assistance Program (SAP), which subsidizes the purchase of basic supportive health products and equipment for persons who require them for ADL. As with the HSP, eligibility criteria relate to an applicant's functional capabilities, and the two programs use a similar financial assessment process to determine applicants' financial eligibility. Under the SAP, singles with greater than \$3,000 and couples with greater than \$5,500 in liquid assets are ineligible for subsidies (117). The program covers non-specialized supplies like catheters, incontinence aids, hospital beds, pressure-relieving mattresses, commodes, wheelchairs, and walkers. Our informants generally seemed to feel that the SAP is well-run and helpful, though informants in regions outside of the Eastern Health region pointed out that the equipment and supplies made available through the program must be sourced from St. John's and then shipped to destination communities. Receipt of equipment and supplies is therefore often delayed, and this can create particular problems for clients who have been discharged from acute care and who require specialized equipment to transition safely back to their home environment. One informant also told us that equipment requiring assembly can often pose challenges for clients in areas where there are few available community-based healthcare providers.

Recognizing the growing need for these programs, in 2012 the DHCS released *Close to Home: A Strategy for Long-Term Care and Community Support Services*, wherein it described its approach to helping individuals with long-term care and community support needs achieve optimal independence and quality of life. The Department also detailed the various new investments it had made to the programs over the previous six years. Among them were:

- \$60.8 million to increase the home support hourly subsidy rate from \$8.04 per hour to \$12.25 an hour;
- \$48.1 million to accommodate growth in the HSP;
- \$1.25 million in changes to SAP eligibility criteria, which made the program accessible to a greater number of people; and
- \$13.1 million in changes to the home support benefit ceilings and the financial assessment process for both programs, which made subsidies available for more clients (119).

In the most recent budget year, the government announced approximately \$180 million in funding for the HSP, "representing an increase of over \$6 million from last year's program that provided support to about 9,000 seniors" (120). Some of our informants observed that client access to these programs has improved significantly as a result of the various changes described above.

Notwithstanding these investments, our key informants noted that there is a significant amount of unmet demand in the province for home care. The current HSP subsidy rate for workers hired directly by clients to provide assistance with basic personal care is \$12.50 an hour, though the program provides a small amount of additional money on a bi-weekly basis to help clients with bookkeeper fees (117). Workers hired through an agency are subsidized at a rate of \$18.40 an hour. But because agencies manage payment of the workers, the client does not receive the extra money for assistance with bookkeepers' fees. Our informants noted that there is a chronic shortage of home support workers and

high turnover in the industry, indicating that these rates may not be sufficient to attract a stable, committed workforce. Home care agencies find it particularly difficult to recruit workers in rural areas, where outmigration has reduced the size of the working-age population. The problem was noted as being especially acute in areas where resource or construction projects like the Muskrat Falls generating facility have created better-paying employment opportunities for workers with entry-level qualifications.

In general, there seems to be a commonly-held yet profoundly mistaken perception that the provision of personal care for persons with dementia constitutes unskilled labour. Our informants rejected this perception and unanimously attested to a pressing need for upskilling within the province's home support workforce.

Furthermore, although the Provincial Home Support Program Operational Standards encourage the hiring of trained workers, there is no standardized dementia-care training required for people who provide home support, and the overhead costs involved in providing training are generally higher than what home care agencies are willing to spend. Consequently, home support workers often have little understanding of their clients' special care needs and, in particular, of the importance of sensitivity to clients' preferences and of encouraging independence. Without the skills required to effectively manage the behavioral symptoms of the disease, home support workers are often burnt out by the demands of the job, particularly as their clients approach the more severe end of the dementia spectrum. The upshot is that clients who are eligible for HSP subsidies are often unable to find a worker who is willing *and* able to do the work. In general, there seems to

be a commonly-held yet profoundly mistaken perception that the provision of personal care for persons with dementia constitutes unskilled labour. Our informants rejected this perception and unanimously attested to a pressing need for upskilling within the province's home support workforce.

Moreover, the maximum HSP subsidy obtainable for persons over 65 is \$2,870 per month (117), which averages out to approximately seven hours a day for clients who hire workers directly, and five hours a day for clients who hire through an agency. Our informants felt that certain clients' needs can readily exceed these amounts. Though people with dementia living in the community generally do not need 24-hour, seven-day-a-week supportive care, many do need assistance at particular times of day, such as early morning, mealtimes, and when retiring for the evening, and some require supervision to prevent elopement. In general, clients who are unable to access the number of home care hours they need often have no other choice than to rely on family members, thus increasing caregiver strain and the likelihood of LTC placement.

Day programs

Well-designed day programs in safe, controlled settings can create opportunities for persons with dementia to engage in the kinds of recreational activities and exercise that have been shown to improve physical functioning and ADL performance, and provide opportunities for social engagement.

Moreover, they also enable family members to take a break from caregiving activities and attend to their own needs. Indeed, a number of our informants pointed out that one of the main barriers preventing family members from accessing support was their inability to take time away from caregiving responsibilities. There was broad consensus among our informants that the general lack of day programs designed specifically for Newfoundlanders and Labradorians with early-stage dementia constitutes a major barrier to their continued independence. At the time of writing, we were able to identify only a small number of available day programs, and very few of them offered therapeutic or personal care services. An exception was the day program offered at Saint Luke's Homes in St. John's, which runs from 9:00am to 4:30pm on Tuesdays and Thursdays and has 20 available spaces for persons aged ≥ 60 years with dementia who are at risk of elopement.³ The program is staffed by a program coordinator, a nurse, and a bus driver, and it also utilizes the various professional services of Saint Luke's Homes, including physiotherapy, occupational therapy, and dietetics, though these latter two services are only offered on an emergency basis. In addition to recreational activities such as community outings, fitness classes, crafts, bingo, and cards, clients can also get assistance with personal care tasks like hair styling or bathing. At the same time, the program creates opportunities for professional assessment and interactions with health care providers that might not otherwise occur. There are a handful of similar programs scattered throughout the province: Western Health offers adult day support programs at Bay St. George Long-Term Care in Stephenville Crossing and at the Charles Legrow Health Center in Port Aux Basques, but few provincial day programs offer the same range of resources as Saint Luke's Homes. As can be imagined, the wait lists for placement within these programs are quite long.

There was broad consensus among our informants that the general lack of day programs designed specifically for Newfoundlanders and Labradorians with early-stage dementia constitutes a major barrier to their continued independence.

The Life Unlimited for Older Adults (LUFOA) committee in Springdale provides an example of how smaller communities can mobilize volunteers to deliver cost-effective day programming in the absence of the kind of institutional resources found in larger urban centres. By partnering with Central Health and the town of Springdale, LUFOA volunteers have been able to offer a range of services designed to promote active living and to decrease isolation among older area residents (121). These include friendly visiting, fitness sessions, a community kitchen, and a variety of intergenerational activities. LUFOA also recently received funding to expand its Care-2-Ride transportation service to the area surrounding Springdale. As successful as the committee's work has been, like most other volunteer organizations it must perennially contend with the twin challenges of fundraising and volunteer burnout. Moreover, its very success calls attention to the benefits that seniors in other parts of the province might derive from similar programming.

³ St. Luke's Homes also run a day program on Mondays, Wednesday, and Fridays which is open to all seniors. Though a number of clients in this program have mild dementia, the program is not specifically designed for this population.

Programs and services delivered by non-profit and community organizations

The principal non-profit service provider for people with dementia in this province is the Newfoundland and Labrador chapter of the Alzheimer Society. The Alzheimer Society offers two closely-related services that are particularly important to the independence of persons with dementia: *First Link* and *the Learning Series*. *First Link* partners with local referring physicians to identify persons newly diagnosed with dementia in order to help them navigate the web of available services. The program also provides regular monthly follow-up. Prior to its launch in Ottawa in 2009, people with dementia and their families tended to make contact with the Society only after they were already in crisis. *First Link* was thus designed to intervene as soon after diagnosis as possible, at a point when clients and their families could contemplate the full range of service options under relatively less challenging circumstances. The program has since spread to nine of ten provinces including Newfoundland and Labrador, where it strives to fill a critical service gap identified by a number of our key informants: health system navigation and follow-up. Many of the problems and difficulties encountered by people with dementia and their families are not medical in nature; rather, they are behavioural and logistical. Once diagnosed, persons with dementia often do not receive follow-up care from their family doctor or other healthcare personnel unless they have a medical issue. In the absence of a formal, province-wide system of case management specifically for persons with dementia living outside of LTC, *First Link* has taken on the responsibility of helping this population access essential services. Though the reaction from clients and families has been positive, the provincial chapter of the Alzheimer Society employs only one paid *First Link* coordinator and relies heavily on volunteers to deliver the program. It does not currently have the capacity to meet the anticipated future demand for the service, and will require additional funding in order to expand.

First Link also connects clients and their families with *the Learning Series* program, a free series of courses that provides participants with a comprehensive overview of dementia, a set of coping strategies, and information about available resources and supports. *The Learning Series* is offered three times a year, and sessions are generally delivered by volunteers. Client feedback on *the Learning Series* has been positive, though completion rates remain low because many participants join at a relatively late stage in the progression of their disease, which provides further impetus for the Alzheimer Society to try to reach people soon after diagnosis. As with the *First Link* Program, *the Learning Series* will require additional resources in order to meet the anticipated future demand for dementia caregiver supports here in the province.

There are two other non-profit service providers of note: the Seniors Resource Centre (SRC) and the Red Cross. The SRC is a charitable, voluntary organization that promotes the independence and well-being of older adults in Newfoundland and Labrador. It offers a range of programs and services including a toll-free information line, volunteer peer support, and planned social activities. Of particular interest to families of seniors with dementia is the SRC's *Caregivers Out of Isolation* program, which began in 2000. The program's founding objectives were to identify the needs of family caregivers, connect them to information and other resources, and stimulate support for caregivers through community volunteer groups and formal caregiver systems. To this end, it established a toll-free Caregiver Line, published a

newsletter, and conducted a province-wide needs assessment. On the basis of the needs assessment, the SRC concluded that “there were minimal resources available for family caregivers in Newfoundland and Labrador, especially in rural communities” (122). Since then, *Caregivers Out of Isolation* has facilitated the development of Regional Caregiver Networks based in various communities throughout the province.

The Canadian Red Cross offers the *Health Equipment Loan Program (HELP)*, which lends health-related equipment to eligible residents of Newfoundland and Labrador for a period of three months, typically while they are waiting to access similar equipment under the SAP. The Red Cross also offers a volunteer-based ride service for clients in the St. John’s area who lack access to affordable transportation. For a nominal fee, the ride service provides transportation to banking and medical appointments.

Home Modification Program

Newfoundland and Labrador Housing offers a Home Modification Program (HMP) for homeowners with income less than \$46,500 per year who require changes to their homes to enhance accessibility. These changes include ramps, grab bars, widening of door frames, and lowering of surfaces. Funding for modifications is provided through grants of up to \$7,500 and repayable loans of up to \$10,000 (\$13,000 in Labrador). However, persons who are *renting* homes are not eligible for this service, and homeowners must have owned their homes for at least five years to be eligible. The Newfoundland and Labrador Housing Home Modification Program is available province-wide.

Residential alternatives for persons requiring level one or two care

In Newfoundland and Labrador, LTC homes are accredited public facilities that are funded by the DHCS and operated by their respective RHAs (123). As stated earlier, LTC facilities offer care and accommodations to people who require level three care or higher, whereas residential care for persons requiring level one or two care (i.e., assistance with daily living and the occasional services of a visiting professional) is for the most part only available from private, for-profit personal care homes and assisted-living facilities. Personal care homes are licensed and monitored by their respective RHAs to ensure they are complying with the Health and Community Services Act, the Personal Care Home Regulations, and any other relevant policies and standards (124). Though neither the DHCS nor the RHAs play a direct role in the funding or operation of personal care homes, public subsidies are available to persons deemed eligible by their RHA on the basis of a financial assessment. As with the HSP, only persons with liquid assets below the allowable level, \$10,000 for single people and \$20,000 for couples, are eligible for a personal care home subsidy.

The scholarly evidence we identified through our literature search is primarily concerned with interventions for people who are still living in their own homes; therefore, personal care homes, assisted living facilities, and other such residential alternatives to LTC do not constitute a major focus of this report. Nevertheless, a number of our informants felt there is a need in the province for a more affordable range of residential care options for persons who have been diagnosed with dementia but who do not require level three care or higher. Protective Community Residences represent one such

option. Like LTC homes, Protective Community Residences, or Dementia Care Bungalows, as they are also known, are public facilities funded by the DHCS and operated by RHAs. The Bungalows offer enhanced assisted living within a smaller, more home-like, and less structured living environment with built-in safeguards against wandering. Bungalows can accommodate up to ten or twelve residents, each with a private room. Each Bungalow employs a case coordinator who facilitates the admissions process, provides ongoing physical and psychosocial support, liaises with other health professionals to ensure the residents' care needs are met, and monitors the performance of unregulated staff. Special care workers provide assistance with ADL and personal care throughout the day and overnight. The core Bungalow

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staff also includes a social worker, a visiting physician, and a recreation therapist/worker. Currently, Bonavista, Lewisporte, and Corner Brook are the only communities in the province with Protective Community Residences, though one is currently being constructed in Clarenville (125).

System Navigation and the Service Landscape

Our evidence synthesis indicates that dementia case management may be an effective means for preventing or delaying placements into long-term care, at least over the short-term. Indeed, a province-wide system of case management specifically for persons with dementia living outside of LTC might well redress one of the most pressing needs identified by our key informants: health system navigation. We heard from our key informants that there is a general lack of awareness among persons diagnosed with dementia and their family caregivers about the various services and programs that might benefit them. If clients do become aware of available services, there is often a forbidding maze of paperwork they must navigate in order to determine their eligibility. We heard that there is often a general lack of communication between different sectors,

professional groups, and program areas within the health care system, and that this often compels clients and their families to serve as their own case managers. As we have seen, the provincial government and the RHAs have invested a great deal of money and energy into a whole range of community support services, but maximizing the benefits to people with dementia would require some additional capacity in the area of system navigation. For example, Western Health has recently created a navigator position to help new and existing clients of the Community Support Program with the financial assessment process. In the absence of this kind of enhanced navigation capacity, some of the types of interventions found to be promising or suggestive may not achieve maximum effectiveness.

Human Resources

The ability to provide quality services for community-dwelling persons with dementia rests largely on the availability of professionally-trained workers. Allied health workers,⁴ in particular, have critical roles to play in the post-diagnostic support of such persons. In Newfoundland and Labrador, their primary responsibilities involve determining clients' eligibility for publicly-funded programs like the HSP and helping them access these programs. In other jurisdictions they run support groups and 'dementia cafés'; develop exercise programs tailored to the special needs of persons with mental health or neurological conditions; organize cognitive stimulation therapy sessions designed to 're-able' clients for the tasks of everyday life; assess clients' dietary regimes to ensure they are getting adequate nutrition; participate in multidisciplinary community outreach teams; and serve as dementia case managers, coordinating the full range of social and health care services required to help clients live independently (126-128).

Our informants expressed great enthusiasm for the potential impacts that community-based allied health workers can have on the lives of persons with dementia, but most felt that additional human resources are needed to realize this potential. The present size of the community-based allied health workforce may enable delivery of the core services enumerated above, but there is little capacity to offer anything more. In many regions, there are lengthy wait lists for initial assessment and very minimal intervention and follow-up. The charts below provide CIHI data about the physiotherapist and occupational therapist workforces in each province by place of employment in 2012, the most recent year for which such data are available. It should be noted here that these data do not distinguish between full-time employees and part-time, temporary, or casual employees. Nevertheless, they show that the numbers of physiotherapists and occupational therapists per 100,000 people are lower in Newfoundland and Labrador (44 and 35, respectively) than in the country as a whole (53 and 40, respectively). Perhaps more significantly, this province has a smaller proportion of *community-based* physiotherapists and occupational therapists than most other provinces.⁵ Though the degree of emphasis on this point varied, our key informants generally agreed that there is a need in this province to expand access to a whole range of community-based services, including physiotherapy, occupational therapy, and dietetics.

Our informants expressed great enthusiasm for the potential impacts that community-based allied health workers can have on the lives of persons with dementia, but most felt that additional human resources are needed to realize this potential.

⁴ In Newfoundland and Labrador allied health workers are represented by the Association of Allied Health Professionals, and include physiotherapists, occupational therapists, social workers, dietitians, pharmacists, speech language pathologists, and psychologists, among others.

⁵ The suppression of digits in Table 4 makes the table somewhat difficult to interpret, but the reader will note that 52.2% of physiotherapists in Newfoundland and Labrador are based in hospitals and 42.9% are employed in private professional practice, leaving less than 5% for *both* the "Community" and "Other" categories.

Table 4: Physiotherapists by Primary Place of Employment and Province/Territory of Registration, 2012⁶

	Hospital		Community		Prof. Practice		Other		Unknown		Total
	Count	%	Count	%	Count	%	Count	%	Count	%	
N.L.	118	52.2	*	*	97	42.9	*	*	0	0.0	226
P.E.I.	36	48.0	*	*	29	38.7	*	*	1	1.3	75
N.S.	221	37.8	44	7.5	223	38.2	41	7.0	55	9.4	584
N.B.	223	47.1	71	15.0	164	34.7	13	2.7	2	0.4	473
Que.	2,168	53.2	58	1.4	1,638	40.2	207	5.1	8	0.2	4,079
Ont.	2,897	44.2	916	14.0	1,335	20.4	1,275	19.5	127	1.9	6,550
Man.	270	37.3	89	12.3	279	38.5	73	10.1	13	1.8	724
Sask.	278	45.5	71	11.6	217	35.5	40	6.5	5	0.8	611
Alta.	699	32.0	327	15.0	995	45.6	109	5.0	51	2.3	2,181
B.C.	836	28.5	281	9.6	1,318	45.0	464	15.8	32	1.1	2,931
Y.T.	8	22.9	6	17.1	13	37.1	8	22.9	0	0.0	35
Total	7,754	42.0	1,875	10.2	6,308	34.2	2,238	12.1	294	1.6	18,469

Table 5: Occupational Therapists by Primary Place of Employment and Province/Territory of Registration, 2012

	Hospital		Community		Prof. Practice		Other		Unknown		Total
	Count	%	Count	%	Count	%	Count	%	Count	%	
N.L.	103	56.6	37	20.3	26	14.3	16	8.8	0	0.0	182
P.E.I.	25	52.1	1*	*	*	*	*	*	0	0.0	48
N.S.	248	60.3	43	10.5	49	11.9	71	17.3	0	0.0	411
N.B.	162	50.9	120	37.7	22	6.9	14	4.4	0	0.0	318
Que.	1,883	48.3	1,062	27.2	429	11.0	186	4.8	338	8.7	3,898
Ont.	2,095	46.1	1,477	32.5	504	11.1	466	10.3	3	0.1	4,545
Man.	281	49.1	131	22.9	46	8.0	95	16.6	19	3.3	572
Sask.	167	53.5	72	23.1	35	11.2	30	9.6	8	2.6	312
Alta.	711	41.9	632	37.2	121	7.1	233	13.7	0	0.0	1,697
B.C.	746	41.1	586	32.3	290	16.0	181	10.0	14	0.8	1,817
Terr.	23	76.7	*	*	*	*	*	*	0	0.0	30
Total	6,444	46.6	4,175	30.2	1,526	11.0	1,303	9.4	382	2.8	13,830

⁶ Source for Tables 4 and 5: Physiotherapist Database & Occupational Therapist Database, CIHI.

Notes: “*” means that the digit has been suppressed in accordance with CIHI’s privacy policy; this digit is from 0-9.

“Primary employment” is the employment, with an employer or in a self-employed arrangement, that is associated with the highest number of usual weekly hours worked.

“Community” includes residential care facilities, assisted-living residences, community health centres, visiting agencies/businesses, and schools or school boards.

“Professional practice” includes group and solo practices/clinics.

“Other” includes post-secondary educational institutions, government, industry, manufacturing and commercial, and other employer types not otherwise specified.

CIHI data may differ from provincial and territorial data as a result of CIHI’s collection, processing, and reporting methodologies.

Considerations for Decision Makers



The considerations we have listed below are based on the synthesis findings as refracted through the professional perspectives of the clinicians, administrators, and decision makers on the project team. Given the nature of our methodology and the limitations of the evidence available for our synthesis, we cannot firmly endorse any particular programs, services, or interventions. Instead, readers should regard the items that follow as considerations that decision makers may wish to bear in mind as they contemplate the local relevance and applicability of the research-based evidence synthesized in the first part of this report.

1. Persons with dementia in Newfoundland and Labrador often try to access services only when they are already in crisis, at which point the range of viable service options may be limited; therefore, decision makers should consider prioritizing early identification and outreach.
2. Persons with dementia and their families often struggle with navigating our provincial health system, identifying and applying for available services, and accessing follow-up care; therefore, building capacity for supporting these tasks should be considered.
3. Chronic shortages of qualified, committed home-support workers are a serious impediment to the Home Support Program's goal of supplementing family and other support networks, especially in rural areas that have been affected by outmigration.
4. The lack of standardized dementia-care training for people who provide home support can compromise the ability of such workers to meet their clients' special care needs and to manage the behavioural and psychological symptoms of the disease.
5. Expanding the number of dementia-friendly day programs would not only provide family caregivers with a much-needed support, but would also create opportunities for persons with dementia to connect with health professionals and engage in the kinds of therapeutic activities and exercises that have been shown to improve physical functioning and ADL performance.
6. Persons with dementia living outside of LTC need a wider range of affordable residential care options, such as the Protective Community Residences in Corner Brook, Lewisporte, and Bonavista.
7. Increasing the potential impacts that community-based allied health workers can have on the lives of persons with dementia and their families may require additional investment in these human resources.

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