

# Evidence *in* Context

Issue: Supporting the Independence of  
Persons with Dementia  
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## Health research – synthesized and contextualized for use in Newfoundland & Labrador Supporting the Independence of Persons with Dementia *in Newfoundland & Labrador*

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Supporting the independence of persons with dementia is a high-priority issue across the province. Our health system recognizes the importance of providing appropriate services for families who wish to have their loved ones “age in place” and/or those who hope to delay admissions into long-term care for family members with dementia for as long as possible.

In 2014, the Newfoundland and Labrador Department of Health and Community Services and the four Regional Health Authorities 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).

For this study, CHRSP 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 our Subject Expert for the project.

Team members decided to focus the synthesis on interventions that could potentially help people with dementia and their caregivers remain sufficiently independent to prevent or delay admissions to long-term care homes. The team then identified a set of outcomes that would be used to assess the interventions described in the research literature, including delayed institutionalization; improvements to performance of

Activities of Daily Living; relieving caregiver burden/ distress; and promoting safety of the care recipient. The synthesis was based primarily on evidence from systematic literature reviews published between January 2010 and January 2015.

To give readers a sense of how much confidence they can place in the effectiveness of a given intervention, we have categorized the evidence for each intervention as:

**Promising** – decision makers can be reasonably confident in the effectiveness of the intervention as a means for achieving the stated outcomes;

**Suggestive** – the intervention may be worth trying, though administrators would be well-advised to evaluate its effectiveness carefully;

**Insufficient at present** – readers should be cautioned against expecting that this intervention will, by itself, yield significant results in achieving stated outcomes.

This document provides a brief summary of the interventions studied in this CHRSP research synthesis, outlines relevant local contextual considerations, and concludes with implications of the research findings for the province’s health system decision makers.



### The Research Question:

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

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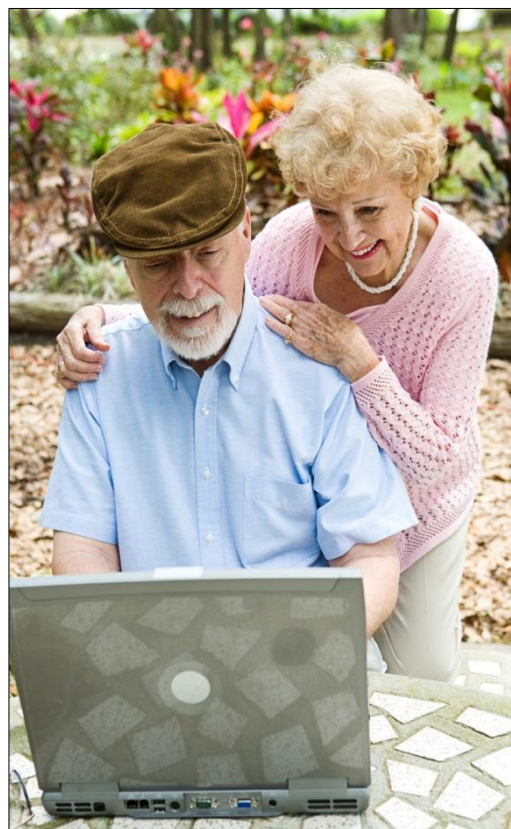
**Disclaimer:** This document is an executive summary of a larger report that contains fully referenced material. We have omitted references from this summary for the sake of brevity, but readers who wish to inspect these references can refer to the full report which is available at [www.nlcahr.mun.ca/chrsp](http://www.nlcahr.mun.ca/chrsp) together with a companion document that details the project methodology.

Read the full report here: [www.nlcahr.mun.ca/chrsp](http://www.nlcahr.mun.ca/chrsp)

## Summary of Review Evidence

The table below outlines the interventions studied and what the evidence tells us about their potential effectiveness:

Evidence Category	Interventions in this category
<b>PROMISING-</b> <i>evidence for the effectiveness of this intervention is provided in one or more high-quality reviews (i.e., AMSTAR score <math>\geq</math> 66.7%) encompassing 5 or more different primary studies.</i>	<ul style="list-style-type: none"> <li>• Psychoeducational support interventions for caregivers of people with dementia</li> </ul>
<b>SUGGESTIVE-</b> <i>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 <math>\geq</math> 33.3%) encompassing more than 1 primary study.</i>	<ul style="list-style-type: none"> <li>• Case management</li> <li>• Physical exercise</li> <li>• Interventions targeting the performance of Activities of Daily Living</li> </ul>
<b>INSUFFICIENT AT PRESENT-</b> <i>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 none on the intervention.</i>	<ul style="list-style-type: none"> <li>• Respite Care</li> <li>• Meditation (for caregivers)</li> <li>• Interventions targeting urinary incontinence</li> </ul>



## Interventions Assessed in this Report

This study looked at systematic review evidence for the following interventions:

- **Psychoeducational supports for caregivers:** These interventions vary in their mode of delivery (face-to-face or internet or telephone delivery) and they also differ in terms of the balance they sought to strike between educational and psychosocial components. 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.
- **Case Management:** There is suggestive evidence for the effectiveness of professionally-delivered dementia case management in achieving short-term reductions in LTC placement.
- **Physical Exercise Programs:** 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 exercise programs for caregivers on caregiver burden is, as yet, uncertain.
- **Interventions Targeting Activities of Daily Living:** There is suggestive evidence for the effectiveness of interventions targeting ADL performance, particularly when they involve face-to-face contact with health professionals.

Finally, with regard to respite care, meditation for caregivers, and interventions that target urinary incontinence, either there is no moderate-to-high quality review evidence based on a sufficient number of primary studies to demonstrate effectiveness or there are an insufficient number of primary studies from which to draw conclusions.

# Supporting the Independence of Persons with Dementia – the Newfoundland and Labrador Context

## Population Factors

While the average age of Canadians is increasing, this trend is especially pronounced in Newfoundland and Labrador. In 2009, the proportion of persons in NL aged 65 years and over was close to the Canadian average; however, by 2036 the province will likely have the highest proportion of older adults in Canada. This demographic pressure alone is expected to increase demand for services to support persons with dementia and their caregivers. The Alzheimer Society of Canada has estimated that in 2038 there will be 257,811 new cases of dementia identified among Canadians aged 65 years and older, 2.5 times the number of new cases in 2008.

The outmigration of working-age residents from rural Newfoundland and Labrador is also expected to have an impact on the service landscape for persons with dementia. The effects of outmigration are quite complex and will vary within and among rural communities; some older adults with dementia will continue to be able to draw on the support of friends and neighbours, and some will prove more vulnerable to the loss of informal sources of support.

Labrador is a noteworthy exception to these trends. In 2011, Labrador had half the proportion of residents  $\geq 65$  years of age than the overall provincial average as well as a significantly higher birth rate. The youthfulness of Labrador's population and its exceptional demographic character means that the prevalence of dementia and the experience of persons with dementia, particularly among aboriginal populations (that can benefit from the support of an extended family structure), may be distinctive.

## The Service Landscape

Community-dwelling persons with dementia in Newfoundland and Labrador can avail themselves of a network of services designed to support their independence. These services are crucial to the success of any interventions that have been designed to help persons 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, functionally-appropriate environments; timely assistance with basic personal care; appropriate professional guidance; and in some cases, supportive aids and equipment.

These services are also important for family caregivers who, as the evidence demonstrates, report significantly lower levels of burden when practical and psychological supports are available to them. The many provincial services we looked at in our study included: the Provincial Home Support Program; the Special Assistance Program; various day programs offered through LTC homes and volunteer organizations; programs and services delivered by non-profit groups; home modification programs; and residential alternatives such as protective community residences or Dementia-Care Bungalows. Some suggested improvements to optimize the effectiveness of these services included enhanced system navigation capacity and improved training for

home support workers.

## Human Resources

The ability to provide quality services for community-dwelling persons with dementia rests largely on the availability of professionally-trained workers. In particular, allied health professionals such as Occupational Therapists and Physiotherapists have critical roles to play in the post-diagnostic support of persons with dementia. In Newfoundland and Labrador, their primary responsibilities involve determining clients' eligibility for publicly-funded programs and helping them access these programs. In other jurisdictions, allied health workers

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. 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 some core services, but there is little capacity to offer anything more. NL has smaller numbers of community-based physiotherapists and occupational therapists per capita than most other provinces in Canada.



# Contextualized Synthesis: Supporting the Independence of Persons with Dementia In Newfoundland and Labrador

## 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.

For the complete CHRSP report, including details on the evidence reviewed by the project team, and for more information about the CHRSP process, please visit the NLCAHR website: [www.nlcahr.mun.ca/chrsp](http://www.nlcahr.mun.ca/chrsp)