



RESOURCE GUIDE FOR SUPPORTING CAREGIVERS AT HOME - FOR HOME CARE SERVICE PROVIDERS



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Improvement**

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INTRODUCTION

In 2012, 8 million Canadians, or 28% of the population aged 15 and over, provided care to family members or friends with a long-term health condition, a disability or problems associated with aging.¹

The Safety at Home Study²⁻⁷ found that the incidence of new caregiver distress in home care (HC) was about 6%, with some regional variation observed. For example the Nova Scotia rate was significantly higher at 11%. Care recipient and provider interviews identified that there is a shared decay of health of the client and unpaid caregivers at home. As HC clients and unpaid caregivers do whatever it takes to keep the client at home the challenges become more stressful for both. If the needs of the caregivers are not adequately addressed the clients are at risk for re-admission to acute or LTC facilities at increased cost.⁸

The Safety at Home authors²⁻⁷ determined that in Canadian home care, as client's illness progressed, caregivers' new and mounting responsibilities included managing medications, equipment, home care visits, and medical appointments; giving baths and personal care; preparing meals; cleaning; doing dishes, laundry, and exterior household maintenance; getting groceries; handling banking and financial management; and keeping the client, family members, and providers up to date. All this was expected, regardless of the caregivers' age, personal health, work obligations, or family situation. Additionally, a client's changing health status and ability to care for themselves, brings pressure for caregivers to take on new, and often more demanding roles. We called this "duty creep," and caregivers indicated that combined with the stress and worry of the illness they increasingly felt the pressure of all the new responsibilities associated with the caregiving role.

Among regular caregivers (those who spent at least 2 hours caregiving each week) 38% of those caring for their child, 34% of those caring for their spouse and 21% of those caring for their parents reported feeling depressed. Those who cared for a spouse or child also reported more health and psychological problems. It has been suggested that this is mainly because of the intensity of care provided.⁹

A review of caregiver literature suggests that older caregivers who experience chronic stress are at a greater risk for injury or for aggravating pre-existing health issues, and their activities are more limited as a result of their caregiving responsibilities. One recognized factor that can put caregivers at risk is the lack of access to resources and services. Recommendations resulting from this review included the screening and monitoring of caregivers, developing support and health promotion services for caregivers, and recognizing caregiver contributions.¹⁰ Currently in Canadian home care, the routine screening of family caregivers for caregiver distress is not done.

A scan of Canadian grey literature shows that some resources to support caregivers in their roles, has been undertaken and created across Canada; however, the resources can be difficult to find, and there is a lack of either provincial or national infrastructure to enable sharing and uptake. The resources included in this toolkit, drawn from national, provincial and regional sources, are an attempt to fill this gap.

This “toolkit” is the result of the previously mentioned scan of the grey literature. While it was not feasible to undertake a true critical appraisal of many of these tools, materials were assessed using the following criteria from the Medical Library Association for evaluating health information from the web.¹¹

- 1 **Sponsorship.** The website sponsor is clearly labeled, a recognized organization and known for producing dependable information.
- 2 **Currency.** In most instances, materials reviewed are less than 5 years old. In rare cases, seminal works or population specific information are included if it they are the most current information that could be found. Tools should have a clear publication/revision date.
- 3 **Clearly Written.** Information presented is based on current research or best practices, based on identified primary sources and presented in a clear manner. For client and family resources, the term “clearly written” is used as they rarely contain references to primary sources. For health care provider and administrator resources, the term “evidence-based’ is used.
- 4 **Audience.** The target audience for the material included is either clearly stated or presented in a way that makes it very clear to the user.

Toolkits that have been included here are marked with an *. Toolkits could be assessed on a general basis only as in some cases there were too many resources to feasibly assess each individually. In other cases, it was hard to separate one resource from it’s companion pieces and individual assessment would not have been useful or practical.

Resources and toolkits marked with a § contain material that would be appropriate for unregulated workers, either for their own knowledge or to share with clients and families. Organizations may wish to adapt some of these resources for continuing education purposes for their staff.

The clinical practice guidelines included in this toolkit were measured against the above criteria **in addition to** the following:

- 5 **Demonstration of rigour in the development process.** The guideline is evidence based. It is built upon a systematic review of the literature and the recommendations are grounded in supporting evidence.
- 6 **Multidisciplinary stakeholder involvement.** The guideline shows evidence of multidisciplinary stakeholders’ involvement in the development process.
- 7 **National interest.** The guideline has national applicability and appeal.
- 8 **Freely available on web.** There is no cost for the included guidelines.

It should be recognized that the assessment of these materials should not be confused with a grading system. For example, being outdated does not necessarily mean that a resource is ineffective. Likewise, being current or evidence-based, does not necessarily mean that the materials are effective. The purpose of the assessment criteria is to make users of this toolkit aware of the strengths and limitations of the various resources.

This toolkit is organized by themes that emerged in the [Safety at Home Study²⁻⁷](#) and by various audiences; however it should be noted that categories are not mutually exclusive. For example, in some cases, clients may find information targeting health care providers useful, while some of the material identified for clients may be useful for care providers, especially home support workers/PSWs. Additionally some of the material for healthcare providers is actually designed to be used and shared with clients for education purposes. Context and purpose must be taken into account.

Some of the included material is copyrighted and requires permission from the developing organization before reproducing. Users of this toolkit should check the copyright information or the web sites of the sponsoring organization.

GENERAL CAREGIVER DISTRESS PREVENTION BEST PRACTICE GUIDELINES

The **Safety at Home Study**²⁻⁷ demonstrated that almost 40% of adverse events in home care are caused by the actions of healthcare personnel and the healthcare system. Incident analysis revealed that the most frequent cause of adverse events in the home was inconsistent planning and delivery of care. The Safety at Home researchers learned that clients and caregivers who are managing their health conditions, are at the same time contending with numerous providers coming into their home needing to know or learn from them about equipment, medications, and other required treatments. In addition, living spaces and outdoor walkways must be maintained. The potential outcomes of balancing these many priorities include physical harm (through trips and slips or medication and equipment errors), to emotional or psychological distress, anxiety, and exhaustion.⁷

Practice guidelines can help provide a consistent approach to supporting caregivers' needs and mitigating the risk of caregiver distress.

Some jurisdictions in Canada, and internationally have developed educational materials and other resources related to supporting caregivers. Some of these resources and tools are available in multiple languages. Specific examples of resources for home care clients and home care client teaching are provided in this toolkit.

Interestingly, there are few best practice guidelines about caregiver distress specifically. Instead, some condition specific related guidelines have begun to do a better job of addressing caregiver support. There are several examples presented below.

CANADA

British Columbia Psychogeriatric Association

This on-line resource provides evidence-informed information and tools about caregiver assessment and interventions, and resources and suggestions to address issues in case management.

**Caregiver Toolkit -*

<http://www.msvu.ca/site/media/msvu/Documents/Service%20Provider%20Resource%20Guide.pdf>

	MET	UNMET	UNKNOWN
Currency	2011		
Evidence based	x		
Audience: Health care providers, program managers, administrators			
Rigour in the development process	x		
Multidisciplinary stakeholder Involvement	x		
National interest	x		
Available on web	x		
Sponsor: BC Psychogeriatric Association			

Heart and Stroke Foundation

A new guideline on supporting patients and care givers has been added to the Canadian Best Practice Recommendations for Stroke Care.

Supporting Patients, Families and Informal Caregivers Following Stroke -
www.strokebestpractices.ca

	MET	UNMET	UNKNOWN
Currency	2013		
Evidence based	x		
Audience: Health care professionals			
Rigour in the development process			x
Multidisciplinary stakeholder Involvement	x		
National interest	x		
Available on web	x		
Sponsor: Heart and Stroke Foundation			

interRAI

The interRAI Home Care Assessment System (HC) and its associated clinical assessment protocols (CAPs) is designed to be a user-friendly, reliable, person-centered assessment system that informs and guides comprehensive care and service planning in community-based settings around the world.

Home Care Clinical Assessment Protocols - <http://www.interrai.org/home-care.html>

	MET	UNMET	UNKNOWN
Currency		2007	
Evidence based	x		
Audience: Health Care Providers, administrators			
Rigour in the development process	x		
Multidisciplinary stakeholder Involvement	x		
National interest	x		
Available on web		x	
Sponsor: interRAI			

Mental Health Commission of Canada

A template for the many types of supports and services that caregivers need at different stages of their loved one's mental illness.

National Caregiving Support Guidelines - www.mentalhealthcommission.ca

	MET	UNMET	UNKNOWN
Currency	2013		
Evidence based	x		
Audience: System planners, policy makers, service providers			
Rigour in the development process	x		
Multidisciplinary stakeholder Involvement	x		
National interest	x		
Available on web	x		
Sponsor: Family Caregivers Advisory Commission of Canada, Mental Health Commission of Canada			

Registered Nurses Association of Ontario

There are several RNAO best practice guidelines that have applicability to supporting family caregivers.

Strategies to Support Self-Management in Chronic Conditions: Collaboration with Clients - <http://rnao.ca>

This guideline is intended to support and enhance the abilities of individuals to manage their chronic illnesses. It has applicability to those nurses and caregivers who are learning to manage a loved one's chronic illness.

	MET	UNMET	UNKNOWN
Currency	2010		
Evidence based	x		
Audience: Nurses, administrators			
Rigour in the development process	x		
Multidisciplinary stakeholder Involvement		x	
National interest	x		
Available on web	x		
Sponsor: Registered Nurses Association of Ontario			

Supporting and Strengthening Families Through Expected and Unexpected Life Events - <http://rnao.ca>

	MET	UNMET	UNKNOWN
Currency		Revised 2006	
Evidence based	x		
Audience: Nurses			
Rigour in the development process	x		
Multidisciplinary stakeholder Involvement		x	
National interest	x		
Available on web	x		
Sponsor: Registered Nurses Association of Ontario			

INTERNATIONAL

National Cancer Institute

A guide for health professionals which provides comprehensive, peer-reviewed, evidence-based information about challenges and helpful interventions for caregivers of cancer patients.

Family Caregivers in Cancer: Roles and Challenges (PDQ®): Supportive care - Health Professional Information - www.cancer.gov

	MET	UNMET	UNKNOWN
Currency	Revised 2014		
Evidence based	x		
Audience: Healthcare Professionals			
Rigour in the development process		x	
Multidisciplinary stakeholder Involvement		x	
National interest	x		
Available on web	x		
Sponsor: National Cancer Institute			

National Institute for Health and Care Excellence

The dementia guideline developed by the National Institute for Health and Care Excellence is another evidence-based, comprehensive international fall guideline from the United Kingdom with a community specific branch. It is available as a PDF document or an interactive algorithm which can be navigated by clicking through the guideline. Information for the public is provided for the benefit of clients and their families. Organizational assessment and auditing tools are also provided.

Dementia: Supporting people with dementia and their carers in health and social care - <http://guidance.nice.org.uk/CG42>

	MET	UNMET	UNKNOWN
Currency	Revised 2012		
Evidence based	x		
Audience: Healthcare professionals			
Rigour in the development process	x		
Multidisciplinary stakeholder Involvement	x		
National interest	x		
Available on web	x		
Sponsor: National Institute for Health and Care Excellence			

CAREGIVER DISTRESS SCREENING

Similarly to the **Safety at Home Study**²⁻⁷, a recent CIHI⁹ study found that caregiver distress was highly associated with home care clients who suffered from significant problems with cognition and daily functioning, when the number of informal care hours was high and when the client exhibited depressive symptoms or various difficult behaviours. Spouses, rather than children or friends of the senior, appeared to be more at risk for distress and potential burnout.

The **Safety at Home Study**²⁻⁷ found inconsistencies in the process of risk assessment in home care. Consistent use of tools that can support risk assessment of home care caregivers could prevent caregiver distress, or admission to long-term care.

This set of resources for service providers addresses the topic of caregiver distress risk assessment. Examples of assessment tools are provided below.

CANADA

Hospital for Sick Children

An instrument to assess the health status, comfort, wellbeing and ease of caregiving of children with severe cerebral palsy.

Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD®)
Questionnaire - http://www.sickkids.ca/pdfs/Research/CPChild/6573-CPCHILD_manual.pdf

	MET	UNMET	UNKNOWN
Currency		2007	
Evidence based	x		
Audience: Healthcare providers			
Sponsor: Sickkids Hospital			

interRAI

The interRAI Home Care Assessment System (HC) and its associated clinical assessment protocols (CAPs) is designed to be a user-friendly, reliable, person-centered assessment system that informs and guides comprehensive care and service planning in community-based settings around the world. In particular, CAPs and the MAPLe identify those who may need further assessment and/or services to prevent caregiver burnout. These resources must be purchased.

Home Care Clinical Assessment Protocols - <http://www.interrai.org/algorithm.html>

	MET	UNMET	UNKNOWN
Currency		2007	
Evidence based	x		
Audience: Home care administrators and providers			
Sponsor: interRAI			

Mount St. Vincent University

A tool to assist practitioners in gathering information related to caregivers' support needs and helps to identify key areas of concern.

The C.A.R.E. Tool. Caregivers' Aspirations, Realities and Expectations (C.A.R.E.) - www.msvu.ca

	MET	UNMET	UNKNOWN
Currency		2001, 2006	
Evidence based	x		
Audience: Home care providers, administrators, researchers			
Sponsor: Mount Saint Vincent University			

A tool designed for use at intake by home care practitioners to assess the level at which caregivers' physical and/or emotional health may be at risk and to determine whether the care being provided is adequate.

The Caregiver Risk Screen - www.msvu.ca

	MET	UNMET	UNKNOWN
Currency		2001	
Evidence based	x		
Audience: Homecare providers			
Sponsor: Mount Saint Vincent University			

INTERNATIONAL

**Family Caregiver Alliance, National Center for Aging & Benjamin Rose Institute on Aging*

A curated package of assessment tools for service providers.

Selected Caregiver Assessment Measures: A Resource Inventory for Practitioners -

www.caregiver.org

	MET	UNMET	UNKNOWN
Currency	2012		
Evidence based	x		
Audience: Practitioners who work with family/informal caregivers			
Sponsor: Family Caregiver Alliance, Benjamin Rose Institute on Aging			

VNA Community Health Care

Caregiver Self-Assessment Questionnaire (adapted from AMA) -

www.connecticuthomecare.org

	MET	UNMET	UNKNOWN
Currency			x
Evidence based			x
Audience: Caregivers			
Sponsor: American Medical Association			

GENERAL CAREGIVER DISTRESS PREVENTION EDUCATION AND TOOLS

A review of caregiver literature suggests that older caregivers who experience chronic stress are at a greater risk for injury or for aggravating pre-existing health issues, and their activities are more limited as a result of their caregiving responsibilities. One recognized factor that can put caregivers at risk is the lack of access to resources and services. Recommendations resulting from this review included the screening and monitoring of caregivers, developing support and health promotion services, and recognizing their contributions.¹⁰

Caregivers have various needs, including a need for information, a need to be involved in decision-making, a need for breaks (respite) from caregiving duties, and help with navigating the health system. However, assessments of potential home care clients usually do not include comprehensive caregiver assessments, which means that their needs go unnoticed.¹⁰

CANADA

British Columbia Psychogeriatric Association

This on-line resource provides evidence-informed information and tools about caregiver assessment and interventions, and resources and suggestions to address issues in case management.

***Caregiver Toolkit -**

<http://www.msvu.ca/site/media/msvu/Documents/Service%20Provider%20Resource%20Guide.pdf>

	MET	UNMET	UNKNOWN
Currency	2011		
Evidence based	x		
Audience: Home care administrators, policy makers and providers			
Sponsor: British Columbia Psychogeriatric Association			

Quebec ministry of health

Documents outlining an initiative experimenting with various interventions to support caregivers of those with dementia and other neuro-degenerative conditions.

Soutenir les proches aidants : Résumés de vingt-sept expériences de répit, de formation et de soutien - <http://msssa4.msss.gouv.qc.ca/fr/document/publication.nsf/fb143c75e0c27b69852566aa0064b01c/d174514205b0f84585256e8300686b05?OpenDocument>

Soutenir les proches aidants : Constats, enseignements, pistes de réflexion Fonds de partenariat sur la maladie d'Alzheimer et les affections connexes - <http://msssa4.msss.gouv.qc.ca/fr/document/publication.nsf/4b1768b3f849519c852568fd0061480d/9d44738248f5c50485256f1d00510166?OpenDocument>

	MET	UNMET	UNKNOWN
Currency		2004	
Evidence based			x
Audience: Home care administrators and policy makers			
Sponsor: Ministère de la Santé et des Services sociaux (Quebec), Janssen-Ortho, Novartis, Pfizer			

INTERNATIONAL

Centers for Disease Control and Prevention

A discussion of the Re AIM framework which is a tool to help practitioners and researchers anticipate pertinent caregiver issues as they engage in planning, conducting, or evaluating caregiver intervention programs and policies.

Assuring Healthy Caregivers. A Public Health Approach to Translating Research into Practice - www.cdc.gov

	MET	UNMET	UNKNOWN
Currency	2008		
Evidence based	x		
Audience: Home care providers and researchers			
Sponsor: Center for Disease Control & Kimberly-Clark Association			

*Champ (Collaboration for Home Care Advances in Management and Practice),
Center for Home Care Policy & Research, Visiting Nurse Service of New York*

The Center for Home Care Policy & Research from the United States developed a comprehensive toolkit which includes materials for professionals, paraprofessionals (unregulated workers) and clients and families. It includes tools for clients in English, Chinese and Spanish, as well as some other languages. Some of these materials deal with supporting caregivers.

***Geriatric Care transitions Toolkit - www.champ-program.org**

Currency	Generally current tools
Evidence based	Material generally referenced
Audience: Homecare providers, clients, caregivers	
Sponsor: CHAMP (Collaboration for Home Care Advances in Management and Practice)	

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