



RESOURCE GUIDE FOR SUPPORTING CAREGIVERS AT HOME - FOR CLIENTS AND FAMILY CAREGIVERS



THE CHANGE
FOUNDATION



Canadian Foundation for
**Healthcare
Improvement**

Fondation canadienne pour
**l'amélioration des
services de santé**



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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 its 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 SUPPORT TOOLS

Almost all (95-98%) home care clients have some level of difficulty with activities such as cleaning, cooking, grocery shopping, and home maintenance (called instrumental activities of daily living, or IADLs). A considerable number (23 –41%) need help with fundamental activities such as bathing, eating, and toileting (called activities of daily living, or ADLs).¹

In 2012, slightly more than 8 million Canadians, or 28% of people aged 15 and over, had provided help or care to a relative or friend with a chronic health problem, spending a median of 4 hours a week in this role.¹ A recent report from the Health Council of Canada¹⁰ suggests that often caregivers are providing between 70-75% of the care required at home. One in four caregivers reported reducing their hours of work in response to their caregiving responsibility.¹ The physical and emotional toll of care, can be a source of distress for care givers.

CANADA

Alberta Health Services

A selection of on-line and print resources for caregivers.

Caregiver College - www.caregivercollege.ca

Supporting Caregivers of Older Adults - www.caregivercollege.org

	MET	UNMET	UNKNOWN
Currency	2008		
Clearly written	x		
Audience: Caregivers			
Sponsor: Capital Health			

Canadian Caregiver Coalition

A website for the Canadian Caregiver Coalition, a national body representing and promoting the voice, needs and interests of family caregivers with all levels of government, and the community. The site contains links to other resources for caregivers.

www.ccc-ccan.ca

	MET	UNMET	UNKNOWN
Currency			x
Clearly written	x		
Audience: Caregivers, researchers, service providers			
Sponsor: Canadian Caregiver Coalition			

Caregivers Nova Scotia

An organization that provides programs, services, resources and advocacy for caregivers.

Where to Begin - www.caregiversns.org

	MET	UNMET	UNKNOWN
Currency	Revised 2013		
Clearly written	x		
Audience: Caregivers			
Sponsor: Caregivers Nova Scotia, Alzheimer Society of Nova Scotia, Nova Scotia Centre on Aging			

The Caregivers Handbook - www.caregiversns.org

	MET	UNMET	UNKNOWN
Currency		2007	
Clearly written	x		
Audience: Caregivers			
Sponsor: CIHR, U of Ottawa, Dalhousie University, IWK Health Centre, Health Canada, Nova Scotia Health Promotion and Protection, Human Resources and Social Development of Canada			

Care – ring Voice Network

On-line or telephone bilingual educational resources for caregivers. Topics include: Advanced Care Planning, Elder Abuse, Power of Attorney, Life with Aging Parents and more. These sessions are helpful for people who are new to caregiving or wish to keep current on how to navigate the health care system or provide self-care.

www.careringvoice.com

	MET	UNMET	UNKNOWN
Currency	2008		
Clearly written	x		
Audience: Caregivers			
Sponsor: Caregivers			

Family Caregivers Network Society & North Shore Community Resources (British Columbia)

A resource guide for North Shore clients and families. Sections on self-care, normal aging and working as a team may be helpful to clients and caregivers outside the specified area.

Resource Guide for Family Caregivers -

<http://www.nscr.bc.ca/information/caregiver/Resource%20Guide%20North%20Shore%20Edition%20Oct2011.pdf>

	MET	UNMET	UNKNOWN
Currency	2010		
Clearly written	x		
Audience: Caregivers			
Sponsor: Family Caregivers' Network Society, North Shore community Resources, J. W. McConnell Family Foundation, Vancouver Coastal Health SMART Fund			

Family Caregivers Network Video Series -

www.youtube.com/watch?v=J-8ezaxZyco&feature=youtu.be

	MET	UNMET	UNKNOWN
Currency	2011		
Clearly written	x		Video
Audience: Caregivers			
Sponsor: Family Caregivers' Network			

Family Caregivers Unite

Website and link to radio show by Dr. Gordon Atherley. The radio show is for family caregivers to connect and listen to topics of interest.

<http://familycaregiversunite.org/>

	MET	UNMET	UNKNOWN
Currency			Current
Clearly written			Radio
Audience: Caregivers			
Sponsor: Family Caregivers Unite			

Famille et des Aînés Québec

A guide designed for caregivers, to help them deal with situations that can present a risk to frail clients, and present practical information that can support their efforts.

Guide de Survie -

http://media.wix.com/ugd/b70678_ea966bc217bc95a2853d6fbbfc1e7a67.pdf

	MET	UNMET	UNKNOWN
Currency	2012		
Clearly written	x		
Audience: Caregivers			
Sponsor: Familles et Aînés Québec, RAANM			

Government of Canada

A website which allows users to click on various parts of Canada to access further information about finances, health, powers of attorney etc.

www.seniors.gc.ca/eng/sb/caregivers/index.shtml

Currency	Last modified – 2013
Clearly written	Yes
Audience: Caregivers	
Sponsor: Government of Canada	

Government of Manitoba

Information and resources for caregivers of older adults. Discusses caregiver tips, stress management, balancing employment etc.

A Guide for the Caregiver - www.gov.mb.ca

	MET	UNMET	UNKNOWN
Currency	2012 (Revised)		
Clearly written	x		
Audience: Caregivers			
Sponsor: Seniors and Healthy Aging Secretariat of Manitoba			

Grenfell Regional Health Service

Caring for Caregivers. A handbook for caregivers - www.seniorsresource.ca

	MET	UNMET	UNKNOWN
Currency		2002	
Clearly written	x		
Audience: Caregivers			
Sponsor: Grenfell Regional Health Services Health Promotion			

*HealthLink BC

By entering the term “caregiving” into the search box, this site includes links to multiple easy-to-understand fact sheets about caregiving, including caregiving specific to several different conditions/diseases. This includes BC-specific resources as well as information that is valid across Canada. Some examples of resource topics are: Caregiving Tips, Heart Failure – Tips for Caregivers and Caregiver Support: Talking About end of Life Decisions

www.healthlinkbc.ca

Currency	Most resources current
Clearly written	Generally clear and easy to understand
Audience: Caregivers	
Sponsor: HealthLink BC	

Safe Medicines for Seniors. A Guide for Caregivers - www.pharmacists.ca

	MET	UNMET	UNKNOWN
Currency		2006	
Clearly written	x		
Audience: Caregiver			
Sponsor: Health Canada, Canadian Pharmacists Association			

Health Charities Coalition of Canada

A guide developed to assist patients, caregivers, friends and families in managing information about the Canadian health care system, which can often be challenging to navigate.

The “How To” Health Guide - www.healthcharities.ca

	MET	UNMET	UNKNOWN
Currency	2011		
Clearly written	x		
Audience: Caregivers and Patients			
Sponsor: Health Charities Coalition of Canada			

****Institut universitaire de gériatrie de Montréal***

This resource website for caregivers has discusses several topics such as day to day living issues, common health issues, long term care and palliative care.

www.aidant.ca

Currency	Most resources appear current
Clearly written	Generally clearly written
Audience: Home care clients and caregivers	
Sponsor: Institut universitaire de gériatrie de Montréal	

On Memory – Alzheimer Society website

Caring for Caregivers tab has 10 signs of stress for caregivers, 10 ways to deal with stress and healthy living strategies that are applicable to all caregivers.

www.onmemory.ca

	MET	UNMET	UNKNOWN
Currency	x		
Clearly written	x		
Audience: Caregivers			
Sponsor: Alzheimer Society			

Public Health Agency of Canada

Lists common sources of stress for care-givers, stress-relieving activities, and other resources.

Self-Care for Caregivers - www.phac-aspc.gc.ca

	MET	UNMET	UNKNOWN
Currency		2005	
Evidence based			x
Audience: Caregivers			
Sponsor: Public Health Agency of Canada			

Regroupement des aidants naturels du Québec (RANQ)

RANQ has a mission to improve the quality of life of caregivers in Quebec. A part of the larger “En route with Trousseau” project, the toolbox is intended for caregivers and provider organizations and contains a variety of individual, group and systems resources.

***The Toolbox** - www.ranq.qc.ca

Currency	Some current documents
Clearly written	Generally clearly written
Audience: Caregivers, home care administrators	
Sponsor: Regroupement des aidants naturels du Quebec (RANQ)	

Seniors Resource Centre Newfoundland and Labrador

A resource to help caregivers manage common caregiver challenges such as communicating effectively with their care receiver, organizing day to day schedules as well as support and respite services, staying healthy, and coping with grief and bereavement.

Guide for Caregivers - www.seniorsresource.ca

	MET	UNMET	UNKNOWN
Currency	2012		
Clearly written	x		
Audience: Caregivers			
Sponsor: Caregivers Out of Isolation, The Seniors Resource Center (Newfoundland), Department of Health and Community Services, Newfoundland and Labrador			

Vancouver Coastal Health

A guide with sections on understanding yourself as the caregiver, the person you are caring for and caring for various needs.

Take Care. A Handbook for Family Caregivers - www.hss.gov.yk.ca

	MET	UNMET	UNKNOWN
Currency	2010		
Clearly written	x		
Audience: Caregivers			
Sponsor: Caregiver Support Program, Vancouver Coastal Health			

Veterans Affairs Canada

A printable, fill-in-the-blanks form to help caregivers identify potential sources of help and keep the information organized.

My Support Network - www.veterans.gc.ca

	MET	UNMET	UNKNOWN
Currency	2014		
Clearly written	x		
Audience: Caregivers			
Sponsor: Veterans Affairs Canada, Government of Canada			

INTERNATIONAL

Center for Disease Control and Prevention

A toolkit with links to various fact sheets, information and links to websites and organizations of interest to caregivers.

***Caregiver Resources** - www.cdc.gov

Currency	Generally current
Clearly written	Generally clearly written
Audience: Caregivers	
Sponsor: Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion, Center for Disease Control and Prevention	

***Family Caregivers Alliance** (*National Center for Caregiving in the US*)

Caregiving information and advice - www.caregiver.org

Fact Sheets - www.caregiver.org

(various languages including Korean, Chinese, Vietnamese and Spanish)

Currency	Generally current
Clearly written	Generally clearly written
Audience: Caregivers	
Sponsor: Family Caregiver Alliance, National Center on Caregiving	

National Cancer Institute

A support guide for cancer caregivers with applicability to many different types of caregivers.

Caring for the Caregiver - www.cancer.gov

	MET	UNMET	UNKNOWN
Currency		2007	
Clearly written	x		
Audience: Caregivers			
Sponsor: National Cancer Institute			

United States Department of Veteran's Affairs

A variety of tools and resources such as diagnoses information sheets, everyday tips and checklists, and information for new caregivers.

***Caregiver Toolbox** - www.caregiver.va.gov

Currency	Generally current
Clearly written	Generally clearly written
Audience: Caregivers	
Sponsor: US Department of Veterans Affairs	

IDENTIFYING RISK OF CAREGIVER DISTRESS

Prevention of caregiver distress ideally requires the development of a multipronged approach incorporating screening, offering education and resources, and offering services including respite. The **Safety at Home Study**²⁻⁷ found inconsistencies in the process of risk assessment. Failure to institute a re-assessment following the identification of a problem, and inconsistencies in implementation of prevention interventions were some of the factors that contributed to adverse events. There are a number of tools that can support risk assessment of home care clients and caregivers.

There are several printable self-assessment checklists for caregivers with scoring guides. These can be helpful for clients to do themselves, or for care providers to use as part of screening strategy for caregiver distress. Most are from the United States.

INTERNATIONAL

American Medical Association

Tools for Caregivers - www.caregiverslibrary.org

	MET	UNMET	UNKNOWN
Currency			x
Clearly written	x		
Audience: Caregivers			
Sponsor: American Medical Association			

Government of Massachusetts

This is a short easy to follow brochure with some photos to complement the instructions.

Caregiver Stress Self-Assessment - www.mass.gov

	MET	UNMET	UNKNOWN
Currency			x
Clearly written	x		
Audience: Caregivers			
Sponsor: Government of Massachusetts			

The United States Veteran Administration

This assessment is intended as a part of the assessment for caregivers of US veterans who require long term care. With adaptation, it could be helpful for Canadian seniors and their caregivers.

Caregiver Self-Assessment for the Caregiver of a Veteran Needing Long Term Care -

www.va.gov

	MET	UNMET	UNKNOWN
Currency	2013		
Clearly written	x		
Audience: Caregivers of Veterans			
Sponsor: VA Healthcare			

CAREGIVER INFORMATION FOR SPECIFIC CLIENT POPULATIONS

The **Safety at Home Study**²⁻⁷ found that caregiver distress was highest among caregivers of dementia clients (13.86%), followed by congestive heart failure clients (7.38%), and lowest for chronic obstructive pulmonary disease clients (6.82%).

A 2010 analysis by the Canadian Institute for Health Information (CIHI)⁹ showed that the strongest associations with caregiver distress, while controlling for other factors, were found where home care clients suffered from significant problems with cognition and daily functioning, where the number of informal care hours was high and where the client exhibited depressive symptoms or difficult-to-manage behaviours. Among caregivers, it was spouses, rather than children or friends of the senior, who appeared to be more at risk for distress and potential burnout.

Caregivers in general 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.¹⁰ Some of the barriers to receiving appropriate and timely information include a lack of coordinated and consistent providers, an absence of 24/7 services, poor communication skills, lack of emotional/spiritual support, and lack of knowledge of dealing with cultural diversity.¹²

Children

CANADA

Alberta Childrens Hospital

A printable resource to help the families of chronically ill children keep track of medical information and care providers. It can be used to document contact information, medical history, clinic visits, admissions, treatments, medications, test results, resources, etc.

Family Journal - www.calgaryhealthregion.ca/ACH/documents/publications/family_journal.pdf

	MET	UNMET	UNKNOWN
Currency			x
Clearly written	x		
Audience: Caregivers (of children), pediatric patients and families			
Sponsor: Family Liaison Council, Alberta Children's Hospital, Calgary Health Region			

***Brain Tumor Foundation of Canada**

A link to Pediatric Patient Handbook (English and French), A Friend in Hope storybook (English, French and Italian) and information, fact sheets and resources on various types of brain tumors.

www.braintumour.ca/229/about-brain-tumours

Currency	Some information undated
Clearly written	Most information clearly written
Audience: Patients with brain tumors and their caregivers	
Sponsor: Brain Tumor Foundation of Canada	

British Columbia Children's Hospital

A searchable list of health pamphlets on a variety of children's health conditions such as pacemaker care, end of life considerations, giving medications to children etc.

***A-Z Health Pamphlets - www.bcchildrens.ca**

Currency	Most information current
Clearly written	Generally clearly written
Audience: Children with various conditions and their caregivers	
Sponsor: BC Children's Hospital	

***About Kids Health Resource Centers - www.aboutkidshealth.ca**

Currency	Most information relatively current
Clearly written	Information generally clear
Audience: Pediatric patients and family caregivers	
Sponsor: BC Children's Hospital	

Heart and Stroke Foundation

This guide is intended as a source of help and reassurance to families whose children have been diagnosed with congenital heart disease.

Heart and Soul. Your Guide to Living with Congenital Heart Disease -

<http://www.heartandstroke.com>

	MET	UNMET	UNKNOWN
Currency			x
Clearly written	x		
Audience: Caregivers of children with congenital heart disease			
Sponsor: Heart and Stroke Foundation, Imperial Oil Foundation			

Holland Bloorview

A series of information sheets for the families of chronically ill children who are looking for, interviewing and training respite workers for their children.

Respite Tip Sheets - www.hollandbloorview.ca

	MET	UNMET	UNKNOWN
Currency			x
Clearly written	x		
Audience: Caregivers of children with disabilities or chronic illnesses requiring a support worker			
Sponsor: Holland Bloorview Kids Rehabilitation Hospital			

Tip Sheets: Interviewing and Hiring Support Workers - www.hollandbloorview.ca

	MET	UNMET	UNKNOWN
Currency			x
Clearly written	x		
Audience: Caregivers of children with disabilities or chronic illnesses requiring a support worker			
Sponsor: Holland Bloorview Kids Rehabilitation Hospital			

Tip Sheets: Training a Respite Worker - www.hollandbloorview.ca

	MET	UNMET	UNKNOWN
Currency			x
Clearly written	x		
Audience: Caregivers of children with disabilities or chronic illnesses requiring a support worker			
Sponsor: Holland Bloorview Kids Rehabilitation Hospital			

Family Resource Center (*variety of conditions such as Downs, facial anomalies, autism etc*) - www.hollandbloorview.ca

	MET	UNMET	UNKNOWN
Currency	2011		
Clearly written			Various documents
Audience: Caregivers of children with disabilities or chronic illnesses			
Sponsor: Holland Bloorview Kids Rehabilitation Hospital			

IWK Health Center

A variety of publications – guide to clubfoot, balancing activity and diabetes management, home aerosol, tube feeding education etc. - some in Chinese, French and Arabic.

***Children’s Health Resources** - www.iwk.nshealth.ca

	MET	UNMET	UNKNOWN
Currency	2014		
Clearly written			Various Documents
Audience: Parents/caregivers of children			
Sponsor: IWK Health Center			

INTERNATIONAL

American Academy of Pediatrics

A webpage with a searchable list of health issues for children including developmental disabilities, chronic illness and heart conditions.

healthychildren.org - www.healthychildren.org

	MET	UNMET	UNKNOWN
Currency	2014		
Clearly written	x		
Audience: Parents/caregivers of children			
Sponsor: American Academy of Pediatrics, healthychildren.org			

Dementia

CANADA

Alzheimer Society

A website of resources and education that can help support the caregivers of those with Alzheimer's and other dementias. Includes warning signs of stress, a guide for reducing caregiver stress, driving information etc. Links to resources are also included.

*www.alzheimer.ca

	MET	UNMET	UNKNOWN
Currency	2011		
Clearly written		x	
Audience: Alzheimer patients and caregivers			
Sponsor: Alzheimer Society Canada			

	MET	UNMET	UNKNOWN
Currency	2011		
Clearly written	x		
Audience: Children and spouses of patients with dementia			
Sponsor: Alzheimer Society of British Columbia			

Canadian Dementia Knowledge Translation Network

A website with a section for teens and parents with information, how to access resources, challenges and sample letters to schools, doctors and lawyers.

When Dementia is in the House - <http://lifeandminds.ca/whendementiaisinthehouse/>

	MET	UNMET	UNKNOWN
Currency	2011		
Clearly written	x		
Audience: Children and spouses of patients with dementia			
Sponsor: Tiffany Chow & Katherine Nichols, University of Toronto Neurology, Dalhousie University, Baycrest, NICE, University of California Berkeley, CDKTN			

Registered Nurses Association of Ontario

Fact sheets

Caring for Persons with Delirium, Dementia and Depression - <http://rnao.ca>

	MET	UNMET	UNKNOWN
Currency			x
Clearly written	x		
Audience: Caregivers of patients with delirium, dementia and depression			
Sponsor: RNAO			

Recognizing Delirium, Dementia and Depression - <http://rnao.ca>

	MET	UNMET	UNKNOWN
Currency			x
Clearly written	x		
Audience: Patients or caregivers of patients experiencing delirium, dementia or depression			
Sponsor: RNAO			

**University of Waterloo Murray Alzheimer Research and Education Program*

A website with links to a variety of workshops, educational materials, and other helpful resources

<https://uwaterloo.ca/murray-alzheimer-research-and-education-program/education-and-knowledge-translation>

Currency	Some material undated
Clearly written	Information generally clearly written
Audience: People living with dementia and their caregivers	
Sponsor: University of Waterloo Murray Alzheimer Research and Education Program	

A site dedicated to providing information and resources to persons with dementia and their family partners in care.

Living with Dementia website - www.livingwithdementia.uwaterloo.ca/

	MET	UNMET	UNKNOWN
Currency	2012		
Clearly written	x		
Audience: Patients with dementia and their family caregivers			
Sponsor: Murray Alzheimer Research and Education Program			

INTERNATIONAL

National Institute on Aging

This website contains a variety of information for clients and caregivers with Alzheimers (and also other types of dementias. We have highlighted some of the main resources available, but there are also others on the website – many in English and Spanish

Caregiver Guide: Tips for Caregivers of People with Alzheimer’s Disease -

www.nia.nih.gov

	MET	UNMET	UNKNOWN
Currency	2010		
Clearly written	x		
Audience: Caregivers of patients with Alzheimer’s disease			
Sponsor: National Institute on Aging			

Caring for a Person with Alzheimer’s Disease - www.nia.nih.gov

	MET	UNMET	UNKNOWN
Currency	2012		
Clearly written	x		
Audience: Caregivers of patients with Alzheimer’s disease			
Sponsor: National Institute on Aging			

Home Safety for People with Alzheimer’s Disease - www.nia.nih.gov

	MET	UNMET	UNKNOWN
Currency	2010		Last updated 2014
Clearly written	x		
Audience: Caregivers of patients with Alzheimer’s disease			
Sponsor: National Institute on Aging			

	MET	UNMET	UNKNOWN
Currency			x (various documents)
Clearly written	x		
Audience: Caregivers of patients with Alzheimer's disease			
Sponsor: National Institute on Aging			

University of Florida, College of Public Health and Health Professions

A clickable on-line resource with sections on caregiving basics, caregiver challenges, caregiver well-being, planning for the future etc.

***AlzOnline** - <http://alzonline.phhp.ufl.edu/>

Currency	Some resources current
Clearly written	Generally clearly written
Audience: Caregivers of patients with Alzheimer's disease	
Sponsor: AlzOnline, University of Florida College of Public Health and Health Professions	

Stroke

CANADA

Canadian Stroke Network

A series of guides, to help clients and families set goals and strive for their maximum recovery following stroke.

Getting on With the Rest of Your Life After Stroke - www.strokebestpractices.ca

	MET	UNMET	UNKNOWN
Currency			x
Clearly written	x		
Audience: Stroke patients and their caregivers			
Sponsor: Canadian Stroke Network			

A Family Guide to Pediatric Stroke - www.strokebestpractices.ca

	MET	UNMET	UNKNOWN
Currency	2011		
Clearly written	x		
Audience: Families of children who have had a stroke			
Sponsor: Canadian Stroke Network			

Heart and Stroke

A comprehensive guide for caregivers to stroke survivors, including sections on incontinence, transfers, skin care etc.

A Guide for Stroke Caregivers - www.heartandstroke.on.ca

	MET	UNMET	UNKNOWN
Currency	2013		
Clearly written	x		
Audience: Stroke caregivers			
Sponsor: Heart and Stroke Foundation			

March of Dimes

A Caregivers Guide to Stroke Recovery - www.marchofdimes.ca

	MET	UNMET	UNKNOWN
Currency			x
Clearly written	x		
Audience: Stroke Caregivers			
Sponsor: March of Dimes Canada, Stroke Recovery Canada, Allergan Canada			

INTERNATIONAL

National Stroke Association

A guide intended to equip caregivers with the knowledge, resources, strategies and tools to navigate the post-stroke caregiving journey.

Careliving Guide – Caring for Yourself and a Stroke Survivor - www.stroke.org

	MET	UNMET	UNKNOWN
Currency			
Clearly written			
Audience: Caregivers			
Sponsor: National Cancer Institute			

Spinal Cord Injuries

INTERNATIONAL

**University of Alabama School of Medicine, Spinal Cord Injury Fact Sheets*

A series of spinal cord injury fact sheets designed for clients and caregivers including topics such as sexuality, weight, caring for caregivers, bladder care and management etc.

www.uab.edu/medicine/sci/uab-scims-information/sci-infosheets

Currency	Range of fact sheet publication dates
Clearly written	Information generally clear
Audience: People with spinal cord injury and their caregivers	
Sponsor: UAB School of Medicine, National Institute on Disability and Rehabilitation Research	

Long Distance Caregiving

INTERNATIONAL

National Institute on Aging

This illustrated 44-page booklet offers information about caregiving from afar.

So Far Away: Twenty Questions and Answers About Long-Distance Caregiving

www.nia.nih.gov

	MET	UNMET	UNKNOWN
Currency	2010		
Clearly written	x		
Audience: Long-distance Caregivers			
Sponsor: National Institute on Aging			

Mental Health

CANADA

Canadian Mental Health Association

This guide includes a section about caring for yourself to avoid burnout and remain an effective companion.

Being There, When Mental Illness Strikes Someone Near You: A guide for a friend, family member or co-worker - www.beingthereguide.com

	MET	UNMET	UNKNOWN
Currency			x
Clearly written	x		
Audience: Friends, family members or co-workers of patients with mental illness			
Sponsor: Katherine Farris & Larry McDonald			

	MET	UNMET	UNKNOWN
Currency	2014		
Clearly written	x		
Audience: Family and caregivers of patients with mental illness			
Sponsor: Canadian Mental Health Association			

Schizophrenia Society of Ontario

A variety of printable fact sheets on topics such as advocacy, coping, families as partners in care, and several justice guides for families. The fact sheets are available in French and English.

***Facts for families** - <http://www.schizophrenia.on.ca/Looking-For-Help/Educational-Resources/Printable-Resources>

Currency	Generally current
Clearly written	Generally clearly written
Audience: Patients with schizophrenia and their caregivers	
Sponsor: Schizophrenia Society of Ontario	

Heart

INTERNATIONAL

American Heart Association

A website with a variety of printable resources for clients and families. Contains resources on caring for clients with heart failure, stroke, as well as understanding blood pressure readings, heart rates, cholesterol etc. There is a series of resources specifically for caregivers, and is available in several languages (English, French, Spanish, Traditional Chinese, Simplified Chinese, Vietnamese).

***Caregiver Resources** - www.heart.org

Currency	Generally current
Clearly written	Generally clearly written
Audience: Caregivers of patients with cardiovascular disease	
Sponsor: American Heart Association	

Cancer/Palliative Care

A study of caregivers of people who are dying found that most caregivers want information about issues such as pain management, how to navigate the system, respite, practical details about giving care, expectations of disease progression, how to deal with the care team, and legal/financial information.¹⁰

CANADA

Alberta Health Services

A Caregiver's Guide. A Handbook to End of Life Care - www.albertahealthservices.ca

	MET	UNMET	UNKNOWN
Currency		2004	
Clearly written	x		
Audience: Caregivers of palliative care patients			
Sponsor: The Military and Hospitaller Order of St. Lazarus of Jerusalem and The Canadian Hospice and Palliative Care Association			

Canadian Cancer Society

*A website with information for people with cancer, their families and caregivers.
We have highlighted 2 resources but there are many others in the French and English links below.*

Living with Cancer. A Guide for People with Cancer and their Caregivers - www.cancer.ca

	MET	UNMET	UNKNOWN
Currency	2012		
Clearly written	x		
Audience: Patients with cancer and their caregivers			
Sponsor: Canadian Cancer Society			

If You're a Caregiver - www.cancer.ca

	MET	UNMET	UNKNOWN
Currency	2014		
Clearly written	x		
Audience: Caregiver of a patient with cancer			
Sponsor: Canadian Cancer Society			

Canadian Hospice Palliative Care Association

A guide about quality of life for the last stages of life.

Living Lessons. A Guide for Caregivers - www.living-lessons.org

	MET	UNMET	UNKNOWN
Currency		2002	
Clearly written	x		
Audience: Caregivers of palliative care patients			
Sponsor: Canadian Hospice Palliative Care Association			

Kidney Cancer Canada

This website contains educational resources, tips and advocacy information for clients diagnosed with kidney cancer and their families.

www.kidneycancer.ca/for-patients-and-caregivers

Currency	Generally current
Clearly written	Generally clearly written
Audience: Patients with kidney cancer and their caregivers	
Sponsor: Kidney Cancer Canada	

Leukemia and Lymphoma Society

A guide designed to help patients and caregivers when they talk to their doctors about tests and treatments.

The AML Guide. Information for Patients and Caregivers - <http://www.llscanada.org>

	MET	UNMET	UNKNOWN
Currency	2012		
Clearly written	x		
Audience: Patients with acute myeloid leukemia and their caregivers			
Sponsor: Leukemia and Lymphoma Society			

Lymphoma Canada

This website contains information for caregivers of those with lymphoma, under headings like “Caring for Someone with Lymphoma”, “Self-Care for Caregivers”, and “Tips for Caregivers”.

www.lymphoma.ca/lymphoma/caregiver-support

	MET	UNMET	UNKNOWN
Currency	2014		
Clearly written	x		
Audience: Caregivers of patients with lymphoma			
Sponsor: Lymphoma Canada			

Northwest Territories Department of Health

A handout providing information about the natural and expected changes people face as they approach death and what caregivers can do to keep them comfortable.

End of Life Care. Information for Caregivers - www.hss.gov.nt.ca/

	MET	UNMET	UNKNOWN
Currency	2010		x
Clearly written	x		
Audience: Caregivers of palliative care patients			
Sponsor: Fort Good Hope Health Centre, NWT, Waterloo Hospice			

INTERNATIONAL

American Cancer Society

A website where caregivers can learn about what to expect in their role for a person with cancer, as well as find suggestions and tips for making sure that they take care of themselves.

www.cancer.org/treatment/caregivers/index

	MET	UNMET	UNKNOWN
Currency	2014		
Clearly written	x		
Audience: Caregivers of patients with cancer			
Sponsor: American Cancer Society			

National Cancer Institute

This site provides a summary of information that includes: An overview of the caregiver's perspective across the illness trajectory in cancer; factors to consider in caregiver assessment; typical caregiver roles and concerns; and interventions for health care professionals.

Family Caregivers in Cancer: Roles and Challenges (PDQ®): Supportive care – Patient Version - www.cancer.gov

	MET	UNMET	UNKNOWN
Currency			x
Clearly written	x		
Audience: Caregivers of patients with cancer			
Sponsor: National Cancer Institute			

Parkinsons

CANADA

Parkinsons Society of Canada

A website to support the caregivers of Parkinsons patients. Communication strategies and dealing with aggressive behaviours are briefly discussed. Available in several languages including German, Italian, Spanish, Chinese and Punjabi.

For Caregivers - www.parkinson.ca

	MET	UNMET	UNKNOWN
Currency			x
Clearly written	x		
Audience: Caregivers of patients with Parkinson's			
Sponsor: Parkinson Society Canada			

Others

Amyotrophic Lateral Sclerosis (ALS) Society of Canada

A manual intended to provide information and helpful hints to individuals and families recently diagnosed and living with ALS.

A Manual for People Living with ALS - www.als.ca

	MET	UNMET	UNKNOWN
Currency		2005	
Clearly written	x		
Audience: Patients with ALS			
Sponsor: Amyotrophic Lateral Sclerosis Society of Canada			

	MET	UNMET	UNKNOWN
Currency			
Clearly written			
Audience:			
Sponsor:			

A series of fact sheets in French and English for people with ALS and their caregivers.

***ALS Fact Sheets** - www.als.ca

	MET	UNMET	UNKNOWN
Currency			x
Clearly written	x		
Audience: Patients with ALS and their caregivers			
Sponsor: Amyotrophic Lateral Sclerosis Society of Canada			

A series of 5 booklets available in English and French on

- *Helping Children Cope with ALS – A Parental Information Guide*
- *When Someone Special had ALS- A booklet for Children*
- *When your Parent has ALS – A Booklet for Teens*
- *Talking with Young People about ALS- For Schools*
- *Talking With Your Patient’s Children About ALS - A Primer for Health Professionals*

Also an interactive website for children and youth in French and English –

***Youth Resources** - www.als.ca/en/publications/youth-resources

Youth Website - www.als411.ca/

Currency	Generally current
Clearly written	Generally clearly written
Audience: Children/Teens with parents suffering from ALS	
Sponsor: Amyotrophic Lateral Sclerosis Society of Canada	

Brain Tumor Foundation of Canada

A link to the Adult or Pediatric Patient Handbook (English and French), A Friend in Hope storybook (English, French and Italian) and information and resources on various types of brain tumors.

Information for You - www.braintumour.ca

	MET	UNMET	UNKNOWN
Currency	2014		
Clearly written	x		
Audience: Patients with brain tumors			
Sponsor: Brain Tumor Foundation of Canada			

**Diabetes Care Community*

Diabetes Care Community is a new Canadian social network and information resource with a focus on families and friends of people living with diabetes.

www.diabetescarecommunity.ca

Currency	Generally current
Clearly written	Generally clearly written
Audience: Patients with diabetes and their families/caregivers	
Sponsor: Diabetes Care Community	

Epilepsy Canada

A website offering a “Living with Epilepsy” tab with information for men, women, children, seniors etc with epilepsy and their caregivers. Also a youth corner with helpful tips for youth with epilepsy and their caregivers.

Living with Epilepsy - <http://www.epilepsy.ca/en-CA/Coping/Living-with-Epilepsy.html>

	MET	UNMET	UNKNOWN
Currency			x
Clearly written	x		
Audience: Patients with epilepsy			
Sponsor: Epilepsy Canada			

Multiple Sclerosis Society of Canada

A guide to assist people with MS and their families deal with the rewards and challenges of caregiving. Sections on care options, costs, financial planning, communication etc. are addressed.

A Guide for Caregivers - http://mssociety.ca/en/pdf/pub_caregiverguide.pdf

	MET	UNMET	UNKNOWN
Currency		2007	
Clearly written	x		
Audience: Caregivers of patients with multiple sclerosis			
Sponsor: Multiple Sclerosis Society of Canada			

Muscular Dystrophy Canada

A website for those living with MD, but also of interest to caregivers. Includes sections on symptom management, respiratory care, equipment and devices etc. Links to other resources such as the Guide to Respiratory Care or Neuromuscular Disorders are included.

Living with MD - <http://muscle.ca/living-with-muscular-dystrophy/>

	MET	UNMET	UNKNOWN
Currency	2014		
Clearly written	x		
Audience: Patients with muscular dystrophy			
Sponsor: Muscular Dystrophy Canada			

Guide to Respiratory Care or Neuromuscular Disorders - <http://muscle.ca>

	MET	UNMET	UNKNOWN
Currency	2013		
Clearly written	x		
Audience: Patients with muscular dystrophy/neuromuscular disorders			
Sponsor: Muscular Dystrophy Canada			

Pulmonary Hypertension Association of Canada

Website with a caregiver tab with sections on caring for yourself, caring for a child with PH, and caring for your caregiver (tips for patients).

Caregivers - www.phacanada.ca

	MET	UNMET	UNKNOWN
Currency			2014
Clearly written	x		
Audience: Caregivers of patients with pulmonary hypertension			
Sponsor: Pulmonary Hypertension Association of Canada			

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