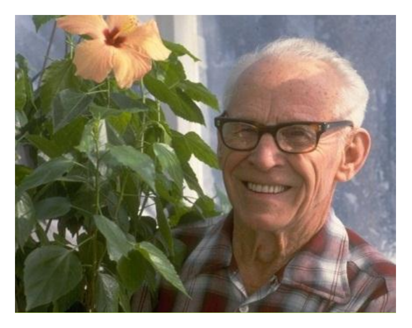
# Supporting Caregivers through Service Provision:

## The Service Provider Resource Guide

Evidence-informed information and tools about caregiver assessment and interventions, and resources and suggestions to address issues in case management.



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## Who We Are

This project has been carried out by Dr. Penny MacCourt, sponsored by the British Columbia Psychogeriatric Association (BCPGA) and funded through a contribution from the Government of Canada. The BCPGA is a professional multi-disciplinary interest group, founded in 1997 by grass roots clinicians working in the field of mental health and older adults. The vision of the BCPGA is to support older adults with (or at risk) mental health problems, their caregivers and health providers, to achieve quality of life and quality care through clinical practice, education, advocacy, research and education.

The perspectives, knowledge and support from our project partners (who also sat on the project advisory group), has been invaluable:

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**Access:**

This document, and companion document “The Caregiver Policy Lens”, can be downloaded from [www.caregivertoolkit.ca](http://www.caregivertoolkit.ca)

**Disclaimer:**

Every effort has been made to ensure the accuracy of the information provided on this website. The views expressed herein do not necessarily represent the views of the Government of Canada or of the BC Psychogeriatric Association.

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# I - PURPOSE AND RATIONALE

There are many personal and social benefits to caregiving. Yet caregiving is also associated with financial strain and with physical and psychosocial symptoms. These symptoms can place the physical and mental health of the caregiver, and their ability to continue to provide care, at risk. In spite of the strains, caregivers' needs are not formally acknowledged or assessed by health and social services in most Canadian jurisdictions and service providers lack evidence-informed tools and resources to do so. The Service Provider Resource Guide for Supporting Caregivers of Older Adults[1] is designed to address these concerns through the development of practical support tools to increase cross and inter-sectoral capacity to address caregiver needs across Canada.

# II - BENEFITS OF USING THE TOOLKIT

- Increased knowledge of issues affecting caregivers of older adults;
- Increased knowledge regarding system stressors in providing attention and resources to caregivers;
- Increased ability to engage in problem identification and problem clarification regarding issues that affect caregiver resiliency;
- Increased ability to engage in problem solving through the provision of evidence-informed support, thereby increasing caregiver resiliency;
- Increased ability to engage in problem identification and problem clarification regarding issues that affect service provider resiliency; and
- Increased ability to engage in problem solving through the provision of evidence-informed support, thereby increasing service provider resiliency.

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[1] Throughout this document senior, older adult and older person are used interchangeably to recognize the differences in terminology across Canada and between sectors.

# III - INTENDED AUDIENCE

The Resource Guide is designed to be used by a diversity of service providers: front line workers, program managers, administrators, health educators, advocates, and anyone interested in strengthening caregiver resiliency through service provision.

# IV - DEVELOPMENT OF THE TOOLKIT

The Resource Guide is grounded in specific values and principles, including:

- *Autonomy through community*: Personal autonomy (including respect, choice and self-determination) is enhanced not by appealing to individualism but rather by developing collective solutions to pressing community problems.
- *Ecological modeling*: A holistic understanding that connects the caregiver, the caring "environment", and the more distant policy environment.
- *Gender-based and diversity lens*: That the roles, responsibilities, and access to resources vary by gender, race, ethnicity, level of ability and sexual orientation, creating a variety of caregiver needs and situations.
- *Values/Principles based*: Principle-based frameworks incorporate empirical evidence and ethical considerations to facilitate a move from approaches based on cost reduction, towards those that also recognize and value caregiving as a worthwhile activity. Recognizes that service provision is driven by social values rarely acknowledge.
- *Stakeholder/experiential involvement*: Service provision must reflect the values and interests of those affected and accommodate to the realities of their environment.
- *Life cycle perspective*: Caregivers should not accumulate disadvantage that will later impose individual or public costs.
- *Population Health Framework for Healthy Aging:* Recognition that health is determined by both collective and individual factors, including: the social and economic environment, the physical environment, health services, personal health practices, and individual capacity and coping skills.
- Practical!

# V - CAREGIVER ASSESSMENT TOOLS: A REVIEW

a. Methods
b. Assessment-related Articles
c. Discussion: Description and reviews of Caregiver Measures

## Methods

A search of the literature using ‘Summon’, a new search engine adopted by the University of Calgary, was the starting point for the search. This search engine performs a simultaneous search of the academic literature as well as newspaper articles, archives, dissertations, museum holdings, reports, and other documents located on the internet. In other words, it captures the grey literature that is commonly missed when conducting academic searches.

The search revealed a vast amount of literature that has been published since 2000 on challenges associated with caregiving, including a number of reports summarizing the various instruments used to measure these challenges.

The following reports were instrumental in the creation of this document:

> Family Caregiver Alliance (2006). *Caregivers Count Too! A Toolkit to Help Practitioners Assess the Needs of Family Caregivers*. San Francisco, CA.
> http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1695
>
> Family Caregiver Alliance (2008). *Practical Tools and Resources for Caregivers.* Invitational Symposium Washington, DC.
> http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=2224
>
> Family Caregiver Alliance (2002). *Selected Caregiver Assessment Measures: A Resource Inventory for Practitioners*. San Francisco, CA.
> http://www.caregiver.org/jsp/content_node.jsp?nodeid=470
>
> Furthermore, the ‘Toolkit to Measure End-of-Life Care’ website: http://www.chcr.brown.edu/pcoc/Quality.htm, supported by the Centre for Gerontology and Health Care Research at Brown University, was cross-referenced. This site describes a number of generic caregiver assessment tools, particularly those measuring quality of life.

Finally, in addition to the ‘Summon’ search, a search of the internet was conducted to ensure that no major documents in the area were missed.

In terms of criteria, all measures included in this document have been published. In other words, scales have undergone peer-review and can thus be deemed acceptable (i.e., valid and reliable) when used with populations for which they were developed. It should be noted that some scales fall in the public domain, others are available but must be accessed via an academic article, while other still must have permission from the author prior to being used (and may require a fee). Those in the public domain have either been linked to a .pdf document or .html document. Also, not all measures included in this document have been developed specifically for the caregiving population. Those developed for the general population are noted in the individual measure descriptions.

There are three sections to the current document:

1. Assessment-related articles
2. Reviews of caregiver measures
3. Caregiver assessment tools

## Assessment-related Articles

Audit Commission (2004). *Support for Carers of Older People*. London, UK: Belmont Press. http://www.audit-commission.gov.uk/nationalstudies/health/socialcare/Pages/olderpeople5.aspx

This is the fifth report in the Audit Commission's series looking at ways to promote the independence and well-being of older people.

Australian Institute of Health and Welfare (2004). *Carers in Australia: Assisting Frail Older People and People with a Disability*. Canberra, Australia: Author.

This report is a joint initiative of the Australian Institute of Health and Welfare (AIHW) and the Australian Government Department of Health and Ageing. It was principally authored by Cathy Hales, with significant contributions from Diane Gibson, Frieda Rowland, Paula Laws and Anne Jenkins.The motivation for an exposition on carers in Australia came from an AIHW project that analysed the likely impact of social trends on future numbers of primary carers (Jenkins et al. 2003). Building on this earlier work, the present report uses data from the 1998 Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers to present a picture of informal care in contemporary Australia—who are the primary carers, who do they assist, and what does caring involve? It explores the impact of caring work and patterns of formal service use with informal care.The findings of this report are based on national data that were 5 years old at the time of writing. However, results from the survey are in close agreement with smaller scale Australian studies and international research on carers and caring. Differences in methodology between the 1998 survey and earlier ABS surveys render time series analysis problematic. Analysis of the data from the 2003 ABS Survey of Disability, Ageing and Carers, due for release in late 2004, will provide a basis for comparison with the projections contained in this report.

Bass, D. (2002). *Content and Implementation of a Caregiver Assessment.* [Issue Brief]. Washington, D.C.: Administration on Aging.

Provides tips for developing the content of a caregiver assessment as well as describes the procedures for implementing and responding to assessment information. The brief includes user-friendly tables which present a broad range of characteristics that might be considered for inclusion in caregiver assessment.

Baxter, E. (2000). Caregiver assessment: Learn about the caregiver, distinct from the person with dementia. *Alzheimer's Care Quarterly, 1* (3), 62-70.

Caregivers are often assessed as part of the care plan for someone with dementia. Unfortunately, this assessment is often only made to clarify the degree to which the person can carry out caregiving tasks. Little has been written with regards to the caregiver as a unique and separate individual with needs and issues of his or her own, separating the caregiver out as a separate component needing a full assessment. This article proposes some areas of assessment related to the caregiver that can be gathered over time while carrying out the care plan for the person with dementia. The key areas described are in addition to, not instead of, a traditional assessment of the person with dementia.

Berg-Weger, M., Rubio, D., & Tebb, S. (2001). Strengths-based practice with family caregivers of the chronically ill: Qualitative insights. *Families in Society, 82* (3), 263-272.

Using a strengths-based perspective, this paper looks at the experiences of family caregiving to the chronically ill. Qualitative research allows researchers and practitioners to gain a deeper understanding of the family caregiver experience, adding breadth to the assessment and intervention process. Themes generated from a qualitative inquiry on the impact of the caregiving experience for the caregiver are explored and discussed in terms of implications for strengths-based practice, thus providing a positive experience for the caregiver and care recipient.

Berkman, B., Maramaldi, P., Breon, E., & Howe, J. (2002). Social work gerontological assessment revisited. *Journal of Gerontological Social Work, 40* (1-2), 1-14.

Research has learned much in the last forty years about the factors critical in a gerontological social work assessment. However, assessment must be constantly readdressed, because the context of health care changes and the research technology that enables the study of factors critical to the assessment process becomes more sophisticated. This paper presents the evolution of assessment research and identifies critical assessment factors as related to the changing social work practice in the context of the country's changing health care environment.

Bogardus, S., Bradley, E., Williams, S., Maciejewski, P., Gallo, W. & Inouye, S. (2004). Achieving goals in geriatric assessment: Role of caregiver agreement and adherence to recommendations. *Journal of the American Geriatrics Society, 52* (1), 99-105.

OBJECTIVES: To determine predictors of recommendation adherence and goal attainment of family caregivers of patients at a geriatric assessment center. DESIGN: One-year prospective cohort study. SETTING: Outpatient geriatric assessment center in Connecticut. PARTICIPANTS: Two hundred consecutive new patients and their family caregivers. MEASUREMENTS: Family caregivers were interviewed after geriatric assessment to ascertain their treatment goals for the patient. Medical records were reviewed to identify treatment recommendations. Family caregivers were interviewed 1 year later to assess adherence to recommendations and attainment of goals. RESULTS: Follow-up interviews were completed with 176 (88%) family caregivers. Common recommendations pertained to physician referral (71%), medications (46%), counselling/education (31%), diagnostic tests (30%), residential planning (26%), healthcare planning (21%), and community services (21%). Goal attainment was reported in 44% to 67% of the patient cases, depending on goal category. Caregiver agreement with recommendations predicted adherence to recommendations (adjusted relative risk (ARR)=1.99, 95% confidence interval (CI)=1.04-5.92) after adjusting for available clinical and demographic factors. In addition, adherence to recommendations predicted goal attainment in adjusted analyses (ARR=1.70, 95% CI=1.09-2.64). CONCLUSION: This study revealed a broad range of treatment recommendations in geriatric assessment and suggests that agreeing with recommendations can promote adherence and that adherence can promote goal attainment. Taken together, the results imply that articulating shared treatment recommendations may improve the quality of health care.

Bradley, P. (2003). Family caregiver assessment – Essential for effective home health care. *Journal of Gerontological Nursing, 29*, 29-36.

Home health care nurses do not routinely assess the health of family caregivers despite their essential contribution to the client's care. In this study, home care nurses collected data on 51 older family caregivers from their caseloads to assess their health. The average age of the caregivers was 75.1 years (*SD* = 6.09). Most (66.7%) were women and were the home health client's spouse (82.4%). These individuals had been caregivers for up to 20 years, and reported spending an average of 13.3 hours per day in this role (*SD* = 9.15). Approximately half (*n* = 25) of the caregivers reported poor or fair health, with 33.3% (17) reporting a decline in their health over the previous 6 months. Unmet health needs included the need for blood pressure monitoring, mammograms, PAP smears, and prostate examinations. Referrals to other health care providers or community agencies were required by 78.4% of the caregivers, 78.4% required health teaching, and 23.5% required home health services themselves. Those requiring home health care were more likely to be on more medications and classify their health as fair or poor. These findings confirm those of a pilot study conducted on 51 other family caregivers. Nurses serving the geriatric population need to conduct systematic family caregiver assessments to identify caregiver health needs that could impair their caregiving ability. In particular, for home health care to be effective, nurses must conduct caregiver assessments.

Carradice, A., Shankland, M. C., & Beail, N. (2002). A qualitative study of the theoretical models used by UK health nurses to guide their assessments with family caregivers of people with dementia. *International Journal of Nursing Studies, 39,* 17-26.

> Some researchers suggest that nurse training does not provide adequate theoretical knowledge to guide mental health nurses' work with carers of people with dementia. In recent years theoretical guidance for working with carers has emerged in the nursing literature. However, little attention has been given to theory practice links. This study used interpretative phenomenological analysis to investigate the theoretical model used by nurses to guide carer assessments. During the analysis the data evolved into a description of the model underlying the nurses' work. In the discussion this model was compared with the stress process model (SPM). This comparison highlighted striking similarities between the themes in the nurses' model of carer stress and the theoretical constructs of the SPM. However, the SPM describes influential links between different constructs which were absent in the nurses' model. The research illustrates developmental training needs for mental health nursing to improve the efficacy of assessments and therefore, interventions.

Davis, L. (2001). Assessing functional ability in persons with dementia: Using family caregivers as informants. *Journal of Neuroscience Nursing, 33* (4), 194-202.

> More than one in five community-dwelling older individuals is unwilling or unable to provide information on functional abilities. In such situations the standard procedure is to augment self-reports with those of family members or other close informants. However, when these reports differ, it often is difficult to determine whether the older individual is overly optimistic about his or her functional abilities or the family informant is unduly pessimistic. This article explores factors that influence family caregiver assessments of functional abilities in older individuals with some degree of cognitive loss or impairment and presents suggestions for enhancing the accuracy and dependability of functional assessments by family informants.

Etten, M. & Kosberg, J. (1989). The hospice caregiver assessment: A study of a case management tool for professional assistance. *The Gerontologist, 29* (1), 128-131.

> A Hospice Caregiver Assessment Inventory was developed to identify the problems of those caring for dying patients. A corresponding Caregiver Intervention Plan was developed from the inventory data and utilized by agency professionals. Findings revealed the problems of caregivers of dying older persons and suggested that they often need counseling and assistance prior to the death of their loved one, as well as following death.

Family Caregiver Alliance (2006). *Caregiver Assessment: Principles, Guidelines and Strategies for Change*. Report from a National Consensus Development Conference (Vol. I). San Francisco: Author. www.caregiver.org/caregiver/jsp/content/pdfs/v1_consensus.pdf

> This report arises from an invigorating landmark event: The National Consensus Development Conference *for* Caregiver Assessment. The National Center on Caregiving at Family Caregiver Alliance (FCA) convened this forum to fill a major gap in policy and practice. A large and growing body of research shows that family members who provide care to persons with chronic or disabling conditions are themselves at risk for physical, emotional and financial problems. Systematic assessment of people with chronic or disabling conditions now occurs routinely in medical, health and social service settings. However, assessment of family caregivers' needs is rare. Thus, we invited leaders and stakeholders to a working conference to advance policy and practice on behalf of family caregivers. From September 7-9, 2005 in San Francisco, 54 recognized experts in caregiving, health and long-term care issues—scholars, practitioners and public officials—deliberated intensively about caregiver assessment. They brought balanced, objective and knowledgeable attention to the issue. We hoped to reach consensus on principles and guidelines for caregiver assessment while building common ground among leaders in the field. We exceeded our expectations.
>
> Volume I, *Caregiver Assessment: Principles, Guidelines and Strategies for Change*, reflects the professional consensus achieved at this conference: the importance to policy and practice of systematically assessing a caregiver's own needs in health care and in home and community settings; fundamental principles and practice guidelines for caregiver assessment applicable to a range of practitioners in a variety of settings; and strategies and actions to advance caregiver assessment as a basic component of practice. Volume II, *Caregiver Assessment: Voices and Views from the Field,* provides four background papers and two personal accounts. Together they portray key issues in caregiver assessment and illustrate the impact of caregiving at home on the family members who provide the care and support. Both volumes are available online at *www.caregiver.org*, or as printed reports, available from Family Caregiver Alliance. Embracing a family-centered perspective requires a fundamental change of thinking in policy and practice. Looking ahead, we hope this report fosters the adoption of the consensus principles and guidelines and serves as a catalyst to strengthen America's caregiving families.

Family Caregiver Alliance (2006). *Caregiver Assessment: Voices and Views from the Field*. Report from a National Consensus Development Conference (Vol. II). San Francisco: Author. See description above for Vol. 1.
www.caregiver.org/caregiver/jsp/content/pdfs/v2_consensus.pdf

Fancey, P., Keefe, J. & Robertson, M.L. (1999). *Development of Screening and Assessment Tools for Family Caregivers – Phase I Report on Review of Non-Validated Tools – Nova Scotia Site*. Ottawa, Canada: Health Transition Fund of Health Canada.

International review of 57 articles and reports focussing on caregiver assessment tools.

Feinberg, L.F. (2004). *The State of the Art: Caregiver Assessment in Practice Settings.* San Francisco, CA: Family Caregiver Alliance.
http://www.caregiver.org/caregiver/jsp/content/pdfs/op_2002_state_of_the_art.pdf

This monograph summarizes the history and background of caregiver assessment; considers the reasons for assessing family care; discusses what, whom, when and where to assess; illustrates areas to assess; highlights examples of existing tools; explores commonalities as well as differences in caregiver assessment instruments; points out areas of caregiver assessment that have been neglected; identifies best practice criteria to consider in designing and implementing assessments; and discusses training issues for practitioners.

Feinberg, L.F., Newman, S., Gray, L., Kolb, K. & Fox-Grage, W. (2004). *The State of the States in Family Caregiver Support: A 50-State Study*. San Francisco, CA: Family Caregiver Alliance.
http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1276

This report focuses attention on a growing issue facing the nation: how to support and sustain those who are the cornerstone of our long-term care system—the dedicated families and informal caregivers of older people and adults with disabilities. This 50-state study is the first to examine publicly funded caregiver support programs throughout the country. It focuses on caregiver support provided through the Older Americans Act's National Family Caregiver Support Program (NFCSP), Aged/Disabled Medicaid waiver programs, and state-funded programs.The report identifies key findings, describes state approaches to providing caregiver support services, offers state-by-state profiles, pinpoints needs and challenges, and expands recognition of family caregiver needs as distinct from the needs of care receivers (i.e., older people and adults with disabilities). The report also identifies emerging themes and the relationship of caregiver support to other home and community-based programs. Through this first nationwide study of caregiver support services in the U.S., we hope to:

- inform policy discussions among federal and state leaders in caregiving and long-term care throughout the nation; and
- advance the public debate about the explicit provision of family support within the context of long-term care systems development.

This report builds on in-depth case studies of ten states' caregiver support programs undertaken by FCA's National Center on Caregiving in 2002 with funding from the U.S. Administration on Aging. As such, it is designed to serve as a reference point for examining future progress and anticipating emerging issues that are likely to shape the future.

Feinberg, L.F., & Newman, S. (2002). *Family Caregiver Support: Policies, Perceptions, and Practices in 10 States Since the Passage of the National Family Caregiver Support Program*. San Francisco, CA: Family Caregiver Alliance.
http://www.caregiver.org/jsp/content_node.jsp?nodeid=451

This report summarizes the preliminary experiences of 10 states grappling with a growing issue facing the nation: how to support and sustain those who are the backbone of our long-term care system, family and informal caregivers of the elderly and adults with disabilities. We hope this report will broaden the perspective of policymakers and program administrators at the federal, state and local levels to:

- Advance the public debate about the explicit provision of family support within the context of long-term care systems development
- Increase understanding of ways to use public funds strategically to support family and informal caregivers
- Assist the aging network to implement the evolving National Family Caregiver Support Program more effectively
- Serve as a reference point for future progress
- Better anticipate emerging issues that are likely to shape the future

This report is a starting point. As states continue to struggle with budget shortfalls, reign in longterm care expenditures and address the mandate of the Supreme Court's Olmstead decision, it is our hope that policymakers, program administrators and advocates will learn from these 10 states, which offer an array of approaches and structures. In the end, we hope that—in every state—we will be better able to identify and respond to families in need.

Feinberg, L.F., Wolkwitz, K. & Goldstein, C. (2006). *Ahead of the Curve: Emerging Trends and Practices in Family Caregiver Support.* Washington, DC: AARP Public Policy Institute.
http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1597

There is no doubt about it. More and more long-term care is provided at home and in the community rather than in nursing homes. Millions of family caregivers make this possible each day. Against the backdrop of growing numbers of people with disabilities needing long-term services and the fiscal constraints of federal and state governments, reliance on family and other informal caregivers is growing. As a result, caregiver programs are increasingly important in sustaining and strengthening our nation's unpaid caregivers. Caregiver programs and supports are located in every state in the nation. Some of these programs and supportive services have been in existence for decades, but most are relatively new or are newly expanded, thanks in part to federal funding from the National Family Caregiver Support Program, enacted in 2000. This paper highlights three "cutting-edge" trends in supporting family caregivers: assessment of caregivers' own needs; consumer direction in family caregiver support services; and collaborations on caregiving between the aging network and health care providers. The purpose of the paper is to provide policymakers, program administrators, and advocates with an overview of these emerging trends; describe state approaches and developing practices; and identify key factors fundamental to successful adoption of these strategies. Innovation in many states is clearly afoot. This report shines a light on three of these innovations, focusing on what works, why it is important, and what is possible. We hope the ideas put forth in this report stimulate continued development of supports for persons who are the linchpins of our country's long-term care system: family and other informal caregivers.

Goetschius, S. (2001). Caring for families: The other patient in palliative care. In M. Matzo & D. Sherman (Eds.), *Palliative Care Nursing: Quality Care to the End of Life* (245-274), New York, NY: Springer Publishing.

This chapter examines interventions and suggestions for palliative care for families in a variety of settings and along the continuum of care that adults may transverse as they approach the end of life.

Guberman, N., Keefe, J., Fancey, P., Nahmiash, & Barylak, L. (2001). *Development of Screening and Assessment Tools for Family Caregivers*. Ottawa, Canada: Health Transition Fund of Health Canada. www.msvu.ca/site/media/msvu/healthCanada.pdf

The goal of the present project was to develop appropriate instruments for assessing and evaluating the specific needs of family caregivers which take into account their reality and conditions and which situate them as essential partners with the formal system in the care of dependent adults. This project's specific objectives were: 1) to develop a screening and an assessment tool for assessing the context, the conditions and the needs of family caregivers;
2) to test and evaluate these tools in CLSCs in Quebec and in home care agencies in Nova Scotia. The primary audience for this project is composed of policy-makers, administrators and practitioners in home care and more widely in front-line care. Our secondary audience includes caregivers, academics, training institutions and the general public.

Guberman, N., Nicholas, E., Nolan, M., Rembicki, Lundh, U., & Keefe, J. (2003). Impacts on practitioners of using research-based carer assessment tools: Experiences from the UK, Canada and Sweden, with insights from Australia. *Health and Social Care in the Community, 11* (4), 345-355.

> Researchers and practitioners in several Western countries have recently developed tools for assessing the situation of the carers of adults who are ill, elderly or have disabilities. The present article describes the impact of three such assessment tools, from Canada, the UK and Sweden, on the professional practice of assessors. All tools were tested in agency-based studies. Focus groups, workshops and interviews with assessors were employed to understand the impact on professionals and their practice. An Australian researcher and case manager comments on these experiences from her unique perspective. The results reveal that the use of carer assessments can lead to changes in the appropriateness of intervention by informing practitioners of issues which are given little attention, but which impact on the adequacy of interventions to the service user. Across the projects, most workers found that the tools facilitated a more comprehensive, in-depth and carer-focused assessment. Experience across all the projects suggests that, used sensitively, such tools and approaches can play a key role in transforming the relationship between carers, and the health and social care system. Giving carers a legitimate voice, acknowledging their perspective and expertise, and making them central to assessment processes accords them status both as active partners, and as individuals with their own needs and aspirations, rather than seeing them primarily as resources. As a result of their experiences, many workers and administrators concluded that home-care programmes must change their mandate to include carers among their clients, raising the issue of available monetary and human resources to meet the needs of this group. In addition, as our Australian colleague points out, time, efficiency, relevance, benefit and minimal intrusiveness are important factors for practitioners which influence their use of assessment tools.

Kaye, L., Turner, W., Butler, S., Downey, R. & Cotton, A. (2003). Early intervention screening for family caregivers of older relatives in primary care practices – Establishing a community health service alliance in rural America. *Family and Community Health, 26* (4), 319-328.

> The Maine Primary Partners in Caregiving project provides a prime example of how disparate community health, social service, and higher education institutions can build a successful rural service alliance for the purposes of screening for family members experiencing stress during the provision of care to impaired older relatives. Community primary care practices are featured as prime sites for the early identification of elder caregivers experiencing stress and burden. Initial project results and implementation challenges as well as recommended strategies for nurturing such community partnerships are presented.

Meilillo, K. & Futrell, M. (1995). A guide for assessing caregiver needs: Determining a health history database for family caregivers. *Nurse Practitioner, 20* (5), 40-46.

> The complex issue of combining caregiving and employment requires an awareness on the part of primary care providers of the health and social impact these responsibilities have on clients. Failure to consider the psychosocial and health-related consequences of caregiving for individuals with dual roles could result in greater health care costs, jeopardize the health of the caregiver, and place the care recipient at risk of institutionalization. The purpose of this article is to offer a guide that can be used as part of a comprehensive health history to assess the caregiving situation and provide a database on which to establish a plan of action. The caregiver assessment guide can be inserted in the client's health record and periodically reviewed during primary care visits.

Montgomery, A. & Feinberg, L.F. (2003). *The Road to Recognition: International Review of Public Policies to Support Family and Informal Caregiving. Issue Brief.* San Francisco, CA: Family Caregiver Alliance.
http://www.caregiver.org/jsp/content_node.jsp?nodeid=1011

> This policy brief highlights where family caregivers now stand in relation to public policies for long-term care. The six countries reviewed (Australia, Canada, Germany, Japan, United Kingdom and the United States) represent diverse philosophies and policies with regard to supporting and sustaining family care of frail elders and persons with disabilities. Also discussed are caregiver assessment, employment leave law and certain tax law provisions. This approach is intended to illuminate where formal and informal systems of long-term care and caregiver support intersect, and where gaps and limitations remain.

Nankervis, J., Schofield, H., Herman, H. & Bloch, S. (1997). Homebased assessment for family carers: A preventative strategy to identify and meet service needs. *International Journal of Geriatric Psychiatry, 12*, 193-201.

> OBJECTIVE: To identify unmet need for services among family carers and their frail or disabled relatives and to facilitate links to services. DESIGN: Intervention study with a subgroup of carer dyads from a random statewide survey of family carers, followed by telephone 2 months post intervention. SETTING: Carer dyads in general community; urban and rural Victoria. PARTICIPANTS: All 186 identified carers were approached. One-third of the dyads were ineligible; of the remainder, 67 (53%) participated, matching refusals on sociodemographic characteristics. Carers were typically married, middle-aged women looking after parents or spouses. Almost half of the care recipients were aged > or = 80; most had multiple disorders and impairments. Follow-up rate was 94%. INTERVENTION: One off,

multidisciplinary home-based assessment of dyad by research team and regional aged care assessment service (ACAT). MAIN OUTCOME MEASURES: "Unmet need': % dyads recommended new services; number services per dyad via ACAT; increases in service range; extension of pre-existing services. Service linkage: % dyads linked to new services; perceived usefulness of linkages. MAIN RESULTS: Dyads recommended a new service (93%); increased range (73%); extensions (41%). Average two services requiring ACAT implementation; commonly respite care, aids and paramedical services. Recommendations related to impairment severity and carer stress. ACAT implemented recommendations (90% relevant dyads); links rated useful (75% relevant dyads). Three-quarters of the carers rated intervention as helpful. CONCLUSION: A preventative programme of needs assessment for carer dyads has considerable potential; (a) identifying needs and engaging new services; (b) providing emotional support.

New Zealand Guidelines Group (2003). *Assessment Processes for Older People*. Wellington, New Zealand: Author.

This guideline outlines the necessary elements of effective assessment processes for older people in New Zealand. It is intended to inform and guide funding agencies, such as the Ministry of Health, District Health Boards (DHBs) and ACC; service providers such as Primary Health Organisations (PHOs); community workers; practitioners from any discipline in primary or secondary health care; and older people and the people who care for them, including family and unpaid carers. This guideline does not detail the specific measures used for assessments within domains and dimensions of health and well-being. It does not outline what domain-specific procedures (including assessments) should be completed following referral to a particular service, nor does it provide guidelines for interventions and follow-up. Domain or condition-specific evidence-based practice guidelines such as guidelines for Elder Abuse (under development); Hip Fracture and Falls Prevention; Support and Management of People with Dementia may be used to complement this guideline. The guideline, while detailing the most effective processes around assessment of older people, is not intended to do more than inform development of service frameworks and does not extend to a detailed analysis of the most effective service configurations to support the recommended assessment processes. The section on implementation is similarly intended as a broad conceptual guide. This edition does not specifically address the needs of all minority populations within New Zealand and this may be considered in future reviews.

Nicholas, E. (2003). An outcomes focus in carer assessment and review: Value and challenge. *British Journal of Social Work, 33*, 31-47.

> A focus on outcomes and a desire to improve assessment and support to carers are central to government policy, crystallized in the 2000 Carers and Disabled Children Act. This paper explores the benefits and challenges of implementing an outcomes approach to carer assessment and review, highlighted by a research and development project, undertaken in partnership with one local authority. The project developed and tested research-based practice tools which aimed to promote carer-centred practice, together with clarity in communication and recording of outcomes intended and achieved. Findings indicated that practice could be enhanced with the help of a clear conceptual framework and tools, flexibly and sensitively used to assist discussion and decision-making with carers about outcomes. Information about outcomes, aggregated from individual records, was perceived as potentially useful for informing service development. Some significant obstacles and challenges also emerged; not least, the subtle but significant culture shift required, and the additional time needed to effectively identify and address outcomes with carers. A number of factors were highlighted as important in introducing such an approach: collaboration with, and between, all stakeholders; training and support for practitioners to include practice in recording outcomes, and opportunities for continuing discussion and reflection during implementation.

Wright, L. & Leahey, M. (2005). *Nurses and Families – A Guide to Family Assessment and Intervention. Fourth Ed*. Philadelphia, PA: F.A. Davis Company.

> This text provides specific how-to guidelines for family assessment and intervention. The major purposes of the book are to: (1) provide nurses with a sound theoretical foundation for family assessment and intervention; (2) provide nurses with clear, concise, and comprehensive family assessment and intervention models; (3) provide guidelines for family interviewing skills; (4) offer detailed ideas and suggestions with clinical examples of how to prepare, conduct, document, and terminate family interviews; (5) provide nurses with an appreciation of the powerful influence of nurse-family collaboration to diminish, reduce, or alleviate illness suffering.

## Reviews of Caregiver Measures

Deeken, J., Taylor, K., Mangan, P., Yabroff, R., & Ingham, J. (2003). Care for the caregivers: A review of self-report instruments developed to measure the burden, needs, and quality of life of informal caregivers. *Journal of Pain and Symptom Management, 26* (4), 922-953.

Family Caregiver Alliance (2002). *Selected Caregiver Assessment Measures: A Resource Inventory for Practitioners*. San Francisco, CA.
http://www.caregiver.org/jsp/content_node.jsp?nodeid=470

Gaugler, J., Kane, R., & Langlois, J. (2000). Assessment of family caregivers of older adults. In R. Kane & R. Kane (Eds.), *Assessing Older Persons – Measures, Meaning and Practical Applications* (320-359). New York, NY: Oxford University Press.

## Caregiver Assessment Tools

Within the literature a number of these challenges are identified including caregiver burden, support, coping, quality of life, relationship issues, care tasks and skills, physical health, mental health (including stress/strain), financial burden, satisfaction with caregiver role, self efficacy/competency, values and preferences, and the care recipient's functional ability. While it may be obvious that some of these challenges are direct outcomes of the caregiving role, it is not as obvious with others. In other words, are these challenges an outcome of caregiving, or do they actually influence the caregiving role? For example, financial burden might influence caregiving, but it might also be an outcome of caregiving.

For those involved in trying to assist caregivers, this distinction is an important one as it may offer guidance when selecting an appropriate instrument. It may also help in terms of deciding when to best administer an instrument.

## Burden/Stress/Strain

The terms burden, stress and strain are quite often used interchangeably in the literature (Thornton & Travis, 2003) and, arguably, they are some of the most extensive concepts researched within the caregiving literature (Bedard et al., 2001; Dumont et al., 2008 ; Gupta, 2004; Pearlin, et al., 1990). Caregiver burden has been around since the early 1980s when Zarit (1980) introduced the Zarit Burden Inventory. Since this time, the Zarit Burden Inventory has undergone revisions, including a Short Form Zarit Burden Interview (Bedard et al., 2001) and a number of other caregiver burden instruments and related stress and strain instrument have been developed. Furthermore, to reflect variations in burden across different diseases, some burden instruments that have been developed are disease-specific.

Zarit Burden Interview

- Measures caregiver appraisal of the impact of caregiving.
- 22 items (5-point scale)
- Zarit, S. H., Reever, K.E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist, 20*, 649-655.
- http://instruct.uwo.ca/kinesiology/9641/Assessments/Psychological/ZBI.html

Short Form Zarit Burden Interview

- Shorter version of the Zarit Burden Interview designed to measure impact of caregiving.

- 12 items (5-point scale)
- Bedard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit Burden Interview: A new short version and screening version. *The Gerontologist, 41*, 652-657.

### Montgomery Burden Interview

- Two scales are used to assess both objective and subjective burden. The objective scale focuses on privacy, time, personal freedom, amount of money available, amount of energy, amount of vacation activities, recreational activities, relationships with other family members, and health. The subjective scale focuses on attitudes and emotional reactions toward caregiving.
- 9 items for objective scale (5-point scale)
- 13 items for subjective scale (‘rarely or never’ to ‘most of the time’)
- Montgomery, R., Gonyea, J. G., & Hooyman, N. R. (1985). Caregiving and the experience of subjective and objective burden. *Family Relations, 34*, 19-26.
- Montgomery, R., Stull, D. E., & Borgatta, E. F. (1985). Measurement and the analysis of burden. *Research on Aging, 7*, 329-361.

### Perceived Caregiver Burden Scale

- Measures caregiver burden in terms of perceptions and feelings about caregivers’ physical and emotional health, family relationships, social life, work, and finances.
- 31 items (4-point scale)
- Stommel, M., Given, C. W., & Given, B. (1990). Depression as an overriding variable explaining caregiver burdens. *Journal of Aging and Health, 2*, 81-102.

### Perceived Caregiver Burden Scale, Revised

- Measures caregiver burden in terms of perceptions and feelings about caregivers’ physical and emotional health, family relationships, social life, work, and finances.
- 13 items (4-point scale)
- Gupta, R. (1999). The revised caregiver burden scale: A preliminary evaluation. *Research on Social Work Practice, 4*, 508-520.

### Perceived Burden Scale

- Measures extent to which caregivers believe that changes have occurred because of problems or concerns with caregiving.
- 22 items (5-point scale)

- Poulshock, S. W., & Deimling, G. T. (1984). Families caring for elders in residence: Issues in the measurement of burden. *Journal of Gerontology, 39*, 230-239.

Screen for Caregiver Burden

- Measures objective and subjective burden relating to occurrence of care demands and distress associated with them.
- 25 items (5-point scale)
- Vitaliano, P. P., Scanlan, J. M., Krenz, C., Schwartz, R. S., & Marcovina, S. M. (1996). Psychological distress, caregiving, and metabolic variables. *The Journals of Gerontology, 51B*(5), P290.

Novel Caregiver Burden

- Measures strain, isolation, disappointment, and emotional involvement.
- 20 items (4-point scale)
- Elmstahl, S., Malmberg, B., & Annerstedt, L. (1996). Caregiver's burden of patients 3 years after stroke assessed by a Novel Caregiver Burden Scale. *Archives of Physical Medicine and Rehabilitation, 77*, 177-182.

Cost of Care Index

- Measures different aspects of burden including personal and social restrictions, emotional health, worthiness of caregiving, relationship with care recipient, and economic costs.
- 4 items for each: a) personal and social restrictions; b) physical and emotional health; c) value investment in caregiving; d) perception of the care recipient as a provocateur; e) economic costs (4-point scales)
- Kosberg, J. I., & Cairl, R. E. (1986). The cost of care index: A case management tool for screening informal care providers. *The Gerontologist, 26*, 273-278.

Caregiver Burden Scale

- Measures caregiver burden at the end of life.
- 18 items (4-point scale)
- Dumont, S., Fillion, L., Gagnon, P., & Bernier, N. (2008). A new tool to assess family caregiver burden during end-of-life care. *Journal of Palliative Care, 24*(3), 151-161.

Problem Checklist

- Measures the problems experienced by carers of patients with dementia.
- 34 items (3-point scale)

- Gilleard, C. J., & Watt, G. (1982). The impact of psychogeriatric day care on the primary supporter of the elderly mentally infirm. In R. Taylor & A. Gilmore (Eds.), *Current trends in British gerontology* (pp. 139-147). Aldershot: Gower Publishing.

Caregiver Burden Inventory

- To measure caregiver burden as it relates to time, developmental comparison with peers, physical health, social relationships, and emotional health.
- 5 items for each: a) time-dependence burden; b) developmental burden; c) physical burden; d) social burden (5-point scale)
- 4 items for emotional burden (5-point scale)
- Novak, M., & Guest, C. (1989). Application of a multidimensional Caregiver Burden Inventory. *The Gerontologist, 29*, 798-803.
- http://www.fullcirclecare.org/caregiverissues/health/burden.html

Role Stress and Rewards Questionnaire

- Measures experience of caregiver role-related stress in the last 2 months including the extent of the distress.
- 12 items (4-point scale)
- Stephens, M. A. P., Franks, M. M., & Townsend, A. L. (1994). Stress and rewards in women's multiple roles: The case of women in the middle. *Psychology and Aging, 9*, 45-52.

Relatives' Stress Scale

- Measures the reaction to caregiving of relative carers of elderly patients with senile dementia living in the community.  Focuses on 3 domains: personal distress in relation to the care recipient, life upset as a result of caregiving, and negative feelings toward the care recipient.
- items (5-point scale)
- Greene, J. G., Smith, R., Geardiner, M., & Timbury, C. C. (1982). Measuring behavioral disturbance of elderly demented patients and its effects on relatives: A factor analytic study. *Age and Ageing, 11*, 121-126.

Caregiver Strain Index

- Measures caregiver strain using yes/no response scales.
- 12 items (2-point scale)
- Robinson, B. C. (1983). Validation of a caregiver strain index. *Journal of Gerontology, 38*, 344-348.
- http://consultgerirn.org/uploads/File/Caregiver%20Strain%20Index.pdf

Family Strain Scale

- Measures subjective burden related to emotional/psychological affect, changes in living in living patterns, and changes in relationships/health.
- 5 items
- Morycz, R. K. (1985). Caregiving strain and the desire to institutionalize family members with Alzheimer's disease: Possible predictors and model development. *Research on Aging, 7*, 329-361.

Caregivers’ Stress Scale

- Measures 15 domains: cognitive status, problematic behaviour, overload, relational deprivation, family conflict, job-caregiving conflict, economic strains, role captivity, loss of self, caregiving competence, personal gain, management of situation, management of meaning, management of distress, and expressive support.
- Series of 15 scales (3-point, 4-point, 5-point scales)
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*(5), 583-594.

Caregiver Distress Activities

- Measures the effort made by the caregiver to decrease the symptoms of stress that result from caregiving.
- 8 items (4-point scale)
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*(5), 583-594.

Caregiver Stress Effects

- Measures aspects of family life that are negatively affected by caregiving role, as well as restrictions in caregiver activities as a result of the caregiving role.
- 8 items for negative changes in elder, caregiver and family relationships
- 5 items for restrictions in caregivers’ activities
- Deimling, G. T., & Bass, D. M. (1986). *The strengths and resources of families caring for impaired elders*: Report to The Retirement Research Foundation: The Benjamin Rose Institute.
- Deimling, G. T., & Bass, D. M. (1986). Symptoms of mental impairment among elderly adults and their effects on family caregivers. *Journal of Gerontology, 41*, 778-784.

Measures of Strain

- Measures 3 domains: difficulty of caregiving (threat to family well-being), negative consequences of caregiving, and perceptions of negative consequences of caregiving on the family.
- 3 items for appraised difficulty of caregiving (4-point scale)
- 3 items for negative consequences of caregiving (2-point scale)
- 2 items for perceptions of negative consequences of caregiving on the family (2-point scale)
- Bass, D. M., & Bowman, K. (1990). The transition from caregiving to bereavement: The relationship of care-related strain and adjustment to death. *The Gerontologist, 31*, 32-42.

Perceived Stress Scale

- Measures the degree to which situations are perceived as stressful.
- 14 items (5-point scale)
- Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior, 24*, 385-396.
- http://www.ncsu.edu/assessment/resources/perceived_stress_scale.pdf

Care-related Strain

- Measures the stress felt by a caregiver as a result of having a relative in a nursing home.
- 7 items (4-point scale)
- Whitlatch, C. J., Schur, D., Noelker, L. S., Ejaz, F. K., & Looman, W. J. (2001). The stress process of family caregiving in institutional settings. *The Gerontologist, 41*, 462-473.

## Caregiver Mental Health Other than Burden/Stress/Strain

Aside from burden, stress and strain, caregiving can elicit a number of other mental health responses. For example, caregiving has been found to have negative outcomes such as depression (Beck et al., 1961; Radloff, 1977), anxiety (Cicirelli, 1998; Rosenberg, 1962), and decreased quality of life (Bass et al., 1999; Gerritsen & van der Ende, 1994), affect (Folkman & Moskowitz, 2000), well-being (Berg-Wenger et al., 2000; Schofield et al., 1997 ) and self-esteem (Skaff & Pearlin, 1992). In has also been found to elicit feelings of guilt (Holley & Mast, 2009). A number of instruments have been developed to assess mental health in general, while other instruments are more focused and measure one particular concept (details provided in parentheses after scale name).

Symptom Inventory (general)

- Measures symptoms of depression, anxiety, and hostility. Tool not designed specifically for caregivers.
- 53 items (5-point scale)
- Derogatis, L. R., & Melisaratos, N. (1983). The Brief Symptom Inventory: An introductory report. *Psychological Medicine, 13*, 595-605.

Brief Symptom Inventory - 18 (general)

- Shortened version of the Brief Symptom Inventory that measures symptoms of depression, anxiety, and hostility. Tool not designed specifically for caregivers.
- 18 items (5-point scale)
- Derogatis, L. R., & Savitz, K. L. (1999). The SCL-90-R, Brief Symptom Inventory, and Mathcing Clinical Rating Scales. In M. E. Maruish (Ed.), *The use of psychological testing for treatment planning and outcomes assessment*. Mahwah, N.J.: Lawrence Erlbaum Associates, Inc.

Symptom Checklist SCL-90-R (general)

- Measures psychological symptoms and distress across 9 symptoms: somatisation, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism. Tool not designed specifically for caregivers.
- 90 items (5-point scale)
- Derogatis, L. R., Lipman, R. S., Rickels, K., Uhlenhuth, E. H., & Covi, L. (1974). The Hopkins Symptom Checklist (HSCL): Self-report symptom inventory. *Behavioral Science, 19*, 1-15.

Positive and Negative Affect Scales (affect/mood)

- Measures psychological well-being according to the extent that people experience different feelings and emotions. Tool not designed specifically for caregivers.
- 20 items (5-point scale)
- Bradburn, N. M. (1969). *The structure of psychological well-being*. Chicago: Aldine.

Vulnerability Scale (affect/mood)

- Measures 4 domains: dysphoria, alienation, annihilation, and denial. Tool not designed specifically for caregivers.
- 13 items
- Weisman, A. D., & Worden, J. W. (1977). The existential plight in cancer: Significance of the first 100 days. *International Journal of Psychiatry in Medicine, 7*, 1-15.

Filial Anxiety Scale (anxiety)

- Measures 2 types of anxiety: anxiety over one's ability to take on a caregiving role, and anxiety over the aging parent's welfare. Tool designed for adult child caregivers.
- 13 items (5-point scale)
- Cicirelli, V. G. (1988). A measure of filial anxiety regarding anticipated care of elderly parents. *The Gerontologist, 28*, 478-482.

Neuropsychiatric Inventory Caregiver Distress Scale (anxiety)

- Measures subjective caregiver distress as impacted by personality changes, depression, psychosis and agitation that can be associated with persons with Alzheimer's disease. Caregivers are asked to rate the severity and frequency of each symptom, and the level of emotional or psychological distress.
- 10 items (6-point scale)
- Kaufer, D. I., Cummings, J. L., Christine, D., Bray, T., Castellon, S., Masterman, D., et al. (1997). Assessing the impact of neuropsychiatric symptoms in Alzheimer's disease: The Neuropsychiatric Inventory Caregiver Distress Scale. *Journal of the American Geriatrics Society, 46*, 210-215.

State-Trait Anxiety Inventory (anxiety)

- Measures anxiety assessing both state (situational) and trait (dispositional) anxiety. Tool not designed specifically for caregivers.
- 40 items (4 point scale)
- Spielberger, C. D., Gorusch, R. L., & Lushene, R. E. (1970). *Manual for the State-Trait Anxiety Inventory*. Palo Alto, California.

Beck’s Depression Inventory (depression)

- Measure of depression based on a time frame of ‘past week’. Tool not designed specifically for caregivers.
- 21 items (4-point scale)
- Beck, A. T., Ward, C. H., Medelson, M., Mock, J., & Erbaugh, J. (1961). An inventory for measuring depression. *Archives of General Psychiatry, 4*, 561-571.
- http://www.fehb.org/CSE/CCSEConference2012/BeckDepressionInventory.pdf

CESD (depression)

- Measures general depression based on past week. Tool not designed specifically for caregivers.
- 20 items (4-point scale)
- Radloff, L. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*, 385-401.
- http://www.mytherapysession.com/PDFs/CES-DDepressionScale.pdf

Self Rating Depression Scale (depression)

- A self-assessed measure of depression. Tool not designed specifically for caregivers.
- 20 items (2-point scale)
- Zung, W. (1965). A self-rating depression scale. *Archives of General Psychiatry, 12*, 63-70.
- http://healthnet.umassmed.edu/mhealth/ZungSelfRatedDepressionScale.pdf

Geriatric Depression Scale (depression)

- Measures depression in older adults in terms of loss, cognitive complaints, somatic complaints, and self-image. Tool not designed specifically for caregivers.
- 30 items (2-point scale)
- Brink, T. L. (1982). Screening tests for geriatric depression. *Clinical Gerontologist, 1*, 37-43.
- http://www.stanford.edu/~yesavage/GDS.html

Self-esteem Scale (self esteem)

- Measures beliefs in one’s worth, competence, and capacity for success. Tool not designed specifically for caregivers.
- 10 items (5-point scale)
- Rosenberg, M. (1962). The association between self-esteem and anxiety. *Journal of Psychiatric Research, 1*, 135-152.
- http://www.wwnorton.com/college/psych/psychsci/media/rosenberg.htm

Caregiver Well-Being Scale (well-being)

- Measures frequency of 4 domains of well-being: low affect, cognitive depression, anxiety, and anger.
- 7 items for low affect, 6 items for cognitive depression, 4 items for anxiety, 4 items for anger (4-point scales)
- Zarit, S., & Whitlatch, C. J. (1992). Institutional placement: Phases of the transition. *The Gerontologist, 32*, 665-672.

Caregiver Well Being Scale (well-being)

- Measures the extent to which caregiver needs are met in relation to love, physical needs, and self-esteem. Based on Maslow's (1968) hierarchy of needs. Also measures non-basic needs in relation to time for self, home, and family.
- 23 items for basic needs (7-point scale)
- 22 items for activities of living (7-point scale)
- Tebb, S. (1995). An aid to empowerment: A caregiver well-being scale. *Health &amp; Social Work, 20*(2), 87.

Health-related Quality of Life (quality of life)

- Measures 8 dimensions of health: physical functioning, role limitations due to physical health problems, bodily pain, general health, vitality, social functioning, role limitations due to emotional problems, and mental health.
- 36 items (2-point, 3-point, 5-point, 6-point scales)
- Ware Jr., J. E., Snow, K. K., Kosinski, M., & Gandek, B. (1993). *The SF-36 Health Survey manual and interpretation guide*. Boston: The Health Institute, New England Medical Center.

Quality of Life in Alzheimer's Disease Scale (quality of life)

- Measures caregiver and care recipient rating of care recipient quality of life in relation to physical health, energy, mood, memory, family self as a whole, ability to do things for fun, and life as a whole.
- 13 items (4-point scale)
- Logsdon, R., Gibbons, L., McCurry, S., & Teri, L. (1999). Quality of life in Alzheimer's disease: Patient and caregiving reports. *Journal of Mental Health and Ageing, 5*(1).

Quality of Life Inventory (quality of life)

- Measures positive mental health or overall life satisfaction with 16 areas. Tool not designed specifically for caregivers.
- 16 times (3-point scale)

- Frisch, M. B. (1992). Use of the Quality of Life Inventory in problem assessment and treatment planning for cognitive therapy of depression. In A. Freeman & F. M. Dattilio (Eds.), *Comprehensive casebook of cognitive therapy*. New York, NY: Plenum Press.
- Frisch, M. B., Cornell, J., Villanueva, M., & Retzlaff, P. J. (1992). Clinical validation of the Quality of Life Inventory: A measure of life satisfaction for use in treatment planning and outcome assessment. *Psychological Assessment, 4*, 92-101.

Schedule for the Evaluation of Individual Quality of Life – Direct Weighting (quality of life)

- Open-ended measure where caregiver is asked to identify 5 areas most important in life and then rate each one using a visual analogue scale, and then assigns a relative weight to each. Tool not designed specifically for caregivers.
- 15 items (3 stages of questions)
- Hickey, A. M., O'Boyle, C. A., McGee, H. M., & McDonald, N. J. (1997). The relationship between post-trauma problem reporting and carer quality of life after severe head injury. *Psychology & Health, 12*, 827-838.

McGill QOLLTI-F (quality of life)

- Measures family caregiver quality of life.  Focuses specifically on caregivers providing care to someone with a life-threatening illness.
- 19 items (scale from 1 to 10)
- Cohen, S. R., Leis, A. M., Kohl, D., Charbonneau, C., Ritvo, P., & Ashbury, F. D. (2006). QOLLTI-F: Measuring family carer quality of life. *Palliative Medicine, 20*(8), 755-767.

Guilt (guilt)

- Measures feelings of guilt and regret related to the caregiver’s relationship with the care recipient.
- 5 items (4-point scale)
- Mullan, J. T. (1992). The bereaved caregiver: A prospective study of changes in well-being. *The Gerontologist, 32*, 673-683.

Guilt Scale (guilt)

- Measures guilt felt by caregivers in relation to their caregiving role.
- 9 items (4-point scale)
- Wells, Y. D., & Jorm, A. F. (1987). Evaluation of a special nursing home unit for dementia sufferers: A randomized controlled comparison with community care. *New Zealand Journal of Psychiatry, 21*, 524-531.

Loss of Self (loss of self)

- Measures sense of loss of self.
- 2 items (4-point scale)
- Skaff, M. M., & Pearlin, L. I. (1992). Caregiving: Role engulfment and the loss of self. *The Gerontologist, 32*, 656-664.

## Financial Burden

Financial burden is one specific component of caregiver burden. Using data from the General Social Survey, Cycle 16, Cranswick (2003) estimated that over 33% of Canadians incurred expenses related to caregiving and that, of these, 66% reported that the expenses were greater than $100 per month (Health Canada, 2002). Furthermore, the majority of Canadian caregivers are in the workforce (Statistics Canada, 2002). Time taken off from one's job to provide care can lead to lost wages and associated benefits. Under circumstances such as these, caregivers can experience financial burden which, in turn, can ultimately lead to declines in the physical and mental health of the caregiver. The following instruments have been developed to assess financial burden as a result of caregiving.

Economic Strain

- Measures degree of financial strain related to caregiving.
- 1 item (2-point scale)
- Aneshensel, C. S., Pearlin, L. I., & Schuler, R. H. (1993). Stress, role captivity, and the cessation of caregiving. *Journal of Health and Social Behavior, 34*, 54-70.

Economic Strains

- Measures caregiver perceptions of current household expenses and standard of living as compared to before caregiving.
- 3 items (5-point scale)
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*(5), 583-594.

Financial Impact Scale

- Measures the financial impact of informal long-term caregiving.
- 20 items (5-point scale)
- Todtman, K., & Gustafson, A. W. (1992). An instrument for assessing informal long-term caregivers. *Journal of Gerontological Social Work, 18*(3&4).

## Support

The inverse relationship between support and caregiver burden is well established. Specifically, greater support reduces the amount of caregiver burden (Bass et al., 1988; Goodman, 1991; Krause & Markides, 1990). It is also important to note, however, that there are different types of support. In a review of literature on support and caregiver burden, Vrabec (1997) identified three dimensions of support; structural; functional; and nature. Structural support is defined as the amount and composition of support available to the caregiver (Coward et al., 1990). Functional support is the type (i.e., emotional, informational, instrumental) of support available or received (Thompson et al., 1993). Finally, the nature of support describes caregiver satisfaction with care, the degree of reciprocity, and whether the relationship is positive or negative (Stewart, 1993). Each type of support is distinct. Therefore, when selecting an instrument, it is important to understand what type of support is captured with the instrument, and how the information will assist in the caregiver assessment process.

Assistance with Caregiving

- Measures assistance with caregiving (yes/no scale).
- 2 items (2-point scale)
- Braithwaite, V. (1996). Understanding stress in informal caregiving: Is burden a problem of the individual or of society? *Research on Aging, 18*, 139-174.

Helping Network Composition

- Measures the presence and helpfulness of 4 types of informal helpers and 4 types of formal helpers.
- 16 items (3-point scale)
- Bass, D. M., & Bowman, K. (1990). The transition from caregiving to bereavement: The relationship of care-related strain and adjustment to death. *The Gerontologist, 31*, 32-42.

Negative Service Attitudes and Experiences

- Measures negative attitudes toward formal services related to the inadequacy of services, as well as the respondent's perceptions that someone in the family has avoided using services because they are in denial about the relative's illness.
- 6 items (4-point scale)
- Bass, D. M., McClendon, M. J., Deimling, G. T., & Mukherjee, S. (1994). The influence of a diagnosed mental impairment on family caregiver strain. *Journal of Gerontology: Social Sciences, 49*, S146-S155.

Service Use: Formal and Informal

- Measures 13 different kinds of help that the caregiver and care recipient may have received over the past 3 months and whether or not they were satisfied with the services. There are also questions asking whether or not they could have used more assistance, if they are aware of the availability of paid assistance, and i they would consider using this type of paid assistance.
- 6 items (2-3 point scales)
- Feinberg, L. F., Whitlatch, C. J., & Tucke, S. (2000). *Final Report: Making choices: Respecting both voices.* San Francisco, CA: Family Caregiver Alliance.

Perceived Emotional Support Scale

- Measures the level of perceived expressive support.
- 8 items (4-point scale)
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*(5), 583-594.

Perceived Social Support for Caregiving

- Measures aspects of self-help support, information exchange, and social support.
- 9 items (5-point scale)
- Goodman, C. C. (1991). Perceived social support for caregiving: Measuring the benefit of self-help/support group participation. *Journal of Gerontological Social Work, 16*, 163-175.

Social Conflict

- Measures negative aspects of supportive relationships with 3 items.
- 3 items (5-point scale)
- Goodman, C. C. (1991). Perceived social support for caregiving: Measuring the benefit of self-help/support group participation. *Journal of Gerontological Social Work, 16*, 163-175.

Social Support Measure

- Measures the amount of information, tangible, and emotional support given and received, the perceived need for support, and the degree of satisfaction with the support. Tool not designed specifically for caregivers.
- 44 items (4-point scale)
- Krause, N., & Markides, K. (1990). Measuring social support among older adults. *International Journal of Aging and Human Development, 30*, 37-53.

Socioemotional Support

- Measures the degree of help and support the caregiver receives from friends and relatives.
- 8 items (4-point scale)
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*(5), 583-594.

Social Isolation

- Measures whether caregiving increased, decreased, or had no effect of caregivers' participation in various social activities.
- 5 items (3-point scale)
- Deimling, G. T., & Bass, D. M. (1986). *The strengths and resources of families caring for impaired elders*: Report to The Retirement Research Foundation: The Benjamin Rose Institute.
- Deimling, G. T., & Bass, D. M. (1986). Symptoms of mental impairment among elderly adults and their effects on family caregivers. *Journal of Gerontology, 41*, 778-784.

Visual Analogue Scale

- Measures caregiver perceptions of the amount of support they believe they 'should' and 'could' provide to care recipients.
- 3 items (visual continuum)
- Wolfson, C., Handfield-Jones, R., Glass, K. C., McClaran, J., & Keyserlingk, E. (1993). Adult children's perceptions of their responsibility to provide care for dependent elderly parents. *The Gerontologist, 33*, 315-323.

## Coping

One's ability to cope with the demands of caregiving can influence caregiver outcomes such as stress/burden (Pearlin et al., 1990). Research in the area of coping typically focuses on identifying the different strategies that caregivers adopt when faced with the challenges of caregiving (Barush, 1988; Folkman & Lazarus, 1980; Jalowiec, et al., 1984; McCubbin et al., 1996). Not surprisingly, different coping strategies result in different outcomes. Understanding how people cope can help inform interventions designed to assist caregivers in their caregiving roles.

Avoidance Scale

- Measures the degree of caregiver involvement in activities that distract them from the caregiving role.
- 5 items

- Braithwaite, V. (1996). Understanding stress in informal caregiving: Is burden a problem of the individual or of society? *Research on Aging, 18*, 139-174.

Coping Inventory

- Measures six dimensions: care management, personal and psychological response to caregiving, interpersonal with spouse, interpersonal with others, financial, and personal health-related. Tool initially uses open-ended responses and then the caregivers rates the effectiveness of the response on a 5-poin scale.
- 34 items (5-point scale)
- Barusch, A. (1988). Problems and coping strategies of elderly spouse caregivers. *The Gerontologist, 28*(677-685).

Coping Strategies Inventory

- Measures six dimensions: problem-solving, help-seeking, existential growth, minimization of threat through diversional activities, fantasy, and blame.
- 48 items (4-point scale)
- Quayhagen, M. P., & Quayhagen, M. (1982). Coping with conflict: Measurement of age-related patterns. *Research on Aging, 4*, 364-377.

Inventory of Coping Strategies

- Measures 4 dimensions: wishfulness, acceptance, intrapsychic, and instrumental.
- 16 items (5-point scale)
- Kiyak, H., Montgomery, R., Borson, S., & Teri, L. (1985). *Coping patterns among patients with Alzheimer's disease and non-demented elderly*. Paper presented at the 38th Annual Scientific Meeting of the gerontological Society of America.

Jalowiec Coping Scale

- Measures differences in levels of burden using 8 coping strategies: confrontive, evasive, optimistic, fatalistic, emotive, palliative, supportant, and self-reliant.
- 40 items (5-point scale)
- Jalowiec, A., Murphy, S., & Powers, M. (1984). Psychometric assessment of the Jalowiec coping scale. *Nursing Research, 33*, 157-161.

Reinterpretation and Acceptance

- Measures emotion-focused and cognitive reframing strategies. Is not specifically designed for caregiving.
- 12 items (4-point scale)

- Braithwaite, V. (2000). Contextual or general stress outcomes: Making choices through caregiving appraisals. *The Gerontologist, 40*, 706-717.

Ways of Coping Checklist

- Measures 5 dimensions: problem-focused coping, wishful thinking, avoidance, seeks social support, and blames self.
- 42 items (4-point scale)
- Lazarus, R., & Folkman, S. (1984). *Stress, Appraisal, and Coping*. New York, NY: Springer Publishing Company.

Family Coping Coherence Index

- Measures sense of coherence as a coping mechanism that caregivers use when managing life changes and stresses.
- 4-items (5-point scale)
- McCubbin, H. I., Larsen, A., & Olsen, D. (1996). Family Coping Coherence Index. In H. I. McCubbin, A. I. Thompson & M. A. McCubbin (Eds.), *Family assessment resiliency, coping and adaption: Inventories for research and practice* (pp. 703-712). Madison, Wisconsin: University of Wisconsin.

## Relationship Issues

As with a number of caregiver challenges, the role of relationships within the context of caregiving can be conceptualized as something that increases caregiving burden/stress, or is actually an outcome of caregiving burden/stress (Bass et al., 1988; Lawrence et al., 1992; Pearlin et al., 1990; Semple, 1992; Strawbridge, 1991; Whitlatch, et al., 2001). Furthermore, there are various relationships can be examined – caregiver and care recipient; caregiver and informal supports (family/friends); caregiver and formal supports; caregiver and employer. Fortunately, there have been a number of instruments developed to capture the varying nature of the relationships and relationship issues.

Caregiving Burden Scale

- Measures two domains: quality of the caregiver-care recipient relationship, and the consequences of caregiving.
- 13 items (5-point scale)
- Gerritsen, J. C., & van der Ende, P. C. (1994). The development of a caregiving burden scale. *Age and Ageing, 23*, 483-491.

Closeness of the Relationship

- Measures caregiver's perception of the closeness of the relationship between the caregiver and the care recipient.
- 6 items (4-point scale)
- Whitlatch, C. J., Schur, D., Noelker, L. S., Ejaz, F. K., & Looman, W. J. (2001). The stress process of family caregiving in institutional settings. *The Gerontologist, 41*, 462-473.

Dyadic Adjustment Scale

- Measure of marital adjustment that has both partners rate the extent to which they agree or disagree with a range of issues. The instrument also measures the frequency with which the couple engage in interactions such as arguing or confiding in each other.
- 32 items (3-point, 5-point, 6-point scales)
- Spanier, G. B. (1977). Measuring dyadic adjustment: New scales for assessing the quality of marriage and similar dyads. *Journal of Marriage & the Family 38*, 15-28.

Family Conflict Scales

- Measures conflict around the family's definition of the illness and strategies for acre, attitudes and actions toward the care recipient, and actions and attitudes toward the caregiver.

- 12 items (4-point scale)
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*(5), 583-594.

Family Hardiness Index

- Measures hardiness in relation to 4 domains: co-oriented commitment, confidence, challenge, and control.
- 20 items (4-point scale)
- McCubbin, M. A., McCubbin, H. I., & Thompson, A. I. (1987). Family Hardiness Index. In H. I. McCubbin & A. I. Thompson (Eds.), *Family Assessment Inventories* (pp. 123-130): The University of Wisconsin-Madison.

Quality of the Caregiver – Care Recipient Relationship

- Measures the quality of the current relationship in relation to general closeness, communication, similarity of views about life, and degree of getting along.
- 4 items (4-point scale)
- Lawrence, R. H., Tennstedt, L. L., & Assmann, S. F. (1998). Quality of the caregiver-care recipient relationship: Does it offset negative consequences of caregiving for family caregivers? *Psychology and Aging, 13*, 150-158.

Relational Deprivation

- Measures the extent to which the caregiver feels separated from parts of their lives that had previously been supported by or shared with the care recipient.
- 6 items (4-point scale)
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*(5), 583-594.

Family Assessment Device

- Evaluates families according to 7 domains: problem solving, communication, roles, affective responsiveness, affective involvement, behaviour control, and general functioning.
- 53 items (4-point scale)
- Epstein, H. B., Baldwin, L. M., & Bishop, D. S. (1983). The McMaster family assessment device. *Journal of Marital and Family Therapy, 9*, 171-180.

Family Adaptability and Cohesion Evaluation Scale

- Measures family cohesion and flexibility. Tool not designed specifically for caregivers.
- 30 items (5-point scale)

- Olson, D., Portner, J., & Bell, R. Q. (1982). *FACES II: Family Adaptability and Cohension Scales*. Minnesota: University of Minnesota.

Loss of Intimate Exchange

- Measures the extent to which caregivers feel they have experienced a loss of closeness and intimacy because of a decline in the care recipient.
- 3 items (4-point scale)
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*(5), 583-594.

Inconveniences in Living Arrangements

- Measure the level of potential inconveniences in living arrangements in the caregiving household in relation to food, social life, leisure activities, employment, household chores, expenses, privacy, and child care.
- 8 items (5-point scale)
- Midel, C. H., & Wright, R. (1982). Differential living arrangements among the elderly and their subjective well-being. *Activities, Adaptation & Aging, 3*, 25-34.

Family Relationship Strain

- Measures strain within the family as perceived by both the caregiver and care recipient.
- 5 items (4-point scale)
- Bass, D. M., Tausig, M. B., & Noelker, L. S. (1988). Elder impairment, social support and caregiver strain: A framework for understanding support's effects. *The Journal of Applied Social Sciences, 13*, 80-115.

Family Conflict

- Measures disagreement concerning treatment of the care recipient.
- 12 items (4-point scale)
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*(5), 583-594.

Family Conflict

- Measures conflict among caregivers who institutionalize their relatives.
- 8 items (4-point scale)
- Semple, S. J. (1992). Conflict in Alzheimer's caregiving families: Its dimensions and consequences. *The Gerontologist, 32*, 648-655.

Social Interaction Measure

- Measures positive aspects of care recipient behaviour such as cooperation, friendliness, and enjoyable to be with.
- 5 items (4-point scale)
- Bass, D. M., McCarthy, C., Eckert, S., & Bichler, J. (1994). Differences in service attitudes and experiences among families using three types of support services. *The American Journal of Alzheimer's Care and Related Disorders & Research, May/June*.

## Care Tasks and Skills

The specific tasks and skill performed by the caregiver are important, including their perception of the role. For example, the specific types of care, the extent of this care, and the impact of the caregiving role on one's everyday activities. These measures differ from support in that their purpose is to inventory the tasks and nature of the tasks rather than the support available.

Caregiving Tasks Scale

- Measures 36 types of assistance that can be provided by caregivers in relation to activities of daily living, decision making, and supervisions.
- 36 items (3-point scale)
- Archbold, P., Stewart, B., Greenlick, M. R., & Horwath, T. (1990). Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing and Health, 13*, 375-384.

Stetz Inventory

- Measures the extent of caregiver tasks.
- 15 items (6-point scale)
- Stetz, K. (1986). The experience of spouse caregiving for persons with advanced cancer. Unpublished Unpublished doctoral dissertation. University of Washington.

Time Constraints Scale

- Measures degree of involvement with questions about whether or not the caregiver missed out on holidays, spent less time with family, and had little time to themselves.
- 8 items (4-point scale)
- Braithwaite, V. (2000). Contextual or general stress outcomes: Making choices through caregiving appraisals. *The Gerontologist, 40*, 706-717.

Role Captivity

- Measures the extent to which caregivers feel trapped as a result of their caregiving roles.
- 3 items (4-point scale)
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*(5), 583-594.

Role Overload

- Measures the extent to which caregivers feel overwhelmed by their caregiving roles.
- 13 items (4-point scale)

- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*(5), 583-594.

## Care Recipient Functional Ability: Impact on Caregiver

Without a doubt, the functional ability of the care recipient is a critical piece of the caregiving role. Not surprisingly, poorer care recipient functional ability (cognitive and physical) leads to greater demands on the caregiver and subsequent negative caregiver outcomes (Chappell & Reid, 2002; Vitaliano et al., 1991).

Behavior and Mood Disturbance Scale

- Measures two dimensions: degree of behaviour and mood disturbance demonstrated by the care recipient.
- 34 items (5-point scale)
- Greene, J. G., Smith, R., Geardiner, M., & Timbury, C. C. (1982). Measuring behavioral disturbance of elderly demented patients and its effects on relatives: A factor analytic study. *Age and Ageing, 11*, 121-126.

Caregiving Hassles and Uplifts Scale

- Measures caregiver appraisal of events occurring in the past week of caregiving as a hassle, an uplift, or both, or neither. Includes 4 subscales: care recipients limitations in ADL, care recipients cognitive status, care recipients behaviour, and practical aspects of caregiving.
- 110 items (4-point scale)
- Kinney, J. M., & Stephens, M. A. P. (1989). Caregiver hassles scale: Assessing the daily hassles of caring for a family member with dementia. *The Gerontologist, 29*, 328-332.
- Kinney, J. M., & Stephens, M. A. P. (1989). Hassles and uplifts of giving care to a family member with dementia. *Psychology and Aging, 4*, 402-408.

Negative Perception of Care Situation

- Measures the extent to which the caregiver defines the caregiving situation in a negative manner.
- 7 items (4-point scale)
- Noelker, L. S., & Townsend, A. L. (1987). Perceived caregiving effectiveness: The impact of parental impairment, community resources, and caregiver characteristics. In T. Brubker (Ed.), *Aging, Health and Family, Long Term Care*. Newbury Park, CA: Sage Publications.

Perceived Burden Measure

- Measures the number of care recipient needs (e.g., transportation, bathing, administering medications).

- 15 items (2-point scale)
- Macera, C. A., Eaker, E. D., Jannarone, R. J., Davis, D. R., & Stoskopf, C. H. (1993). A measure of perceived burden among caregivers. *Evaluation & the Health Professions, 16*, 204-211.

Physical Labor Scale

- Measures whether the care recipient needs physical assistance with eating, bathing, dressing, toileting, medications, shopping, and cleaning.
- 11 items
- Morycz, R. K. (1985). Caregiving strain and the desire to institutionalize family members with Alzheimer's disease: Possible predictors and model development. *Research on Aging, 7*, 329-361.

Revised Memory and Behavior Problems Checklist

- Measures two domains: the frequency of problematic behaviours in persons with dementia, and the caregiver reactions to these behaviours.
- 24 items (5-point scale)
- Teri, L., Truax, P., Logsdon, R., Uomoto, J., Zarit, S., & Vitaliano, P. P. (1991). The screen for caregiver burden. *The Gerontologist, 31*, 76-83.
- http://www.alz.org/national/documents/c_assess-revisedmemoryandbehcheck.pdf

Vigilance/Disruptiveness Scale

- Measures whether care recipient needs reminding or watching for various tasks or symptoms.
- 13 items
- Morycz, R. K. (1985). Caregiving strain and the desire to institutionalize family members with Alzheimer's disease: Possible predictors and model development. *Research on Aging, 7*, 329-361.

## Caregiver Physical Health

Not surprisingly, one's ability to provide care is largely dependent upon one's physical health. Caregiving tasks can be physically very demanding when one considers activities such as heavy housework, bathing, yardwork, and lifting. Caregivers, who themselves have functional limitations, may be unable to provide the necessary care (Deimling, 1986; Whitlatch et al., 1999). Continued caregiving may also exacerbate existing health conditions leading to premature declines in physical health (Kurtz et al., 2004; Pinquart & Sörensen, 2007; Schulz & Beach, 1999). Furthermore, the physical strain of caregiving places the caregiver at an increased risk of injury and illness (Kurtz et al., 2004; Pinquart & Sörensen, 2007; Schulz & Beach, 1999).

General Health Survey Questionnaire Short Form 36 (SF-36)

- Measures 8 domains: physical functioning, role limitations due to physical health problems, bodily pain, general health, vitality, social functioning, role limitations due to emotional problems, and mental health. Tool not designed specifically for caregivers.
- 36 items (2-point, 3-point, 5-point, 6-point scales)
- Ware Jr., J. E., Snow, K. K., Kosinski, M., & Gandek, B. (1993). *The SF-36 Health Survey manual and interpretation guide*. Boston: The Health Institute, New England Medical Center.

General Health Survey Questionnaire Short Form 12 (SF-12)

- A shortened version of the SF-36.
- 12 items (2-point, 3-point, 5-point, 6-point scales)
- Ware Jr., J. E., Snow, K. K., Kosinski, M., & Gandek, B. (1993). *The SF-36 Health Survey manual and interpretation guide*. Boston: The Health Institute, New England Medical Center.

Caregiver Subjective Physical Health

- Measures caregiver's perception of physical health status.
- 4 items (3-point scale)
- Whitlatch, C. J., Feinberg, L. F., & Stevens, E. J. (1999). Predictors of institutionalization for persons with Alzheimer's disease and the impact on family caregivers. *Journal of Mental Health and Ageing, 5*, 275-288.

General Health Perceptions Scale

- Measures self-reported physical health. Tool not designed specifically for caregivers.
- 5 items (scale ranging from 0 to 100)

- Ware Jr., J. E., Snow, K. K., Kosinski, M., & Gandek, B. (1993). *The SF-36 Health Survey manual and interpretation guide*. Boston: The Health Institute, New England Medical Center.

Perceived Health Index

- Measures both caregiver and care recipient perceptions of self-health status with items that assess worry, exhaustion, aches, and pains.
- 4 items (5-point scale)
- Deimling, G. T., & Bass, D. M. (1986). *The strengths and resources of families caring for impaired elders*: Report to The Retirement Research Foundation: The Benjamin Rose Institute.

Physical Health Deterioration

- Measures caregiver perceptions about whether they are sick more often, have more aches and pains, feel physically worse, tend to be more nervous, and have less energy.
- 5 items (4-point scale)
- Deimling, G. T., & Bass, D. M. (1986). Symptoms of mental impairment among elderly adults and their effects on family caregivers. *Journal of Gerontology, 41*, 778-784.

## Self efficacy/Competency

Self efficacy is defined as “a person’s belief about her or his ability to organize and execute courses of action to manage given situations” (Steffen et al., 2002, p. 74). The concept, however, is dependent on the situation so that people can have high self efficacy in one situation but low self efficacy in another situation. As such, a number of measures of self efficacy specific to caregiving have been developed. In relation to caregiving, the concept of self efficacy is said to help explain the challenges brought about by the caregiving role (Bandura et al., 1985; Steffen et al., 2002; Zeiss et al., 1999).

Caregiving Competence
- Measures the caregiver’s evaluation of the adequacy of their own performance in the caregiving role.
- 4 items (4-point scale)
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*(5), 583-594.

Caregiving Effectiveness
- Measures perceptions of caregiving effectiveness.
- 3 items (4-point scale)
- Noelker, L. S., & Townsend, A. L. (1987). Perceived caregiving effectiveness: The impact of parental impairment, community resources, and caregiver characteristics. In T. Brubker (Ed.), *Aging, Health and Family, Long Term Care*. Newbury Park, CA: Sage Publications.

Revised Scale for Caregiving Self Efficacy
- Measures caregiver self-efficacy in relation to self-care and obtaining respite, responding to disruptive patient behaviours, and controlling upsetting thoughts brought about by caregiving activities.
- 51 items (range from 0% to 100%)
- Zeiss, A., Gallagher-Thompson, D., Lovett, S., Rose, J., & McKibbon, C. (1999). Self-efficacy as a mediator of caregiver coping: Development and testing of an assessment model. *Journal of Clinical Geropsychology, 5*, 221-230.

Caregiver Competence
- Measures level of caregiver competence. Caregivers are first asked a series of questions. The responses to these questions are then reviewed by a 3-person clinical team and assigns a rating of competence for each of the 5 domains as well as an overall rating of competence.

- 21 items (2-point, 4-point scales)
- Kosberg, J. I., & Cairl, R. E. (1992). Burden and competence in caregivers of Alzheimer's Disease patients: Research and practice implications. *Journal of Gerontological Social Work, 18*, 85-96.

## Values and Preferences

Everyone possesses a unique set of values and preferences.  Not only do these values and preferences influence one's decision to become a caregiver/not become a caregiver, they also have the ability to influence ones: approach to caregiving; decisions made during caregiving; the priority one gives to caregiving; and satisfaction with care.  Values and preferences are, however, individualistic, and attempts to influence them might not only be futile, they may be considered unethical.  It is important, however, to have a sense of a caregiver's preferences and values.  For example, it can help those around understand why a caregiver is behaving in a particular manner. Furthermore, this understanding may provide clues as to how a caregiver may respond when faced with particular challenges in terms of decisions and tasks.  There have been a number of instruments developed to measure values and preferences in relation to such areas as decision-making, culture, willingness to care, and institutionalization.

Willingness to Care Scale

- Measures the experiences of informal caregivers for persons living with AIDS and their attitudes towards providing emotional, instrumental, and nursing support.
- 30 items (5-point scale)
- Abell, N. (2001). Assessing willingness to care for persons with AIDS: Validation of a new measure. *Research on Social Work Practice, 11*, 118-130.

Desire to Institutionalize

- Measures the desire of the caregiver to institutionalize the care recipient.
- 6 items (2-point scale)
- Morycz, R. K. (1985). Caregiving strain and the desire to institutionalize family members with Alzheimer's disease: Possible predictors and model development. *Research on Aging, 7*, 329-361.

Factors Influencing Placement Decision

- Measures the reasons a caregiver decides to move their relative to a care facility.
- 19 items (4-point scale)
- Aneshensel, C. S., Pearlin, L. I., Mullan, J. T., Zarit, S., & Whitlatch, C. J. (1995). *Profiles in caregiving: The unexpected career*. San Diego: Academic Press.

Community Service Attitudes Inventory

- Measures 5 domains of attitudes toward community services: concern for opinions of others, confidence in service system, preference for informal care, belief in caregiver independence, and acceptance of government services.
- 25 items (4-point scale)
- Collins, C., Stommel, M., King, S., & Given, C. W. (1991). Assessment of the attitudes of family caregivers toward community services. *The Gerontologist, 31*, 756-761.

Cultural Justifications Scale

- Measures cultural reasons why families provide care to the elderly.
- 10 items (4-point scale)
- Dilworth-Anderson, P., & Marshall, S. (1996). Social support in its cultural context. In G. R. Pierce & B. R. Sarason (Eds.), *Handbook of social support and the family*. New York, NY: Plenum Press.

Decision Control Inventory

- Measures the care recipient's level of involvement in 15 dimensions of daily decision-making. Can be given to both caregiver and care recipient.
- 15 items (4-point scale)
- Feinberg, L. F., & Whitlatch, C. J. (2002). Decision-making for persons with cognitive impairment and their family caregivers. *American Journal of Alzheimer's Disease and Other Dementias, 17*, 1-8.

Informed Decision Making

- Measures the degree to which the caregiver perceives specific types of information helpful to the decision-making process.
- 18 items (3-point scale)
- Fortinsky, R. H., & Hathaway, T. J. (1990). Information and service needs among active and former family caregivers of persons with Alzheimer's Disease. *The Gerontologist, 30*, 604-609.

Values and Preferences Scale

- Measures both caregiver and care recipient values and preferences for care in relation to environment, social interaction, autonomy, self-identity, and family caregiver issues.
- 37 items (3-point scale)
- McCullough, L. B., Wilson, N. L., Teasdale, T. T., Kolpakchi, A. L., & Skelly, J. R. (1993). Mapping personal, familial and professional values in long term care decisions. *The Gerontologist, 33*, 324-332.

Nursing Home Stressors

- Measures 3 domains of nursing home stressors: nursing assistants' communication with family, nursing assistants' support for families, and measures of positive and negative interactions.
- 6 items for nursing assistants' communication with residents' family, 5 items for nursing assistants' support for families, and 10 items for measures of positive and negative interactions (3-point scales)
- Whitlatch, C. J., Schur, D., Noelker, L. S., Ejaz, F. K., & Looman, W. J. (2001). The stress process of family caregiving in institutional settings. *The Gerontologist, 41*, 462-473.

Quality of Care Scale

- Measures caregiver perceptions of quality of care.
- 6 items (4-point scale)
- Bass, D. M., Noelker, L. S., & McCarthy, C. A. (1999). The inflence of formal and informal helpers on primary caregivers' perceptions of quality of care. *The Journal of Applied Gerontology, 18*, 177-200.

FAMCARE

- Measures satisfaction with quality of care provided at end of life.
- 20 items (5-point scale)
  Kristjanson, L. J., Sloan, J. A., Dudgeon, D., & Adaskin, E. (1996). Family members' perceptions of palliative cancer care: Predictors of family functioning and family members' health. *Journal of Palliative Care, 12*(4), 10-20.
- http://www.promotingexcellence.org/downloads/measures/famcare.pdf

The AIDS Caregiver Scale

- Measures both personal satisfaction and stress associated with caring for someone with AIDS.
- 14 items (7-point scale)
- Ferrari, J. R., McCown, W., & Pantano, J. (1993). Experiencing satisfaction and stress as an AIDS care provider: The AIDS Caregiver Scale. *Evaluation & the Health Professions, 16*, 295-310.

Caregiving Satisfaction Scale

- Measures long-term satisfaction and the rewards of caregiving.
- 15 items (4-point scale)
- Strawbridge, W. J. (1991). The effects of social factors on adult children caring for older parents. University of Washington.

Carer Satisfaction

- Measures caregiver satisfaction with services for stroke patients related to in-patient services and services after discharge.
- 9 items (4-point scale)
- Pound, P., Gompertz, P., & Ebrahim, S. (1993). Development and results of a questionnaire to measure carer satisfaction after stroke. *Journal of Epidemiology and Community Health, 47*, 500-505.

## Multidimensional Instruments

CARE Tool (Long and Short Versions)

- These instruments were designed to assess a number of domains using an open-ended format. Areas addressed in the instruments include: caregiving work, informal and formal work, living arrangements, other responsibilities, financial contributions, physical and emotional health, family relations, crisis and longterm planning, and service support.
- Keefe, J., Guberman, N., Fancey, P., Barylak, L., & Nahmiash, N. (2008). Caregivers' aspirations, realities, and expectations: The CARE Tool. *Journal of Applied Gerontology, 7*(3), 286-308.
- http://www.msvu.ca/en/home/community/Centres_Institutes/centreonaging/projects/caregiverassessment/instruments.aspx

Caregiver Risk Screen

- Measures whether a caregiver is at risk and the level of urgency required for intervention. To be used by home care agencies at intake.
- 12 items (4-point scale)
- Guberman, N., Keefe, J., Fancey, P., Nahmiash, N., & Barylak, L. (2001). Screening and assessment tools for informal caregivers: Identifying services to meet the needs of these potential clients. *Rehab and Community Care Management, Spring*, 24-26.
- http://www.msvu.ca/site/media/msvu/CRS%20%20English%20WATERMARK.pdf

California Caregiver Uniform Assessment Tool

- Measures various dimensions of caregiving including support, functional level of the care recipient, caregiver memory and behavioural problems, caregiver health, burden, placement, and information needs.
- California Caregiver Resource Centers. (2003). *California Caregiver Uniform Assessment Tool*: Family Caregiver Alliance.
- http://caregiver.org/caregiver/jsp/content/pdfs/tk_california_assessment_tool.pdf

Caregiver Reaction Assessment

- Measures the reactions of caregivers providing care to elderly care recipients with a variety of illnesses. Focuses on 5 domains: caregiver esteem, lack of family support, impact on finances, impact on schedule, and impact on health.
- Disrupted schedule (5 items measured on 5-point scale)
- Financial problems (3 items measured on a 5-point scale)

- Lack of family support (5 items measured on a 5-point scale)
- Health problems (4 items measured on a 5-point scale)
- Caregiver esteem (7 items measured on a 5-point scale)
- 24 items (5-point scale)
- Given, C. W., Given, B., Stommel, M., Collins, C., King, S., & Franklin, S. (1992). The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairment. *Research in Nursing and Health, 15*(271-283).

Sense of Competence Questionnaire

- Measures 3 domains related to competency as a caregiver: satisfaction with care recipient, satisfaction with own performance, and caregiving consequences.
- Satisfaction with care recipient as a recipient of care (7 items measured on a 4-point scale)
- Satisfaction with one's own performance (12 items measured on a 4-point scale)
- Consequences of involvement in care for the personal life of the caregiver (8 items measured on a 4-point scale)
- Scholte op Reimer, W. J. M., De Haan, R. J., Pijnenborg, J. M. A., Limberg, M., & Van den Bos, G. A. M. (1998). Assessment of burden in partners of stroke patients with the Sense of Competence Questionnaire. *Stroke, 29*, 373-379.

Caregiver Appraisal Measure

- Measures various aspects of caregiving including subjective caregiving burden, impact of caregiving, caregiving satisfaction, caregiving/mastery, and caregiving ideology.
- Subjective caregiving burden (13 items measured on a 5-point scale)
- Impact of caregiving (9-items measured on a 5-point scale)
- Caregiving satisfaction (9 items measured on a 5-point scale)
- Caregiving/master (12 items measured on a 5-point scale)
- Caregiving ideology (4 items measured on a 5-point scale)
- Lawton, M. P., M. H. Kleban, et al. (1989). Measuring caregiving appraisal*. Journal of Gerontology: Psychological Sciences,* 44, 61-71.

Aspects of the Caregiving Role

- Measures various aspects of the caregiving role including finances, health, independence, caregiver respect and recognition, personal and emotional life, and life as a whole.
- Life satisfaction (6 items measured on a 5-point scale)
- Positive and negative affect scale (20 items)
- Health (5 items)

- Social support (7 items measured on a 5-point scale)
- Overload (3 items measured on a 5-point scale)
- Family environment (6 items measured on a 3-point scale)
- Satisfaction (6 items measured on a 5-point scale)
- Resentment (5 items measured on a 5-point scale)
- Anger (4 items measured on a 5-point scale)
- Schofield, H. L., Murphy, B., Herrman, H. E., Bloch, S., & Singh, B. (1997). Family caregiving: Measurement of emotional well-being and various aspects of the caregiving role. *Psychological Medicine, 27*, 647-657.

Caregiver Well-Being

- Measures 4 domains related to caregiver well-being: physical health, mental health, financial resources, and social participation.
- Physical health (2 items; frequency of physician visits and self-rated health)
- Mental health (4 indicators)
- Financial resources (2 items; household income and perceived financial status)
- Social participation (7 items: number of visits, number of contacts, time, satisfaction)
- George, L. K., & Gwyther, L. P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. *The Gerontologist, 26*, 253-259.

Family Caregiving Factors Inventory

- Measures 4 domains related to caregiving: caregiving resources, caregiver self-expectations, caregiving task difficulty, and knowledge of the care recipient.
- Caregiving resources (17 items measured on a 3-point scale)
- Caregiver self-expectations (9 items measured on a 2-point scale)
- Caregiving task difficulty (6 items scored from ‘very poor’ to ‘very well’)
- Knowledge of the care recipient (10 items scored from ‘very poor’ to ‘very well’ )
- Shyu, Y.-I. L. (2000). Development and testing of the Family Caregiving Factors Inventory for home health assessment in Taiwan. *Journal of Advanced Nursing, 32*(226-234).

Finding Meaning Through Caregiving Scale

- Measures 3 domains related to the meaning of caregiving: loss\powerlessness, provisional meaning, and ultimate meaning.
- Loss/powerlessness (19 items measured on a 5-point scale)
- Provisional meaning (19 items measured on a 5-point scale)

- Ultimate meaning (5 items measured on a 5-point scale)
- Farran, C. J., Miller, B. H., Kaufman, J. E., Donner, E., & Fogg, L. (1991). Finding meaning through caregiving: Development of an instrument for family caregivers of persons with Alzheimerès Disease. *Journal of Clinical Psychology,* 55, 1107-1125.

Mental Health Effects

- Measures 3 domains related to the mental health of the caregiver; perceived burden, consequences of caregiving, and social change index.
- Perceived burden (1 item measured on a 5-point scale)
- Consequences of caring (17 items measured on a 5-point scale)
- Social change index (13 items measured on a 5-point scale)
- Pruchno, R. A., & Resch, N. L. (1989). Aberrant behaviors and Alzheimer's disease: Mental health effects of spouse caregivers. *Journal of Gerontology, 44*, S177-S182.
- Pruchno, R. A., & Resch, N. L. (1989). Mental health of caregiving spouses: Coping as mediator, moderator, or main effect? *Psychology and Aging, 4*, 454-463.

Bakas Caregiving Outcomes Scale

- Measures life changes resulting from caregiving in relation to emotional well-being, ability to cope with stress, self-esteem, relationship with friends and family, physical health, time for social activities, future outlook, and relationship with care recipient.
- 10 items (7-point scale)
- Bakas, T., & Champion, V. (1999). Development and psychometric testing of the Bakas caregiving outcomes scale. *Nursing Research, 48*(5), 250-259.

Appraisal of Caregiving

- Measures the extent to which caregivers experience caregiving as a threat or harm to important life goals and financial security; as providing an opportunity for personal growth, challenge, or strengthening of a relationship; and as a problem that either could be changed or must be accepted.
- 7 items for threat (7-point scale)
- 3 items for challenge (7-point scale)
- 2 items for controllability (7-point scale)
- Folkman, S., & Lazarus, R. S. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behavior, 21*, 219-225.

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# VI - CAREGIVER INTERVENTIONS: A REVIEW OF PROVEN AND PROMISING PRACTICE [2]

## Interventions

### *Psychoeducation*

According to Pinquart and Sörensen (2006), the results from numerous intervention studies show that psychoeducational interventions are significantly effective at decreasing caregiver burden, depression and negative care recipient symptoms. The effects are modestly positive for enhancing SWB and there are no significant effects on delaying the time to institutionalization of a care recipient. Parker et al (2008) found that psychoeducational interventions modestly decreased depression and burden and enhanced SWB whilst having no significant effect on self-rated health, self-efficacy or time to institutionalization. Gallagher-Thompson and Coon (2007) found that psychoeducational interventions (such as behaviour management skills training, depression management, progressively lowered stress threshold (PLST), and anger management skill training) as a category of interventions showed a notable effect size (0.81). While the reporting of results was not as detailed as Pinquart and Sörensen (2006), the reported benefits of this intervention category include the reduction of caregiver distress (e.g., depressive symptoms, anxiety, and/or feelings of anger and frustration) and improvement of caregiver coping skills and self-efficacy.

In the context of ‘home care’, Schoenmakers et al (2010) looked at psychosocial interventions and their impact on depression and burden. Although they pooled psychoeducational interventions, CBT and general support in their analyses, they found a slight decreasing effect on burden and depression, which may point to the possible effect of the home setting for delivering interventions to the populations studied versus a clinical/remote site. Lastly, Eagar et al (2007) report their review of psychoeducational interventions as positive for caregivers.

Data from several different reviews and meta-analyses show that there is encouraging evidence in support of psychoeducational interventions for caregivers. There are, however, also conflicting results of the specific outcomes that psychoeducational interventions may have an impact on. The lack of consistent categories of interventions makes the comparability between reviews limited and there is also uncertainty as to the size of the treatment effect. Nonetheless, a modest to significant effect of this type of intervention has been observed in multiple studies and across many sites and a range of caregivers. For these reasons psychoeducational interventions ought to be considered relatively “effective” types of interventions to make available.

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[2] Methods are reported at the end of this section, p. 84.

While there are a large variety of psychoeducational interventions, there is evidence to suggest that certain features of these interventions and/or how they are delivered may influence their effectiveness. Specifically, it has been shown that providing educational materials alone to caregivers does increase awareness of caregiving related issues but it has no impact on burden, SWB, depression, CR symptoms or time to institutionalization ( see Table 5 & Eagar et al., 2007). Rather, active interventions that provide an opportunity for caregivers to practice and role-play appear to be more effective at reducing burden, depression and CR symptoms while enhancing SWB and knowledge of caregiving related issues. (Pinquart & Sörensen, 2006; Parker, Mills, & Abbey, 2008).

### *Cognitive Behavioural Therapy*

Cognitive behavioural therapy based interventions have been shown to decrease depressive symptoms as well as reduce caregiver burden and anxiety (Pinquart & Sörensen, 2006; Parker et al., 2008;Gallagher-Thompson & Coon, 2007). Fairly robust treatment effects were observed for CBT interventions although the number of studies in the reviews and meta-analyses were small, so caution is needed in interpreting these results. It is noteworthy that several of the studies on which the reviews were based selected for caregivers who showed depressive or anxious symptoms.

Caregivers with depression are the most likely to benefit from receiving CBT based interventions and the effectiveness of this intervention for this group underscores the importance of careful assessment and screening. As noted by Gallagher-Thompson (2007) “individual CBT appears to be very effective for those caregivers with significant levels of depression, and group CBT-based interventions are effective for those who are highly stressed but not necessarily clinically depressed.” The importance of providing interventions to caregivers that match their needs will enhance the outcomes for those caregivers, in part because the caregiver is likely to observe the interventions as effective and will likely continue with the treatment more so than if they intervention was not meeting their particular needs. (Zarit & Femia, 2008).

### *Counseling/Case Management*

Counseling/case management interventions has been demonstrated in reducing caregiver burden but not having any significant effect on depression, SWB, time to institutionalization, or CR symptoms.

Zarit & Femia (2008) state that while case management is a service caregivers are highly likely to receive, the relative modesty or absence of effects on caregiver outcomes may be explained by the fact that case management seeks to direct caregivers to services. While beneficial in theory, there is another side to the experience of caregiving which it may overlook, which is the psychological difficulty with ‘turning over the care of their relative to formal service providers’ (Zarit & Femia, 2008). The phenomenon of caregivers experiencing additional stress/anxiety when engaging with services is also a salient issue in studies of respite services (Schoenmakers, Buntinx, & DeLepeleire, 2010).

Some positive effects on caregivers receiving case management have been documented early on in the intervention, however when followed up at 12 to 18 months, these positive effects had disappeared (Zarit & Femia, 2008). Also, no significant effects were noted on burden or depression reduction.

## *Respite*

The data showing whether or not respite programs are effective interventions for caregivers of older adults are mixed.

Pinquart & Sörensen (2006)report that caregivers showed decreased burden and depression and increased SWB while no significant effects were observed for time to institutionalization, CR symptoms or knowledge/awareness of caregiver issues. An experimental study by Zarit et al (1998) demonstrated that how much respite care a caregiver received made a difference as to whether or not any therapeutic effect was observed. They found, in fact, that reductions in anger and depressive symptoms were possible if CR were able to attend adult day services at least twice a week for three months. While these results point to positive evidence in favour of respite services, Schoenmakers et al (2010) found that respite care actually increased burden. These mixed results on respite interventions were also found in a meta-analysis of respite programs conducted by Mason et al (2007) where adult day care, respite packages, in home respite, host family respite and institutional respite were all looked at. Varying strengths of experimental study were pooled and it was found that a small effect in favour of reduction of burden and a slightly larger but still modest reduction in depression. These results were heavily cautioned because of methodological weaknesses of the underlying studies. The pooled results show relatively modest or weak support and where the individual interventions show more robust findings, the generalizability of the findings outside of the experimental design (e.g. to wider populations) is unknown. When ‘unpacked’, individual subcategories of respite such as adult day services show positive effects, in agreement with other studies. Qualitatively there is evidence in support of respite programs, however statistically (as a category) the studies conducted to date do not reliably demonstrate impacts on caregivers. According to Mason et al (2007), the “existing evidence base does not allow any firm conclusions about effectiveness or cost-effectiveness to be drawn and is unable to inform current policy and practice.” Further, a Cochrane Review conducted by Lee (2004) that was based on three RCTs also found that “no evidence of efficacy of respite care for people with dementia or their caregivers.” It should be noted that none of the studies included in Lee (2004) provided respite for longer than six weeks and one of the studies used a pay-per-use version of respite services rather than a free of charge model.

The complexity of the caregiving process for both caregiver and CR presents a significant challenge to those who wish to understand and measure outcomes of interventions such as respite. The variability of experimental results suggests a greater understanding of what caregiving means to a caregiver (e.g. caregiver appraisal) is required and should form part of any intervention strategy, especially if/when caregivers entrust the care of their loved ones to others.

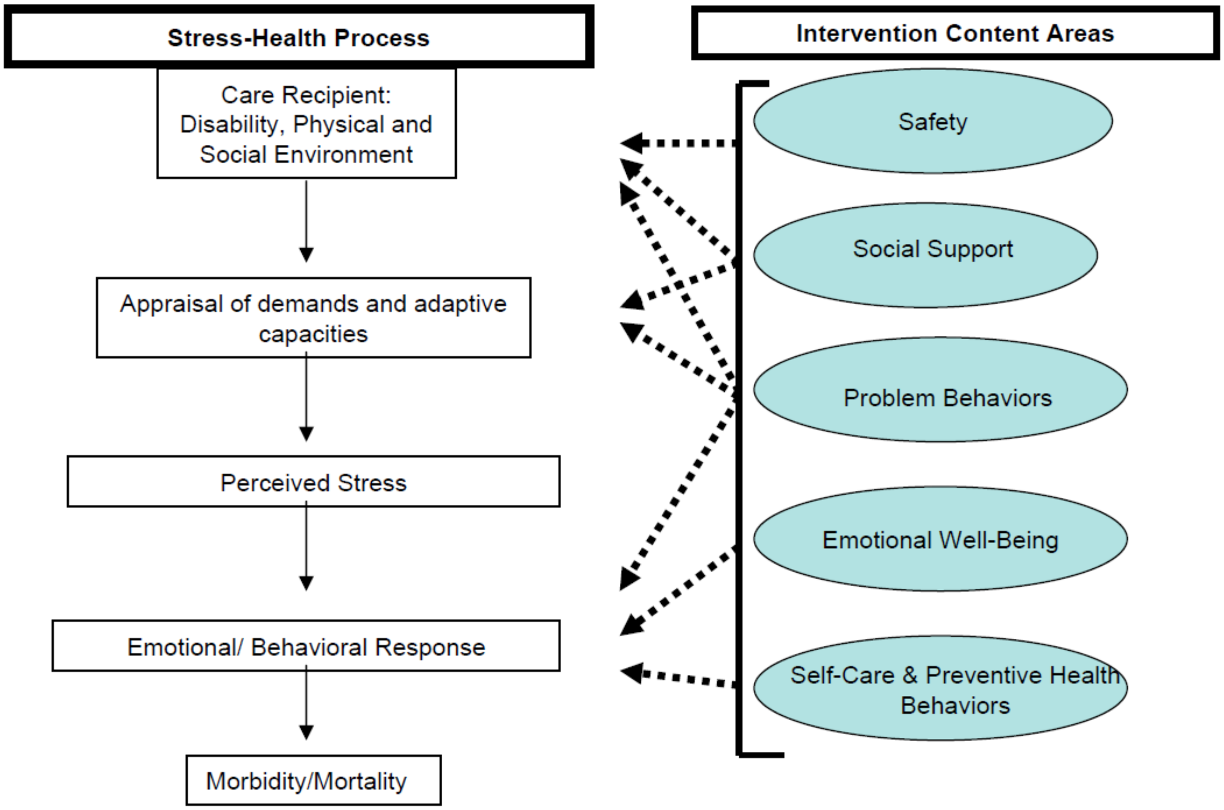
### *Multicomponent*

Multicomponent interventions, by definition, employ a variety of methodologically distinct approaches to address caregiver needs. The intent underlying the use of multicomponent interventions is to recognize that the complexity of caregiving issues is best addressed by a variety of components rather than just one. The heterogeneity of interventions subsumed by this category, therefore, has made it somewhat more difficult to analyze than more homogenous/intervention types. For example, even though Parker et al (2008) recognize that the majority of multicomponent interventions studies they identified showed a significantly positive effect, these studies could not be pooled for meta-analysis. Coon et al (2009) highlighted an intervention that demonstrated significant positive effects on depressive symptoms that persisted for 3 years after an intervention. Conversely, Pinquart & Sörensen (2006) were able to pool studies and found that multicomponent interventions significantly influenced the time required for a CR to be institutionalized, but that these interventions had no effect on burden, depression, SWB, CR symptoms or caregiver knowledge/awareness. The caution in looking at multicomponent interventions in the meta-analysis rests in the variability of the structure and delivery of the components. The findings from Pinquart & Sörensen (2006) are contrasted with a multi-site multicomponent caregiver intervention known as the Resources for Enhancing Alzheimer's Caregivers Health (REACH) study.

REACH was a landmark multi-site randomized clinical trial designed to test the effectiveness of several different caregiver interventions and then analyze the pooled effects. According to Schulz (2005) "this research program was able to link specific elements of a multicomponent intervention to caregiver outcomes, showing that interventions that actively engage the caregiver in skill acquisition aimed at regulating their own behavior result in significant improvements in caregiver depression." Thus, the outcomes that multicomponent interventions impact may vary depending on the particular mix of components – a point that highlights the importance of being able to assess the strength of intervention evidence for sources of bias or error.

Aside from identifying specific programs that demonstrated positive effects on burden and depressive symptoms in certain populations, the key finding was that interventions should be able to respond to varying needs of caregivers and therefore be tailored, wherever possible, to the individual. The initial REACH I trial gave rise to a follow up randomized clinical trial, REACH II, which used a multicomponent approach to addressing caregiver needs in an adaptive framework (Belle et al., 2006). Theoretically, the REACH trials are underpinned by the "stress-health" model and the REACH II interventions sought to employ interventions that would address the pathway of issues that comprise the proposed stress-health mechanism (see Figure 1).

**Figure 1: Framework for REACH II intervention (Belle et al 2006)**



The REACH II trials demonstrate that adapting a multicomponent intervention to a multi-ethnic population of caregivers is both possible and effective in addressing depressive symptoms, burden and quality of life of caregivers.

The categories of interventions show that caregivers have several options to address their particular needs, and that each of those interventions, while some more modestly effective than others, depends on a wide variety of factors that can influence how effective any particular intervention will or won't be. It is warranted to discuss briefly some of the factors that modulate these outcomes as they are pertinent considerations for any program or intervention geared towards caregivers.

**Table: Summary of Better Practices for Select Caregiver Interventions**

| Intervention | Better Practices |
|---|---|
| **Psychoeducation** | Active participation of CG (Peacock & Forbes, 2003) role playing or applying the attained knowledge and abilities during homework. Merely providing information in a classroom format and very limited time for discussion is insufficient for reducing stressors and influencing caregiver |

| | |
|---|---|
| | burden and depression. (Pinquart & Sörensen, 2006) |
| **Support** | Individual strategies were more effective than group strategies (although group strategies offered some benefit to SWB) |
| **CBT** | Individualized CBT shows more pronounced results than group based in depressed caregivers and group based interventions are more effective for less severely distressed caregivers (Gallagher-Thompson & Coon, 2007) |
| **Respite** | Longer treatment times are required for therapeutic effects to be realized (Zarit, Stephens, Townsend, & Greene, 1998) |
| **Multicomponent** | Structured programs are more efficacious than unstructured programs (Pinquart & Sörensen, 2006). Interventions that actively engage the caregiver in skill acquisition aimed at regulating their own behavior result in significant improvements in caregiver depression (Schulz et al., 2005). |

## Factors Influencing Caregiver Programs

The use of the term caregiver as a descriptor of a particular population masks the reality that the term as refers to an incredibly heterogeneous population. Caregivers can range in age, gender, relationship, ethnicity, socioeconomic status, educational level and functional status with each of these dimensions significantly impacting the nature and extent of the support they provide as well the appraisal of the caregiving experience itself. Pinquart & Sörensen (2006) describe five factors that are key to caregiver interventions, namely:

1. Group vs individual setting
2. Dosage
3. Caregiver age
4. Caregiver Gender
5. Type of relationship with care receiver

What the literature and studies have demonstrated, however, is that in addition to the abovementioned dimensions, there can be significant impacts based on:

6. Ethnicity
7. Socioeconomic status
8. Educational level
9. Functional status

A further layer of complexity is added when one considers that it is not only these dimensions that influence the outcome of any given intervention, but also the intersection of these dimensions with each other that can shape the experience of the caregiver and ultimately the success or failure of any program within a particular population. Several of these factors are discussed in detail below.

### Setting

Whether an intervention is delivered in a group setting or on an individual basis has been shown to have an impact on its effectiveness (Gallagher-Thompson & Coon, 2007; Pinquart & Sörensen, 2006; Cassie & Sanders, 2008). Interventions, such as support groups, can increase caregiver sense of social support whereas an individual interaction may not achieve this. Conversely, individualized support was found to be more effective than group based support for other outcomes, such as CG burden and depression. Individuals may not be inclined to open up in front of their peers (perhaps for cultural reasons) or they find that learn from the experiences of others (e.g. peer learning) is preferable. Thus, considering what outcomes are important to address for the caregiver can assist in determining the most appropriate setting for some interventions.

## Dosage

For many of the interventions profiled, it is has been identified that the question of “how much is enough?” can make the difference between the success and failure of an intervention. According to Zarrit et al (2008), “in the caregiver literature we can find examples of studies that expected to produce far-reaching changes while providing fairly minimal exposure to treatment. Treatment will not be effective if not delivered at a high enough frequency or intensity to make a difference in the targeted stress processes.” While more systematic investigation into interventions is required, it has been shown that in both respite care (Zarit et al., 1998) and in multicomponent interventions (NYUCI), better outcomes are achieved when assistance is available in sufficient amounts and across time.

## Caregiver Age

Intervention studies have identified the age of the caregiver as being a factor that can influence whether certain types of intervention will be effective or not. The needs and concerns of older adults are distinct than those of younger carers. The capacity to provide care, for example, is a point of concern for older carers who may also be experiencing declines in health and function. Programs designed specifically for older caregivers, such as the Older Carers Program (Hancock, Jarvis, & L'Veena, 2007), demonstrate that interventions based specifically around the particular respite need of older caregivers can be effective.

## Caregiver Gender

Profiles of caregivers of older adults show that the majority of these individuals are women, either spouses or daughters or daughters-in-law. In many of the intervention studies investigated, the majority of the samples were comprised of women caregivers and in certain studies, the interventions were exclusively geared towards female caregivers. In Pinquart & Sörensen (2006 )there was an important effect by gender of caregiver that was identified for, namely that interventions had a negative impact overall on SWB and that interventions generally reduced depression. Whilst the latter finding is encouraging, the former shows that perhaps the intended effect of interventions may be reducing well-being instead of enhancing it, and thus warrants further careful exploration as to why this may be the case. Other interventions geared towards women caregivers do show positive effects, although caution is required given their limited generalizability. The findings that men and women have a differential awareness of illness symptoms and/or attitudes towards institutionalization (and its impact on caregiver well-being) reiterates the importance of careful assessment of a care recipients care options, and an assessment of caregiver needs and expectations of supportive interventions. A caregiver assessment tool developed by Guberman et al (2001) provides a Canadian example of the type of process required in consideration of particular caregiver dimensions (Guberman, Keefe, Fancey, Nahmiash, & Barylak, 2001)

## Relationship with Care Receiver

The relationship of caregiver to a care receiver has also been shown to influence the extent to which interventions will be effective or not. In particular, spousal caregivers and children caregivers, while sharing similar needs also have distinct challenges and needs that are important to consider when determining types of interventions. Kang (2006), found that predictors of caregiver emotional strain shared between adult children and spouses included “care recipients’ disruptive behaviour, caregiver’s perceived overload, family disagreement, limitations on the caregiver’s life, and utilization of personal coping strategies by the caregiver” however ‘race’ of the care recipient and availability of respite uniquely predicted adult caregiver strain. In terms of specific interventions, adult children caregivers were found to respond more favourably to counseling and education interventions than older spousal caregivers. (Schoenmakers et al., 2010). Whilst having a primary caregiver may be common, there are often many individuals involved in the provision of care. As such interventions need to recognize that a ‘constellation’ of caregivers may exist with multiple individuals participating in the care and the decision making process for care. The presence of multiple voices can add to the complexity of a caregiving situation such that caregivers may experience stress not only from the challenging behaviours of a care recipient but also from negotiating the other participants in the care giver role.

## Ethnicity/Culture

The culture and/or ethnicity of individuals can play a profound role in their well-being. In the caregiving context, caregivers may experience varying levels of conflict with their own cultural identities and the social constructions of their surroundings. Beliefs about illnesses, such as dementia, help seeking behaviour and cultural competence/awareness on the part of service/treatment providers are all salient issues related to ethnicity and culture of caregivers. Similarly, differences between ethnocultural groups’ response to and satisfaction with interventions has been shown to vary (REACH II, REACH) significantly and illustrates that “one size does not fit all”.

According to the Public Health Agency of Canada (2003),

> Some persons or groups may face additional health risks due to a socio-economic environment, which is largely determined by dominant cultural values that contribute to the perpetuation of conditions such as marginalization, stigmatization, loss or devaluation of language and culture and lack of access to culturally appropriate health care and services

Beliefs about an illness and about the perceptions of certain illnesses can vary from culture to culture. For example, with dementia, Hinton (2005) found that caregivers vary in their explanatory beliefs of dementia (e.g. biomedical vs folk) depending on whether they were of a certain culture or educational level. In looking at South Asian family caregivers, Katbamna et al (2004) found that “societal attitudes towards disability and the fear of obligation prevented the seeking and accepting of help from wider social networks…the evidence does not support the assumption about extended families, and their willingness and ability to support carers.” Thus it is critical that those providing services and structuring programs not only take into account that there are cultural variations on beliefs about illnesses of older adults, but also on provision of care. Attitudes and beliefs about ethnocultural minorities need to be carefully considered as stereotypes of filial piety, for example, may lead treatment providers to believe that individuals do not want care because they are of a certain culture or because they do not ask for it directly (perhaps because doing so would be considered ‘shameful’). Conversely, there may be expectations by treatment providers that extended family caregivers are able and willing to provide assistance to caregivers and care recipients when in fact that may not be the case.

A dimension of ethnocultural populations that is particularly important with respect to services and service access for older adults in Canada is immigration status. Because older adults who have been in Canada for less than ten years do not have full access to government and social benefits, the financial responsibility falls on those who are sponsoring these older adults to provide assistance when or if the seniors are unable to do so themselves. Thus, for caregivers of sponsored seniors the stakes (and potential stressors) are much higher. They are more responsible for the financial needs of the care recipients, which in turn makes the care recipients all the more vulnerable and dependent. Should a care receiver require additional supportive care, the caregiver will have to be the one to pay for the services. Recognizing immigration status of an older adult is an important component to recommending appropriate service options to family members who may or may not be able to access services typically recommended for caregivers (e.g. in home respite services).

A highly promising intervention for Chinese female caregivers demonstrates that interventions can be successfully tailored to accommodate ethnocultural beliefs about dementia. Specifically, Gallagher-Thompson et al (2007) provided an in-home behavioural management (IBHM) psychoeducational support program, based on CBT theoretical underpinnings. This intervention was able to show significant effects on caregiver depressive symptoms and caregiver related stress. The decision to modify components of the intervention, such as delivery of the behavioural management in-home versus an external setting, and to adapt the language and communication style (e.g. rephrasing “assertiveness training” to “practicing ways to communicate effectively with those who can assist with caregiving”, as well as particular content issues (e.g. the perception that it is shameful for spouses to seek help from adult children), were made by consulting with focus groups of individuals before the implementation of the program.

Alongside issues of ethnocultural minorities, another minority population, namely lesbian, gay, bisexual and transgender (LGBT) caregivers experience challenges that shape the caregiving experience as well as service provision/utilization. Specifically, LGBT individuals may experience barriers to accessing services because of their own encounters with discrimination or prejudice. Older LGBT adults may be perceived not to have 'families' or support for families, whereas the literature shows this not be the case. Thus, intervention options that include family members (e.g. family support therapies), or religiously based/affiliated support interventions can be impacted by treatment provider beliefs/stereotypes about LGBT individuals and what would be considered "appropriate" care. As Coon (2004) points out, there may be hesitation for LGBT caregivers to participate in support groups that would involve them self-disclosing their sexual orientation/status. Further, older LGBT may experience difficulties disclosing or "coming out" that younger individuals would not.

A CBT based intervention named SURE 2 (Sharing & Support, Unhelpful Thoughts/Behaviours & Understanding, Reframes & Referrals, Education & Exploration) (Coon, 2004) that has been designed for use in support LGBT focused support groups offers a promising counseling tool. Underpinning the SURE2 and other LGBT interventions is the provision of a “safe place” where LGBT individuals are able to discuss their multiple social roles through the lens of their LGBT identity. Sensitivity to and awareness of LGBT caregiver issues by treatment providers is important in providing appropriate advice and referrals for interventions and programs.

## Intersectionality

It is important to discuss briefly the use of the above categories in approaching caregivers of older adults. First, although these categories are important, often recognized as social determinants of health, they are constructions and should be recognized as such. They are helpful at ‘simplifying’ seemingly disparate information under certain ‘headings’, however the caregiving experience is both rich and complex, so caution would be warranted when seeking to “simplify” categories of interventions or even categories of older adults. The fact that so much of the literature has shown incredible variability in outcomes reflects the challenge of the categories used in sample selection and analysis. How accurately these particular categories are in reflecting the essential components of the caregiver experience is certainly up for debate. A dimension to that debate, however, also has to include the extent to which these categories interact with one another, and their combined effect on the caregiving experience, not just at the individual level, but also at the group/community level and also at the broader policy levels. Second, it is important to recognize that factors such as age, gender, relationships with care recipients and ethnicity/culture are interconnected and that the caregivers and care recipients are constantly navigating and negotiating their own identities as they respond to their broader sociocultural contexts as well as to evolving health conditions.

The literature for caregiver interventions demonstrates the breadth of ideas that have been put forward about what can be done to provide support for caregivers of older adults experiencing distress. In attempting to identify and distinguish interventions that are successful from those that are not, the research has uncovered a number of factors that both individually and in concert, influence the outcome of an intervention in a given population. As such, the success of an intervention depends on more factors than just the content or type of intervention itself; who the intervention is directed to, when and for what length of time are all incredibly important questions for which the current evidence has only peripherally has addressed. The seductive nature of relying on the experimental studies to demonstrate "certainty" of an outcome's effectiveness can be tempered by the results that these experimental studies have borne out – namely that there is a high degree of variability with respect to effect size.

Still, there are common features to interventions as well as the factors that shape those interventions that warrant the use of categories, especially for the purposes of analysis. Part of the benefit of having so many studies to draw from is that in many of the trials there some features of programs or interventions that appeared to help enhance the effectiveness on caregiver outcomes. These features are discussed in the section on recommended practices.

## Recommended Practices

Several studies and research groups internationally have identified the key features and components of interventions and programs that increase the likelihood of successful outcomes in caregiver interventions. By looking at these various recommendations, a sense of what constitutes "better practices" that are empirically based can be gained and can help serve as a framework for planning translational adaptation of research trials into community based programs.

The Michigan Dementia Coalition (Cameron, Massuch, & Wishart, 2008), as part of their state plan to "Increase support for family members who provide care for persons with dementia at home" formed a Caregiver Support Workgroup (CSW) that reviewed evidence-based interventions for caregivers of individuals with dementia and came up with a set of recommendations for based on their review. The following are their recommendations for "effective interventions for caregivers of persons with dementia:"

1. ***Conduct Assessments*.** Complete *a* thorough assessment of the caregiver and the caregiving situation to determine an effective intervention plan that is best suited for the individual circumstance.
2. ***Utilize Multi-Component Interventions***. Using multiple interventions or techniques simultaneously increases the chances of effectively addressing the variety of caregiver needs.
3. ***Offer Interventions with Higher Intensity.*** The frequency and duration of intervention contacts or events are important considerations. More frequent contacts or events over a longer period of time are more likely to alleviate caregiver depression and care receiver symptoms.
4. ***Promote Consumer-Directed Interventions.*** Caregivers who have more choice, control, and flexibility in their home care options are significantly more satisfied with overall service options which can reduce premature nursing home placement of the care receiver.

These four recommendations are highly complementary to four "characteristics of effective interventions" that Zarit et al (2008) lay out. The recommendations are that studies be/use:

1. A psychological rather than purely educational approach: Educational interventions assume behavioural changes arise from new knowledge whereas psychological or psychotherapeutic interventions actively apply the information and allow for participants to practice new skills, gain feedback and develop plans for implementation in particular situations
2. Multidimensionality: Interventions that are multidimensional offer the best options at addressing the complexity of caregiver stress and burden
3. Flexibility: Caregivers have different needs across time and circumstances, so interventions that can be adaptive not only to the variability across caregiver groups and backgrounds but also across the evolving caregiver needs have shown promising outcomes
4. Sufficiency in the amount or dosage: Providing adequate support for caregivers is essential in realizing the goals of an intervention. A challenge identified in many of the studies, especially in respite, is understanding how much of an intervention is sufficient to address caregiver strain.

Effective programs appear to share several characteristics. Specifically, the following factors have been associated with the most positive outcomes for family caregivers. These factors should be carefully studied and built into efforts to support family caregivers:

1. **Contact with a helper over time**
2. **Contact with a helper who has specific intervention protocols to follow**
3. **Interventions and care plans tailored to the caregiver's specific needs**
4. **Multi-component interventions that include a combination of knowledge, skill building, problem solving and counseling**
5. **Interventions with higher intensity** (e.g. greater frequency and duration)
6. **Using a combination of home-visiting, telephone follow-up, internet and telehealth technology to deliver,** and,
7. **Programs developed and implemented locally and involving agency collaboration**.

(See http://www.rosalynncarter.org/caregiver_intervention_database/)

These components, while from different origins, are remarkably consistent and complimentary with one another. The overarching theme that appears to define the landscape of caregiver interventions is that one size does not fit all; that one single solution or intervention is not sufficient to address caregiver needs in providing care to older adults. Remarkably, the importance of finding out from care givers themselves what their determinants of well-being are as well as the stated aims they may have when seeking out assistance in the first place has been largely overlooked in the formal academic literature on caregiver interventions.

Alongside the difficulty in identifying effective interventions in the experimental context is the challenge of how best to translate the knowledge and the program /intervention from an experimental study into a community program. The realities of community programs/interventions include limited time/resources of staff to carefully measure/evaluate individuals as well as the variety in training levels of individuals delivering the intervention(s), their level of adherence, as well as the diversity of caregivers. The critical balance required between making a program effective (i.e. true to the components that had an actual clinical effect) and making a program accessible to the community (i.e. allowing for potentially more variability in who can benefit from the program) is one that is still being sought after in the field of translational research. Several of the recommended programs, most notably the REACH II and NYUCI have undergone replications/modifications for deployment in various community settings (Burgio et al., 2009).

The REACH II study gave rise to the REACH OUT (Offering Useful Treatments) intervention which has provided valuable insights into translating a multicomponent caregiver intervention in the context of “real world” challenges (Burgio et al., 2009). Case managers who were involved in the REACH OUT program stated that the effectiveness of the intervention may have been enhanced if there were staff dedicated specifically to the REACH OUT program as carrying existing workloads on top the REACH OUT program of activities made management of cases difficult. Materials related to content that case managers suggested be included as part of the caregiver education modules included topics such as communicating with doctors/health professionals, bereavement and information geared towards younger caregivers. Further, information geared towards female older adult caregivers and their responsibilities associated with caregiving was highlighted as an area for future development.

The large number of programs and interventions for caregivers that exist require the combination of being able to understand the broader types of categories, as outlined above, as well as the assessment of quality of the evidence underpinning programs/interventions. Even with the knowledge of both, a framework for being able to translate the experimental studies into practical programs can be daunting. One approach put forth by Schulz et al (2005) lists four components of practical significance to selection of interventions:

1. Effects on symptomatology
2. Quality of life of CG/CR
3. Social Significance
4. Acceptability to clients (social validity)

Another more comprehensive framework for translation of research interventions into community based caregiver programs is the Reach, Effectiveness, Adoption, Implementation and Maintenance (RE-AIM) framework. In a report prepared by the Centre for Disease Control (2008), the overall aim of the RE-AIM Framework is described as being able “to focus attention and critical thinking on essential program elements that can improve the sustainable adoption and implementation of effective, evidence-based programs and policies.”

### ***Effective Evidence Based Programs***

The following are brief summaries of the programs identified as effective evidence based programs.

*New York University Caregiver Intervention (NYUCI)*

Counseling and support intervention for spouse caregivers that is intended to improve the well-being of caregivers and delay the nursing home placement of patients with Alzheimer’s disease. The program also aims to help spouse caregivers mobilize their social support network and help them better adapt to their caregiving role. The program consists of four components, the first two of which are delivered within 4 months of enrollment in the study: (1) two individual counseling sessions of 1 to 3 hours tailored to each caregiver’s specific situation, (2) four family counseling sessions with the primary caregiver and family members selected by that caregiver, (3) encouragement to participate in weekly, locally available support groups after participation in the intervention, and (4) ad hoc counseling, counseling provided by telephone to caregivers and families whenever needed to help them deal with crises and the changing nature of their relative’s symptoms. The program is delivered by counselors with advanced degrees in social work or allied professions. http://www.nrepp.samhsa.gov/ViewIntervention.aspx?id=74

*Resources for Enhancing Alzheimer's Caregiver Health II Intervention*

Resources for Enhancing Alzheimer’s Caregiver Health II (REACH II) is a multicomponent psychosocial and behavioral training intervention for caregivers (21 years and older) of patients with Alzheimer’s disease or dementia. The intervention is designed to reduce caregiver burden and depression, improve caregivers’ ability to provide self-care, provide caregivers with social support, and help caregivers learn how to manage difficult behaviors in care recipients. REACH II participants are provided with educational information, skills to manage care recipient behaviors, social support, cognitive strategies for reframing negative emotional responses, and strategies for enhancing healthy behaviors and managing stress. Methods used in the intervention include didactic instruction, role-playing, problem-solving tasks, skills training, stress management techniques, and telephone support groups. http://www.nrepp.samhsa.gov/ViewIntervention.aspx?id=129

*Coping with Caregiving*

A psycho-educational group intervention that teaches mood management skills through two key approaches: first, an emphasis on reducing negative affect by learning how to relax in the stressful situation, appraise the care-receiver's behavior more realistically, and communicate more assertively; and second, an emphasis on increasing positive mood through the acquisition of such skills as seeing the contingency between mood and activities, developing strategies to do more small, everyday pleasant activities, and learning to set self change goals and reward oneself for accomplishments along the way.

*Skills training for spouses of patients with AD*

Two 12-week intervention groups (patient-focused skills training, caregiver-focused skills training) were compared with a control group. In Week 2, each caregiver attended 1 of 2 3-hr workshops: 1) Patient-Change Workshop, consisting of introductions, presentation of general behavioral principles as they relate to dementia symptoms, overview of in-home training sessions, and review of caregiver-completed Problem Behavior Tracking forms 2) Self-Change Workshop, consisting of introductions, presentation of three self-change strategies, overview of in-home training sessions, and review of completed Problem Behavior Tracking forms. In Weeks 3-12, trained staff visited caregiver for 1 hr at home to individualize skills training to caregivers' needs.

*Individualized plan of care based on Progressively Lowered Stress Threshold (PLST) model*

Individualized plan of care based on the Progressively Lowered Stress Threshold (PLST) model (need environmental modifications because of declining cognitive/functional abilities; this reduces stress and promotes functional adaptive behavior); community-based psychoeducational intervention, combined with routine information and referrals. Approximately 3 to 4 hours of in-home intervention, and biweekly follow-up phone calls for 6 months

*Savvy Caregiver*

Savvy Caregiver is intended to train families and others for the unfamiliar role they face as caregiver for a relative or friend with Alzheimer's disease or another dementia. Savvy Caregiver is a 12-hour training program that is usually delivered in 2-hour sessions over a 6-week period

*STAR-C Intervention*

STAR-Caregivers (STAR-C) is a standardized intervention to help family caregivers identify, reduce, and manage difficult behavioral symptoms of their relative with Alzheimer's disease. Behavioral symptoms are a major cause of family caregiver stress, burden, and depression. STAR-C decreases both the symptoms and the caregivers' related feelings of stress, burden, and depression. http://www.rosalynncarter.org/caregiver_intervention_database/

## Conclusion

The landscape of interventions for caregivers of older adults is reflective of the diversity of ideas to address caregiver health and well being that have been explored to date. The multiple studies, contexts and stakeholders provide a rich pool to draw sound and established interventions from – a definite advantage for caregivers, care recipients, care workers and program planners alike. The recognition that caregiving may lead to negative experiences on the part of the care provider underscores the importance of the sustainability of the ability for a care giver to continue to offer the most appropriate care possible, both for their loved ones as well as themselves. The growing recognition that who the caregiver "is", their experiences and particular issues, their characteristics, and more than anything else, their needs, should be paramount in connecting caregivers and recipients to services. This "needs-based" approach highlights the importance of interventions, of whatever category, to be able to respond to the particular needs of caregivers. The particular question for those wishing to support caregivers has typically been "what works?" however a more critical perspective ((Eagar et al., 2007)) frames that question as:

- Which carers?
- Should receive which services?
- From whom?
- At what expected cost?
- With what expected effect?

The reality when considering interventions or programs for caregiver support requires recognizing that the caregiver experience is complex, often involving overlapping and interdependent factors . An intervention will only be as 'effective' as the outcome it is set out to address is clear. Thus, creating and offering caregivers programs designed to address issues they may not be experiencing may not only be ineffective, but also to be potentially harmful.

Whether an intervention is delivered in groups or at the individual level highlights the differing outcomes that should be considered before recommending programs based on one format or the other. For example, while group based activities may enhance social awareness, it may preclude individuals from opening up about issues that are causing them distress. Alternatively, the use of individual based interventions may assist in developing effective/adaptive coping behaviours, it may not offer the appropriate support for addressing social isolation.

Another very important consideration is "how much" or the "dosage" of an intervention is necessary and sufficient to obtain the intended caregiver outcome. Certainly on a program by program basis this will vary, however it is important to take note that programs/interventions identified for adult day programs, for example, showed conflicting results in caregiver outcome based on the length of time caregivers were given access to/used these services. Further the long term impact (i.e.

“maintenance effects”) of certain interventions has been shown to improve as the duration of the services increases (see NYUCI for example).

Factors such as caregiver age, gender, relationship and ethnicity/culture show particular importance in “effectiveness” of any program or intervention. Recognizing that older women spouses will have different experiences, needs and appraisals of the caregiving role than will male adult children, for example, highlights whether certain features of a psychoeducation intervention would be well received or ineffective at addressing caregiver burden. That such a scenario could vary even further if the individuals in question were from either Chinese backgrounds or ‘South Asian’ backgrounds and either self identified as GLBT or not illustrates that one size fits all programming could not realistically be effective at addressing caregiver distress and how it is expressed and experienced by these different caregivers. The interplay of these different categories is something that also requires attention as the temptation to give weight to individual categories without recognizing that they are dynamic constructions can lead planners and program deliverers to unintentionally discriminate or introduce barriers to effective care based on their own biases.

Recognizing the heterogeneity of caregivers as well as the multiple factors at influence in the caregiving experience, there still exists the range of interventions that have been shown, depending on the outcomes sought, to be effective for caregivers. The fact that psychoeducational interventions, cognitive behavioural therapy, counseling/case management, respite and multicomponent interventions have all demonstrated either broadly or specifically that they are of merit is important. In the search for ‘ideal’ interventions, the literature has begun to acknowledge that no one intervention will fully address the complexity of issues experienced by caregivers. The innovations applied to familiar programs illustrate that it may be possible to enhance existing programs with better practices rather than starting anew. Encouragingly there are also examples of evidence-based programs identified in this review where that has been the case.

Additionally, there are a number of examples of emerging practices that show promise for particular populations. With the dimensions identified by this review, those in the position to support those who are providing care to older adults will be able to draw upon the collective better practices and frameworks to translate these pilot programs into context appropriate programs. Indeed, as both established and pilot programs alike consistently show, the possibility for innovation is ever-present and the ability to respond to caregiver needs using both established techniques as well as new technologies should be embraced thoughtfully and critically.

## Method

Literature was searched in Ageline, CINAHL, Medline, PsychInfo, and Socindex between 2005 and 2010 as well as the Cochrane Library for programs and/or interventions related to informal caregivers. There was particular interest for studies in Canada however the search strategy did not yield a large number of results and so the search was expanded to include literature outside of Canada. In addition to these databases, searches using Google and Google scholar and hand searching of key references and caregiver association websites yielded additional sources. The types of studies of interest included randomized controlled trials, experimental/quasi-experimental studies, meta-analyses and systematic reviews.

Searches were conducted using the following keywords: caregiver or caregiving AND (services or interventions or programs or project or pilot or evaluation); additional terms such as review and meta-analysis were also included to identify sources. No specific illnesses or disorders were searched however restrictions were placed on population age (of care recipients) to find studies about caregivers for older adults.

The extensive amount of research on caregivers (especially caregivers of those with dementia) was reflected by the large number of articles describing programs and interventions for these individuals. Within such a large selection of programs were several important and extensive meta-analyses that were used to contextualize and inform the categories of interventions.

The use of meta-analyses and systematic reviews in this report stems from the types of research issues that they are effective in addressing, such as effectiveness, process of service delivery, salience, safety, acceptability, cost effectiveness and to lesser degree appropriateness and satisfaction with service. In addition, the reliability and quality of the evidence from meta-analyses are significantly enhanced because of the pooling of studies.

Individual intervention studies covered in this review include randomized and non-randomised control trials, quasi-experimental, controlled before & after studies, interrupted time series and case control studies. As the goal of this review was to determine effective or promising programs and interventions for caregivers of older adults, a means of assessing the quality of the studies and interventions was required, and as such two sets of evaluation frameworks were drawn on: the National Institute for Clinical Excellence (NICE) guideline “Methods for development of NICE public health guidance” as well as a framework used by Pinquart & Sörensen (2006).

The study quality assessment framework used by Pinquart & Sörensen (2006) scored intervention studies according to the following criteria:

1. Whether participants were randomly assigned to intervention and control condition (1=yes, 0=no/nor reported),

2. whether the intervention and control group did not differ by sample characteristics at *T*1 (1=yes, 0=no),
3. whether both groups had at least 10 participants (because studies with small sample sizes are more error prone; 1=yes, 0=no),
4. whether the attrition rate was < 10% (1=yes, 0=no),
5. whether well-validated outcome measures were used (1=yes, 0=no)

The sum was then calculated with higher scores reflecting higher quality studies. A study/intervention was considered to be "effective" if showed a significant effect on a core outcome (described below) using a well controlled study (score of 4 or higher on Pinquart & Sörensen (2006) scale or better than a 2++ on the NICE guideline). If a study showed a significant effect on a core outcome but it was a lower quality study it was deemed to be "promising".

Key web sites/databases were also searched that house collections of evidence-based interventions for caregivers. These sites (see below) include a variety of interventions variable levels of methodological rigor underlying the profiled/presented programs. The quality of the evidence was sufficiently high, however, to warrant their inclusion and review. These sites are:

**Table 1: List of Evidence Based Caregiver Intervention Websites**

| Site/organization | Web Address | Number of CG programs listed |
|---|---|---|
| **Family Caregiver Alliance** | Innovations Clearinghouse<br>http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=2319 | >50 |
| **Rosalyn Carter Institute for Caregiving** | Caregiver Intervention Database<br>http://www.rosalynncarter.org/caregiver_intervention_database/ | >50 |
| **SAHMSA's National Registry of Evidence-based Programs and Practices** | http://www.nrepp.samhsa.gov/Search.aspx | 2 |

For many reasons, establishing "effective" and "promising" programs was a challenging undertaking. The combination of an extensive selection of programs as well as methodologically heterogeneous studies made it clear that the distinction was not only at the level of "effective" and "promising" but that the results had to be "meaningful" given the extent of the evidence now gathered on what has been shown to enhance outcomes for intervention studies on caregivers. To address this challenge, a number of 'better' practices were identified from several meta-analyses as well as from research groups having performed similar types of reviews for "effective" caregiver intervention programming. Thus, once studies were collected and assessed for level of evidence "quality" they were further subject to a collection of parameters drawn from dimensions of better practice. These dimensions are described in the table below:

**Table 2: Dimensions of Effective Caregiver Interventions**

| Dimension | Definition |
|---|---|
| **Accessibility** | The intervention or program uses materials that take into account the challenges of the caregiver (e.g. appropriate language, financially accessible, timing/duration) |
| **Assessment** | The intervention contains a rigorous up-front assessment of the caregiver, their needs and particular situation |
| **Group or Individual** | The intervention is administered in either a group or individual (or mixed) setting. Mixed interventions use both individual and group settings at different points in time |
| **Culturally Competent** | The intervention is aware of cultural factors, norms and beliefs of the caregiver and care recipient. Materials are in appropriate languages and delivery/administration of programs takes into account the various cultural needs (translators, gender appropriate settings) of participants. |
| **Adaptable** | The program can be tailored to the needs of the caregiver, with relevant needs being addressed as required |
| **Variety of communication methods** | Different media options are available (e.g. audio/visual in addition to text materials) and in person options are available in addition to telephone support |
| **Duration of Contact** | The intervention is of sufficient length and intensity to adequate address caregiver needs. |

Each of these factors (except for “group or individual”) was given a score of low, medium or high, with higher scores reflecting a more effective practice component. The group or individual was not scored but may be used to decide a more effective option in the case of a tie. The scores were then weighted and summed and programs ranked according to their total score.

### *Outcomes*

An initial challenge in looking across the many reviews was the observation of various schemes for categorizing interventions. The meta-analysis by Pinquart & Sörensen (2006) strikes a reasonable balance between “chunking” similar types of interventions together and “slicing” interventions apart so as provide meaningful insights into popularly studied interventions. The categories of interventions used by Pinquart & Sörensen (2006) are:

1. Psychoeducational
2. Cognitive Behaviour Therapy
3. Counselling/Case Management
4. General Support
5. Respite
6. Training of Care Recipient
7. Multicomponent

Another set of categories of interest are the outcomes that many of the interventions and programs set out to achieve. While there is considerable variation across studies as to what outcomes are being measured, what they are being measured with and the exact definition of the outcomes themselves, several recurring outcomes are often cited as primary or secondary outcomes relevant to caregivers. For ease of reference, the clustering for these outcome categories is also based on Pinquart & Sörensen (2006). The common set of outcomes measured are:

1. Burden
2. Subjective Well Being
3. Depression
4. Knowledge/Awareness of Caregiver
5. Care Recipient Symptoms
6. Time to Institutionalization

## Results:

Over 1700 abstracts and titles of peer reviewed studies were reviewed for programs or interventions relevant to caregivers. Because the primary interest was in looking at specific programs or interventions for caregivers, studies that looked at interventions primarily geared to care recipients were not included in the review but were retained as they also assist in the understanding of potential intervention avenues for caregiver services. Interventions that include care recipient components were, however, included. In total 96 sources were retained for closer analysis which included 13 reviews/meta-analyses (covering over a combined 313 intervention studies – see Table 3 below). Further, as mentioned in the Table 1 above, key web sites that contained databases of evidence-based interventions for caregivers were also searched. Given that the NREPP was of high quality in its reporting of evidence both of the caregiver interventions listed (Resources for Enhancing Alzheimer's Caregiver Health – REACH II; and the New York University Caregiver Intervention – NYUCI) were retained (and categorized as effective).

The use of high quality meta-analyses allowed for reliable assessment of the impact of interventions on outcomes. By pooling the results of many studies, it was possible to ascertain whether or not particular interventions had a significant effect on particular outcomes, and what the extent of that impact is. As can be seen in the Table 4 below generated from Pinquart & Sörensen (2006), there are noticeable effects of interventions such as psychoeducation on a broad set of outcomes whereas (according to Pinquart & Sörensen) multicomponent interventions show no significant impact on most of the outcomes except for time to institutionalization. It is important to note, however, that there are other studies that show results contrary to those presented in Table 4, such as Parker et al (2008) on an individual basis, so the findings presented should be treated with caution (discussed below).

A total of 7 evidence-based programs were identified that addressed different caregiver health/well-being outcomes with 3 of the 7 scoring very well and on a relative basis are better supported than the remaining 4 on "better practice" measures. The remaining programs are, nonetheless, effective options for the outcomes they address. These programs are summarized in Table 7 below and ranked according to their score. A large number of interventions for caregivers were identified, with many of them being variations on types of interventions (e.g. variations of support groups, telephone based interventions or respite to name a few). There were also a number of innovative programs which were identified in the course of this review but have not been evaluated. Because the primary aim of this review was to identify effective programs/interventions those that could be classified emerging practices or those for which either the amount or quality of data was insufficient to reliably establish the effect of the intervention were excluded. It would be of limited practical value to present promising programs without both the context of the intervention landscape as well as the wealth of information about features of programs that have been shown to enhance the effectiveness of many current/popular programs. In this way, the “innovation” and promise is not necessarily in the form of radically different programs, but rather incremental innovations gained through years of data and study of existing programs. The primary benefit of this perspective is that rather than looking solely for programs per se, is that the potential for modification or “fine tuning” represents a more resource conscious strategy that takes into account the role of resources as a constraining factor in program planning.

### Table 3: Summary of Reviews and Meta-Analyses

| Author | Title | Pub Date | Type | Disorders Covered | Effect Size Rep | # of Studies | Years Covered | Type of Lit Covered | Area of focus | Categories of Intervention |
|---|---|---|---|---|---|---|---|---|---|---|
| Cassie,K. M.; Sanders, S. | Familial caregivers of older adults | 2008 | Systematic Review | Dementia Frailty | N | 16 | 1988-2008 | Controlled & uncontrolled trials, meta-analyses | Caregiver Interventions (All) | individual; group; multimodal; technology based |
| Etters, L. et al | Caregiver burden among dementia patient caregivers: a review of the literature | 2008 | Review | Dementia | N | NS | 1996-2006 | All peer reviewed lit | Caregiver Burden | |
| Gallagher-Thompson & Coon | Evidence-Based Psychological Treatments for Distress in Family Caregivers of Older Adult | 2007 | Systematic Review | Dementia | N | 19 | 1980-2005 | Intervention studies | Psychologically based interventions | Psychoeducational/skill building; Pyschotherapy / counselling; Multicomponent studies |
| Lee et al | A meta-analysis of interventions for informal stroke caregivers | 2007 | Meta-analysis | Stroke | Y | 4 | 1966-2005 | Intervention studies (experimental) | Caregiver Interventions (All) | |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| Lee, H; Cameron, MH | Respite care for people with dementia and their carers | 2004 | Systematic Review | Dementia | N | 3 | All years - 2005 | RCT | Caregiver Interventions (All) | |
| Mason, Anne et al | The Effectiveness and Cost-Effectiveness of Respite for Caregivers of Frail Older People | 2007 | Meta-analysis | Not restricted - most studies retrieved were on Dementia | Y | 22 | 1980-2005 | Well-controlled effectiveness studies, uncontrolled studies. | Respite | Adult Day Care; Respite Packages (multiple respites); In home respite; Host Family Respite; Institutional; Multidimensional; Video |
| Parker, D. et al | Effectiveness of interventions that assist caregivers to support people with dementia living in the community: a systematic review | 2008 | Meta-analysis | Dementia | Y | 30 | 2000-2005 | Intervention studies | Caregiver Interventions (All) | psychoeducational; support; multi-component; other |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| Pinquart, Martin; Sörensen, Silvia | Helping caregivers of persons with dementia: which interventions work and how large are their effects? | 2006 | Meta-analysis | Dementia | Y | 127 | 1982-2005 | Intervention studies | Caregiver Interventions (All) | psychoeducational;CBT;Counselling/CM;General Support;Respite;Training of CR;Multicomponent;Miscellaneous; Group vs. Individual |
| Powell, J. et al | A systematic review of networked technologies supporting carers of people with dementia | 2008 | Systematic Review | Dementia | N | 15 | All years - 2007 | Controlled & uncontrolled trials, meta-analyses, pre/post | Technologies for support | |
| Schoenmakers, B. et al | Supporting the dementia family caregiver: The effect of home care intervention on general well-being | 2010 | Meta-analysis | Dementia | Y | 26 | 1980-2007 | RCT and Controlled Trials | Caregiver Interventions (All) | Psychosocial; Respite; Case Management; Communication Technology; Physical Exercise; Communication Skills |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| Schulz, R. et al | Evidence-based caregiver interventions in geriatric psychiatry | 2005 | Systematic Review | Dementia + Stroke | N | 51 (Dementia = 41) | 1999-2005 | RCT | psychosocial family caregiver interventions | |

**Table 4: Impact of Caregiver Intervention on Key Outcomes**

| | Outcome | | | | | |
|---|---|---|---|---|---|---|
| **Intervention** | **Burden** | **SWB** | **Depression** | **Knowledge/ Awareness of CG** | **CR Symptoms** | **Time to Institutionalization** |
| Psychoeducational | Decreased ++ | Increased + | Decreased ++ | Increased ++ | Decreased ++ | no effect |
| CBT | Decreased ++ | no effect | Decreased ++ | no effect | no effect | no effect |
| Counselling/CM | Decreased ++ | no effect | no effect | no effect | no effect | no effect |
| General Support | no effect | Increased ++ | no effect | no effect | no effect | no effect |
| Respite | Decreased ++ | Increased + | Decreased ++ | no effect | no effect | no effect |
| Training of the CR | no effect | no effect | no effect | no effect | Decreased + | not mentioned |
| Multicomponent | no effect | no effect | no effect | no effect | no effect | Decreased + |
| Misc | | | | | | |
| Variable | | | | | | |
| **Individual** | no effect | no effect | no effect | no effect | no effect | no effect |
| **Number of Sessions** | no effect | no effect | Decreased + | no effect | no effect | Increased++ |
| **% female CG** | no effect | Decreased + | Decreased++ | Increased ++ | no effect | Increased+ |
| **% spouses** | no effect | no effect | no effect | no effect | no effect | Increased++ |
| **Year of publication** | Decreased + | no effect | no effect | no effect | no effect | no effect |

+ = significant result at p<0.05

++ = significant result at p<0.01 or lower

No effect = statistically insignificant

### Table 5: Detailed effects of Active vs Information Only Psychoeducational Interventions (Pinquart & Sörensen 2006)

| Outcome | Psychoeducational | Psychoeducational - Active | Psychoeducational - Info only |
|---|---|---|---|
| Burden | Decreased ++ | Decreased++ | no effect |
| SWB | Increased + | Increased + | no effect |
| Depression | Decreased ++ | Decreased++ | no effect |
| Knowledge/Awareness of CG | Increased ++ | Increased ++ | Increased ++ |
| CR Symptoms | Decreased ++ | Decreased+ | no effect |
| Time to Institutionalization | no effect | no effect | no effect |

### Table 6: Meta-analysis of Psychoeducational Interventions ( Parker et al 2008)

| Outcome | Psychoeducational | Support |
|---|---|---|
| Burden | Decreased+ | Decreased + |
| SWB | No effect | not mentioned |
| Depression | Decreased + | not mentioned |
| Health | no effect | not mentioned |
| Self Efficacy | no effect | not mentioned |
| Time to Institutionalization | not mentioned | not mentioned |

| Table 7: Effective Evidence Programs for Caregivers of Older Adults | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| **Program Name** | **Interv'n Category** | **Outcome** | **Evidence quality** | **Access** | **Adapt-ability** | **Assess m.** | **Variety of communication methods** | **Group or Individual** | **Duration of Contact** | **Culturally Competent** |
| New York University Caregiver Intervention (NYUCI) | Support | 1: Caregiver physical health<br>2: Caregiver depressive symptoms<br>3: Caregiver social support<br>4: Caregiver appraisal of patient memory and behavior<br>5: Length of time to nursing home placement of care recipient | High | High | High | High | Med | Mixed | Med | High |

| Table 7: Effective Evidence Programs for Caregivers of Older Adults | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| **Program Name** | **Interv’n Category** | **Outcome** | **Evidence quality** | **Access** | **Adapt-ability** | **Assess m.** | **Variety of communication methods** | **Group or Individual** | **Duration of Contact** | **Culturally Competent** |
| Resources for Enhancing Alzheimer's Caregiver Health II Intervention | Multicomponent | 1: Caregiver quality of life<br>2: Prevalence of caregiver clinical depression | High | High | Med | Med | Med | Mixed | Med | High |

**Table 7: Effective Evidence Programs for Caregivers of Older Adults**

| **Program Name** | **Interv'n Category** | **Outcome** | **Evidence quality** | **Access** | **Adapt-ability** | **Assessm.** | **Variety of communication methods** | **Group or Individual** | **Duration of Contact** | **Culturally Competent** |
|---|---|---|---|---|---|---|---|---|---|---|
| Coping with Caregiving (Gallagher-Thompson - 2008) | Psycho-education | Depressive symptoms, adaptive coping strategies | Med | High | Med | Low | Med | Group | Low | High |
| Skills training for spouses of patients with AD (Bourgeois et al 2002) | Psycho-education | CG Mood; CG Anxiety; CG Depressive symptoms | Med | Med | High | Med | Low | Individual | Low | Low |

**Table 7: Effective Evidence Programs for Caregivers of Older Adults**

| Program Name | Interv'n Category | Outcome | Evidence quality | Access | Adapt-ability | Assessm. | Variety of communication methods | Group or Individual | Duration of Contact | Culturally Competent |
|---|---|---|---|---|---|---|---|---|---|---|
| Individualized plan of care based on Progressively Lowered Stress Threshold (PLST) model (Buckwalter 1999) | Psycho-education | Depressive symptoms, tension anxiety, anger-hostility, fatigue-inertia, confusion-bewilderment | Med | Med | Med | Med | Low | Individual | Med | Low |
| Savvy Caregiver (Ostwald/ Hepburn 2007) | CG Knowledge Skills | Burden (also response to CR behr) | Med | Med | High | Low | Low | Group | Low | Low |
| STAR-C Intervention (Teri et al, 2005) | CR behaviour/CG Knowledge Skills | Depressive Symptoms Anxiety | Med | Med | Med | Med | Low | Individual | Low | Low |

## Discussion

The literature for interventions for caregivers of older adults is largely dominated by information pertaining to older adults with dementia. As seen in the number of systematic reviews and meta-analyses on interventions, not only are there many studies on dementia related caregiving, but there are also many randomized clinical trials of interventions that have been conducted. Caregivers for older adults with other conditions such as stroke, cancer, and Parkinson's disease have received much less attention in the published literature, although there are a handful of promising studies that speak to ((Schulz, Martire, & Klinger, 2005), (Lee, Soeken, & Picot, 2007),(Mason et al., 2007),(Eagar et al., 2007)) specific interventions in these populations. While providing proper care to older adults requires an understanding of the particular challenges associated with any health condition, a recent synthesis by Eagar et al (2007) points out that:

"There are no major differences highlighted in the review literature between the carers of different types of care recipients beyond some expected differences in the need for support and practical assistance arising from facing the emotional pressures of dealing with challenging behaviours in people with dementia….The types of needs that are described within the different reviews within the sub-sets of types of carers, shows the commonality in the types of needs, and the range of the measures that were reported in the literature to describe those needs."

Thus even though the majority of the literature on interventions for caregivers of older adults was based on older adults having dementia, there appears to be some merit in looking to these programs to assist with caregivers of older adults generally.

A consequence of the variety of reviews and meta-analyses was that each review used slightly different categories to describe the interventions (see Table 3 for the different categories of interventions covered ). As noted by Schulz et al (2005), there is a need to "develop a standardized taxonomy for characterizing and measuring multicomponent psychosocial interventions (Czaja, Schulz, Lee, & Belle, 2003). The application of a clearly articulated and useful taxonomy would enable us to better describe and compare interventions across studies as well as link intervention components to specific outcomes."

For the purposes of this review, the classification scheme used by Pinquart and Sörensen (2006) was used because it sufficiently covers the spectrum of commonly used interventions. Reviews dedicated specifically to certain interventions, such as Mason et al's (2007) review on respite, identify in detail types of respite care that more broad reviews s do not elaborate on. Nonetheless, these interventions are discussed below under the following headings provided by Pinquart and Sörensen (2006):

**Table 8: Definition of Intervention Categories**

| Intervention | **Definition (Pinquart & Sörensen, 2006):** |
|---|---|
| **Psychoeducational** | Interventions of this type primarily provide information on dementia and caregiving related issues. The defining characteristic is the educational component, so even though support groups may be included in this group, the primary objective of the groups is educational not necessarily supportive. |
| **Cognitive Behaviour Therapy** | Interventions using CBT aim to identify and modify beliefs and behaviours to better deal with the demands of providing care and/or enhance subjective well being. |
| **Counseling/Case Management** | The goal is to resolve pre-existing personal problems that complicate caregiving, to reduce conflicts between caregivers and CRs, and/or to improve family functioning. Providing direction to CG on how to navigate and connect to systems/services is part of this category. |
| **General Support** | Interventions that are less structured than psychoeducational and therapeutic interventions, such as support groups, where CG can share personal feelings and concerns. |
| **Respite** | This is a planned, temporary relief for the caregiver through the provision of substitute care. Respite may be delivered as a center-based daycare program that offers congregate care for a certain number of weekly hours, in-home respite, and institutional respite |
| **Training of Care Recipient** | Because physical and cognitive decline and behavior problems of the CR are associated with caregiver burden and depression memory clinics and programs aimed at improving competence of the CR may also have a positive effect on |

| | |
|---|---|
| | caregiver outcomes |
| **Multicomponent** | Some studies combine different forms of interventions, such as education, support and respite |

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# VII - Issues in Ongoing Case Management

## Introduction

This section is designed to:

- Provide an overview of common issues that may arise between: caregivers and care recipients, and between service providers and caregivers,
- Highlight the possible tensions these issues can create for service providers,
- Provide awareness, assessment tools, and best practices that you can use to address and resolve these issues.

The goal of this section is to facilitate your ability to engage in:

- *Problem identification* - Identify potential sources of tension between caregivers and care recipients, and between caregivers and service providers,
- *Problem clarification* – Use the assessment tools to gather information as to the impact of the issue,
- *Problem resolution* – Problem solve through exploring the resources and tips included in this section that provide innovate examples of how to work collaboratively to develop and sustain caregiver resiliency.

It can be difficult to recognize that caregivers can require an equal amount of attention and support as the care recipient. Even if you are aware of their needs, you most likely have a limited amount of time, a heavy workload, relatively few resources, and daily disruptions that make it challenging to provide appropriate care to your clients, much less their caregivers. In this sense caregivers can feel marginalized and abused by the very policies, programs and services that are meant to help reduce the negative impacts of caregiving. As a service provider, you must navigate these systemic impediments while understanding that caregivers may be providing care within complex interpersonal dynamics, struggling with a range of transitions and crises, be experiencing challenging emotions, and facing multiple legal and ethical issues.

Little attention has been paid to the relationship between paid formal caregivers and informal caregivers. Existing research identifies that the relationship is a dynamic process that changes over time, and can include some tensions. Service providers can have ambiguous feelings that informal caregivers are both the problem and the solution to the care of ill family members or friends. Caring work is *relational work*, and requires that those who provide professional caregiving services look at both their own, and informal caregivers', assumptions, role expectations and responsibilities, as well as how negotiations between the two types of caregivers take place (Ward-Griffin and

McKeever, 2000: 93). Without a shared perspective between service providers and caregivers, issues can become entrenched and irresolvable, to the detriment of all involved and unintentionally increasing caregiver burden and distress.

Given that relatively few services are available for caregivers, including them in your circle of care may seem overwhelming. Yet if we ignore their needs, the results can be disastrous for the care recipient, the caregiver, service providers, larger systems of support, and society at large. What this section provides are easy to use tips and resources to support caregivers that can be integrated into your daily routines. This section is designed to:

- Provide an overview of common issues that may arise between: caregivers and care recipients, and between service providers and caregivers,
- Highlight the possible tensions these issues can create for service providers,
- Provide education, assessment tools, and helpful tips on other resources that you can use to address and resolve these issues. The goal of this section is to facilitate your ability to engage in:

*Problem identification*

- Identify general challenges facing caregivers
- Identify potential sources of tension between caregivers and care recipients
- Identify potential sources of tension between caregivers and service providers
- Identify potential sources of practice tensions for service providers

*"We often don't know what kinds of questions to ask; others have a hard time asking".*

- *Caregiver*

*"There's a lack of understanding of what's coming, and people don't – or can't – plan. This leads to crisis points where all that's left is the emergency room. But on the other hand, sometimes that's the only way to get the care recipient on a waiting list for long-term care".*

- Policy analyst

*"The truth is that different service providers can have different interpretations of policy or service".*

- Service provider

*"Frail elderly caregiver spouses often too tired or stressed to actually 'access the system'…in our region, seniors must call a 1.800 number, work through a series of "press this number" on the phone to eventually talk to someone…then must fill out forms that arrive in mail BEFORE their file or case gets any attention. Many don't or can't call number and need help filling out the forms"*

- Policy analyst

*Problem clarification* and *resolution*

- If indicated, use the assessment tools to gather information as to the impact of the issue.
- Problem solve through exploring the resources and tips that provide innovate examples of how to work collaboratively to develop and sustain caregiver resiliency.

Throughout this section you will see quotes from caregivers, service providers, policy analysts and others involved in caregiving. These were taken from the over 300 people we talked with across Canada.

## Issues that can arise between caregivers and care receivers

Issues between caregivers and care receivers can cause a great deal of stress for service providers. Service providers can mistakenly assume that the expectations, values and goals of caregivers and care recipients are always in alignment. Service providers need to be aware that caregivers experiencing family conflict have significantly higher perceived burden and poorer mental health than caregivers without conflict. Service providers can only provide relevant services through understanding, respecting and anticipating the potential for differences between caregivers and care recipients. Effective partnerships between formal and informal caregivers depend on understanding diverse family perspectives such as the following.

1. **Caregivers and care recipients may not agree on service options or most appropriate plan of care**

*"My mother is hostile to me; she's very angry about being sick – and she's been aggressive to me her whole life. I get it all day long. And there's no help; she won't go to respite because she says she doesn't need it, and the service providers don't see the need because they're rarely around".*

- Caregiver

*"Service providers often don't see the level of help required because all they see is that the work is done (i.e. clean house, clean client) and not the amount of work that goes into it – they think the caregiver doesn't need help".*

- Caregiver

*"There's a conflict between my personal plans and the burden of responsibility. It's hard because I don't know about my own boundaries, or have the time/resources to explore my own self and identity".*

- Caregiver

Caregivers and care recipients may have different desires and goals when it comes to the provision of care. This may hold particularly true for care recipients who are do not want to transfer to long-term care or increase home-based services due to fear, or unrealistic expectations of what the caregiver can provide. Alternatively, caregivers may have a difficult time agreeing with care decisions made by the person they are caring for, even when they feel they have to respect the choice.

Tensions for service providers: You may be asked, by either the caregiver or the care recipient, to take sides. You may feel that you want, or need, to side with either the caregiver or the care recipient. Alternatively, you may avoid important topics of conversation relevant to care in an attempt to minimize conflict.

### 2. Family dynamics

Family dynamics are one of the most commonly reported sources of tension between caregivers and service providers. Family dynamics can be a significant reason that caregivers do not reach out for help. Common issues include:

- Family members may not agree with each other about who should provide care, how care should be provided, or what roles and responsibilities are reasonable to expect from caregivers.
- The primary caregiver may feel resentment or anger in having to provide the majority, or all, of care.
- The caregiver and the care recipient may have a long history of personal conflict, including abuse.
- Gender assumptions, where female family members are "naturally" expected to provide the majority of care due to their gender.

*"There's a generation gap between caregivers and care recipients – they don't know how to ask questions, or do research – they don't want to be a pain, but then this means that it's all the responsibility of the caregiver".*

- Caregiver

*"My parents don't want to talk about their needs because they see it as private so it's hard to know what's going on".*

- Caregiver

*"There are real generational issues between caregivers and care recipients: desires for privacy, shame, not wanting to be a burden, loss of identity and changes of role. These are hard both for the caregiver and the care recipient, and they impact the ability to provide care".*

- Service Provider

- Caregiving can fundamentally change the relationship between husbands and wives, children and parents.

Tension for service providers: Your ability to provide the best possible care may be compromised due to family dynamics. For example, you may be challenged to set appropriate boundaries when there is more than one family member in the home and differences of opinion exist. You may find the caregiver or the care recipient discusses certain aspects of family history you are uncomfortable hearing. Service providers across Canada reported that family dynamics caused difficulties in communication, decision making, and assessment of both care recipient and caregivers.

*"Family relationships can be a barrier to caregivers reaching out; sometimes the caregiver is asking for help but the rest of the family is saying "no, we can do it" but that means really only the main caregiver. But families often don't see what's happening in the [care recipient's] home".*

- Caregiver

### 3. Role expectations between caregivers and care recipients

Providing and receiving care can be both extremely intimate and extremely isolating; because of this, caregivers and care recipients can struggle with defining appropriate boundaries. Caregivers may feel that care recipients should be able to do "more" for themselves, and experience increasing frustration as the care recipient declines. Watching the decline of a person can be painful, and caregivers may express this by not believe that the illness is 'real' or that it's only 'temporary'. Alternatively, the care recipient may feel that the caregiver should devote all of their energies to the care relationship.

*"There's a lack of socializing for me as a caregiver because I spend all my time with my father so I wind up doing nothing outside the house and I don't have any hobbies. Also he wants me to be around all the time and he makes me feel guilty if I want to do something on my own".*

- Caregiver

Tension for service providers: Service providers may find themselves in the middle of ongoing disputes about these expectations. You may be asked to support one side over the other. These concerns may create a less enjoyable work environment, impacting your ability to provide care. You may be challenged to provide appropriate services if needs are either masked or overstated.

### 4. Generational Issues

As children of the "Sandwich Generation" increasingly provide care to their parents, generational issues have become more pressing. For the older generation receiving care, desires for privacy, role changes, feelings of shame regarding illness and not wanting to be a burden may not be well understood or communicated to their children. For the generation providing care, they may feel frustrated by these "old-fashioned" values and beliefs. For example, many caregivers expressed exasperation that their parents insisted on continuing to see their GP rather than changing clinicians, even though the GP did not have knowledge or experience in the health concerns of the older adult. Caregivers of parents may feel an increased burden of care due to generational differences. While younger caregivers may feel more comfortable in discussing mental health issues, older caregivers may still feel a stigma in caring for someone who has mental health issues (including dementia), and/or feel that they should be able to do everything themselves without asking for help. Where younger caregivers can have unrealistic expectations of what the health care system can provide, older caregivers may not reach out for services due to lack of knowledge of what services are available.

Tensions for service providers: Similar to role expectations, family dynamics and differences in opinion regarding care options, generational issues can cause difficulties for service providers. For example, within medical settings, older caregivers may be "passive" in accepting advice and decisions where the younger caregiver may desire more information and communication. You may find that the older care recipient and the younger care provider offer different understandings of a situation, or in the need for services.

**Resources and Practical Tips for addressing issues between caregivers and care recipients:**

1. Do not assume facts about a situation or relationship without talking with the caregiver.
2. Be aware of language – not everyone identifies with the terms “loved one” in talking about the care recipient.
3. Be prepared that not all family members, caregivers and care recipients may have the same understanding or desires regarding care.
4. Be self-aware. You may yourself be an informal caregiver, and be triggered by family dynamics that resemble your own.
5. Assess – Use the appropriate assessment at the back of this Guide to identify level of impact on caregiver. Offer appropriate resources based on assessment.
6. Educate – Provide the caregiver with information from the links below.
7. Accept– Realize that you cannot always resolve long-standing or complex issues.

Alzheimer Society of Canada. “What to expect brochure”. http://www.alzheimer.ca/en/We-can-help/Resources/~/media/Files/national/Core-lit-brochures/What_to_Expect_2012_e.ashx

Family Caregiver Alliance. “Caregiving and sibling relationships: challenges and opportunities”. http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=868

disability Navigator. “Resolving Conflicts Related to Caregiving**”.** http://www.virginianavigator.org/vn/DetailSN.aspx?contentId=650&.f=0

## Issues that can arise between caregivers and service providers

Many sources of potential conflict between caregivers and service providers are due to system issues. A system issue is one that stems from the complexities of our modern system of government with many layers of departments, organizational responsibility, and priorities. Examples of system issues are: time constraints, confidentiality requirements, and other aspects of service provision that can lead a lack of knowledge of what service providers can and cannot do. System issues are frustrating because caregivers and service providers both justifiably feel they have very little control over them. Across Canada, service providers discussed the realities of providing care in an environment of increased workloads, resource constraints, and funding cutbacks.

### 1. Time constraints

The lack of service providers' time was the most common issue highlighted by service providers and caregivers alike as a source of tension. Service providers in every field repeated their frustration with ongoing struggles for time to provide the fundamentals of care, much less having time to focus on caregivers. Time constraints also affect caregivers as they are increasingly required to provide comprehensive and complex care to a care recipient while balancing work and raising children. Many caregivers provide care willingly, yet they also report feeling invisible and taken for granted by a health care system that requires their labour, but not does value their time.

<u>Tensions for service providers:</u> Given a full work load, you may feel overwhelmed in having to include caregivers in your circle of care. Your time constraints can lead to tensions where caregivers may want and/or need extra time from you and you are not able to provide for these needs.

*"When you're running around [because you have so many clients], you can't build a relationship. And then people feel they are not important because you can't pay attention to them".*

- Registered nurse

*"For some caregivers, we service providers are the only people they see all day – and we're only there for 15 minutes".*

- Home care aid

*"As a palliative care provider, I have time that no one else has. I go and sit and talk and listen and dig and then go and find the resources. These patients are not asking for rocket science, but the social worker's load is so heavy that they haven't talked to them - they don't even know them."*

- Registered nurse

Your lack of time can further frustrate caregivers who may already be at “wit’s end” due to their own time constraints.

### 2. Confidentiality

Privacy is an important component of ethical care. As a service provider, you are legally bound to respect a client’s confidentiality. Yet confidentiality requirements can lead to a ‘bottlenecking’ where:

- Lack of knowledge between service providers renders a continuum of care impossible, creating caregiver distress
- Lack of information increases the difficulty for caregivers to know and plan long-term care placement or other caregiving concerns
- Caregivers, out of frustration, may persistently question all levels of service providers in a desire to access any possible pertinent information, even outside the purview of a specific service provider.

<u>Tensions for service providers</u>: Confidentiality requirements can cause serious problems for both caregivers and service providers, negatively impacting relationships and care planning. Service providers may be faced with a range of confidentiality concerns, including: lack of confidentiality standardization between service providers, mounting frustration from caregiver inquires, and family assumptions of ‘right’ to information regardless of relationship to care recipient.

### 3. Caregiver lack of systems knowledge

Another common source of tension centres on caregivers’ expectations regarding the health care system and individual service providers who work within it. Service providers across the country highlighted how caregivers’ lack of education about how local, regional and provincial services ‘work’ results in this tension. Caregivers agree, stating that they often don’t know what kinds of questions to ask or what kinds of information they need. Many recounted no information being shared, or relevant information being shared only once a crisis point had been reached, rather than in a preventative manner. This lack of knowledge extends to service providers as well, where caregivers can become frustrated by service provider’s ignorance of existing services and what they provide. Caregivers can be frustrated from lack of information about services, inconsistent information about services, and what to expect from service provision. Unrealistic or differing expectations centre on:

- Appropriate level of home, hospital or long-term care help required

- Uncertainty as to who is responsible for the primary care of the care recipient
- Uncertainty as to whom can deliver appropriate care
- What caregivers can reasonably expect from the caregiving role as the care recipient declines due to disease progression
- What supports for caregivers can be delivered by service providers

Tension for service providers: Unrealistic or differing expectations can create an environment where trust, cooperation and inclusion are compromised. Caregivers may feel that service providers are withholding services and that their needs are being minimized. Lack of knowledge can make caregivers fearful about leaving the care recipient with a service provider, thereby increasing difficulty in developing a relationship of trust. Service providers may feel their efforts are ignored, and that systemic constraints on their ability to provide care are interpreted as disinterest and/or negligence.

### 4. Other system issues

Time constraints, confidentiality issues and a lack of education of the health care system are not the only system issues affecting the resiliency of sustainable caregiving. Other issues that cause tensions between caregivers and service providers include:

- *The number and diversity of service providers:* Caregivers must deal with a staggering number of diverse service providers, many of whom do not share basic information with each other. This can be disrupting and stressful for both the caregiver and the care recipient.

- *Lack of privacy:* Caregivers welcome an array of service providers into their home and into their lives. In exchange they can lose a sense of privacy and ownership of space.

**Examples of system issues causing tension between caregivers and service providers**

The “First Bed Policy” (British Columbia and Ontario) stipulates that patients being discharged from hospital to long-term care must take the first bed available in a care facility, regardless of location.

Older spousal caregivers may need long-term care placement for themselves as well as for their spouse, yet face involuntary separation based on differing levels of care needs. Service providers report that couples are willing to live at risk rather than be separated, thereby ensuring a crisis.

Hospital discharge practices may not include the caregiver and their concerns in their planning. Service providers and caregivers alike report unsafe discharges without liaising with community services, pharmacies or family member(s).

- *Not being able to control timing of service provsion:* Service providers' work schedule may not be convenient for caregivers' needs. Further, service providers' schedules can frequently change, placing a burden of unpredictable care on to the caregiver.
- *Critera for services*: Some programs meant for respite and/or to ease the burden of caregiving can increase caregiver distress if care recpeients do not meet the critiera for program admission.

Tensions for service providers: System issues create multiple sources of tension between caregivers and service providers. As the 'face' of health care and other complex systems, service providers are in the frontline of caregiver frustration and lack of knowledge. In a work environment of increasing constraints on time and other resources, caregiver needs can be construed as demanding or unreasonable. As a service provider, you may be encouraged to be increasingly stringent with resources, or have no way to help caregivers in need, leading to ethical distress. Alternatively, as a way to mitigate distress, some caregivers may 'hide' behind a job description in order to avoid feelings of distress.

*"Because they are stressed out, and we don't have time to establish a relationship [with the caregiver], some caregivers want to 'micromanage' everything a service provider does, making it stressful for both parties".*

- Community health worker

*"The lack of regulation and knowledge between service providers is a source of stress for caregivers because they don't know what to expect day-to-day".*

- Health care educator

**Resources and Practical Tips in managing issues between service providers and caregivers:**

1. Be aware that your services can unintentionally cause caregiver burden and distress.
2. Be aware that your services may only be one of many that caregivers negotiate with.
3. Acknowledge the caregivers' critical role in supporting the care recipient.
4. Acknowledge the caregivers' frustration without discussing your own.
5. Be clear, and if needed repeat, what services you can and cannot provide.
6. Be clear about confidentiality requirements before any conversation starts.
7. Ask specific questions to evaluate caregiver knowledge of relevant service provision.
8. Assess – Use the appropriate assessment at the back of this Guide to identify level of impact on caregiver. Offer appropriate resources based on assessment.
9. Educate – Provide the caregiver with information from the links below. Access further provincial and federal resource information from the Caregiver website.

Caregivers Nova Scotia. "The Caregivers' Handbook".
http://women.gov.ns.ca/assets/files/Publications/Caregivershandbook.pdf

Manitoba Provincial Government. "A Guide for the Caregiver".
http://www.gov.mb.ca/shas/publications/caregiver.pdf

VON. "Caregiving Guide".
http://www.von.ca/en/caregiver-guide/healthinfo-family_caregiver.aspx?guide=1

## Systemic Tensions for Service Providers

Service providers may have to interact with many different organizations. In turn, each of these organizations is a complex system that has many administrative layers, personnel, and departments. At times, tensions can arise within or between systems about the purpose and objectives of their goals, and as the last section explored, these tensions can have an unintended negative impact on caregivers. The majority of service providers we consulted with expressed frustration with the lack of political will and leadership in "cutting through the red tape" in creating programs and policies specifically aimed to address caregiver needs. This relative lack of prioritization is evidenced as most provinces still do not have a strategic vision for caregivers. Other systemic tensions include:

1. **Caregivers' needs are not addressed in their own right**

Our society relies on caregivers to provide the bulk of daily care, yet their needs are not recognized or addressed separately from care recipients. Caregivers lack formal status within our society, or our health care systems. In turn, this affects quality of care and quality of life of the care recipient. Without recognition of caregivers' own support needs, not only is the ability to provide care is negatively impacted, but results in greater emotional, physical and financial strain for the caregiver. System resources such as assessment tools legitimize the right of caregivers to be heard, and assists service providers in finding ways to target immediate concerns and needs.

<u>Tensions for service providers</u>: Due to workload issues and resources constraints, service providers struggle to provide appropriate care to clients, much less caregivers. Relevant caregiver assessments can be challenging to find, and many assessments add substantially to an already overwhelming workload. Once assessed, follow-through and services to address caregivers' needs may

*"The 'political' side of providing services needs to be highlighted. The truth is that we don't put out some information because of budget issues; we don't want more people accessing the services. It's very controversial to say "I want to spend more money now to save the system later"".*

- Policy Analyst

*"There are no real goals in service provision about providing care to caregivers, so that leads us to a sticky place where staff are trying to work a balancing act between what they can provide and what they should provide".*

- Program Manager

*"Caregivers often just not on the radar for service providers – we don't even have enough time for the clients"*

- Community health worker

not be available, leading to feelings of frustration for both service providers and caregivers.

### 2. Acute Care Focus

The majority of organizations that service providers liaise with are health focused. Within the culture of health care systems, the dominant focus is on acute care interventions – disease management rather than prevention. Therefore, any attempts to provide resources to reduce caregiver burden are also acute care focused. This causes significant problems for service providers who attempt to provide preventive resources to sustain resilient caregivers. What many caregivers need are services for care recipients that focus on non-medical independent activities of daily living, allowing respite for themselves.

Tensions for service providers: Service providers can be constrained by the culture of the organizations they work within, and liaise with. You may recognize caregivers' needs and not be able to provide resources to meet these needs, even at the most basic level, leading to feelings of frustration and distress. As a service provider, you may question the efficacy of your work.

### 3. Lack of integration

The way we have organized our institutions means that many caregiver issues are seen to be the responsibility of one department, organization, or interest group. For example, dementia has been conceptualized as a "health" issue, and any resources to address dementia come from that perspective. This creates department, organizational and intellectual "silos" that function as a barrier to constructing creative inclusive solutions. Jurisdictional issues and thinking are made worse by geographic disparities between rural and urban centres with regional variation between availability of services. Systematic tensions generated from lack of integration include:

*"In our quest to professionalize services, we have lost focus on the unmet needs of people who don't need an MRI – they just need a ride to the store"*

- Policy analyst

*"The left hand never knows what the right hand is doing".*

- Program developer

*"With hospital discharge and follow-up with community care, it's often entirely up to caregiver to figure it out. So some caregivers are not filling out prescriptions because doctors not telling them why they are prescribed and we don't find out until it's too late".*

- Community health worker

- Inability to provide consistent support to caregivers through the care recipients' illness trajectory
- Fragmentation of relationship with caregivers between community, hospital, and long-term care
- Lack of knowledge of existing resources outside of service providers' field of expertise
- Significant delays between assessment and follow-up services and resources

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Tensions for service providers: Lack of integration can place significant burden on those working within care systems and organizations. Service providers often do not have the "insider" knowledge required to access resources and supports from different organizations and departments. You may feel overwhelmed by the administrative requirements of each department or organization, and not attempt to access potential resources to reduce caregiver burden. Alternatively, you may feel stress from requesting these services and not knowing if or when they may be available.

### 4. Under-resourced services

Nearly everyone we spoke with mentioned the need for further funding of services to address the needs of caregivers, particularly social supports. Although there are many well-intentioned individuals working within our care systems, the organizational culture ensures that focus is given to crisis intervention rather than prevention. In an era of funding cutbacks and resource constraints, programs and services that are not acute care focused face increased downsizing, thereby ensuring a continuation of a culture of crisis for caregivers. This places further stress on acute care programs and policies as the only source of help, overwhelming the ability of our care systems to effectively deal with medical crisis, much less basic needs.

Tensions for service providers: Service providers are in a unique position to directly see the impact of funding decisions on caregivers. However, they may often feel they do not have the administrative skills or political power to effect positive

*"Caregivers are leaving their loved ones in ER – I hear that every day. I try to say that the last place you want to leave your frail elderly demented parents is in ER, but they feel they have no other choice".*

- Administrator

*"We have a real dilemma when you look at the statistics of people accessing residential care; we know that a lot of people are going into it because of caregiver burnout rather than client health issues. It's the caregiver's needs that change, not the clients".*

- Program manager

*"The time waiting on a waitlist is awful – by the time there is placement the caregiver is way beyond burnout, yet the system is willing to have that happen in order to keep people out of care as long as possible. They say it's about aging at home, but no services to do it, and they expect caregivers to do it all, so it's about saving money".*

- Community health worker

change. This can lead to feelings of frustration, distress and even lead to disengagement and/or leaving their job. Service providers may work in an organization that struggles with funding, and have to direct significant energy on securing adequate financing, taking away from their ability to provide support to caregivers.

### 5. Tensions between service providers

All of these system issues can lead to tensions *between* service providers. Service organizations are forced to manage with fewer resources and supports, heavier workloads, and increased competition for funding dollars. This negatively affects the ability of service providers to be sustainable and resilient in their daily work, and increases the potential of service providers venting their frustrations on each other or other care organizations. In turn, this significantly affects the ability to provide resources and support to caregivers.

An additional concern that creates tensions between service providers is the lack of regional and national regulation for home support workers. While the overwhelming majority of home support workers are compassionate individuals educated in meeting the needs of their clients, the lack of standardization can create practice differences between various service providers and organizations, which in turn can negatively affect caregiver resiliency. Service providers can also have different understandings of how to best work within the system constraints and tensions they face every day, which can lead to multiple challenges for everyone involved.

<u>Tensions for service providers</u>: A culture of tension in the workplace can significantly decrease job satisfaction. If you do not feel supported by your organization and your peers, you may cope by “hiding” behind your job description rather than trying to address pressing issues with your clients and their caregivers that would substantially improve their quality of life. Alternatively, you may work far beyond a sustainable capacity in an attempt to personally solve some

*“Benchmarks of care shouldn’t be based on budget; rather there should be a service or philosophy of care. We’re going in the opposite direction of where we should be going”*

- Program manager

Service Provider #1: *“My days get longer and longer because I can’t leave a client in distress, in a total mess, or crying. So I often work a 12-hour day even though I’m only paid for 8-hours”.* Service Provider #2: “*But this can let people off the hook about what the real needs of this population are, because it becomes hidden by your extra work”.*

- Two service providers talking during a consultation of these system tensions. You may feel that some of your colleagues do not have the same work ethic as yourself, leading to further fragmentation of work relationships and feelings of trust.

**Resources and Practical Tips to address system issues:**

Be aware:

1. Recognize that your field of work, and your organization, may have a specific “culture” that can impact how you view caregivers, and how you are able to do your job.
2. Recognize that many of the challenges and tensions you face are not due to your clients, their caregivers, other service providers, or your ability to provide care.
3. Recognize that other service providers also face many of the same challenges, and may be feeling the same level of frustrations.

Be present:

4. One of the best things you can do to support caregivers is to listen. While you may not have a great deal of time, even five minutes of uninterrupted attention gives caregivers valuable space to talk about their concerns, and to feel heard, even if you do not have any solutions.

Be proactive:

5. Read through the links on the Caregiver Toolkit Website to see how other organizations have innovatively addressed system tensions. www.caregivertoolkit.ca

## Transitions, Crises, and Difficult Conversations

Caregivers commonly go through several transitions as the care recipient declines. There is no one “model” for how to best respond to transitions; caregivers may experience many challenging emotions, others very few. Some caregivers may find earlier transitions more challenging; others may find transitions later in the disease process more difficult to handle. There are four common transitions that many caregivers must face. The *first* transition occurs when the caregiver begins helping with instrumental activities of daily living (e.g. cooking, cleaning, and money management). The *second* transition occurs when the caregiver begins helping with activities of daily living (e.g. bathing, dressing, eating, going to the bathroom). The *third* transition occurs when the caregivers transfers the care recipient to hospital or long-term care. The *fourth* transition occurs when the care recipient dies. Transitions are difficult for caregivers in many ways, including role changes for both caregiver and care recipient, anticipatory grief, physical and emotional exhaustion, and negative emotions associated with caregiving. The ability to have even brief informative and compassionate conversations with caregivers about “what to expect” during transitions in the illness trajectory can significantly reduce caregiver distress. However, conversations with caregivers about transitions can be a daunting task. Adding to the above factors, transition conversations with caregivers can be made more difficult by:

- Caregiver concerns that the care recipient will be “taken away”
- Not wanting to hear “bad news”
- Care recipients refusing to accept they can no longer be cared for at home, making it difficult to plan for the future
- Service providers expert knowledge about care recipients’ decline (particularly in dementia) may be

*“Service providers don’t know that dementia is terrifying not only for the one who has it, but also for the one who is providing care. Because you’re losing the person, you don’t know how they’re going to be day-to-day”.*

- Caregiver

*“It’s hard for caregivers to talk to the people they are caring for at times because those people are scared about the changes, and don’t want to find out or know – so refuse help that in turn would decrease caregiver burden”.*

- Service provider
-

*“We need to find a way to make end-of-life care conversations empowering – so that the conversations are to help people make decisions for themselves instead of the system making them for you, or winding up in acute care with suffering and no hope”.*

- Policy analyst

questioned by caregivers because they are afraid or do not see the decline.

- Caregivers not wanting to “frighten” care recipients with these conversations.
- Care receivers may not want formal care (due to privacy, fear, abusive relationship, etc.) and expect caregiver to provide all care.
- Tensions between what caregiver wants and what care recipient wants, causing division for the service provider.
- Focus on the care recipient rather than the caregiver masks that they also experience transitions requiring support and resources

Taken together, these barriers to discussions with caregivers about transitions lead to a “culture of crisis”, where caregivers often only access services once a situation has become unmanageable. For caregivers, the lack of family support in conjunction with physical and psychological exhaustion facilitates crisis situations. Our care system also reproduces a culture of crisis through for caregivers by privileging acute care interventions over prevention. Crises also arise from lack of resources, caregivers not knowing what questions to ask, and/or not knowing what services are available. One way that service providers can alleviate this crisis culture is to engage in challenging conversations on these difficult topics. Below you will find a framework and tips for having difficult conversations.

- Most caregivers, if they are looking for help or advice are interested in how they can better improve the care recipients’ quality of life. Framing your conversation about possible resources to achieve this goal can also be an opening for discussions of help and support they may need for themselves.

**Examples of Difficult Conversations:**

- Changes in IADL (Independent Activities of Daily Living)
- Change in physical care needed for recipient
- Cognitive changes in care recipient
- Hospital discharge
- Respite and self-care for caregivers
- Transition to long-term care
- End-of-life care
- Family dynamics
- Elder abuse/caregiver abuse
- Difficult emotions including stress, anger, grief, and resentment

- Explain to caregivers how it is in their best interest to have service provision early to avoid burn out, rather than seeing it as a failure. Highlight that getting the help and support they need will make them better caregivers.

- Discuss confidentiality issues early in the relationship with all caregivers so there are no surprises.

- Caregivers may be experiencing conflict and/or challenging emotions. Do not take it personally if a caregiver expresses frustration, anger or apathy.
- Reassure caregivers that these emotions are appropriate to express, as long as they are done respectfully.

- Do not overwhelm them with detailed information. Be prepared to repeat information over several visits.

- Ask questions:
    - Ask caregivers if they understand what you are telling them. You can also ask them what their understanding of the information is.
    - Repeat and rephrase what they tell you. Ask if you got it right or if you are assuming certain things.
- Provide positive verbal feedback.

- Ask if they are interested in knowing about what to expect as the care recipient declines. Offer printed resources from your local organizations.

- Explain common transitions and crisis moments using resources from the Caregiver Toolkit website.

### 4 Steps to a Successful Outcome in Difficult Conversations

**1. Define Your Purpose.** Be direct in your conversation and let the other person know why you want to have a conversation. Phrase your purpose clearly and with compassion.

**2. Inquiry**. Cultivate an attitude of discovery and curiosity. Try to learn as much as possible about the person and their point of view. Try to let them talk until they are finished. Ask questions to clarify. If you are limited for time, tell the person to focus on one or two issues and/or agree upon a specific amount of time.

**3. Acknowledgement.** This means showing that you’ve heard and understood what the person has said. Repeat back to them what you think they have said. Use “I” phrases such as “I hear you saying…” or “I think you are telling me that…”

(Continued next page)

- Provide information on who to contact when they notice these changes.

Transitions into, out of, and within the caregiving role should be monitored for adverse health effects on the caregiver, with interventions tailored to the individual's location in the caregiving trajectory. Using the following assessment tools can help with that goal.

**4 Steps to a Successful Outcome in Difficult Conversations (continued)**

**4. Problem Solving.** Ask the person what they think the solution is. Ask how and if things could be done differently with existing resources. Acknowledge that the problem may not have an immediate solution. Do not promise any solutions you cannot provide or facilitate.

**Practical Resources for transitions, crises, and difficult conversations:**

Public Health Agency of Canada.
“Communicating with Seniors: Advice, Tips and Techniques”.
http://www5.mississauga.ca/rec&parks/websites/oaats/mental_health/docs/Communications_Seniors.pdf

Nova Scotia Mental Health Services.
“Communicating with the Adult Children of Elderly Patients”.
http://www.gov.ns.ca/health/mhs/pubs/Communicating-with-the-Adult-Children-of-Elderly-Patients.pdf

## Difficult Emotions in Caregiving

Caregiving can provide many positive emotions, both for those who are providing care, and for those who are receiving care. Caregivers report feelings of closeness, appreciation, love, and sense of purpose and meaning in being able to provide care. Yet caregiving can be stressful both emotionally and physically. Many caregivers also report struggling with difficult emotions, particularly as the care recipient's needs increase. Other factors such as family dynamics, age of the caregiver, finances, and type of illness can also negatively affect caregivers' ability to cope with difficult emotions. Some of these emotions are an inevitable part of the caring process. However, if unchecked, these emotions can lead to burnout, depression, abuse of care recipient, substance abuse, physical health problems, and/or premature placement of the care recipient.

Caregivers can be resistant to asking for help in dealing with difficult emotions. They may mistakenly believe that these emotions are a sign they are selfish, lack personal capacity, or are doing something wrong. They may feel that reaching out to others, much less service providers, is an indication of weakness or an invasion of their privacy. Caregivers may not be able to admit to themselves they are experiencing these emotions, or feel overwhelmed by them. All of these reasons can increase the inherent challenges for service providers in identifying and addressing the impact of these emotions.

The good news is that many of these negative effects can be avoided or attenuated with early intervention. That means ensuring that caregivers get evaluated and offered help, just as care recipients do.

<u>Tensions for Service Providers:</u>

Caregivers may direct their emotions at service providers, particularly regarding frustrations about desired levels of support. Service providers may have difficulties in not taking these emotions personally. Alternatively caregivers may

*"As a caregiver I put everybody else ahead of me and I get lost. I resent that nobody has come and said "help is out there".*

- Caregiver

*"There's the grief of losing the person, even when you feel relief".*

- Caregiver

*"It's the notion of sacrifice – you bring in all your own emotions to the caregiving process and you're not allowed to express them. And you're supposed to be able to support the [care receivers] even though there's nothing to support you".*

- Caregiver

*"It's hard when the person you care for who has dementia start having erratic behaviours, including shoplifting. And when I'm dealing with the aftermath of that, there's a stigma on me like I'm not doing a good enough job. I'm angry, and I'm frustrated, and there's no one to talk about it".*

- Caregiver

express unwillingness to discuss any difficult emotions or their potential impacts, making it challenging for service providers to provide appropriate services. Service providers may also experience difficult emotions stemming from their daily work including:

- Frustrations about workload, resource constraints, and other system issues
- Personal dislike of certain clients, caregivers and/or colleagues
- Their inability to “fix” all the problems they are faced with
- Moral distress and/or exhaustion from witnessing suffering
- Common unavoidable triggers (family dynamics, challenging behaviours, etc.)

Unchecked, these emotions can negatively impact the well-being of service providers, including: burnout, depression, substance abuse, and seeking out other forms of employment. These emotions can also impact your ability as a service provider to provide appropriate support. Caregivers experiencing difficult emotions who do not have support may become abuse to the care recipient, leading to legal and ethical issues for service providers, the topic of the next section.

Common emotions associated with caregiving:

Anger

- At care recipient
- At yourself
- At other family members
- At healthcare professionals
- At God

Denial

- Of the care recipients’ decline
- Of need to provide assistance
- Of the loss of relationship continuity

Fear

- Of own mortality
- Of the future
- Of the unknown
- For the care recipient

Other common emotions:

- Guilt
- Frustration
- Indecision
- Hopelessness
- Overwhelmed
- Regret
- Joy and Thankfulness

**Tips and resources for difficult emotions in caregiving:**

1. Acknowledge caregivers' emotions. There are times caregivers just want to be heard and validated. See the Toolkit section on "Difficult Conversations" for tips on how to acknowledge caregivers.
2. Educate. Provide a brochure or other short pieces of information on difficult emotions in caregiving , for example:

   "Reducing caregiver stress". Alzheimer's Society of Canada. A two-page brochure for caregivers outlining common stressors and how to cope effectively with caring for someone with dementia. http://www.alzheimer.ca/en/We-can-help/Resources/~/media/Files/national/Core-lit-brochures/reducing_caregiver_stress_2011_e.ashx

   "Dementia, Caregiving and Controlling Frustration". Family Caregiver Alliance. A printable webpage for caregivers outlining practical tips of how to deal with frustration. http://www.caregiver.org/caregiver/jsp/print_friendly.jsp?nodeid=891

3. Assess – Use the appropriate assessment at the back of this Guide to identify level of impact on caregiver. Offer appropriate resources based on assessment such as local respite information, local counselling and/or support group information to caregivers.
4. Acknowledge the impact of caregivers' emotions on you, but don't take it personally.
5. Acknowledge your own limitations to provide solutions.

## Legal and Ethical Issues

### 1. Power of Attorney

A Power of Attorney (POA) is a legal agreement that documents the right of someone to act on someone else's behalf. There are different types of Power of Attorney, including one that deals specifically with financial concerns and another type that focuses on personal concerns, such as housing and health care. A Power of Attorney can be made to start immediately, upon mental incapacity, or until mental incapacity. The caregivers you work with may have Power of Attorney for the care recipient, and may have to make difficult decisions about finances, placement into long-term care, and/or other potentially life-altering actions. While not everyone has a Power of Attorney document, they are becoming increasingly common and as a service provider you should have general knowledge of what the basic rights and responsibilities are for a POA. Common decisions made by those with POA include: banking transactions, real estate decisions, and health care decisions.

Power of Attorney documents can be exceptionally helpful under difficult circumstances. They document who is responsible for what decisions. Unfortunately, there are some people who misuse the rights associated with being a Power of Attorney.

Tensions for service providers: You may feel that the Power of Attorney is not acting in the best interests of the care recipient. There may be more than one person acting as a Power of Attorney, in different capacities, and you may not know the appropriate person to talk to about a specific issue. If there is more than one Power of Attorney, they may not agree with each other, and ask you as a service provider to take sides. The Power of Attorney may not feel comfortable, or have enough information to, make important decisions and ask for the service provider's opinion, putting you on the spot.

### 2. Abuse

*Emotional Abuse*

This is the most common type of abuse in the caregiving relationship. Emotional abuse is any actions or words that cause emotional pain or distress. Caregivers can be both participants to, and recipients of, of emotional abuse. This includes verbal outbursts, such as swearing, as well as the use of demeaning and humiliating comments directed at the caregiver or the care recipient. Persons from all economic, ethnic and social backgrounds can become victims of abuse. Common forms of emotional abuse include:

- Intimidation through yelling or threats
- Humiliation and ridicule
- Habitual blaming or scapegoating
- Isolating through cutting social contacts
- Ignoring or neglecting the person
- Manipulation of person through feelings of fear, guilt, or love.

Caregiver stress and isolation are reported as two of the main causes of elder abuse. Caregivers can become overwhelmed by the task of taking care of the senior, and have no supports to turn to, and express their frustration on the care recipient. In turn, caregivers can experience emotional abuse by care recipients. Common causes of emotional abuse towards caregivers include changing behaviours due to dementia and/or frustration at the disability or disease progression. Emotional abuse is particularly common where there are conflicted family dynamics. Caregivers can also experience emotional abuse by their family members who expect the individual to provide all of the care to the care recipient, regardless of desire or ability.

Tensions for service providers: As both caregivers and care recipients can be socially and geographically isolated, with brief and/or infrequent visits from service providers, emotional abuse can be difficult to identify. Caregivers and care recipients may be embarrassed or feel their privacy is invaded by reporting emotional abuse. They may also not understand they are engaging in these behaviour or state that the relationship has "always been this way". Service providers can also experience emotional abuse by caregivers and/or their care recipients. You may see a service provider emotionally abusing a caregiver or a care recipient by neglecting to see or act on basic care needs. You may not be

*"Service providers in care homes are often too busy to provide adequate care. And if your parent is quiet, then they often get overlooked – even if that's because they are quiet because they are so sick. Then you have to and bring it up with the nurses and then you are seen as a trouble maker, so you're worried to bring it up".*

*- Caregiver*

*"I wish I didn't have to [be a caregiver]. I don't want to, and I feel very resentful that I have to do it. I don't even like my father and I'm doing all the work. I'm winging it all by myself even though there are other family members – they have moved away. And it's frustrating, because they have money, and I don't".*

*- Caregiver*

able to provide the resources necessary to address emotional abuse, other than a punitive "reporting" procedure that, through criminalization, benefits neither the caregiver nor the care recipient.

*Financial Abuse*

This is a common type of abuse in the caregiving relationship. Caregivers can be both participants to, and recipients of, of financial abuse. Financial abuse perpetrated by caregivers of seniors is on the rise, including:

- Unauthorized use of seniors' bank account or sources of credit (credit cards, line of credit)
- Unauthorized use of pensions, other monthly incomes, or settlements (such as the Aboriginal School settlements given to First Nations' elders)
- Unauthorized sale or mortgaging of the seniors' home (or seniors agreeing only under pressure)
- Unauthorized sale of seniors' personal items (jewellery, vehicle, or other expensive items)

> *"When you are [labelled alternative level of care] in a hospital convalescing, it now costs $29 a day and many people don't have that but they need to wait for placement, so the caregiver then has to pay for it. And they can't come home because caregivers can no longer look after them. And many are in for many weeks. And if you don't pay it, the bill gets sent to a collection agency. Where is that money going to come from?"*
>
> - *British Columbia Caregiver*

Caregivers who engage in this form of financial abuse may feel justified through perceived need, a sense of entitlement, or feeling that the senior's money is "just sitting there".

Caregivers are often the ones who take on the significant financial burden in caring. Sometimes, despite the caregiver's best efforts, it is difficult to have the care recipient understand the expenses related to their illness or disability. When as senior has financial resources but refuses to contribute to their care, caregivers can also be subject to financial abuse. Financial abuse of caregivers can include:

- Demanding paid in-home assistance when it is not needed
- Spending monies on drugs or alcohol rather than necessary items of care
- Refusing to spend money on services in ways that would reduce caregiver burden

<u>Tensions for service providers:</u> Like emotional abuse, financial abuse may be hard to identify. Caregivers or care recipients may not wish to talk about the abuse, or feel that it is a natural part of the caregiving relationship. As a service provider you may be aware of the financial challenges of the caregiver, how system issues can worsen financial concerns, and yet be unable to provide resources that would decrease caregiver burden. If you suspect financial abuse, you may not be aware how to formally assess or report these concerns.

### *Physical Abuse*

Physical abuse is less common than emotional or financial abuse. Physical abuse is non-accidental use of force against another that results in physical pain, injury, or impairment. Caregivers can be both participants to, and recipients of, of physical abuse. In the caregiving relationship, abuse includes not only physical assaults such as hitting or shoving but also the inappropriate use of drugs, restraints, or confinement. The vast majority of caregivers attempt to provide competent, compassionate care. Yet caregivers can also physically abuse their care recipients. Caregivers can become overwhelmed with frustration at the level of the care recipient's needs, especially as they increase. Toxic family dynamics, other difficult emotions, isolation, and cultural norms are also factors that feed into the physical abuse of care recipients.

This is the least common type of abuse against caregivers, and generally occurs when the older care recipient suffers from some form of dementia. Especially in the later stages of dementia, due to medication and/or cognitive changes, the care recipient may engage in challenging physical behaviours such as slapping or kicking. Caregivers may not have the training or the ability to safely engage with the care recipient, and use abusive measures to try to control the situation or out of self-defence. However, some care recipients may consciously engage in the physical abuse of caregivers. This can be a continuation of

*"Calling people 'abusive' is all too often used as a way to deny care, when really it's about not having the services in place or about a misunderstanding, which is really hard for family members".*

- Caregiver

*"A husband can bring over his wife [from another country] but then he cuts her off from the family back home, and cuts off any source of income. Then he gets sick, and frustrated…the isolation makes abuse all the easier to get away with…and some people [in the community] think it is culturally acceptable".*

– Caregiver

*[Service providers] tell us that violence is a constant and ongoing part of working in Canadian facilities. The violence they experience is physical, verbal and sexual. Racism is also common. Almost all…have experienced some form of violence. And nearly half experience physical violence on a daily basis.*

Out of Control": Report on Violence in Long-Term Care a cycle of abuse, particularly when the care recipient is male.

Tensions for service providers: Caregivers may feel ashamed at perpetrating, or being recipients of, physical abuse. They may not want to discuss the topic, or seek help. Service providers may not report physical abuse they experience caring for others, due to feelings of uncertainty, embarrassment, or lack of knowledge of what constitutes physical abuse. Labelling a client as abusive can cause limitation or withdrawal of needed services, thereby adding to caregiver distress.

**Tips and Resources for engaging with abuse issues:**

1. Use the relevant caregiver assessment in this resource guide to identify the risk of abuse.
2. If you see abuse, or someone tells you they are being abused, listen carefully and reassure them that:
    - It is not their fault
    - They are not alone
    - Help is available
    - Label abuse behaviours and/or actions as abusive
    - Provide resources
    - Support their right to make their own decision
    - Respect their privacy/confidentiality
3. If help is refused:
    - Remind them that you are willing to provide assistance in the future if they wish
    - Maintain contact with the person
    - Provide referrals/resource as appropriate
4. If you are faced with an emergency or there is a threat of imminent harm call 911.
5. If you have been abused, report the incident to your supervisor.

### 3. Capacity, Competency and Decision-Making

Caregivers make many decisions as part of providing care. Some of these are relatively minor, such as what time of day to organize a doctor’s visit. Other decisions are more complex, particularly if the caregiver has Power Of Attorney. As a service provider working with caregivers, you may at some point have to either informally or formally assess a caregiver’s capacity to make decisions. Capacity and competency are often used to mean the same thing, but there is a difference. Capacity means an individual’s ability to make an informed decision. Competency is the legal term to define this capacity. It refers to a judge’s determination of an individual’s ability to make decisions, to understand the meaning and importance of legal documents. Competency includes:

- Ability to gather relevant knowledge required to make a decision
- Ability to generate and evaluate alternatives before making a decision or taking an action
- Ability to consider and evaluate the risks and rewards associated with each options
- Ability to have input from others (where appropriate)
- Ability to commit to a decision without reconsidering, unless information or circumstances makes it necessary to do so
- Ability to evaluate the effectiveness of decisions after they have been made

Competency also means that caregivers are able to provide care that meets the basic needs of the care recipient, as well as being able to take care of themselves. Service providers can support caregiver competency through validating their knowledge, experience, providing appropriate resources and information. Alternately, service providers can damage caregiver competency by ignoring or minimizing their experience and knowledge thereby eroding confidence. Caregiver competency requires a sustainable system of support, including provision of services and information.

<u>Tensions for Service Providers</u>: It may be difficult to know when assessment of competency is required. You may have access to few or no resources for supporting caregiver competency, challenging your ability to provide support. Due to workload and other resource constraints, you may not have the time to engage with caregivers on this topic until a crisis occurs. As a service provider, you yourself may have areas in your work life where you feel you lack competency. This lack of competency in turn can negatively impact the resiliency and competency of the caregiver.

### 4. Living at Risk

Caregivers are increasingly expected to provide care for people who are living longer with complex needs. This translates to more caregivers living at risk. Living at risk can means a situation where individuals are aware of the presence of danger which if not correctly or skilfully managed can result in harm, or even death. Caregiver risk includes physical and psychological aspects such as:

- Higher rates of injury through transfers of care recipient or other untrained heavy physical labour
- Higher rates of illness (such as diabetes, arthritis) due to exhaustion and stress
- Higher rates of death
- Higher prevalence of depression and anxiety
- Higher rates of alcohol and drug use
- Higher rates of physical and social isolation

Caregiving can be a major health risk, depending on the type of care being provided and by whom. Caregivers who are older, socially and/or geographically isolated, or who have financial concerns all live at higher risk than caregivers who have strong social and financial supports. Caregivers who are providing sole care for those with complex care needs, advanced dementia, and/or who are at end of life are also at higher risk for physical and psychological problems. System issues can also place caregivers at risk, including early discharge policies, lack of service integration, and long-term care placement policies.

Living at risk is a part of caregiving. While there is no one way to best way to minimize this risk, awareness of what the risks are and how they may affect the caregiver is an important aspect of providing ethical service provision. Helping caregivers analyze the risks and the benefits of providing care can substantially improve a caregiver’s ability not only to provide competent care, but also to validate their own health and wellbeing as important.

<u>Tensions for service providers:</u> You may have difficulty knowing when it is reasonable to have a conversation with a caregiver about their level of risk. Caregivers may not want to talk about their risks, feeling that they should be able to provide all aspects of care, until a crisis occurs. Caregivers may allow risk to increase in order to avoid having to talk with their care recipient about difficult topics. As a service provider, you may not have adequate resources to decrease caregiver’s risk, leading to feelings of frustration or distress.

## 5. Confidentiality

Confidentiality is ensuring that information is accessible only by those authorized to have access. In health care confidentiality is particularly important, and there are many systems in place to ensure that confidentiality is respected. Without confidentiality, care recipients may rightly fear that sensitive information is being shared inappropriately, at best embarrassing them and at worst putting them at risk.

However, as mentioned previously, these systems for respecting confidentiality can negatively impact caregivers' ability to provide care. This is particularly relevant for those caring for someone with a later stage dementia where they cannot provide competent input into their care. The caregivers, service providers, and policy analysts we spoke to repeatedly brought up the problems raised by confidentiality, including:

- The inability to plan for the future on a personal and/or professional level
- Uncertainty as to what to expect from the care recipient's disease progression
- Uncertainty as to what to expect from the caregiving role
- Lack of knowledge regarding medications, resources, and required follow-ups
- Inability to navigate the health care system

While it is vitally important to respect confidentiality, many institutions and service providers are unable to differentiate between patient or client confidentiality and information that can and should be shared with caregivers. Caregivers have the right to certain information in order to maintain their level of wellbeing and their personal safety. Providing the information necessary for ethical, competent caregiving will facilitate greater caregiver involvement and understanding of the care recipient's illness journey, as well as facilitating continuity of care.

*"Right now I'm not legally allowed to access information from another institution. On top of that, under the new Privacy Act I am not allowed to talk about any aspect of the care recipient until I get a signed affidavit from the care recipient. That makes my job very difficult".*

- *Social Worker*

- *Service Provider*

Service provider tensions: As a service provider, you have to negotiate a delicate balance between caregiver's needs and the potential for breach of confidentiality. There can be good reasons not to share certain information. Caregivers can use sensitive information in ways that do not benefit the care recipient. The care recipient may not want the caregiver to have specific information, even though it would benefit the caregiver. Caregivers may assume that they have a right to any and all information on the care recipient.  If there is more than one caregiver, there may be tension as to who is the appropriate person to share information with. As a service provider, you may not be able to access information that is necessary to provide ethical, competent care. There may be inconsistency between service providers' interpretation of confidentiality statutes and/or a lack of clear procedures governing interactions with caregivers and care recipients.

**Tips and Resources for engaging with POA, Competency, and Confidentiality Issues:**

1. Ask the caregiver if they have Power of Attorney, and if they understand the rights and responsibilities of their role.
2. Inform caregivers about services, programs and resources available to them regarding Power of Attorney, Capacity and Living at Risk issues listed in the resource section at the back of this guide.
3. Use the assessments at the back of this guide to inform your understanding of caregiver's capacity.
4. Use the assessments in this resource guide to inform your understanding of caregiver's level of living at risk.
5. Discuss confidentiality requirements as soon as possible after meeting the caregiver.

## Inclusion and Diversity

Caregivers are a diverse group, with diverse needs, desires and abilities. Understanding the diversity of caregivers so that they are not marginalized means being aware of how ethnicity, cultural heritage, faith, income, mental health, and sexual orientation can influence a person's experience as a caregiver. Caregivers' needs and appropriate solutions vary depending on their ethnicity, income, physical and mental health, culture, and gender – and where the care receiver is in their illness journey and/or type of illness. Diversity can become marginalization when these differences are not recognized, or worse, discriminated again. Many caregivers are marginalized for more than one reason. Service providers can marginalize caregivers due to:

- Lack of knowledge or bias of diverse ethno-cultural peoples, including: recent immigrants, First Nations, Métis, and Inuit communities, and Canadian Africans.
- Gender "invisibility", or the assumption that females naturally want to be caregivers, without examining the gender bias in our society.
- Ignoring or placing value judgements on caregivers who live on low incomes.
- Ignoring or placing value judgements on caregivers' mental health.
- Sexual orientation. GBLT caregivers may face unique (and unaddressed) issues from other caregivers, due to their sexual orientation.

Caregivers can be socially and economically marginalized due to their provision of care, including blame or stigma associated with some illnesses. Inclusion and diversity go hand in hand; acknowledging and valuing a range of cultures, genders, ethnicities, sexual orientations,

*"We need free services that connect us to the broader community that also has similar experiences, age and interests – that would help us out. It's not just about needing direct caregiver support. Give us information and programs through immigration services about healthy living so that we can be good caregivers and reduce the burden on the health care system".*

- *Recent immigrant caregiver*

*"For gay people in a hospital setting there is the issue of legitimacy. Same sex caregivers seem to be in a position of having to constantly prove their care relationships over and over again. If you have a care recipient who has dementia or a severe illness, they're not in a position to identify their own next of kin and you might have family members who climb in and claim that for themselves when they haven't been providing care".*

- *Social worker*

disabilities, capacities, interests, values, beliefs and opinions. To provide inclusive, ethical, and competent services to caregivers, basic knowledge of your caregiving population is essential. Cultural competence is the possession of knowledge and skills that enable providers to deliver culturally appropriate care and services. Otherwise, social exclusion results in economic, social, political and cultural disadvantage, adding to caregiver burden.

Tensions for service providers: You may not have the support you need to provide culturally competent services. You may not have the knowledge or experience necessary to provide culturally competent care, and your workplace may not provide resources to educate yourself. You may feel uncomfortable or judgemental of cultural differences. Those who have been marginalized by mainstream services may not trust or seek out services in times of need. Existing assessments and services may not be culturally relevant.

*"If you're the only woman in the room, service providers automatically assume that you're the caregiver – there needs to be an awareness of how gender expectations in society play out in everyday perceptions".*

*- Caregiver*

*"I come from a culturally diverse area – Aboriginals from Innu, Inuit, and Métis make up a portion of my region's population. Culturally there are many barriers still in this day and age that continue to plague people of my community to meet on common ground".*

*- Service provider*

**Resources for encouraging inclusion and diversity:**

**Cultural Competency Guide for Health Care Professionals. Nova Scotia Department of Health.**

The guide is divided into five self-contained sections, each applicable to different groups of professionals working in the primary health care system, including administrative staff as well as front line service providers.
http://www.healthteamnovascotia.ca/cultural_competence/Cultural_Competence_guide_for_Primary_Health_Care_Professionals.pdf

**Cultural Diversity and Caregiving. Family Caregiver Alliance.**

This audio seminar addresses diversity issues and caregiving and the cultural beliefs held by various groups about the care of older family members. It highlights caregiver support programs which have successfully implemented cultural outreach strategies and the lessons learned from these promising practices.
http://www.caregiver.org/jsp/content_node.jsp?nodeid=1880

## Stress and Self-Care

*"You have to know where to draw the boundaries as a service provider so you don't burn out because you're feeling guilty that you can't do it all". – Service Provider*

The chances are that you became involved in service provision because you are a compassionate individual. Working as a service provider can be extremely rewarding and inspiring, but these professions can also be stressful and draining. It is natural that when we bear witness to other people's suffering, it affects us. We must remain aware of this and pay particular attention to our own well-being. All too often, those dedicated to the care and treatment of others do so while neglecting themselves. Self-care is particularly important as it is difficult to assist and serve others if you are chronically stressed out, burned out, drained and/or overwhelmed. If unchecked, these can become chronic, leading to apathy, depression and ultimately, burnout.

### 1. Awareness

Being a resilient service provider requires that you are aware of yourself first and foremost. It is very difficult to provide appropriate care to others if you are not attuned to your own needs, limits, emotions and resources. Awareness also means practicing self-acceptance – you cannot solve every problem every time. Tips on improving awareness:

- Identify your abilities and weaknesses together, and build on them together rather than focusing only on weaknesses.
- Practice acceptance of inevitable stressors.
- Be aware of possible triggers by client's family dynamics that resemble your own.
- Perform regular check-ins with the H.A.T. questions: Am I feeling hungry? Am I feeling angry? Am I feeling tired?

### 2. Boundary setting

For some people, learning to say "no" is challenging, in part because service providers work to help others. Yet if you do not set limits, you can be consumed with demands on your time and energy. There is always a new need to be filled and new work to be done. Service providers can also draw inappropriate boundaries by doing too much unpaid labour. While well intentioned, these types of inappropriate boundaries hide the extent of the need for services for individuals, caregivers, and communities.

Frequently engaging in unpaid labour can also function in a negative way by making it expected of all services providers. Learning to set appropriate limits or to negotiate the boundaries of new responsibilities is vital to avoid burnout. Tips for setting boundaries:

- Never immediately say “yes” to a request if asked to take on additional work. Tell the person that you will get back to them once you have looked at your schedule/calendar. This will give you time to better understand how, and if, you can fit in this new work.
- Establish professional boundaries between you and people you work with (both colleagues and clients). Take responsibility only for your own work and stay out of other peoples’ business.
- Always stop at some point in your workday for the basics: food, water, stretching (if you are at a desk), and a moment away from your current project/responsibility. Doing so will not only give you a minute to breathe, but will also help you focus and serve others better.
- With those you provide services, try to remain aware of boundary “blurring” including: inappropriate self-disclosure, giving or receiving gifts, consistently going above and beyond your job description, and developing friendships.
- Understand that you cannot meet all of the needs of those you serve. Attempting to do so can cause boundary blurring, emotional and physical exhaustion, and cause significant ethical issues for other service providers.
- Realize that boundaries are flexible depending on the person and context. Think through how you can set boundaries during difficult times including: emergencies, challenging family dynamics, and transitions.
- Mark the boundary between work and private life with a small transition ritual (e.g. telling our colleagues your day is over, listening to a favourite piece of music, walking home from work, etc.)

### 3. Balance

For many service providers, having balance in their lives can be challenging. Work often requires great reserves of physical, emotional and cognitive energy, leaving little “left over” at the end of the day. Without balance between work, play and rest, you will not be able to sustain your physical or emotional health. Basic aspects of balance include: getting adequate sleep, engaging in relaxing activities (reading, taking a walk, visiting with family and friends), exercise, and eating well. Tips for achieving balance:

- If you are someone who has challenges in balancing your life, try focusing on one aspect of a balanced lifestyle for a week.
- Create a space every day where you are disconnected from your computer, your phone and other forms of communication. It doesn't have to be long – even 15 minutes will help you relax. Use that space for activities you enjoy.
- Do something at which you are not expert or in charge.

### 4. Consult and collaborate with other colleagues

Your colleagues are most likely the best suited to understand what you are going through. Maintaining supportive work relationships helps prevent isolation and can increase feelings of connection, validation, and shared understanding. If it is your work environment that is causing the stress, try to find one or two supportive colleagues to share your feelings with. Always remember that there is a difference between healthy venting and malicious gossip – while the latter may make you feel better in the short term, it contributes to a toxic workplace. Tips for collaboration:

- Understand that everyone you work with is a human being, with unique needs, experiences and motivations. Just because someone thinks or works in a different manner than you, that does not mean s/he is wrong or bad.
- Stay away from pessimists.
- Treat people well. If you are positive and supportive in your work relationships you will reap the rewards from others treating you in the same way whether they are clients or colleagues.
- Evaluate your work environment in terms of 6 key dimensions: work load, control, reward, sense of community, respect, and similar values. What is unsatisfactory and what can be done without adding substantially to your workload?
- Use humour. Not only does it help to lighten the mood, it can improve your physical well-being.

### 5. Professional resources and support

There are many reasons service providers do not seek out help, including but not limited to: always taking care of others before taking care of oneself, viewing unresolved stress as a sign of inadequacy or failure, feeling that you should be aware of all helping resources for all problems, that you should have the helping skills to take care of yourself, and the tendency to intellectualize and/or disassociate from the emotional impact of your work.

A sign of a resilient service provider is one who knows when to ask for help. If you find that you would like professional help but do not seek it out because of one or more of the above reasons, it's time to practice self-acceptance: you cannot solve every problem every time. Seek out professional help when you are:

- Experiencing high levels of distress
- Experiencing significant changes in relationships
- Not functioning well at work for increasing periods of time
- Self-medicating with alcohol, sleep or drugs
- Unable to find relief with self-help strategies
- Experiencing physical problems

Identify warning signs:

- Thinking that you are indispensible
- Negative thinking
- Extreme, exaggerated, or misplaced emotional reactions
- Getting away physically but not mentally
- Just “getting through” every day and/or neglecting responsibilities
- Agitation and loss of concentration
- Eating or sleeping too little, too much, or poorly
- Lack of energy, headaches, body aches, frequent/prolonged illnesses
- Developing or worsening bad habits
- Depression
- The neglect of family relationships
- Poor work relationships

(adapted from “Coping with caring”)

# IIX - PROVINCIAL AND FEDERAL ECONOMIC SECURITY POLICIES TO SUPPORT CAREGIVERS

## Federal

### Caregiver Tax Credit

Caregivers may be eligible for a credit if they maintained a dwelling where both they and a dependent lived at during any time in last year.

http://www.cra-arc.gc.ca/tx/ndvdls/tpcs/ncm-tx/rtrn/cmpltng/ddctns/lns300-350/315/menu-eng.html

### Compassionate Care Benefits

Employment Insurance Compassionate Care benefits are available to employed family members caring for a gravely ill relative at risk of dying within 26 weeks. These benefits are offered through Human Resources and Social Development Canada (HRSDC).

http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml

### Infirm dependant deduction

You may claim a deduction for each infirm relative dependent on you or your spouse**.** http://www.cra-arc.gc.ca/tx/ndvdls/tpcs/ncm-tx/rtrn/cmpltng/ddctns/lns300-350/306/menu-eng.html

### Personal disability credit

A person with a disability may claim a credit if a qualified professional certifies that: 1) A severe mental or physical impairment markedly restricted all, or almost all, of the person's basic activities of daily living during the year; and, 2) The impairment was prolonged, which means it lasted or is expected to last at least 12 months. Only doctors, optometrists, psychologists, occupational therapists, and audiologists are qualified to certify impairment.http://www.cra-arc.gc.ca/tx/ndvdls/sgmnts/dsblts/menu-eng.html

### Medical expenses credit

You may claim a credit for medical expenses that you or your spouse paid for yourself or your spouse, children, grandchildren, parents, grandparents, brothers, sisters, uncles, aunts, nieces, or nephews who depended on you for support.

http://www.cra-arc.gc.ca/tx/ndvdls/tpcs/ncm-tx/rtrn/cmpltng/ddctns/lns300-350/330/llwbl-eng.html

## Provincial

### Manitoba

Manitoba Primary Caregiver Tax Credit

Manitobans who act as the primary caregivers for family members or others are eligible for a refundable $1,020 tax credit ($1,275 starting in 2011).
http://www.manitoba.ca/finance/tao/caregiver.html

Manitoba Caregiver Recognition Act

The purposes of this Act are to: 1) increase recognition and awareness of caregivers; 2) acknowledge the valuable contribution they make to society; and 3) help guide the development of a framework for caregiver recognition and caregiver supports. http://web2.gov.mb.ca/bills/39-5/b042e.php

### Quebec

Quebec Respite Tax Credit

The maximum tax credit is $1560 per year. The credit equals 30% of the total expenses incurred during the year to obtain specialized respite services for the care and supervision of a person, up to $5200.
http://www.revenuquebec.ca/en/citoyen/credits/credits/credit_remb/repit/

### Nova Scotia

Nova Scotia Caregiver Benefit Program

The program is targeted at low income care recipients who have a high level of disability or impairment as determined by a home care assessment. If the caregiver and the care recipient both qualify for the program, the caregiver will receive the Caregiver Benefit of $400 per month.
http://www.gov.ns.ca/health/ccs/caregiver_benefit.asp

# IX - PROVINCIAL AND NATIONAL RESOURCE DIRECTORY

## Newfoundland and Labrador

**Caregivers Out of Isolation - Seniors Resource Centre of Newfoundland and Labrador**
This service offers a toll-free phone line for information and emotional support, referrals, resources, newsletter, access to caregiver networks around the province, and support groups.
Toll-free: 1-800-563-5599/Telephone: 1-709-737-2333
Website: www.seniorsresource.ca/caregivers/

**For Seniors – Department of Health and Community Services**
The government of Newfoundland and Labrador provides a comprehensive overview of provincial services and supports available to seniors including: information on health, financial and legal information including community support services focused on care.
Website: http://www.health.gov.nl.ca/health/seniors/index.html

**Seniors and the Law in Newfoundland and Labrador – Department of Health and Communication**
Topics included are wills, estate planning, Enduring Power of Attorney and Advanced Care Directives.
Website: http://www.health.gov.nl.ca/health/seniors/final_booklet.pdf

## Prince Edward Island

**Caregivers' Information – The Government of Prince Edward Island**
The government of PEI provides a comprehensive overview of provincial services and support available to caregivers.
Website: www.gov.pe.ca/infopei/index.php3?number=16214&lang=E

**Supports for Seniors – Department of Community Services, Seniors and Labour**
The government of PEI provides information on services and support designated to assist seniors. Topics include: health and wellness, home care and support, housing assistance, and financial and legal assistance.
Website: www.gov.pe.ca/sss/index.php3?number=1018612&lang=E

**Prince Edward Island Seniors' Guide – Seniors' Secretariat**
This extensive guide includes a section on legal and financial assistance section.
Website: https://www.gov.pe.ca/photos/original/Seniors_Guide09.pdf

## New Brunswick

**Seniors Guide to Services and Programs: Seniors and Healthy Aging Secretariat, Government of New Brunswick**
This site provides 50-page PDF document of community supports, services, and programs related to being, and caring for, an older adult. The site also provides a comprehensive booklet for caregivers on how to develop and implement a support plan, including: supports, caregiver roles, living accommodations, financial resources, power of attorney, services available in different communities, meal preparation, transportation needs and availability, and social activities.
Website: www.gnb.ca/0182/index-e.asp

**The Public Legal and Information Services of New Brunswick (PLEIS)**
This service provides provincial-specific planning ahead information, covering topics such as Wills, Estates Planning, and Managing Financial and Personal Affairs.
Website: http://www.legal-info-legale.nb.ca/en/planning_ahead

## Nova Scotia

**Caregivers Nova Scotia**
Caregivers Nova Scotia Association is dedicated to providing recognition and practical supports to friends and family giving care. Their mission is to ensure that the caregivers of Nova Scotia are recognized, valued and supported by using non-partisan, collaborative approaches to:

- raise public awareness of caregiver issues;
- influence public policy with respect to caregivers at the national and provincial levels;
- provide caregiver education and support;
- act as a clearinghouse of information on caregiving; and
- monitor demographic trends and their impact on caregivers.

Services for caregivers take many forms, including workshops, informative newsletters focused on caregiving issues, a book and video lending library, telephone caregiver assistance and community based peer support groups.
Toll free in Nova Scotia 1-877-488-7390/Telephone 1-902-421-7390
Website: www.caregiversns.org

**Personal Directives in Nova Scotia – Government of Nova Scotia**
This 2-page brochure provides information on the Personal Directives Act.
Website: http://www.gov.ns.ca/just/pda/_docs/Personal_Directive_4-panl_brochure.pdf

## Québec

**Caregiver Support Centre – Centre de santé de services sociaux Cavendish**
The Caregiver Support Centre responds to the needs of caregivers and provides support in their daily living. The Centre offers direct and easy access to services, a flexible and varied type of response, and encourages the active participation of caregivers in its operation, decision-making process and in a wide variety of activities. The Caregiver Support Centre is a ‘cutting-edge’ program composed of numerous direct services including a drop-in respite program for caregivers, an in-home stimulation program, information, education and support from volunteer peer counsellors, short-term counselling, and bilingual telephone service “Care-ring Voice”, for information, support and workshops.
Toll free: 1-866-396-2433/Telephone: 1-514-484-7878
Website: http://www.cssscavendish.qc.ca/en/care-and-services/caregiver-support-centre/

**Services for Caregivers - L’ Institut universitaire de gériatrie de Montréal**
This website lists 681 organizations, associations and institutions that provide support for caregivers in Quebec, Ontario, Manitoba and New Brunswick. Categories listed include information services, psychological support, training activities, support services and respite, social integration activities and care professional. The site is in French, although can be translated through Google.
Website: www.aidant.ca

**Planning Ahead – Government of Quebec**
Covers province-specific information about living wills and power of attorney.
Website: http://www.curateur.gouv.qc.ca/cura/en/majeur/client/prevoyant/index.html

## Ontario

**Guide to Programs and Services for Seniors in Ontario - Ontario Seniors' Secretariat**
A comprehensive guide providing information on the many programs and services that are available to Ontario's seniors. This Guide was developed by the Ontario Seniors' Secretariat with help from other provincial ministries, the federal government and many organizations that work on behalf of the interests and well-being of Ontario's seniors. Each entry in this guide includes a brief description about the organization and its services, and contact information. The Guide also includes a glossary, which helps to explain some of the terms and phrases about health, housing and legal issues.
Website: www.seniors.gov.on.ca/en/seniorsguide/introduction.php

The **Collaborative Seniors' Portal Network (CSPN)**
This is a national project that has produced a valuable online resource called Seniors' Info. The site is currently focused on Ontario but provides a list of legal resources in the Advance Care Planning, Wills and Estate and Other Legal Resources for Seniors sections.
Website: www.seniorsinfo.ca

**Power of Attorney and Living Wills – Office of the Public Guardian and Trustee**
This 21-page publication answers province-specific questions about Powers of Attorney, Living Wills and Public Guardians or Trustees. A Power of Attorney kit is also provided for downloading.
Website: http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/livingwillqa.pdf

## Nunavut

**The Home and Community Care (HCC) – Government of Nunavut**
This program helps Nunavummiut care for themselves with help from family and community members and to keep their sense of independence and well-being. The Home and Community Care program provides health care and support services, based on an assessment, in the comfort of an individual's home when he or she needs extra attention due to illness, poor health, or disability. The Home and Community Care program provides a variety of services, including homemaking, personal care, nursing care, respite care, and rehabilitation. For more information please contact the Territorial Home and Continuing Care Coordinator at (867) 975-5933

### Planning for Possible Loss of Independence & Managing and Protecting their Assets –Government of Nunavut

The Department of Health and Social Services helps to educate about making future financial and health decisions through 2 informative, plain-language brochures designed for caregivers.
Website:
http://www.gov.ns.ca/seniors/pub/financialplanningprotection/hrsdc_seniorsbrochure_en-04_final.pdf
http://www.gov.ns.ca/seniors/pub/financialplanningprotection/hrsdc_seniorsbrochure_en-03_final.pdf

## Manitoba

### Seniors and Health Aging – Government of Manitoba

This website provides a central source of information and referral for seniors and their families, seniors' organizations and government departments. Organized through geographically diverse 'resource councils', particular emphasis is given to support services and housing for seniors.
Website: www.gov.mb.ca/shas/resourcesforseniors/index.html

*See also "Services for Seniors" in the Quebec section*

### A Legal Information Guide for Seniors – Government of Manitoba

This comprehensive document includes provincial-specific sections on Wills and Estates, Power of Attorney, and Health Care Directives.
http://www.gov.mb.ca/shas/publications/guide_for_seniors.pdf

## Saskatchewan

### Directory of Services and Social Activities for Older Adults

The Saskatoon Health Region, Saskatoon Council on Aging and the University of Saskatchewan, College of Kinesiology has published a Directory of Services and Social Activities for Older Adults. The Directory is designed to offer information about resources, services and social activities to be used by older adults in the Saskatoon area, their families and caregivers, as well as interested agencies, groups and institutions.
Website: www.saskatooncaregiver.ca/directory.html

**Caregiver Information and Support, Saskatoon Council on Aging**
The Council has two main functions: operating a Resource Walk-in Centre to enhance the quality of life for older adults, and working with local agencies to initiate, implement, and evaluate projects useful to older adults in our community. The Resource Centre is also home to the Caregiver Information and Support (Formerly known as Caregiver Information Centre) which provides assistance to caregivers and others who are looking for information or services. Services include advocacy, social programs, education, drop-in programs, computer lessons, a resource centre, and special needs transportation.
Website: www.scoa.ca

**The Public Legal Association of Saskatchewan (PLEA)**
This website has three relevant sections in their Legal Resource listing under "Older Adults", for those who want reading material. The Life after 60 section contains details about getting legal advice and making decisions for the future, such as guardianship. The Older Adults and the Law section contains information on the various types of Powers of Attorney, Health Care Directives, Guardianship and making these appointments. Abuse of Older Adults describes the types of possible abuse and lists numerous contacts for reporting abuse, at the bottom of the section.
Website:
http://www.plea.org/legal_resources/search/view/?start=0&limit=5&cat=23&pcat=4

## Alberta

**Alberta Caregivers Association**
The Alberta Caregivers Association (ACGA) is the province's only grassroots organization exclusively dedicated to helping caregivers maintain their own well-being. They are an organization of caregivers for caregivers that helps them maintain their own well-being over the caregiving journey. They offer information, education, support, networking, advocacy, and community development to make caregivers' lives less difficult.
Telephone: Tel: (780) or (877) 453-5088
Website: www.albertacaregiversassociation.org

**Seniors and Community Supports – Government of Alberta**
A comprehensive overview of the services and supports that are available to Alberta's seniors, including information on financial concerns, health, continuing care, and protection.
Website: www.seniors.gov.ab.ca

**Making Life Decisions – Government of Alberta**
This website provides information about wills, personal directives (often called living wills), guardianship and trusteeship.
Website: http://www.services.gov.ab.ca/Living/13767.aspx?Ns=13705+13707&N=770

## British Columbia

**Family Caregivers Network Society**
Some of the products and services that the Family Caregivers Network Society provides to family caregivers and the community are:

- Family caregiver support groups
- Telephone or in-person caregiver support
- Information and referral to community resources
- Assistance in navigating the healthcare system
- Educational workshops
- Resource library
- Resource Guide for Family Caregivers
- Lunch and Learns sessions for employees

Toll-free line within BC: 1-877-520-3267/Telephone: 250-384-0408
Website: www.fcns-caregiving.org

**BC211 (Formerly Information Services Vancouver)**
Information Services Vancouver is British Columbia's largest provider of information and referral services. The "Red Book Online" provides detailed descriptions of over 5,600 community, social, and government agencies across the province.
Telephone: 1-604-875-6431
Website: www.bc211.ca

**Seniors BC – Government of British Columbia**
SeniorsBC.ca is a new website that provides information about government programs and services for older adults. Included on the website are sections on health care, finances, benefits, housing, transportation and more. Users can find answers to timely questions in the “Frequently Asked Questions” section. Resources such as the BC Seniors’ Guide and Healthy Eating for Seniors handbook can be found in PDF format on the website.
Website: www.seniorsbc.ca

**People’s Law School**

The People’s Law School is a non-profit society that provides free and impartial legal information in plain language. Available resources include many useful publications, such as Writing Your Will, Power of Attorney, and Being an Executor. The People’s Law School makes a special effort to serve seniors and others with distinct needs. The People’s Law school does not provide legal advice directly to individuals, but may refer them to other sources of assistance.
Website: http://www.publiclegaled.bc.ca/

## Northwest Territories

**NWT Seniors Society**

This service is provided to inform seniors and elders about programs and services which can be of assistance to them. The service is also available to help seniors and elders who are having difficulty accessing the programs if for some reason they are unable to get the assistance they need. The Seniors’ Information Line is a single point of entry for seniors and elders across the NWT. The service is provided through telephone access which is located in the Yellowknife office. The website also provides the Seniors’ Information Handbook, a convenient resource and contains a comprehensive source of information about programs and services available in the NWT.
Toll-free: 1-800-661-0878/Telephone: 920-7444
Website: www.nwtseniorssociety.ca

**Controlling Your Financial Future – Public Trustee for the Northwest Territories**

The Department of Justice provides an educational Power of Attorney document entitled Controlling Your Financial Future, for those who want to choose someone to oversee their financial decisions during their lifetime, if they become incapable.
Website: http://www.justice.gov.nt.ca/pdf/PublicTrustee/making_pa.pdf

## Yukon

**Services for Seniors – Government of Yukon**

A comprehensive overview of the services and supports that are available to seniors in the Yukon, including information on advance directives, community health centres, continuing care, health, housing, benefits, residential care, abuse, and housing.
Website: www.gov.yk.ca/services/people_seniors.html

## National

**Canadian Caregiver Coalition**

The Canadian Caregiver Coalition is the national voice for the needs and interests of family caregivers. They are a bilingual, not-for-profit organization made up of caregivers, caregiver support groups, national stakeholder organizations and researchers. The Coalition acts as a clearinghouse for a range of educational and developmental tools and resources from many sources. They provide links to practical tools and information, including:

- Resources developed by innovative community education and support programs across the country
- Reviews of existing educational tools and resources and how to access to them
- Library resources (books and videos) specific to caregiving
- Informational brochures
- Other resources for developing caregiver supports

Website: www.ccc-ccan.ca

**Alzheimer's Society**

The Society consists of a national office, 10 provincial organizations and more than 140 local groups across the country. The Alzheimer Society provides both support, information and education to people with Alzheimer's disease and related dementias, families, physicians and health-care providers. They also have a range of electronic resources for caregivers and service providers.
Toll-free: 1-800-616-8816/Telephone: (416)488-8772
Website: www.alzheimer.ca

**Caregiver Connect – VON**

This website offers a wide range of information for caregivers. Information is offered on caregiving for specific health conditions, a range of caregiver tools, and an excellent directory of provincial and national caregiver resources.
Website: http://www.von.ca/en/caregiver-connect/home/default.aspx

**The Canadian Centre for Elder Law (CCEL)**

The CCEL is a non-profit organization committed to helping older adults in their relationship with the law and to provide research and education on legal issues of significance to older adults.
Website: http://www.bcli.org/ccel

# X - GLOSSARY OF TERMS

**Caregiver**

“Caregivers”, also referred to as “informal caregivers”, “primary caregivers” and “carers” are defined as family members and friends who care for someone with whom they have a relationship, typically without pay. It is important to note that although these terms are used by health and social service systems family and friends who provide care to seniors may or may not identify themselves as caregivers.

**Service Provider**

A service provider is an individual or an institution that provides services for caregivers and/or (more commonly) care recipients. Service provision usually includes social, preventive, curative, promotional, or rehabilitative care in a systematic way. Service providers include health care professionals (such as doctors, nurses, therapists, and pharmacists) allied health professionals (such as social workers, case managers and home care workers), and administrators (working in long-term care, hospitals, clinics, social agencies, or home care agencies). Service providers work in both the public and private sector.