



Caregiver Consultation 2010: Towards a Provincial Caregiver Strategy

**Preliminary Report on Results from Survey
of Caregivers, Professionals, and Service Providers**

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About the Alberta Caregivers Association (ACGA)

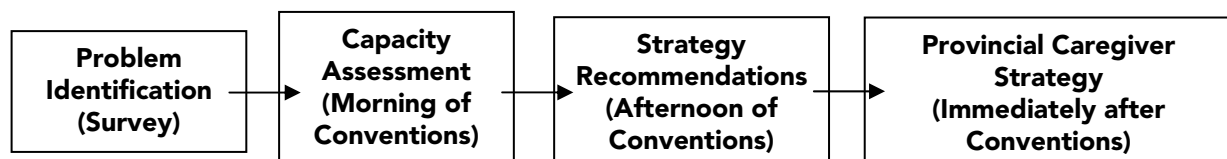
The ACGA defines a caregiver as “a family member or friend who provides care for someone living with challenges due to disability, illness, or age”. We provide information, education, support, networking, and advocacy to further our mission, namely to empower and promote the well-being of caregivers in Alberta. We pride ourselves on being *an organization of caregivers for caregivers*: we are to-date the only organization in Alberta that is exclusively geared towards protecting the well-being of caregivers. The ACGA employs a community development approach in all aspects of its work. This is evident in the use of participatory approaches to understanding issues relevant to caregivers and positive collaboration with stakeholders like public policy makers and professionals in addressing systemic issues.

Background to the Consultation Process

Caregivers, those who care for a family member or friend living with challenges owing to illness, disability or old age, are an essential part of our social and health systems. They provide between 80% and 90% of the care required by persons with long-term conditions, saving our health system billions of dollars each year. Their caregiving role can be stressful, isolating, and have a negative impact on their physical, mental, and financial health. And yet, caregivers are often invisible: they receive little recognition and largely insufficient support in their critical role.

The ACGA is leading a consultation process to create the first community-driven, comprehensive provincial caregiver strategy in Canada. We are supported by our Consultation Committee which includes representatives from academic institutions, disability-serving organizations, professionals, and caregivers. This is not a government-funded activity; instead, it is being resourced primarily from the ACGA’s own funds, donations, small grants, and delegate fees in order to ensure an independent process. We are entirely dependent on the support of stakeholders to recruit participants, including allied health professionals, representatives from service providing agencies, and caregivers from urban and rural areas.

The strategy will highlight the issues that caregivers face everyday, and identify tangible solutions and supports that government, service providers and community agencies can develop and implement to better serve the needs of Alberta’s caregivers. The overall process, which includes a survey over the summer and two conventions in October, is comprised of four parts:



Background to the Survey

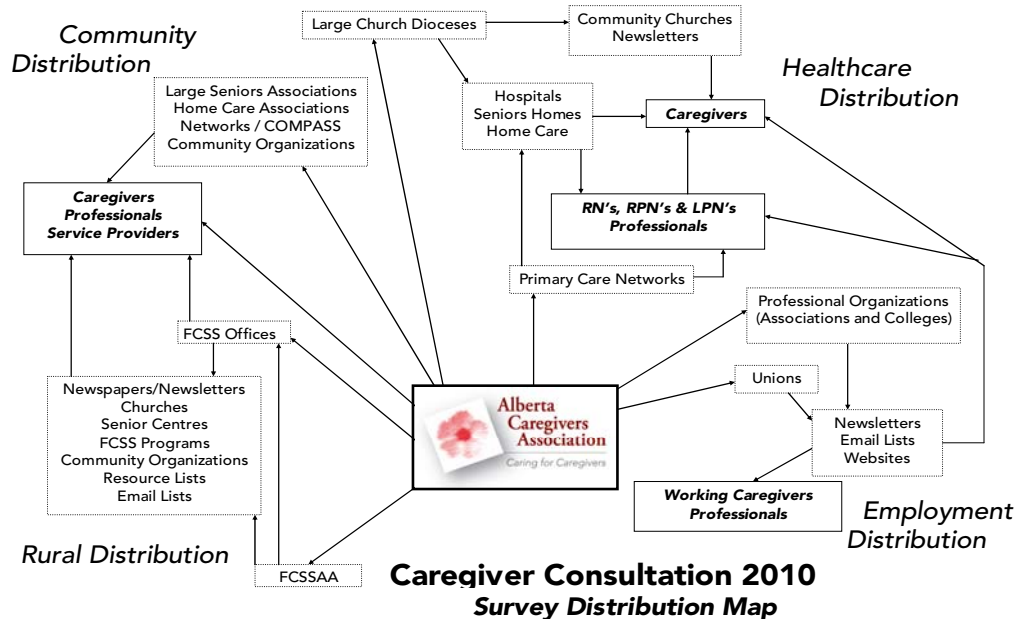
The first step in the consultation process is to identify the challenges that Alberta's caregivers face. A survey was developed in consultation with our committee members, focusing on eight domains adapted from the discussion themes from the National Conference on Caregiving held in Ottawa in 2005:

- Personal and Interpersonal Factors
- Awareness and Recognition of the Caregiver Role
- Economic Security
- Employment and Workplace Supports
- Information on Programs, Services, & Resources
- System Navigation
- Respite Supports
- Community-based Supports

The survey captured the experiences of caregivers by soliciting comments and recollections from caregivers and those with second-hand knowledge (e.g. service providers) regarding challenges, barriers, and other problems.

Survey Promotion

Due to the very small budget available for this consultation, the survey was promoted through key gatekeepers identified by the ACGA, including service providers, primary care, unions, employers, professional colleges, and others. The diagram below illustrates the reach of the survey using this approach.



Data Collection and Analysis

Survey responses were collected using Survey Monkey. Those individuals who did not want to use the online survey were given the option of completing the survey over the phone. Participants were asked if they were responding as caregivers or service providers. A group of caregivers (e.g. a support group) could also submit a joint submission. For each of the eight domains listed above, a comment box was provided so that respondents could offer their personal insights. In many cases, responses contained poignant, first-hand accounts of problems experienced by caregivers or witnessed by service providers in contact with them. After two months and almost 200 completed surveys (many more were only partially completed), comment box data was collected for the purpose of analysis.

Analysis of survey responses was conducted separately for service providers and caregivers using adapted qualitative methods. Synthesis (combining results) performed at the end. Saturation (the point when no new ideas or comments are discovered) was reached approximately half-way through coding and categorization of the data; the remainder of the surveys were reviewed nonetheless so as to ensure that no new themes or substantial evidence was missed.

Preliminary Themes Emerging from the Survey

- Impact of Caregiver Role on Relationships with Family and Friends
- Balancing Caregiver Role and Other Life Roles
- Impact of Caregiver Role on Health and Well-Being
- Enhancing Awareness and Recognition of Caregivers in All Sectors
- Caregiver Perspectives on their Own Role
- Financial Costs of Caregiving
- Financial Insecurity of Caregivers
- Difficulties with Accessing Financial Assistance
- Impact on Work Productivity, Education Goals, and Career Trajectories
- Inconsistency and Uncertainty of Workplace Support
- Communication with Health Professionals
- Treatment of Caregiver by Health Professionals
- Availability of Information for Supports, Services, and Resources
- Privacy Protection and Communication of Necessary Information
- Difficulty Finding and Accessing Services in a Fragmented System
- Quality of Care Services in Institutions and the Home
- Unavailability of Respite Care When Needed
- Role of Family and Friends in Respite for Caregivers
- Availability of Community-Based Supports
- Disparity between Urban and Rural Settings

Domain 1: Personal and Interpersonal Factors

Description of Domain

- Physical, mental, or emotional health
- Relationship with care recipient
- Relationship with spouse and/or children
- Relationships with family members or friends
- Participation in social and community activities

“It affects every aspect of your life. Bottom Line: We need to find a way to find quality of life again and minimize the tremendous stress. One can run themselves down very quickly when the need to purchase groceries conflicts with the caregiver’s role.” (Caregiver)

“Caregivers are often involved in the caregiving field as their place of employment and their values to care for others both at work and at home supersedes their self-care.” (Service Provider)

“Often the burden of caregiving falls on specific family members and we often don’t pay attention to family dynamics when looking to the family for decision making and care provision. We often increase the burden by not exploring the family situation in depth.”(Service Provider)

“Over time I have had little contact with friends. As time goes on it becomes more and more difficult to connect or reconnect due to time limitations. I have become somewhat isolated and anything social for me adds stress to an already busy schedule. It feels better just stay home and have a relaxing evening all the while knowing that I need to have a social life.” (Caregiver)

Key Findings

- Tensions between caregiver and other family members (spouse, children, siblings, parents)
- Caring for care recipient makes it hard to have quality time
- Families adapt to another family member’s role as caregiver
- Conflicts with family members lead to resentment, anger
- Other family members not available, especially if they live out of town or have busy lives
- Support network of friends shrinks: feel “shunned” by friends and left out of community events
- A natural part of the life cycle, but one of the most stressful
- “Put my life on hold”: give up goals, social life, career, being a part of lives of other family members
- Only energy to make sure care recipient’s well-being is maintained and they have meaningful life (but not self)
- Always worried, feeling guilty, sadness, depression
- Development of major physical and mental problems
- High stress increases risk of abuse, neglect and exploitation
- High degree of emotional issues: feeling burnt out and hopeless

Domain 2: Awareness and Recognition

Description of Domain

- Awareness of caregiving in general public
- Awareness of caregiving before becoming a caregiver
- Caregivers as a special group deserving of formal recognition
- Government recognition of caregivers' role and consequences
- Professionals' recognition of caregivers' role and consequences

"We are all getting older. Sooner or later most of us will be affected in some way. Through education and the proper organizations like this one spreading the word it can only bring about positive changes in folks attitudes regarding long term care." (Caregiver)

"These are the unsung heroes who work tirelessly in ensuring that the person being looked after receives the best care possible...More public awareness must be given for those who are caregivers. There is no National Caregivers Day, no special treatment for them. They work tirelessly, often suffering from burn out because of insufficient assistance available to them." (Service Provider)

"We need to educate others and talk about caregiving more in society. When someone is in the early stages of dementia or has brain damage, quite often others don't see the "real challenges" that a caregiver has, therefore less support is given to them (this includes all professionals as well as family members, friends)." (Service Provider)

Key Findings

- Extremely important but not enough recognition
- People understand importance of child care, but not care for elderly or disabled
- Concern that awareness is there, but being "swept under the rug" by government; saving from cuts passes costs to caregivers
- Public sees role as simply supervision, not aware of complexity, intensity, and stresses
- Professionals, service providers, government, employers, and general public do not recognize role of caregivers
- Value is not given to caregivers; belittled by the system
- Professionals do not recognize that their contribution is brief and limited compared to 24-hour responsibility of caregiver
- Public is not prepared for caregiving because they are unaware of its consequences
- Same needs as child care – flexibility in hours, need for support and day care – but not seen in the same way
- Negative stigma associated with being a caregiver

Domain 3: Economic Security

Description of Domain

- Out-of-pocket expenses for care recipient needs
- Effects on savings
- Effects on spending for other family needs
- Financial security as a caregiver
- Availability of financial assistance

“There is no such thing as economic security for me, as I even had to sell my house to make ends meet. I cannot work, and now I am pushing 60 therefore worn out, and too old even if I could work. My pension will not amount to much, as I have lost 14 years owing to my daughter’s illness, treatments, and being her caregiver.” (Caregiver)

“Some cannot access their CPP yet, some don’t qualify for AISH, but their [care recipient] can no longer work...but the wife must continue to work because now they solely support the household (some still have children at home too), but there is very little to no support/services for someone to stay with the husband or an appropriate day program for them to go to.” (Service Provider)

“I find that I have had to be an advocate for equipment for my husband. He has had his wheelchair replaced...I urged the Physio Dept at the long-term care facility to send a letter requesting financial help with the purchase. [Community-based service] came through and covered the cost, but if I had not checked and requested that we apply, I may have had to pay the full price.” (Caregiver)

Key Findings

- “You just do what you have to do”: take a financial hit
- Using personal savings, RRSPs for care of care recipient; using savings puts caregiver in jeopardy in the future (retirement)
- Unable to work or work part-time in low-paying job for flexibility; no financial assistance if leaving paid work
- Having care recipient in assisted living or other placements is like carrying a second mortgage, plus high cost of “add-ons” like laundry, food, medication delivery, bathing
- Out-of-pocket costs: special diet, home adaptations, travel, and accommodations for treatment in big cities, time off work, medications, home care, wheelchairs and other equipment
- Financial resources available to help with out-of-pocket costs, but hard to find and requires persistence despite setbacks
- Funding is limited to special groups but still not sufficient
- Funding available for children disappears once they turn 18
- Most caregivers not aware of funding programs
- Poverty if caregiver is single-parent, elderly, or low-income
- Concerns about future financial security of care recipient when caregiver not there to cover expenses

Domain 4: Employment and Workplace

Description of Domain

- Effects on employment attendance, punctuality
- Effects on employment reliability and productivity
- Work hours or location flexibility for caregiving
- Support from employers or workplace policies
- Effects on career and/or educational aspirations

“It is very difficult to be the best employee you can be when you need to take time off work, ask for frequent shift changes/accommodations to provide care for a loved one.” (Service Provider)

“[A] workplace sponsored training that I enrolled in last fall was dropped as a result of the increased dependency of my mom on my time. Career development has all but stopped due to my lack of time and lower energy level.” (Caregiver)

“I was in a work environment that believed you needed to be at your desk 9-5 or you weren’t working. My elderly mother fell in 2007...which required 90 days in hospital and follow up care – I had to take my entire annual vacation days to look after her or I would have had to take a leave of absence without pay – totally inflexible.” (Caregiver)

“[M]y current employer has been supportive, but for how long before it wears out? Also, I do worry that my time away is viewed as a lack of commitment.” (Caregiver)

Key Findings

- Work productivity suffers: exhausted and cannot work efficiently
- Performing caregiving duties while at work: phone calls to care recipient, booking appointments, etc.
- Job worries because taking too much time off for caregiving and emergencies
- Miss out on promotions, pensions, benefits, career development
- Many supportive supervisors/employers and work environments, but uncertainty about extent of concessions
- No protection from being fired for needing time to care for care recipient
- Use all holidays and personal days to care for care recipient: burnt out and stressed
- Holding two full-time jobs: paid work plus caregiving responsibilities
- Take positions that do not offer advancement at low pay and no pension or benefits as trade off for flexibility
- Not financially or emotionally able to retire due to caregiving

Domain 5: Information on Programs and Services

Description of Domain

- Information received on care recipient's condition
- Getting information about care recipient's condition or treatment from professionals
- Information on health or social services relevant to caregiver's or care recipient's needs
- Information received on providing care for care recipient
- Information available on the internet

"There is often times not much information readily available unless you have a computer – which many seniors do not. Even with a computer, the information is not available in rural Alberta – because the services are NOT available." (Caregiver)

"I don't have a clue what happens as my Dad won't allow me into the exam room and the doctor won't make time after the exam to fill me in on any concerns, even though I am the one who cares for Dad. I can't rely on Dad telling me the truth (because he won't) so when Dad needs to go through emergency cause he is ill and I am asked what's going on, I can't fully answer." (Caregiver)

"Access to information about care options is difficult to obtain. Some health professionals have been extremely helpful in sharing information and follow up needs while others have been difficult to work with." (Caregiver)

Key Findings

- Caregiver may be provided with initial information but then left to "muddle through"
- Professionals may not provide information to caregiver on care recipient's condition, which affects ability to provide care
- Protection of privacy for care recipient conflicts with caregiver's need for information; care recipients may not understand or choose not to pass on information
- Resourcefulness and persistence of caregivers are determining factors in their ability to get information and resources
- Communication among providers (e.g. doctors, allied professionals, support workers) inadequate
- Government websites are difficult to navigate and lead caregivers to out-of-date, inappropriate, or missing content
- Too much focus on internet; seniors and low-income people may not have computers
- Rural services are lacking, so information availability is moot
- Information on services in rural areas mainly passed through word-of-mouth; no directories like in big cities
- Response time to information requests can be very long if they respond at all: problematic especially in crises or emergencies
- Staff too busy, sometimes provide misinformation or inappropriate referrals

Domain 6: System Navigation

Description of Domain

- Finding and getting services for caregiver or care recipient
- Working relationships with professionals
- Getting services to help with basic needs (shelter, food, transportation, etc.)
- Help with planning or arranging for future needs of caregiver or care recipient
- Involvement in decision-making for care recipient's treatment or care

"It's almost like seniors care and support services are the best kept secret of Alberta and only the most astute and determined caregivers will be able to ask the right question, to the right person, at the right time to get the answer they need for their specific situation. (Service Provider)

"I was treated as though I was responsible to care forever, no question...I was actually told that my children and I 'didn't matter', [only] the patient did – our problems or concerns were to be kept to ourselves or figure out a way to deal with the trauma on our own time..." (Caregiver)

"We live outside of Edmonton and no one will deliver my daughter's medical supplies, medical formula, medications to our home. Oxygen is the only one who delivers." (Caregiver)

"Working with individuals that have secondary disabilities is very difficult. Often they do not fit into a system that is frustrating for anybody that works with them. There are populations in our community that will never fit into the mandate of any system." (Service Provider)

Key Findings

- Difficulty accessing services because care recipient feels they do not need help or do not want to be labelled as "disabled"
- Services available in cities are not available in rural areas
- Staffing shortages make it hard for them to answer questions or follow-up on needs
- Lack of case management for the caregiver and ensuring continuity across different providers
- Funding is structured in a way that prevents many individuals who do not fit from accessing services
- Long delays between testing, assessments, treatment planning, access to services
- Limited staffing in care facilities results in caregiver continuing role in personal care
- Homecare workers: shortages and turnover, overworked and underpaid, burned out, not kept in loop, limited training
- Lack of housing and services for younger adults and those with some conditions (dementia, mental health, comorbidity)
- Immigrants and transient populations do not know how to access services

Domain 7: Respite

Description of Domain

- Use of respite services offered by health system
- Having time for family vacations, travel, or attending important events
- Time off when caregiver needs a break
- Help from family members, friends, neighbours, or volunteers
- Someone to help in a crisis when caregiver needs to leave care recipient

“What breaks? What vacations? We farm. We do eldercare. There are NO breaks.” (Caregiver)

“We currently have good respite services for our daughter. However, that will change once she turns 18.” (Caregiver)

“The difficulty with respite is the type of facility offered: a bed in long term care facility is not suitable for lots of people. Most loved ones do not want to be in this atmosphere.” (Service Provider)

“Have not had to use respite care at this point in our situation however, believe it will become a factor. As a caregiver you feel guilty when unable to provide care, whether it is because of work, vacation, or an emergency. You don’t want to have to ‘ask’ someone else to carry your load.” (Caregiver)

Overview of Findings

- Caregivers have difficulty asking for help or knowing who to ask
- Caregivers need emotional support to accept respite and overcome feelings of guilt
- Cost for in-home care is very expensive
- Care recipients may not want respite because facility environment is not suitable
- Long waiting list for respite beds and not available when needed
- Respite not available on short notice or in emergency situations, such as when the caregiver is sick or dies
- Respite not available if care recipient has mental health issues
- Respite workers poorly paid with high turnover
- Difficulties finding care that caregiver trusts and feels comfortable leaving care recipient
- Family members and friends may be available for respite, but may place strain on relationships and reduce support network
- Few respite beds in “nice home setting” for comfort of care recipient and peace of mind of caregiver
- Respite outside normal working hours is difficult to obtain

Domain 8: Community-Based Supports

Description of Domain

- Assistance from community organizations (e.g. food bank, seniors centre, legion, etc.)
- Assistance from faith community (e.g. churches or other faith institutions)
- Assistance from organizations related to care recipient's condition
- Assistance from service-providing businesses (e.g. home care, medical equipment, drivers, etc.)
- Assistance from community businesses (e.g. grocery store, post office, etc.)

"Since he is lonely, he tends to try to make conversation and they [at the grocery store] got tired of listening to him. So far the other store has developed some tolerance. What we really need is a companion to spend about 1-2 hours a day with him, who can take him shopping and keep him on task..." (Caregiver)

"Since my father's mental decline is age-related, there is no support...[Rural service provider] has nothing for him and so it goes. We do our best as a family to look after him and his loneliness." (Caregiver)

"Organizations differ from community-to-community and do not advertise all the services they do offer. Sometimes this is on purpose to prevent an onslaught of requests." (Service Provider)

"Funders of paid supports often see [community- and faith-based] resources as reliable alternatives diminishing the need for paid support. It is not the case that volunteered supports are adequate to provide the consistency needed for the safety and wellbeing of the person requiring care." (Service Provider)

Overview of Findings

- They are invaluable service providers, but community organizations do not have the resources to serve all the need
- Very few services directly for caregiver needs; caregivers need to search themselves for support groups and other assistance
- Smaller rural communities may be better than larger ones at rallying community support
- Information and support services provided by community organizations are difficult to get in rural areas because of costs
- Faith communities provide emotional support, but difficult to access practical support
- Not enough appropriate services for housing and transportation for many conditions
- Difficulties finding, accessing, and understanding range of programs available
- Large discrepancy between availability in cities vs. rural areas
- Community-based supports are inconsistent and cannot replace formal services

Next Steps

This preliminary report gives an overview of the initial findings from the survey component of our consultation process. Further analyses and discussion elements will be added in the final version. This report is being circulated to stakeholders – including government, illness-specific organizations, service providing agencies, professional colleges, and others – for their feedback. Their input will be incorporated into the final version of the survey report and distributed to delegates prior to their participation in our conventions at the end of October.

Contact Information

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