

**ALBERTA CAREGIVERS
ASSOCIATION
INFORMATION GATHERING INITIATIVE
FINAL REPORT**

***SHINING A LIGHT ON
FAMILY CAREGIVERS'
ISSUES, STRENGTHS & NEEDS***

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Prepared by

Linda Barrett MSc, RN



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EXECUTIVE SUMMARY

I. PROJECT DESCRIPTION

A. RATIONALE AND PURPOSE

To guide planning activities in this newly established organization, the Board of the Alberta Caregivers' Association (ACA) identified the need for local information in the Edmonton area about the lived experience of a variety of family members who are providing care to a loved one living with a chronic condition. The purpose of this project was therefore to gather information on issues, strengths, and needs from a variety of primary caregivers of adult loved ones with chronic illness, regardless of the medical diagnosis contributing to life changes for the family unit. Ultimately, the aim was to describe the commonalities experienced across primary caregivers in order to influence programs and services in support of primary caregivers in general.

B. METHODS

To avoid additional burdening of already busy caregivers, the board opted to approach existing disease-specific organizations with the request to hold a focus group session in a regularly scheduled meeting time. Those organizations selected for focus groups were required to meet two inclusion criteria: (1) the organization provided an ongoing support group for individuals in a caregiver role, and (2) the care recipients of these caregivers were adult family members diagnosed with a chronic medical condition. Participants were recruited from eight different organizations in the Edmonton area.

One trained facilitator conducted all eight focus groups using three focus questions (provided in the results section below). During each session: (1) confidentiality of the discussion was requested of all present and assured by the ACA in any subsequent documentation of the ideas shared, (2) the facilitator then recorded all answers to the focus questions, and (3) the respective group validated the flipchart recordings as being reflective of the ideas communicated.

Subsequent to the completion of all focus groups, written individual group information was shared with the respective group through the regular group leader. Care was taken to remove any identifying comments to ensure the privacy of its members.

All data were entered verbatim for the respective group by key question into MS Word. General analytic procedures for content consisted of descriptive analysis across all eight groups within-categories (i.e., within-questions) to note patterns and themes, and to make contrasts and comparisons.

II. SUMMARY RESULTS

A. PARTICIPANTS

Approximately 60 individuals participated in eight focus groups held between September 2002 and January 2003 in a regularly scheduled meeting time of the respective caregiver support group (See Appendix A – Group List). The relationship of the caregiver to the care recipient varied: wife, husband, daughter, daughter-in-law, son, son-in-law, and mother. However, in the majority, participants were female and in their middle years of life, with the youngest in the third decade and the oldest over 70 years.

B. FINDINGS BY FOCUS QUESTION

Question #1 - *WHAT ARE THE PERSONAL ISSUES THAT YOU EXPERIENCE IN COPING DAY TO DAY IN YOUR CAREGIVER ROLE?*

ISSUES FACED BY PRIMARY CAREGIVERS ACROSS DISEASE CONDITIONS: Regardless of the chronic condition, common issues faced by all primary caregivers of adult family members were identified. Eight themes were of particular note:

- **Handling negative thoughts and emotions:** (Sub-Themes: Being on an emotional roller coaster; Constant guarding, apprehension, and fear; Guilt and self-berating; Frustration and resentment; Feelings of being overwhelmed and trapped; Sadness over “missing out on life with spouse”; Feelings of abandonment and not being valued by others; and Feelings of loneliness and isolation)
- **Disturbed sleep**
- **Physical impacts on caregivers**
- **Adjusting perceptions of one’s relationship with the care recipient**
- **Coping with difficult family dynamics** (Sub-Themes: Denial of family member’s condition; “Normal” appearing ill family member; Lack of family member(s) understanding of the 24 hour a day seven days a week situation; Criticism of caregiver’s actions by relatives, particularly those living at a distance; and Manipulative behaviour by the ill family member)
- **Physical environmental barriers to social interaction**
- **Navigating the service systems**
- **Financial hardships**

Question #2 - *WHAT ARE THE STRENGTHS THAT YOU BRING TO OR HAVE DEVELOPED IN COPING DAY TO DAY IN YOUR SITUATION?*

STRENGTHS IDENTIFIED BY PRIMARY CAREGIVER PARTICIPANTS: Common themes across all groups about the strengths developed by primary caregivers to cope with the issues faced were identified as follows.

- Developing specific strategies to handle difficult moments
- Letting go of control and becoming more focused on the present
- Developing supportive relationships
- Protecting self from unhelpful comments and advice-giving from others
- Changing expectations of the care recipient and their relationship
- Continuous adaptation to the needs of their care recipient
- Learning about and dealing with care systems
- Increased knowledge about many topics
- Personal growth
- Learning to care for own health and well-being
- Supportive environmental factors
- Hope for the future

FOUR MAJOR INTERNAL CHANGES EXPERIENCED BY PRIMARY CAREGIVERS: From the above 12 strength themes, four major internal changes appeared to evolve in these caregivers to assist with coping in response to the externally imposed caregiver experience.

- 1. Evolving World View/Perspective**
- 2. Increasing Assertiveness**
- 3. Becoming System Savvy**
- 4. Developing Caregiver Wisdom**

Question #3 - IF WE WERE ABLE TO GRANT YOU SEVERAL WISHES, WHAT WOULD HELP TO MAKE YOUR LIFE BETTER AS A CAREGIVER?

MAIN RECOMMENDATIONS IDENTIFIED BY PRIMARY CAREGIVERS FOR A BETTER

LIFE: Primary caregivers across all eight focus groups identified the following key needs which, in their opinion when met, would facilitate primary caregivers in general in our society to have a better life.

- 1. Peer education and peer support for primary caregivers.**
 - Provide peer education and support about the lived experience of being a primary caregiver
 - Provide specific peer education and support on navigating the service systems involved in the care of adult family members living with chronic conditions
- 2. Focused information and resources for and about primary caregivers.**
 - Develop a central resource for primary caregivers and for information about primary caregivers (e.g., maintain a databank on primary caregivers needs, issues etc.)
 - Advocate for and develop programs that provide a range of appropriate respite for caregivers to enable the healthy coping of the family unit
- 3. Increase societal understanding of caregivers' roles through raising the public profile of primary caregivers and their issues, strengths, and needs.**
- 4. Educate health professionals about the caregiver experience and the wisdom that primary caregivers have and can contribute as part of the care team.**
- 5. Advocate for systems changes to ease the issues faced by primary caregivers and enhance the quality of life for caregivers and their care recipients.**

C. LIMITATIONS

Potential limitations of the results of this information gathering initiative include: some participant's input may have been limited by lack of comfort in speaking in a group situation, primary caregivers who do not attend support groups may not be represented, and project findings are not directly generalizable to other samples or populations of primary caregivers.

It should be noted, however, that the above results do provide valid direction for these specific caregivers as well as offer guidance on the potential issues, strengths, and needs of primary caregivers in general.

IV. SUMMARY AND CONCLUSION

The main findings of this project suggest that there are common issues faced by primary caregivers of adult loved ones, regardless of disease condition. Furthermore, those issues need to be addressed to ensure the health and well-being of the family unit in coping with chronic conditions as greater demands from an aging population are placed on the family in the face of stressed public service systems. To that end, these caregivers view peer education and peer support as fundamental for those living the primary caregiver role. Moreover, heightened public awareness about the issues is also essential to raise the general understanding of society about the vital contributions of primary caregivers. Raising such public understanding could help shine a light on the need for policy and system changes to reduce the stressors experienced by those in primary caregiver roles, both now and in the future, for the ultimate benefit of the whole family.

SHINING A LIGHT ON FAMILY CAREGIVERS' ISSUES, STRENGTHS & NEEDS

I. PROJECT DESCRIPTION

A. RATIONALE

To guide planning activities in this newly established organization, the Board of the Alberta Caregivers' Association (ACA) identified the need for local information in the Edmonton area about the lived experience of a variety of family members who are providing care to a loved one living with a chronic condition. A broad approach to describing these experiences was deemed priority given the limitations of a disease-specific focus and the dearth of information about the shared experience of caregivers across all chronic conditions.

B. PURPOSE

The purpose of the project was therefore to gather information on issues, strengths, and needs from a variety of primary caregivers of adult loved ones with chronic illness, regardless of the medical diagnosis contributing to life changes for the family unit

Ultimately, the aim was to describe the commonalities experienced across primary caregivers in order to influence programs and services in support of primary caregivers in general.

C. METHODS

C.1 PARTICIPANT RECRUITMENT

- ❑ To avoid additional burdening of already busy caregivers, the board opted to approach existing disease-specific organizations with the request to hold a focus group session in a regularly scheduled meeting time.
- ❑ Those organizations selected for focus groups were required to meet two inclusion criteria: (1) the organization provided an ongoing support group for individuals in a caregiver role, and (2) the care recipients of these caregivers were adult family members diagnosed with a chronic medical condition.
- ❑ Participants were recruited from eight different organizations in the Edmonton area (see Appendix A) using the following procedures:
 - a) Initial project communication to an identified contact person for each of the groups in the Edmonton area who met the inclusion criteria.
 - b) An information sheet and the proposed questions were then sent to the contact person for distribution to and discussion of the request by the membership (See Appendices B.1 and B.2).
 - c) Respective group leaders communicated back to the ACA about their specific group consent or decline to the focus group proposal.
 - d) Once verbal group consent was obtained, the suggested meeting date was confirmed with the focus group facilitator and the specific group.

C.2 THREE KEY FOCUS QUESTIONS

The three key focus group questions below were designed to elicit the perceptions of primary caregivers about their personal issues, their strengths in coping, and what they needed for a better life as a caregiver. **The three key questions were:**

- ❑ **What are the personal issues that you experience in coping day to day in your caregiver role?**
- ❑ **What are the *strengths* that you bring to or have developed in coping day to day in your situation?**
- ❑ **If we were able to grant you several wishes, what would help to make your life better as a caregiver?**

Two subsidiary questions “What was the least helpful support you have experienced?” and “Any other comments or suggestions?” were also asked at each focus group.

C.3 FOCUS GROUP PROCEDURES

- One trained facilitator conducted all eight focus groups.
- The regular group leader for the respective group attended to provide introductory and concluding remarks but remained silent (i.e., if not a primary caregiver of an adult) during the discussion to ensure a focus on caregiver ideas.
- The president, vice-president and treasurer of the ACA attended the sessions to introduce and provide consistent context for the information gathering initiative and to observe the group discussion.
- After assuring confidentiality of the discussion and obtaining verbal consent at the outset of each group session, the facilitator recorded all answers to the focus questions on a flipchart.
- During each session, the respective group validated the flipchart recordings as being reflective of the ideas communicated.
- Subsequent to the completion of all focus groups, written individual group information was shared with the respective group through the regular group leader. Care was taken to remove any identifying comments to ensure the privacy of its members.

C.4 DATA ANALYSIS

- All data on the flipchart sheets were entered verbatim for the respective group by key question into MS Word (See Appendices C.1 to C.8).
- General analytic procedures for content consisted of descriptive analysis across all groups within-categories (i.e., within-questions) to note patterns and themes, and to make contrasts and comparisons (Miles & Huberman, 1994).
- Analysis results are described below in Section II.

II. RESULTS

A. PARTICIPANTS

Approximately 60 individuals participated in eight focus groups held between September 2002 and January 2003. All were held in a regularly scheduled meeting time of the respective caregiver support group with the regular group leader present to provide introductory and concluding remarks. The relationship of the caregiver to the care recipient varied: wife, husband, daughter, daughter-in-law, son, son-in-law, and mother. However, in the majority, participants were female and in their middle years of life, with the youngest in the third decade and the oldest over 70 years.

B. FINDINGS

The following provides the main findings of the data analysis for each of the key questions asked of the participants of all eight focus groups.

B.1 WHAT ARE THE PERSONAL ISSUES THAT YOU EXPERIENCE IN COPING DAY TO DAY IN YOUR CAREGIVER ROLE?

The personal issue themes described across all focus group participants include: handling negative thoughts and emotions, disturbed sleep, physical demands of the role, coping with difficult family dynamics, physical environmental barriers, ongoing adjustment to a changing relationship with the loved one, navigating the service systems, and dealing with financial and legal issues. Because these issues are best expressed in the words of the caregivers, each of the eight themes is briefly outlined below together with representative quotations from individual focus group participants. Findings from the responses to the subsidiary question about the least helpful support are also documented below.

B.1.1 Eight Core Personal Issues Identified:

Issue #1 – Handling Negative Thoughts and Emotions

All caregivers identified dealing with a number of negative thoughts and emotions as a major issue in caring for a loved one. Specific themes across all groups include:

- **Being on an emotional yo-yo or roller coaster –**
“The unpredictability of [CR’s] reactions is still what throws me...I expect a pattern” (Caregiver)

“I have to change at a moment’s notice [i.e., in response to CR’s reactions]...it’s exhausting...I feel like a wet spaghetti” (Caregiver)

“I feel angry - blow up and then I feel guilty – it has destroyed my self-esteem” (Caregiver)
- **Constant Guarding/Apprehension/Fear:**
“I feel I can only express positive emotions in his presence ...to keep him calm and relaxed” (Caregiver)

“I’m always walking on glass to keep the peace” (Caregiver)

"I'm always on the alert" (Caregiver)

"I feel on edge...everything comes from left field" (Caregiver)

"Fear of the unknown" (Caregiver)

- **Guilt and Self-berating:**

"I'm always second guessing myself and feel less and less confident that I am doing the right thing" (Caregiver)

"I feel guilty going out without him...what kind of a wife would leave a husband at home and go out for supper?" (Caregiver)

- **Frustration and Resentment** : This was often expressed in response to having to meet another's needs all the time with no time to nurture oneself or in response to apparent lack of understanding and criticism on the part of other family members.

"Why can't other family members help out?" (Caregiver)

"Everything has to be done on [CR's - spouse] terms" (Caregiver)

"I feel like I am nothing to [CR – spouse] ...the focus is on giving plus plus...to meet his needs...serving him like a maid until I feel like I can drop" (Wife Caregiver)

"I have lost my social life. My choices are go late and leave early [i.e., CR-spouse tires easily] or go alone and worry about him the whole time" (Caregiver)

"One day you get a call and your whole life is twisted...dreams and hopes you had for your child are gone...you have the responsibility [for adult child]" (Caregiver)

"The constant demand is like someone sucking all your energy out of you" (Caregiver)

"The tension builds up and I get angry. I have stormed out the door...I went right out and stayed out til I cooled down." (Caregiver)

"It's like I live in this convent with no sex and no talk [with spouse]" (Caregiver)

- **Feelings of being overwhelmed and trapped:**

"No personal space...constant shadowing by [CR]" (Caregiver)

"I need to maintain my sanity – need to be healthy to care for [CR], but no time for me, so how do you look after yourself?" (Caregiver)

"I am one step away from needing care myself" (Caregiver)

"I am housebound...[CR] is so depressed it's getting me down" (Caregiver)

- **Sadness - over "missing out on life with spouse":**

"We don't have the closeness that we used to...I have to ask for hugs now..." (Caregiver)

"I feel gyped...not how I pictured it [my life]...I had a vision of being cared for..." (Caregiver)

"I am faced with growing old alone" (Caregiver)

"Letting go of my dreams...a house, trips ...life as I expected it to be [with spouse]" (Caregiver)

- **Feelings of abandonment and not being valued by others:**
 - "Some [friends] are interested, others are absolutely not interested in your changed situation" (Caregiver)*
 - "No emotional support from [CR- spouse]" (Caregiver)*
 - "I don't count anymore" (Caregiver)*
 - "I feel sorry for myself at times...it's a surprise when someone asks about me!" (Caregiver)*
 - "I've lost my identity...my name is now 'how's your mother' " (Caregiver)*
- **Feelings of loneliness and isolation:**
 - "Others don't see the demands...[CR-spouse] is self-focused and needy all the time" (Caregiver)*
 - "You don't get it until you've lived it [i.e., being a 24/7 caregiver]...get the tiredness, what you have to do for you to survive" (Caregiver)*
 - "Friends and family don't understand [my 24/7] reality" (Caregiver)*
 - "I don't know what to say...when friends ask "how's [CR]?" (Caregiver)*

Issue #2 – Disturbed Sleep

Caregivers identified that disturbed sleep because of CR needs and/or their own personal issues, made it difficult to cope with the constant demands of the primary caregiver role.

- "I am up at night...sometimes two or three times [with CR]" (Caregiver)*
- "[CR] is up four times a night...is afraid of making a mess...makes me worn out...blow up easily...raises my blood pressure" (Caregiver)*
- "At the end of the day I am [very] stressed...it takes hours to settle down to sleep" (Caregiver)*
- "[I have] decreased amount of sleep as well as lack of undisturbed sleep" (Caregiver)*

Issue #3 – Physical Demands

Caregivers described major physical impacts on themselves because of the condition of their family member.

- "Physically it's hard...especially on my back...have to pull him up from the floor after he has fallen...[CR-spouse] refuses to let me call the ambulance or other help...an invasion of our privacy...have to avoid extra costs" (Caregiver)*
- "Falls are a big issue...it is expensive to call for help...[CR] is dead weight and I am alone" (Caregiver)*

Issue #4 – Physical Environmental Barriers to Social Interaction

Caregivers identified that barriers in the physical environment limited their ability to participate in normal social activities, especially when their loved one had mobility issues.

“Physical barriers make it difficult for us to go out with him in a wheelchair...e.g., reception at family wedding” (Caregiver)

“Physical access to homes and a lot of stores” (Caregiver)

“Access to public bathroom facilities...especially of the opposite sex” (Caregiver)

Issue #5 – Coping with Difficult Family Dynamics

Overall, caregivers reported that taking on the primary caregiver role puts increased pressure on the family unit and can exacerbate or cause issues and negative emotions or behaviours amongst family members. Five sub-themes within this major theme were noted:

- **Denial of family member’s condition:** Caregivers reported that some family members don’t want to believe or accept the ill member’s decreasing abilities to function. This has led to family conflicts over what care the ill family member requires and how best to provide it.
- **“Normal” appearing ill family member:** The normal appearance of the ill loved one contributed to other family members not grasping or accepting the ill family member’s decreased judgment or behavioural problems and the need for certain care/treatment approaches.
- **Lack of family member(s) understanding of the 24 hour a day seven days a week (24/7) situation:** Participants described that other family members often don’t understand the 24/7 reality of the loved one’s condition and what the primary caregiver is coping with. This has led to unhelpful advice giving and lack of support by those who do not understand.
- **Criticism of caregiver’s actions by relatives living at a distance:** Direct or implied criticism by those family members living at a distance was described as a major issue by these caregivers. For example, *“They give me advice but don’t understand the real situation – they sometimes interfere in the best treatment plan that we are trying to adopt based on the situation here” (Caregiver).*
- **Manipulative behaviour by the ill family member:** Caregivers reported that the ill family member sometimes pitted or played one member against another.

Over all, for these caregivers, difficult dynamics tended to be experienced with those family members who were more distant (socially and/or physically) and therefore less involved with the care of the loved one.

Issue #6 – Adjusting Perceptions of the Relationship with the CR

A sixth issue theme described by these participants was the need to make fundamental changes in how they perceived their relationship with the ill family member. This change was often labeled as “role reversal” or “becoming a parent” to the loved one and described with sadness as a letting go of the previous spousal or child-parent relationship.

“I’ve lost my mother...now have an old extra child or baby” (Daughter Caregiver)

[CR has become] “a child and a stranger in an adult body” (Wife Caregiver)

“I am now a single parent...it is not a partnership anymore...I can’t share issues going on in the family with him anymore” (Wife Caregiver with a young family)

Issue #7 – Navigating the Service Systems

Participants described much difficulty in learning how to find their way through the systems that provide services for ill persons and their caregivers. They also described some unhelpful behaviours on the part of some health professionals.

“Health professionals don’t want to commit themselves to answering ‘where will he be in 6 mos, 5 yrs’...It’s like they want to avoid increasing your despair so that you won’t give up now [as a caregiver].” [Possible interpretations by caregivers: Health professionals do not tell all that they know about the prognosis; health professionals may be less than honest about the prognosis for fear that you will not stay in the caregiver role]

“Difficult to find out what resources are available for [CR] and [CG]” (caregiver)

“Professionals [in home care and long term care] are constantly changing...it’s hard to keep them up-to-date” (caregiver)

“Have had to fight the system for everything that [CR] needs...it is hard...that is crap...” (Caregiver)

Issue #8 – Financial Hardships

Financial issues were mentioned by a number of caregivers in all focus groups.

“Many caregiver expenses are not covered” (caregiver)

“A Catch 22...disability pension is a little over the maximum allowed to qualify for financial aid...it’s a struggle to make ends meet” (caregiver)

B.1.2 Subsidiary Question on Least Helpful Support:

When asked to describe the least helpful support that they had experienced in the caregiving role, the following themes emerged:

- Others who give advice after the situation has occurred or without fully appreciating the 24/7 reality of the situation

- Unhelpful advice from health professionals who do not try to understand the 24/7 reality of the caregiver/care recipient situation
- Judgment by relatives living-at-a-distance
- Long term care staff who put their own routine needs ahead of the resident's need (e.g., "put her back to bed early for staff of oncoming shift rather than allowing to stay up to attend activities that she enjoys").

B.2 WHAT ARE THE STRENGTHS THAT YOU BRING TO OR HAVE DEVELOPED IN COPING DAY TO DAY IN YOUR SITUATION?

In response to the second key question asked of all eight groups, the focus data revealed twelve themes related to the strengths developed over time by these participants in their day-to-day caregiving experience.

Twelve Themes Related to Caregiver Strengths:

- **Specific coping strategies for difficult moments** – Participants described a number of specific coping strategies that helped them get through difficult moments:
 - Guiding principles/mottos/prayers
 - Activity – "When I am sad I go for a walk" (caregiver), "I bake" (caregiver)
 - Emotional release – "I cry in private" (caregiver), "... vent to a trusted person" (caregiver)
 - Apply knowledge and skills gained in one's career – "it has prepared me to cope with..." (Caregiver)
- **"Letting go of control and becoming more focused on the present"** – Participants described a number of behaviours that indicated personal transitions over time to a stronger focus on the present and a letting go of the need to control what would happen in the future. This was expressed through statements such as: "putting it in God's hands", "prayer", "valuing the good moments when they happen", "learning to go along with the flow and to not try to argue or explain everything", "attack problems as they come", "learning to live day to day and sometimes hour to hour", etc.
- **Supportive relationships** – Caregivers described the importance of being able to vent with a trusted person as well as the value of being in a support group with others going through a similar experience. They also reported pleasant surprises in pre-existing relationships: some friends were there for them in a way that was very helpful and they would not have predicted. Caregivers also described strengthened family bonds through working together to solve the care needs of the ill family member.
- **Protecting self from "unhelpful advice and comments"** – Some caregivers reported learning to limit the type of information that they shared with others to avoid triggering in these people a need to provide 'advice'.
- **Change in expectations of CR** – Participants described the importance of learning to view negative behaviours as being caused by the illness. This enabled them to cease trying to reason or argue with the CR and allowed the caregiver to act in a more objective way to handle the situation, e.g., avoid emotional reactions to CR behaviour.
- **Continuous adaptation to needs of care recipient** – Caregivers described a continuous process of transition in their role with the gradual loss of their loved one's

abilities, including moves to long term care. These ongoing transitions required them to continually adapt to the needs of their family member.

- **Understanding & Dealing with Care Systems** – Participants reported the development of political and communication skills in order to deal with the many issues they encountered in interacting about care needs with health programs and services.
- **Increased knowledge** – All groups described gaining increased knowledge of self, others, the disease condition, specific coping strategies, and the system.
- **Personal growth** – Participants described a number of personal changes that developed over time in their caregiver role. These were: increased empathy/compassion for others, being less judgmental, becoming more patient and tolerant, being more giving, having increased positive self-talk, being more independent and more confident [e.g., “[I’ve discovered] *I am equal to anybody, I actually have an opinion*” (Caregiver)], and becoming a stronger person overall. Some participants reported feeling satisfaction with acting on the personal value of loyalty to their loved one, especially a spouse through better or worse.
- **Caring for self (own health and well-being)** – Some caregivers described a number of behaviours that indicated they were making an effort to look after their own health and well-being. These behaviours included: meditation, physical activity, life outside the caregiving role (e.g. volunteering in the community), taking prescribed medications, attending psychological counseling, attending support groups, taking brief time-outs (minutes or hours) and regular longer breaks (days & occasional weeks) from the role, pursuing learning opportunities, and planning for the future.
- **Supportive Environmental Factors** – The caregivers identified that both social and physical aspects of the environment are more supportive than they used to be (e.g., changes in role expectations and opportunities for women, adaptations to accommodate the physically challenged such as those in wheelchairs etc.). While more social and physical environmental change was seen as necessary to support caregivers and their loved ones in our society, achievements thus far were recognized by these participants as helping the family unit in its pursuit of health and well-being.
- **Hope** – Some of the participants were able to express hope for the future. This was articulated through caregiver intentions to contribute by using the experience to benefit others. It was also expressed by hope for their children’s increased ability to face future adversity as well as their children’s potential to work towards positive social change through their early sensitization to the impacts of chronic conditions.

B.3 IF WE WERE ABLE TO GRANT YOU SEVERAL WISHES, WHAT WOULD HELP TO MAKE YOUR LIFE BETTER AS A CAREGIVER?

Analysis of participant responses to the third key question revealed five main themes. Each is outlined below together with the proposed goal(s) and the specific documented caregiver ideas for the theme. These are also summarized for the reader’s convenience in Appendix D.

Theme #1 – Peer Education & Support for Caregivers

Goal 1: *Provide peer education and peer support to caregivers about the lived experience of caring for a family member*

- Help Caregivers to recognize that negative emotions are a normal experience in the primary caregiving role
- Help caregivers to “know that they are not alone”
- Provide workshops on self-esteem building and other personal growth topics related to the caregiver role
- Assist with increasing knowledge for dealing with new situations as a caregiver
- Facilitate opportunities to hear from other caregivers about their situations, how they feel and what they do to cope
- Be a support through the caregiver personal adjustment process (i.e., the deconstruction and reconstruction of views of self, her or his relationship with CR, and life in general)

Goal 2: *Provide specific peer education and support to Caregivers on navigating “The System”*

- Help with “who to contact in which department for what service” in the various systems and programs
- Develop and update a handbook for caregivers’ orientation to continuing care written from the peer perspective
- Provide an experienced caregiver buddy to caregivers who are new to the continuing care setting to assist with their personal adjustment process

Theme #2 – Be a Resource To, With, and About Caregivers

Goal 1: *Advocate for or develop programs that provide respite for caregivers*

- Help provide brief break time (2 hours) away from CR, both planned & urgent
- Assistance with appointments, activities, outings for CR
- Establish caregiver network for participation in social activities
- Provide a camp or retreat for caregivers
- Advocate for increased caregiver relief options for regular, planned mini-breaks of a few days and more extended breaks of a few weeks

Goal 2: *Develop a central resource for information and referral for & about Caregivers*

- Provide current information related to questions on caregiving and caregivers.
- Develop print resources such as checklists on specific topics
- Provide proactive coaching in handling caregiving situations
- Develop “Peer Support Program” for non-judgmental peer to peer caregiver counseling
- Develop a mobile resource, e.g., a traveling van stocked with information and take it to different locations (like the blood donor clinic model)
- Provide a central registry for rural areas
- Contribute information and referral on legal issues:
 - Wills, power of attorney, personal directives, enduring power of attorney, guardianship, trusteeship
- Be a resource to the community for caregiver information by developing and maintaining a databank:
 - Conduct ongoing evaluation and documentation of caregivers’ issues and experiences
 - Provide caregiver information to families and the general public, governments, health professionals, and others.

Theme #3 – Increase Societal Understanding of Caregivers’ Roles

Goal: *Raise the profile of Caregivers to increase understanding in the General Public and Governments at all Levels*

- Give a VOICE to family caregivers’ experiences
- Provide information about primary caregivers in general to the public to raise awareness about caregivers and their needs:
 - for example, conduct media campaigns
- Help move from society viewing us as passive receivers of information without choice to being viewed as individuals with choices regarding how much we take on as a caregiver.
- Help society to recognize that we are the experts in caring for our family member and that we need to be consulted with NOT told what to do and then be expected to do it.

Theme #4 – Educate Health Professionals

Goal: *Educate health professionals about the Caregiver experience & the wisdom that Caregivers can contribute*

- Help health professionals to understand:
 - The issues we are coping with
 - That we have developed wisdom for our specific caregiving situation
 - That we need to be included as an equal in any care planning process
 - That our wisdom can help others in understanding the caregiver experience

- As part of their various university program curricula, educate “soon to be” health professionals from all disciplines about the caregiver role, its issues, its contributions, and its needs.
- Educate those who are newly graduated before they have to unlearn unhelpful approaches to family caregivers.

Theme #5 – Advocate for System Changes

Goal: *Advocate for system changes to enhance quality of life for Caregivers and their Care Recipients*

- Work in partnership with like-minded organizations and agencies to influence caregiver issue identification and planning for the future:
 - Identify gaps in programs and systems, e.g., home care gaps, portability of programs across provincial boundaries, etc.
 - Work towards making changes that enable a better life for caregivers and their care recipients
- Provincial Ombudsman for Caregivers to help get information from different government departments
- Address financial issues:
 - Benefits for performing the CG role
 - Subsidies, CG allowances – *“The model of foster parent program would work - I gave up my job to do this” (CG)*
 - Tax breaks for family caregivers
 - Training programs to help to upgrade caregivers’ job skills so that they can support their family at an adequate level, especially in the case of younger caregivers whose main breadwinner is no longer able to work.
- Identify and address legal issues

III. SUMMARY FINDINGS AND DISCUSSION

A. ISSUES FACED BY PRIMARY CAREGIVERS ACROSS DISEASE CONDITIONS

Regardless of the chronic condition, common issues faced by all primary caregivers of adult family members were identified. Eight themes were of particular note:

- ***Handling negative thoughts and emotions:***
 - Being on an emotional roller coaster
 - Constant guarding, apprehension, fear
 - Guilt and self-berating
 - Frustration and resentment
 - Feelings of being overwhelmed and trapped
 - Sadness over “missing out on life with spouse”
 - Feelings of abandonment and not being valued by others
 - Feelings of loneliness and isolation

- ***Disturbed sleep***
- ***Physical impacts on caregivers***
- ***Adjusting perceptions of one's relationship with the care recipient***
- ***Coping with difficult family dynamics***
 - Denial of family member's condition
 - "Normal" appearing ill family member
 - Lack of family member(s) understanding of the 24 hour a day seven days a week situation
 - Criticism of caregiver's actions by relatives, particularly those living at a distance
 - Manipulative behaviour by the ill family member
- ***Physical environmental barriers to social interaction***
- ***Navigating the service systems***
- ***Financial hardships***

B. STRENGTHS IDENTIFIED BY ALL FAMILY CAREGIVER PARTICIPANTS

Common themes about the strengths developed by primary caregivers to cope with the issues faced were also identified as follows.

- Developing specific strategies to handle difficult moments
- Letting go of control and becoming more focused on the present
- Developing supportive relationships
- Protecting self from unhelpful comments and advice-giving from others
- Changing expectations of the care recipient and their relationship
- Continuous adaptation to the needs of their care recipient
- Learning about and dealing with care systems
- Increased knowledge about many topics
- Personal growth
- Learning to care for own health and well-being
- Supportive environmental factors
- Hope for the future

FOUR MAJOR INTERNAL CHANGES EXPERIENCED BY PRIMARY CAREGIVERS

On further analysis these 12 themes can be distilled into four major internal changes that appeared to evolve in these caregivers in response to the externally imposed caregiver experience.

These major internal changes include:

1. Evolving World View/Perspective:

Caregivers appear to go through, and in some cases were able to articulate, a process of deconstruction and rebuilding of their personal worldview in response to living the imposed caregiver experience (i.e., triggered by the medical diagnosis of a family member). The above documented themes support this major caregiver change in that they described an eventual learning: to let go of control and becoming more present oriented, to change their expectations of the primary relationship, to appreciate supportive features in the environment (i.e., individuals, groups and other resources), and to discover personal hope for the future.

2. Increasing Assertiveness:

In the themes above, caregivers described a number of behaviors that indicate the development of confidence and ability to be assertive. Such behaviors included: protecting self through active avoidance of triggers to “unhelpful advice”, seeking out supportive relationships, seeking opportunities to educate self on providing care and for personal coping, taking action to get CR needs met by the system, taking action to care for self, and participating in actions to make life better for caregivers in general.

3. Becoming System Savvy:

This major theme entails learning about the various care systems and how to navigate through them to get the services that a loved one requires. Caregivers reported developing the communication and political skills necessary to not be intimidated by the system and to enable assertion for their family members’ needs. Having gained and used these skills, caregivers then reported feeling that they had done their best to care for/help their loved one. For spouses, this was also described as satisfying because they had lived up to their marriage commitment to their partner.

4. Developing Caregiver Wisdom:

Over time these participants appeared to develop knowledge, skills, insight and judgment as caregivers. This caregiver wisdom appears to include—not only *factual* knowledge about their loved ones’ condition and care needs as well as practical skills in effectively providing care and working with the care systems—but *experiential* knowledge that can be gained only through living the primary caregiver life. Coming to value and take care of self was perceived as acting for the long-term well-being of both the loved one and self. Ultimately, experienced caregivers recognized that they could not sacrifice their own health in caring for the loved one.

C. LIMITATIONS OF THE INITIATIVE

Potential limitations of this information gathering initiative should be noted. First, with respect to the above findings, input from some participants may have been limited by their lack of comfort in speaking out in a group situation. The attendance of three members of the ACA plus the facilitator may also have contributed to this lack of comfort in speaking within the discussion group format. Second, the information gathering initiative was limited to those who are connected with a caregiver support group and therefore may not be reflective of the issues, strengths, and needs of those who do not join such groups. Finally, project findings are specific to this participant sample and not directly generalizable to other caregiver samples or populations of primary caregivers. It should be noted, however, that the results do provide valid direction for these specific caregivers and offer guidance on the potential issues, strengths, and needs of caregivers in general.

D. MAIN RECOMMENDATIONS IDENTIFIED BY FAMILY CAREGIVERS FOR A BETTER LIFE

Primary caregivers across all eight focus groups identified the following key needs, which when met would facilitate primary caregivers in general in our society to have a better life.

- 1. Peer education and peer support for primary caregivers.**
 - Provide peer education and support about the lived experience of being a primary caregiver
 - Provide specific peer education and support on navigating the service systems involved in the care of adult family members living with chronic conditions
- 2. Focused information and resources for and about primary caregivers.**
 - Develop a central resource for primary caregivers and for information about primary caregivers (e.g., maintain a databank on family caregivers needs, issues etc.).
 - Advocate for and develop programs that provide a range of appropriate respite for caregivers to enable the healthy coping of the family unit.
- 3. Increase societal understanding of caregivers' roles through raising the public profile of primary caregivers and their issues, strengths, and needs.**
- 4. Educate health professionals about the caregiver experience and the wisdom that caregivers have and can contribute as part of the care team.**
- 5. Advocate for system changes to ease the issues faced by primary caregivers and enhance the quality of life for caregivers and their care recipients.**

IV SUMMARY AND CONCLUSION

The main findings of this project suggest that there are common issues faced by primary caregivers of adult loved ones, regardless of disease condition. Furthermore, those issues need to be addressed to ensure the health and well-being of the family unit in coping with chronic conditions as greater demands from an aging population are placed on them in the face of stressed public service systems. To that end, these caregivers view peer education and peer support as fundamental for those living the family caregiver role.

Moreover, heightened public awareness about the issues is also essential to raise the general understanding of society about the vital contributions of primary caregivers. Raising such public understanding could help shine a light on the need for policy and system changes to reduce the stressors experienced by those in primary caregiver roles, both now and in the future, for the ultimate benefit of the whole family.

