

The Caregiving Experience

Providing care for someone in need is no easy task and a sizable portion of CARP's membership is familiar with the process. More than four in ten (41%) CARP members is currently a caregiver while just under six in ten (59%) of members stated that they were currently not a caregiver.

Less than one in five (19%) members is caring for someone with a physical disability while three in every twenty (15%) members is providing care for someone with dementia. This number is likely to increase over time as members get older. Alternatively put: (46%) of all current caregivers within CARP are caring for someone with a physical disability while (37%) of all current caregivers are caring for someone with dementia.

<i>“Are you yourself a caregiver of someone with one of the following disabilities?” (Check all that apply)</i>	
Answer Choices	Responses
A physical disability	18.98%
Dementia	15.43%
Mental illness	3.03%
Cancer	4.57%
Terminal illness	1.97%
Episodic illness	2.74%
Chronic conditions (ongoing lifelong disease ex: Multiple Sclerosis)	7.82%
No, I am currently not caring for someone with a disability	46.00%
No, but I have been a caregiver in the past 5 years	13.16%
Other (please specify)	12.76%
Total	100%

Almost nine in ten (87%) caregivers are looking after just one person while just over one in ten (13%) is providing care to two people or more.

<i>“How many people are you the primary caregiver for?”</i>	
Answer Choices	Responses
1	87.48%
2	10.37%
3	1.36%
4	0.24%
5	0.00%
6+	0.56%
Total	100%

Almost half (48%) of CARP members are caring for their spouse or partner, while roughly one in three (29%) is providing care to their parent(s).

<i>“What is your relationship with that person(s)? They are your...”</i>	
Answer Choices	Responses
Parent	29.49%
Child	7.50%
Sibling	3.32%
Spouse or Partner	48.31
Non-Immediate family member (ex: aunt, cousin)	4.11%
Friend	7.43%
Other (if so please tell us)	7.50%
Total	100%

Over half of respondents (52%) are providing care to someone in need twenty hours or less a week while less than one in three (29%) is providing care to someone in need for more than forty hours a week.

<i>“How many hours a week would you say you provide care to someone in need?”</i>	
Answer Choices	Responses
Five hours or less	22.34%
Eleven to twenty hours	29.99%
Twenty-one to thirty hours	11.68%
Thirty One to forty hours	6.87%
More than forty hours	29.12%
Total	100%

Sole caregivers spend significantly more time providing care than assisted-caregivers with over (35%) working more than 40 hours per week. Among assisted-caregivers, less than one in four (24%) were spending more than forty hours a week providing care.

<i>“How many hours a week would you say you provide care to someone in need?”</i>						
	Five hours or less	Eleven to twenty hours	Twenty-one to thirty hours	Thirty-one to forty hours	More than forty hours	Total
Yes I have Assistance	26.32%*	34.44%*	9.62%	6.02%	23.61%	100%
No I am a sole caregiver	17.29%	25.08%	14.24%*	7.97%*	35.42%*	100%

* Statistically significant at the 95% confidence level ($p < 0.05$).

Caregivers are quite stressed overall. When asked to rate their level of stress on a scale from one to five (one meaning very low levels of stress while five meaning very high levels of stress), the average (or mean) response was 3.5 with over half of respondents (54%) rating their stress levels as a four or higher while less than one in ten (7%) rated their stress levels at one.

<i>“On a scale from one to five, how much stress does being a caregiver have on your day-to-day living (one meaning very little stress while five indicates very high levels of stress)?”</i>							
	1	2	3	4	5	Total	Weighted Average
	7.27%	10.23%	28.98%	32.19%	21.33%	100%	3.50

Responses from the survey highlight female caregivers experience greater levels of stress than their male counterparts, with women having a higher mean stress-score than men. When members were asked to scale their stress levels, the relationship between men and women was statistically significant.

These differences were pronounced at the two ends of the stress-scale with a greater percentage of men rating their levels of stress at one while a greater percentage of women rated their levels of stress at five. The statistical significance shows that the differences in the percentages between men and women are not a result of chance.

<i>“On a scale from one to five, how much stress does being a caregiver have on your day-to-day living?”</i>							
	1	2	3	4	5	Total	Average
Men	11.94%*	12.47%	29.44%	31.83%	14.32%*	100%	3.24
Women	4.65%*	9.71%	29.14%	30.64%	25.85%*	100%	3.63

* Statistically significant at the 95% confidence level ($p < 0.05$).

Less than one in five members (18%) has experienced issues with employment as a result of providing care. Those who have experienced issues with employment were asked to rate the intensity of their workplace or employment issues on a scale from one to five. The mean score of respondents was 3.32 with less than half (45%) rating their workplace intensity at a four or higher. This means that while most caregivers are not experiencing a lot of difficulty in the workplace, those who are experiencing difficulty experience a lot of it.

<i>“Have you ever experienced issues with employment as a result of providing care? (ex: forced to work fewer hours, treated differently due to missed hours, or even resigned due to time commitments for care)?”</i>							
Answer Choices				Responses			
Yes				18.31%			
No				81.66%			
Total				100%			
<i>“On a scale from one to five, how would you rate the intensity of your workplace or employment issues?”</i>							
	1	2	3	4	5	Total	Weighted Average
	13.30%	12.02%	29.18%	20.17%	25.32%	100%	3.32

Providing care to someone in need can take a toll on the physical health of the caregiver them self. Roughly half (48%) of caregivers have experienced health issues, at least in part, due to the provision of care. When asked to rate the level of impact caregiving has had on their physical health, the mean score was 3.67 while over half (55%) of respondents rated the impact caregiving has had on their health as a four or higher.

<i>“Did you begin to experience health issues, at least in part, due to the provision of care?”</i>							
Answer Choices				Responses			
Yes				48.20%			
No				51.80%			
Total				100%			
<i>“On a scale of one to five, how much of an impact has being a caregiver had on your physical health and well being? (One meaning very little impact while five indicates very large impact)”</i>							
	1	2	3	4	5	Total	Weighted Average
	0.49%	3.44%	35.88%	34.09%	21.10%	100%	3.67

When the findings from whether respondents experienced health issues were cross tabulated with respondents' age, significance was found in members ages 76 and older. Contrary to the assumptions guiding this cross tabulations, respondents over the age of 76 experienced significantly less likely to report that they had experienced health issues, at least in part, due to their provision of care.

<i>“Please select one of the ranges below that best reflects your age”</i>								
	Under 50	50-55	56-60	61-65	66-70	71-75	76+	Total
Yes	0.00%	2.40%	7.93%	19.19%	26.38%	24.35%	19.74%*	100%
No	0.17%	1.22%	5.22%	15.13%	28.70%	24.52%	25.04%*	100%

*Statistically significant at the 95% confidence level ($p < 0.05$).

Providing care for someone in need can place a toll not only on caregivers' physical health and wellbeing, but also their wallets. More than six in ten (62%) respondents do not experience financially induced stress. However, among the four in ten (38%) that do experience financially induced stress, (57%) rated their level of stress levels at a four or higher. The mean stress-score for those who said they were experiencing financially induced stress was 3.67.

<i>“Do the financial strains associated with being a caregiver ever contribute to your stress levels?”</i>							
Answer Choices				Responses			
Yes				37.65%			
No				62.35%			
Total				100%			
<i>“On a scale of one to five, how would you rate that level of stress? (One meaning very little impact while five indicates very large impact)”</i>							
	1	2	3	4	5	Total	Weighted Average
	1.23%	8.64%	32.92%	36.42%	20.78%	100%	3.67

Caregiving at Large

Overall, those who provide care for someone in need with the assistance of formal care or homecare are generally satisfied with the level of care they receive. However, there are differences between those who use formalcare and those who use homecare.

<i>“For the individual(s) that you are caring for, can you please tell us whether the care they need is being provided to them in their own home, a more formal institution such as a nursing facility, or are they not receiving care at all? (please check the one that best applies – some people know more than one person who requires care)”</i>	
Answer Choices	Responses
Homecare	57.26%
Formalcare	16.76%
None of the above	25.98%
Total	100%

Homecare is a more widely utilized option for CARP members with almost six in ten (57%) stating that the individual they are caring for is receiving the care they need in their own home. Just over three in twenty (17%) members is receiving care in a formal institution such as a nursing home. It is also interesting to note that over one in four (26%) of members reported that the individual they are looking after is not receiving any specialized form of care at all. It may be wise for CARP to communicate to these members in particular if a homecare advocacy campaign or strategy is put into place as these members may be more likely to utilize homecare as an option if it was more accessible or practical.

<i>“How satisfied are you with the level of care they are receiving at that institution?”</i>	
Answer Choices	Responses
Very satisfied	43.91%
Somewhat satisfied	42.61%
Somewhat dissatisfied	12.17%
Very dissatisfied	1.30%
Total	100%
<i>“How long did the individual requiring care have to wait to be admitted to the facility?”</i>	
Answer Choices	Responses
Less than a month	38.84%
Two to six months	27.68%
Six months to a year	16.52%
One year to two years	6.25%
Two years or more	7.59%
Still waiting	3.13%
Total	100%

Among those who are providing care to someone in a formal institution such as a nursing home, the overall levels of satisfaction are quite high with almost nine in ten (87%) being either somewhat or very satisfied with the option. Additionally, more than six in ten (67%) members waited six months or less to admit the individual(s) they are caring for into a facility.

<i>“How satisfied are you with the level of care they are receiving in their own home?”</i>	
Answer Choices	Responses
Very satisfied	43.14%
Somewhat satisfied	38.11%
Somewhat dissatisfied	15.09%
Very dissatisfied	3.65%
Total	100%
<i>“How much difficulty did you go through to find the appropriate assistance you needed for homecare?”</i>	
Answer Choices	Responses
Extremely difficult	19.77%
Somewhat difficult	39.97%
Not very difficult	26.36%
Not at all difficult	13.90%
No difficulty at all	0.00%
Total	100%

Homecare experiences comparable levels of satisfaction as formal care with eight in ten (81%) members being either very or somewhat satisfied with their homecare option. Finding homecare, however, is not an easy task. One in five members (20%) stated that they found finding assistance for homecare to be extremely difficult while four in ten (40%) found the process to be somewhat difficult. Part of CARP’s homecare advocacy campaign/strategy should focus on ensuring that it is easier for members to find the assistance they need for homecare.

<i>“How satisfied are you with the level of care they are receiving in their own home?”</i>								
	Under 50	51-55	56-60	61-65	66-70	71-75	76+	Total
Very satisfied	0.00%	1.03%	4.14%	10.69%	28.97%	25.17%	30.00%*	100%
Somewhat satisfied	0.00%	1.61%	5.65%	18.15%*	27.42%	26.61%	20.56%	100%
Somewhat dissatisfied	0.00%	2.73%	8.18%	20.00%*	30.00%	20.00%	19.09%	100%
Very dissatisfied	0.00%	3.57%	14.29%	17.86%	39.29%	10.71%	14.29%	100%

*Statistically significant at the 95% confidence level ($p < 0.05$).

When evaluating the satisfaction of receiving care at home, caregivers ages 76 or older selected very satisfied significantly more than any other age groups, while respondents ages 61-65 had greater level of variance while straddling both the ‘Somewhat Satisfied’ and ‘Somewhat Dissatisfied’ categories. This would be an ideal target group to focus on should CARP undertake a homecare advocacy campaign/strategy.

<i>“If today you learned that you were to become a caregiver, do you believe that you would have the support networks or resources available to immediately help you in your role?”</i>	
Answer Choices	Responses
Yes	38.44%
No	61.55%
Total	100%
<i>“Is this because you do not have...?(check all that apply)”</i>	
Answer Choices	Responses
The workplace accommodations	7.44%
The time needed to provide care	14.32%
Anyone to help share the responsibilities of providing care	56.84%
The financial means to adequately provide care	39.37%
Other (please specify)	22.60%
Total	100%

When non-caregivers were asked if they found out that they had to become caregivers today, more than six in ten (62%) said they would not have the support networks or resources available to immediately help them in their role.

Among those who said they would not be prepared, almost six in ten members (57%) said they would not be prepared due to the lack of anyone to help share the responsibilities of providing care; while just under four in ten (39%) said they would not be prepared due to the lack of financial means to adequately provide care.

Although we do not have definitive evidence to prove it, we are of the belief that there could be a caregiving crisis among CARP members and among older Canadians at large. Those who are ages 61-70 will most likely become more vulnerable over time as a result of aging and the likelihood of someone they know developing an illness and will thus require care.

This finding is of vital importance to CARP Advocacy as a substantial portion of members are vulnerable to the pressures of caregiving if they were to become one. The inherent limitations placed on these non-caregivers withhold their efficacy and levels of care that they are able to provide, meaning that individuals who are forced to receive care from unprepared members may suffer. CARP Advocacy should take this finding into account and push for greater resources for potential caregivers to access if the situation presented itself.