



Respite Needs of People Living with Schizophrenia

Results of a National Survey of Schizophrenia Society of Canada Members



A REASON TO HOPE. THE MEANS TO COPE.
SCHIZOPHRENIA SOCIETY OF CANADA
SOCIÉTÉ CANADIENNE DE LA SCHIZOPHRÉNIE
UNE SOURCE D'ESPOIR, DE SOUTIEN ET D'ENTRAÏDE.

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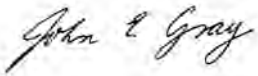
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TABLE OF CONTENTS

THE RESPITE PROJECT	5
INTRODUCTION AND PURPOSE	5
PROJECT ORGANIZATION	6
QUESTIONNAIRE DEVELOPMENT	6
SURVEY MAIL-OUT	7
RESPONSES	8
DATA MANAGEMENT AND ANALYSIS	8
WHAT CAREGIVERS SAID	9
WHO RESPONDED TO THE SURVEY	9
CHARACTERISTICS OF CAREGIVERS	9
CHARACTERISTICS OF CARE RECIPIENTS	10
THE CAREGIVER ROLE	12
COPING WITH CAREGIVING AND CAREGIVING SUPPORTS	15
PERCEIVED IMPACT OF CAREGIVING ON HEALTH AND QUALITY OF LIFE	16
TAKING A BREAK FROM CAREGIVING AND CAREGIVING SUPPORTS	19
SERVICES AND SUPPORTS	22
THE MEANING OF RESPITE	23
WHAT CARE RECIPIENTS SAID	24
WHO RESPONDED TO THE SURVEY	24
CHARACTERISTICS OF CARE RECIPIENTS	24
INFORMATION ABOUT COPING	25
SERVICES AND SUPPORTS NEEDED FOR BETTER ILLNESS MANAGEMENT	28
SUMMARY & IMPLICATIONS	29
SUMMARY OF FINDINGS FROM CAREGIVERS	29
SUMMARY OF FINDINGS FROM CARE RECIPIENTS	30
PROGRAM IMPLICATIONS	31
APPENDIX I – AUXILIARY TABLES CAREGIVER SURVEY	32
CHARACTERISTICS OF CARE RECIPIENTS	34
INFORMATION ABOUT THE CAREGIVER ROLE	37
IMPACT OF CAREGIVING	40
APPENDIX II – AUXILIARY TABLES CARE RECIPIENT SURVEY	41
CHARACTERISTICS OF RESPONDERS	41
INFORMATION ABOUT COPING	44
KINDS OF HELP RECEIVED	45
AREAS WHERE MORE HELP IS NEEDED	46
APPENDIX III – CAREGIVER SURVEY	47
APPENDIX IV – CARE RECIPIENT SURVEY	56
APPENDIX V – WHAT RESPITE MEANS TO FAMILY MEMBERS	61

THE RESPITE PROJECT

INTRODUCTION AND PURPOSE

This national survey was conducted by the Schizophrenia Society of Canada as part of a two-year project funded by the J.W. McConnell Family Foundation to document the respite needs of Schizophrenia Society of Canada members.

For over a decade, The J.W. McConnell Family Foundation has funded initiatives to better respond to the respite needs of family caregivers in Canada. In 1999, the McConnell Foundation launched a national initiative called the *Respite for Family Caregivers Program* in which respite was viewed as an outcome achieved by the caregiver when given a break away from the caregiving relationship, rather than any predefined replacement care service focused on the care receiver. From this perspective, respite is understood broadly, as anything that contributes to a caregiver’s emotional, spiritual, social, or physical rejuvenation, enabling them to have the resources they need to care for their disabled family member or friend. In addition to the principle of “respite as outcome”, two additional principles — that of voice and choice — underlie the respite projects funded by the J.W. McConnell Family Foundation. *Voice* recognizes the need for family members to be involved in the development of policies and services intended to benefit them. *Choice* refers to the importance of ensuring that available services and supports provide a range options from which users can select the ones that best address their needs and circumstances.

With these broad goals in mind, the Schizophrenia Society of Canada undertook two surveys to learn about the respite needs of its members. The first surveyed family caregivers, and the second, individuals living with a psychiatric disability. Having both perspectives of caregivers and care recipients makes this project unique. Information from these surveys will help the Schizophrenia Society of Canada develop an action plan to raise awareness about the importance of respite for people living with a psychiatric disability and advocate for programs and supports that will be responsive to their expressed needs.

PROJECT ORGANIZATION

The project was headed by a Project Director from the Schizophrenia Society of Canada. A Project Evaluator was contracted from Queen's University. A Project Advisory Committee composed of Schizophrenia Society members from different parts of Canada was created to help steer the project. Project staff and Project Advisory members had regular teleconference meetings. Once survey results were tabulated, a face-to-face workshop was held in Ottawa, between the Project Staff, the Project Advisory Committee, interested provincial representatives, and chief executive officers of the organization (including a Board Member, the President, and the Chief Executive Officer) to share results, obtain feedback, and develop an action plan. A representative of the Victorian Order of Nurses—the agency responsible to the McConnell Family Foundation for managing the Respite Family Project—also attended this meeting.

QUESTIONNAIRE DEVELOPMENT

A review of published literature and agency reports revealed little that addressed the respite needs of people living with a mental illness such as schizophrenia and no questionnaires could be found to meet our specific needs. Therefore, two questionnaires were developed for this project—one to assess caregiver respite needs (contained in Appendix III), the other to assess the respite needs of people living with schizophrenia (contained in Appendix IV). Broad concepts, and in some cases questions for these surveys, were abstracted from the available respite literature, much of which was targeted to the needs of families caring for elderly parents with Alzheimer's disease. Additional questions were developed by Project and Advisory group members.

Both surveys were entirely descriptive so did not contain scales requiring rigorous testing and validation. Questions were not formally pre-tested, but they were extensively reviewed by members of the Advisory Committee as well as other members of the organization and project staff for content, format, and wording. A communications expert provided advice on wording and formatting. French-language translations were undertaken by translators hired by the Schizophrenia Society of Canada and reviewed for content equivalence by bilingual project staff.

SURVEY MAIL-OUT

The national membership list was used to provide contact details for all registered members. Unfortunately, this list did not contain identifying data to allow us to differentiate members eligible for this survey (caregivers and care recipients) from other Society members—mental health providers and other patrons who provide financial support to the organization through their membership fees. Therefore, surveys were mailed to a sample of all members. All surveys included a stamped, self-addressed envelope to facilitate easy return.

To ensure even national coverage, a randomly selected sample from each of five regions was surveyed: British Columbia, the Prairie Provinces, Ontario, Quebec, and the Atlantic Provinces. In all areas but Quebec, 375 individuals were surveyed. In Quebec, the total membership of 315 was included.

With the exception of Quebec, each selected household received an insert in their regular national newsletter package containing both surveys. The surveys were colour coded and clearly marked for either a “Caregiver” or a “Care Recipient”. The Caregiver survey was directed to the primary caregiver, defined as the person in the household that provided the most care. Unique identification numbers were used to identify each returned survey. Two reminder notices were sent out several weeks apart to individuals who had not responded. In Quebec, the provincial Schizophrenia Society mailed out French-language versions of both surveys to all registered members with no follow-up reminders. The data collection plan received clearance from the Queen’s University Research Ethics Board signifying that the privacy and confidentiality of respondents was upheld, and that the data would be treated in ethically appropriate ways.

RESPONSES

A total of 534 completed surveys were received—362 from individuals who identified themselves as care providers, and 172 from individuals who identified themselves as care recipients. Three hundred and twenty-two members returned blank surveys indicating that they were neither caregivers or care recipients and an additional 102 surveys were returned with an unknown or invalid address.

Response rates could not be calculated because the number of members eligible to be surveyed could not be determined from the membership lists. The 534 completed surveys reflects approximately 38% of the sample (excluding those known to be ineligible from the return surveys, and those with invalid addresses). The sampling information is summarized in **Table 1**.

Table 1: Sampling Information

Region	All Members	Sample Selected	Returned Ineligible	Sample Remaining	Total Responding
BC	1,625	375	78	297	90
Prairies	1,092	375	96	279	121
Ontario	1,593	375	54	321	110
Quebec	315	315	8	307	102
Maritimes	395	375	86	289	108
Returned to sender	–	–	102	–	–
Missing region	–	–	–	–	3
Total	5,020	1,815	322	1,493	534

DATA MANAGEMENT AND ANALYSIS

Completed questionnaires were returned to the Schizophrenia Society of Canada. The unique study number linking the questionnaire to the membership directory was deleted from each survey to make them anonymous. Anonymized questionnaires were then sent to Queen's University researchers for data entry and analysis. Open-ended comments on the French-language surveys were translated into English for analysis. Translations were organized by the Schizophrenia Society of Canada and reviewed by a bilingual member of the project team.

WHAT CAREGIVERS SAID

WHO RESPONDED TO THE SURVEY

Three hundred and sixty-two family members responded to this national survey. Table 2 shows they were fairly evenly distributed across regions, with slightly more from the Prairie Provinces and Ontario. Relative to the membership as a whole, a greater proportion of family members in Quebec and the Atlantic provinces responded to the survey. It is estimated that approximately 60% of the membership are family members, however, this may vary from region to region.

Table 2: Region of Residence

Region of Canada	Respondents		Membership	
	Total	%	Total	%
British Columbia	66	18%	1,625	32%
Prairie Provinces	84	23%	1,092	22%
Ontario	81	23%	1,593	32%
Quebec	66	18%	315	6%
Atlantic Provinces	63	18%	395	8%
Total	360	100%	5,020	100%

CHARACTERISTICS OF CAREGIVERS

Responders were mostly female (80%) and ranged in age from 26 to 85 years. The average age was 63 years. Males ranged in age from 30 to 84 years with an average age of 66 years. Almost half of all respondents (41%) were beyond retirement age. The majority were married or living in a common-law relationship (68%). Just less than a third (29%) were widowed, separated or divorced, and 3% had never married. Almost half (44%) reported University-level education and 29% reported college or technical school. The remainder were predominantly high school trained (24%). Three percent had not proceeded beyond grade school.

The majority (61%) were not employed. Twenty-seven percent were employed on a full-time basis, 10% were employed part-time, and 3% reported occasional employment. Of the 221 family members (61%) who indicated they were not employed, the majority (87%) were retired. Twelve percent were homemakers and the remaining 2% reported they were disabled or unemployed. With the exception of age, where men were an average of about three years older than women, there were no gender differences in any of the remaining socio-demographic characteristics.

CHARACTERISTICS OF CARE RECIPIENTS

Caregivers were asked to provide descriptive information concerning their care recipients. Based on this information, care recipients were mostly male (80%) and ranged in age from 18 to 87 years with an average of 49 years. The majority were not married (79%). Twelve percent were married or living common-law and the remainder (9%) were separated, widowed, or divorced. Over half (55%) had a high school education or less. Twenty-one percent had received college or technical training and 25% had gone to university. Over a third (38%) were unemployed and a quarter (25%) were on disability. A quarter (26%) were employed: 5% on a full-time basis, 8% on a part-time basis, 9% on an occasional basis, and 4% in supported employment. A third (33%) lived alone and a quarter (23%) lived with their parents. Ten percent lived with relatives; either a spouse (8%) or another relative (2%), and 3% lived with friends. The remainder lived in supported housing (13%), a group home (10%) or other arrangements (8%).

Most (82%) had been given a diagnosis of schizophrenia by a doctor at some time in their lives. Twelve percent had received a diagnosis of depressive disorder and 4% an anxiety disorder. Less than once percent had received a diagnosis of substance abuse or other disorder. Almost one in five (18%) had received multiple diagnoses. Almost half (41%) received their first psychiatric treatment within the first year of symptoms appearing. The remainder waited from 1-33 years. When asked to compare their care recipient's current mental health to one year ago, a third (37%) thought that it had improved, half (51%) thought that it was about the same, and 11% thought that it had declined.

Table 3 shows the types of services used by care recipients (or family members on behalf of care recipients) in the year prior to the survey. The number of services used by care recipients ranged from 0-23. Almost half (45%) used between 2-5, and approximately a quarter (26%) used more than five. Seventeen percent did not use any of these services in the year prior to the survey, and 13% had used only one. The most common type of care (for about half of recipients) was medication management and individual therapy. Emergency services were used by approximately a third. Approximately one quarter were hospitalized or accessed case management services. Leisure and housing programs were used by about one in four and the remaining programs were used by one in ten care recipients or less. Over night respite programs were used by only one percent of the care recipients.

**Table 3: Services Used in the Past Year
(in descending order of frequency)**

Service	Total	%
Medication management	194	54%
Individual therapy	149	41%
Emergency or crisis services	114	32%
Inpatient hospitalization	102	28%
Case management	96	27%
Leisure or recreation program	78	22%
Housing or residential program	76	21%
Group therapy	48	13%
Transportation service	48	13%
Supported employment	46	13%
Education or training program	45	12%
Home visit program	42	12%
Assertive community treatment	39	11%
Family therapy	34	9%
Consumer group	33	9%
Day care program or day hospital	31	9%
Meal preparation or delivery	30	8%
Legal services	26	7%
Day program	24	7%
Home help	22	6%
Companionship program	16	4%
Over night respite program	6	1%
Consumer-run business	4	1%
Total	362	100%

THE CAREGIVER ROLE

The majority of responders were parents of a person with schizophrenia. Sixty-seven percent were mothers and 18% were fathers. The remainder were siblings (8%), spouses (4%) or other relatives or friends (3%). Some were new to caregiving, having been caregivers for less than a year. Others had been caregivers for up to 50 years. More than half had been providing care for a decade or more (median = 13 years).

For half (49%), the demands of caregiving fluctuated since they had become caregivers—sometimes they were high and sometimes they were low. For almost one in ten (9%), the demands of caregiving had steadily increased over time. One in four (25%) reported declining demands, and 16% indicated that demands had stayed about the same. In the year prior to the survey, however, caregiving responsibilities had changed little (**Table 4**), with about a third of respondents reporting that they provided regular care.

Table 4: Caregiving responsibilities over the last 3 months and 1 year

Caregiving Responsibilities	Past 3 Months		Past Year	
	Total	%	Total	%
24 hours a day	7	2%	8	3%
Full time (most days)	39	13%	41	13%
Part time (half the days)	49	16%	51	16%
Occasional (a few days)	117	38%	130	41%
Seldom (a few hours)	82	27%	75	24%
None	13	4%	10	3%
Total	307	100%	315	100%

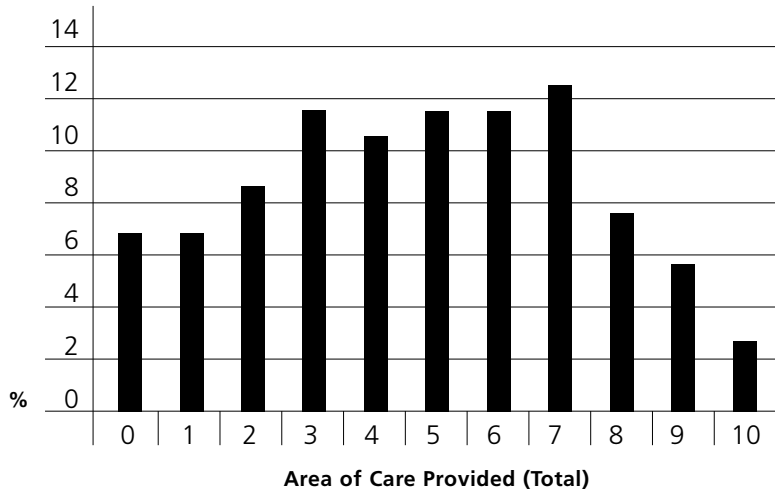
Table 5 shows the kinds of care provided in the three months prior to the survey in order of frequency. Providing emotional support was the most frequent type of care; provided by all but 15% of the sample. Half provided emotional support on a daily basis. All but about a third provided financial support and half helped to manage finances. Providing help with housework, general supervision, help with structuring time, and companionship outside of the home were also reported by approximately half of the responders. Approximately 40% coordinated health and mental health services, and 20% provided personal care. Fifteen percent helped to coordinate legal services.

Table 5: Kinds of care provided in the last 3 months (Total 362)

Type of Care	Daily	Weekly	Monthly	None Reported	Total
Emotional support (telephone checks, motivation)	50%	28%	7%	15%	100%
Financial support	18%	16%	30%	37%	100%
Managing finances	17%	15%	24%	43%	100%
Help with housework (laundry, shopping)	12%	25%	16%	47%	100%
General supervision	22%	19%	10%	49%	100%
Help with structuring time (organizing activities, maintaining outside contacts)	13%	22%	14%	51%	100%
Companionship (help with making friends, socializing outside of the home)	14%	20%	15%	51%	100%
Coordination of health and mental health services (making appointments, arranging services, transportation)	8%	9%	22%	61%	100%
Personal care (bathing, eating, dressing, taking medication)	10%	4%	3%	83%	100%
Coordination of legal services	3%	2%	9%	85%	100%

Figure 1 shows the amount of care provided in the previous three months by summing across the various care types. Seven percent of family members reported that they had not provided care in the past three months. One in five had provided care in most every area surveyed. The average family member provided care in five of the ten areas identified.

Figure 1: Amount of care provided in the previous 3 months



A summary score was created to evaluate the overall intensity of care provided. A score of 3 was assigned when an area of care was provided on a daily basis; a 2 was assigned when an area of care was provided on a weekly basis; a 1 was assigned when an area of care was provided on a monthly basis; and a 0 was assigned when no care was reported. Scores were then summed for each individual across all of the care items to provide an index of care intensity. The maximum score possible was 30, indicating that all of the ten services were provided on a daily basis. The minimum score possible was 0, indicating that no care was provided. **Table 6** summarizes these scores into four broad categories of intensity. Approximately 40% of family members had been providing either high or moderate intensity care in the three months prior to the survey.

Table 6: Intensity of Services Provided in the past 3 months

Intensity of Care	Total	%
No care provided (0)	25	7%
Lower intensity (1-10)	188	52%
Moderate intensity (11-20)	121	33%
High intensity (21-30)	28	8%
Total	362	100%

COPING WITH CAREGIVING AND CAREGIVING SUPPORTS

Three quarters of family members experienced some difficulty coping with their caregiver role and one in ten indicated they were experiencing great difficulty. Almost a quarter reported that they were often overwhelmed or stressed out because of the demands of caregiving.

Table 7 shows that a minority of family members felt they had consistent supports necessary to help them in their caregiving role. For example, over a third reported that they never or rarely had enough practical help and close to half indicated that they never or rarely had enough social support from their family or friends. Over half reported that they rarely or never get enough information and support from mental health providers, and the majority (65%) said that they never or rarely have enough time off from caregiving to pursue their own activities.

Table 7: Caregiving Supports

Are you getting enough...?	Rarely or Never		Sometimes		Most of the time	
	Total	%	Total	%	Total	%
Practical help from family and friends	130	37%	113	32%	107	30%
Social support from family and friends	159	45%	97	28%	97	28%
Information and support from mental health providers	167	48%	109	31%	74	21%
Time off from caregiving to pursue own activities	224	65%	75	22%	44	13%

PERCEIVED IMPACT OF CAREGIVING ON HEALTH AND QUALITY OF LIFE

Family members were asked whether their emotional health, physical health, and quality of life had changed as a result of caregiving (**Table 8**). Two-thirds reported some negative impact on their emotional health and quality of life and 44% reported some negative impact on their physical health. The most common impact on family members' emotional health (reported by over half) was that it fluctuated over time. However one in five reported a decline. Almost a quarter (23% or 84) reported that they were currently taking medications prescribed by a doctor or psychiatrist to help with their emotional health.

The most common experience with respect to physical health (reported by over half) was that it stayed the same; however almost a third indicated fluctuations and close to one in five reported a decline. Over half (53% or 192) reported taking prescription medication.

Table 8: Perceived Impact of Caregiving on Health and Quality of Life

Type of Change	Emotional Health		Physical Health		Quality of Life	
	Total	%	Total	%	Total	%
Improved	29	8%	6	2%	17	5%
Declined	57	16%	61	17%	96	28%
Stayed the same	84	24%	189	54%	111	32%
Fluctuates	181	51%	94	27%	122	35%
Total	351	100%	350	100%	346	100%

Concerning the impact of caregiving on quality of life, over a quarter reported that their quality of life had declined because of caregiving and a third reported fluctuations. The proportion of family members reporting improvements was small or negligible. If improvements were to occur, however, they were most likely to be emotional.

Table 9 shows the impact of caregiving on seventeen dimensions of life. The first six items refer to different aspects of personal care. In most cases, close to a third of family members reported that their caregiving role interferes with their ability to attend to their own health and wellness. The next block of items refers to social support and the ability to maintain relationships with family and friends. A third of family members reported that caregiving always or frequently interfered with these aspects of their social and family life. The next two items describe the impact of caregiving on employment. One in ten family members reported that their caregiving role always or frequently interfered with their employment schedules, although it should be noted that this item was not considered applicable by two-thirds of the responders. Approximately one third had frequent difficulties keeping up with household routines and chores. More than one third of the family members responding indicated that caregiving had frequently or always interfered with their future security and well-being in terms of planning for the future or saving money. Almost two-thirds thought that caregiving had frequently or always interfered with their peace of mind, and one third reported regular problems in maintaining a good quality of life.

Table 9: Frequency with which caregiving role interferes with different dimensions of life (%)

Dimension	Always	Frequently	Seldom	Never	% of*
Get enough rest	5%	26%	50%	18%	338
Maintain regular sleep	6%	22%	46%	26%	333
Pursue own interests	7%	31%	41%	21%	338
Have free time for self	7%	31%	41%	21%	337
Attend to physical health	7%	20%	40%	33%	335
Attend to emotional health	8%	29%	38%	26%	333
Maintain family relationships	8%	25%	36%	31%	332
Socialize with family or friends	8%	26%	40%	25%	333
Take a holiday	17%	25%	36%	22%	328
Maintain employment	6%	4%	28%	61%	137
Maintain regular work schedule	5%	10%	35%	50%	135
Keep up with household chores	8%	20%	37%	36%	328
Maintain family routines	7%	20%	48%	25%	335
Plan for the future	19%	26%	30%	25%	326
Save money	16%	20%	33%	31%	325
Have peace of mind	29%	33%	30%	8%	335
Maintain a good quality of life	11%	26%	43%	19%	333

*excludes non applicable and missing responses

Table 10 counts the number of times family members indicated that they “always” or “frequently” found that caregiving interfered with these aspects of their lives, grouped into four broad categories. Three quarters of responders reported significant impacts in one or more areas and 20% indicated impacts in more than 10 areas. The average (median) number of areas significantly affected was 4.

Table 10: Areas of life that are “always” or “frequently” interfered with because of caregiving

Number of areas impacted	Total	%
No areas impacted	92	25%
1-5 areas impacted	127	35%
6-10 areas impacted	72	20%
More than 10 areas impacted	71	20%
Total	362	100%

A summary score was created to evaluate the overall intensity of the impact that caregiving was perceived to have had. A score of 3 was assigned when a dimension “always” interfered; a 2 was assigned when a dimension “frequently” interfered; a 1 was assigned when an area of care “seldom” interfered; and a 0 was assigned when a dimension “never” interfered, or was left blank. The maximum score possible was 51 indicating relatively constant interference in every dimension of life.

Table 11 shows that more than one in ten family members found that caregiving interferes with most dimensions of their life to a moderately/high or high degree. Slightly more than a quarter reported moderate impact reflecting some impact in multiple areas. However, the majority (52%) had scores on the lower end of the spectrum indicating low/moderate or low impact. No impact was reported by less than one in ten family members.

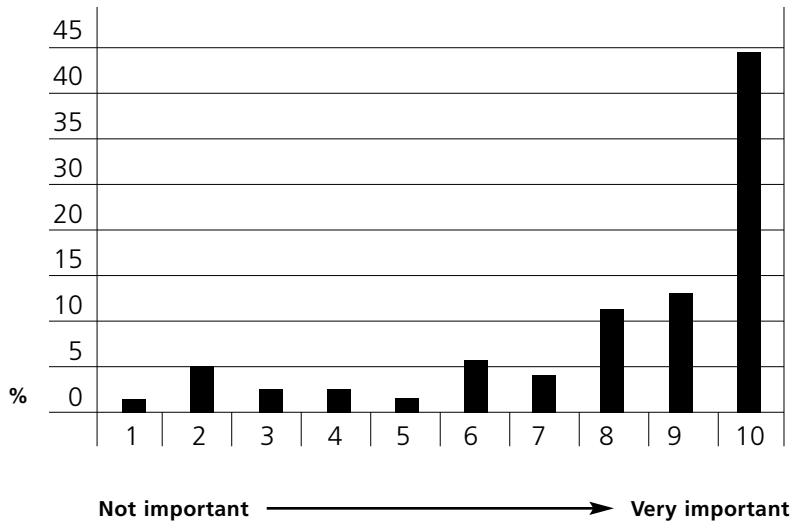
Table 11: Intensity of Impact of Caregiving

Intensity of Impact	Total	%
None reported (0)	27	7%
Low (1-10)	79	22%
Low/moderate (11-20)	110	30%
Moderate (21-30)	101	28%
Moderate/high (31-40)	37	10%
High (41-51)	8	2%
Total	362	100%

TAKING A BREAK FROM CAREGIVING AND CAREGIVING SUPPORTS

Having the opportunity to have a break from caregiving was highly rated. **Figure 2** shows that almost three quarters of the family members surveyed rated the importance of having a break from caregiving as 8 or higher on a 10-point scale of importance. Almost half gave it the highest possible rating.

Figure 2: Importance of having a break from caregiving



Family members were asked to specify what kind of break would be best suited to their current needs. Multiple responses were encouraged. Three quarters of responders indicated that some type of break was needed, and 10% chose more than one type.

Table 12 shows the types of breaks best suited to family members' current needs in order of priority. A quarter indicated that they did not currently require a break. Otherwise, the two most commonly identified breaks were blocks of days and a flexible break schedule that would vary in intensity according to the course of the illness. However, current needs spanned the entire gamut of possibilities and every type was endorsed by almost one in ten family members.

Table 12: Type of break best suited to current needs (multiple responses allowed)

Type of break	Total	%
Occasional breaks that last several days	101	31%
A flexible break schedule that varies in intensity according to the course of the illness	95	29%
Occasional full day breaks	31	9%
Regular over-night breaks	31	9%
Regular full-day breaks	31	9%
Regular daily breaks for a few hours a day	31	9%
Occasional daily breaks for a few hours a day	21	6%
No break needed	76	23%

Most family members could clearly identify a number of psycho-social benefits they would experience if given respite (a break) from caregiving. These are listed in **Table 13** in order of the frequency of responses. It should also be noted that some family members identified negative consequences to having a break from caregiving, but these were so infrequent (1-3%) that they have not been presented here. Similarly, some thought that having a break would have no effect on their emotional and family life. (A more complete breakdown of these items is contained in the tables in Appendix I.) Table 11 shows that having a break from caregiving would be expected to have far-reaching benefits across a wide range of emotional, social, instrumental, health, and quality of life dimensions.

Table 13: Psychosocial benefits of respite from caregiving

Area of Impact	Total	%
Peace of mind	215	71%
Emotional health	204	68%
Quality of life	210	67%
Quiet time	192	65%
Taking a holiday	191	65%
Physical health	177	60%
Interacting with friends	163	55%
Satisfaction with caregiving	155	54%
Interacting with family	144	50%
Keeping up with household chores	136	47%
Maintaining a close relationship with spouse	121	38%
Maintaining employment	38	11%

Family members were also asked to identify the types of services and supports that, if more available, would help them be more effective in their role as caregiver. **Table 14** lists these in order of the frequency of responses. The majority (87%) indicated that they required more or better access to one or more services (including respite services). Sixty-eight percent endorsed items relating to greater information and advice. Almost half (46%) indicated that they needed more social support and 37% indicated that they needed more respite—either time away from caregiving or more respite services.

Table 14: Services and supports that would help family members be more effective caregivers

Type of service	Total	%
Outreach and companionship programs to provide social opportunities for the person who is ill	182	56%
More open relationship with mental health staff and doctors regarding treatment options	175	54%
Financial compensation for caregiving expenses	130	40%
More information about respite services that are available in your community	110	34%
Greater social support from family and friends	108	33%
Better access to crisis and emergency services	90	28%
More respite services	88	27%
More information on effective caregiving	91	28%
More information about the illness	87	27%
Financial advice	87	27%
Help in managing service bureaucracies	87	27%
Advice on benefits	85	26%
Legal advice	84	26%
Support from other families with an ill relative (family support groups)	84	26%
More opportunities to take time out from caregiving	92	25%

SERVICES AND SUPPORTS

The majority of family members (83%) had never used a respite service. Of the seventeen percent that had, the majority (71% of 62) had only ever used one service. The remainder had used several different services (up to four). **Table 15** lists these in order of frequency. Other services and supports that were identified included long term care, group homes and assertive community programs, crisis centers and emergency care, and friends or family who took occasional responsibility for caregiving.

Table 15: Types of respite services used (% of 62 family members using any respite service)

Service	Total	%
A home visit program to provide interim care	25	40%
A home help program (to help with housework or yard work)	15	24%
A day program	12	19%
Over-night respite beds	10	16%
Other service or support	26	42%
Total	62	100%

Reasons for not using respite services varied (**Table 16**). Most commonly family members did not use respite services because the care recipient did not live in their home. The second most commonly cited reason was that family members had been able to get along without them. Close to a third did not know of any respite services in their community. One in five caregivers indicated that the person who received care was uncomfortable with outside respite services. One in ten said they were not eligible for respite services. Slightly fewer did not feel comfortable with turning care over to someone else. Poor quality services, or programs that were full, were infrequently identified as barriers to accessing respite care. Almost half (43%) identified multiple (two or more) barriers.

Table 16: Reasons for not using respite services (% of 300 family members who did not use any respite service)

Service	Total	%
Doesn't live in home	136	46%
Have gotten along without them	124	41%
I don't know of any	84	28%
Care recipient uncomfortable	54	18%
Not eligible	30	10%
I'm not comfortable	22	7%
The programs aren't very good	5	2%
The programs are full	2	1%
Total	300	100%

THE MEANING OF RESPITE

Family members were asked to tell us, in their own words, what respite would mean to them. A complete listing of their comments (slightly edited for grammar and spelling) is contained in Appendix V.

Overwhelmingly, they said rest and renewal without fear—a worry-free breather. For some, this meant a few hours a day when they could pursue their own interests, take a break from daily routines to recharge, and regroup. For others, it meant having a temporary replacement—someone who was knowledgeable about schizophrenia, caring, and who could be trusted to ensure that their loved ones were safe and happy. For still others, it meant a hiatus, a brief intermission, a block of time away to recharge and refresh. In many instances the meaning of respite included adequate rehabilitation and community supports to ensure that care recipients had a place to go where they could be happily involved in activities that were meaningful, interesting, and commensurate with their intelligence and skills. In other instances this meant opportunities for companionship and socialization, to help loved ones create emotional ties that transcended the caregiver role—opportunities to decrease emotional dependencies and enlarge social skills. In the words of the family members themselves...

Respite means to forget about schizophrenia for a while.

It means mental and physical rest

Rest and renewal

...refresh and recharge the emotional batteries

A time out from worry.

A replacement for me as a caregiver

A chance to get away from the routine by utilizing outside help.

A period of reduced responsibility.

A pause...a rest.

Rest from the daily grind of responsibility. A time when my needs/wishes come first.

Temporary freedom.

Freedom from worry, housework...time to pursue my interests.

A break from the constant concern.

Peace.

Peace of mind and complete trust.

Respite means having a safe and appropriate haven for my loved one.

It would be great if respite was recognized a necessity and given freely with a blessing for rest and renewal.

WHAT CARE RECIPIENTS SAID

WHO RESPONDED TO THE SURVEY

Schizophrenia Society of Canada members who have a mental illness were also surveyed. One hundred and seventy-two responded. Responders were fairly evenly distributed across the five regions of the country. Comparing to the total membership (which is composed of both family members and people who have schizophrenia), British Columbia and Ontario may have been under-represented, and Quebec and the Atlantic Provinces may have been over-represented in this sample.

Table 17: Region of Residence

Region of Canada	Sample		Membership	
	Total	%	Total	%
British Columbia	24	14%	1,625	32%
Prairie Provinces	37	22%	1,092	22%
Ontario	29	17%	1,593	32%
Quebec	36	21%	315	6%
Atlantic Provinces	42	25%	395	8%
Total	168	100%	5,020	100%

CHARACTERISTICS OF CARE RECIPIENTS

Care recipients who responded to this survey were mostly male (63%) and ranging in age from 19 to 84 years with an average age of 43 years. Three-quarters were single and had never been married. Fifteen percent were widowed, separated, or divorced. Eleven percent were married.

A third (32%) reported a University level education and 29% reported college or technical training. Almost half (40%) reported high school or less. Almost a third (32%) were employed outside the home, either in full-time work (8%), part time work (13%), occasional employment (6%), or supported employment (5%). An additional 8% were students. The majority (62%), were not in the workforce either because they were home-makers (4%), retired (6%), disabled (27%), or unemployed (25%).

Almost all (92%) had been diagnosed by a doctor at some time in their lives as having schizophrenia. Almost a third (30%) had received a diagnosis of depression at some time, and a quarter (24%) an anxiety disorder. Six percent had received a diagnosis of substance abuse and 5% had received other diagnoses. Just over a third (38%) had received more than one diagnosis in their lives. Most (81%) indicated they had come to accept their diagnosis.

Almost half (45%) had received treatment within the first year of their first symptoms. Almost one in five (19%) did not receive treatment for six years or longer. Five percent waited over 15 years. Half (51%) considered that their overall mental health was the same as it had been one year ago. Almost half (42%) considered that it was better and a small percentage (7%) thought that it was worse.

INFORMATION ABOUT COPING

One in five (21%) reported that they were not having difficulties coping with their illness. The majority were experiencing some difficulty (68%) or great difficulty (11%). For most (68%), their needs for help had remained about the same in the past year. Nineteen percent indicated that they needed more help now than a year ago, and 13% felt that they needed less.

Responders received support in helping them manage their illness from a variety of sources. Two main sources were family and mental health providers. For example, in a usual month, 79% received support from one or more mental health workers (including psychiatrists) and 72% received support from one or more family members. Just over a third (37%) received support from their family doctor, and slightly less (27%) received support from a friend.

Table 18 shows the types of help received. Responders most frequently received emotional support, companionship, and help with housework. Approximately one third received frequent help with managing finances, general supervision, structuring time, and coordinating health and mental health services. Approximately one in five reported receiving help with personal care; the majority of these on a daily basis.

Table 18: Types of help received (% of 172)

Service	Total	% Frequent Help*	% Daily Help
Emotional support	88	51%	20%
Companionship	78	45%	14%
Help with housework	73	43%	9%
Managing finances	65	38%	12%
General supervision	62	36%	18%
Structuring time	59	35%	16%
Coordination of services	57	33%	6%
Personal care	30	18%	12%

*refers to daily, weekly, or monthly help

Table 19 shows the range of services and supports used by responders during the year prior to the survey, as well as their overall assessment as to whether they had been useful. These are presented in order of frequency of use.

Table 19: Services and assessment of value

Service	Used Service % of 172 (total)	% of Users who Found Service to be of Considerable Value
Individual therapy	44% (76)	62%
Medication management	34% (59)	56%
Leisure or recreation program	20% (35)	71%
Transportation service	20% (34)	62%
Case management	20% (34)	47%
Inpatient hospitalization	19% (33)	39%
Emergency or crisis services	17% (29)	45%
Home help (housework or yard work)	15% (25)	60%
Group therapy	15% (25)	48%
Consumer group	15% (25)	93%
Supported employment/job training	14% (24)	50%
A home visit program	13% (23)	65%
Housing or residential program	13% (23)	61%
Meal preparation or delivery	11% (18)	78%
Educational or training program	10% (18)	72%
A day program	9% (15)	67%
Assertive community treatment	7% (12)	75%
Companionship program	5% (9)	56%
Family therapy	5% (9)	33%
Day care program or day hospital	5% (8)	38%
Consumer-run business	4% (7)	43%
Legal services	3% (6)	33%
Over night respite program	3% (5)	80%

Consumer groups were considered to be the most valued service by those who used them, but only 15% of responders had used a consumer group in the year prior to the survey. Similarly, most of those using over night respite programs reported them to be of considerable value, however only 5 individuals (3% of the sample) used them. Programs that were considered to be of least value included legal services (used by only 3%), family therapy (used by 5%), and day care or day hospital programs (used by 5%). Individual therapy and medication management were the most frequently used services and reported to be of considerable value by those who used them.

Table 20 shows the areas where responders reported that they rarely or never got enough help and support. The greatest deficiencies (reported by half) were with respect to support for education and training. Approximately one in four identified a need for more money for leisure activities, practical help around the house, and support to find a job. One in five reported that they rarely or never got enough information from mental health providers about treatment options or coping strategies, and approximately one in ten reported that they rarely or never received enough support from family, friends, or mental health providers.

Table 20: Areas where help received is rarely or never enough

Service	%	% out of total
Support to further education and training	44%	154
Money for leisure activities	27%	171
Practical help around the house	25%	166
Support to find a job	25%	167
Information from mental health providers	19%	168
Social support from family and friends	12%	170
Support from mental health providers	9%	166

SERVICES AND SUPPORTS NEEDED FOR BETTER ILLNESS MANAGEMENT

Responders identified a wide range of services and supports that they believed would help them better manage their illness (**Table 21**). Chief among these was the creation of better public attitudes toward people with a mental illness and the reduction of social stigma. Better access to traditional health and mental health services (such as family doctors or crisis services) were among the least frequently cited areas of need, being identified by only about one in ten responders.

Table 21: Services and supports that would help with illness management

Service or Support	Total (of 172)	Percent (of 172)
Better public attitudes toward people with a mental illness (less social stigma)	99	58%
More money for leisure time and recreation	92	54%
Better medications with less side effects	83	48%
More friends	75	44%
More support from other people who have a similar illness	53	31%
Help finding leisure and recreation activities	52	30%
More assistance in furthering education and training	48	28%
More information about my illness	44	26%
More assistance with transportation to and from places	40	23%
More emotional support from my friends	38	22%
A better relationship with my psychiatrist	36	21%
More emotional support from my family	34	20%
More mental health services	34	20%
More money for medical expenses	34	20%
More advice on financial planning	34	20%
More help getting a job	31	18%
Places to go overnight to take a break away from the people I live with	30	17%
More practical help around the house	27	16%
More legal advice	27	16%
More help finding a place to live	24	14%
A better relationship with the mental health centre staff	21	12%
Better access to a family doctor for medical treatment	21	12%
Better access to crisis and emergency services	21	12%
Better access to a family doctor for mental health treatment	17	10%
A better relationship with hospital staff	16	9%
More help taking my medications	5	3%

SUMMARY & IMPLICATIONS

SUMMARY OF FINDINGS FROM CAREGIVERS

The typical responder to our survey was an aging mother of a middle-aged son with schizophrenia who was not married, not working, and actively involved in the mental health treatment system.

Most commonly, the demands of caregiving fluctuated with the course of the illness. For about one in ten, the demands of caregiving had been steadily increasing. In the year prior to the survey, a third had been providing regular care (most every day) with little fluctuation in demands. In addition to emotional support, the most common types of care provided included financial support and assistance, help with instrumental activities (such as housekeeping), general supervision and time management, and social support. Almost half were actively involved in coordinating health and mental health care. One in four provided personal care (such as bathing or help with medications) and a smaller number helped coordinate legal services. Almost half of the family members responding were providing care and assistance in multiple areas.

Three quarters expressed some difficulties coping with their caregiving role—*sometimes* feeling overwhelmed or stressed out. One in ten expressed great difficulty, *often* feeling overwhelmed and stressed out. Social and practical support from family, friends and mental health providers was often lacking, and two-thirds rarely had enough time off from caregiving to pursue their own activities.

Three quarters of responders reported that caregiving had negatively impacted their life in one or more areas, and one in five reported pervasive impacts across multiple areas of functioning. For example, two-thirds reported that caregiving had negatively impacted their emotional health, and almost half felt that it had been detrimental to their physical health. A quarter felt that their quality of life had steadily declined since they began caregiving and a third felt that it fluctuated. Most often, caregiving interfered with family members' ability to attend to their own health and wellness, but there were also negative impacts on social support, family routines, and family functioning—often making it difficult to maintain relationships with family and friends.

The majority of family members felt that having a break from caregiving was highly important. They could envision a wide range of emotional, social, instrumental, health, and quality of life benefits. Most commonly, they felt that a flexible break schedule, including blocks of days away from caregiving, would be most helpful. While social support from family and friends, and better access to mental health services in times of need were the most frequently identified areas requiring improvement, almost a third indicated that they also needed more respite services.

More than three quarters of family members had never used a respite service, often expressing multiple reasons. In about half of the cases they did not use respite services because their care recipient did not live in their home. Half were reluctant because that they had gotten along without respite services so far, and almost a third didn't know of any services in their community. One in five indicated that their care recipient felt uncomfortable accessing outside respite services and one in ten said they weren't eligible for support and a slightly smaller number of care providers expressed similar discomfort.

SUMMARY OF FINDINGS FROM CARE RECIPIENTS

The typical responder to our survey of people living with schizophrenia was a middle-aged male who was single and not employed. While virtually all had received a diagnosis of schizophrenia from a doctor, over a third had received another diagnosis at some time in their lives. Half had waited over a year from the time they first experienced symptoms until the time they first received treatment, with the wait times ranging from 1 year to 38 years. The majority had come to accept their diagnosis. Almost half had noted improvements in their mental health over the past year. Despite this, the majority reported they were still having difficulty coping with their illness. Most (68%) felt that their needs for assistance hadn't changed over the past year, but almost one in five thought that they needed more help.

The most frequently cited sources of help in managing their illness were mental health providers, such as psychiatrists or caseworkers, and family members. In a typical month, 79% received help from mental health professionals and approximately the same proportion (72%) received help from family members. Most often (about half the time), responders received emotional support, companionship, and help with housework. One third received help with managing finances, general supervision, structuring time, and coordination of services. A small proportion (18%) received help with personal care.

In addition, responders had used a number of services in the year prior to the survey. The most frequently used were individual therapy (used by almost half) and medication management (used by a third), whereas the least frequently used services were over night respite (3%), legal services (3%), and consumer-run businesses (4%). The most valued, but often the least accessed services were consumer run groups (valued by 93% of the 25 users) and over night respite programs (valued by 80% of the 5 users).

The most frequently identified area of need—where help was rarely or never enough—was support for further education and training (44%). Approximately a quarter needed more money for leisure activities, more practical help around the house, and more support to find a job. More information from mental health providers was identified as a need by approximately one in four. Approximately one in ten said they rarely had enough support from family, friends, or mental health providers.

Finally, respondents identified a wide range of supports and services that would help them manage their illness better and achieve better social integration. At the top of the list, identified by half or more, were better public attitudes toward people with mental illnesses (58%), more money for leisure time and recreation (54%), and better medications with less side effects (48%). At the bottom of the list were supports and services related to medical and mental health management such as help with taking medications (3%), a better relationship with hospital staff (9%), or better access to a family doctor (10%).

PROGRAM IMPLICATIONS

Based on the results from these surveys, the following respite supports should be given high priority:

- companionship programs that address the social, emotional, and leisure needs of people who have schizophrenia while at the same time meeting the respite needs of their care-givers,
- flexible in-home supports for care-givers and care-recipients that are (a) provided by people who are knowledgeable about schizophrenia, (b) acceptable to care recipients, (c) acceptable to care providers, and (d) easily titrated to meet changing needs,
- partial and full day programs that provide a safe and stimulating environment for people with schizophrenia to further their education, training, and job preparedness,
- over night beds that can be easily accessed by people with schizophrenia to provide respite from their usual care-giving environment and/or added supports in times of greater need.

APPENDIX I > AUXILIARY TABLES CAREGIVER SURVEY

CAREGIVER SURVEY CHARACTERISTICS OF RESPONDENTS

Characteristic	Total	Percent
Gender <ul style="list-style-type: none"> • Male • Female • Missing 	74 287 1	21% 80% –
Age group <ul style="list-style-type: none"> • 26-35 years • 36-45 years • 46-55 years • 56-65 years • 66-75 years • 76-85 years • Missing 	4 14 65 126 104 41 8	1% 4% 18% 36% 29% 12% –
Marital status <ul style="list-style-type: none"> • Married or common-law • Widowed, separated, or divorced • Single (never married) • Missing responses 	246 104 12 0	68% 29% 3% –
Highest level of education <ul style="list-style-type: none"> • Grade school • High school • College or technical school • University • Missing responses 	12 85 103 59 3	3% 24% 29% 44% –

Province of residence		
• British Columbia	66	18%
• Alberta	56	16%
• Saskatchewan	11	3%
• Manitoba	17	5%
• Ontario	81	23%
• Quebec	66	18%
• New Brunswick	14	4%
• Nova Scotia	30	8%
• Newfoundland	10	3%
• Prince Edward Island	9	3%
• Missing responses	2	–
Employed outside the home		
• Full time employment	97	27%
• Part time employment	35	10%
• Occasional employment	9	3%
• Not employed	221	61%
• Missing responses	0	–
Type of Unemployment		
• Retired	189	87%
• Homemaker	25	12%
• Unemployed	1	1%
• Disabled	3	1%
• Employed	141	–
• Missing responses	0	–

CHARACTERISTICS OF CARE RECIPIENTS

Characteristic	Total	Percent
Gender <ul style="list-style-type: none"> • Male • Female • Missing 	279 71 12	80% 20% –
Age group <ul style="list-style-type: none"> • 10 years old or less • 11-25 years • 26-35 years • 36-45 years • Missing 	11 288 34 7 22	3% 85% 10% 2% –
Marital status <ul style="list-style-type: none"> • Married or common-law • Widowed, separated, or divorced • Single (never married) • Missing 	43 30 279 13	12% 9% 79% –
Highest level of education <ul style="list-style-type: none"> • Grade school • High school • College or technical school • University • Missing 	28 165 73 83 13	8% 47% 21% 24% –

<p>Employment Status</p> <ul style="list-style-type: none"> • Employed full-time • Employed part-time • Occasional employment • Supported employment • Full-time student • Part-time student • Homemaker • Retired • Disabled • Unemployed • Missing 	<p>17 27 32 15 9 14 6 7 85 132 18</p>	<p>5% 8% 9% 4% 3% 4% 2% 2% 25% 38% –</p>
<p>Current living arrangement</p> <ul style="list-style-type: none"> • Parents • Spouse • Other relatives • Friends • Supported housing • Group home • Alone • Other • Missing 	<p>81 27 8 9 45 35 114 27 16</p>	<p>23% 8% 2% 3% 13% 10% 33% 8% –</p>
<p>Diagnoses given by a doctor (multiple responses allowed – each out of 100%)</p> <ul style="list-style-type: none"> • A form of schizophrenia • A depressive disorder • An anxiety disorder • A substance abuse disorder • Other 	<p>288 43 14 4 1</p>	<p>82% 12% 4% 1% <1%</p>

<p>Number of diagnoses received</p> <ul style="list-style-type: none"> • 1 • 2 • 3 • 4 • 5 • Missing 	<p>288</p> <p>43</p> <p>14</p> <p>4</p> <p>1</p> <p>12</p>	<p>82%</p> <p>12%</p> <p>4%</p> <p>1%</p> <p><1%</p> <p>–</p>
<p>Time until first psychiatric treatment (following the first appearance of symptoms)</p> <ul style="list-style-type: none"> • Within the year • 1 year • 2 years • 3 years • 4 years • 5 years • 6-10 years • 11-15 years • 16-20 years • Over 20 years • Missing 	<p>138</p> <p>53</p> <p>24</p> <p>21</p> <p>13</p> <p>17</p> <p>42</p> <p>8</p> <p>7</p> <p>11</p> <p>28</p>	<p>41%</p> <p>16%</p> <p>7%</p> <p>6%</p> <p>4%</p> <p>5%</p> <p>13%</p> <p>2%</p> <p>2%</p> <p>3%</p> <p>–</p>
<p>Care recipient's mental health compared to one year ago</p> <ul style="list-style-type: none"> • Better • Worse • About the same • Missing 	<p>130</p> <p>39</p> <p>179</p> <p>14</p>	<p>37%</p> <p>11%</p> <p>51%</p> <p>–</p>
<p>Number of services used in the year prior to the survey</p> <ul style="list-style-type: none"> • None • 1 • 2-5 • 6-10 • More than 10 • Missing 	<p>62</p> <p>47</p> <p>162</p> <p>79</p> <p>12</p> <p>0</p>	<p>17%</p> <p>13%</p> <p>45%</p> <p>23%</p> <p>3%</p> <p>–</p>

INFORMATION ABOUT THE CAREGIVER ROLE

Characteristic	Total	Percent
<p>Responders relationship to the person receiving care</p> <ul style="list-style-type: none"> • Mother • Father • Brother or sister • Spouse • Other relative or friend • Missing 	<p>238</p> <p>62</p> <p>29</p> <p>14</p> <p>12</p> <p>7</p>	<p>67%</p> <p>18%</p> <p>8%</p> <p>4%</p> <p>3%</p> <p>–</p>
<p>Length of time care has been provided</p> <ul style="list-style-type: none"> • Less than 5 years • 6-10 years • 11-15 years • 16-20 years • 21-25 years • Over 25 years • Missing 	<p>53</p> <p>83</p> <p>62</p> <p>60</p> <p>36</p> <p>34</p> <p>34</p>	<p>16%</p> <p>25%</p> <p>19%</p> <p>18%</p> <p>11%</p> <p>10%</p> <p>–</p>
<p>Living proximity</p> <ul style="list-style-type: none"> • Live in the same house • Live in the same city • Live within a 2 hour drive • Live more than 2 hours away • Missing 	<p>99</p> <p>163</p> <p>67</p> <p>21</p> <p>12</p>	<p>28%</p> <p>47%</p> <p>19%</p> <p>6%</p> <p>–</p>
<p>Demands of caregiving since caregiving began</p> <ul style="list-style-type: none"> • Demands have steadily increased • Demands have steadily decreased • Demands have stayed the same • Demands fluctuate • Missing 	<p>32</p> <p>86</p> <p>56</p> <p>168</p> <p>20</p>	<p>9%</p> <p>25%</p> <p>16%</p> <p>49%</p> <p>–</p>

<p>Usual caregiving responsibilities during the past 3 months</p> <ul style="list-style-type: none"> • 24 hours a day • Full time (most days) • Part time (half the days) • Occasional (a few days) • Seldom (a few hours) • None • Missing 	<p>7 39 49 117 82 13 55</p>	<p>2% 13% 16% 38% 27% 4% –</p>
<p>Usual caregiving responsibilities during the past 12 months</p> <ul style="list-style-type: none"> • 24 hours a day • Full time (most days) • Part time (half the days) • Occasional (a few days) • Seldom (a few hours) • None • Missing 	<p>8 41 51 130 75 10 47</p>	<p>3% 13% 16% 41% 24% 3% –</p>
<p>Type of care (provided in the past 3 months (multiple responses each out of 100%))</p> <ul style="list-style-type: none"> • Personal care • Help with housework • Coordination of health & mental health services • Emotional support • Help structuring time • Companionship • Managing finances • General supervision • Financial support • Coordination of legal services 	<p>62 191 141 308 177 177 206 185 228 54</p>	<p>17% 53% 39% 85% 49% 49% 57% 51% 63% 15%</p>

Amount of care provided in the past 3 months		
• None	25	7%
• 1 area	24	7%
• 2 areas	31	9%
• 3 areas	45	12%
• 4 areas	41	11%
• 5 areas	43	12%
• 6 areas	44	12%
• 7 areas	48	13%
• 8 areas	30	8%
• 9 areas	21	6%
• 10 areas	10	3%

IMPACT OF TIME OUT FROM CAREGIVING SURVEY

Description	Type of Impact % (total)			
	Positive	Negative	No Impact*	Unsure
Your quiet time	65% (192)	2% (6)	29% (85)	5% (14)
Keeping up with household chores	47% (136)	3% (8)	45% (129)	6% (17)
Interacting with your friends	55% (163)	1% (4)	37% (110)	6% (18)
Maintaining employment	11% (38)	<1% (1)	86% (292)	2% (7)
Maintaining a close relationship with your spouse	38% (121)	1% (3)	58% (183)	3% (10)
Interacting with your family	50% (144)	1% (3)	43% (123)	6% (18)
Taking a holiday	65% (191)	3% (8)	26% (75)	7% (20)
Your satisfaction with caregiving	54% (155)	3% (9)	30% (84)	13% (37)
Your overall emotional health	68% (204)	1% (4)	19% (57)	11% (33)
Your overall physical health	60% (177)	1% (4)	28% (84)	11% (31)
Your peace of mind	71% (215)	3% (8)	18% (55)	9% (26)
Your quality of life	67% (201)	2% (5)	23% (70)	8% (23)
*includes "not-applicable"				

APPENDIX II > AUXILIARY TABLES CARE RECIPIENT SURVEY

CHARACTERISTICS OF RESPONDERS

Characteristic	Total	Percent
Gender <ul style="list-style-type: none"> • Male • Female • Missing 	<p>108</p> <p>64</p> <p>0</p>	<p>63%</p> <p>37%</p> <p>–</p>
Age group <ul style="list-style-type: none"> • 15-25 years • 26-35 years • 36-45 years • 46-55 years • 56-65 years • 66-75 years • 76-85 years • Missing 	<p>12</p> <p>39</p> <p>51</p> <p>45</p> <p>19</p> <p>3</p> <p>2</p> <p>1</p>	<p>7%</p> <p>23%</p> <p>30%</p> <p>26%</p> <p>11%</p> <p>2%</p> <p>1%</p> <p>–</p>
Marital status <ul style="list-style-type: none"> • Married or common-law • Widowed, separated, or divorced • Single (never married) • Missing responses 	<p>19</p> <p>26</p> <p>127</p> <p>0</p>	<p>11%</p> <p>15%</p> <p>74%</p> <p>–</p>
Highest level of education <ul style="list-style-type: none"> • Grade school • High school • College or technical school • University • Missing responses 	<p>7</p> <p>61</p> <p>49</p> <p>54</p> <p>1</p>	<p>4%</p> <p>36%</p> <p>29%</p> <p>32%</p> <p>–</p>

Province of residence		
• British Columbia	24	14%
• Alberta	27	16%
• Saskatchewan	3	2%
• Manitoba	7	4%
• Ontario	29	17%
• Quebec	36	21%
• New Brunswick	8	5%
• Nova Scotia	31	18%
• Newfoundland	3	2%
• Prince Edward Island	3	2%
• Missing responses	1	–
Employed outside the home		
• Full time employment	14	8%
• Part time employment	22	13%
• Occasional employment	10	6%
• Supported employment	8	5%
• Full time student	5	3%
• Part time student	8	5%
• Homemaker	6	4%
• Retired	10	6%
• Disabled	46	27%
• Unemployed	42	25%
• Missing responses	1	–
Current Living Arrangement		
• Live with parents	39	23%
• Live with spouse	18	11%
• Live with other relatives	1	1%
• Live with friends	5	3%
• Live in supported housing	19	11%
• Live in group home	15	9%
• Live alone	65	38%
• Other	10	6%
• Missing responses	0	–
Due to rounding, not all numbers total 100%		

<p>Diagnoses given by a doctor (multiple responses allowed – each out of 100%)</p> <ul style="list-style-type: none"> • A form of schizophrenia 159 92% • A depressive disorder 51 30% • An anxiety disorder 42 24% • A substance abuse disorder 11 6% • Other 5 5% 		
<p>Number of diagnoses received</p> <ul style="list-style-type: none"> • 1 106 62% • 2 35 20% • 3 26 15% • 4 4 2% • Missing 1 – 		
<p>Time until first psychiatric treatment (following the first appearance of symptoms)</p> <ul style="list-style-type: none"> • Within the year 75 45% • 1 year 24 15% • 2 years 13 8% • 3 years 7 4% • 4 years 8 5% • 5 years 7 4% • 6-10 years 14 8% • 11-15 years 10 6% • 16-20 years 3 2% • Over 20 years 5 3% • Missing 6 – 		
<p>Care recipient's mental health compared to one year ago</p> <ul style="list-style-type: none"> • Better 71 42% • Worse 11 7% • About the same 86 51% • Missing 4 – 		
<p>Have come to accept diagnosis</p> <ul style="list-style-type: none"> • Yes 137 81% • No 8 5% • Unsure 2 14% • Missing 3 – 		

INFORMATION ABOUT COPING

Characteristic	Total	Percent
<p>In the last year how have you coped with your illness</p> <ul style="list-style-type: none"> • With no difficulty • With some difficulty • With great difficulty • Missing 	<p>35</p> <p>115</p> <p>19</p> <p>3</p>	<p>21%</p> <p>68%</p> <p>11%</p> <p>–</p>
<p>In a usual month who helps you manage your illness? (multiple responses, each out of 100%)</p> <ul style="list-style-type: none"> • Mother • Father • Brother • Sister • Other relative • Friend • Spouse • Adult child • Family doctor • Psychiatrist • Mental health case worker • Other mental health worker • Other 	<p>88</p> <p>64</p> <p>22</p> <p>36</p> <p>17</p> <p>46</p> <p>14</p> <p>4</p> <p>63</p> <p>111</p> <p>67</p> <p>33</p> <p>42</p>	<p>51%</p> <p>37%</p> <p>13%</p> <p>21%</p> <p>10%</p> <p>27%</p> <p>8%</p> <p>2%</p> <p>37%</p> <p>65%</p> <p>39%</p> <p>19%</p> <p>24%</p>
<p>Total mental health professionals helping to manage illness (as based on item above)</p> <ul style="list-style-type: none"> • 0 • 1 • 2 • 3 	<p>36</p> <p>71</p> <p>55</p> <p>10</p>	<p>21%</p> <p>41%</p> <p>32%</p> <p>6%</p>
<p>Have your needs for help changed in the last year?</p> <ul style="list-style-type: none"> • Needed more help • Needed less help • Needs stayed about the same • Missing 	<p>33</p> <p>22</p> <p>117</p> <p>0</p>	<p>19%</p> <p>13%</p> <p>68%</p> <p>–</p>

Type of Care	Frequency of Care* % of Total Sample (Number)		
	Daily	Weekly	Monthly
Personal care (bathing, dressing, taking medications)	12% (21)	5% (8)	1% (1)
Help with housework (laundry, shopping)	9% (16)	22% (37)	12% (20)
Coordination of health and mental health services (making appointments, arranging services, transportation)	6% (11)	11% (19)	16% (27)
Emotional support (telephone checks, motivation)	20% (34)	17% (30)	14% (24)
Help with structuring time (organizing activities, maintaining outside contacts)	16% (27)	13% (22)	6% (10)
Companionship, help with making friends, socializing outside of the home	14% (24)	20% (35)	11% (19)
Managing finances	12% (20)	9% (16)	17% (29)
General supervision	18% (31)	12% (21)	6% (10)

*Each row shows the percentage out of the total sample indicating daily, weekly, or monthly care needs for each item. The remainder were not applicable or missing.

AREAS WHERE MORE HELP IS NEEDED

Are you getting enough...	Most of the time	Sometimes	Rarely	Never	NA	% out of Total
Practical help around the house	58%	15%	8%	17%	1%	166
Social support from family and friends	69%	19%	8%	4%	0	170
Information from mental health providers about treatment options and coping strategies	59%	23%	14%	5%	0	168
Support from mental health providers	64%	26%	7%	2%	1%	166
Money for leisure activities	46%	26%	15%	12%	2%	171
Support to find a job	18%	12%	10%	15%	46%	167
Support to further education and training	27%	16%	14%	30%	12%	154

APPENDIX III > CAREGIVER SURVEY

Survey for Family Caregivers

This survey is for people who provide care to someone living with a mental illness. Your answers will help the Schizophrenia Society of Canada discover the challenges and supports in the caregiving role and assist in putting forward recommendations to develop national caregiver respite initiatives. Your responses will be kept entirely confidential. To help us in sending out reminder notes, your survey has been assigned a unique study number. Once it is returned, the study number will be deleted and your survey will be entirely anonymous.

Please return your survey in the stamped, self-addressed envelope provided by April 4, 2005.

It should take about 20 minutes to complete the survey.

The primary caregiver in your family is the most appropriate person to complete this survey. The primary caregiver is the individual in your family that provides the most care.

Caregiver Information > First, we would like to get to know a little bit about you.

1. **Are you** Male, or Female

2. **How old were you on your last birthday?** _____ years.

3. **What is your current marital status?**
 Married or common-law Widowed, separated, or divorced Single (never married)

4. **What is your highest level of education?**
 Grade School High School College or technical school University

5. **Where do you live?**
 British Columbia Alberta Saskatchewan Manitoba Ontario
 Quebec New Brunswick Nova Scotia Newfoundland Prince Edward Island

6. **Are you currently employed outside of the home?**
 Yes No

If yes, are you employed:
 Full-time Part-time Occasionally

If no, are you:
 Retired Unemployed A Homemaker Disabled

Information About Your Caregiving Role > Next, we would like to know a bit about your relationship to the person with a mental illness who receives your care and the kinds of care you provide.

7. What is your relationship to the person who receives your care?

- I am his/her... Mother Father Brother or sister Spouse
 Adult child Other relative Friend Other

8. How long have you provided care? _____ months _____ years

9. How close do you live to each other?

- We live in the same house We live in the same city We live within a two hour drive
 We live within a day's drive We live more than a day's drive Uncertain

10. Have the demands of caregiving changed since you began your caregiving role?

- Demands have steadily increased Demands have steadily decreased
 Demands have stayed about the same Demands fluctuate (sometimes high, sometimes low)

11. How would you describe your usual caregiving responsibilities...

- During the *past year*? 24 hours a day Full time (most days) Part time (half the days)
 Occasional (a few days) Seldom (a few hours) None

- During the *past 3 months*? 24 hours a day Full time (most days) Part time (half the days)
 Occasional (a few days) Seldom (a few hours) None

12. In the past three months, what kinds of care have you provided?

Type of care	Daily	Weekly	Monthly	N/A
Personal care (bathing, eating, dressing, taking medications)				
Help with housework (laundry, shopping)				
Coordination of health and mental health services (making appointments, arranging services, transportation)				
Emotional Support (telephone checks, motivation)				
Help with structuring time (organizing activities, maintaining outside contacts)				
Companionship (help with making friends, socializing outside of the home)				
Managing finances				
General supervision				
Financial support				
Coordination of legal services				
Other (Specify)				

Coping as a Caregiver > In this section we will ask you questions about how you are coping with your caregiving role and the kinds of challenges you may experience as a caregiver.

13. In general, how are you coping with your caregiving role?

- With no difficulty With some difficulty With great difficulty

14. How would you rate your current emotional health? (Place an X on the line)

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
PoorExcellent

15. Has your emotional health changed as a result of caregiving?

- It has improved It has declined It has stayed the same
 It fluctuates (sometimes good, sometimes bad)

16.. Do you currently take any medications that have been prescribed by a doctor or psychiatrist to help you with your emotional health?

- Yes No Uncertain

17. How would you rate your current physical health? (Place an X on the line)

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
PoorExcellent

18. Has your physical health changed as a result of caregiving?

- It has improved It has declined It has stayed the same
 It fluctuates (sometimes good, sometimes bad)

19. Do you currently take any medications that have been prescribed by a doctor to help you with your physical health?

- Yes No Uncertain

20. How would you rate your current quality of life? (Place an X on the line)

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
PoorExcellent

21. Has your quality of life changed as a result of caregiving?

- It has improved It has declined It has stayed the same
 It fluctuates (sometimes good, sometimes bad)

22. Are you getting enough practical help from your family and friends?

- Most of the time Sometimes Rarely Never

23. Are you getting enough social support from your family and friends?

- Most of the time Sometimes Rarely Never

24. Are you getting enough information and support from mental health providers?

- Most of the time Sometimes Rarely Never

25. Are you getting enough time off from caregiving to pursue your own activities?

- Most of the time Sometimes Rarely Never

26. Do you ever feel overwhelmed or stressed out because of the demands of caregiving?

- Often Sometimes Rarely Never

27. Does your caregiving role ever interfere with your ability to...

	Always	Frequently	Seldom	Never
Get enough rest				
Maintain a regular sleep schedule				
Pursue your own interests				
Have free time for yourself				
Attend to your own physical health				
Attend to your own emotional health				
Maintain family routines				
Maintain family relationships				
Socialize with family or friends				
Maintain employment				
Maintain a regular work schedule				
Keep up with household chores				
Plan for the future				
Save money				
Take a holiday				
Have peace of mind				
Maintain a good quality of life				

Taking a Break from Caregiving

28. How would you rate the importance of having time away from your caregiving responsibilities? (Place an X on the line)

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
 Not important Important

29. What kind of time away would be best suited to your current needs? (check as many as apply)

- No breaks needed Regular daily breaks for a few hours a day Regular full-day breaks
- Regular over-night breaks Occasional daily breaks for a few hours a day Occasional full-day breaks
- Occasional breaks that last several days
- A flexible break schedule that varies in intensity according to the course of the illness
- Other: _____

30. How would having time out from caregiving impact...

Breaks	Impact			
	Positive	Negative	No impact	Unsure
Your quiet time				
Keeping up with household chores				
Interacting with your friends				
Maintaining employment				
Maintaining a close relationship with your spouse				
Interacting with your family				
Taking a holiday				
Your satisfaction with caregiving				
Your overall emotional health				
Your overall physical health				
Your peace of mind				
Your quality of life				

31. Which of the following things would help you be a more effective caregiver? (check as many as apply)

- Financial compensation for caregiving expenses More information on effective caregiving
- More information about the illness
- More information about respite services that are available in your community
- More open relationship with mental health staff and doctors regarding treatment options
- Legal advice Financial advice on benefits Help in managing service bureaucracies
- Greater social support from family and friends
- Support from other families with an ill relative (family support groups)
- Outreach and companionship programs to provide social opportunities for the person who is ill
- Better access to crisis and emergency services More opportunities to take time out from caregiving
- More respite services

32. What does respite mean to you?

33. Have you ever used a respite service?

No, because... (check as many as apply)

- I have been able to get along without them I don't know of any in my community
- I am not eligible for any respite services The programs are full
- The programs aren't very good I don't feel comfortable turning care over to someone else
- The person who receives care from me is uncomfortable with outside respite care
- The person who receives care from me does not live in my home
- Other: _____

Yes (check as many as apply)

- A home-visit program to provide interim care
- A home help program (to help with housework or yard work) A day program
- Over-night respite beds Other: _____

Care Recipient > Finally, we would like you to tell us a bit about your care recipient.

34. **Gender** Male, or Female

35. **Age at last birthday** _____ years.

36. **Current marital status**

Married or common-law Widowed, separated, or divorced Single (never married)

37. **Highest level of education**

Grade School High School College or technical school University

38. **Employment status**

Employed full-time Employed part-time Occasional employment
 Supported employment Full-time student Part-time student Homemaker
 Retired Disabled Unemployed

39. **Current living arrangement**

Lives with parents Live with spouse Live with other relatives Live with friends
 Live in supported housing Live in a group home Live alone
 Other: _____

40. **Diagnoses given by a doctor (Check as many as apply).**

Don't know A form of schizophrenia A depressive disorder An anxiety disorder
 A substance abuse disorder Other (specify) _____

41. **Age at first symptoms** _____ Years old

42. **Age at first psychiatric treatment** _____ Years old

43. **Care recipient's mental health compared to one year ago**

Better Worse About the same

44. Please look at the list of services below. Tick off the services used by either you or your care recipient in the past year and whether you think they were of value.

Type of Service	Used	Value			
		Considerable	Some	None	Don't know
Medication management					
Emergency or crisis services					
Inpatient hospitalization					
Individual therapy					
Family therapy					
Group therapy					
Day care program or day hospital					
Case management					
Assertive Community Treatment					
Housing or residential program					
Meal preparation or delivery					
Transportation service					
Leisure or recreation program					
Consumer group					
Consumer-run business					
Companionship program					
Legal services					
A home visit program					
A day program					
Over-night respite program					
Home help (housework or yard work)					
Educational or training program					
Supported employment/job training					

45. Thinking about the future needs of your care recipient, what would give you the greatest peace of mind? Please rank these in order of importance from 1 (most important), to 10 (least important). Use each number only once. Use an X to indicate an item that is “not important”.

- _____ Guaranteed housing _____ Steady employment _____ Education or skills training
_____ More leisure time activity _____ More friends _____ Less stigma and discrimination
_____ Guaranteed access to mental health services _____ More respite services
_____ An assured income _____ Greater continuity of mental health care

46. What can the Schizophrenia Society of Canada do to help you better manage your caregiving responsibilities?

47. Thank you for completing this survey. Do you have any additional comments you would like to make?

APPENDIX IV > CARE RECIPIENT SURVEY

Survey for Persons Living with a Mental Illness

This survey is for persons who live with a mental illness. It asks about your experiences managing your illness and what extra services and supports you might need. Your answers will help the Schizophrenia Society of Canada to discover the respite supports that are the most helpful and put forward recommendations that can be used to develop national caregiver respite initiatives. Your responses will be kept entirely confidential. To help us in sending out reminder notes, your survey has been assigned a unique study number. Once it is returned, the study number will be deleted and your survey will be entirely anonymous. **Please return your survey in the stamped, self-addressed envelope provided by April 4, 2005.**

It should take about 20 minutes to complete the survey.

Information About You > First, we would like to get to know a little bit about you.

1. **Are you** Male, or Female

2. **How old were you on your last birthday?** _____ years.

3. **What is your current marital status?**
 Married or common-law Widowed, separated, or divorced Single (never married)

4. **What is your highest level of education?**
 Grade School High School College or technical school University

5. **Where do you live?**
 British Columbia Alberta Saskatchewan Manitoba Ontario Quebec
 New Brunswick Nova Scotia Newfoundland Prince Edward Island

6. **Are you currently employed or going to school?**
 Full-time Part-time Occasional employment Supported employment
 Full-time student Part-time student Homemaker Retired Disabled Unemployed

7. **What is your current living arrangement?**
 Live with parents Live with spouse Live with other relatives Live with friend(s)
 Live in supported housing Live in a group home Live alone
 Other: _____

8. Has a doctor ever diagnosed you with... (check as many as apply).

- A form of schizophrenia A depressive disorder An anxiety disorder
 A substance abuse disorder Other (specify) _____

9. Compared to one year ago, is your mental health... Better Worse About the same

10. How old were you when you first experienced symptoms? _____ years.

11. How old were you when you first received psychiatric treatment? _____ years.

12. Would you say you have come to accept your diagnosis? Yes No Unsure

Information about how you cope with your illness > Next, we would like to get to know a bit about how you cope and the kinds of care you receive to assist you in managing your illness.

13. In the last year, how have you coped with your illness?

- With no difficulty With some difficulty With great difficulty

14. In a usual month, who helps you manage your illness? (check as many as apply)

- Mother Father Brother Sister Other relative Friend Spouse
 Adult child Family doctor Psychiatrist Mental health case worker
 Other mental health worker Other: _____

15. What kinds of help do you get?

Type of care	Daily	Weekly	Monthly	N/A
Personal care (bathing, dressing, taking medications)				
Help with housework (laundry, shopping)				
Coordination of health and mental health services (making appointments, arranging services, transportation)				
Emotional Support (telephone checks, motivation)				
Help with structuring time (organizing activities, maintaining outside contacts)				
Companionship, help with making friends, socializing outside of the home				
Managing finances				
General supervision				
Other: Specify:				

16. Are you getting enough practical help around the house?

- Most of the time Sometimes Rarely Never

17. Are you getting enough social support from your family and friends?

- Most of the time Sometimes Rarely Never

18. Are you getting enough information from mental health providers about treatment options and coping strategies?

- Most of the time Sometimes Rarely Never

19. Are you getting enough support from mental health providers?

- Most of the time Sometimes Rarely Never

20. Do you have enough money for leisure activities?

- Most of the time Sometimes Rarely Never Not applicable

21. Are you getting enough support to find a job?

- Most of the time Sometimes Rarely Never Not applicable

22. Are you getting enough support to further your education and training?

- Most of the time Sometimes Rarely Never

23. Have your needs for help changed in the past year?

- Needed more help Needed less help Needs stayed about the same

**24. Which of the following things would help you manage your illness better?
(check as many as apply)**

- More practical help around the house More money for medical expenses
 More assistance with transportation to and from places More information about my illness
 More help taking my medications Better medications with less side effects
 More mental health services More help getting a job More help finding a place to live
 A better relationship with my psychiatrist A better relationship with the mental health centre staff
 Better access to a family doctor for medical treatment
 Better access to a family doctor for mental health treatment
 A better relationship with hospital staff More emotional support from my family
 More emotional support from my friends More friends
 More support from other people who have a similar illness
 Better access to crisis and emergency services More money for leisure and recreation
 Help finding leisure and recreation activities More assistance in furthering education and training
 More legal advice More advice on financial planning
 Places to go overnight to take a break away from the people I live with
 Better public attitudes toward people with a mental illness (less social stigma)
 Other: _____

25. Have you used any of these services in the last year and did you think they were of value?

Type of Service	Used	Value			
		Considerable	Some	None	Don't know
Medication management					
Emergency or crisis services					
Inpatient hospitalization					
Individual therapy					
Family therapy					
Group therapy					
Day care program or day hospital					
Case management					
Assertive Community Treatment					
Housing or residential program					
Meal preparation or delivery					
Transportation service					
Leisure or recreation program					
Consumer group					
Consumer-run business					
Companionship program					
Legal services					
A home visit program					
A day program					
Over-night respite program					
Home help (housework or yard work)					
Educational or training program					
Supported employment/job training					

APPENDIX V > WHAT RESPITE MEANS TO FAMILY MEMBERS



Q32 – What does respite mean to you?

- A break.
- It means relief or a let-up but I'm not sure what it means in the context – It seems to mean having someone to temporarily house the sick family member or bring care in.
- Meaningful rehab services that would benefit (appeal to) the individual and his intellect.
- A break away from caregiving.
- I can manage on my own it is the ill person who needs the help.
- When a person is very ill it would be of tremendous help if a respite service were available right away.
- Time away from responsibilities – an opportunity to renew energy etc.
- A vacation.
- Short period of relief.
- Not sure.
- Taking a break from daily concerns.
- A break from care giving in this case.
- A break from responsibilities, but only if he is also enjoying himself ie summer camp for more than 3 days every three or four years.
- Seeing my son spending more days happily occupied in activities meaningful to him with friendly people supervised in a safe stable environment.

- Break from stress.
- Temporary relief.
- Responsible.
- Respite means to have sick family member being cared for in a safe friendly caring environment.
- Respite means that another person with some training in the mental health field would be available if requested to provide assistance to my family member in his daily life, when I am going to be unavailable. I would therefore have to prearrange this service.
- A chance for a consumer to be more independent, to socialize with people his own age. A “breather” for the family caregiver – a worry free breather – not wondering is he okay? will he remember to take his meds?
- Getting away from day to day responsibilities.
- Respite means not having to worry about my loved one when my husband and I are on vacation. Can’t be away for more than 2 weeks. Our daughter can help manage (with difficulty) to hold it together for that amount of time.
- Release from the responsibilities of caregiving.
- I do not need this service. Social interactions with friends would be helpful such as him assisting with such things as bowling scores, teaching music, English etc.
- Not applicable.
- To me respite means that I can pursue some other goals (responsibilities of my life) while I am assured that my son will be looked after. This takes some worries off me and I can sleep better.
- A break.
- Not having to worry about his safety and well being.
- Very helpful for full time caregivers. In our case not needed at present.
- Respite means, my ability to take a break from caregiving, while having another trusted caregiver taking over for me so that I don’t have to worry about routine disruption and can get peace of mind and rest.
- I don’t really understand what it means. I think it is having someone come in and look after the ill person to give you a break.
- A break from responsibilities.

- Their service provider would take our son to give us (the parents and siblings) a break from this terrible illness that he has no control over. We get the YWCA to come and take him out mostly in the evenings. His quality of life has changed to some extent. Although when he gets comfortable with staff he starts talking unaware he does it. There are days when talking to him he does not hear me, but as soon as staff comes in he stops talking or yelling.
- Total time out and time away from demands of family member.
- I am more interested in having programs for the person who is ill to help them get back to greater health than I am in respite programs. Though a respite program that would allow me to go on a holiday would be great. The last time I went on a holiday without my son was June 2003 – he attempted suicide by jumping off a bridge. He was saved because someone saw him jump and called the police.
- Taking a break.
- A total break from the ongoing worry which is impossible and unrealistic. These questions are moot.
- Respite means my mother would take a companionship program so she would have people her own age group to entertain or have friendships with. This would give me relief that she has someone else that she can rely on and enjoy. It takes away my guilt when I have other things and can't always be there when she expects or needs someone.
- Short break to pursue quite uninterrupted solace with the knowledge that ill family member was safely being cared for.
- Opportunity for our son to become more socially adept especially with women. Help with his household chore, home cooked meals.
- When our son is in relapse then a break is needed. There are no social programs in place in the area.
- Just knowing there is help out there when the ill person needs help desperately. That kind of help just has not been there I'm afraid. Perhaps there is help out there, its just not working in my situation.
- Time so I could be away without fear of something going wrong in my absence.
- The ACT team has provided highly skill support to our son, support that we "craved" for the ten years that we struggled without any respite as caregivers.
- Getting a break or rest from stress causing situation that one experiences because of the illness of one's loved one. It can be short term, temporary, easily accessible.
- It means an overnight or several overnights where someone else has responsibility for the family member, usually a non relative.
- I do not require respite services, as my son is a 38 year old adult living in his own home and doesn't require a great deal of assistance. We seem to manage through the rough times on our own.

- Time out from care giving 3-5 days out, 2-3 hours out to go shopping.
- Time to “recharge batteries”.
- Respite is having someone else take over the caregiving duties. This allows the primary caregiver time away to pursue interests, activities or rest.
- In my present circumstances financial compensation for what I have done and the juggling act I am doing with employment and caregiving would be the greatest benefit. If I don’t have access to a case manager and the present mental health system remains as difficult to navigate money would help.
- A break from caregiving.
- Someone to take over caregiving role.
- Respite means having someone else care for your affected loved one when you require a break. Should be arranged on a regular basis.
- Relief and a break in general.
- More help, but my son mostly relies on me to make his dinners, decorate the house he rents from us and make some decisions. He is fairly independent, but sometimes hard to manage.
- Time to be able to go away on holiday etc and know that my loved one is cared for or being checked on. To give the responsibility to someone else for a while.
- Some person to take over care for a few days etc. We do not have a respite place for schizophrenics with a substance abuse problem.
- I am not sure what it means.
- Assistance with caregiving. I am not a direct caregiver. We don’t live in the same town/house. Most of my care is financial assistance. I am 69 and still working to make ends meet. I wonder if I will ever be able to retire.
- Respite means to forget about schizophrenia for a while.
- It means mental and physical rest.
- Day away activities for mental health client or job training with reason so they can feel useful or valued.
- Respite means getting a break or a holiday away from the stress of caregiving.
- Being able to go away for a least one long break (2 weeks) and two smaller breaks throughout the year literally replenishes me and enables me to carry on as my son’s caregiver. But I have to have my own peace of mind by knowing there is someone helping our son out whilst we are away.
- Having ill person lodged and cared for away from the home for a few weeks.

- Having a few days away to reflect.
- Temporary care for physically or mentally handicapped.
- My greatest role as a caregiver is to provide emotional and financial support. Seeing as my son does not have any close friends I feel responsible for providing him with a “welcoming home”. Hence the friendly phone calls and Sunday dinners. To me respite means getting away from all my responsibilities for a short period of time. I make sure that I take at least one holiday a year.
- Means to receive relief from caregiving to pursue other activities.
- Having the type of services that are currently available in my community. Subsidized housing.
- Getting a break from routine from the responsibility.
- Rest and renewal.
- A period of time without caregiving responsibilities.
- Relieving me of the responsibilities of looking after him. We have never had respite services he is not that bad.
- Respite could mean another person takes on a specific responsibility occasionally – or could mean someone takes over completely and permits the caregiver to have a vacation. I do not need this service but I know many do.
- Special program to help with care of persons with mental illness.
- Time out.
- Relief from the constant stress and effort required to support our daughter.
- Care for the ill relative in the way of periodic visits to him/her by a medical person who will detect psychiatric problems or signs of depression by talking to him/her.
- Being able to take time to refresh and recharge the emotional batteries to be able to continue caring for the ill person without “burning out”.
- A replacement.
- To have time to myself without anxiety for the care recipient.
- An opportunity to be relieved of all caregiving responsibilities while at the same having the peace of mind knowing that my son is coping with his illness.
- Temporary comprehensive care in order to give information, calming down etc caregivers some time off. I could use a person who would check on him daily or 2 times a day (just a phone call is all that is needed sometimes) and be there to receive his calls when he needs advice.

- Respite means a break from day to day strains and stresses of taking care of an individual with schizophrenia, Having peace of mind knowing he is living in a safe environment where he would not be prayed upon by drug dealers.
- To me respite means support during crisis periods.
- Better education for me to be a trustee for my brother's discretionary trust. A computer course to help me keep financial records – a major frustration. Free information on how to be a trustee. Our family really sweated for a long time to learn how. More and easier subsidized housing. Much time spent searching for affordable housing and long letter writing campaign to request more.
- A break away from an ill person.
- Getting away from the constant mental and physical stress.
- Complete responsibility for patient.
- A time out from worry. Time out from preparing meals. An opportunity to take a vacation with the assurance my brother and home would be taken care of in my absence.
- If the person you care for does not want to be in unfamiliar surroundings with unfamiliar people there can be no respite care. Respite care means I can get away by myself while knowing my loved one is looked after.
- My son lives alone and generally manages his own life. Medication and emotional support are important. Having contact with a good doctor is also important.
- It would mean that my whole life wouldn't be dealing with an ill family member who I am afraid of.
- Time to rest and gather my wits.
- A replacement for me as a caregiver.
- Peace of mind would be when someone else could be available to supervise and check up on my son. We are still mothers and all this seems like nagging to an adult son. Sufficient food and he is diabetic. Checking that he has eaten after insulin injection and prior to going out. Someone else to help budget money.
- Time off – getting away sometimes.
- So far respite means nothing to me.
- Any time away from all responsibilities for my son – knowing that he will be cared for while mother is not available.
- Respite to me means having a break from my responsibility, but knowing that my son is being cared for in all areas. Then I can relax and know he is okay.
- A safe place for the person to go for overnight or for a week's vacation.

- Separation time from the person with an ailment.
- Time of relief or rest from the chores of maintaining two households.
- Having time off from caregiving. Having a rest.
- Care giving in our absence. So we can go on vacations etc. and be worry free knowing that our son has somebody to have an eye on him.
- Not having to do everything all by myself for ill son. Having someone take over for a while (day, week etc). Not having to shoulder the entire burden.
- Knowing my son is getting the best care, physically and mentally helps me.
- Respite for me would mean having an organization provide a companion or employee to check on my son daily / or every few days to assist with groceries, money management companionship.
- Short term help from caregiving to enable the caregiver or family to take care of their own needs either for a few hours, weekend or a short vacation and or emergencies.
- Giving families a break from day to day care. Vacation time for families (care givers).
- Someone to oversee my son's needs occasionally.
- I am not sure I understand the concept. It is something we have never considered.
- A chance to get away from the routine by utilizing outside help.
- Relief from the constant burden of caregiving.
- Interval or break. Would be useful during periods if illness came back strongly.
- It means someone taking the place of a full time caregiver for a brief period.
- Being free of dealing directly with the perceptions and utterances of those who are in a mentally ill state. This is impossible to achieve if such a person is a member of your immediate family. The stress just builds and builds, calling on more reserves and patience than most ordinary people possess.
- A period of reduced responsibility.
- Respite would mean that I would have a few hours three or four times a week to myself, without having to do groceries or other shopping and to be able to stay away over night once or twice a year – just for time out for myself.
- Respite would be important if I became ill and my daughter were alone.

- Having an ill person taken care by someone else while the caregiver is getting quality time away for her/him self.
- Relief from responsibilities.
- Being able to take time away and feel sure that someone is looking out for my offspring.
- When we had her living with us it would have meant everything. That was in the 1980's and it seemed to be non-existent. After she was accepted into the system, life began again for us although forever changed.
- A break, a pause, a rest.
- I don't know.
- Having a break from my son. He lives with me at the moment in a 1 bedroom apartment, sleeps on the sofa or floor as the whim directs him. He seldom goes out, he has no friends, although I'm expecting he'll go out more in the warmer weather. He is non compliant — nothing wrong with him.
- Outside professional assistance, medical, social support, assisted living, home help. Help take the pressure off caregivers; give the patient independence from family. I don't know of any program developed for people who are trying to live on their own. Assisting persons with a mental illness.
- When I asked for respite services at local schizophrenia society I was told I was not eligible. It was only for disabled to get him out of the house and into activities. I believed that so carried the load myself. Two months ago I learned that my friend gets respite for himself (not necessarily disabled son) so he can continue to function and keep family together. That's what I thought respite was for. If I could have a home help program (house yard) our quality of life would have MORE.
- Peace of mind and complete trust that my son is in the right place.
- Respite means 2 things 1 – giving the caregiver a break and or 2 – giving the ill person an alternative home situation where someone else will offer him or her care.
- Respite means quality time for the caregiver and the client. A time out to renew the caregivers vitality and a time out for the client to learn new skills or hobbies or simply socialize.
- A time away from stress to relax be at peace be entertained (books movies etc) so as to forget problems.
- Vacation more than a few days without worry.
- Support, break, care.
- Having my daughter under full care at a group home.
- Ability for time out from regular responsibilities either a free morning or after noon up to 3-4 days.

- Respite care to me is a person or persons to take charge of our son for either a few days or a week. Perhaps even for a holiday period. Our life seems to be governed completely by the illness and a break away would be so helpful.
- Rest from daily grind of responsibility.
- A time when my needs / wishes come first.
- A break from the routine of always being a positive effect on the person who is ill.
- While on a break from caregiving not having to worry at all about person with illness.
- Freedom, burden lifted, relax more.
- Providing a safe place for ill person so that caregiver can relax and have a break and are able to deal effectively with issues without interrupting rest of caregiver.
- Getting rid of the mental illness itself.
- Temporary freedom.
- I have this as my son lives away from home with one week each month at home with us.
- Respite means to me for mental health persons to help more with the client to feel more self assured, increase self esteem and also have more job opportunities to feel like they are part of society.
- My son's illness has been stable. I am lucky, many caregivers need a break. I don't for now. It would be nice to have it available.
- Taking a break from caregiving.
- A break from the constant concern that daughter is ok. Is she wearing clean clothes? Is she keeping her apartment clean enough that it won't stink and she will be evicted. Laundry duties, taking her to get groceries.
- Having a true break from being concerned about our son. Being able to forget his situation for a while.
- Just getting away to relax, be myself, not having any demands, a darned good holiday.
- Knowing someone can be there for our son while we travel or work.
- If you are providing full time care, being able to get away for some mix of short (2 hour) medium (2 days) longer (2 week) breaks.
- Someone to take responsibility for caregiving.
- Being temporarily relieved from responsibility and worry and abuse.

- Peace.
- Respite means a break, a rest from what you are doing with the knowledge that the person you are caring for is well looked after, happy, safe. it would be great if respite was recognized as necessary and given freely with a blessing for rest and renewal.
- Time away from caregiving with confidence he is content in a secure happy environment.
- Ten years or more ago I would have said respite was a necessity. I never had the opportunity as nothing was in place. I had to rely on family and friends for help.
- A few hours a week away in a quieter place to relax, read, go for a walk, listen to classical music.
- Someone relieving another of the burden of responsibilities while caring for an ill loved one. Giving me a chance to enjoy time alone with a friend or other well family member. To indulge in something fun and relaxing.
- Knowing someone who understands the illness is there to check on him daily and assist him if needed when and if I go away for a couple of days.
- The fact that my son lived for about 15 years in a minimum support group home gave him a secure feeling and to me a feeling of respite care. However he has recently had to move to a private adult living home which provides more care physically but he has become more emotionally dependent on me. Respite care now would mean development of other emotional supports.
- It means time to take care of my physical and mental needs so that I can be a better caregiver. Time to recharge and reconnect with my husband.
- Help, relief support. Someone who shares the burden of helping so we know we are not alone. Someone else who knows, cares and thinks about our son. To be the only people in his life is a smothering burden. He needs more than a psychiatrist who gives a prescription. He needs someone who wants to know him and sees him as worth knowing. Our problem is that even though our son often blames us for ruining his life he will not relate to anyone or go anywhere.
- Relief of caregiving. Would have been more important for me when I was still working. Not so much now since retired.
- A period free from caregiving.
- Respite would mean someone to talk to; someone to take over supervision of physical health, appointments some shopping, nutrition. A lessening of responsibility. Though our son manages wonderfully well and is doing better than he ever has, there are more areas here he needs learning and supported experience, recreation, social life etc. now that he is more independent. We have had to provide the transition and social activities, recreation etc. I worry about the future because of my age.
- This would be very useful to me and my sons. I never heard of this until about a year ago where I met a woman who was one. So if you could please tell me more about it.

- Respite means short breaks away from caregiving responsibilities, that is either the caregiver going away or the family member going away from the caregiving environment.
- Financial compensation for the wage loss when the caregiver for 2 is also a caregiver for themselves. Also the caregiver financially helps buy clothes, toiletries as family members on assistance can't afford to.
- Freeing one from emotional and physical stress. Giving one time to live one's own life and having space for one's own needs.
- Respite means having a safe and appropriate haven for my loved one. It allows the caregiver to have a time off.
- Relief.
- Respite means just not having to think about the illness and our son at all – however that is unrealistic because he is our son and my wife thinks about him and how he is doing everyday.
- Temporary delay. Time away from problem.
- A brief interval of relief.
- Having time away from care giving responsibilities to re-energize. The “sadness of the illness never goes away though so the emotional strain is always there”.
- A break to recharge.
- Support is essential for the caregiver – families need to be made aware of services in their community (sadly some families want nothing to do with their loved one who is suffering from mental illness).
- More Pact teams.
- Respite means services or individuals available to fill in or take over in areas of caregiving.
- Respite means to have support in the community for the care recipient and the care giver.
- So far, I've not had to really utilize any special respite services, but have been very appreciative of mental health nurses who have come to our home on a regular monthly basis and sometimes more often if necessary to administer medication by injection when that was used, or just to check on the care recipient. This is quite helpful and it means someone (professional health care person) is monitoring the situation besides the psychiatrist who only spends a very short time with the patient about every 2-3 months. It is reassuring to me – it gives the patient an opportunity to let health care professional know how they feel etc.
- A break from always having to “be there” for my daughter, whether it's for a couple of days or a couple of weeks.
- A place to have your mental charge stay and be cared for a while.

- Because my relative has now deteriorated to the point of being permanently mentally incompetent to care for himself (application has been made to family court for this status) respite means having relative in a safe, secure environment so parents can return to a normal life-style without worry about relative.
- Time out. Relief. Chance to regroup. Ability to relax without being on guard.
- Respite to me would mean that someone would provide daily contact and be a friend to my family member in case any problems arise – if I were not available.
- It means to be able to get away from the responsibilities of caring for a mentally ill person and to be able to have a quiet place to meditate to restore hope, humor and capacity to return to the responsibilities required.
- Respite to me means having one or two weeks away from my ill relative. I could be at home or on vacation without the requirement of providing meals, transportation and interaction.
- Freedom from worry, housework, time to pursue my interests.
- Supervised care for mentally ill relative so parent can have some free time.
- Relief from time to time from constant care of loved one.
- Intermission from the care without worry two or three days a few times a year.
- It means that I can relax and de-stress.
- I am not exactly sure just what it means.
- A period of time spent away from the care recipient who can be supervised or monitored by some trustworthy person(s) lasting several days or more.
- I know what it must mean to some caregivers, but at this time I don't need it. However, down the road this could change if my son becomes intolerant to his medication once again.
- Time to get a life back, freedom however small the time to try to relax.
- No worry.
- Respite means having time out or breaks from caregiving.
- Getting away for a spell to be able to come back into the situation fresh and strong again.
- Personally, it means my daughter will have a feeling of reassurance in thinking of her future and experience a little happiness. This last point necessitates a part-time job.

- A break period means rest and relaxation, time that is free of worry or guilt for leaving the person affected with someone else. The person affected by the illness must be willing to go to this place and see it as a vacation and not something being forced on them.
- A break period shows that people other than myself; one of my sisters and one of my brothers, care about our sister who is affected by schizophrenia.
- I had a period of respite when she decided of her own accord to enter a group home for a greater sense of independence.
- Time to rest.
- Time to take care of myself. You accept that the other person's illness becomes a part of your own life; it is just like any other handicap and you adapt. To love someone means sharing the good times and the bad times. Looking after oneself through the other person is also good.
- Have the time and the financial means to take better care of my son when he needs me. Working full-time (I cannot afford to cut back on working hours) I have to "drop" my son just when he needs me to spend time with him most (in times of crisis). It tears me up inside not being able to look after him the way I would like to in those critical moments.
- A place where the person close to you who is affected by the illness could live temporarily, and be happy there while we had some down time (a trip or other kind of break).
- To have peace of mind, be able to leave my son with someone who is trained and competent and enjoy an evening out once a week with my husband.
- I am with him for one week out of the month. The remaining time he rents a room from a woman who herself has psychoses. She is undergoing mental health treatment. I worry about the situation because they plan on being married soon. I am afraid of my son having a relapse and her having a relapse on top of that. A break for me would be relief from my fears, but of course you can't do much about those.
- If the family member affected by the illness could achieve stability, it would save a lot of worry. It has been six years now that we have been dealing with this illness and she (the person who is ill) has yet to be stable. We had to go so far as making a formal complaint against the hospital in order to have the right to care – it is unbelievable.
- Receive some financial assistance to pay for household help. Have easy access to professionals at social services to help the individual with the illness or the family. Note: I already have this help and I am very satisfied.
- To let go. To look after myself.
- A time to refuel in every sense of the word.
- A break offers mental, psychological relief but at the same time, it allows me to behave as though the problem doesn't exist anymore, and provides a moment of escape.

- Time to rest; stopping and taking care of yourself; doing something you love to gain a better perspective, and seeing people outside of psychiatry. Getting outside help to free up time for oneself.
- Go to the movies, out to a restaurant, take a vacation, spend time with my boyfriend, be with my son and speak with him when he is doing well. When he gets better and is with us, that in itself is a relief, as well as when I feel hopeful that he will reintegrate socially.
- A period of time where we have some peace of mind! That way, when the phone rings, we wouldn't be saying to ourselves: "him again??" and if it were, "and now what??" . But, if we are 'forgotten', we wouldn't have to worry, and more importantly, feel guilty if problems do arise.
- Time to stop, relief. If the job of keeping track of my son is 'delegated' to someone, the expense is very heavy (and I pay for everything in double): rent, television, food, heating, clothing, etc.
- Much, since I am the only caregiver in the family for my son.
- Re-energize, prevent a feeling of being overwhelmed and invaded, stress-relief, rediscover oneself.
- Given that my relationship with the person affected by the illness fluctuates, a break would be a form of insurance that this individual (my brother) has access to the appropriate resources to support him. Unfortunately, when he cuts himself off from his family, I often have the impression that he has no other support to replace us. So, I would say an emotional or mental break.
- To know that the needs of the person affected by the illness are met; to be able to take a vacation with peace of mind.
- The chance to look after my personal life; to recuperate physically and emotionally, to improve my quality of life and my relationship with my partner.
- It would help to empty my mind completely and then fill it up again with peace and joy.
- A little oxygen to better care for the person who is ill, think of things besides the illness, refuel and restore energy levels.
- The understanding of family, friends and the public.
- Not having to regularly call my brother twice a week and talk to him for hours. I don't feel like talking to anyone on some nights. But it isn't too heavy a burden to bear.
- Peace, restful sleep.
- To know that my son feels good about himself and is able to live a normal life.
- To no longer be preoccupied with the illness of the person close to you. To stop thinking of what his life could have been like if he had been directed properly from the time he was 20 years old.
- To be able to leave the house (my daughter) for a long period of time (a month) without worrying.

- To envisage a future with hope that the situation will improve, meaning that my son will attain a certain degree of autonomy, and that he will be able to benefit from sustained professional help.
- Relief for me has always meant that he be with a host family. I am satisfied with that. I believe that good people surround him. He calls three times a day with new problems. You get used to it. He comes home once or twice a month. I buy all of his clothes – it's ok. After 30 years, you see things differently and you accept the illness.
- I take my son fairly often on weekends. I go shopping with him. As he is with a host family, I have a lot of time for myself.
- I don't have these kinds of problems, as my son is independent.
- A break would be the ability to go on holidays (for about two weeks) when I wish.
- Mother's care, which I provide in place of services, acts like a security net enveloping my son who is ill, my daughter (who suffers from a reactionary depression as a result of her brother's numerous suicide attempts), my relationship with my husband and generally all those close to me. One must not underestimate the scope of problems created for other family members, in understanding the word "relief".
- Have a rest with the knowledge that my son is happy and safe.
- To step back and get some perspective when the person affected by the illness isn't respecting his/her limits. Have someone take over who can work on gaining an understanding of limitations. Work in the same way. Have financial support at least for medication, especially when the person's condition improves. Performs just a bit too well for help but not enough to contribute.
- Relief is not the top priority in my case. I would much rather have a dialogue and collaborative relationship with the professional treating my son. I get the impression that they are evasive.
- Allow myself to take care of me a little.
- To have more intimacy and closeness with other members of the family (husband and other children).
- Relief means that responsibilities related to (the ill person) are lessened, because I don't feel supported anymore.
- More than anything, the certainty that everything is being done in the best possible way so that the person affected can control his or her illness and succeed in living as 'normally' as possible.
- I have to financially support my child (who is a parent), and we have no financial or fiscal acknowledgement of this reality. Due to this obligation, we forego certain activities that we would be engaging in otherwise.
- Think of myself a little bit to get some rest because I worry a lot about the future, about her health and how she will manage financially.
- To be able to go on holidays while a responsible person who is informed about the issues takes over with our sons during our absence.

