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Impact of schizophrenia on carers in New Zealand:

The cost of caring

Final report

Submitted to

Supporting Families in Mental Illness –
Schizophrenia Fellowship New Zealand (SFNZ) and



JANSSEN-CILAG

AUSTRALIA

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LIST OF ABBREVIATIONS

ACC	Accident Compensation Corporation (New Zealand)
AUS	Australia
DHB	District Health Board
GP	General Practitioner
MAU	multi-attribute utility
NZ	New Zealand
NZD	New Zealand Dollars
PHO	Primary Health Organisation
QoL	quality of life
SD	standard deviation
SFNZ	Supporting Families in Mental Illness also known as Schizophrenia Fellowship New Zealand or Te Rōpū Manaaki i Te Wairua Tuakoi Aotearoa

Executive summary

It is widely reported that caring for someone with schizophrenia has both an economic and a non-monetary impact (Chen *et al.*, 2004; Tsang *et al.*, 2002; Laidlaw *et al.*, 2002; McDonell *et al.*, 2003; Milliken & Rodney, 2003; Rudge & Morse, 2004; Tsang *et al.*, 2003). The family role in caring for a relative living with schizophrenia was recognised in clinical practice guidelines prepared by the Royal Australian and New Zealand College of Psychiatrists (RANZCP, 2004). Family intervention has been shown to reduce the burden of illness and was included in treatment recommendations (RANZCP, 2004). SFNZ (Supporting Families in Mental Illness or Schizophrenia Fellowship of New Zealand) recognises the burden that families or *whanau* (the extended family/group) can experience in caring for a mentally ill relative by recommending support and education as part of its charter (SFNZ, 2005). A lifetime prevalence of schizophrenia of 0.3% has been reported which is in comparison to a prevalence of 6.7% in women, 6.8% in men on remand; and 6.0% in sentenced men in New Zealand prisons (Oakley-Browne *et al.*, 1989; Simpson *et al.*, 1999).

A study of carers of people with schizophrenia in Australia was designed in conjunction with a general population utility valuation study that was conducted for Janssen-Cilag in Australia February 2004. The objectives of this study were to obtain information on the impact of schizophrenia on the lives of carers in Australia, to quantify the costs involved in being a carer of someone with schizophrenia, and to determine how much carers would be willing-to-pay (WTP) for schizophrenia treatment. An adaptation of the questionnaire was performed to allow the collection of data to identify and quantify the impact of disease on caregivers in New Zealand.

The New Zealand questionnaire contained seven main sections; demographics, time spent caring for someone with schizophrenia, costs associated with caring, questions regarding employment while caring, caring and unpaid activities, information about the person with schizophrenia being cared for and additional questions regarding caring.

The questionnaire was conducted in face-to-face group sessions around New Zealand. The study participants were recruited by SFNZ and represented a broad section of the community and provide a good basis to evaluate the impact of schizophrenia in the community. The majority of participants were parents caring for their child with schizophrenia. Participants spend about 52 hours a week caring, which is not limited to the impact of schizophrenia.

Carers who were from Maori cultural backgrounds reported significantly greater average time spent caring in comparison to carers from a non-Maori background. Approximately three-quarters of the people with schizophrenia, whose carers completed the study, had additional psychological illnesses – most commonly anxiety, depression and substance abuse.

Direct costs incurred weekly by the carers' range from an average of \$NZ7.61 on medical costs to \$NZ71.64 on food, clothing and living expenses. Additional expenses ranged from \$NZ0.5 for replacing lost keys to \$NZ1500 for new bedding. There was no difference in the costs incurred due to living expenses and medical costs across the district health board (DHB) regions. However, carers of Maori cultural identity indicated significantly higher weekly expenditure on prescription medications in comparison to non-Maori background carers, \$NZ5.71 versus \$NZ0.36 ($p=0.0001$).

Almost half of the carers surveyed were in paid employment; however, almost 40% were unable to engage in their usual employment because of their caring responsibilities. This situation was experienced for 7.3 days on average in the month before the survey was applied. The average drop in weekly income due to reduction in paid employment was approximately \$NZ221. Roughly 16% of participants reported being unable to work at all due to caregiving and this resulted in an average weekly loss of income of \$NZ350. Whilst schizophrenia-related illness requires the most care (73%) additional psychological illnesses significantly contribute to the burden of care. Overall, the time spent caring for someone with schizophrenia tended to be higher for respondents from the South Island in comparison with respondents from Auckland and the North Island. Conversely, the proportion of time spent caring for other mental illness was significantly lower for respondents from the South Island. Carer ethnicity is not a significant determinant of the proportion of time spent caring.

On average, the people with schizophrenia in their care had been diagnosed 12.7 years previously, with one carer reporting a diagnosis made 52 years ago. Approximately 35% of carers stated that they provided a higher level of care when the person with schizophrenia was hospitalised. Half the carers reported the person they care for was hospitalised at least once in the previous 12 months, which accounted for approximately 3136 in-patient days. The majority of people with schizophrenia described in this study were prescribed some form of antipsychotic, primarily clozapine, olanzapine and risperidone (tablets), over the past three months. There was no difference in the number of hospitalisations or visits to healthcare professions across the DHB regions or according to ethnic background.

More than three-quarters of carers reported that the person they care for had previously been in paid employment. Approximately one-fifth of carers reported that the person they care for had not been in paid employment in the past month, which was in the main, attributable to schizophrenia. The average number of hours worked per week by people living with schizophrenia who were in paid employment was 17.6 hours. Half of the carers indicated that the person they cared for had changed jobs because of caring for someone with schizophrenia with a subsequent average loss of earnings of an average of \$NZ134.40 per week.

Many people living with schizophrenia in this study have experienced crime, either as the victim or offender, in the last six months. These people reported a number of incidents of harmful behaviour, either toward carers or self-directed, including attempted suicide.

Common themes to emerge from the carers were the alienation, isolation and stigma that are associated with schizophrenia, and by association, with the carer and their family. Carers report stress and anxiety due to the responsibility of caring, compounded by the lack of opportunities for the person in their care, frustration with the lack of services, and the inability to plan or to have respite periods.

This report focuses on the burden of illness reported by carers of people with schizophrenia in New Zealand. As seen with the Australian study, the manifestations of schizophrenia are not restricted to the diagnosed person, but also those people who care for them, as quantified in direct and indirect costs of the condition and related disorders. Social relationships, and carers' mental health is clearly affected by the responsibility of being a caregiver.

1 Introduction and background

Caregivers provide assistance to a person under their care in support of the activities that they are unable to provide for themselves (Chien *et al.*, 2004). Studies have demonstrated that caregivers can have negative physiological and psychological responses to caring for someone with a chronic illness (Chen *et al.*, 2005; Chien *et al.*, 2004; Tsang *et al.*, 2003; Vitaliano *et al.*, 2003). In the case of chronic mental illness, caring is also associated with significant economic costs (Clark, 1994).

The impact of caring for someone with schizophrenia is economic, but also has non-monetary consequences (Chen *et al.*, 2005; Laidlaw *et al.*, 2002; McDonnell *et al.*, 2003; Milliken & Rodney 2003; Rudge & Morse 2004; Tsang *et al.*, 2002; Tsang *et al.*, 2003). Demands of caregiving include paying for psychiatric care, adopting a supervisory role, dealing with stigma associated with mental illness and emotional distress, dealing with possible substance abuse problems and patient suicide attempts (McDonnell *et al.*, 2003). Other burdens include guilt and increased stigma and isolation (Rudge & Morse 2004; Tsang *et al.*, 2002; Tsang *et al.*, 2003). Some caregivers report being discriminated against, avoiding social situations and not telling others about their family member's condition (Tsang *et al.*, 2003). Some siblings have reported fears about the hereditary nature of schizophrenia and their potential to develop the condition (Stalberg *et al.*, 2004).

A lifetime prevalence of schizophrenia of 0.3 per 100 persons (0.3%) was reported in a study carried out in the urban setting of Christchurch, New Zealand (Oakley-Browne *et al.*, 1989). A systematic review to determine schizophrenia prevalence gave an overall lifetime prevalence of 0.55 per 100 persons. Lifetime prevalence estimates range from 0.12% in a Hong Kong study to 1.6% in Puerto Rico (Goldner *et al.*, 2002). For comparison, a lifetime prevalence range of 10 to 18 per 1000 persons has been estimated for Australia (Access Economics, 2002). Prevalence appears to peak in the 25–44 year age group for the reported New Zealand population. Goldner and associates (2002) report a one-year recovery rate of 33.3%, that is, one-third of people with schizophrenia will not report an episode in the previous 12 months.

A national study of psychiatric morbidity in New Zealand prisons was conducted to determine the lifetime prevalence of schizophrenia and related disorders (schizophreniform, delusional, schizoaffective disorders). This study estimated a lifetime prevalence of schizophrenic disorders of 6.7% in women, 6.8% in men on remand; and 6.0% in sentenced men (Simpson *et al.*, 1999). Of the prison population, approximately 23% are currently receiving mental health medication (Simpson *et al.*, 1999). The authors report that overall, 6% to 8% of the New Zealand prison population will have developed schizophrenia and related disorders. When compared with the

lifetime prevalence of schizophrenia reported by Oakley-Browne *et al* (1989), these results indicate that there is a markedly elevated rate of schizophrenia over that found in the general community. The New Zealand prison study reported that approximately half of all inmates in the study are of Maori ethnicity and another 8.3% are of Pacific Island ethnicity (Simpson *et al*, 2003). However, lifetime prevalence of schizophrenia and related conditions is similar across all ethnic backgrounds including European/other, Maori and Pacific Island (Simpson *et al*, 2003). A study by Sachdev (1989) reported that the first psychiatric admission rate for schizophrenia psychoses was approximately 17 per 100,000 for the Maori population, compared with 11 per 100,000 for the overall population. This trend is seen for readmission rates for schizophrenia. Importantly, a higher mean length of stay for schizophrenia was reported for Maori New Zealanders, 191 days compared with 290 days for non-Maori New Zealanders (Sachdev, 1989).

Additional burden is created if the caregiver has to deal with the legal/judiciary system (James 1996; Milliken & Rodney 1996; Tsang *et al*, 2002). An Australian study found that the burden of caring for forensic psychiatric patients (those who had been arrested for various crimes) was greater than the burden of caring for people with non-forensic histories. The additional areas of burden included the stigma created by the sensationalising of cases by the media. Family problems also arose due to the fact that many family members are victims of violence at the hands of the person they care for, and as such, do not want to support them through the judicial process. There is also the potential for disintegration of the family unit when homicide occurs and the victim is the carer (James, 1996).

The economic impact of schizophrenia in New Zealand has not been estimated. In Australia, the costs (direct and indirect) of schizophrenia were estimated at \$AUD1.85 billion in 2001, with carer costs estimated to account for \$AUD88 million (Access Economics, 2002). The family burden in caring for a relative living with schizophrenia was recognised in clinical practice guidelines prepared by the Royal Australian and New Zealand College of Psychiatrists (RANZCP, 2004). These guidelines recognised that families may not only have the physical burden of care, but also experience psychological and social effects themselves. Family intervention has been shown to reduce the burden of illness (RANZCP, 2004). SFNZ recognises the burden that families or *whanau* (the extended family) can experience in caring for a mentally ill relative by recommending support and education as part of its charter (SFNZ, 2005).

A study of impact of schizophrenia on carers in the Australian population was initiated in 2003 with a decision to extend the questionnaire to the New Zealand setting in 2005. The aim of this study is to collect information regarding the direct and indirect carer costs and impact of caring for carers of people living with schizophrenia in New Zealand.

2 Study objectives

The objectives of this study were to determine:

- the direct costs associated with caring for someone with schizophrenia in New Zealand
- the indirect costs associated with caring for someone with schizophrenia in New Zealand
- the impact of schizophrenia on other aspects of carers' lives.

3 Methods

3.1 Survey participants

Participants for the study were recruited through the SFNZ (Supporting Families in Mental Illness also known as Schizophrenia Fellowship of New Zealand). The study included people who identified themselves as a caregiver of someone with a diagnosis of schizophrenia. The study planned to include at least 50 caregivers. Based on a pilot study in Australia, this sample size was considered adequate. Potential participants were informed about the survey at a regular group meeting and invited to take part in the survey. Participants were compensated for their time with the choice of a \$NZ50 gift voucher or could choose to donate \$NZ50 to SFNZ.

3.2 Ethical considerations

This survey had approval of the New Zealand Multi Region Ethics Committee (MREC) as supported by the SFNZ (Te Rōpū Manaaki I Te Wairua Tuakoi Aotearoa). All patients gave written informed consent prior to participation in the survey. No names of participants were collected during the survey; therefore, all data were de-identified at the onset of the study. Individual response data were treated as confidential both during and at the completion of the study. Privacy regulations were adhered to at all times. The SFNZ maintained the list of names and addresses independently of M-TAG, and Solutions for Health and kept control of the code numbers. At no point did Solutions for Health or M-TAG have access to participants' details.

3.3 Questionnaire

The questionnaire was first developed for application in the Australian setting in 2003. The initial Australian study instrument was tested in a pilot study before application in a broader population of carers. For the New Zealand study, the sections detailing indirect and direct costs of caring from the original questionnaire were retained and adapted to the New Zealand setting, with advice from people familiar with the New Zealand environment, including input from the SFNZ.

The questionnaire contained seven main sections; demographics, time spent caring for someone with schizophrenia, costs associated with caring, questions regarding paid employment and caring, caring and unpaid activities, information about the person with schizophrenia they care for, and additional questions regarding caring. Each of the sections is described below. A copy of the questionnaire is presented in **Appendix A**.

3.3.1 Demographic information

The following basic demographic information was collected from the participants:

- age
- district health board (DHB) region
- sex
- ethnic group that the participant affiliates with
- marital status
- educational status (highest level completed)
- eligibility for reduced payments for medical/pharmaceutical costs
- method of payment for medical/pharmaceutical bills for own care
- out of pocket personal expenditure on medical expenses in past month
- income level.

3.3.2 History of caring

Participants were asked the following questions relating to their history of caring:

- whether they were the sole caregiver
- relationship to the person in their care
- length of time they have been caring for someone with schizophrenia
- whether they live with the person they care for
- time per week spent caring
- level of care needed when the person they care for is hospitalised
- any long term physical illnesses that add to caring
- additional psychological conditions that add to caring time
- overall time spent caring.

3.3.3 Costs of caring

Participants were asked the following questions regarding their out of pocket costs associated with caring:

- average amount of money spent per week on things for the person they care for including:
 - Medication and medical expenses
 - food
 - living expenses
 - clothing
 - cigarettes
 - travel expenses
 - other medical expenses (eg appointment costs)
- additional costs over previous 3 months
- receipt of any government financial benefits
- use of government or non-government support services and associated costs.

3.3.4 Employment and caring

Participants were asked whether they were currently undertaking any paid employment. Those who answered that they were in paid employment, were also asked:

- the number of hours worked in the past month
- whether in the past month they had taken time off work to provide care for the person they care for
- the amount of time taken off work related to caring
- whether there were days when they were less able to carry out their normal duties at work due to caring, and if so, how many days and the extent to which this occurred.

For those who indicated that they were currently not in any paid employment, they were asked whether this was directly related to their need to care for the person with schizophrenia.

All participants were asked the following questions regarding employment and caring:

- had they ever reduced the number of hours they worked due to caring for someone with schizophrenia?
- had they ever changed jobs due to caring for someone with schizophrenia and what the reduction in income was attributable to reduction in work or change of job?

With regard to unpaid work, participants were asked:

- about any unpaid activities (such as household, volunteer or committee work) in the past month?
- were there days in the past month when they were unable to do unpaid activities because of their role as carer for someone with schizophrenia, and on how many days this occurred?
- were there days when they were less able to carry out their unpaid work due to the burden of caring, and the number of days this occurred?
- had they reduced their amount of unpaid work as a direct consequence of caring for someone with schizophrenia, and by how much?

3.3.5 Information regarding the person they care for

Questions were then asked about the person with schizophrenia cared for by the participant.

They were asked the following questions in relation to the person in their care:

- length of time since diagnosis
- number of hospitalisations in the past 12 months
- length of time for the hospitalisation/s
- was the person in their care currently hospitalised because of their schizophrenia?
- had the person in their care been hospitalised for any condition not related to schizophrenia, and the length of time for each hospitalisation
- was the person in their care currently hospitalised for any condition not related to schizophrenia?

Participants were asked to nominate the number of times the person in their care had attended appointments in relation to their schizophrenia for each of the following: general practitioner (GP), psychiatrist, psychologist, case manager, occupational therapist, health and welfare officer, social worker, life skills programs or any other services they might access. Participants were also asked to provide any information they had about the medication taken by the person in their care.

In terms of employment of the person in their care, participants were asked:

- had the person being cared for ever been in paid employment, and if schizophrenia was the reason for them not having had paid employment
- had they engaged in any paid or unpaid work in the past month
- how many hours per week they worked
- if they had taken any time off due to schizophrenia in the past month, and if so, how much
- if they had reduced their time working in paid or unpaid positions due to schizophrenia
- if they had ever changed jobs due to schizophrenia
- by how much their weekly income had reduced due to job changes or working time reductions because of schizophrenia or related conditions.

3.3.6 Additional questions regarding caring

A set of additional questions was asked to determine other issues related to caring. Participants were made aware that the questions may or may not relate to their experience with schizophrenia and could omit any questions they felt unable to answer.

Questions asked to determine possible additional stress associated with caring were whether the person they care for in the past six months had:

- been a victim of violent crime (eg, mugging, assault)
- been a victim of non-violent crime (eg, burglary, theft of property or money)
- been arrested or 'picked up' by the police
- spent a night in jail
- caused damage to property
- attempted suicide
- deliberately hurt themselves
- hurt their carer or another person.

Participants were then given space to describe any other areas of life impacted by or additional costs or burdens they associated with caring for someone with schizophrenia.

3.4 Administration of questionnaire

Data collection was through face-to-face sessions organised by SFNZ. Group sessions, arranged through the SFNZ, were conducted in Auckland, Christchurch and Palmerston North between August and December 2005. Sessions began with an explanation of the background and aims of the research. Carers then completed the questionnaire in their own time. The time taken for completion of the questionnaire was approximately 35 minutes. A researcher was available to provide clarification where required.

3.5 Statistical analysis

The sample size for the survey was based on a pilot study of similar design carried out in Australia. The proposed number of carers to be recruited was 50.

Basic descriptive statistics were derived from the demographic data. For continuous variables, central tendency measures such as means, medians and standard deviations (SD) are reported. For categorical responses, the number and the percentage of respondents falling into each category are provided. Simple frequency tabulations are presented for demographic factors.

All statistical analyses were performed using Stata v8.1 (Stata Corporation, 1997). Basic concepts were tabulated from the qualitative answers although no in-depth qualitative analysis was performed.

The relationships between burden of care and respondents geographic location and ethnicity were explored. The association between categorical variables was tested with the Fisher's Exact test. For continuous variables the Kruskal-Wallis non-parametric rank test was utilised.

4 Results

4.1 Participation

A total of 51 participants indicated that they were willing to participate in the group session to complete the questionnaire conducted through the Schizophrenia Fellowship of New Zealand.

4.2 Demographics

Table 1 shows the demographic information for all participants. The age of the participants ranged from 34 to 76 with a mean age of 57.4 years (standard deviation [SD] = 10.6). The majority of participants in this survey belonged to either the Auckland (39.2%) or Mid-Central (27.5%) DHB regions.

In regard to the ethnicity of the study population, 36 (70.6%) participants classified themselves as being of European descent, 9 (17.7%) of Maori descent and 3 (5.9%) of Asian descent.

Forty-five (88.2%) participants were female. Twenty-eight (54.9%) of the participants were married, 8 (15.7%) were divorced and 4 (7.8%) reported that they had never been married.

With reference to the sample's highest educational level, 14 participants (27.5%) had completed a bachelor degree or higher level of qualification, 5 (9.8%) had completed an advanced diploma, 3 (5.9%) had completed a tertiary education certificate, 12 (23.5%) had completed School Certificate level education or its equivalent, and 14 (27.5%) had completed secondary education below School Certificate level.

Eleven (21.6%) participants reported incomes of more than \$NZ1000 a week, 8 (15.7%) participants reported incomes between \$NZ500 and \$NZ999, while a further 27 (52.9%) participants reported that their incomes were less than \$NZ499 a week. Another 2 (3.9%) participants reported a negative income (see **Table 1**).

Table 1 Summarised demographic information

Demographic variable	Number of participants	Percentage of participants
DHB region		
Auckland	20	39.2
Canterbury	3	5.9
Mid Central	14	27.5
Waitemata	5	9.8
Nelson-Marlborough	1	2.0
Otago	4	7.8
South Canterbury	1	2.0
Southland	2	3.9
Missing	1	2.0
Gender		
Male	6	11.8
Female	45	88.2
Ethnic group		
European	36	70.6
Maori	9	17.7
Pacific peoples	0	0.0
Asian	3	5.9
Other	3	5.9
Marital status		
Never married	4	7.8
Widowed	5	9.8
Divorced	8	15.7
Separated but not divorced	3	5.9
De facto	3	5.9
Married	28	54.9
Highest level of education		
Postgraduate degree level	4	7.8
Graduate diploma level	2	3.9
Bachelor degree level	8	15.7
Advanced diploma or diploma	5	9.8
Tertiary Education Certificate level	3	5.9
Secondary education (School certificate or equivalent)	12	23.5
Secondary education (did not complete school cert)	14	27.5
Primary education	0	0.0
Pre-primary education	0	0.0
Other education	2	3.9
Missing	1	2.0

Table 1 continues...

Table 1 continued

Demographic variable	Number of participants	Percentage of participants
Income (NZD)		
\$2000 or more per week	1	2.0
\$1500–1999	3	5.9
\$1000–1499	7	13.7
\$800–999	1	2.0
\$700–799	2	3.9
\$600–699	2	3.9
\$500–599	3	5.9
\$400–499	6	11.8
\$300–399	5	9.8
\$200–299	9	17.7
\$160–199	3	5.9
\$80–159	3	5.9
\$40–79	1	2.0
\$1–39	0	0.0
Nil income	0	0.0
Negative income	2	3.9
Missing	3	5.9

Abbreviations: DHB, District Health Board; NZD, New Zealand Dollars

Table 2 shows participants eligible for reduced patient payments for any medical and/or pharmaceutical costs. Twenty-eight (54.9%) participants reported having/using a community services card and 11 (21.6%) participants reported that they belonged to a primary health organisation. A further 8 (15.7) participants reported having/using a high user health card and another 5 (9.8%) reported having/using a prescription subsidy card. Two (3.9%) other participants were eligible for reduced payments either through accident compensation or by other unspecified means.

Table 2 Eligibility for subsidised medical and/or pharmaceutical costs

Service	Number of participants ^a	Percentage of participants ^a
High User Health Card	8	15.7
Community Services Card	28	54.9
Prescription subsidy card	5	9.8
Belonging to Primary Health Organisation (PHO)	11	21.6
Accident Compensation Corporation (ACC)	1	2.0
Any other	1	2.0

^aParticipants could answer more than one option so numbers may add to more than 100%

Table 3 shows participants' sources of funding for medical and/or pharmaceutical bills for their own care. (This does not include subsidies directly paid by the government to doctors, pharmacists or other health professionals). Twenty-two participants (43.1%) reported using personal funds, 9 participants (17.7%) reported using NZ Superannuation and 7 (13.7%) reported using the invalids' benefit subsidy. A further 7 (13.7%) reported using private health insurance while another 7 (13.7%) reported other sources of funding such as relatives, investments and the Australian war veterans' pension.

Table 3 Funding sources for medical and/or pharmaceutical costs for own care

Source of funding for remaining medical costs	Number of participants ^a	Percentage of participants ^a
Wages or salary	22	43.1
NZ Superannuation	9	17.7
Unemployment Benefit	2	3.9
Domestic Purposes Benefit	4	7.8
Sickness Benefit	1	2.0
Invalid Benefit	7	13.7
Disability Allowance	4	7.8
Accident Compensation Corporation payments (ACC)	1	2.0
Private health insurance	7	13.7
Another source	7	13.7

^aParticipants could answer more than one option so numbers may add to more than 100%

In reference to out-of-pocket expenses for their own medical costs in the past month, 27 (52.9%) reported having spent over \$NZ30.00, of these 6 (22.2%) reported spending over \$NZ100.00 (see **Table 4**).

Table 4 Out-of-pocket medical expenses in the past month

Out-of-pocket expenses (NZD)	Number of participants	Percentage of participants
\$0.00	14	27.5
\$0.01–30.00	9	17.7
\$30.01–50.00	11	21.6
\$50.01–100.00	10	19.6
More than \$100.00	6	11.8
Missing	1	2.0

Abbreviations: NZD, New Zealand dollars

4.3 Experience with caring for someone with schizophrenia

Twenty-six participants (51.0%) indicated that they were the sole caregiver for the person with schizophrenia for whom they provide care.

Of the people who were carers, 32 (62.8%) were parents, 2 (3.9%) were the spouse or partner of the person they care for, 3 (5.9%) were siblings, 10 (19.6%) were another family member and 3 (5.9%) were a friend or neighbour. One (2.0%) other participant reported they were an age concern volunteer.

On average, participants reported being a carer to a person with schizophrenia for 12.0 years (range = 4 months to 31.3 years; median = 9.9; SD = 8.2). Twenty-four (47.1%) respondents indicated that they lived with the person they care for, and 21 (41.2%) respondents said the person they cared for lived elsewhere. A further 6 (11.8%) respondents indicated that they sometimes lived with the person in their care. Of those people with schizophrenia who lived elsewhere or only sometimes lived with their carer, 8 (15.7%) were currently living alone, 1 (2.0%) was living with another family member and 17 (33.3%) had other living arrangements. These other living arrangements included sheltered housing, hospitals and shared housing. Of those people who indicated they did not live with the person in their care, an average of 4.5 hours travel time per week was reported (range = 0-24; median = 2; SD = 6.5).

There was no difference in sole caregiver status or living arrangements in relation to ethnicity ($p=0.46$).

On average, participants reported caring for the person with schizophrenia for 52.1 hours per week (range = 0.5–168; median = 22.5; SD = 57.8), which is higher than the 37.1 hours reported in the ACT/NSW study.

Participants were then asked to estimate if the time they spent actively caring differed if the person they cared for was hospitalised. Nine (17.7%) stated that they provided less care than usual, 15 (29.4%) stated they provided the same amount of care and 18 (35.3%) said that the care they provided increased. Seven (13.7%) stated that the person in their care had never been hospitalised. Two respondents did not answer this question.

When asked if they perceived the time spent caring to also be due to medical conditions other than schizophrenia, 21 (41.2%) replied in the affirmative. Participants were able to list more than one condition. The four most common conditions listed were:

- asthma (n = 4)
- diabetes (n = 3)
- obesity (n = 2)
- kidney conditions (n = 2).

Participants were also asked if the person they cared for had any other mental health conditions that added to the time spent caring. Forty-three (84.3%) carers indicated that the person in their care had other mental health conditions as well as schizophrenia. Participants could list more than one additional condition. The other major mental health conditions experienced were:

- depression (n = 26)
- anxiety (n = 24)
- anxiety and depression (n = 16).

A full list of the concurrent medical conditions is presented in **Appendix B**.

Participants were then asked to estimate the percentage of time they spent caring because of schizophrenia, physical illness and other mental illnesses. The average time divided between schizophrenia, physical illness and other mental illness were:

- schizophrenia 72.7% (range = 20–100; median = 80; SD = 28.5)
- physical illness 9.1% (range = 0–50; median = 0; SD = 14.4)
- mental illness 18.3% (range = 0–80; median = 10; SD = 24.6).

Interestingly, respondents who lived in the DHB regions of the South Island reported greater average weekly time caring, 88.1 hours, compared with respondents living in Auckland and the North Island, 40.7 and 43 hours, respectively; however, this trend was of marginal statistical significance ($p=0.05$). In addition, carers of Maori background reported significantly greater average time spent caring, 89.2 hours per week, in comparison to carers from a non-Maori background, 44.2 hours per week ($p=0.02$).

The proportion of time spent caring for someone with schizophrenia, independent of physical or other mental illnesses, is significantly higher for respondents from the South Island, 91%, compared with respondents from Auckland, 60.3%, and the North Island (excluding Auckland), 74.2% ($p=0.031$). Conversely, respondents from the DHB regions of the South Island spend a smaller proportion of their time caring for mental illnesses other than schizophrenia, 2.2%, in comparison with carers from Auckland, 24.4%, and the North Island (excluding Auckland), 23.1% ($p=0.028$).

Additional analyses showed that the proportion of time spent caring for someone with schizophrenia, independent of physical or other mental illnesses, is not significantly different for carers of different ethnic backgrounds. Furthermore, the proportion of time spent caring because of physical and mental illnesses other than schizophrenia is not significantly influenced by ethnicity.

4.4 Costs associated with caring

4.4.1 Weekly costs

Table 5 shows the average weekly costs paid by carers for the person with schizophrenia in their care. Participants reported spending on average \$NZ1.20 (range = 0–15; median = 0; SD = 3.2) per week on medications and \$NZ3.05 (range = 0–30; median = 0; SD = 7.6) on non-prescription medication. Other expenses included \$NZ30.00 (range = 0–150; median = 20; SD = 32.5) on food, \$NZ16.71 (range = 0–400; median = 0; SD = 61.5) on clothing and \$NZ14.00 (range = 0–50; median = 10; SD = 14.5) on travel. Overall this equates to carers reported spending an average of \$NZ64.96 every week on the person with schizophrenia who they care for.

Participants reported additional spending on a number of expenses, ranging from 30 cents on light bulbs to \$NZ1500 for a new bed and bedclothes. A full list of the other expenses is presented in **Appendix B**. The data were explored for geographic and ethnic differences, and in general, there was no evidence of significant differences in medication costs or living expenses, including food and clothing. However, carers who self-reported being of Maori background indicated significantly higher average weekly expenditure on prescription medications in comparison to carers of a non-Maori background, \$NZ5.71 versus \$NZ0.36 ($p=0.0001$).

Table 5 Carers' weekly expenditure for the person in their care

Costs (NZD)	N	Average	Range	Median	SD
Buying prescription medication	43	1.21	0–15	0	3.2
Buying non-prescription medication	43	3.05	0–30	0	7.6
Other medical expenses (eg appointment costs)	43	3.35	0–50	0	10.5
Food	43	30.00	0–150	20	32.5
Living expenses (eg phone, bills, rent)	43	13.40	0–65	0	20.1
Travel (public transport, petrol, taxis)	43	14.00	0–50	10	14.5
Cigarettes	43	6.98	0–70	0	16.2
Clothing	42	16.71	0–400	0	61.5

Abbreviation: NZD, New Zealand Dollars

Note: 8–9 participants did not respond to this question

4.4.2 Three-monthly costs not mentioned above

Participants were asked to list any additional costs they had experienced in the past three months. Overall 17 participants reported that they had paid for additional expenses, that is, in addition to the weekly expenses summarised in **Section 4.4.1**, in the past three months. A full list of additional costs that were incurred in the last three months is presented in **Appendix B**.

4.4.3 Receipt of any carer financial benefits

Participants were asked if they received any financial assistance from the government in the last three months in terms of specific carer payments. Three (5.9%) reported receiving domestic purposes benefit and none reported receiving a carer support subsidy. Five (9.8%) reported receiving other government financial benefits such as accommodation support and respite care.

4.4.4 Use of groups or services for help associated with caring

Table 6 outlines which services were accessed and the average number of times these were used in the past three months. The majority of carers had accessed services provided by the SFNZ ($n = 28$), GP ($n = 22$), or other support/community groups ($n = 17$). Carers accessed these services once or twice a month on average. A list of the other services used by carers is provided in **Appendix B**. The average use of services accessed by carers in the past 3 months was similar irrespective of carers' ethnic background.

Table 6 Services used by carers in the past 3 months

Service	Number of carers using this service	Average use over past 3 months	Range
SFNZ	28	5.1	1–20
Church group	9	7.5	1–16
GP	22	2.3	1–5
Counsellor/psychologist	13	3.0	2–6
Police	8	1.3	1–2
Other support group	16	9.1	1–36
Other community group	5	5.3	1–16
Other services #1	14	4.7	1–10
Other services #2	4	3.0	3–3

Respondents were asked to indicate any services they, or other family members (excluding the person in their care), had used in the past six months. **Table 7** shows the number of respondents who had accessed each service, and the average number of times it was accessed over a six-month period, along with the average cost associated with using the service. Other services included costs such as support organisations' membership fees and educational material.

Table 7 Services used by carers and family members in the past six months

Service	Number of respondents who used service	Average times used in six month period	Average cost per visit
Counselling related to caring for someone with schizophrenia	10	4.4	711.43
Training or education sessions in how to cope with caring for someone with schizophrenia	19	9.6	148.21
Other services #1	10	8.6	121.00
Other services #2	2	Not reported	50.00

4.5 Employment and caring

4.5.1 Carer paid employment

Of the participants surveyed, 24 (47.1%) had participated in paid employment in the past month. Of those in paid employment, their average number of hours worked per week was 26.2 (range = 2–60; median = 25; SD = 16.3). Nine (37.5%) of these people had taken time off work specifically due to caring for someone with schizophrenia in the past month.

Thirteen (54.2%) people who had participated in paid employment in the last month stated that caring for someone with schizophrenia had meant that they were less able to carry out their usual employment activities, with this happening, on average, 7.3 days (range 2–28; median = 3; SD = 8.4) in the past month. When asked to rate the impact caring had on their work on the days they were less able to work on a scale of 0 to 10, the majority of these respondents (53.3%) provided a rating of 5 or more on the scale.

Seven (29.2%) respondents participating in paid employment in the last month reported having to reduce the number of hours in paid employment due to caring from someone with schizophrenia, with an average change being from 30.0 to 16.3 hours. Five other participants (20.8%) reported having changed their jobs due to caring. The average drop in yearly income for these people was \$NZ221.17 (range 0.00–1000.00; median = 137.00; SD = 294.76).

4.5.2 Carer not being in paid employment in the past month

Table 8 shows the reasons given by participants as to why they had not participated in paid employment in the past month. Eight (15.7%) participants reported that this was due to caring for someone with schizophrenia and 7 participants reported that this had reduced their income on average of \$NZ350 per week (range 200–550; median = 300; SD = 135.4).

Table 8 Reasons for not being in paid employment in the past month

Reason	Number of participants	Percentage of participants
Retirement because of age	7	13.7
Home duties/child care	4	7.8
Retirement due to carer's illness or disability	4	7.8
Stopped work to care for person with schizophrenia	8	15.7
Other	5	9.8
Not applicable	17	13.3
Missing	6	11.8

4.5.3 Caring and unpaid activities

Of the participants surveyed, 39 (76.5%) had participated in unpaid activities in the past month. Of these people, 16 (39.0%) stated that caring for someone with schizophrenia had meant that they were completely unable to carry out their unpaid activities, with this happening, on average, 4.2 days (range 1–14; median = 4; SD = 3.0) in the past month. The ability to participate in unpaid activities is not impacted by ethnicity ($p=0.72$). Seventeen (41.5%) participants also stated that there were days when they had been less able to carry out their unpaid activities in the past month due to caring, and that this had occurred on 4.7 days (range 1–16; median = 4; SD = 4.2). Fourteen (34.2%) stated that in the past year they had to reduce the amount of unpaid work they did, due to caring, and the average reduction was from 10.9 hours (range 3–20; median = 12.5; SD = 6.4) to 5.4 hours (range 0–20; median = 4; SD = 6.3).

4.6 Information about the person with schizophrenia who is cared for

4.6.1 Medical history regarding schizophrenia

The people who are being cared for by the participants had been diagnosed with schizophrenia, on average, 12.7 years ago (range = 0.25–52; median = 10; SD = 10.2). In relation to hospitalisation in the past 12 months, 24 participants (47.1%) reported the person they care for had been hospitalised during that time. Ethnicity did not significantly impact on the annual rate of hospitalisation ($p=0.72$). Overall, these admissions accounted for approximately 3136 days in hospital in the past year. Five people (9.8%) indicated that the person in their care was hospitalised at the time of the survey due to schizophrenia. A total of 5 (9.8%) people indicated that the person in their care was hospitalised for something other than schizophrenia in the previous year with one person still currently hospitalised.

Table 9 lists the appointments attended by people with schizophrenia over the past six months. Other appointments attended by people with schizophrenia are shown in **Appendix B**.

Table 9 Reported appointments of the person cared for in the past six months

Appointments	Number of people carers reporting appointments	Average number of appointments
GP	49	1.1
Psychiatrist	48	2.8
Psychologist	49	1.4
Case manager	48	3.3
Occupational therapist	49	0.9
Health and welfare officer	49	0.4
Social worker	49	1.4
Life skills/ job program or advisor	49	0.8

There was no association between the number of hospitalisations or visits to associated healthcare professionals and geographic location of the respondent.

Table 10 shows the number of respondents who indicated the person they care for was on each of the following medications. The range of medication regimens is presented. A full list of respondents' answers is presented in **Appendix B**, as can a list sorted by brand name, where possible.

The primary antipsychotic agents prescribed were olanzapine (29.4%), risperidone tablets (29.4%) and clozapine (23.5%). There were no clearly dominant antipsychotic therapy regimens or combination therapies. **Table 10** presents data as provided by carers, and hence, may not appear to be complete. A list of all responses to this question is presented in **Table B5, Appendix B**.

Table 10 Patient medication uses as reported by carers

Drug name	Mean days/month	Number of patients	Percentage of patients
Antipsychotic medications			
Risperidone (tablets)	1–6 mg daily	15	29.4
Risperidone (injection)	37.5 fortnightly	3	5.9
Clozapine	15–600 mg daily	12	23.5
Halperidol	5 mg twice daily	3	5.9
Lithium	250–1000 mg daily	6	11.8
Olanzapine	2.5 mg–20 mg daily	16	31.3
Seroquel	NR	2	3.9
Chlorpromazine	NR	3	5.9
Flupenthixol (injection)	NR	1	2.0
Zuclopenthixol	150–200 mg fortnightly	1	2.0
Antidepressant medications			
Nortriptyline	NR	1	2.0
Venlafaxine	50 mg daily	1	2.0
Fluoxetine	NR	3	5.9
Citalopram	NR	1	2.0
<i>Unspecified</i>	N/A	1	2.0
Anti-anxiety medications			
Diazepam	5 mg daily	4	7.8
Lorazepam	1 mg daily	2	3.9
Sedatives			
Zopiclone	NR	2	3.9
<i>Unspecified</i>	N/A	1	2.0
Other medications			
Epilim	500 mg daily	2	3.9
Simvastatin	NR	1	2.0
Pantoprazole	NR	1	2.0
Aspirin	NR	1	2.0
Propanolol	10 mg three times daily	2	3.9
Trimeprazine	25 mg daily	1	2.0
Famotidine	NR	1	2.0
Benzotropine	NR	2	3.9
B ₁₂ (injection)	NR	1	2.0
Clonazepam	NR	1	2.0
Levodopa	NR	1	2.0
Indigestion medication	NR	1	2.0
Exopil	100 mg	1	2.0
Risedronate	NR	1	2.0
Preperotone	5 mL twice daily	1	2.0
<i>Unknown</i>	N/A	8	15.7

Footnote: Where the medication identity was unclear the carer's response was directly transcribed.

4.6.2 Paid employment

Thirty-nine (76.5%) participants reported that the person they cared for had been in paid employment at some time in the past. For those who stated the person they cared for had never been in paid employment, 9 (75%) stated that this was due to their schizophrenia. For those who indicated it was not due to schizophrenia, reasons given were the person was a child ($n = 1$), had other physical disabilities ($n = 1$) or was unable to concentrate ($n = 1$).

Seven (18.0%) stated that the person they cared for had been in paid employment in the past month for an average of 17.6 hours per week (range = 8–40; median = 14; SD = 11.4). Four (57.1%) of these respondents indicated that the person they care for had taken time off work because of their schizophrenia or related condition in the past month with an average of 10.8 hours (range = 2–24; median = 8.5; SD = 9.4) taken off. Twenty-six (68.4%) respondents indicated that the person in their care had previously worked, on average, for 31.1 hours per week, (range = 10–40; median = 32; SD=9.7) which was reduced to an average working week of 3.2 hours (range = 0–20; median = 0; SD = 6.6) due to their schizophrenia.

When asked if the person in their care had ever changed jobs because of schizophrenia, 19 (50.0%) stated that was the case. Of those participants who reported a reduction in earnings due to schizophrenia-related job changes, the average earnings drop was \$NZ134.40 per week (range = 2–250; median = 150; SD = 86.0). Two (10.5%) of these respondents reported that the person in their care had changed jobs in the past year due to schizophrenia.

Of those who answered that the person they cared for had not been in paid employment in the past month, 27 (87.1%) stated that this was due to their schizophrenia. Those who indicated it was not schizophrenia preventing employment in the past month, stated it was because of the person was a university student ($n = 1$), seasonal worker ($n = 1$), aged ($n = 1$) or was unable to concentrate ($n = 1$).

4.6.3 Unpaid activities

Carers indicated a reasonably high level ($n = 21$; 41.2%) of participation in unpaid activities in the month before the survey. Schizophrenia or related conditions meant that 13 (61.9%) people with the illness could not undertake unpaid activities on an average of 7.6 days (range 1–20; median = 7; SD = 5.9) in the previous month. Of those, 26 (51.0%) participants who stated the person they cared for had not participated in any unpaid activities in the last month, 22 (84.6%) said this was due to schizophrenia or related disorders.

4.6.4 Additional questions regarding caring

Table 11 shows the number of participants who reported the person they care for had been a victim of crime, had contact with law enforcement, had damaged property or had tried to hurt themselves or others over the past six months.

Table 11 Additional questions regarding other aspects of caring for someone with schizophrenia

Occurred in the past 6 months	Number of participants	Percentage of participants
Been a victim of violent crime	7	13.7
Been a victim of non-violent crime	8	15.7
Been arrested or picked up by police	10	19.6
Spent a night in jail	5	9.8
Caused damage to property	12	23.5
Attempted suicide	3	5.9
Deliberately hurt themselves	7	13.7
Hurt the carer or someone else	8	15.7

Participants were then asked to describe any additional costs or burdens that the questionnaire had not dealt with regarding caring for someone with schizophrenia, including less tangible and emotional issues. **Table 12** outlines the themes of the written answers and the number of people who identified this issue as needing to be taken into consideration.

Table 12 Additional costs and burdens associated with caring for someone with schizophrenia

Theme	Number of participants	Percentage of participants
Burden of constant care	12	23.5
Alienation/isolation from previous friends, neighbours and family	11	21.6
Need for respect from medical professionals	9	17.6
Stigma of mental illness	8	15.7
Stress and anxiety (general)	8	15.7
Financial cost of caring	7	13.7
Lack of mental health communities and facilities	6	11.8
Lack of support for carers and consumers	5	9.8
Grief for lost potential	5	9.8
Lack of understanding of schizophrenia in the community	3	5.9
Fear of the future for the person they care for	2	3.9
Difficulty of communication with the person they care for	2	3.9

5 Discussion

The objectives of the study were to gain information on the impact of schizophrenia on the lives of carers and to collect some basic data on the costs involved in being a carer of someone with schizophrenia. The study participants were all recruited via SFNZ and appeared to be from a broad background providing a good basis for evaluating the impact of schizophrenia in the community. The majority of carers were women, of European descent, were married and have household incomes less than \$NZ500 a week. About half the carers considered themselves the sole caregiver.

The majority of participants were parents caring for their child with schizophrenia. Duration of time spent caring was on average 12.0 years. Overall, participants reported spending about 52.1 hours a week caring for the person with schizophrenia; this is in comparison to 37 hours reported in the Australian carers report.

Caring was not limited directly to the impact of schizophrenia. Of those people with schizophrenia in the study, more than three-quarters had concurrent psychological illnesses, most commonly anxiety and depression, which is similar to what was reported in the Australian carers' study. Whilst schizophrenia-related illness required the most care (73%) additional psychological illnesses also significantly contributed to the burden of care. Overall, the time spent caring for someone with schizophrenia tended to be higher for respondents from the South Island in comparison with respondents from Auckland and the North Island. Conversely, the proportion of time spent caring for other mental illness was significantly lower for respondents from the South Island.

Interestingly, the average time spent caring for someone with schizophrenia was significantly higher for carers from Maori background in comparison with carers of non-Maori background. However, the breakdown of time spent caring because of schizophrenia symptoms (independent of physical and other mental illness), physical illness and other mental illnesses is not significantly different across ethnicities.

Direct costs incurred weekly by the carers' range from an average \$NZ7.61 on medical costs including medications, to \$NZ71.64 on food, clothing, travel and living expenses. There appeared to be a considerable difference in the reported medical costs between New Zealand and Australia. As in the Australian carers' report, the majority of respondents stated that they spent nothing on medical expenses and cigarettes for the person they care for, in addition the majority of New Zealand carers reported spending nothing on living expenses or clothing. Carer out of pocket expenses for prescription medications for people with schizophrenia was significantly higher for respondents of a Maori background.

The majority of participants had sought advice from the SFNZ and/or GPs in the previous three months, on average of once or twice a month. In addition, a large number of participants and their families had sought schizophrenia-related services in the last six months at significant financial cost. Utilisation of services was not affected by ethnic background, that is, the use of support services was similar irrespective of ethnicity.

Only about a quarter of participants reported receiving a carer allowance or payment. Almost half of the carers surveyed were in paid employment; however, more than a half were unable to engage in their usual employment due to responsibilities of caring. This happened on average for 7.3 days in the past month. Approximately a quarter of respondents had to reduce the number of hours in paid employment due to caring for someone with schizophrenia by an average of 14 hours per week. The average drop in weekly income was approximately \$NZ221. Less than 20% of participants reported being unable to work at all due to care giving. This, however, resulted in an average weekly income loss of \$NZ350.

The impact of caring for someone with schizophrenia is clearly not limited to paid employment. The majority of carers participated in unpaid activities in the last month; however, they were also less able to fulfil their activities, on average four days per month, due to responsibilities of caring.

A third of the carers stated they provided a higher level of care when the person with schizophrenia was hospitalised. Twenty-four (47%) participants reported the person in their care was hospitalised at least once in the previous 12 months, accounting for 3136 hospital days. In contrast, the Australian population reported an annual hospitalisation rate of approximately 12%, which accounts for 2282 hospital days. There was no difference in the number of hospitalisations or visits to healthcare professions across the DHB regions or ethnic background.

The majority of people with schizophrenia being cared for by respondents in this study had been prescribed some form of antipsychotic over the previous three months. The primary antipsychotic agents prescribed were olanzapine (29.4%), risperidone tablets (29.4%) and clozapine (23.5%). There were no clearly dominant antipsychotic therapy regimens or combination therapies. In 15% of cases, the respondents were unable to specify the drug taken.

The burden of illness associated with schizophrenia is not restricted to direct and indirect costs of the condition and related disorders. Many people with schizophrenia in this study had experienced crime, either as the victim or offender, in the last six months. People with schizophrenia also reported a number of incidents of harmful behaviour, either toward carers or self-directed, including attempted suicide.

One of the common themes to emerge from asking the participants to record any additional costs or burdens, including less tangible and emotional issues, was the alienation, isolation and stigma that is associated with schizophrenia and therefore by association also with the carer and their family. Carers report stress and anxiety due to the responsibility of caring; a general lack of opportunities for people with schizophrenia and frustration with the lack of services.

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Appendix A: Questionnaire

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CARERS' QUESTIONNAIRE **IMPACT of SCHIZOPHRENIA on** **CAREGIVERS in New Zealand**

Thank you for assisting us by answering this anonymous questionnaire. Your answers will provide important information about the general impact and cost of schizophrenia.

The questionnaire will take about 35 minutes to complete. Feel free to ask staff from Solutions for Health or M-TAG if you require explanation of the meaning of any of the questions. Please return the completed questionnaire before you leave today.

2005

Instructions for completing this questionnaire

1. Please read each question carefully. Some questions ask you to remember things that have happened in the past **12 months**, others ask about the past **6 months**, **3 months**, **1 month** or **7 days**. Please make sure you note the time period associated with each question.
2. For some questions, we need you to tell us about the impact of schizophrenia on **your** life and **your** feelings towards this. Other questions ask you to indicate the impact that schizophrenia has on the life of the person you care for. We ask that you complete both sets of questions.
3. For most questions, you will simply need to put a tick (✓) in the box that best answers the question for you, as shown in the example below.

Example: Are you male or female?

Male ☒ ₁

Female ☐ ₂

4. For some questions, we need you to provide us with a written answer, as shown in the example below.

Example: How old are you?

3	4
---	---

5. Occasionally, you will see a scale of numbers after the question, as shown below. Place a cross (×) or tick (✓) through the number that represents where you fit on the scale.

Caring did
not affect
my work

☐ 0☐ 1☐ 2☒☐ 4☐ 5☐ 6☐ 7☐ 8☐ 9☐ 10

Caring did
not allow
me to work
at all

6. Sometimes, you will be asked to pick one option out of a list, as shown below. Place a cross (×) or tick (✓) through the number that represents where you fit on the scale.

Example: Thinking about how you generally feel:

You do not feel anxious, worried or depressed

You are slightly anxious, worried or depressed

You feel moderately anxious, worried or depressed

You are extremely anxious, worried or depressed

<input checked="" type="checkbox"/>	1
<input type="checkbox"/>	2
<input type="checkbox"/>	3
<input type="checkbox"/>	4

7. Please use a ballpoint pen (not a pencil) when filling out this questionnaire.
8. If you make a mistake when filling out the questionnaire, simply cross out the mistake and write the correct answer.
9. All questionnaires will be entered into a database using *only* a code number. All data will be reported in summary form *only*. Your anonymity is assured. Your contact details are never seen by anyone who will ever see the content of the completed questionnaires.

Section 1

Questions about you

The following section asks 11 questions about you.

Please answer all of the questions.

_____|_____|_____|
Day/Month/Year

 \square_1 \square_2

(Please tick one answer only)

□ 1

 \square_2

3

□₄

5

.....

□ 1

 \square_2 □₃

4

□₅

□ 6

1.7 Your highest level of education *completed*?

(Please tick one answer only)

- | | | |
|--|--------------------------|----|
| Postgraduate degree | <input type="checkbox"/> | 1 |
| Graduate diploma or graduate certificate | <input type="checkbox"/> | 2 |
| Bachelor degree | <input type="checkbox"/> | 3 |
| Advanced diploma or diploma | <input type="checkbox"/> | 4 |
| Tertiary Education Certificate level | <input type="checkbox"/> | 5 |
| Secondary education (School Certificate or equivalent) | <input type="checkbox"/> | 6 |
| Secondary education (did not complete School Cert | <input type="checkbox"/> | 7 |
| Primary education | <input type="checkbox"/> | 8 |
| Pre-primary education | <input type="checkbox"/> | 9 |
| Other education (please specify) | <input type="checkbox"/> | 10 |

.....

1.8 Do you have any of the following that make you eligible for reduced patient payments for any medical and/or pharmaceutical costs?

(Please tick either yes or no for each item)

- | | Yes | No |
|---|----------------------------|----------------------------|
| High User Health Card | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| Community Services Card | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| Prescription subsidy card | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| Belong to Primary Health Organisation (PHO) | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| Accident Compensation (ACC) | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| Any other (please specify) | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |

- 1.9 How do your medical and/or pharmaceutical bills for your own care get paid? (Do not include subsidies paid directly by the government to your doctor, pharmacist or other health professional for medical or pharmaceutical costs)

(Please tick either yes or no for each item)

	Yes	No
Wages or salary	<input type="checkbox"/> 1	<input type="checkbox"/> 2
NZ Superannuation	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Unemployment benefit	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Domestic Purposes Benefit	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Sickness benefit	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Invalids benefit	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Disability Allowance	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Accident Compensation Payments (ACC)	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Private health insurance	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Another source (please specify)	<input type="checkbox"/> 1	<input type="checkbox"/> 2

- 1.10 How much did you pay out of pocket from *personal funds* for your own medical costs over the past **month**? (Include any payments you made for doctors, prescriptions, investigations etc. Do **not** include the cost of your premium for private health insurance.)

(Please tick one answer only)

\$0.00	<input type="checkbox"/> 1
\$0.01–30.00	<input type="checkbox"/> 2
\$30.01–50.00	<input type="checkbox"/> 3
\$50.01–100.00	<input type="checkbox"/> 4
More than \$100.00	<input type="checkbox"/> 5

- 1.11 What is your average weekly gross income from all sources (before tax)? (If you are married or in a de facto relationship, add your spouse's income to your own.)
(Please tick one answer only)

- | | |
|--|-----------------------------|
| \$2000 or more per week
(> \$104,000 per annum) | <input type="checkbox"/> 1 |
| \$1500–1999 per week
(\$78,000–103,999 per annum) | <input type="checkbox"/> 2 |
| \$1000–1499 per week
(\$52,000–77,999 per annum) | <input type="checkbox"/> 3 |
| \$800–999 per week
(\$41,600–51,999 per annum) | <input type="checkbox"/> 4 |
| \$700–799 per week
(\$36,400–41,599 per annum) | <input type="checkbox"/> 5 |
| \$600–699 per week
(\$31,200–36,399 per annum) | <input type="checkbox"/> 6 |
| \$500–599 per week
(\$26,000–31,199 per annum) | <input type="checkbox"/> 7 |
| \$400–499 per week
(\$20,800–25,999 per annum) | <input type="checkbox"/> 8 |
| \$300–399 per week
(\$15,600–20,799 per annum) | <input type="checkbox"/> 9 |
| \$200–299 per week
(\$10,400–15,599 per annum) | <input type="checkbox"/> 10 |
| \$160–199 per week
(\$8320–10,399 per annum) | <input type="checkbox"/> 11 |
| \$80–159 per week
(\$4160–8319 per annum) | <input type="checkbox"/> 12 |
| \$40–79 per week
(\$2080–4159 per annum) | <input type="checkbox"/> 13 |
| \$1–39 per week
(\$1–2079 per annum) | <input type="checkbox"/> 14 |
| Nil income | <input type="checkbox"/> 15 |
| Negative income | <input type="checkbox"/> 16 |

Section 2

Time spent caring

This section contains general questions about your relationship to the person with schizophrenia whom you care for, and the level of care that you provide.

There are 11 questions in this section.

Please try to answer all relevant questions.

- 2.1 Are you the sole caregiver for the person with schizophrenia whom you care for?

Yes ☐ 1
No ☐ 2

- 2.2 What is your relationship to the person with schizophrenia whom you care for?

	Yes	No
Husband/wife/partner	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Child	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Sibling (brother or sister)	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Another member of the family	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Friend/neighbour	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Other (<i>please specify</i>):	<input type="checkbox"/> 1	<input type="checkbox"/> 2

- 2.3 How long have you been caring for the person with schizophrenia, specifically in relation to their schizophrenia?

_____ Years
AND
_____ Months

- 2.4 Do you live with the person with schizophrenia whom you care for?

Yes ☐ 1 Go to Question 2.7
No ☐ 2 Go to Question 2.5
Sometimes (*please specify, e.g. half the week, whenever they come home*): ☐ 3 Go to Question 2.5
.....

- 2.5 If you answered 'No' or 'Sometimes' to Question 2.4, approximately how much time **per week** do you spend travelling to where he/she lives (including public transport, car travel etc.)?

_____ hours

- 2.6 If you answered 'No' or 'Sometimes' to Question 2.4, what are the living arrangements of the person you care for?

They live alone ☐ 1
They live with other family members ☐ 2
Other (please specify): ☐ 3

- 2.7 How much time **per week**, on average, do you spend directly caring for the person with schizophrenia? (*Caring includes housework, meals, organising appointments, helping with day-to-day living such as dealing with the bank on their behalf etc.*)

_____ hours for _____ days a week

- 2.8 When the person you care for has been in hospital, how would you rate any change in the level of caring provided by you? (*Think about the time you spend doing the caring and travelling. Also think about the other things you do for the person with schizophrenia.*)

The level of care I provide is **less** than usual ☐ 1
The level of care I provide is the **same** as usual ☐ 2
The level of care I provide is **more** than usual ☐ 3
The person I care for has never been hospitalised ☐ 4

- 2.9 Does the person you care for have any long-term physical illnesses that add to the time you spend caring for them (*e.g. hepatitis, cardiovascular problems or other medical problems*)?

Yes ☐ 1
No ☐ 2
If yes, can you please outline the conditions below: ☐ 3

- 2.10 Does the person you care for have any additional psychological conditions that add to the time you spend caring for them (*e.g. anxiety, depression, substance use*)?

Yes ☐ 1
No ☐ 2
If yes, can you please outline the conditions below: ☐ 3

- 2.11 Please think about the time you spend caring for the person with schizophrenia, including the time you spend caring for this person due to additional physical or other mental illnesses (as mentioned in Questions 2.9 and 2.10).

The symptoms of the conditions you mentioned in Questions 2.9 and 2.10 can often be intertwined with the symptoms of schizophrenia. If possible, we want you to think about them separately. Some of the care you provide might not be necessary if these conditions were not present.

What percentage of the total time you spend caring for the person with schizophrenia is taken up because of each of the following:

- schizophrenia symptoms and behaviour
- physical illnesses
- other mental illness.

Percentage of time spent caring because of schizophrenia symptoms independent of physical and other mental illness _____ %

Percentage of time spent caring specifically because of physical illnesses _____ %

Percentage of time spent caring specifically because of other mental illnesses _____ %

Total time spent caring _____ %
Must add up to 100%

Section 3

Costs associated with caring

This section contains general questions about
the amount of money you spend
caring for someone with schizophrenia.

The time frames associated with questions in
this section change, so please
read each question carefully.

There are 5 questions in this section.

Please try to answer all of the questions.

3.1 How much of your own money do you spend **per week**, on average, on things related to caring for the person with schizophrenia?

Buying prescription medication	\$ _____
Buying non-prescription medication	\$ _____
Other medical expenses (e.g. appointment costs)	\$ _____
Food	\$ _____
Living expenses (e.g. phone or electricity bills)	\$ _____
Travel (including public transport, petrol for car, taxis)	\$ _____
Cigarettes	\$ _____
Clothing	\$ _____
Other (<i>please specify</i>):	\$ _____
Other (<i>please specify</i>):	\$ _____
Other (<i>please specify</i>):	\$ _____
Other (<i>please specify</i>):	\$ _____

3.2 If there were any further costs to you in the past **3 months** that are not included above and that may not be weekly expenses, please list the nature and amount of the cost to you below

The following questions relate to payments you may receive or services you may access due to caring for someone with schizophrenia.

3.3 Have you received any of the following government financial benefits in the past **3 months** for being a carer?

(Please tick either yes or no for each item)

	Yes	No
Domestic Purposes Benefit	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
Carer Support Subsidy	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
Other (please specify):	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
Other (please specify):	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂

3.4 In the past **3 months**, have you accessed any of the following services/groups for **yourself** in relation to caring for someone with schizophrenia?

(Please tick either yes or no for each item.)

Group/service	Accessed the service in the past 3 months?		Number of times used in past 3 months?
	Yes	No	
Schizophrenia Fellowship NZ	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	
Other support group (please specify): _____	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	
Church group	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	
Other community group (e.g. Salvation Army) (please specify): _____	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	
General Practitioner	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	
Counsellor/psychologist	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	
Police	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	
Other (please specify): _____	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	
Other (please specify): _____	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	

- 3.5 In the past **6 months**, have **you or other members of your family** (excluding the person with schizophrenia) attended any of the following services in relation to caring for someone with schizophrenia?
(Please tick either yes or no for each item.)

Services used in the past 6 months		Number of times you have accessed this service in the past 6 months	Estimated amount of money you have spent on this service in the past 6 months
Counselling related to caring for someone with schizophrenia	Yes <input type="checkbox"/> ₁ No <input type="checkbox"/> ₂		
Training or education sessions in how to cope with caring for someone with schizophrenia	Yes <input type="checkbox"/> ₁ No <input type="checkbox"/> ₂		
Other (please specify): _____	Yes <input type="checkbox"/> ₁ No <input type="checkbox"/> ₂		
Other (please specify): _____	Yes <input type="checkbox"/> ₁ No <input type="checkbox"/> ₂		

Section 4

Caring and paid employment

This section contains general questions about the impact of caring for someone with schizophrenia on your employment.

The time frames associated with questions in this section change, so please read each question carefully.

There are 11 questions in this section.

Please try to answer all relevant questions.

- 4.1 In the past **month**, did you have any paid employment? *(This includes full-time, part-time and temporary paid work.)*

Yes ☐₁
No ☐₂

Go to Question 4.2

Go to Section 5

- 4.2 In the past **month**, how many hours per week (on average) did you work in your paid job?

_____ hours/week

- 4.3 In the past **month**, did you have to take any time off paid work because of caring for someone with schizophrenia?[]

Yes ☐₁
No ☐₂

Go to Question 4.4

Go to Question 4.5

- 4.4 How much time did you take off paid work in the past **month** because of caring for someone with schizophrenia?

_____ hours/week
or
_____ days/week

- 4.5 In the past **month**, were there days when you were at paid work but were less able to carry out your normal working activities because of caring for someone with schizophrenia? *(For example, were you distracted, tired due to providing care, or had to deal with problems associated with care?)*

Yes ☐₁
No ☐₂

Go to Question 4.6

Go to Question 4.8

- 4.6 On how many days during the past **month** did this happen?

_____ days

- 4.7 On these days, to what extent did caring for a person with schizophrenia affect your paid work? Think about whether you were unable to do your normal amount or type of work, or whether you could not do your work to your normal standard. *(Please put a tick through a number on the following scale – a low number means that, on average, caring affected you to a small degree while you were working, while a larger number means that caring more severely affected your work.)*

Caring did not affect my work	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10	Caring did not allow me to work at all
-------------------------------------	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------	-----------------------------	---

- 4.8 In the past **year**, have you had to reduce the amount of paid work you do because of caring for someone with schizophrenia? *(For example, did you move from a full-time job to part-time employment?)*

Yes	<input type="checkbox"/> ₁	<i>Go to Question 4.9</i>
No	<input type="checkbox"/> ₂	<i>Go to Question 4.10</i>

- 4.9 By how much have you reduced your working hours because of caring for someone with schizophrenia?

From _____ hours/week
To _____ hours/week

- 4.10 Have you ever changed your job because of caring for someone with schizophrenia?

Yes	<input type="checkbox"/> ₁
No	<input type="checkbox"/> ₂

- 4.11 If you have reduced your hours and/or changed your job in the past year because of caring for someone with schizophrenia, by how much has this reduced your income each week?

\$_____ per week

Please now turn to Section 5 and start at *Question 5.3*

Section 5

Caring and unpaid activities

This section contains general questions about the impact of caring for someone with schizophrenia on your unpaid activities.

The time frames associated with questions in this section change, so please read each question carefully.

There are 9 questions in this section.

Please try to answer all relevant questions.

- 5.1 In Section 4 you stated that you were currently not in paid employment. What is the **main** reason you are not in paid employment?

- | | | |
|---|---------------------------------------|---------------------------|
| Currently looking for work | <input type="checkbox"/> ₁ | <i>Go to Question 5.3</i> |
| Retirement because of age | <input type="checkbox"/> ₂ | <i>Go to Question 5.3</i> |
| Home duties/child care | <input type="checkbox"/> ₃ | <i>Go to Question 5.3</i> |
| Retirement due to your illness or disability | <input type="checkbox"/> ₄ | <i>Go to Question 5.3</i> |
| Stopped work to care for person with schizophrenia | <input type="checkbox"/> ₅ | <i>Go to Question 5.2</i> |
| Other (please specify): | <input type="checkbox"/> ₆ | <i>Go to Question 5.3</i> |
-

- 5.2 If you have stopped working because of caring for someone with schizophrenia, by how much has this reduced your income each week?

\$ _____ per week

- 5.3 In the past **month**, have you done any unpaid activities (*not including caring for a person with schizophrenia, but including any volunteer work, caring for someone else in the family, household work, work associated with social activities such as being a committee member etc.*)?

- | | | |
|-----|---------------------------------------|---------------------------|
| Yes | <input type="checkbox"/> ₁ | <i>Go to Question 5.4</i> |
| No | <input type="checkbox"/> ₂ | <i>Go to Section 6</i> |

- 5.4 In the past **month**, were there days when you were completely unable to carry out your unpaid activities because of caring for someone with schizophrenia? (*For example, were you were unable to attend a meeting; unable to do the grocery shopping, or unable to do volunteer work?*)

- | | | |
|-----|---------------------------------------|---------------------------|
| Yes | <input type="checkbox"/> ₁ | <i>Go to Question 5.5</i> |
| No | <input type="checkbox"/> ₂ | <i>Go to Question 5.6</i> |

- 5.5 On how many days in the past **month** did this happen?

_____ days

- 5.6 In the past **month**, were there days when you were less able to carry out your normal unpaid activities because of caring for someone with schizophrenia? *(For example, were you unable to attend a meeting on time; or unable to do the grocery shopping at a supermarket though you could get to the local shop?)*

Yes ☐ ₁ *Go to Question 5.7*
No ☐ ₂ *Go to Question 5.8.*

- 5.7 On how many days in the past **month** did this happen?

_____ days

- 5.8 In the past **year**, have you had to reduce the amount of unpaid work you do because of caring for someone with schizophrenia? *(For example, did you stop volunteering?)*

Yes ☐ ₁ *Go to Question 5.9*
No ☐ ₂ *Go to Section 6*

- 5.9 By how much have you reduced your unpaid hours because of caring for someone with schizophrenia?

From _____ hours/week
To _____ hours/week

Section 6

Questions about the person you care for

This section contains general questions about the person with schizophrenia whom you care for.

These questions ask about their employment, diagnosis and medication.

If you would prefer to complete this section in consultation with the person you care for, please do so. We have included these questions in the carer questionnaire to be able to collect information about the people being cared for, as this may impact on the level of care required.

There are 24 questions in this section.

Please try to answer all relevant questions.

USE OF MEDICAL SERVICES BY THE PERSON WHOM YOU CARE FOR

6.1 When was the person you care for diagnosed with schizophrenia?

_____ months ago
or
_____ years ago

6.2 In the past **12 months**, has the person you care for been hospitalised because of their schizophrenia?

Yes ☐ ₁ *Go to Question 6.3*
No ☐ ₂ *Go to Question 6.5*

6.3 If you answered 'Yes' to Question 6.2, for how long was he/she hospitalised? *(If more than once, please indicate the duration of each hospitalisation. If currently hospitalised please include the time they have spent in hospital to date))*

6.4 Is the person you care for currently hospitalised because of their schizophrenia?

Yes ☐ ₁
No ☐ ₂

6.5 In the past **12 months**, has the person with schizophrenia whom you care for been hospitalised due to a non-schizophrenia-related illness?

Yes ☐ ₁ *Go to Question 6.6*
No ☐ ₂ *Go to Question 6.7*

- 6.6 If yes, for how long was he/she hospitalised? *(If more than once, please indicate the reason for the each hospitalisation and the duration of each hospitalisation. If they are currently in hospital for a non-schizophrenia-related illness, the length of time of this hospitalisation should be given as the length of stay to date)*

- 6.6a Is the person with schizophrenia whom you care for currently hospitalised due to a non-schizophrenia-related illness?

Yes ☐ ₁
 No ☐ ₂

- 6.7 Please indicate how many times in the past **3 months** the person you care for has attended an appointment with the following people in relation to/due to schizophrenia.

General Practitioner	_____	times
Psychiatrist	_____	times
Psychologist	_____	times
Case manager	_____	times
Occupational therapist	_____	times
Health and welfare officer	_____	times
Social worker	_____	times
Life skills/job program or advisor	_____	times
Other (please specify): _____	_____	times
Other (please specify): _____	_____	times
Other (please specify): _____	_____	times

MEDICATION USED BY THE PERSON YOU CARE FOR

- 6.8 This question refers to *prescription medication* that the person you care for has taken for schizophrenia and related conditions (e.g. medication they may take for side effects) in the past **3 months**.

For each medication, please state the name of the medication, the amount of medication taken each time it is administered, the strength of the medication (if known) and the frequency it is taken.

If you are not sure, please write as much information as you can remember.

Name of tablet/ capsule/liquid/ injection	Total number of tablets/capsules/ injections, or total mL of liquid, taken at one time	Strength of each tablet/capsule/ liquid/injection	Frequency (number of times taken and how often)
<i>Example: Risperdal</i>	<i>1 tablet</i>	<i>1 mg</i>	<i>Twice daily</i>

EMPLOYMENT

These questions relate to the employment of the person you care for. Please answer as many of the question as you can.

- 6.9 Has the person you care for **ever** been in paid employment? *(This includes full-time, part-time and temporary paid work.)*

Yes ☐ ₁ *Go to Question 6.12*
No ☐ ₂ *Go to Question 6.10*

- 6.10 If you answered 'No' to Question 6.9, is this because of their schizophrenia?

Yes ☐ ₁ *Go to Question 6.22*
No ☐ ₂ *Go to Question 6.11*

- 6.11 If you answered 'No' to Question 6.10, please indicate why the person you care for does not work *(e.g. due to age, illness other than schizophrenia).*

Go to Question 6.22

- 6.12 Has the person you care for been in paid employment in the **past month**? *(This includes full-time, part-time and temporary paid work.)*

Yes ☐ ₁ *Go to Question 6.15*
No ☐ ₂ *Go to Question 6.13*

- 6.13 If you answered 'No' to Question 6.12, is this because of their schizophrenia?

Yes ☐ ₁ *Go to Question 6.18*
No ☐ ₂ *Go to Question 6.14*

- 6.14 If you answered 'No' to Question 6.13, please indicate why the person you care for has not been in paid employment in the past **month** (*e.g. age, illness other than schizophrenia*).

- 6.15 In the past **month**, how many hours per week (on average) did the person you care for work in a paid job?

_____ hours/week

- 6.16 In the past **month**, did the person you care for have to take any time off their paid job due to schizophrenia or related conditions?

Yes ☐ ₁ *Go to Question 6.17*
No ☐ ₂ *Go to Question 6.18*

- 6.17 How much time did the person you care for take off work during the past month due to schizophrenia or related conditions?

_____ hours/week
or
_____ days/week

- 6.18 Has the person you care for had to reduce the amount of paid work they do because of schizophrenia? (*For example, did they move from a full-time job to a part-time*)

Yes ☐ ₁ *Go to Question 6.19*
No ☐ ₂ *Go to Question 6.20*

- 6.19 By how much have they reduced their working hours because of schizophrenia?

From _____ hours/week

To _____ hours/week

- 6.20a Has the person you care for ever changed paid jobs because of schizophrenia

Yes ☐ ₁ *Go to Question 6.21a*

No ☐ ₂ *Go to Question 6.22*

- 6.20b If the person you care for has reduced their hours and/or changed their paid job because of schizophrenia or related conditions, by how much has this reduced their income each week?

\$_____ per week

- 6.21a Has the person you care for changed paid jobs **in the past year** because of schizophrenia

Yes ☐ ₁ *Go to Question 6.21b*

No ☐ ₂ *Go to Question 6.22*

- 6.21b If the person you care for has reduced their hours and/or changed their paid job **in the past year** because of schizophrenia or related conditions, by how much has this reduced their income each week?

\$_____ per week

OTHER UNPAID WORK

- 6.22 In the past **month**, has the person you care for participated in any unpaid activities (*e.g. volunteer work, household work, work associated with social activities such as being a committee member etc.*)?

Yes ☐ ₁ *Go to Question 6.23*

No ☐ ₂ *Go to Section 6.22a*

- 6.22a If the person you care for has not participated in any unpaid activities in the **past month**, is this due to schizophrenia or related disorders?

Yes ☐ ₁ *Go to Section 7*
No ☐ ₂ *Go to Section 7*

- 6.23 In the past **month**, were there days when the person you care for was completely unable to carry out their normal unpaid working activities due to schizophrenia? *(For example, were they unable to attend a meeting, unable to do the grocery shopping, or unable to do volunteer work?)*

Yes ☐ ₁ *Go to Question 6.24*
No ☐ ₂ *Go to Section 7*

- 6.24 On how many days in the past **month** did this happen?

_____ days

Section 7

Additional questions regarding caring

This section contains further questions about caring for someone with schizophrenia. These questions ask about issues that have been shown to place extra burden on those caring for people with schizophrenia.

We are aware that the questions asked in this section are not representative of everyone with schizophrenia.

These questions may or may not relate to your experience with schizophrenia. If they do, we ask that you complete as many of the questions as you feel comfortable. Please leave out any that you do not feel able to answer.

There are 8 questions in this section.

These questions relate to contact the person whom you care for has had with law enforcement in the past **6 months**.

- 7.1 In the past **6 months**, has the person with schizophrenia whom you care for been a victim of any violent crime (*e.g. robbery, mugging, assault*)?

Yes	<input type="checkbox"/> 1
No	<input type="checkbox"/> 2
Don't know	<input type="checkbox"/> 3

- 7.2 In the past **6 months**, has the person with schizophrenia whom you care for been a victim of any non-violent crime (*e.g. theft of property/money*)?

Yes	<input type="checkbox"/> 1
No	<input type="checkbox"/> 2
Don't know	<input type="checkbox"/> 3

- 7.3 In the past **6 months**, has the person with schizophrenia whom you care for been arrested or 'picked up' by the police?

Yes	<input type="checkbox"/> 1
No	<input type="checkbox"/> 2
Don't know	<input type="checkbox"/> 3

- 7.4 In the past **6 months**, has the person with schizophrenia whom you care for spent a night in jail?

Yes	<input type="checkbox"/> 1
No	<input type="checkbox"/> 2
Don't know	<input type="checkbox"/> 3

- 7.5 In the past **6 months**, has the person with schizophrenia whom you care for caused damage to property?

Yes	<input type="checkbox"/> 1
No	<input type="checkbox"/> 2
Don't know	<input type="checkbox"/> 3

- 7.6 In the past **6 months**, has the person with schizophrenia whom you care for attempted suicide?
- Yes ☐ 1
- No ☐ 2
- Don't know ☐ 3
- 7.7 In the past **6 months**, has the person with schizophrenia whom you care for deliberately hurt themselves (*e.g. cutting themselves*)?
- Yes ☐ 1
- No ☐ 2
- Don't know ☐ 3
- 7.8 In the past **6 months**, has the person with schizophrenia whom you care for hurt you or someone else?
- Yes ☐ 1
- No ☐ 2
- Don't know ☐ 3
- 7.9 When talking with people who care for others with schizophrenia, it becomes apparent that there are many areas of life associated with caring for someone with schizophrenia that are not able to be given a numeric value but are nevertheless important (*e.g. feelings of isolation from friends and neighbours, stigma etc.*).
- We would like you to add in the space below any other 'costs' or 'burdens' you feel need to be taken into consideration when attempting to describe caring for someone with schizophrenia.
-
-
-
-
-
-
-
-
-

Thank you for completing the questionnaire.

Please tick which one of the following you would like to receive in compensation for your time:

Westfield \$50 voucher ☐

Petrol \$50 voucher ☐

Donate \$50 to Schizophrenia Fellowship NZ ☐

Appendix B: Additional results

Section 2

Table B 1 and **Table B 2** present reported concurrent medical conditions in **Section 2** of the questionnaire

Table B 1 Reported concurrent physical illnesses

Medical condition	N	%
Asthma	4	7.8
Born deaf, mitral valve damage, haemach	1	2.0
Brain damage	1	2.0
Breast cancer	1	2.0
Kidney condition	2	3.9
Diabetes	3	5.9
Gout, bronchial problems	1	2.0
Parkinson's disease	1	2.0
Requires glycine free diet	1	2.0
Obesity	2	3.9
Osteoporosis	1	2.0
Rod in leg and dislocated ankle	1	2.0
Emphysema	1	2.0

Table B 2 Reported concurrent psychological conditions

Medical condition	N	%
Anxiety	24	47.1
Depression	26	51.0
Gambling addiction	1	2.0
Obsessive-compulsive disorder	3	5.9
Self harm	1	2.0
Eating disorder	1	2.0
Bipolar	1	2.0
Substance abuse	7	13.7
Memory impairment	1	2.0
Hearing impairment	1	2.0
Emotional instability	2	3.9
Tardive dyskinesia	1	2.0
Paranoia	2	3.9
Agoraphobia	1	2.0
Social withdrawal	1	2.0
Megalomania	1	2.0

Section 3

Table B 3 presents responses from participants who answered ‘other’ to Question 3.1: ‘How much of your own money do you spend per week, on average, on things related to caring for the person with schizophrenia?’

Table B 3 Other costs associated with caring (Question 3.1)

Description	Cost (NZD)
Dental accounts	300
New bed and bed clothes	1500
Outings	700
Deodorant and toiletries	NR
Gym	15
Dancing	5
Choir	6
Subscription	1
Replacing lost keys	0.5
Light bulbs	0.3
Soap, shampoo and toilet paper	50
Unpaid bills (varied)	NR
Phone	16
Phone	30
Marae fees	10
Cleaning materials	NR
Cleaning windows	NR
Fortnightly picnic	2
Glasses	10
Contact lens solution	5
Haircuts	3
Phone	10
Haircuts	5

Abbreviation: NR, not reported; NZD, New Zealand Dollars

Table B 4 presents the responses from participants who answered that they had incurred further costs in the past three months (Question 3.2) that are not represented in Question 3.1.

Table B 4 Other costs associated with caring in the last three months
(Question 3.2)

Description	Cost (NZD)
Rugby tickets	NR
Clothing (varies)	NR
Necessary purchases	NR
Subscription glasses	NR
Bedding, furniture, drapes and blinds	250
Sporting and extra activities	10
Caring for dependents of schizophrenic	NR
Optometrist	100
Word processor	200
Study materials	80
Gifts	30
Petrol	80
Social outings	NR
Rent	400
Airfare	564
Dentist	368
Osteopath	295
Rent	940
Replacing TV	NR
Christmas functions	20
Specialist	300
Lawyer	NR
Gifts / per week	20
Cost of living	200

Abbreviation: NR, not reported; NZD, New Zealand Dollars

Table B5 Reported use of other support, community or service groups in the previous 3 months

Other support group
ADHD association Caring Communities Inc. Cornwall House Equip Family Support Steering Group Gateway Maori Mental Health Mind Matters Pegasus Bay Schizophrenia Fellowship Public Trust Supporting Families With Mental Illness Te Korowhai Aroha Te Kotuku Ki te Rangi Cooperation with other groups Youth line supervision group
Other community group
Alcoholics Anonymous AFE concern Catholic diocesan committee Salvation Army Temple group
Other service group #1
Auckland Hospital CATT team Catholic diocesan committee Community support worker Levin Mental Health Services Member of a zone team Mental health community worker NMDHB case manager Other resources Psychiatry survivor Service users Heart monitor for stress Te Whetu Tawera Mental Health WINZ government agency for financial support
Other service group #2
Dunedin City Council Logan City Mental Health Services Australia Psychiatrist St Luke's Mental Health

Table B6 Reported use of service groups in the previous 6 months

Other service group #1
ADHB family steering group
Attendance at psychiatrist appointments
Education in helping to cope with anxiety
Manawatu Schizophrenia fellowship
Meeting with local MP and health
Private neuro-psychiatrist
Schizophrenia Fellowship meeting
Supervision group at Y line
Talk by public trust organised by Schizophrenia Fellowship
Work link seminar run by Baptist mental
Other service group #2
General info on running group homes
Professionals to voice concerns

Section 6

Table B7 Reported other appointments

Appointment	N	%
Community support worker	4	7.8
Nurse	2	3.9
Case worker	1	2.0
Dietician	1	2.0
Key worker	1	2.0
Pen support	1	2.0
Poytech course	1	2.0
Schizophrenia Fellowship Tapestry Club	1	2.0
Taylor centre	1	2.0
Schizophrenia Fellowship	1	2.0

Table B 8 presents reported medication usage in **Section 6** of the questionnaire.

Table B 8 Reported medication usage

Treatment	Dose	Strength	Regimen	Treatment	Dose	Strength	Regimen
Clozapine	?	600 mg	Per day	Diazepam	2	5 mg	Once
Clozapine	2.5	100 mg	Once	Risperidone	2 tablets	?	Once daily
Nortriptyline	2 tablets	?	Twice daily	Seroquil	4 tablets	?	Twice daily
				Lipex	1 tablet	?	Once daily
				Somac	1 tablet	?	Once daily
				Cartia	1 tablet	?	Once daily
Olanzapine	1	5 mg	2	Lithium	?	?	?
Risperdal	5 tablets	?	Daily	Lyprexa	?	?	?
Consta				Chlorpromazine	?	?	As required
Clozapine	1 morning, 3 night	100 mg	Per day	Lithium carbonate	2	250 mg	Twice daily
Clozapine	?	15 mg	Evening				
Risperidone	?	2x2 +1x3	3	Haloperidol	?	5 mg	2 night
				Propanolol	?	10 mg	Three times daily
							Night
				Methotrimeprazine	1-2	25 mg	
Olanzapine	?	15 mg	Once daily	Epilim	2 tablets	500 mg	Once daily
Risperdal	1 tablet	1 mg	Once daily	Epilim	1 tablet	500 mg	Once daily
				Lithium	2 tablets	1000 mg	Once daily
Clozoril	?	?	?	Prozac	?	?	?
Clozapine	?	?	?	Famotadine	?	?	?
				Prozac	?	?	?
				Epilim	?	?	?
Risperidone	1 tablet	6 mg	Once daily	Lorazepam	1 tablet	1 mg	Once daily
?	?	?	Morning and evening				
Risperdal	1 tablet	?	Twice daily	Risperdal	?	?	Once daily
Olanzapine	?	?	Twice daily	Cogentin	?	?	Once daily
				Imovane	?	?	Once daily
Olanzapine	?	?	Once daily	Olanzapine	?	?	As required
Haloperidol	Tried and stopped	?	?	Serenace	Tried and stopped	?	?
				Arapax	Tried and stopped	?	?
Risperdal	?	4 mg	Doesn't take it	Antidepressants	?	?	Doesn't take it
Olanzapine	?	20 mg	Once daily	Prozac	1	?	?
Clozapine	Tablets	60 0mg	Twice daily	B12	Injection	?	Once daily
				Clonazepam	Tablets	?	Twice daily
Olanzapine	?	?	Once daily	Sinemet	Tablets	?	Three times daily
				Harpedrol	?	?	Mornings
?	Injection	?	Twice monthly	Intergestion medication	?	?	Mornings
Risperdal	?	?	?	Consta	Injection	37.5	Fortnightly
				Exopil	1 tablet	100 mg	?
Risperdal	2 tablets	1 mg	Once daily	Clozapine	3	25 mg	Twice daily
Clozapine	3	100 mg	Twice daily	Olanzapine (hospital)	?	15 mg	Daily
Olanzapine	?	2.5 mg	Daily	Imovane (Hospital)	?	2 mg	Daily
				Clopixol (Hospital)	?	200 mg	Fortnightly
				Clopixol	?	150 mg	Fortnightly
Seroquel	6 tablets	?	Daily	KemKemadrin	?	?	?

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?	?	?	?				
Olanzapine	1 tablet	?	Once daily	Benzodiazapine	½ tablet	?	Once daily
?	?	?	?				
Clozapine	?	?	Medication plan changes every 3 months	Olanapine	?	?	?
				Haloperidol	?	?	?
				Risedronate	?	?	?
				Chlorpromazine	?	?	?
Diazepam	?	?	?	Lithium	?	?	?
				Chlorpromazine	?	?	?
Olanzapine	1 tablet	10 mg	Twice daily	Lithium	1 tablet	250 mg	Three times daily
				Propanolol	1 tablet	5 mg	Twice daily
?	?	?	?				
Risperidone	?	6	Once	Diazepam	1	5	Once
Olanzapine	2 tablets	12.5 mg	Once daily				
Respirodine	1 tablet	1 mg	Daily	Clozapine	1 tablet	100 mg	Daily
?	?	?	?				
Olanzapine	?	?	Once				
Clozapine	?	?	?				
Tranquilliser	1 tablet	?	Once daily	?	2 tablets	?	Daily
				Herbal preperotone	?	5 mL	Twice daily
?	?	?	?				
Lithium	?	1000 mg	Evening	Lithium	?	400 mg	Morning
				Respiridal consta	Injection	37.5	Fortnightly
				Respiridal consta	Oral	1 mg	?
Risperidal consta	Injection	?	Fortnightly	Venafaxilene	1 tablet	50 mg	Daily
Flupenthixol	Injection	?	Three weekly	Olanzapine	1 tablet	?	Daily
Risperidone	?	?	?				
Clozapine	5 tablets	?	Night	Lorazepam	?	?	?
Risperdal	1 tablet	?	Once daily				
Olanzapine	?	20 mg	Once daily	Citalopram	1 tablet	?	Once daily