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# The Wesley Report

**Keeping minds well:  
Caring till it hurts**



## **Acknowledgements**

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And finally, a very special thank you to our clients for sharing their personal experiences in this report.

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## Foreword

**Mental health problems don't just affect the sufferer. More than 85 per cent of people caring for a relative with a mental health issue report negative consequences for their own mental, physical and financial health. Many of these carers—particularly those in their teens—suffer in silence, eventually creating even more serious problems for their communities.**

For some teenagers, there are no trips to the movies, after-school sport or time spent just hanging out with their friends. Instead, their days are consumed by the demands of looking after a parent with a major mental health issue.

Shopping, cooking, paying the bills, taking mum to the doctor, dealing with Centrelink, very often coping with violence—these are the everyday realities for many of the people surveyed for The Wesley Report, *Keeping minds well: Caring till it hurts*.

It's a relentless and frequently depressing experience for people of any age but particularly for teenagers who are being robbed of the opportunity to enjoy and build their own lives at a formative stage. Of even more concern, however, is the fact that this stressful role frequently leads to the carers developing mental health issues themselves—depression, anxiety, substance abuse—as they spend, in many cases, more than 10 years under terrible pressure.

While this should be a serious concern for our community, respondents of all ages in this report also detail negative consequences across all other parts of their lives: their physical health, finances, relationships with friends, study, jobs and careers. It is the younger carers who report the greatest impact.

A staggering 85 per cent of respondents report some type of negative impact on their physical or mental health, which is a real tragedy.

Wesley Mission has long been aware of the shocking toll taken on people looking after a relative with a serious mental health issue. Our counselling and respite services struggle to cope with the demand with their limited resources.

Yet while there is a certain amount of help available, one of the sad findings of this Wesley Report is that a third of carers feel too ashamed to access support, victims of the stigma that still surrounds mental health issues in our community and detailed in previous Wesley Mission research. Again, sadly, it is the teenage carers who are least likely to seek help.

If this report can raise community awareness of the plight of the hidden legion of carers leading desperate lives in our cities and suburbs, and reduce some of the stigma around mental health generally, then it will have achieved its purpose.

I would like to thank everyone who contributed to our policy forum which helped define a range of actions that can flow from this report.

These recommendations—particularly those around early intervention—can provide structure and direction to governments and service providers as they seek to most effectively support the carers described in this report.

Caring for someone with mental health issues can be an overwhelming and lonely experience. Much more needs to be done to support the people caught in this situation and we sincerely hope that this report can act as a stimulus for increased community awareness and action.



Rev Dr Keith V Garner  
CEO/Superintendent  
Wesley Mission

## Executive summary

People who care for a family member with a mental health issue are the unsung heroes of our community. They more often than not sacrifice their time, money and even their careers to ensure that those they support can manage and fulfil their often challenging lives. Yet their caring comes at a cost, with an overwhelming number declaring that their caring experience as a child has provided a lasting negative impact into adult life.

### Key findings

#### Looking after a relative with mental health issues exposes the caregiver to a range of risks and deterioration in quality of life

Nearly half of caregivers (47 per cent) reported that looking after someone with a mental health issue had affected them “a lot”. Almost 90 per cent of respondents reported a negative impact on their physical and mental health; three quarters said their role had adversely affected their relationships with family and friends, and 57 per cent said their employment and financial situation had deteriorated. Of concern, almost one third of caregivers reported experiencing family violence as a result of their relationship with the relative. Such negative effects increased with the length of time spent caregiving, and particularly affected women.

#### Many caregivers are still reluctant to seek help

While more than half (56 per cent) of caregivers had accessed support services, one third (36 per cent) reported that they had been afraid to ask for help, particularly those who had been caring for longer periods.

#### Caregivers who were exposed to the caring role under 16 years of age are at greatest risk of negative consequences

The impact felt by those who started caregiving when they were under 16 years of age is considerably higher than those who were exposed when they were older. The role affects their financial status, and mental and physical health. They are also more likely to have experienced stigma because of their association with a relative with a mental health issue. Those exposed to the caregiving role at an early age are also the ones most likely to be afraid to ask for help, despite the fact that they generally have positive attitudes towards health services when they do approach them.

#### Coping strategies vary

Caregivers use a range of coping mechanisms, preferring things like taking a break, finding comfort in their faith and looking on the positive side to seeking professional help or taking up exercise. They are least likely to use avoidance strategies such as pretending to others that everything is OK or avoiding discussion. Age appears to be related to the use of avoidance coping strategies, with younger caregivers being more likely to report using all avoidance strategies than older respondents.

#### Caring goes on for a long time

The majority (64 per cent) of carers had been in their caregiving role for more than six years and almost half (43 per cent) indicated that they had been caregiving for more than 10 years.

## Looking after a relative with mental health

issues exposes the caregiver to a range of risks and deterioration in quality of life. Almost 90 per cent of respondents reported a negative impact on their physical and mental health.



## Compiling this report

**A preliminary review of literature suggests that the impact on caregivers looking after someone with a mental health issue may have been overlooked and may not be as clearly understood as other caregiving situations (such as looking after someone with a physical disability).**

### Background

Since 2006 Wesley Mission has produced a range of research reports into social problems in these areas in order to inform its own work, to raise community awareness and to drive change. This report continues that practice.

Wesley Mission commissioned research consultants Urbis to undertake a study to provide insight into the experiences, challenges and coping approaches of people (called “caregivers” in this report) who have a family member/partner with mental health issues. There has been limited research into this topic, and the research looked specifically at:

- the profile of these caregivers in Australia
- the impact that their role had on the caregivers
- the coping strategies that caregivers use

This study is not intended as an exhaustive exploration of caregivers in Australia. Rather, it provides a snapshot of the current caregiver profile, defined as those who have experienced an impact as a result of having a relative with a mental health issue.

The authors acknowledge that respondents may have commented on experiences that occurred years prior to taking part in the research and, as a result, their responses may have been influenced by outdated community attitudes and differences in service provision.

It is also important to note that the aims of this study were not to evaluate mental health services or assess the experience of these services among caregivers. While interaction with these services was explored, the focus is on understanding the profile and coping strategies in relation to this use rather than assessing the effectiveness of the service.

The definition of “impact” is also an important consideration. All respondents in this study had to agree that their relative had had at least “a little” impact on their lives. As such, this is not a population study (for example, it does not provide penetration data in relation to caregivers in Australia), but a summary of the population.

### The data-gathering process

This research had three stages:

- a review of existing literature
- an online quantitative study
- a stakeholder policy workshop

This report primarily details the findings from the quantitative research, while also incorporating the conclusions from the stakeholder policy workshop.

### A preliminary review of literature

Urbis conducted a preliminary review of literature as part of this study. The review focused on documents published between 2001 and 2011, although where earlier material was found to be important, this was also included in the analysis. Australian and international literature was included; however, the focus was on research conducted in Australia.

The review suggested that the issue of the impact on caregivers looking after someone with a mental health issue may have been overlooked and may not be as clearly understood as other caregiving situations (such as looking after someone with a physical disability). This oversight contrasts with the increasing importance of family in new service models.

### Online survey

The quantitative research involved a national online survey of 1,002 caregivers across Australia who completed a questionnaire in November/December 2011. Fieldwork quotas were set to ensure full geographic coverage (by State/Territory). No other quotas were set, given the unknown population parameters.

For inclusion in the study, respondents had to:

- have an immediate relative/partner with a mental health issue, either at the time the questionnaire was completed or prior to completion
- report that their life had been affected by the relative/partner's mental health issue to some degree

In addition, for the purposes of the research, the person being cared for had to be related (parent, child, sibling, spouse/former spouse or grandparent).

The online survey approach was deemed the most appropriate, given the limited focus of this study and the need for a nationally representative sample (where no penetration data was available in terms of population size).

Respondents were drawn from a nationally representative, research-only online panel.

Respondents are recruited to the panel using a variety of online and offline methods to reduce attitudinal bias. Respondents are limited to participating in two studies in a year.

The term "mental health issue" was used throughout the screening and the survey, as it was felt that this was broader than "mental illness", with breadth of definition being more appropriate for this exploratory study. Mental health issues included depression and anxiety, illnesses such as schizophrenia or bipolar disorder, conditions including bulimia and anorexia as well as addictions to drugs and alcohol that may or may not have been diagnosed.

Table 1 provides a comparison of the sample against 2011 ABS population figures.<sup>1</sup>

No quotas were set in terms of age and gender as a review of the literature did not provide any nationally representative penetration figures about the population of caregivers in Australia.

A copy of the online questionnaire can be found in Appendix A.

## Policy workshop

In December 2010, Wesley Mission conducted a stakeholder policy workshop to review the preliminary findings of the survey and develop a range of policy recommendations.

Participants were drawn from the academic, clinical, government and NGO sectors, including senior representatives from the Australian Institute of Family Studies, the NSW Mental Health Coordinating Council, the University of New South Wales School of Public Health and Community Medicine, the NSW Institute of Psychiatry, the Black Dog Institute and Wesley Mission.

The findings from this workshop are in Chapter 6.

**Table 1: State/Territory-based comparison of the obtained sample against ABS 2011 data**

	ABS 2011 data		Online survey sample	
	Population	Proportion (%)	Population	Proportion (%)
<b>NSW</b>	7,303,690	32	327	33
<b>VIC</b>	5,624,090	25	272	27
<b>QLD</b>	4,580,725	20	182	18
<b>SA</b>	1,657,001	7	85	8
<b>WA</b>	2,346,410	10	88	9
<b>NT/TAS/ACT*</b>	1,106,153	5	48	5

\*For the online study, NT, Tasmania and the ACT were collapsed into one variable

<sup>1</sup> Australian Bureau of Statistics (2011). Australian Demographic Statistics. Table 04. Estimated resident population, States and territories, Jun 2011. Data cube: Excel spreadsheet, cat. no. 3010, Viewed 05 January 2012, <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3101.0Jun%202011?OpenDocument#Data>

## Chapter 1:

# Who are the caregivers?

- half of all carers have been in a caring role for more than 10 years
- seventy per cent of carers are female
- sixty per cent of carers care for someone with depression





## Chapter 1: Who are the caregivers?

Overall, caregivers had been caring for significant amounts of time, with the majority of respondents reporting that they have been in their caregiving role for more than six years. Almost half indicated that they had been caregiving for more than 10 years.

### Profiles of courage

For the purpose of this report, “caregivers” are defined as those who have experienced an impact as a result of caring for a relative with a mental health issue.

### Age and gender

More female caregivers completed the questionnaire (70 per cent female, compared to 30 per cent male). This gender ratio is consistent with literature on Australian caregivers (see Pirkis et al 2010<sup>1</sup>).

Half the caregivers (49 per cent) were aged 54–64 and 40 per cent were aged 25–44. Less than one in 10 was aged 18–24 and only four per cent were aged 65 and over. Male caregivers were more likely to be older than female caregivers, with the majority of males (65 per cent) aged over 45.

### Income

One quarter of respondents had a total annual household income between \$35,000 and \$64,000. The same proportion had a total annual household income between \$85,000 and \$149,000; only a small proportion had an annual income of over \$150,000.

Male and female caregivers reported similar levels of income, although males were slightly more likely than females to report an annual household income of \$85,000–\$149,000.

### Household composition

A large proportion (83 per cent) of caregivers who took part in the study lived with family. In this instance, family could refer to a spouse/partner, children or other family members. Just over one in 10 caregivers (13 per cent) lived alone and a small proportion lived in a shared house (four per cent).

More than half of the caregivers aged 45–64 years of age reported living alone.

### Education

More than half of caregivers were university or trade educated, with 54 per cent having obtained an undergraduate university degree or trade (or equivalent). A further 12 per cent were qualified to a postgraduate level (for example, Masters). One third had completed secondary school as their highest educational qualification, including the Higher School Certificate or Leaving Certificate.

### Language

English was the main language spoken at home for almost all respondents (92 per cent). Only a small proportion (eight per cent) spoke another language at home.

### Who do they care for?

The survey asked caregivers to indicate the mental health issue that their relative suffered from, selecting from nine broad categories. Respondents were able to select multiple responses.

In a majority of cases, the respondent’s relative suffered from depression (67 per cent). Almost half (42 per cent) had a relative who suffered from anxiety or stress-related conditions and one in five relatives (20 per cent) suffered from drug and/or alcohol abuse. A smaller proportion (17 per cent) suffered from bipolar disorder (see Figure 1.1).

Most respondents (84 per cent) indicated that their relative’s illness had been formally diagnosed by a health professional such as a GP, psychologist or other mental health professional.

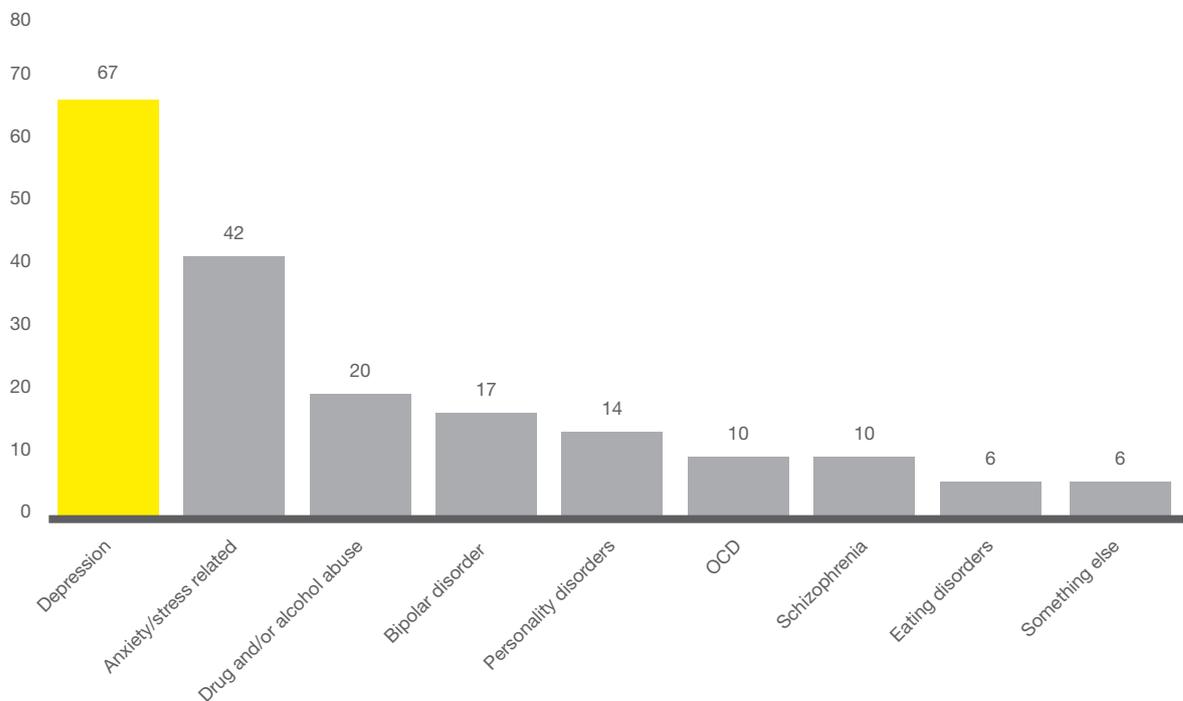
<sup>1</sup> Pirkis, J., Burgess, P., Hardy, J., Harris, M., Slade, T., Johnston, A. (2010). *Who cares? A profile of people who care for relatives with a mental disorder*. Australian and New Zealand Journal of Psychiatry, 44: 929-937

While there were relatively few demographic differences in the mental health issue profile, there were some key differences:

- female relatives were significantly more likely to suffer from depression (70 per cent) and anxiety (46 per cent) than males (62 per cent and 35 per cent respectively). However, male relatives were significantly more likely to suffer from schizophrenia (15 per cent) than females (six per cent)
- relatives aged 25–44 (70 per cent) and 45–54 (69 per cent) were significantly more likely to suffer from depression than those aged over 55 (60 per cent). Those who suffered from eating disorders were significantly more likely to be under 25 (16 per cent) or 25–44 years of age (nine per cent), when compared to those aged 45–54 (four per cent) or 55+ (two per cent)

- as might be expected, those relatives aged over 55 were significantly less likely to suffer from drug and/or alcohol abuse (11 per cent) compared to those aged under 25 (25 per cent), those aged 25–44 (24 per cent) and those aged 45–54 (21 per cent)
- relatives who suffered from drug and/or alcohol abuse were more likely to be identified by caregivers as undiagnosed (36 per cent) than diagnosed (18 per cent)

**Figure 1.1: Reported mental health issue of the relative (%)**



A5: What mental health issue does/did this relative suffer from?  
 Base: All respondents (n=1,002)

### The long haul

Overall, caregivers had been caring for significant amounts of time, with the majority (64 per cent) of respondents reporting that they have been in their caregiving role for more than six years (see Figure 1.2). Almost half (43 per cent) indicated that they had been caregiving for more than 10 years and a small number (five per cent) had been caring for less than one year.

**“Every area of my life has been impacted each and every day for as long as I can remember. It’s had an enormous impact on my emotional, mental and physical health. It never ends.”**

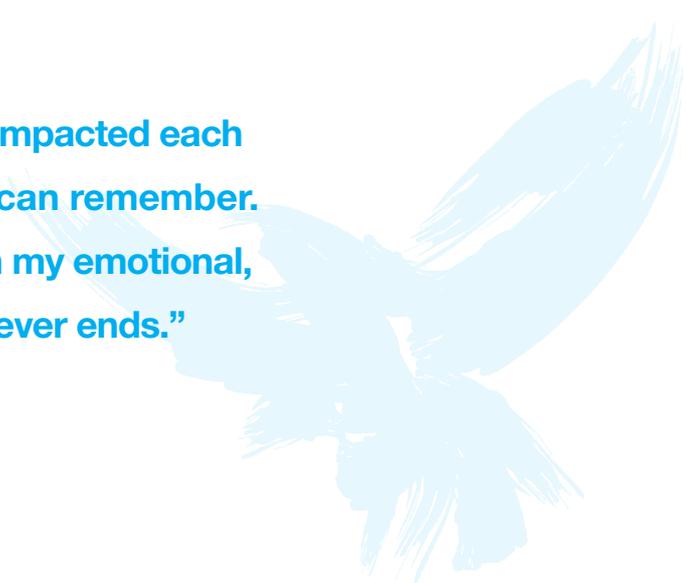
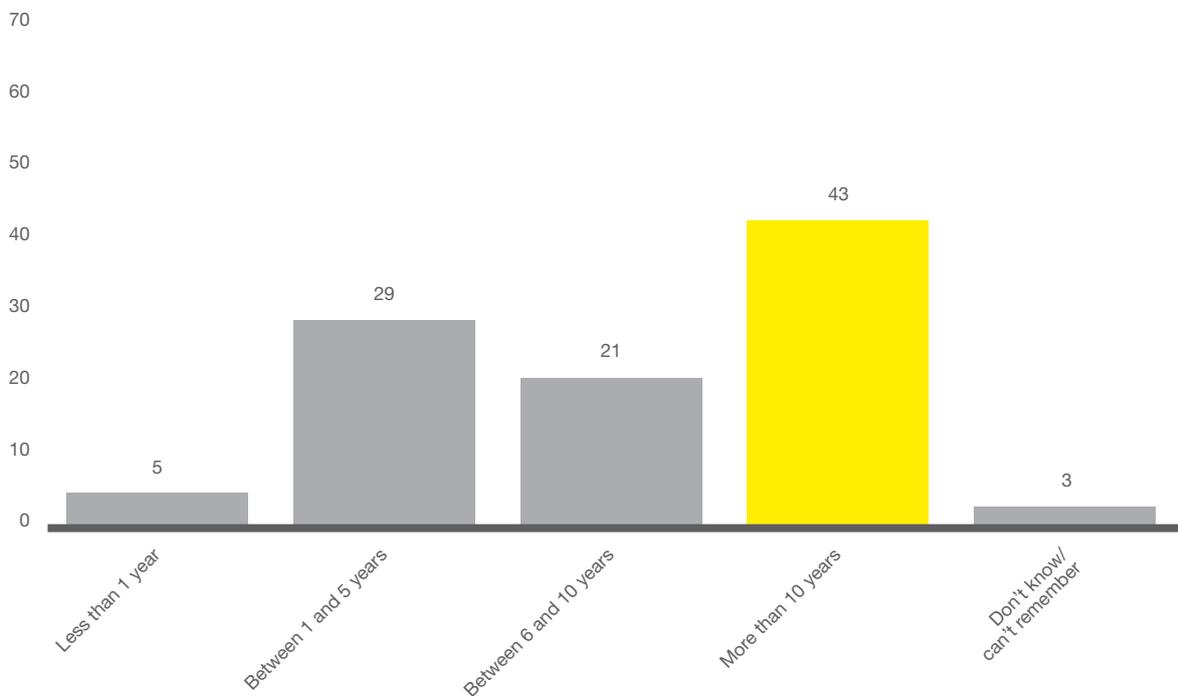


Figure 1.2: Length of time in caregiving role (%)



A7: How long has your relative's mental health issue(s) had an impact on your life?  
Base: All respondents (n=1,002)

## Looking after mum and dad

Caregivers who completed the online survey were most likely to be caring for their mother or father (34 per cent), a partner (22 per cent) or a sibling (20 per cent).

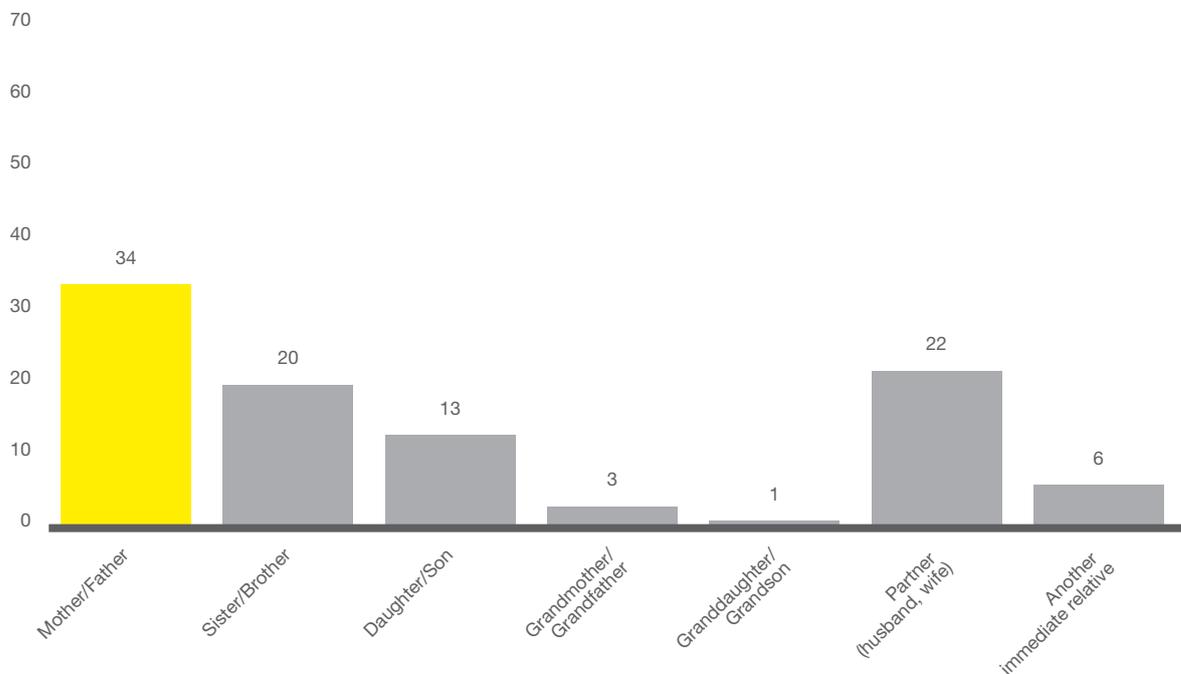
Figure 1.3 shows the relationship of relatives to their caregivers.

Carers who began caring when they were 16 or younger were significantly more likely to be caring for their parent (58 per cent) compared to 24 per cent who began caring for their parent when they were over 16.

There were significant differences between the length of time in a caregiving role and the relationship between the relative and carer.

Caregivers who had been caring for more than 10 years were significantly more likely to be caring for their mother or father (43 per cent) or their brother or sister (23 per cent) than caregivers who had been caring for a shorter time. Those who had been caring for between one and five years were significantly more likely to be caring for their son or daughter (17 per cent) or their partner (29 per cent) compared to longer-term caregivers.

Figure 1.3: Relationship of relative to carer (%)



A2: And is this relative your ...?  
Base: All respondents (n=1,002)

## Chapter 1: Who are the caregivers?

### Living arrangements

Just under half (45 per cent) reported that their relative lived with them. Of these, caregivers 18–24 years of age were significantly more likely to have their relative live with them (64 per cent) compared to those 25–44 years of age (46 per cent) or aged 45–64 (41 per cent).

A third of caregivers (33 per cent) reported that their relative lived in another household, while one in 10 said their relative lived on their own (see Figure 1.4).

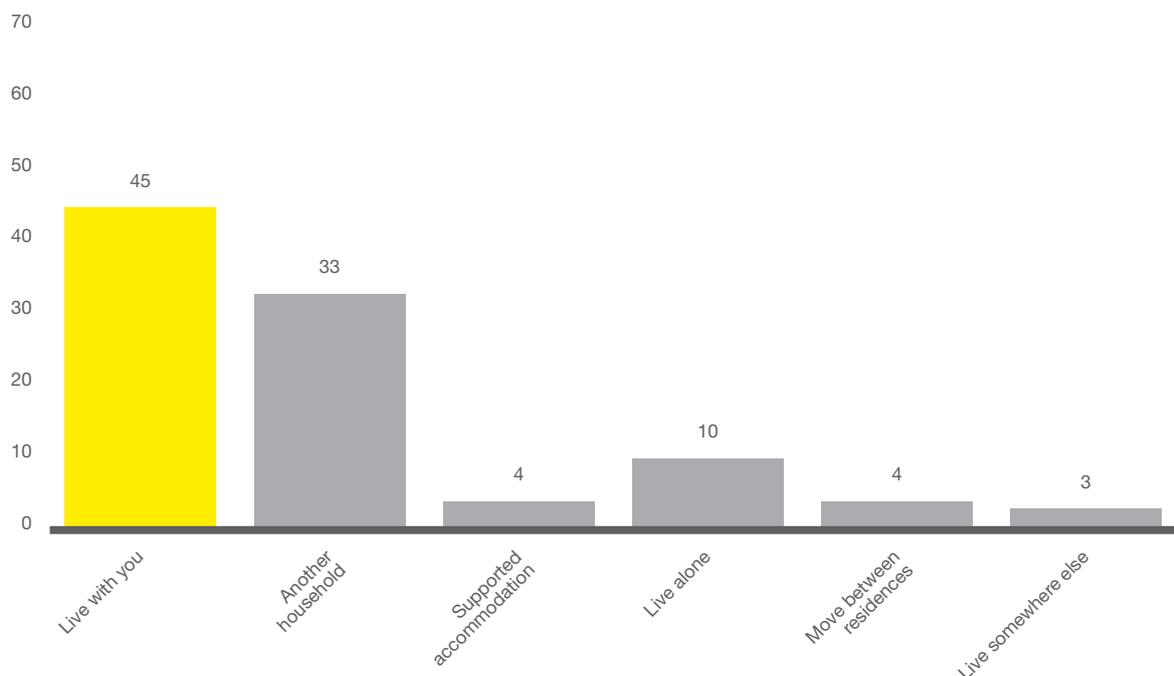
Relatives over 55 were significantly more likely to live in supported accommodation (15 per cent) or alone (15 per cent).

For those caregivers whose relative lived with them, their relative was most often their partner (87 per cent), mother or father (41 per cent), or son or daughter (44 per cent).

### “I felt obliged to stay living with her and not move away”



Figure 1.4: Living arrangements of relative (%)



A9: Did/does this relative mainly ...?

Base: All respondents (n=1,002)

Results sum to less than 100% as less than 1% indicated that their relative was “homeless” (4 respondents) and they are included in the base for analysis but not charted

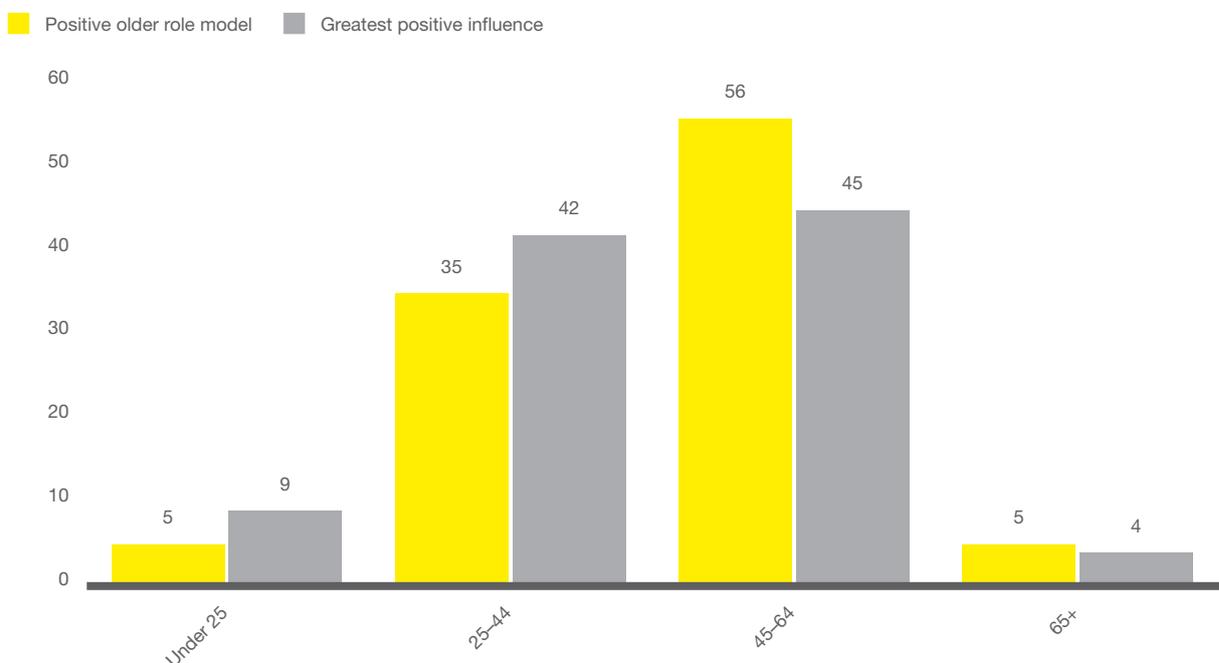
## Sole responsibility

Just over half of respondents (56 per cent) reported that they were not the primary caregiver, while 40 per cent stated that they were their relative's primary carer.

Primary caregivers tended to be older and to be more likely to look after younger relatives, while secondary caregivers tended to be younger and to be more likely to look after their older relatives (see Figure 1.5).

Almost three quarters of primary caregivers reported that their relative lived with them (72 per cent) compared to 27 per cent of secondary caregivers. Primary caregivers were also significantly more likely to be caring for their partner (49 per cent) or their son or daughter (21 per cent) than secondary caregivers; while secondary caregivers were more likely to be caring for their brother or sister (28 per cent) or a grandparent (five per cent).

Figure 1.5: Primary carer status by age of the relative (%)



A6: And would you say that you are/were this relative's primary carer (i.e. the person responsible for their care most of the time)

SQ1: Can you tell me which of the following age brackets you fall into?

Base: All respondents who indicated that they were either a primary or secondary carer (n=957)

Chapter 2:

# Caring till it hurts

**“Life revolves around them 24/7. You have no idea what the day is going to bring, you have no idea what the middle of the night is going to bring. You cannot bring friends home and you cannot make plans to go anywhere unless you have a backup person helping out ... life sucks and there is nothing you can do about it.”**





## Chapter 2: Caring till it hurts

**More than half (58 per cent) of those who began caregiving before 16 indicated that their life had been affected “a lot”, significantly more than those who had been exposed to the caregiving role later in life (44 per cent).**

The review of literature for the report revealed that there was a lack of information on the impact on the person caring for a relative with a mental health issue. One of the core aims of this survey was to better understand that impact, which was measured from several perspectives:

- self-perceived overall impact of the caregiving role
- ramifications for finances, employment and study opportunities
- health effects, including their mental and physical health
- impact on relationships with friends, family and the broader community
- experience of stigma

### Overall impact on caregivers

As part of the screening process for the study, all respondents were asked to indicate the degree to which their relative’s mental health issue had led to an impact on their life<sup>2</sup> (see Figure 2.1).

Almost half (47 per cent) of respondents indicated that their life had been affected “a lot” and a similar proportion (42 per cent) indicated that their life had been affected to “some degree”. Only one in 10 (11 per cent) stated that their life had been affected “a little”.

While a skew towards higher impact is clear at an overall level, the findings also suggest that there are some aspects of both the caregiver’s situation and their relationship to the relative which affect the degree of impact.

### Length of time exposed to the caregiving role

Those who had been exposed to a relative with a mental health issue for more than 10 years were significantly more likely to indicate that their life had been affected “a lot” (57 per cent) compared to those exposed for less than one year (29 per cent) or between one and five years (32 per cent).

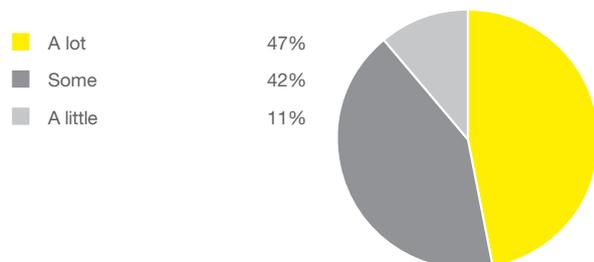
### Relationship to relative

Those who indicated that the relative was their spouse or their child were significantly more likely to indicate that their life had been affected “a lot” (57 per cent and 64 per cent respectively) than those with other relationships.

### Illness

Those who indicated that the relative suffered from a drug and/or alcohol issue were more likely to be affected “a lot” (61 per cent) compared to those who had a relative suffering from anxiety (50 per cent) or depression (47 per cent).

**Figure 2.1: Impact of having a relative with a mental health issue (%)**



A3: Thinking about this relative/these relatives, did their mental health issue ...?  
Base: All respondents (n=1,002)

<sup>2</sup> Those who indicated that their relative’s illness had “no impact” on their life were screened out of the study. Thirty-eight respondents were screened out at this stage.

### Location of the relative

Not surprisingly, those who indicated that the relative was living with them were more likely to experience greater levels of impact than those who lived elsewhere (56 per cent compared to 40 per cent indicating that their life had been affected “a lot”).

### Gender of relative

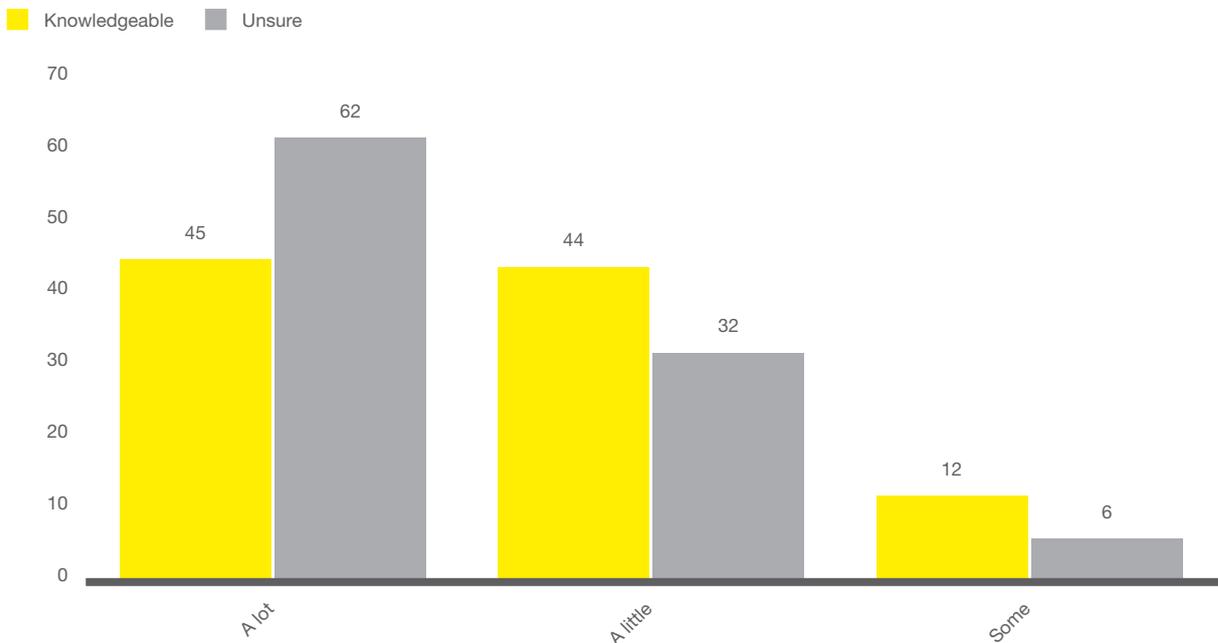
Those caring for male relatives were more likely to indicate that their life had been affected “a lot” compared to those caring for female relatives (52 per cent compared to 43 per cent).

### Gender of caregiver

The inverse relationship was true for the gender of the carer, with female caregivers significantly more likely to be affected than males (50 per cent compared to 41 per cent).

Beyond relationship/situational factors, those who were classified as “unsure” in relation to their ability to navigate the mental health system<sup>3</sup> were more likely to indicate that their life had been affected “a lot” (62 per cent) compared to those who were classified as more knowledgeable (45 per cent). This may indicate that knowing where to get information and support may have a long-term influence on the caregiver (see Figure 2.2).

Figure 2.2: Influence of knowledge of the mental health system on impact (%)



A3: Thinking about this relative/these relatives, did their mental health issue ...?  
C2a: How much do you agree or disagree with the following statements ...?  
Base: Unsure: those scoring “disagree” or “strongly disagree” on three or more statements at C2a (n=186)  
Knowledgeable: Those scoring “agree” or “agree strongly” to three or more statements at C2a (n=542)

<sup>3</sup> Those classified as “unsure” answered code 1-2 (disagree strongly or disagree) to three or more statements at question C2a in relation to their understanding of where to seek help, knowing where to get support, perception that help and assistance was appropriate, and perception that help and assistance was easy to access for relatives

## Chapter 2: Caring till it hurts

Exploring impact in more detail, all respondents were asked to indicate the impact that their caregiving role had on 11 specific aspects of their lives (see Figure 2.3).

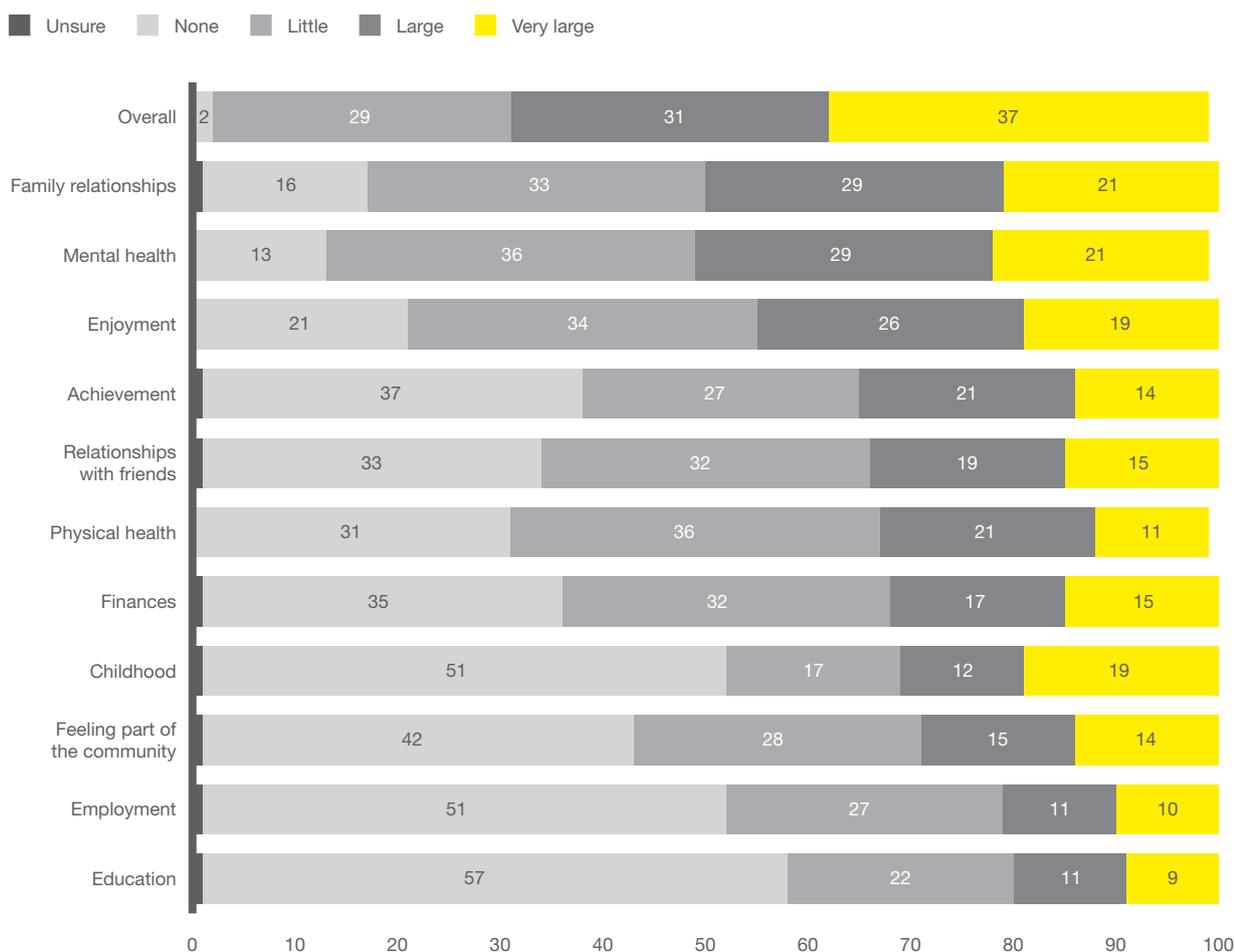
Impact on family relationships, mental health and enjoyment appear to be most keenly felt by caregivers, with around half (50 per cent for family relationships and mental health, and 45 per cent for enjoyment) indicating that their life had been affected to a large or very large degree. Fewer than one in five indicated that their life had not been affected on each of these elements.

Around one in three caregivers indicated that their life had been affected to a large or very large degree in relation to achievement (35 per cent) and relationships with friends (34 per cent).

Three in 10 respondents indicated that the impact on their physical health, finances or childhood were large or very large and 29 per cent felt that their ability to feel part of a community had been affected to a large or very large degree.

Focusing only on respondents who began as caregivers when under 16, the proportion who felt that their childhood was affected rises to 44 per cent, reinforcing the disproportional impact that this group may face in relation to caring for a relative with a mental health issue.

**Figure 2.3: Impact ratings on 11 key indicators (%)**



B1: The next questions are about how your relative who has a mental health issue has impacted your life. When you think about that relative with a mental health issue, how much of an impact have they had on ...?  
 Base: All respondents (n=1,002)  
 Note: may not add to 100% due to rounding

A lesser impact was reported in relation to education and employment, with more than half of caregivers feeling that their life had not been affected as a result of their experiences (57 per cent and 51 per cent respectively).

For those who did indicate that their education or employment had been affected, there were no significant differences in relation to the level of educational attainment achieved between this group and all other respondents. It is possible that the “impact” in this sense manifested itself in a delayed attainment of credentials or take-up of more flexible employment options (as opposed to lower education qualifications per se). Without further qualitative investigation, however, it is not possible to draw any further conclusions.

Length of exposure to the caregiving role, age at which the individual was exposed to the relative with a mental health issue, primary carer status and experience of associated stigma were associated with a greater degree of impact on family relationships.

### Length of caregiving

Those caring for more than 10 years were significantly more likely to feel that their family relationships have been affected to a very large extent (28 per cent) compared to those who have been caring for a shorter period (13 per cent for less than one to four years and four per cent for less than one year).

### Primary carers

Those who are the primary carer were more likely to indicate a very large impact on family relationships as a result of their caregiving role (26 per cent compared to 18 per cent).

### Experience of stigma

Those who had experienced all three types of stigma measured (directed at them, directed at their relative, affecting their relative’s recovery) were significantly more likely to report a very large impact on family relationships (37 per cent), compared to those who had not experienced this broad level of stigmatisation.

Beyond impact on family relationships, these factors were consistently linked to higher degrees of reported impact.

Obviously, because of the nature of the caring relationship there is considerable overlap in relation to these categories (for example, 35 per cent of those who have been caring for more than 10 years are also the primary carer). That said, the consistency of differences across all elements of impact measured is clear and the effect of the caregiving role in light of these consistencies needs to be considered.

Put simply, it is apparent that the more exposure an individual has had (either in terms of time or proximity), the more likely they are to feel that their life has been impacted to a greater degree. The findings do not show evidence that caregivers shut off after a certain time and become immune to the challenges (despite not necessarily being the primary carer); rather, the opposite appears to be true.

All respondents who indicated that their life had been affected to a “large” or “very large” extent on a specific element were then asked a series of questions to understand how their life had been affected. The following section provides detail on impact in relation to:

- caregiver mental and physical health (85 per cent of all respondents affected)
- relationships with family and friends (74 per cent of all respondents affected)
- finances and employment (57 per cent of all respondents affected)

### Specific impact on physical and mental health

This report found that 85 per cent of all respondents indicated that their physical or mental health had been affected as a result of their caregiving role.

Caregivers were more likely to report an impact on their mental health rather than physical health. The vast majority (88 per cent) indicated that they had felt “downhearted and blue” as a result of their relationship, with a similar proportion (81 per cent) indicating that they had felt agitated and found it hard to relax and wind down (see Figure 2.4).

More than two thirds of respondents indicated that they had felt less patient with others as a result of being involved with their relative and 51 per cent indicated that they felt like they had nothing to look forward to.

In terms of physical effects, more than half (54 per cent) indicated that they felt unhealthy or unfit as a result of caregiving for their relative, with those indicating that the relative lived with them being more likely than those whose relative lives elsewhere (60 per cent compared to 48 per cent).

Of concern, 60 per cent of those who experienced a mental or physical impact felt guilty or felt like the mental health issue was their fault. It is apparent that those caring for a child with a mental health issue (73 per cent) and females (62 per cent) are most likely to indicate that they feel a sense of guilt.

Almost three in 10 (28 per cent) of caregivers had developed or exacerbated a physical injury. A similar proportion (27 per cent) indicated that they drank more alcohol as a result of their caregiving role.

On almost all elements related to physical health, those on lower incomes (less than \$35,000) were significantly more likely to indicate an impact compared to those earning \$85,000–\$149,000 or more than \$150,000:

- sixty two per cent of those earning less than \$35,000 felt unhealthy or unfit, compared to 48 per cent of those earning \$85,000–\$149,000 and 42 per cent of those earning over \$150,000
- thirty five per cent had developed or exacerbated an injury, compared to 23 per cent and 17 per cent
- thirty nine per cent had started to take medication, compared to 27 per cent and 17 per cent

These findings may reflect difficulty in accessing support services (for example, lifting assistance, respite services), leading to increased injury, lack of physical fitness and a greater reliance on alcohol and medication.

Those in a primary care role were also more likely than other groups to have experienced most of the physical and mental health effects listed. Again, it is plausible to assume that this is a result of greater exposure to the physical demands of caregiving and the inter-relationship between primary carer roles and lower incomes.

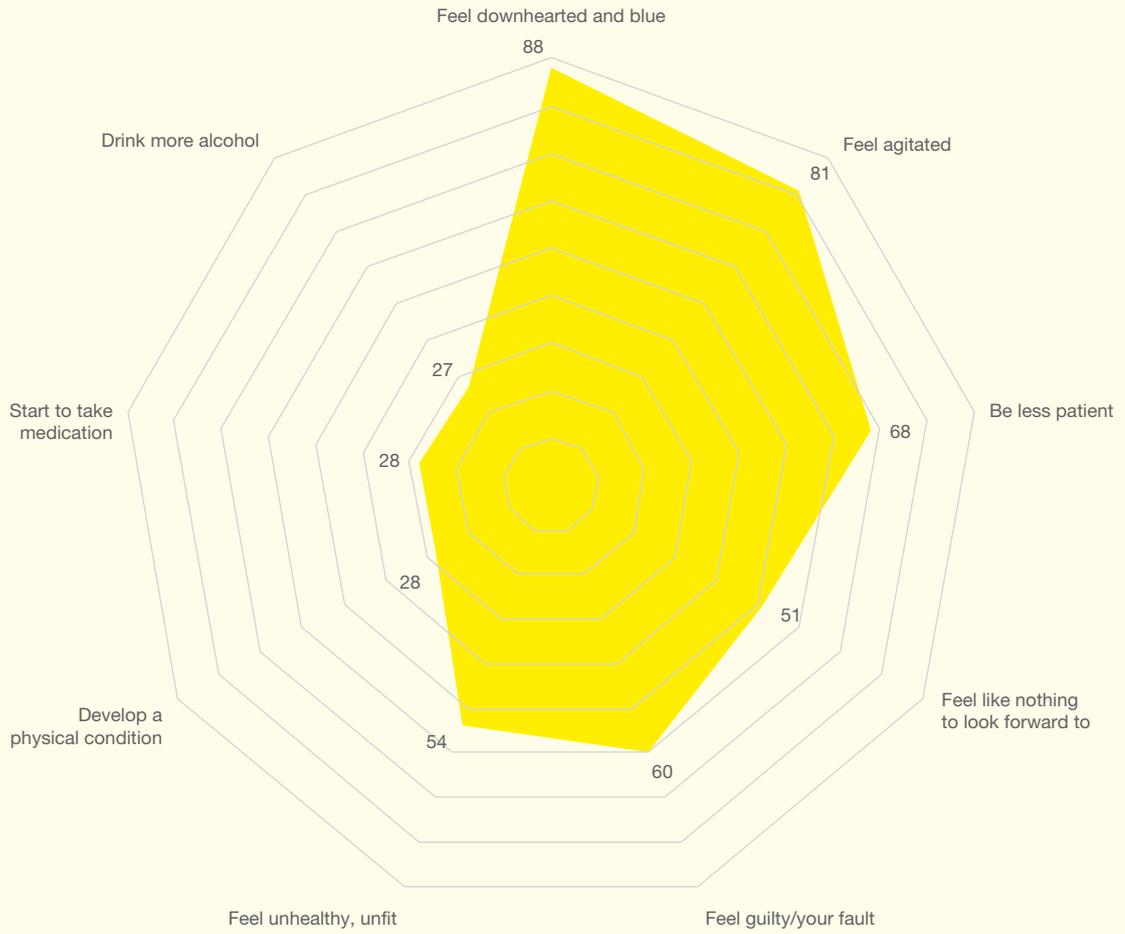
Other differences by demographic groups include:

- caregivers for a partner were most likely to indicate that they had felt agitated and unable to wind down compared to those caring for a parent or a sibling
- males were significantly more likely to drink more alcohol (35 per cent) compared to females (23 per cent)

**“When the problems arose there was no way of telling when or where this would occur. I was verbally abused and physically abused.”**



**Figure 2.4: Mental and physical health impact (%)**



B2b: Thinking about the impact on your mental and physical health, has/did being involved with or caring for this relative lead you to ...?  
 Base: All respondents who indicated that there had been an impact on their mental or physical health at B1 (n=853)



## When the phone rings

Kathleen has always worked as a receptionist. But there were certain calls she dreaded receiving. They were the crisis calls from her daughter, Debbie, who suffered from depression, anxiety, suicidal thoughts and, more recently, schizophrenia.

When Debbie was a teenager, she called Kathleen one night from a refuge in Kings Cross.

## Wesley Mission story: When the phone rings

“I thought she’d gone to stay with a girlfriend,” Kathleen said.

Debbie’s father also had schizophrenia and she was finding his outbursts hard to live with. So, she moved into a refuge and then into Wesley Mission supported accommodation.

It would be one of several cries for help over the years.

“In those days it was very taxing emotionally because you never knew when the phone would ring and when it did you’d think, ‘what’s happening now’? Kathleen said.

“She rang me at work one morning and said, ‘Mum, I can’t get out of bed. I’m shaking and shaking’.

“She’d ring me at work and say, ‘I’ve just taken an overdose of medication’,” Kathleen said.

On a particularly busy day at work, Kathleen got a call from Debbie to say she had attempted suicide and was in hospital recovering.

Working in the health sector, Kathleen has benefitted from access to people experienced in mental health who could point her to the right assistance and resources. Despite this, the journey has been tough.

She remembers battling doctors to get a definite diagnosis of Debbie’s condition. She also found it difficult to find support other than having medication prescribed.

Ultimately, the stress took its toll on Kathleen.

“I just broke down at work one day and was advised to see a counsellor,” she said.

Reflecting on that time now, Kathleen said that the counsellor taught her that she needed to take care of herself.

She makes time now to go shopping and meets friends more often. Once a year, she takes a holiday. Kathleen has also been attending a support group for carers for the past three years.

After the last suicide attempt, Debbie moved back home with Kathleen. They’ve now established good communication around Debbie’s condition. Debbie can articulate when her mental health is deteriorating. Kathleen can also see the warning signs and is able to chat to Debbie about it.

“I’m always on the lookout for Debbie’s warning signs,” Kathleen said. “She’ll become very quiet and subdued.”

For both women it has been a process of educating themselves about schizophrenia.

Kathleen has done a lot of reading and attended many talks on the subject.

For her part, Debbie has learned some useful coping mechanisms. If she wants to relax, she’ll go into her room, start burning incense and put on some calming music.

Debbie also recently attended a program called Meaningful Engagement run by Wesley Mission’s Home and Carer Support Services. The program teaches participants to better manage social and work environments.

While Debbie attended the course, Kathleen had more time to take a break from the pressure of caring for her daughter.

The Wesley Mission program also gave Debbie more confidence in managing her condition and she has recently said she would be comfortable living on her own again.

Before Kathleen went away on a trip recently, Debbie showed her a list of emergency contacts she had prepared for the times when her condition took a turn for the worse.

For Kathleen, it is a relief to see her daughter taking responsibility for managing her condition.

**“She rang me at work one morning and said, ‘Mum, I can’t get out of bed. I’m shaking and shaking’.”**

### Specific impact on relationships with family and friends

Almost three quarters (74 per cent) of respondents indicated that they had experienced problems with their family and other relationships as a result of their caregiver duties.

Reviewing the specific impact for these respondents, 73 per cent indicated that they had reduced contact with friends (see Figure 2.5). Those caregiving for a partner are particularly prone to social withdrawal, with almost all (93 per cent) indicating that they had less contact with friends.

Around two thirds (64 per cent) of respondents indicated that they had experienced family breakdown. Of concern, almost one third of respondents indicated that they had experienced family violence as a result of their relationship with a relative with a mental health issue.

Focusing on family breakdown, those who had been in a caregiving role for a longer period were significantly more likely to report this, with 72 per cent indicating that this had occurred compared to 52 per cent of those caregiving for under a year and 53 per cent of those caregiving for one to four years.

Caregivers who were living alone were also more likely to report family breakdown.

Looking at family violence, there were some key demographic differences in the population:

- again, we see the cumulative impact of length of exposure, with those caring for longer periods being more likely to report family violence (42 per cent compared to 22 per cent of those caregiving for under a year, 15 per cent of those caregiving for one to four years and 29 per cent of those caregiving for six to 10 years)
- it is apparent that respondents caregiving for a relative with a more complex issue, such as schizophrenia, personality disorders, drug and alcohol abuse or bipolar disorder, were more likely to have experienced family violence than those caregiving for someone with depression or anxiety
- female respondents were more likely to report family violence (34 per cent compared to 24 per cent of males), as were those who reported that their relative remained undiagnosed at the time of participating in the study (41 per cent compared to 29 per cent of those diagnosed)
- some state differences were also seen in relation to family violence, with residents of NSW being more likely to report this as an impact (41 per cent) compared to residents in Victoria (25 per cent), South Australia (26 per cent) and those in the ACT, Tasmania or the Northern Territory (12 per cent)

**“My relationship with my father has suffered, as he felt he had to take mum and move away from my sister and I to give us the best chance of living a ‘normal’ life.”**

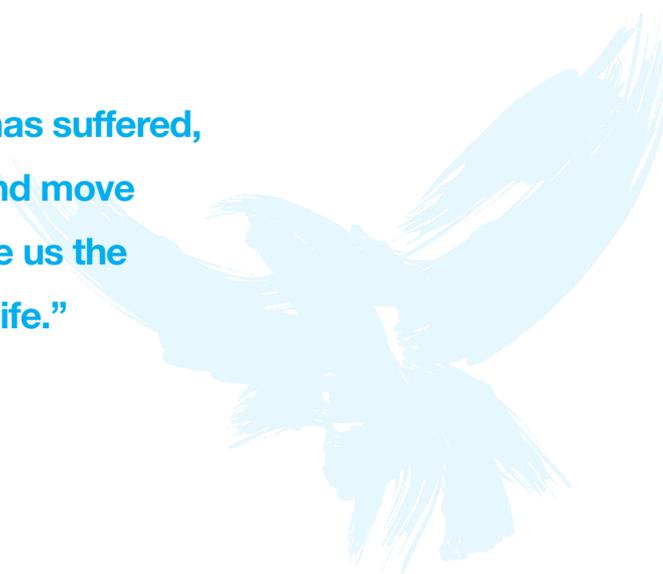
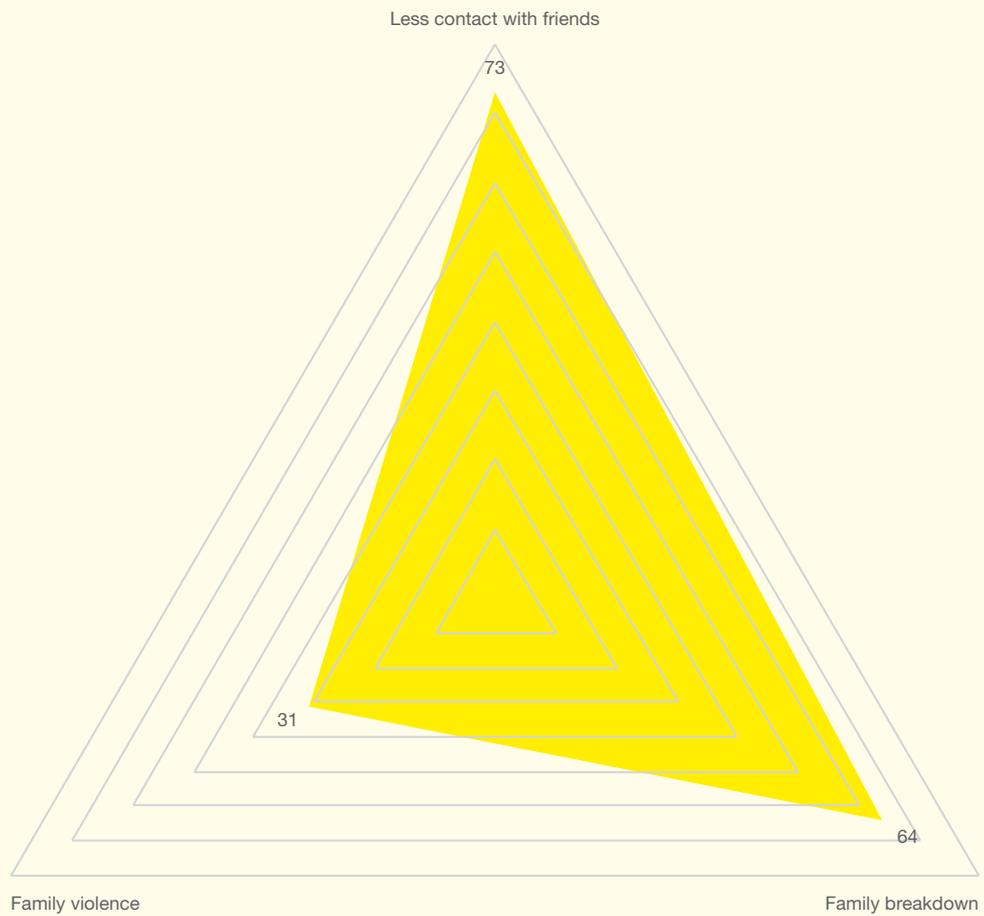


Figure 2.5: Impact on relationships (%)



B2d: Thinking about the impact on your relationships, has/did being involved with or caring for this relative lead to ...?  
Base: All respondents who indicated that there had been an impact on their relationships with family and friends at B2c (n=737)

### Specific impact on finance, employment and education

Fifty seven per cent of respondents indicated that their financial or work/study situation had been affected.

Within this group, having to draw on or rely on savings was the impact felt by the highest proportion of respondents, with 70 per cent indicating that this had occurred (see Figure 2.6). Interestingly, the experience was relatively equal and consistent across all groups (including income groups, gender groups, age groups and caregiver relationships).

Just under half (44 per cent) of the caregivers indicated that they had been forced to rely on government assistance. In addition, around one third said that they had had to sell possessions (32 per cent).

More than half (58 per cent) indicated that they had needed to reduce the number of hours of work or study, 35 per cent had taken a job with less responsibility and 33 per cent had been required to take a job with a lower salary.

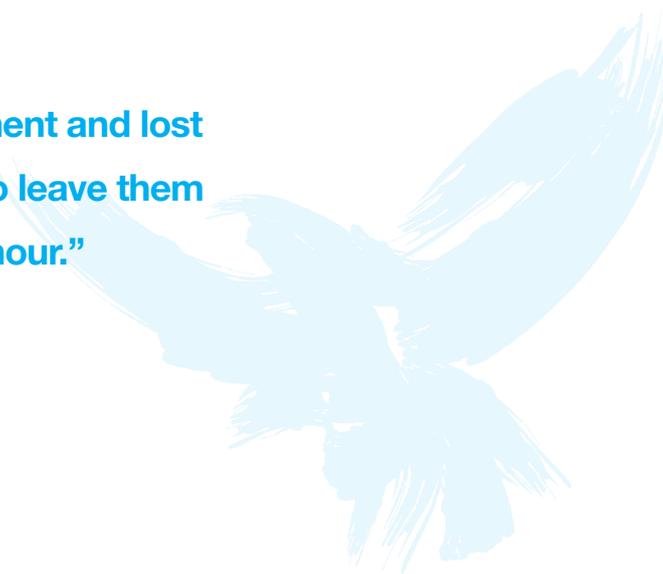
While caregivers experience financial and employment/educational effects across the entire caregiving cycle, there was no consistent evidence that the impact was greater for those who had been caregiving for a longer period of time.

As with mental and physical health effects, primary carers were more likely to have experienced all types of financial and employment/education impact than those in secondary caregiver roles. Those caregiving for a partner also appear to be disproportionately affected compared to those caring for their children or siblings. This potentially reflects the current benefit structure and the inter-relationship between partner/parent carer relationship and primary caring responsibility (which is accompanied by a greater access to benefits than a secondary carer relationship).

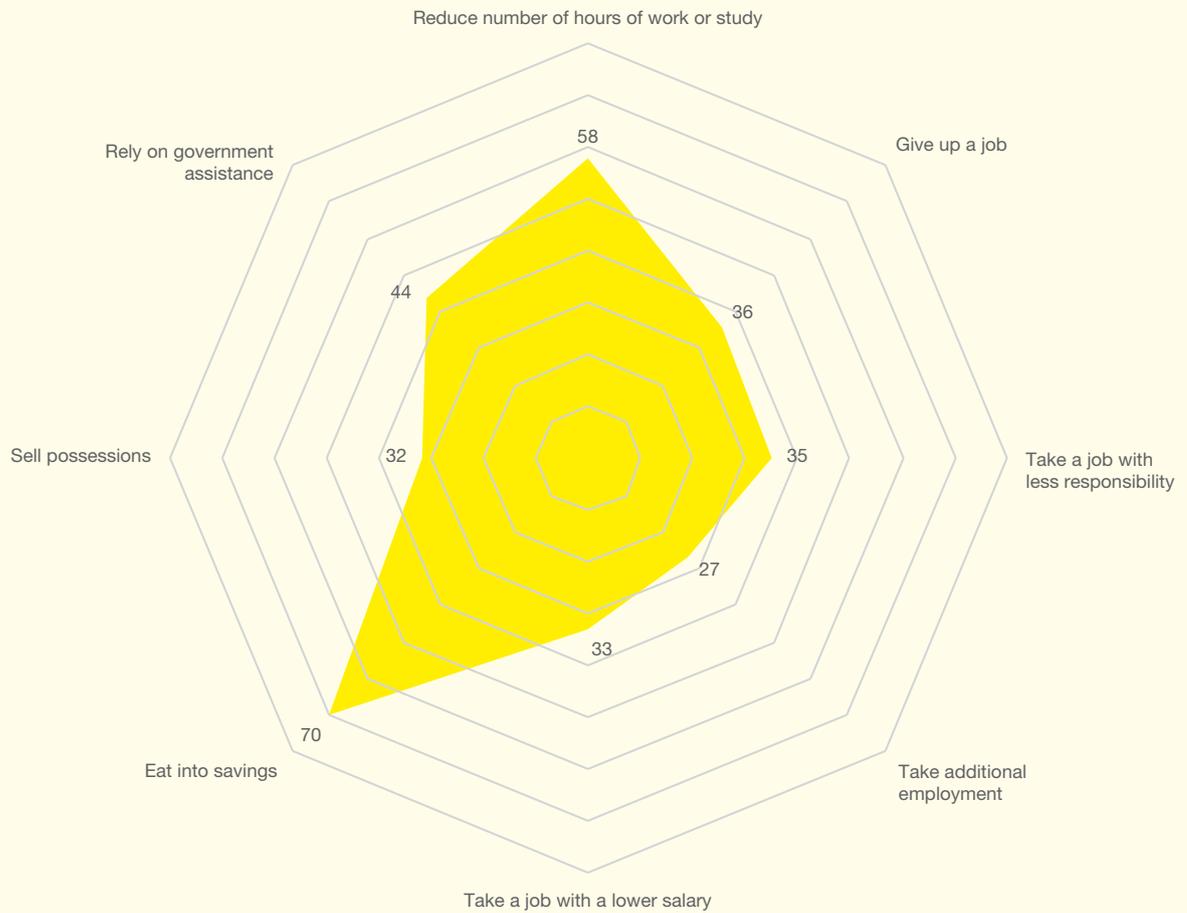
Education and income appear to influence specific financial or employment/education impact:

- those with postgraduate qualifications were less likely to have had to rely on government assistance compared to those with high school/trade qualifications or undergraduate qualifications (23 per cent, compared to 52 per cent and 45 per cent respectively)
- caregivers with postgraduate qualifications were also significantly more likely to have had to reduce the number of hours of work/study (70 per cent), compared to 57 per cent of undergraduate and 54 per cent of high school/trade-qualified caregivers
- those on lower incomes were also significantly more likely to be on government benefits

**“I had to leave full-time employment and lost all my savings as I was unable to leave them unsupervised for more than an hour.”**



**Figure 2.6: Impact on finance and employment (%)**



B2c: Thinking about the impact on your financial and employment or education situation, has/did being involved with or caring for this relative lead you to ...?  
 Base: All respondents who indicated that there had been an impact on their financial or employment/education situation health at B1 (n=571)

### Experience of stigma

All respondents were asked to cite examples of stigma they had experienced across three broad areas:

- stigma which had an impact on them as caregivers
- stigma which had an impact on the immediate family of the caregiver
- stigma which had an impact on the wellbeing of the relative

Sixty per cent of respondents agreed that stigma they had experienced had affected the immediate family, with approximately one quarter disagreeing and 20 per cent either being unsure or neither agreeing or disagreeing with the statement (see Figure 2.7).

Fifty per cent of respondents agreed that stigma had an impact on them personally. Around one third (32 per cent) disagreed with this statement.

A similar proportion (49 per cent) indicated that stigma had affected their relatives' wellbeing while 27 per cent disagreed.

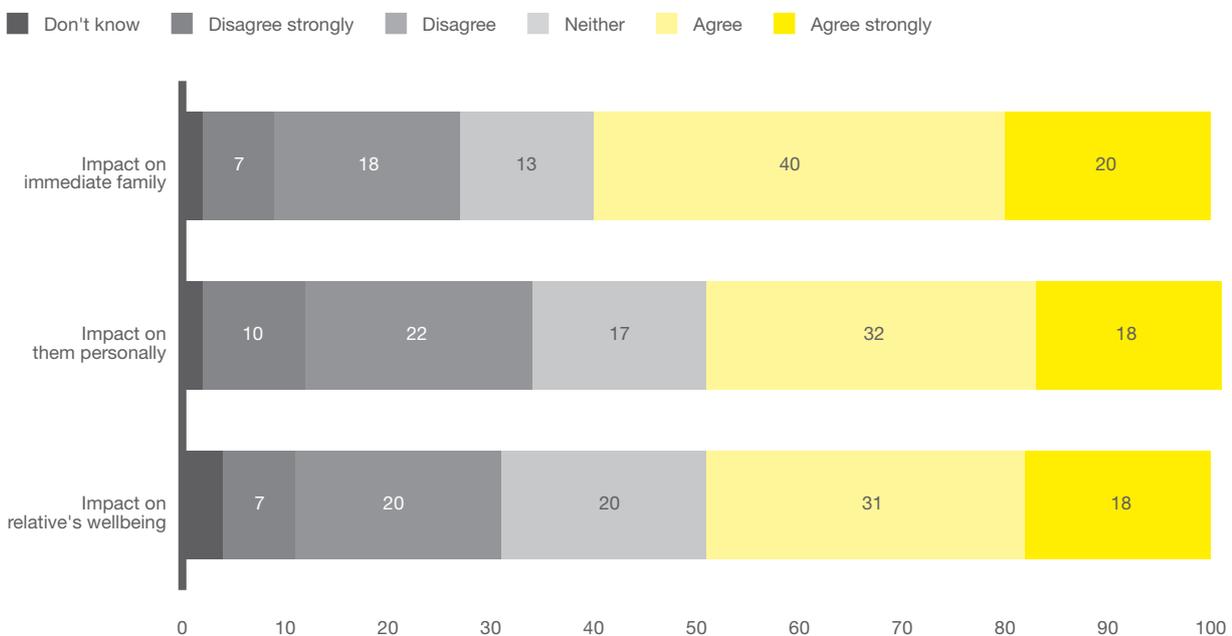
Stigma appears to be experienced across all caregiver segments, with relatively few sub-group differences.

That said, those who have been caregiving for longer were significantly more likely to report an impact on the family, themselves and the wellbeing of their relative. It is possible that this indicates earlier community attitudes about mental health issues being reflected, as some of these caregivers would have been involved in caregiving for a considerable period of time, and this needs to be taken into consideration in interpreting these findings.

In addition, those employing avoidance coping strategies appear to be disproportionately affected by all types of stigma, although it is not possible to say whether their coping strategy has potentially aggravated this impact or been employed as a result of the stigma.

Caregivers of a relative with schizophrenia, personality disorders or drug and/or alcohol disorders were also more likely to indicate that stigma had an impact compared to those caregiving for a relative with anxiety or depressive disorders.

Figure 2.7: Types of stigma experienced (%)



D2: How much do you agree or disagree that the stigma you have experienced about your relative's mental health issue has ...?  
 Base: All respondents (n=1,002)

**Caregivers of a relative with schizophrenia, personality disorders or drug and/or alcohol disorders were more likely to indicate that stigma had an impact compared to those caregiving for a relative with anxiety or depressive disorders.**



## Chapter 3:

# Coping with caring

- in general, carers are more likely to use cognitive coping strategies such as acceptance and faith
- young carers are more likely to cope through avoidance strategies





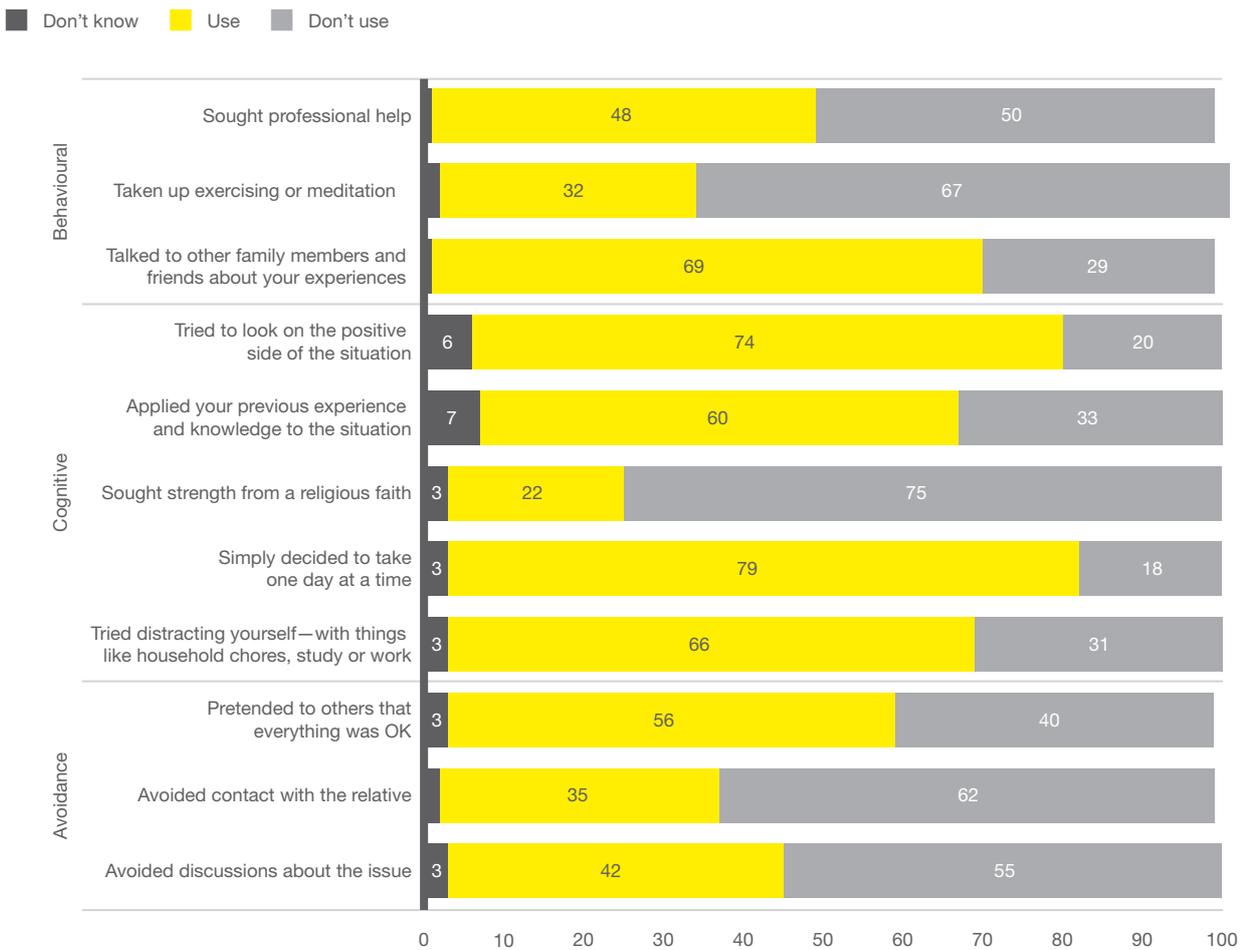
## Chapter 3: Coping with caring

Younger caregivers are more likely to use avoidance strategies than other carers. This is a significant finding as it highlights the importance of having early intervention strategies in place to assist younger caregivers implement more positive coping approaches.

Respondents were asked to identify the strategies and mechanisms they have used to help them cope with the experiences of caring for a relative with a mental health issue. Their responses were grouped into three broad categories:

- **behavioural:** related to external behaviour such as problem solving, talking to others and seeking professional help
- **cognitive:** involving internal processes such as acceptance, positive thinking and faith/religious beliefs
- **avoidance:** strategies such as not talking about the problem, turning to alcohol/drugs and distancing oneself from the ill relative

Figure 3.1: Coping strategies (%)



D1: To help you cope with the experience of caring for and being involved with a relative with a mental health issue, have you ...?  
 Base: All respondents (n=1,002)

Overall, more respondents reported using cognitive strategies to help them cope (see Figure 3.1). Behavioural strategies were the second most frequently used approaches.

Caregivers used avoidance strategies the least and of those strategies, they were most likely to pretend that everything was OK (56 per cent) or avoid any discussion of the issue (42 per cent).

### Behavioural strategies

There were some sub-group differences in these coping strategies:

- those caregiving for a child (74 per cent) or sibling (73 per cent) were significantly more likely to talk to friends or family than those who cared for their partner (62 per cent)
- caregivers who did not have their relative living with them were more likely to talk to family/friends (73 per cent) than carers who had a relative living in their household (65 per cent). Caregivers who had the relative living in their household were more likely to have sought professional help (54 per cent)
- those with an undergraduate university degree (51 per cent) were more likely to have sought professional help than those carers who had a secondary school qualification (44 per cent)
- those with an income under \$35,000 were significantly more likely (57 per cent) than caregivers with a higher income (\$85,000–\$149,000) to seek professional help (44 per cent)

### Cognitive strategies

Age differences also played a part in different types of cognitive coping strategies:

- people over 45 were much more likely to report taking it “a day at a time” than caregivers aged 25–44. These caregivers were also more likely to look on the positive side (77 per cent) than carers aged 18–24 (63 per cent)
- caregivers aged 18–24 were significantly more likely to try distracting themselves with chores or study (82 per cent) than older caregivers

### Avoidance

Caregivers who were younger were significantly more likely to report using most avoidance strategies than older respondents.

Caregivers who cared for a relative suffering from drug/alcohol abuse were also significantly more likely to use avoidance strategies.

If the relative suffered from schizophrenia (50 per cent), bipolar disorder (48 per cent) or a personality disorder (53 per cent), their caregiver was more likely to avoid contact with them, and these carers were more likely to not know where to seek help (45 per cent).

**“Caring for him was depressing and time consuming for me, but lovingly accepted.”**





## **So many carers seem to have given up**

**Louise\* is a very strong, feisty woman.**

**She has to be to cope with the crushing responsibilities she bears. One is caring for her 32-year-old son Richard who was diagnosed with drug-induced psychosis and bipolar disorder some 15 years ago when he was a high-achieving student at a well-known private school.**

## Wesley Mission story: So many carers seem to have given up

Richard has been pretty much unmanageable ever since, in and out of psychiatrists' offices and rehab centres. While the drug use has stopped, the alcoholism hasn't and he receives constant treatment.

Louise's other daunting responsibility is caring, 24/7, for her 12-year-old foster son, John. He has epilepsy and autism, can't speak, still requires nappies and has a mental age of around two.

While The Wesley Report points to the mental health risks faced by carers looking after loved ones with mental health problems, Louise seems different.

In her early 60s, she is full of positive energy, selling real estate part-time while also completing a psychology degree.

"I don't have any magic formula but somehow I seem to manage—I can't really explain why," Louise says.

Louise's husband left the family when he couldn't cope with their son Richard's erratic and often violent behaviour. A subsequent relationship with another man left Louise quite literally holding the baby. The man's daughter by an earlier relationship had given birth to John but neither she nor her dad wanted to take responsibility for someone so severely disabled. So, by the time John was five, and weighed just 10kg through neglect, the Department of Community Services asked Louise if she'd care for the boy. She didn't hesitate.

What's all the more remarkable about Louise is that her own childhood was not a good preparation to face and cope with such enormous challenges.

Abandoned by her parents when she was two, Louise spent years shuffling between boarding school and foster parents, some of whom abused her terribly. But fate stepped in and she finally ended up with a wealthy foster mum who brought her up during her teens.

In the early days of Richard's illness, Louise admits to sitting in the local park crying her eyes out. She did attend "very helpful" counselling at Wesley Mission, but more in an effort to learn techniques to help Richard rather than herself.

In the final analysis, two things helped, and continue to help get her through.

"I suppressed my emotions and concentrated on the day-to-day practical issues of making sure he took his medication and got to medical appointments. I also researched all the treatment options."

Her other pillar is her Christian faith.

"I belong to a wonderful local church where the people give me such solid support, such as visiting me when I'm sick."

This is not to say that being a carer hasn't had a huge negative impact on Louise's life, even if it hasn't left her depressed.

"It's a constant financial challenge with Richard and John's medical bills. The demands of caring mean I can only work part-time to top up the pretty meagre carer's allowance I receive," she said.

"It also affects my social life in that prospective partners are easily put off when they see my situation."

Louise is no stranger, however, to the prevalence of depression and other mental health problems among other carers.

"The mums I meet at the moment through John's special school are deeply depressed," she said.

"Very often their husbands have deserted them because they can't deal with the situation, and the women have lost interest in looking after themselves: they are overweight, hygiene goes out the window, and their clothes look like they've slept in them. They are very angry about their situation."

**"The mums I meet at the moment through John's special school are deeply depressed."**

Sadly, Louise says that one of the most depressing things about being a carer is the constant battle to negotiate the medical system, a problem borne out in Wesley Mission's research.

"It's very hard to get information from doctors about where to go for help with people like Richard, who has both addiction issues and bipolar disorder. When I finally got him into rehab facilities it was through my own efforts rather than through help from the doctors," Louise said.

"He's also very difficult to deal with and many professionals just can't be bothered putting up with that.

"There really needs to be an education campaign among doctors and psychiatrists about how to handle people like Richard. It makes me angry because it shouldn't be this hard."

## Chapter 4:

# Looking for help

- of all respondents, 56 per cent had accessed a service
- of those who had accessed a service, 82 per cent accessed counselling or psychological services





## Chapter 4: Looking for help

Ease of access, as opposed to lack of awareness, may prevent caregivers from using services, with most agreeing that they know where to go for information and support but do not agree that access is easy.

Respondents were asked about their use, and perception of, mental health services, both those aimed at assisting caregivers and the relative with a mental health issue.

It is important to note that the purpose of this study is not to evaluate these services. Rather, service use was raised to provide insight into the relationship between stressors and help-seeking behaviour.

As this is a retrospective study, participants were asked to consider all service interactions that they may have experienced and, as a result, perceptions may reflect old service models, clinician attitudes and community perceptions. This should be taken into account when interpreting the findings.

### Service use summary

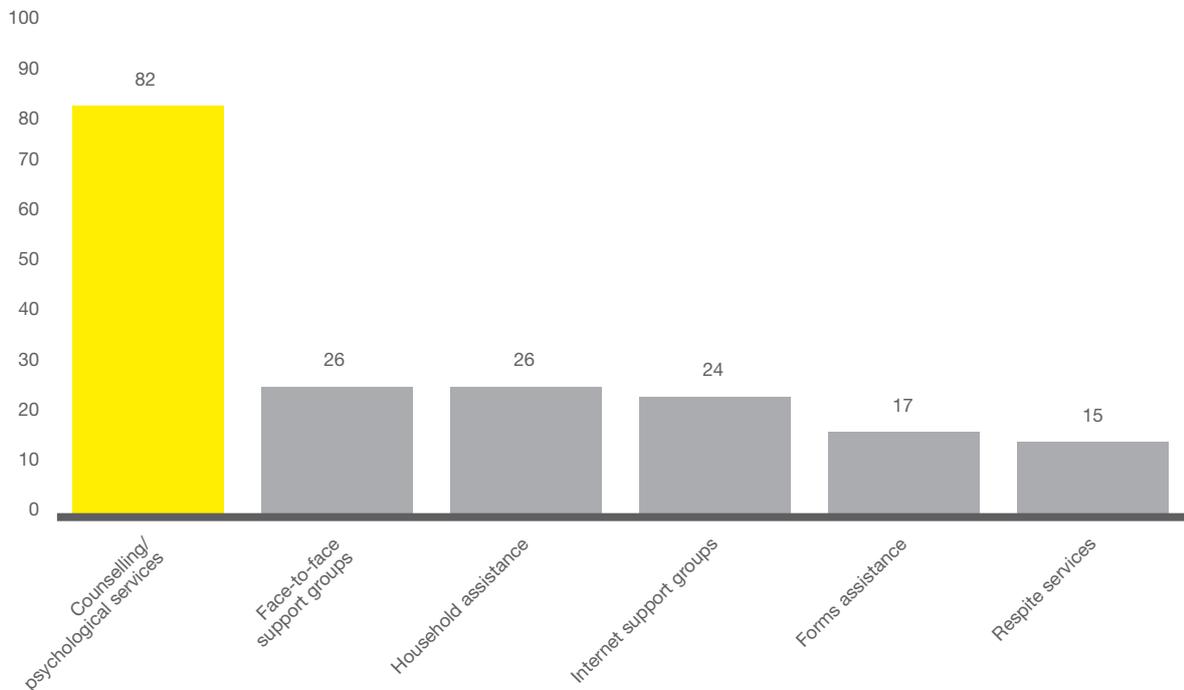
#### Use of support services

More than half (56 per cent) of respondents had accessed at least one of the following services:

- counselling or psychological services
- support groups
- respite services
- help with household tasks
- support groups on the internet
- help with completing government or legal forms

Counselling and psychological services were the most used, with 82 per cent of caregivers having accessed one kind or another (see Figure 4.1). One quarter of caregivers had attended support groups and sought assistance with household chores.

Figure 4.1: Specific services accessed (%)



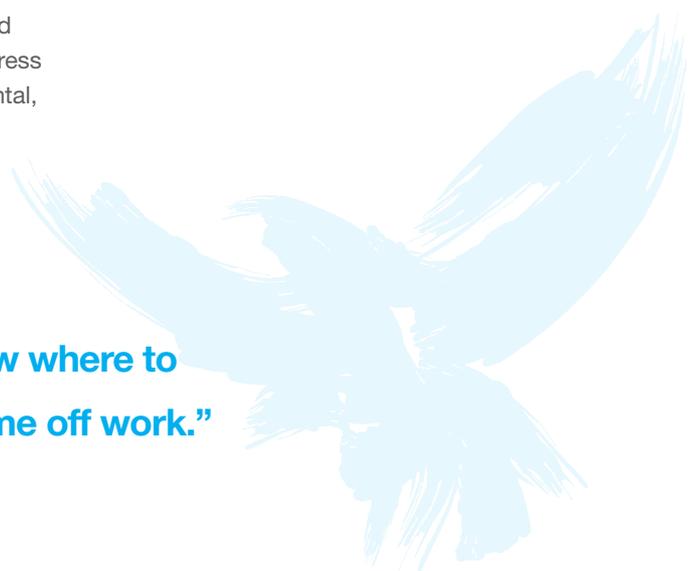
C1a: As a result of your experiences with the relative with a mental health issue, have you ever used any of the following services listed below to help you personally?  
Base: All respondents who had used at least one service listed (n=563)

One in five had accessed internet support groups, 17 per cent had sought assistance with government or legal forms and 15 per cent had accessed respite services.

Caregivers who sought support were more likely to report experiencing higher degrees of negative impact in their lives, with this being particularly the case for those who had accessed counselling/psychological services or face-to-face support.

This is an important insight and highlights the need for early intervention to provide services before stress reaches levels where it affects the caregiver’s mental, physical, social and financial health.

Table 4.1 compares impact across the four most commonly used services.



**“I got depressed as I didn’t know where to turn for help and had to take time off work.”**

**Table 4.1: Impact of service access**

	Counselling or psychological (used n=461)		Face-to-face support (used n=144)		Internet support (used n=137)		Help with household tasks (used n=149)	
	Used	Not used	Used	Not used	Used	Not used	Used	Not used
Overall impact	82	57	83	66	76	67	70	68
Finances	43	23	49	29	52	29	35	32
Physical health	46	22	55	29	49	30	40	31
Mental health	67	36	69	47	64	48	56	49
Employment	31	13	35	19	32	19	28	20
Education	28	12	33	18	37	18	31	18
Achievement	47	25	49	33	45	34	47	33
Family relationships	64	39	69	47	65	48	54	50
Relationships with friends	46	24	54	31	48	32	43	33
Enjoyment	58	34	64	42	57	43	54	43
Feeling part of the community	41	18	47	26	46	26	36	28

B1: When you think about that relative with a mental health issue, how much of an impact have they had on ...?

C1a: As a result of your experiences with the relative with a mental health issue, have you ever used any of the following services listed below to help you personally?

Base: All respondents (n=1,002)

Blue: Significant differences

**Attitudes to services for caregivers**

Ease of access, as opposed to lack of awareness, may prevent caregivers from accessing services, with most agreeing that they know where to go for information and support but don't agree that access is easy (see Figure 4.2).

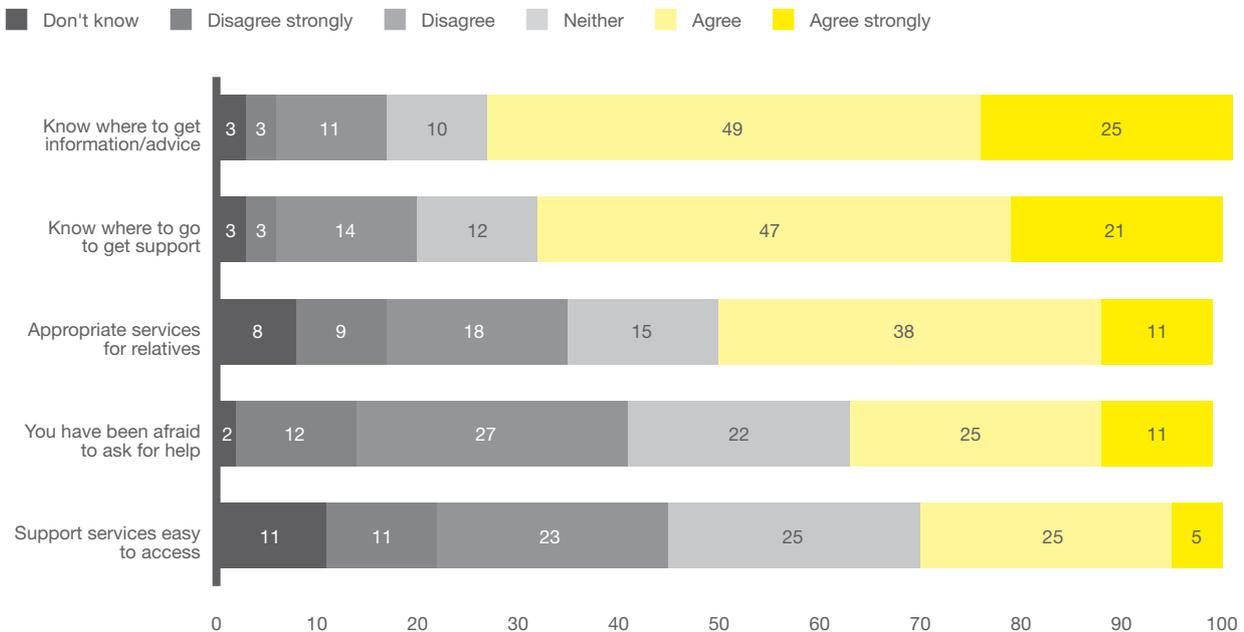
Two thirds (68 per cent) of respondents agreed that they knew where to get support and a similar proportion (74 per cent) indicated that they knew where to get information and advice. There were relatively few meaningful differences across demographic groups on this issue.

Just under half (49 per cent) agreed that there were appropriate services for the relatives of those suffering from a mental health issue. One quarter (27 per cent) disagreed that services were appropriate and eight per cent were not able to answer the question. Older caregivers (those aged 65+) were more likely than some other caregiver groups (middle aged carers) to feel that services were appropriate.

One third (36 per cent) of respondents agreed that they had been afraid to ask for help, with those who had been caring for a longer period of time being significantly more likely to agree with this statement (10+ years 41 per cent, compared to 22 per cent for those caregiving for less than a year, 34 per cent for those caregiving for one to four years and 33 per cent for six to 10 years). As with impact, it is possible that these differences reflect longer-term carers' exposure to an older mental health system and outdated community attitudes.

Less than one third (30 per cent) agreed that services for caregivers were easy to access, with 34 per cent actively disagreeing with this statement, 11 per cent indicating that they could not answer this question and 25 per cent indicating that they neither agreed nor disagreed. There were no differences across demographics for perceptions of ease of access.

**Figure 4.2: Awareness/understanding of information and services (%)**



C2a: How much do you agree or disagree with the following statements ...?  
Base: All respondents (n=1,002)

Half (50 per cent) of caregivers indicated that they had contact with mental health services as a result of their relationship with the relative (for example, visits to medical and psychological professionals, assessment services, etc).

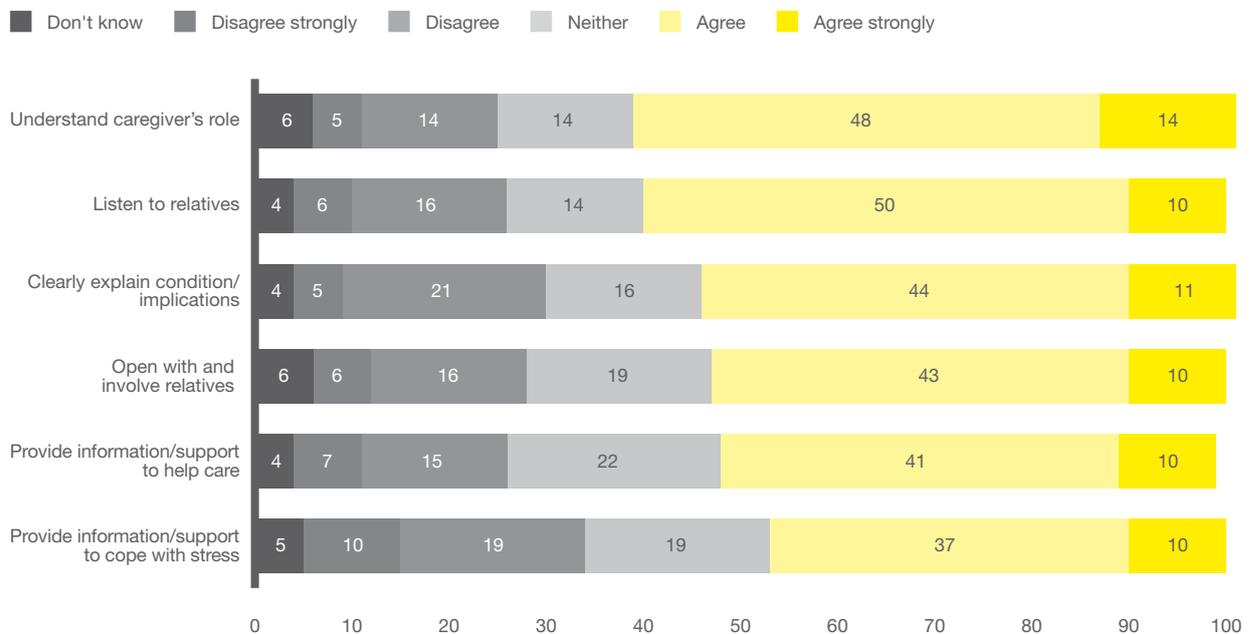
It is apparent that there may be some room for improvement in provision of information for caregivers, while perception that mental health services understand and listen are strong.

Two thirds (62 per cent) of respondents felt that mental health services understood the role that extended family plays in the patients' lives. One in five (19 per cent) disagreed with this statement. There were no meaningful differences across sub-groups on this question.

A similar proportion (60 per cent) agreed that mental health services listened to relatives, while 22 per cent disagreed with this statement. Again, there were few differences across demographic groups.

Respondents were least likely to agree that mental health services provide information and support to assist them to cope with the stress of caregiving or to assist them to provide care to their relative. As with other elements of mental health service provision, perceptions were consistent across demographic groups.

**Figure 4.3: Perception of services for a relative with a mental health issue (%)**



C4: How much do you agree or disagree with the following statements ...?  
 Base: All respondents who had contact with mental health services at C3 (n=503)



## Jim's persistence

Jim's wife, Maggie, first experienced mental health issues 40 years ago when she had post-natal depression after the birth of her two sons.

This developed into severe bipolar disorder which Maggie has suffered from ever since. Add to this her subsequent alcoholism, and the dementia that has resulted, and you begin to get a picture of Jim and Maggie's home life.

## Wesley Mission story: Jim's persistence

Jim has always been the carer for his wife. Initially it was only after work but in the past six years it's been a full-time role. Jim's days consist of cooking, cleaning and making sure Maggie takes her medication and doesn't bring alcohol into the house.

Jim acknowledges that the difficulties have definitely taken their toll on the couple's relationship.

"There's no trust there anymore," he said.

Maggie hasn't always appreciated Jim's care and it has led to a lot of conflict.

"I walk on eggshells most of the time, particularly when her mood swings too high," he said. "That's the most difficult thing."

"Knowing how to express your concern or advice is difficult without being accused of being a control freak."

At one time Maggie's abuse of alcohol was so bad that Jim had her hospitalised under the Inebriates Act. It's still a painful issue between the couple.

The family also lives in the shadow of the suicide of their son, Jack, a few years ago. Jack also had bipolar disorder and lived interstate as he found contact with his mother worsened his own condition. Ultimately, it is believed that work pressures led to his death.

Both Maggie and Jim have done all they can over the years to help improve her condition. Maggie first sought help at Wesley Hospital Kogarah in 1980. Jim takes her there regularly when her condition deteriorates.

Jim has also done his research to better understand the issues involved and attended lectures on alcoholism and bipolar disorder. He started to understand that there was a limited amount he could do to help Maggie.

This understanding has been a saving grace for Jim as he doesn't hold himself responsible for the decisions his wife has made.

"You've just got to accept that's the way things are," he said.

"Progressively, you learn to roll with the punches but this doesn't mean things are cosy."

Jim's career was in the steel industry where moving house is often necessary. However, moving made Maggie's condition worse and Jim declined several opportunities for advancement to avoid this.

He was also very conscious of the time commitment to care for his wife and how a promotion might impact this.

It is not a surprise to Jim to hear that many people in his position suffer mentally and emotionally. He is always careful to take time out when things are getting too much.

Walking the dog helps with the daily pressures. When the strain gets too much, Jim will make use of respite care for Maggie and take himself on a holiday.

"Maggie and I used to take holidays together," he said. "But if she took a turn for the worse, it would be really difficult to get appropriate care."

One advantage of Maggie going to Wesley Hospital Kogarah regularly is that the staff get to know her and treatment is much easier.

You would think that Jim would have no energy at the end of each day but in the struggle to keep himself going over the years, he looked for interests to take his mind off things.

In recent years, he established an advocacy group for other British pensioners living in Australia.

Jim is also gradually developing support systems and his relationship with the staff at Wesley Hospital Kogarah is a key part of this. While the hospital cares for Maggie, staff are also very conscious of the impact on Jim and provide him with advice and support.

After decades of extreme difficulties, Jim's patience and perseverance are evident in his continued commitment to Maggie.

"If you lose patience, you've lost the battle," he said.

**"Progressively, you learn to roll with the punches but this doesn't mean things are cosy."**

Chapter 5:

# A huge burden on the young

Those who start caring while under the age of 16 are likely to care for longer and experience a higher level of impact than those who are older in a caring role.





## Chapter 5: A huge burden on the young

The impact felt by those who started caregiving when they were under 16 is considerably higher than those who were exposed when they were older. The role affects their financial status, and mental and physical health. They are also more likely to have experienced stigma because of their association with a relative with a mental health issue.

One of the groups of interest to Wesley Mission are caregivers under 16 years of age. Reviewing the findings for this group, it is clear that the impact on them is considerably higher than those who were exposed to the caregiving role at an older age.

In terms of defining “caregiver who was exposed prior to the age of 16 years”, this was considered to be a respondent who self-identified that this was the case and that caregiving had had at least “a little” impact on their life.

Respondents who had been caring for more than 10 years were removed from the base of caregivers who had been exposed under 16 because of their experience with an outdated mental health system.

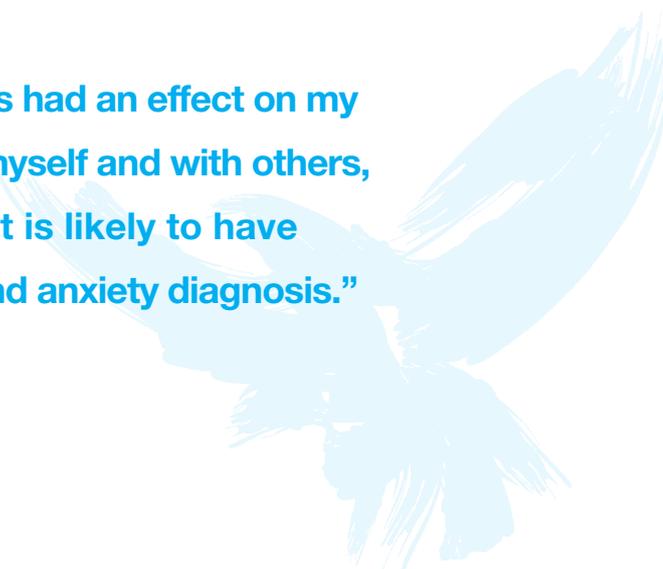
Table 5.1 provides specific examples of the impact on caregivers who began caring under the age of 16 years.

These carers were significantly more likely to have experienced impacts on finances, mental health, growing up and education opportunities in addition to their perceived ability to achieve personal goals and get involved in the community.

The largest difference between those who were exposed to a caring role under 16 years of age and other carers is related to impacts on mental health, with 67 per cent of those exposed early indicating that this had been affected, compared to 49 per cent of all other carers.

On several aspects of mental, physical and financial impacts, those exposed to the caring role at an early age are significantly more likely to report an impact, when compared to all other carers. This difference is most keenly felt when it comes to needing hours for work or study, where 73 per cent of those who have been exposed at an early age are likely to feel that they have been impacted in this way, compared to 56 per cent of all other carers.

**“My father frightened me and this had an effect on my self-esteem, my confidence in myself and with others, and my overall mental health. It is likely to have contributed to my depression and anxiety diagnosis.”**



**Table 5.1: Overall impacts for those exposed to caring at an early age (%)**

<b>Overall impact on caregivers (top 2 score large or very large impact)</b>	<b>Early exposure (n=96)</b>	<b>Total other carers Minimum (n=896)</b>
Your finances	43	31
Impact on mental health	67	49
Education opportunities	36	19
Ability to achieve personal goals	46	34
Ability to feel involved in community	38	28
Impact on childhood/growing up	44	30

**Table 5.2: Impact of caregiving on specific measures for those exposed to caring at an early age (%)**

<b>Mental and physical impact</b>	<b>Early exposure (n=84)</b>	<b>Total other carers (n=769)</b>
Feel like you had nothing to look forward to	63	49
Feel guilty	73	59
<b>Financial and employment impact</b>	<b>Early exposure (n=62)</b>	<b>Total other carers (n=509)</b>
Reduce the number of hours you are able to work/study	73	56
Take on additional employment	37	25
<b>Use of services—respondents answered yes/no</b>	<b>Early exposure (n=66)</b>	<b>Total other carers (n=497)</b>
Respite services	27	13
Support groups on the internet	33	23
<b>Information and advice-seeking behaviour—net agree score</b>	<b>Early exposure (n=96)</b>	<b>Total other carers (n=906)</b>
Afraid to ask for the help that you may need from support services	55	35
Support services for relatives are easy to access	39	29
Mental health services are open with and involve relatives of those with mental health issues	61	52
Mental health services provide you with the information and support to help you cope with the stresses of having a relative with a mental health issue	55	45
<b>Stigma</b>	<b>Early exposure (n=96)</b>	<b>Total other carers (n=906)</b>
Experienced personal stigma	60	49



## When the child carer grows up

Helen\* has excelled at surviving since taking on the role of carer for her brother when she was six. Her mother had schizoaffective disorder and often neglected them.

## Wesley Mission story: When the child carer grows up

Now in her early 40s, Helen still sometimes plays this role. But the many years of putting others first have taken their toll on her. Seeing a psychologist after the breakdown of her marriage, Helen found she had depression and complex trauma response. She now attends group sessions at Wesley Hospital Ashfield.

The mental health problems result in her using anger as a defence mechanism when she is stressed. While she manages her work relationships very well, her condition makes for very rocky personal relationships.

“I’m like a pressure cooker,” she said. “I explode like a volcano.”

When Helen was a child, her mother was unable to cope with many of the demands of daily life and screamed and cried when it all became too much.

Helen had the responsibility of getting her brother to school and picking him up. As a teenager she worked two jobs to keep the money coming in, did the grocery shopping and prepared meals, while still getting her homework done.

She always felt a sense of shame about her mother and brother, who developed addictions as a teenager.

“The biggest challenge was keeping the household running so that nobody knew,” Helen said.

A boyfriend of her mother’s sometimes beat Helen. Her mother threatened to send her to a children’s home if she told anyone.

The trauma and pressure took its toll early, with Helen attempting suicide as a child as well as self-harming.

In this context, Helen learnt to neglect her own emotional needs to take care of others. This became a habit that she continued into her adult life. This way of living ultimately led to her current mental conditions. She was never taught healthy ways to deal with her situation and never had any support.

It seems like the ultimate kick in the teeth that this quality that enabled her to help her family for so many years now sees her burdened by mental health issues.

Her story shows the cost to many people who are carers for family members with a mental health problem, especially child carers.

Helen does not live with her mother or brother now. However, she continually checks on her mother, who frequently suffers from psychosis. She also helps her brother when he is not in prison.

Helen met her former husband at 17. He was very committed to family and an ordered home life. When they married, he sought to insulate their household against the erratic behaviour of Helen’s mother and brother by limiting her contact with them.

“My husband gave me very defined limits on my involvement with my family and their access to my daughters,” Helen said.

“It was my escape from a really difficult situation.

“It gave me a lot of security and a sense of balance but it didn’t take away the toxic guilt and shame,” she said.

While her husband may have had the best intentions in establishing boundaries, the emotional pull for Helen to play the role of carer was stronger. She started to once again place herself under immense pressure to take care of her mother and brother while pretending to stay within the limitations her husband had set.

**“Finding out that I have a disorder has been really bad and really good.”**

At one point, her brother asked her to help him take care of his child who had inherited his drug addiction.

“So I would do all of those kinds of things for my brother, go and pick him up, drag him out of bed, drag him to court, sit there all day, race home to pick up my kids from primary school to get home to cook dinner, then go to work that night,” she said.

Under this strain the marriage eventually fell apart in a nasty split. In the aftermath, Helen started to see a psychologist, who referred her to the group therapy sessions at Wesley Hospital Ashfield, which she has found very helpful.

Helen is happy with the progress she is making but wrestles with her evolving understanding of herself—and of her relationship with her family.

“Finding out that I have a disorder has been really bad and really good,” she said. “Bad in the sense that it crumbled my façade. I thought I was the normal one.”

## Chapter 6:

# Implications for policy

- **Wesley Mission acknowledges that relatives, in addition to the primary caregiver, also require support**
- **Wesley Mission calls for a cohesive, proactive approach among health services, GPs, and schools**
- **Wesley Mission calls for all services involved with carers to acknowledge their different needs**





## Chapter 6: Implications for policy

**This report acknowledges the current work on policy by the mental health and carer sectors at both state and federal levels, in particular the National Carer Strategy<sup>1</sup> developed by the Federal Government.**

The recommendations below result from discussion with several bodies including the Association of Relatives And Friends of the Mentally Ill NSW, Australian Institute of Family Studies, Carers NSW, Inspire Foundation, Mental Health Co-ordination Council, NSW Institute of Psychiatry, NSW Police Force Mental Health Intervention Team, University of New South Wales—School of Public Health and Community Medicine and University of Sydney—School of Public Health.

### Need for earlier intervention

A high percentage of those exposed to caregiving before 16 go on to care for an extended period of time (around one third care for more than 10 years), with length of exposure being a critical factor in the degree of impact on most elements measured. There may be a need to refine caregiver identification strategies and provide more funded early intervention options to reduce the impact on education, stigma and the emotional/social impact of caregiving.

### Recommendations

Acknowledging the work already done at both federal and state levels in formulating policy to improve information-sharing among relevant carer services, Wesley Mission calls for a cohesive, proactive approach among health services, GPs and schools in identifying young carers and ensuring that their needs are met through referrals to relevant services, support and advice. Wesley Mission commends the Fourth National Mental Health Plan<sup>2</sup> for recommending the expansion of support services and tailored mental health responses.

### Involve schools in education about caregiving

It is critical to raise awareness among teachers, school counsellors and parents about caregiver experiences and support options.

### Recommendations

Wesley Mission recommends that it be mandatory for teachers to be provided with an understanding of presenting issues for children or young people who may be caregivers.

### Improve professional education

Provide GPs, social workers, psychologists and other allied health professionals with greater exposure to and understanding of the role of relatives in caregiving and the impact this has.

### Recommendations

Wesley Mission recommends that professionals are not only informed about the experiences of the patient but also about the experiences of the family in the caring role. This could be implemented in the workplace and during the tertiary training of health, teaching and allied professionals, by ensuring a working understanding of appropriate responses.

<sup>1</sup> Department of Families, Housing, Community Services and Indigenous Affairs (2011). *National Carer Strategy*. Viewed 28 February 2012, [http://www.fahcsia.gov.au/sa/carers/pubs/national\\_carer\\_strategy/Pages/default.aspx](http://www.fahcsia.gov.au/sa/carers/pubs/national_carer_strategy/Pages/default.aspx)

<sup>2</sup> Department of Health and Ageing (2009). *Fourth national mental health plan: an agenda for collaborative government action in mental health 2009-2014*. Viewed 28 February 2012, <http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-f-plan09>

**Wesley Mission recommends that it be**  
mandatory for teachers to be provided with an  
understanding of presenting issues for children  
or young people who may be caregivers.



### Recognise that relatives need help too

In addition to the primary caregiver, other relatives of those with a mental health issue also need help with coping. This is a critical step in implementing a more holistic, integrated care system.

#### Recommendations

Wesley Mission has highlighted in this research that relatives, in addition to the primary caregiver, also require support when caring for a family member with a mental health issue. Frontline service providers should be aware of family and carer needs as they treat a person with a mental health issue and facilitate appropriate support and responses.

### Increase emergency intervention services for caregivers

More emergency respite is vital, given the fluid nature of mental health problems (where long periods of relative calm are punctuated by periods of intense stress). This is different from intervention for caregivers of those with a physical disability where stress levels are more uniform.

#### Recommendations

Wesley Mission recognises the Federal National Carer Strategy's acknowledgement that "support for carers should be timely, responsive, appropriate and accessible". Wesley Mission asks both state and federal governments to ensure the capacity of intervention and respite services so that all carers have access to visible and culturally appropriate support when it is needed.

### Recognise different needs among caregivers

Not all caregivers are the same and solutions and approaches need to be tailored to their differing needs. There may be a need to re-focus on young caregivers specifically and to build the evidence base about best practice approaches for this group.

#### Recommendations

Wesley Mission supports the Federal Government's policy to "provide a range of flexible respite and support options for carers" and calls for all services involved with carers to acknowledge their differing needs for financial support, respite and advice. The Fourth National Mental Health Plan (p32) calls for "tailored mental health care responses for highly vulnerable children and young people who have experienced physical, sexual or emotional abuse, or other trauma".

**“What you can do is be there to support your loved one, encourage and show them that you love them. The only exception is when the situation becomes abusive, you must leave for your own safety and try to organise some intervention from professionals.”**



## Improve cross-sector linkage

A more integrated social care system was seen as critical in making service access easier for caregivers. This linkage was seen to go beyond government-provided health care services and to include a need for greater collaboration between volunteer and community-based organisations. This starts with awareness within the health care/community care system of the services available to caregivers and the benefits of caregivers accessing these services.

## Improve links between the mental health system and other services

This is particularly relevant when addressing the relationship between domestic violence and mental health problems where issues may first be noticed by family counselling or drug and alcohol services.

### Recommendations

Wesley Mission supports plans for greater cross-centre information sharing to provide more effective care for both caregivers and those in their care. Steps have already been taken at the federal level in the National Carer Strategy to create policy around frontline information and service links. The Fourth National Mental Health Plan calls for “targeted prevention and early intervention programs for children and their families through partnerships between mental health, maternal and child health services, schools and other related organisations”. Wesley Mission calls for such an action plan to expand beyond the government sector to include an integrated and collaborative approach including both the government and non-government sectors.

Wesley Mission calls for more proactive sharing of information to ensure that services for the person with a mental health issue are communicating both with the caregivers and any services they engage.

Mental health services and information should be part of the government “hub” strategy of drawing together services in one centre. Not only should Medicare, Centrelink and Human Services be co-located but integrated with local community and allied health services. Young caregivers are often reluctant to tell their story many times to different providers. The sharing of information and the co-location of services under one roof reduces the prevalence of this problem, allowing for better client outcomes, delivery, cost efficiencies and avoidance of duplication.

## Educating caregivers about their rights

Some caregivers may deliberately not be seeking advice and support because of the potential impact on government benefits they receive. They may also be unaware of their rights and options and see caregiving as axiomatic: something that anyone would do. Educating caregivers about their legal rights and financial assistance options is a first step towards facilitating easier access to the health care and support system and allaying their fears, making the seeking of assistance seem “normal”.

### Recommendations

Wesley Mission recognises through this report that carers may not necessarily know where to get help or find out about their entitlements.

Wesley Mission calls for relevant services to ensure that carers are directed to relevant information hubs where they can have access to information on available services, and through easily accessible and relevant web-based information.

# Appendices

**Quantitative research involved a national online survey of 1,002 caregivers across Australia who completed a questionnaire in November/December 2011.**

**In order to be included in the study, all respondents had to:**

- have an immediate relative/partner with a mental health issue, either at the time the questionnaire was completed or prior to completion**
- report that their life had been affected by the relative/partner's mental health issue to some degree**



# Appendix A: Questionnaire

## Section A: Family experience with mental health issues

The first set of questions are about you and your relatives—please remember that your responses to this questionnaire are confidential.

**SQ1.** Firstly, can you tell me which of the following age brackets you fall into?

Please tick one box.

<input type="checkbox"/> 1	18–24 years
<input type="checkbox"/> 2	25–34 years
<input type="checkbox"/> 3	35–44 years
<input type="checkbox"/> 4	45–54 years
<input type="checkbox"/> 5	55–64 years
<input type="checkbox"/> 6	65+ years
<input type="checkbox"/> 7	Prefer not to say

**A1.** Do any of your relatives (including step-family and family-in-law) currently suffer or previously/ever suffered from a mental health issue?

A mental health issue could include things like problems with depression and anxiety, illnesses such as schizophrenia or bipolar disorder, conditions including bulimia and anorexia as well as addictions to drugs and alcohol that may or may not have been diagnosed.

<input type="checkbox"/> 1	Yes—one or more of my relatives currently suffers from a mental health issue
<input type="checkbox"/> 2	Yes—one or more of my relatives previously suffered from a mental health issue
<input type="checkbox"/> 3	No—none of my relatives have had a mental health issue

**[IF CODE 3 TO A1 (NO RELATIVE WITH A CURRENT OR PREVIOUS MENTAL HEALTH ISSUE) —THANK AND CLOSE]**

**A2.** And is this relative your ...

Please tick one box for each relative who has suffered a mental health issue.

<input type="checkbox"/> 1	Mother	<input type="checkbox"/> 11	Wife
<input type="checkbox"/> 2	Father	<input type="checkbox"/> 12	Former wife
<input type="checkbox"/> 3	Sister	<input type="checkbox"/> 13	Husband
<input type="checkbox"/> 4	Brother	<input type="checkbox"/> 14	Former husband
<input type="checkbox"/> 5	Daughter	<input type="checkbox"/> 15	Partner
<input type="checkbox"/> 6	Son	<input type="checkbox"/> 16	Former partner
<input type="checkbox"/> 7	Grandmother	<input type="checkbox"/> 17	Step-sister/ sister-in-law
<input type="checkbox"/> 8	Grandfather	<input type="checkbox"/> 18	Step-brother/ brother-in-law
<input type="checkbox"/> 9	Granddaughter	<input type="checkbox"/> 19	Step-daughter
<input type="checkbox"/> 10	Grandson	<input type="checkbox"/> 20	Step-son
		<input type="checkbox"/> 22	Another relative

**A2a.** Were you under the age of 16 years when you first became aware of your relative/s mental health issue?

Please tick one box.

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

**A3.** Thinking about this relative/these relatives, did their mental health issue ...

Please tick one box.

<input type="checkbox"/> 1	Affect your life a lot
<input type="checkbox"/> 2	Have some effect on your life
<input type="checkbox"/> 3	Have a little effect on your life
<input type="checkbox"/> 4	Have no effect on your life

**[IF CODE 4 TO A3 THANK AND CLOSE]**

**IF MORE THAN 1 RELATIVE AT A2 PLEASE READ A4—ELSE SKIP TO A5**

**A4.** From this point forward, we want you to answer the questions thinking only about the relative whose mental health issue had the most impact on your life. Was this your ...

Please tick one box for each relative who has suffered a mental health issue.

<input type="checkbox"/> 1 Mother	<input type="checkbox"/> 11 Wife
<input type="checkbox"/> 2 Father	<input type="checkbox"/> 12 Former wife
<input type="checkbox"/> 3 Sister	<input type="checkbox"/> 13 Husband
<input type="checkbox"/> 4 Brother	<input type="checkbox"/> 14 Former husband
<input type="checkbox"/> 5 Daughter	<input type="checkbox"/> 15 Partner
<input type="checkbox"/> 6 Son	<input type="checkbox"/> 16 Former partner
<input type="checkbox"/> 7 Grandmother	<input type="checkbox"/> 17 Step-sister/ sister-in-law
<input type="checkbox"/> 8 Grandfather	<input type="checkbox"/> 18 Step-brother/ brother-in-law
<input type="checkbox"/> 9 Granddaughter	<input type="checkbox"/> 19 Step-daughter
<input type="checkbox"/> 10 Grandson	<input type="checkbox"/> 20 Step-son
	<input type="checkbox"/> 22 Another relative

**[IF ONLY CODE 19 ONLY—THANK AND CLOSE]**

**A5.** What mental health issue does/did this relative suffer from?

Please tick all boxes that apply.

<input type="checkbox"/> 1 Depression
<input type="checkbox"/> 2 Anxiety or stress-related illnesses (including Post Traumatic Stress Disorder)
<input type="checkbox"/> 3 Eating disorders (eg anorexia nervosa, bulimia)
<input type="checkbox"/> 4 Schizophrenia
<input type="checkbox"/> 5 Bipolar disorder (manic depression)
<input type="checkbox"/> 6 Obsessive-compulsive disorder
<input type="checkbox"/> 7 Personality disorders
<input type="checkbox"/> 8 Drug and/or alcohol abuse
<input type="checkbox"/> 9 Something else _____ (RECORD)

**A6.** And would you say that you are/were this relative's primary carer (i.e. the person responsible for their care most of the time)?

Please tick one box.

<input type="checkbox"/> 1 Yes
<input type="checkbox"/> 2 No
<input type="checkbox"/> 3 Not sure

**A7.** How long has your relative's mental health issue had an impact on your life?

Please tick one box.

<input type="checkbox"/> 1 Less than 1 year
<input type="checkbox"/> 2 Between 1 and 5 years
<input type="checkbox"/> 3 Between 6 and 10 years
<input type="checkbox"/> 4 More than 10 years
<input type="checkbox"/> 5 Don't know/can't remember

**A8.** Were these mental health issue(s) formally diagnosed by a health professional such as a GP, psychologist or other mental health professional?

Please tick one box.

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

**A9.** Did/does this relative mainly ...

Please tick one box.

<input type="checkbox"/> 1 Live with you
<input type="checkbox"/> 2 Live in another household
<input type="checkbox"/> 3 Live in supported accommodation (assisted living or aged care)
<input type="checkbox"/> 4 Live alone
<input type="checkbox"/> 5 Move between residences and locations
<input type="checkbox"/> 6 On the streets (homeless)
<input type="checkbox"/> 7 Live somewhere else

**A9a.** And which of the following age categories does this relative fall into ...

Please tick one box.

<input type="checkbox"/> 1 Under 18 years of age
<input type="checkbox"/> 2 18–24 years of age
<input type="checkbox"/> 3 25–45 years of age
<input type="checkbox"/> 4 55–65 years of age
<input type="checkbox"/> 5 Older than 65 years
<input type="checkbox"/> 6 Don't know/prefer not to say

## Appendix A: Questionnaire

### Section B: Impact

The next questions are about how your relative who has a mental health issue has impacted your life.

**B1.** When you think about that relative with a mental health issue, how much impact have they had on ...

Please use a scale of 1–4, where 1 is no impact and 4 is a very large impact.

Please tick one box per row.

	No impact at all	A little impact	A large impact	A very large impact	Unsure
Your life overall	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Your finances	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Your physical health	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Your mental health	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Your employment situation and ability to work	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Your education situation and ability to study	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Your ability to achieve what you want to achieve	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Your relationships with other family members	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Your relationships with friends	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Your ability to enjoy yourself	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Your ability to feel part of the community	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Your childhood/growing up	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

**IF CODE 2–4 AT B1a (LIFE GENERALLY) ASK B2a—ELSE SKIP TO B2b**

**B2a.** Thinking about the impact on your life overall ... If you feel comfortable, please tell us how being involved with or caring for this relative had an impact on you.

OPEN

Prefer not to answer this question  1

**B2b.** Thinking about the impact on your mental and physical health, has/did being involved with or caring for this relative, lead you to ...

ONE RESPONSE PER ROW

	Yes	No
Feel downhearted and blue	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Feel agitated or find it hard to wind down and relax	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Be less patient with others around you	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Feel like you had nothing to look forward to	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Feel guilty—as if you were somehow responsible for the issue	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Feel unhealthy, unfit and uncomfortable	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Develop/exacerbate a physical condition or injury	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Start to take medication/increase the dosage of medicines that you may be taking	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Drink more alcohol	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Be affected physically or mentally in another way	(Specify)	

**IF CODE 2–4 AT B1b OR B1e OR B1f (FINANCE OR EMPLOYMENT OR EDUCATION)**

**ASK B2c—ELSE SKIP TO B2d**

**B2c.** Thinking about the impact on your finances, employment or education, has/did being involved with or caring for this relative, lead you to ...

ONE RESPONSE PER ROW

	Yes	No
Reduce the number of hours you are able to work/study	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Give up a job/give up study or education	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Take a job with less responsibility	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Take a job with a lower salary	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Take on additional employment for the additional money	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Eat into your savings	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Sell assets or possessions	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Rely on government benefits	<input type="checkbox"/> 1	<input type="checkbox"/> 2
To be affected financially, with work or study, or in another way	(Specify)	

**B2d.** Thinking about the impact on your relationships has/did being involved with or caring for this relative lead to ...

	Yes	No
Less contact with your friends	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Family breakdown	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Family violence	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Affects on your relationships or the things you can do in another way	(Specify)	

## Appendix A: Questionnaire

### Section C: Seeking help and the use of services

The next questions are about some of the services that you may have used.

**C1a.** As a result of your experiences with the relative with a mental health issue, have you ever used any of the services listed below to help you?

**C1b.** And was this service provided by ...

Please tick one box per row.

	C1a		C1b				
	Yes	No	A church/ religious organisation	Another type of volunteer/ community/ educational organisation	A private agency	A government agency	Somewhere else
Respite services (to give you a break)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Support groups on the internet	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Counselling or psychological services to help you cope	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Support groups where you meet face-to-face	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Help with household tasks like cleaning and gardening	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Help to complete legal or government forms	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

**C2.** How much do you agree or disagree with the following statements?

Please tick one box per row.

	Disagree strongly	Disagree	Neither	Agree	Agree strongly	Don't know/ not sure
You know where to go to get information and advice about mental health issues	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
You know where to go to get support in relation to mental health issues	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
There are appropriate support services available for relatives of those who have a mental health issue	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
You are or have been afraid to ask for the help that you may need from support services	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Support services for relatives are easy to access	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6

**C3.** As a result of your experiences with a relative with a mental health issue, have you had any contact with mental health services — for example, assisting your relative with counselling services, assessment services, visits to medical/psychological professionals and experience of health services more generally?

Please tick one box.

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

**C4. How much do you agree or disagree with the following statements?**

Please tick one box per row.

	Disagree strongly	Disagree	Neither	Agree	Agree strongly	Don't know/not sure
Mental health services listen to the relatives of those with mental health issues	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Mental health services are able to clearly explain the condition and its implications for family members	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Mental health services understand the role that extended family members play in their relative's lives	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Mental health services are open with and involve relatives of those with mental health issues	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Mental health services provide you with the information and support to help care for those with a mental health issue	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Mental health services provide you with the information and support to help you cope with the stresses of having a relative with a mental health issue	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6

**C5. And what three words would you use to describe your experiences of mental health services?**

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## Appendix A: Questionnaire

### Section D: Stigma and coping

The next questions are about how you cope with having a relative with a mental health issue.

**D1.** To help you cope with the experience of caring for and being involved with a relative with a mental health issue, have you ...

Please tick one box per row.

	Yes	No	Don't know/ not sure
Talked to other family members and friends about your experiences	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Taken up exercising or meditation	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Sought professional help	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Tried distracting yourself—with things like household chores, study or work	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Simply decided to take one day at a time	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Sought strength from a religious faith	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Applied your previous experience and knowledge to the situation	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Tried to look on the positive side of the situation	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Avoided discussions about the issue	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Avoided contact with the relative	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Pretended to others that everything is OK	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

**D1a.** And have you done anything else to help you cope?

(Verbatim)

**D2.** Some people have indicated that they have faced stigma and discrimination as a result of their relative's mental health issues.

How much do you agree or disagree that the stigma you have experienced about your relative's mental health issue has ...

Please tick one box per row.

	Disagree strongly	Disagree	Neither	Agree	Agree strongly	Don't know/ not sure
Had an impact on you personally	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Had an impact on your immediate family more broadly	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Hindered your relative's wellbeing	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6

## Section E: Demographics

Before we finish, just a few more quick questions about you and your household—this is just to make sure we have a good cross-section of households from across Australia. Your answers cannot be used to identify you in any way.

**E1.** What is the postcode where you live?

**E2.** What is the highest level of education you have completed?

- 1 No formal schooling
- 2 Primary school
- 3 Some secondary school
- 4 Completed secondary school (HSC, Leaving Certificate, etc)
- 5 Trade or technical qualification (eg TAFE)
- 6 Undergraduate university diploma/degree or equivalent
- 7 Postgraduate university diploma/degree or equivalent

**E3.** Is English the only language spoken at home?

- 1 Yes
- 2 No (specify):

**E4a.** Do you currently have private health insurance?

- 1 Yes
- 2 No

**E4b.** Do you currently receive any government pensions or allowances as part of a caring role for your relative? (All answers are confidential.)

- 1 Yes
- 2 No
- 3 Prefer not to say

**E5.** Which of the following best describes your household situation?

- 1 Live alone — **GO TO E7**
- 2 Live with a spouse or partner, no children — **GO TO E7**
- 3 Live with a spouse or partner, with children
- 4 Live with other family members
- 5 Live in a group or shared household

**E5a.** Are there any children aged under 18 living with you? (If yes) How many?

- 1 Yes
- 2 No
- 3 Prefer not to say

**E6.** Do you have a religious faith?

- 1 Christian
- 2 Catholic
- 3 Muslim
- 4 Hindu
- 5 Other (specify):

**E6a.** How would you describe your faith?

**E7.** What is your approximate total annual household income before tax?

- 1 Less than \$20,000
- 2 Between \$20,000 and \$35,000
- 3 Between \$35,000 and \$50,000
- 4 Between \$50,000 and \$70,000
- 5 Between \$70,000 and \$100,000
- 6 Between \$100,000 and \$150,000
- 7 Between \$150,000 and \$200,000
- 8 More than \$200,000
- 9 Prefer not to say
- 10 Don't know



## **More services mean better outcomes**

**This Wesley Report focuses on the help we provide to carers of a family member with a mental health problem, acknowledging that mental health problems affect more than just the individual. That's why Wesley Mission looks for comprehensive solutions that address the family needs and provides services to match.**

## Help keep minds well

**Wesley Mission provides a range of respite and mental health services for both carers and the people they are caring for.**

### Respite services

Caring for someone with a mental health issue can be tremendously challenging, both physically and emotionally. By providing a break, respite care enables carers to sustain their ongoing responsibilities, and look after their own emotional wellbeing.

Wesley Mission's in-home respite service provides short-term help with transport, shopping, showering and meal preparation, as well as providing companionship to both the carer and the person being cared for.

Carers can choose to take a break for a few hours a week or overnight.

Respite is also available at Wesley Mission's assisted living residential homes. The person being cared for might need a change of scenery, more companionship or additional support to recover and return to independent living.

In addition to respite services provided by Wesley Mission, Commonwealth Respite and Carelink Centres can also help carers navigate the broad range of services that provide in-home and external respite, plus support with travel.

### Psychological counselling services

Wesley Mission offers free or low-cost counselling services for individuals and families. Our counselling services work to improve mental health in the community and provide the resources to keep minds well.

Our psychologists can assist people:

- experiencing depression, anxiety or stress
- having trouble coping with life challenges, such as being a full-time carer
- wanting to improve their overall emotional wellbeing

This service is available at a number of locations in Sydney. Wesley Psychological Services normally charges clients a nominal amount over the Medicare rebate fee.

# Caring hurts

The caring can't stop but the damage to those caring can. Through comprehensive counselling and respite services Wesley Mission helps young carers manage their challenging roles and find hope on the other side.

**Please send your donation today**

**Fill in the coupon overleaf  
or call 1800 021 821.**





**Yes, I want to help keep minds well.**

I/We would like to give to the work of Wesley Mission

Title: (Rev/Dr/Mr/Mrs/Miss/Other) \_\_\_\_\_

First name: \_\_\_\_\_

Surname: \_\_\_\_\_

Company name: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_

Postcode: \_\_\_\_\_

Phone (work): \_\_\_\_\_

Mobile: \_\_\_\_\_

Email: \_\_\_\_\_

Amount: \$

I have enclosed my Cheque/Money Order  
(payable to Wesley Mission)

OR

Please charge my:

Visa  MasterCard  Amex  Diners

Card no.

Expiry date: \_\_\_\_\_ / \_\_\_\_\_

Name on card: \_\_\_\_\_

Signature: \_\_\_\_\_

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[Web. www.wesleymission.org.au/donate](http://www.wesleymission.org.au/donate)

[Email. appeals@wesleymission.org.au](mailto:appeals@wesleymission.org.au)

**Thank you.**

Donations of \$2 or more are tax-deductible.

Wesley Mission 220 Pitt St Sydney NSW 2000 ABN 57 996 964 406

Wesley Mission is a part of the Uniting Church in Australia.

**Help keep minds well**

**Lifeline**

Wesley Mission runs Lifeline Sydney and Sutherland which is an anonymous and confidential crisis telephone counselling service delivered by qualified volunteers who provide support and information 24/7.

Lifeline can be reached on **13 11 14**.

**Wesley Hospitals**

Wesley Hospital Ashfield and Wesley Hospital Kogarah provide expert in-patient and day patient care for people suffering and recovering from a range of psychiatric illnesses, including alcohol dependency, drug addiction, anxiety, depression, bipolar disorder, borderline personality disorder, psychosis and veterans' service-related trauma.

Both hospitals recognise that the support of carers is integral to recovery from mental health issues. A range of assistance is provided to carers, including support during the admission process and referral to other support networks and professional bodies.

**Wesley Mission helps hundreds of carers each year cope with the challenges of looking after their relatives.**

In 2011, we:

- responded to more than 6,500 phone calls from carers
- provided respite and other assistance to more than 770 carers, of whom more than half were new clients
- received more than 60 referrals from GPs
- answered more than 180 calls from medical practitioners seeking information and advice
- counselled more than 60 carers through our psychological services
- provided psychiatric treatment for carers' relatives at our hospitals at Ashfield and Kogarah

## **Help spread the word**

**Let others know about the plight of carers by tearing out this poster and displaying it in your workplace.**



# Caring hurts

No child should feel helpless, especially when caring for a parent with a mental health problem. Like their love, a child's care is never ending—but comes at a personal cost. Wesley Mission's respite care and counselling can give hope.

Give the gift of hope and donate today. Call 1800 021 821  
[www.wesleymission.org.au/donate](http://www.wesleymission.org.au/donate)







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