



**Carers' perspectives on caring:
A qualitative analysis of open-ended
responses to the
Carer Health and Wellbeing Index survey
2007**

Kate E. Holland

Consultant: Professor R. Warwick Blood

Faculty of Communication and International Studies

University of Canberra

3 March 2008

For

Carers Australia

Publisher: Carers Australia
Unit 1, 16 Napier Close
DEAKIN ACT 2600
Telephone: 02 6122 9900
Facsimile: 02 6122 9999
Email: caa@carersaustralia.com.au
Website: www.carersaustralia.com.au

Date: 3 March 2008

ISBN 978-0-9586916-9-7

© 2008 University of Canberra, Deakin University, Australian Unity and Carers Australia

This work is copyright and may not be reproduced either in whole or part without the prior written approval of Carers Australia.

Table of Contents

Executive Summary	i
1 Introduction.....	1
1.1 Aim	2
1.2 Review of some of the literature.....	2
2 Method.....	4
3 Findings: What is it like to be a carer?	6
3.1 Carers feel undervalued in society.....	7
3.2 Carers need access to quality respite	12
3.3 Becoming a carer is a life changing experience	19
3.3.1 New responsibilities and considerations	19
3.3.2 Additional expenses	22
3.3.3 Potential risks.....	23
3.3.4 Caring as life enriching	24
3.3.5 Caring as identity defining	25
3.4 The impact of caring on health and wellbeing	26
3.4.1 Being constantly on-call.....	27
3.4.2 Strain on family relationships.....	28
3.4.3 Loss and letting go	30
3.4.4 Isolation.....	35
3.4.5 Carers' wellbeing is a function of that of the care recipient.....	36
3.4.6 Anxieties about the future	38
3.5 Carers are frustrated with government bureaucracy	46
3.6 Other notable, but not so common, comments.....	49
4 Discussion.....	53
4.1 Limitations.....	56
4.2 Methodological considerations and future research	56
5 Conclusion	58
6 References.....	59

Executive Summary

This report is a supplement to *The Wellbeing of Australians – Carer Health and Wellbeing* published in October 2007. It is based on an analysis of carers' responses to Question 68 of the Carer Health and Wellbeing questionnaire, which asked people to provide additional comments about the experience of being a carer if they wished. More than 500 people took the opportunity to share their thoughts and feelings about what it is like to be a carer. This report identifies the common features of being a carer that were analysed in these submissions. In summary, carers:

- believe that the Carer Allowance is not enough
- believe that more respite services and facilities are desperately needed
- are frustrated about waiting lists and being unable to plan for respite
- would prefer no respite than substandard respite
- are concerned that there is a lack of suitable and supported accommodation available for a loved one when they can no longer accommodate their needs

In addition to, and as a consequence of, these aspects of being a carer, many carers:

- feel that they and the important work that they do is undervalued in society
- believe that the government is out of touch with their needs and the realities of their lives (both the carers and the people they care for)
- are financially insecure because of the sacrifices they make to be a carer and the additional expenses that it entails
- are time poor as a result of their caring role being “24/7”
- are highly anxious about the future of the person they care for and themselves
- put the needs of the person they care for ahead of their own, often to the detriment of their own health, wellbeing, lifestyle and other relationships
- want it to be recognised that caring is a full-time job for many carers

1 Introduction

The closest thing to understanding the experience of being a carer – apart from personal experience – is to read the stories and thoughts of carers themselves.

Qualitative, open-ended responses take us beneath the surface and provide invaluable data for shedding light on the ways in which people interpret and construct their lived experience, in this case, of being a carer. They allow us to gain an insight into what it is like to be a carer and to deepen our understanding of how the needs of carers could be better met. Carers' own words are used throughout the report to illustrate the issues they emphasised in their submissions and to convey a sense of what the life of a carer is like. Each submission is identified with a number and a brief description of the type of caring role the person has, when and where this information was provided.

Importantly, this report is primarily concerned with the experience of being a carer, lest readers become concerned that the experience of the care recipient is being neglected. The experience of people who require care is, of course, an important and vital area of research in its own right, as the Disabilities Movement has been arguing for years. Moreover, it must be acknowledged that depicting recipients of care, such as the elderly, disabled, terminally ill and people diagnosed with a mental illness, among others, as predominantly passive and in need is potentially harmful to these people and their self image (see Keith, 1992). It is thus acknowledged that the point of view of the recipient of care (sometimes described as the 'caree' by carers) is absent from this report. This is a potential limitation that could be alleviated by reading the report in conjunction with research with care recipients. It is also important that we recognise that being a carer and a recipient of care need not be mutually exclusive roles and that polarising their needs may be unhelpful and unproductive (Keith, 1992). Nonetheless, while many carers see themselves as proxy service users, their needs and values do not automatically accord with those of the person they care for. This is an extremely complex area and it is not the primary focus of this research. This report focuses on the lived experience of carers and, in that sense, it ought not to be seen in any way as a reflection on those for whom they care.

1.1 Aim

There were a number of interlocking themes to emerge in the additional comments people provided with the Carer Health and Wellbeing questionnaire. The primary aim of this report is to give voice to these and to provide a sense of what the experience of caring is like for some carers in Australia. The report does not aim to draw general conclusions about the experience of being a carer.

1.2 Review of some of the literature

Research into the experience of unpaid caregiving has been growing since the 1980s with the introduction of ‘community care’ policies in countries such as Britain and Australia. There is now a large body of research that sheds light on various aspects of the experience of being a carer. Most of these studies use qualitative methods, particularly interviews, and employ some variation of narrative, thematic or grounded theory analyses. In broad terms the research can be divided into that which focuses on the emotional and social impact of caring and that which examines the effectiveness of interventions to support carers. Needless to say, what follows is a brief summary that does not do justice to the diversity of caring research.

The scope of research in this area includes studies looking at: the emotional and social support needs of family carers (Chambers, Ryan & Connor, 2001); loneliness and depression among people who care for those with Alzheimer’s disease (Beeson, 2003); psychosocial interventions for carers of people with dementia (Pusey & Richards, 2001); caregivers’ experiences of support and non-support (Neufeld & Harrison, 2003; Stoltz, Willman & Udén, 2003; Wiles, 2003); interventions to help caregivers in cancer and palliative care (Harding & Higginson, 2003); the challenges faced by mothers of children with long-term care needs (Yantzi, Rosenberg & McKeever, 2006); carers and employment (Arksey, 2003; Yeandle, Bennett, Buckner, Shipton & Suokas, 2006); self-help groups for carers (Munn-Giddings & McVicar, 2006); the experience of daughters caring for dying parents (Read & Wuest, 2007); caring for older adults and caregiving purposes (Caron & Bowers, 2003); the experience of carers of a spouse with Multiple Sclerosis (Cheung & Hocking, 2004); and the meanings of respite to carers of seniors and children with learning disabilities (Chappell, Reid & Dow, 2001; Hartrey & Wells, 2003).

For the purposes of this report, it will suffice to identify some of the findings that are especially pertinent to the research at hand. The experience of people caring for senior relatives, particularly aging parents, is increasingly common, and Stoltz et al. (2006) sought to fill a gap in the research in this area by exploring the meaning of ‘support’ for these carers. They used narrative interviews in which participants were asked to narrate about their experiences of support as well as its absence. Of interest are the experiences of non support the researchers identified in carers’ narratives. In particular, family carers spoke about being forsaken, being unable to attract attention to their situation, being met with thoughtlessness, being anxious about deciding on future actions, being powerless in the face of a loved one’s suffering, feeling irreplaceable, being alone with responsibility, and being unappreciated by government or the person they cared for (Stoltz et al., 2006). While these findings relate to the narratives of people who care for seniors in their own homes, they are also consistent with the experiences of other types of carers, including many whose accounts are included in this report.

2 Method

The data upon which this report is based were obtained via the Carer Health and Wellbeing Index survey conducted by Carers Australia in partnership with Deakin University and Australian Unity. The survey was sent to carers around Australia and a report based on its findings was published in October 2007 – *The Wellbeing of Australians – Carer Health and Wellbeing*. This report did not address the final item on the questionnaire, which invited people to provide open-ended responses in the form of additional comments:

Open ended. If you have anything you would like to tell us about your caring experience, please attach a piece of paper with your comments.

This report is based on the comments that people provided in response to this invitation and is intended to be a qualitative supplement to the report. Given the present concern with seeing the world from the perspective of carers, this study makes realist assumptions about language and the link between what carers said and their experience of being a carer. It is important to acknowledge that there are more complex ways of addressing the data, but for the purposes of this report a descriptive approach is more amenable to attending to the large body of data generated by the open-ended survey question. This approach assumes that it is better to let the words of carers ‘speak for themselves’ than to attempt to reinterpret them and, inevitably, reframe them for the reader. People have, after all, taken time out of their busy lives to put their experiences and feelings into writing and the least this report can do is honour this.

In light of the large number of additional comments received, decisions about which excerpts to include in the report have been made with the aim of illustrating identified themes. All of the comments received, however, have informed the findings and discussion. Each submission was read and reread with the aim of identifying common features of the caring experience as described by carers. Excerpts that illustrated specific themes and relationships between themes were noted and are presented in verbatim form throughout the report in support of the thematic analysis. The not-so typical issues that people raised are also summarised but the primary focus is the

common features of the caring experience. No attempt was made to identify one dominant theme or topic in each submission because it is clear that they are interlocking – one aspect of the experience of being a carer feeds into another and so on and it would do a disservice to the complexity and intensity of the caring role to suggest otherwise.

People were not provided with any specific criteria for their responses (that being the nature of an open-ended question) and thus people's submissions touched on a range of different aspects of the experience of being a carer. Some people took a 'day in the life' approach while others took a more 'life story' approach. Some people took the opportunity to air their concerns and to identify some of the problems that non-profit organisations such as Carers Australia may wish to present to government and/or other bodies who are in a position to instigate change. Some also offered solutions to the problems identified. Needless to say, these submissions made for fascinating and highly engaging reading.

It is important in qualitative research to be upfront about the situational constraints that shape our inquiry and to acknowledge that the interpretations that we make are always value laden and never final (Denzin & Lincoln, 2000). As the principal data analyst, I must acknowledge that I am not a carer or a care recipient, or at least I do not consider myself to be in the usual sense of these terms. This has both advantages and disadvantages: On the one hand it means that I can approach the data with an open mind to the extent that, while I have preconceived ideas and assumptions about 'caring', I am able to distance myself from these for the purpose of entering the world of the carers who submitted responses. On the other hand, to the extent that the personal is inescapably political, I am unable to bring any expertise by experience to the analysis.

3 Findings: What is it like to be a carer?

The following section is structured in terms of themes that emerged from people's submissions. However, it must be acknowledged that these themes are not discrete and nor are they the only way of interpreting the data. Each aspect of being a carer needs to be understood in relation to the others and to the caring experience as a whole. The following two excerpts, for example, reflect some of the main themes that emerged in people's comments and that are discussed in this report:

Since caring for mum I have been diagnosed with high blood pressure, a heart condition and pre-diabetic. I am convinced this is because of the lack of understanding and genuine help available. My carer payment is a joke. I am on call 24/7 and my hourly rate is something like 0.2 cents. Paid carers (agency) who sleep over are paid \$30.07 a hour plus additional hourly costs for wakeups!...I'm paid just over \$200 a fortnight. You do the maths. Why is one type of carer regarded as an expert and paid accordingly, and the unpaid carer is viewed as loser and remunerated as such. That is why self-esteem is progressively ground down.

(ID 2591, carer of mother, no specifics)

My financial future is precarious! My health is precarious! I am tired of all the efforts I have put in every direction, to services and systems which should be supporting me to enable my son to get his education and myself to have more leisure time. Relationships are very difficult. I have a partner who lives 5 mins away, he tries to be supportive, but gets annoyed sometimes at the true lack of time we can spend together.

(ID 1153, carer of son with multiple physical disabilities)

The significance of these comments is that they illustrate the impossibility of being able to separate one aspect of being a carer from another. These excerpts aptly capture the many aspects of being a carer and the way in which they interact upon the uneasiness that many carers experience. They also capture the way in which carers make sense of their role as carers and the impact this has on their life. For the authors of these excerpts, the caring experience is constructed as a source of actual health problems and anxiety about health, which is not recognised, remunerated or supported

and, therefore, has a negative impact on their self esteem, financial security and relationships with others.

The description of the carer payment as “a joke” in the first excerpt directs us to one of the most common themes to emerge from the data - Carers feel undervalued by society for the work they do and, in turn, the money they save the government. It is through this lens that many of the other themes to emerge from people’s comments on the caring experience can be understood.

3.1 Carers feel undervalued in society

The common view among carers that they are insufficiently acknowledged and rewarded for the sacrifices they make to be a carer is aptly summarised in the following excerpt:

The main concerns I have centre round the lack of appropriate respite care, the cost of same and the financial insecurity that caring brings. Having to step away from one’s career and forfeit the security of superannuation as a result is a bitter pill to swallow when the CARERS PAYMENT is so inadequate & in no way reflects my worth as an individual doing a crucial task caring for two people & therefore saving the community much financial input.

(ID 1896, original caps, carer of husband for 15 years and son for 28 years, no specifics)

This same person also suggested that the current emphasis on depression and counselling issues is disguising the reality that carers are not being adequately recompensed for the work they do and the financial worry that comes with this. For many carers proof that they are undervalued is experienced in the form of the lack of appropriate respite services and financial assistance available to them. Another carer described the Carer Payment, which they say works out to be \$1.50 per hour, as a “National Disgrace” for which they hold the economic rationalism of the Howard government accountable.

The following excerpts shed further light on the ways in which carers work through the perception that they are not being fairly remunerated for the work they do:

Carer payment, even when combined with the carer allowance, is minisculely more than unemployment benefits, yet a job is being performed, usually nearly if not actually 24 hours per day, 7 days per week (which as a professional, would be well paid, with other benefits including, superannuation), with a huge degree of additional expenses...

(ID 3735, carer of aged husband who was also treated badly in an aged care facility)

There needs to be a whole different approach to the carer's "Wage". They need to [be] paid at (at the very least) an equivalent to a nurse's aid base wage. Because that is essentially what they do. Many have to do more than that and most have to be there 24/7.

(ID 21, full time carer for 10 years, no specifics)

On my current funding, I can purchase only about one weekend and one day of respite per quarter. During my working life, which finished when my son was born, as a registered nurse, I received an equivalent amount to the 24 hour rate just for being on call to come in to work for after hours operations when I worked as a theatre nurse – for doing nothing but being available! I feel incensed by this – it undervalues the contribution I make to the community as a full-time carer as well as undervaluing the vital work that my respite workers provide.

(ID 3482, carer of 14 year old autistic son)

What is clear from these comments is the taken-for-granted assumption of these carers that the caring role they perform is work and should therefore be recognised as such and rewarded accordingly by the government. It is significant also that in the final excerpt the carer makes a comparison between the hourly rate of pay received by some nurses for merely being on call and that which respite workers are paid. For this carer, this discrepancy is another example of the way in which caring work is devalued. As the authors of the first and second comments suggest, most family carers

are on call 24/7 and, unlike paid carers, they do not receive the financial rewards such as superannuation and yet they bear the added expenses associated with caring.

In the above excerpts there is a real sense that carers feel that they are being unfairly treated relative to the sacrifices they make and the additional expenses and responsibilities that come with being a carer. This sense of unfairness is also conveyed in the following comment in which there is an implicit link between lack of respite and being undervalued:

I feel that carers are under valued in the community & by governments. Give us a fair go. We need help, & respite too.

(ID 1601, carer, no specifics)

By far the most common sentiment expressed by carers was that they feel undervalued for the work they do. As the following excerpts show, carers used various analogies to emphasise their position in the social hierarchy:

Carers are the modern slaves of the 21st century.

(ID 1437, carer of two adult children, one with mental illness and one with severe to moderate physical and intellectual disabilities)

We are cheap labour when you look at it. The government need to wake up and look at us see what we do and pay us for it so we can live.

(ID 1667, carer of child, no specifics)

We are saving the government a lot of money and yet they do not help us, and anything we want we have to fight for and have to be treated like second class citizens especially with Centrelink.

(ID 1712, carer of grandchildren, no specifics)

We were once normal, happy people – just like you, with a bright future. Our only crime was to unknowingly give birth to a child with a disability. Then we became second class citizens overnight.

(ID 1119, carer of child with disability, no specifics)

These references to “modern day slaves”, “cheap labour” and “second class citizens” powerfully evoke the common view among carers that they are undervalued. This is consistent with the finding that carers believe that people see them as lesser beings, as having less status in society (Cheung & Hocking, 2004). The reference to “our only crime” in the final comment is also significant in the context of comments from other people that they felt like they were being punished for being carers, as the following excerpts show:

I have saved the government thousands of dollars by choosing to remain with my husband & son yet I feel I am penalised for doing so.

(ID 3362, carer of husband, who is blind and has epilepsy and depression, for 25 years and carer of son who has cerebral palsy for 24 years)

It would be easier not to have to be a carer. I could work have money & buy my kids things that other kids have or go to see a movie go an just buy a pair of shoes or a jumper when needed. We are given these kids to care for by god & then punished by the government for having them by just giving enough money to survive not live life to its full.

(ID 1667, carer of child, no specifics)

It is disturbing that some carers see themselves as so unappreciated that they feel as though they are being punished for, in the case of the last comment, having children that need more care than others. Nonetheless, perceptions such as these are unsurprising when a value is put on just how much carers may be saving the government and the community, as a carer does in the following comment:

Unless more funding is made available to people like me with high dependency people to care for, we will not be able to continue to care for our loved ones at home and instead it will cost the community 10 or 20 times as much in hospital/rest home care. It is utterly non-sensical and heart breaking.

(ID 1127, carer of high dependency person with illness and disabilities)

For some carers it was the sacrifices they had made to take on their caring role and the consequences this has had for their own health and wellbeing that added to their feeling of being undervalued. The following excerpts give a sense of this:

I strongly feel that carers don't get the recognition they deserve. I believe I have saved the Federal Government several million dollars in choosing to care for my husband at home to the detriment of my health.

(ID 3522, carer of husband after a major stroke)

I have saved the government & the public of Australia uncountable funds & effort to my detriment & what do I get from this a poultry amount & a bonus (ok it helps) but what about my individuality, pride, status, economic and health downfall. How do I get back into the community, find a partner. Not a lady I know or met want my excess baggage, parents or health problems.

(ID 1428, carer of aged parents up until 40 days ago)

The reference to individuality, pride and status in the second comment is significant because it is suggestive of the sacrifices that many carers make – not just economically but in terms of how they feel about and see themselves, and how they relate to the rest of the world. Moreover, as the author of the first excerpt says, caring can be detrimental to the carer's health. These issues are elaborated later in relation to health and wellbeing.

What is particularly apparent in the comments referred to thus far is the strong sense of bitterness and resentment carers express at not being given a 'fair go'. This is compounded by their feeling that by caring for a loved one they are doing the right thing by the government and society, not to mention the person they care for. In this sense, it is a slap in the face for carers to have the value of their caring work diminished by being inadequately remunerated or their Carer Allowance reduced because they have sought paid employment in order to keep themselves and their families afloat. As one carer said:

I feel very strongly that we are penalised heavily because they take the pension away if you work too much. My husband can't work and has no assets or savings neither do I. If I was to lose my job I would lose my house and car.

(ID 1841, carer of husband who is blind and deaf)

The Carer Allowance is certainly not enough to pay off a house and a car and account for other living expenses, let alone purchase respite, and so many carers have to work. However, their ability to do so is made increasingly difficult by not being able to access respite. It is little wonder that some carers feel that they are being punished and that carers as a whole are second-class citizens. It may well be that carers are being condemned, or at least channelled into, to lives of poverty – a process facilitated by the government system in its current form.

Many carers commented on being unable to access respite and/or having experienced inadequate respite. These kinds of experiences reinforce their view that they are undervalued by society and also contribute significantly to the emotions they experience in connection with their role as carers. As is evident in some of the comments already discussed, many carers describe their caring role as “24/7” and emphasise that caring is a full time job. However, unlike other full-time jobs, many carers struggle to access suitable respite. The consequences to carers of not being able to access respite are discussed later. But first what are carers’ concerns about respite?

3.2 Carers need access to quality respite

Carers referred to a shortage of respite services and hours, a need for more specialised respite facilities, long waiting lists and dissatisfaction with respite services when accessed. In relation to the previous theme, the following comment is explicit in its suggestion that the money carers are saving the government by caring for their loved ones in their own homes should be directed into funding for respite:

The other issue is respite availability. More beds need to be allocated as carers need regular breaks during the year in order to be able to keep looking after a loved one in their own home which, of course, is saving the

government thousands of dollars a year rather than having to fund more nursing home beds.

(ID 3001, carer of 82-year-old husband confined to a wheelchair due to loss of leg)

The importance of respite as described in this quote is to enable carers to have regular breaks so that they can continue to care for their loved one. The suggestion is that more short-term (eg. one week in a month) respite beds are needed rather than full-time nursing home beds. The underlying assumption is that it is more expensive for the government to fund nursing home beds than it would be to direct this money into forms of respite that enable carers to continue caring, and to continue to save the government money by doing so.

Some carers expressed concerns about the lack of available respite services and facilities to meet the specific needs of care recipients, as is shown in the following comments:

Our mother is high-care but after 2 unhappy experiences we believe there are not adequate facilities to cater for people such as Mum who need assistance with daily care but are not bed-ridden, ill and/or suffering dementia.

(ID 2502, carer of 91-year-old mother who is frail, osteoarthritic and incontinent)

Our daughter requires 24 hr help and mainly supervision and is assessed as 'high needs'. However, there are no respite facilities that would be **appropriate** for our daughter or for that matter any younger person with a severe disability.

(ID 1675, original bold, full time carer of wife who is a chronic migraine sufferer and 28-year-old daughter who suffered permanent ABI [Acquired Brain Injury] five years ago)

I feel there is a desperate need for more respite houses and trained staff especially men to deal with these people with challenging behaviours.

(ID 1265, original underline, carer of son with autism and who can self-harm)

It is clear from these excerpts that carers are particularly concerned that respite facilities are suited to the specific needs of the person they care for. For the author of the first comment appropriate respite means that facilities are able to accommodate the physical needs of an elderly person while respecting that they continue to be mentally alert and aware. For the author of the second it means that facilities are appropriate to the age of the care recipient. For the author of the final comment it means that facilities are equipped with staff who are able to deal with the particular behavioural challenges of the care recipient. There is no one size fits all when it comes to respite facilities and the care they provide and yet, as the author of the second excerpt says, the lack of appropriate facilities indicates the failure of federal and state governments to understand the true needs of disabled people and their carers.

Another concern for carers is the lack of respite hours they are allocated and the penalties that they incur if and when more respite is needed. This is illustrated in the following excerpts:

Respite care is limited to 63 days per year – the equivalent of 5.25 days per month – after which the carers payment is forfeited. This needs to increase to enable families, such as our own, to maintain a healthy sanity level.

(ID 2805, full time carer of child with a disability, no specifics)

Centrelink regulations regarding the time allowed per annum when a carer may be relieved of duty without financial penalty are not very reasonable. There is no provision for “time off” if a carer requires extended time owing to an operation or illness.

(ID 2799, carer of son with a disability – progressive and non-remitting MS)

As a carer of 14 years, I can see a vital need for the yearly respite allocation of days to be increased to relieve the build-up of “carers’ stress problems”.

(ID 3866, carer of husband after stroke)

These comments suggest another level at which carers feel that they are penalised for being carers. They also highlight the importance that carers attach to respite – it can

enable families to maintain healthy sanity levels, provide for carers to cater to their own health care needs, and relieve stress. As the following comment shows, access to respite can also enable people to engage in paid work while maintaining the quality of the care they provide:

Day respite has been essential for me to be even able to work part-time and working part-time is my time out. It has helped me survive caring on a long-term basis.

(ID 3655, carer of husband and mother, no specifics)

Research by Yantzi et al. (2006) with mothers of children with high support needs found that for some of them, like the author of the above comment, paid work was a type of respite that provided a break from their continuous and monotonous caregiving activities. Access to respite can also give carers the break they need to value more highly the traits of the people they care for, which often go unnoticed because of the pressure being experienced by the carer, as the following excerpts suggest:

I think people also often misunderstand what is needed and assume that we all need a break from our children. This is not the case. What is often needed is help with the endless chores so that we have the time and energy to enjoy being with our children.

(ID 2407, carer of autistic son)

The Carer role is quite taxing in and of itself. Anything that can be done to reduce the complexity of the support mechanisms used by carers (on behalf of those needing carer) will reduce the level of stress suffered by carers and allow them to devote more time to providing care.

(ID 3955, carer of elderly parents)

Opportunities for respite could also have the benefit of enabling recipients of care to gain a sense of independence and personhood in their own right. On the other hand, not having access to respite can have detrimental consequences for carers, as the following comment suggests:

I believe if I had continued to receive adequate respite support (which for me was one weekend per month – not an unreasonable request I believe), I would not be in my current situation, tired, burnt out, depressed and taking ever increasing amounts of anti-depressant medication that don't really work because what I really need is time out!

(ID 3482, carer of 14-year-old autistic son)

It is evident from the discussion thus far that carers place enormous value on appropriate and quality respite. Conversely, they are frustrated by some of the problems in relation to allocation, provision and quality of available respite. This is the focus of the following section.

The length of waiting lists for respite care is a source of frustration for carers. One carer used the notion of 'invisible queues' to explain their frustration in relation to the process of seeking respite and the impossibility of being able to plan respite. This makes it difficult for carers to make plans of their own, as the following comments show:

Would like to be able to put my wife in care when I want a break. Currently there is no place that when you ring up and want to place her in care, they always can't give you a date to bring her in. They say we will ring you and tell you to bring her in the next day. I can't plan for a break like that.

(ID 1910, carer of wife, no specifics)

It is also difficult to see how it serves the best interests of either the person to whom care is being given or the person providing the care. Neither can plan their lives other than by seizing opportunities that unexpectedly come up.

(ID 1191, carer of husband, no specifics)

It is extremely difficult for me to make any appointments for myself – my whole focus is centred around the wellbeing of my adult child and her child, with another due any day.

(ID 2587, carer of adult child with illness and grandchild, no specifics)

These comments highlight an apparent shortcoming in the systems in place to provide respite, one of the consequences of which is to leave carers and care recipients in the dark in regards to making plans in their life. As the author of the second excerpt suggests, it is difficult to see how the seemingly spontaneous nature of respite availability is in the best interests of the person being cared for or the carer.

The problem with respite services for some carers is that they do not cater to the needs of the person they care for. As an example, one carer reported that when inquiring about getting respite for her husband for a morning or afternoon she was told that he had to be able to go to the toilet by himself. As her husband has had a stroke and is unable to do this, she said:

It seems as though those that need respite most are those unable to get it.

(ID 2771, carer of husband who had stroke)

After describing the difficult process of applying for respite, the following comment illustrates the frustration experienced by a carer when respite services are unable to care in the way that is required:

Then you have the experience of receiving a respite package, fill out all the paperwork again to be then advised as your daughter requires Midazolam in the event of a seizure that 'sorry – we can't do your respite' unless you agree to them not administering Midazolam.. "By the way – if your daughter doesn't have Midazolam is that going to be a problem?" Yes – she will continue to fit. Sorry – no respite. Sometimes you wonder if it's worth applying for respite at all.

(ID 1058, carer of child with a disability from birth)

In this excerpt there is a sense in which no respite is better than poor quality respite or respite that does not meet the needs of the carer and the person in need of care. These findings are consistent with previous research identifying the limitations of respite (Wiles, 2003).

For other carers accessing respite is by no means a guarantee of receiving respite. Rather, what is meant to give them a break from caring actually increases their

anxiety. This anxiety is exacerbated for carers who have previously experienced inadequate respite, as the following comment suggests:

My wife has gone into respite, that is my wife being housed in a nursing home for a set amount of time – usually 2 weeks, on a few occasions. This service was meant to provide me with time out. However, I have found that it doesn't give me the stress free break that it's intended for. We have tried different nursing homes each time and on all occasions we have found that the services that are provided are just inadequate.

(ID no survey)

As a result of this experience, this 84-year-old war veteran says that he does not get much of a break from caring for his wife who suffered a massive stroke. If, as he suggests, available services are not run in the interests of people servicing them, neither the carer or the recipient of care are likely to receive any respite. Another carer wrote:

Having placed mum in respite on two occasions I can tell you that one worries if the person is being looked after well, is the place clean, are the staff kind and responsive, and that dominates one's thinking. So the notion of respite is purely theoretical, and generally, useless. Carers often don't use respite services because most are crap; you are meant to accept a lower standard of service, because that's all that is on offer.

(ID 2591, carer of mother, no specifics)

These comments reflect a desire to protect the self and the dignity of the person being cared for, which for many carers is their primary concern, and can also be seen in terms of resistance to the implied expectation that carers are so desperate that they would make do with substandard respite services for their loved one. In describing how her family had been profoundly affected by the mistreatment of her husband in an aged care facility one carer wrote:

Additionally, we now face the prospect that the moment I can no longer care for my husband, the care provider who will take over, will overly medicate him, to manage him. That is, will chemically restrain and thereby lessen

whatever capabilities he now has left, until the illness progresses further, and itself takes away what is left. I have been actually told this, in so many words.

(ID 3735, carer of husband with Alzheimer's who was mistreated in aged care facility)

What these excerpts show is that many carers have empirical evidence upon which their anxieties about using respite services are based. One or two bad experiences are enough to make people reluctant to leave a loved one in the care of another care provider, or to leave them with constant anxiety and feelings of guilt if and when they choose to. Similar anxieties result from respite carers not being adequately trained:

...I do come across a lot of stress when I do go away on respite. They send me people who are not trained to work with people who are physically and intellectually disabled in wheel chair. When I do go away for a break all I do is worry.

(ID 3927, no specifics)

What is significant about these comments is that they show that merely having access to respite is not enough, and may in fact do more harm than good to both carers and care recipients. While it is clear that access to *quality* respite is highly valued by carers, the availability of these services is far less clear and many carers who have been fortunate enough to access respite have been less than satisfied with its delivery.

3.3 Becoming a carer is a life changing experience

What we have established thus far is that many carers feel undervalued by society because they are inadequately remunerated for their work as carers, and also that they highly value access to quality respite that allows them to have an anxiety free break from caring and to engage in paid work if desired. These features of the caring experience and the excerpts that have been used to illustrate them are also suggestive of some of the more specific ways in which becoming a carer changes people's lives. This is the focus of the following section.

3.3.1 New responsibilities and considerations

People have to take on new responsibilities and take into account new considerations when they become a carer, as the following excerpt suggests:

Life before 'caring' seems like a distant memory. Since our 6 ½ year old son was diagnosed with moderate autism, we have travelled a rollercoaster of denial, frantic attempts to get services, dealing with a whole new world of specialists, astounded and bewildered at the inadequate support services and lack of funding dealing with all this whilst having to handle a household, work to get incomes, save for our unknown future and explain to people what was going on with us and our son.

(ID 3461, carer of child with autism)

This excerpt captures the particular new responsibilities that 'caring' brings with it as distinct from the equally 'new' responsibilities that come with becoming a parent. Becoming a carer brings with it new and often unexpected responsibilities and considerations or, as this carer says, "a whole new world". This excerpt conveys the sense of being overwhelmed by having to juggle each of the elements of this new changed world. It also highlights some of the things that do not help people in making the transition to being a carer, such as difficulty accessing services, inadequate services and lack of funding. This is all going on in the midst of seeking to adapt one's self to a new life and the grief that comes with the realisation that things will never be as they were. The author of the above comments went on to describe how the pressures of caring have resulted in both her and her husband being on antidepressants and her husband also on high blood pressure medication.

The following excerpt also highlights the many and varied responsibilities and considerations that being a carer entails:

I guess what I am saying is that not only do I have a huge carer role, which has changed my life, I have to deal with grief and loss, I am trying to cope with an illness within our family that receives virtually no validation or assistance, I am also trying to cope with government departments, the medical profession, expensive treatments and doubting/confused family and friends.

(ID 3587, carer of two adult children with CFS/ME and husband with Asperger's)

Many people experience grief and loss when they become carers. For this carer this is made all the more difficult because of the status of the illness of the care recipient. This comment also highlights the new responsibilities, considerations and relationships, such as with government departments and the medical profession, which people take on when they become carers.

Some carers commented on the lack of information available to them about support services upon becoming a carer. One suggested that there needs to be an accessible handbook on caring and that this would be preferable to training courses that bombarded people with large amounts of information in a short period of time. An 84-year-old war veteran commented on the lack of information and advice he was given when taking his wife home after she had a massive stroke:

What a shock I was in for. With no kitchen or cooking skills, no knowledge of how the washing machine or dryer operated and as for attending to my wife's hygienic needs – this was all a whole new category for me. What a mess it all became.

(ID, no survey, full-time carer of invalid wife)

As this comment shows, becoming a carer often means acquiring new skills such as household related duties, in addition to skills that pertain directly to the care needs of the person being cared for. The wife and carer of a husband who had a stroke also described the challenges of having to take on new responsibilities, such as household maintenance, dealing with health professionals and monitoring medication. This is a common experience for carers of all kinds.

The experience of being a carer, for many people, could be described as a struggle and this includes a struggle for services, for help, for respite – these things on top of the daily struggles that come with the practicalities of being a carer. This struggle with and against the system can also manifest itself in carers having to take on an advocacy role. This is often the case for parents of children of school age. As one person said:

I am so tired of fighting the system – education, council – for a fair go for my daughter. I don't consider my caring role as the main issue in my life. It is the advocacy and fighting for services that make it really hard.

(ID 7052, carer of child with a disability, no specifics, and ageing dad)

What is particularly significant about the excerpts in this section is that they undermine any perceptions that becoming a carer simply means learning about the care needs of the care recipient. It is clear that becoming a carer is far more complex. In addition to obtaining the skills to provide for the care needs of a loved one, some carers are also required to take on board duties that were previously the responsibility of the care recipient. Similarly, in addition to having to provide for the basic care needs of her child, for the carer of a child with a disability the bigger and more difficult issue is learning how to fight the system to ensure a 'fair go' for her child.

3.3.2 Additional expenses

Becoming a carer can also bring with it new and unexpected costs, which many carers struggle to meet and that can be a source of considerable anxiety. The following excerpt provides an insight into the added expenses and responsibilities associated with being a carer and it goes to the lack of financial assistance that people receive to manage these responsibilities:

Certainly the allowance of 90 odd dollars a fortnight only partly covers the costs involved in caring, by the time you take into consideration medications, extra washing, special diet, physio and other specialists, specialists' fees, costs of driving to appointments (time & petrol), parking fees, time spent at various Dr's appointments, implementing and following the programs, providing the specialised care, providing specialised equipment, the extra time and support that the person being cared for needs to achieve tasks, ensuring that the person has a good quality of life and is as comfortable as possible, this is all so much more than you need to do for the average child or adult in your care.

(ID 7098, carer of child, no specifics)

When one takes into account the additional costs associated with being a carer it adds weight to carers' claims that they are undervalued in society and also that the

government is out of touch with their needs. As the above passage suggests, the Carer Allowance does not go far in the face of the listed expenses. This carer also makes the important point that these expenses are not 'normal' and would not apply to the 'average' child or adult in receipt of care. Indeed, not all carers have the same expenses and this adds further weight to the view among carers that a one size fits all approach to financially assisting carers is inadequate.

The added expenses of being a carer include not only having to purchase special types of equipment that a loved one needs because of their disability, condition or illness. It can also relate to the fact that because many care recipients are house bound a lot of the time they use more power, as a carer of a child with a disability pointed out. There are also the costs associated with damage caused by people being cared for after they have had a violent outburst causing damage to property, which was the experience of one carer.

3.3.3 Potential risks

Caring can often also expose people to risks that they would not normally have been exposed to. One carer referred to some of the risks that are associated with caring for someone in your own home:

There are other ready risks of serious harm and injuries to a carer, which have potential for permanent disablement, not only through a violent person, but when heavy lifting or giving assistance is involved. Sole carers are disadvantaged by isolation, and hazards may be exacerbated if the plan and design of the home is unsuitable for a wheelchair, or movement on wet surfaces in the bathroom.

(ID 3476, elderly sole carer of a son with mental illness)

Some carers said that they were unable to afford the type of equipment and household adjustments that would make their caring duties safer to perform for both themselves and the person they care for. As the above comment suggests, being a carer can involve risks, particularly to physical health and wellbeing. It can also impact people's health and wellbeing in numerous other ways.

3.3.4 Caring as life enriching

One could be forgiven for thinking that being a carer is an entirely negative experience but some carers did refer to how being a carer had changed them and their lives for the better. While admitting that the caring was sapping their resources, one carer suggested that the survey did not reflect its positive aspects:

However, the driving force of my caring experience is the ability to make a difference to my disabled child. This is limitlessly rewarding, though intangible.

(ID 1132, carer of disabled son, no specifics)

As this person suggests, it is difficult to put a price or a value on the difference she makes to her disabled child's life. The following comments also reveal some of the positive aspects of being a carer:

A good point to make is that caring is not all bad – I've learnt a lot and met some wonderful people. I feel that I'm doing something really valuable that makes a genuine difference to my loved one.

(ID 1991, carer of husband disabled through chronic disease)

To provide so completely for another person is scary at times and really tough, yet it is also such a profound privilege. Knowing that someone's quality of life is so much the better just because you are helping them is a humbling thing.

(ID 7098, carer of child with disability, no specifics)

For these carers, as with the first, it is the difference that they are making to another person's life by caring for them that enriches their own lives. Being a carer can also be a valuable learning experience, as this comment from a mother concerned about her daughter's ability to lead an independent adult life suggests:

Personally, my carer role – unexpected as it was and sometimes devastating - has given me a better understanding of people and an appreciation of social justice.

(ID 3971, carer of adult daughter, no specifics)

Another person also reflected on the positive side of taking on new roles and responsibilities as a result of being a carer:

...as more is demanded of me I believe I have become a stronger and more mature person. I now do many things and take more responsibilities than I ever would have done had I still had a strong, healthy husband to rely on.

(ID 3757, carer of husband with Parkinson's Disease)

For other carers it was important to not be overwhelmed by self pity and to try and look on the bright side:

I am nearly always tired but have a good relationship still, with my husband for whom I am carer. The main thing is to rise above feeling sorry for myself at these times. There is still a lot of wonderful things in the world.

(ID 2077, carer of husband, no specifics)

Comments about the positive, life enriching aspects of caring were the exception, and most carers reflected on the struggle that it can be. This is by no means to generalise about carers views on what it is like to be a carer but it is to recognise that the majority of carers emphasised the difficulties they confront as carers. For many carers the reasons the above carers give for finding the caring experience enriching are those same reasons that they give as to why it is such a struggle. For example, the realisation that being a carer means providing so totally for another person can bring with it a profound sense of loss and isolation.

3.3.5 Caring as identity defining

Being a carer can also change people's lives in the way that it comes to define their identity. The following comments evoke the loss of self experienced by carers:

When do I get a chance to be a human being in my own right rather than strictly the parent of a child with a disability?!

(ID 1514, carer of son with disability)

It's been very hard on me emotionally & financially. My life has been overwhelmed at times with my role as carer. It defines who I am.

(ID 2869, former carer of father, mother, sister and niece, no specifics)

My social circle is limited to parents of *atypical* children. I feel disconnected from parents with *typical* children. I'm so sick and tired of hearing about disabilities. I thought I was more than just a mother of a disabled child. I wish I had spent more time laughing when I was young because I don't laugh that much anymore. My life is so full of 'should haves' these days.

(ID 7076, original italics, carer of 6-year-old son who has autism)

Caring for my children and supporting my husband has been all I can manage whilst trying to manage my health as well. I have no energy for a social life and have found also that I have very little to talk about other than my role at home. My friends and family do not understand.

(ID 3587, carer of 2 adult children with CFS/ME and a husband with Asperger's)

What is clear from these excerpts is the extent to which carers' lives come to revolve around those for whom they care. As the final comment suggests, this is exacerbated when a person is responsible for caring for more than one family member, which seems to be a common experience among carers.

The following section looks at some of the consequences of the life changing aspects of being a carer that have been identified thus far, with a particular emphasis on the impact that caring can have on people's health and wellbeing.

3.4 The impact of caring on health and wellbeing

Having to take on board new responsibilities and considerations while struggling to account for the additional expenses associated with caring can seriously impact the way carers see and experience the world, themselves, their families and those they care for. It can also significantly change people's expectations of the future and their financial wellbeing, not to mention their general sense of health and wellbeing, as is

evident in some of the comments already discussed. This section will elaborate these in more detail.

Some carers identified specific physical and psychological health problems. However, for the most part people described a more general malaise in relation to their lifestyle, self-worth and related matters. It is important that these not be reduced to simplistic diagnostic labels but, rather, that they be understood in the context of the changes to people's lives and lifestyles that becoming a carer can mean.

3.4.1 Being constantly on-call

Most of the features of being a carer that are discussed in this section can be understood as products of the 24/7 nature of being a carer. Many carers are on-call all the time. This is illustrated by the following comments:

I feel the thing which gets you down as a carer is the constancy of the situation. I go to bed every night listening for any call or movement and often wake thinking I have heard him call only to come to his room and find him sleeping soundly. When you wake in the morning you wake to the same routine every day even now when we have personal care help.

(ID 3821, carer of adult son, wheel-chair bound and with severe brain injury)

When the person I am caring for goes to hospital my job still goes on every day as I have to be there 24/7 as no one can communicate with the person I care for – not one hospital can get a full time interpreter to help with communication so I must stay there at all times.

(ID 681, full time carer for 19 years)

The constancy of the caring role, often owing to the inability to access respite, can also jeopardise a carer's ability to meet their own healthcare needs, as the following comment suggests:

My caring responsibility assumes my entire time – 24/7 I needed surgery & could not have it done as there was no-one to assume the caring role for the time required.

(ID 1154, carer of adult child, no specifics)

Many carers referred to neglecting their own health care needs as a consequence of the all-encompassing nature/reality of their caring role. A number of carers commented on their deteriorating health as a result of not having time to exercise. These aspects of being a carer relate back to a lack of respite and the lack of value attached to the role of carers in our community. It is not difficult to understand how having to be constantly on call can profoundly impact the wellbeing of carers and, for many carers, put a significant strain on their relationships with others.

3.4.2 Strain on family relationships

Problems with accessing respite when it is desired can add to the strain of being a couple who care for a disabled child, as the following excerpt shows:

We always have to ensure there is someone at home to take care of our son which means we don't do a lot of stuff together. We used to go for walks and ride our bikes on the weekend. There are few spontaneous outings – let's go out to dinner takes a bit of preparation. Holidays have to be well planned and if needed respite booked far in advance (this creates its own problems as respite agencies only book a couple of months in advance and if you are planning a holiday that you have to book a long time ahead, you don't know at the time if you can get respite!).

(ID 2375, carer of 19-year-old son with intellectual impairment and a mild motor dysfunction)

This comment accords with those discussed earlier from carers who are frustrated by the system of applying for and accessing respite. What it means for this couple is that they can no longer do the things they used to do – simple things like going for a walk or out to dinner, not to mention taking a holiday – because one of them always has to assume the responsibility of carer.

Many carers describe experiencing strains on their relationships, particularly their marriages, as a result of the all-consuming nature of being a carer. This is shown in the following excerpts:

Absolutely adore my child but having trouble coping. Haven't had a weeks holiday since 1989. Desperately need a couple of wks off to keep my sanity & my marriage.

(ID 3416, carer of adult child with profound disability)

Our marriage has suffered massively due to caring role – either my husband or I has to be responsible person for son's care – minimal time as a couple – over years relationship has all but dissolved – now relationship merely consists of being co-carers for our son.

(ID 3685, carer of 10-year-old son with cerebral palsy and who has severe physical disabilities)

For carers such as these it would seem that having some time off from their caring role is essential if their relationships are to be nurtured. This of course raises the problem of the availability and the adequacy of respite, which as we have seen is a major problem for carers. It is not just marriages that can suffer when one or both partners are responsible for caring for a child. Some carers expressed a sense of guilt about neglecting another child or children as a result of caring for another, as the following comments show:

I feel our second child, who is 20 years old, has missed out on a lot of things because of our daughter's disability. We did not have much time for him and to attend activities that he was interested in when younger.

(ID 279, carer of 23-year-old daughter with an intellectual disability)

It gets so hard 3 kids having to tell them they have to wait for shoes or a school jumper because you can't afford it this pay.

(ID 1667, carer of child, no specifics)

These comments are further examples of the way in which carers' lives come to revolve around the needs of the care recipient to the detriment of the carer's own identity, their relationships with others and their ability to meet the needs of other family members.

3.4.3 Loss and letting go

Loss is a recurring theme that emerged in carers' comments on the caring experience and its impact on their lives, as the following comment shows:

I do not feel any resentment for being 'given' my carers role or towards my child, but it has 'impacted' on all other areas of my life that are/were important to me, so I do feel 'loss'.

(ID 3517, carer of daughter, no specific)

Many people described a sense of regret about lost time and lost opportunities, a loss of self and a loss of freedom. One carer described how her husband's disability meant that they had been unable to travel and do the things they thought they would. Of this, she said:

So, I think it takes a special kind of person to carry on cheerfully despite the disappointment in the way life panned out.

(ID 1913, carer of husband with disability, no specifics)

For other carers having to care for an adult child means that their ability to take holidays is restricted:

We always wanted to be part of the 'gray nomads', and really see this country of ours. We could never go on long trips with Mike, it was too difficult, but it looks as if we will never be able to do it – but we continue to need and want a life of our own – be it just a short time.

(ID 2005, carers of 28-year-old son, no specifics)

As this carer laments, just because they recognise that they may never be able to, does not stop them from yearning for a "life of our own". For other carers, having to resign themselves to possibly never being able to travel or take holidays, as their peers are doing, is a source of resentment, which is captured in the following comment:

When I am in a group with seniors at gym & they talk about travel & holidays I resent the fact I have not had trips & under present circumstances never will.

(ID 3281, carer of disabled person for 11 years, no specifics)

For other carers the loss associated with being a carer, particularly when it is expected to be a lifetime responsibility, is felt on many levels:

I can't help but think at times how different my life could have been. I probably would have returned to full-time work once my children were old enough and we possibly might have had money saved but instead we have none. My husband and I had our children while we were still young and we had plans to travel but all that has changed now.

(ID 3377, carer of 14-year old son who is intellectually disabled with a form of epilepsy)

This comment reveals the way in which being a carer impacts on a person's ability to work full-time, which can in turn impact their ability to carry out the plans they once had for the future. The following excerpt, in which a wife refers to her husband's wasted university qualifications and reduced wage, also reveals the sense of loss that comes with having to make sacrifices with regards to one's career:

My husband has completely abandoned the career path he set for himself and all the university qualifications he has, to take up positions that enabled us to care for our son together. He enjoys his current job but is on a much lower pay scale that he was when my son was born. We don't talk about how this makes him feel...

(ID 2375, carer of 19-year-old son with intellectual impairment and mild motor dysfunction)

Her comment that they do not talk about how this makes him feel suggests that it may well be something that affects her husband's self worth and identity as a husband, father and provider. There is a similar sense of loss and disappointment in the following comment:

The biggest challenge I face as a carer is having to put my career on hold. After working so hard for six years, juggling the care of my own children, a part-time job, university studies (at which I excelled) and caring for my frail-

aged mother I am really disappointed that this caring role is basically excluding me from satisfying, part-time work in my chosen field.

(ID 2273, carer of elderly mother)

This comment captures the feeling of being let down after struggling to achieve things in one's life and then finding that the opportunities to use one's qualifications are restricted by the responsibilities of being a carer. This comment is also suggestive of the need for more flexible working conditions for carers.

A common feature of being a carer is the loss of paid employment and the benefits and opportunities that ensue from that, such as building friendships, networking, socialising, companionship, validation and praise, not to mention financial security and independence. The following excerpts shed light on the value that some carers place on paid employment:

I need to work for the social interaction as well as the sense of achievement and the extra cash never goes astray. ... I feel work is beneficial to gain the necessary skills to get a job when my caring role ends. It is very hard for a carer, after devoting their lives to caring to find a job to support themselves when the caring role ceases. There is not the opportunity to gain skills, make social contacts and save for the future.

(ID 3719, carer of husband, no specifics)

I would like to be out in the workforce not only to be so much better off financially (it's absolutely disgusting the pittance we are expected to live on) but for the social interaction.

(ID unreadable, carer of daughter, no specifics)

Being in paid employment has rewards that are not just monetary. Paid employment is a source of validation that one does not receive if and when they are being paid so little (a "pittance") as that of the Carer Allowance. In paid employment there is the possibility of being praised, thanked and otherwise rewarded for the work you do. This is not the experience of many carers, especially when the people they care for are unable intellectually/cognitively to appreciate the care and support they are receiving. Being unable to participate in paid employment and enjoy its numerous benefits can

lead to loss of self esteem, which in turn can affect the way in which people see themselves as carers and the quality of the care they provide, as the following comment implies:

I am now in my ninth year of caring and I am a different carer now than I was in the earlier stage of this unpaid career. I don't believe that I am as good a carer now because my original confidence which I had developed from my paid career has been depleted over time due to a lack of support and useful input.

(ID 3388, carer of sibling, no specifics)

This comment is significant in that it demonstrates the importance of a paid career for instilling confidence and, conversely, highlights the way in which this can dissipate over time in relation to the length of time that one has been a carer.

Not all carers experience the same kind of loss. Loss can depend very much on the stage in a person's life that they become a carer. However, it seems from the above comments that having to let go of plans and dreams is a common manifestation of loss among carers of all kinds.

The life of a carer is often strictly regimented, which can lead carers to experience a loss of spontaneity and freedom. The loss of being able to be carefree because of always having to be responsible can be a source of resentment for carers and, as the following comment shows, this feeling can lead to feelings of guilt:

I hate that I resent (sometimes) the intrusion his illness has had on my life, career & family. I know he can't help his condition & when I feel this way I am filled with guilt. I would just like to do things that other people do without having to think of the consequences my actions might have on my husband's well being. I'm sure that most carers feel the same – we get old before our time.

(ID 512, carer of husband who suffers post-traumatic stress disorder)

Even when carers receive some respite (eg. 10 hours per week), this time is accounted for and must be used economically, as the following comment highlights:

This is just a typical event in the life of a carer. Others take being able to get up and go where ever they wish, when ever they wish for granted, I have to plan with top precision everything I do out of the home, including the grocery shopping.

(ID 903, carer of 19-year-old daughter with Autism and Down Syndrome)

As this person suggests, being a carer can turn even the most mundane activities, such as doing the shopping, into an exercise to be planned and conducted with military precision. The following comments are further illustrations of the constantly on call, highly regimented life that some carers live:

I have to admit even though I wouldn't change my life there are days when I come home from work and wish I could just veg out, do something spontaneous or just be alone. When you are a carer you don't have that choice.

(ID 421, carer of daughter with an intellectual disability who is nonverbal)

I find my days are controlled by a timetable!!

(ID 1791, carer, no specifics)

There are times when I feel trapped and there is no end in sight.

(ID 1654, carer of husband with Type 1 diabetes)

Sometimes – and I think this must happen to all older ladies – I feel smothered and long to go on a holiday by myself.

(ID 2, carer of husband disabled after spinal operation)

It is significant that some of these carers yearn to be alone, to not have to be on call all the time, to be able to do things without always having to take another person into account. It is a clear reminder that many carers feel isolated within their caring role and often defined by it, as has already been discussed.

3.4.4 Isolation

Another common feature of being a carer is isolation. As the following comments show, this is closely associated with loss in the sense that it is common for people to lose touch with people who they had relationships with prior to becoming a carer, often because of the amount of time they have to devote to their caring role. The following comments give a sense of the isolation felt by many carers:

The caring consumes almost all my time. I feel isolated – I have no time to work on friendships – so friends I did have have moved on & I am no longer an integral part of their lives.

(ID 1154, carer of adult child, no specifics)

Not many ordinary people truly understand what it is like being locked up with a disabled person 24/7. So much of the time it is just her and me. It's just wonderful if someone drops in – for her and me – a chance to talk to someone other than each other.

(ID 2387, carer of daughter who is physically disabled and suffers mental issues, no specifics)

Some carers also described a feeling of aloneness and a yearning for contact with someone other than the person they care for, as in the second excerpt above. For other carers, isolation is more directly related to the characteristics of the people they care for, as in the following comments:

I feel very socially isolated as neither of the people I care for can converse in any meaningful way.

(ID 2658, carer of elderly mother and 29-year-old disabled son)

We have been isolated by his behaviour particularly myself and my daughter as people don't want anything to do with our family – only because they don't understand.

(ID 7127, carer of son who has autism)

The following excerpt evokes the isolation that a spouse can experience when facing life and its challenges while caring for a spouse whose disability limits their ability to provide support:

My husband's condition is dementia and this means that increasingly he is less able to provide personal support and understanding to me both in relation to his own condition and also in my concerns for some of our adult children who have serious health issues. Sometimes I feel rather isolated and alone because of this.

(ID 2619, carer of husband who has dementia)

As these comments show, isolation can take a variety of forms. For some people it is a product of not having the time and space to develop relationships. For others, such as the author of the above comment, it can be a result of the loss of meaningful communication and shared understanding brought about by a spouse's condition. The physical care needs of the person being cared for can also restrict the carer's ability to go certain places and enjoy kinds of activities that most of us take for granted, such as going shopping or to the movies. Difficulties accessing respite can exacerbate the loneliness experienced by carers because it also restricts the time and space available to them to live their own lives. This in turn feeds back into the loss of identity experienced by many carers.

3.4.5 Carers' wellbeing is a function of that of the care recipient

Just as a carer's identity comes to revolve around that of the care recipient, so too can their own health and wellbeing. It is common for carers to put the needs or the perceived needs of the person they care for ahead of their own, often because their own wellbeing is so intimately connected to that of the person they care for. In this sense, what hurts the care recipient hurts the carer. This can often take the form of grief, which is vividly captured in the following comment:

It is also difficult to manage the grief of losing my active and outgoing son to that of a bedridden invalid who has little social contact now with his friends as he is rarely able to go out.

(ID 1623, carer of son, no specifics)

The following excerpts are suggestive of the way in which carers' health and wellbeing is often dependent upon or intimately connected to the extent to which the needs of the person they care for are met:

I do not need respite as such but the instability of my son causes me continuous stress. More care for the disability or mental health person would give respite to their Carer anyway.

(ID 1615, 58-year-old son lives in residential care lodge, no specifics and not clear if person is a carer any longer)

My emotional wellbeing is attributed to my child's behaviour. When the behaviour is good, I don't feel that I have too many concerns. When the behaviour is not so good I become more negative.

(ID 2115, carer, no specifics)

I am a carer and my needs and those of others like me are extremely important. However, my needs, carers' needs, are not as important as the needs of my daughter and others receiving care and support. She is the one who gets the services (ie respite, day programs etc, transport) so hers are the PARAMOUNT needs. My needs run a very close second.

(ID 3971, original caps, carer of daughter, no specifics)

Carers often act, or do not act, out of a desire to protect the self of the person they care for, which can mean putting the needs of those they care for ahead of their own, even if this is potentially detrimental to their own sense of wellbeing. The following excerpt illustrates this point:

As yet, I have not made use of respite care. My daughter is very sensitive about the burden she thinks she is and to put her into respite care would destroy her. She would see it as me getting rid of her because she is a nuisance. Then she would react very violently.

(ID 2387, carer of daughter who is physically disabled and suffers some mental issues)

For this carer the reason for not seeking respite is to protect her daughter's self and, in turn, her relationship with her daughter. It is this same duty to protect that is evident in the comments of those carers who have had negative experiences with other people caring for their loved ones. From this perspective, one can understand a carer's decision not to seek respite even if it means that they neglect their own health needs. To an outsider this may seem difficult to understand but for carers, protecting the self of the person they care for may be even more important to their own health and sense of wellbeing.

From the discussion thus far it is clear that the health and wellbeing of carers is dependent on a range of factors, not least of which is the wellbeing of the person they care for. Another area in which this is evident is in comments from carers expressing anxieties about the future.

3.4.6 Anxieties about the future

Carers' anxieties manifest themselves at a variety of levels, each of which interacts with and upon the other. Anxieties about the future were a common feature in many people's comments on the caring experience and, as is vividly illustrated in the following excerpt, this can seriously impact on their wellbeing, particularly when a carer feels so totally and absolutely responsible for the needs of the person they care for:

I and a good number of my 'disabled' circle of mums often discuss the horrible 'choice' we might make one day...we do not want to leave our disabled loved ones here in this world without us. I am crying now because I know how shocking it is to say such a thing. I am a sane and rational person, not depressed or suicidal, or in danger of any self harm, just very stressed about the future.

(ID 3762, carer of disabled adult daughter and 85 year old mother)

This comment highlights the way in which carers come to see themselves as irreplaceable in the lives of those who they care for, which can exacerbate their anxieties about the future. Many carers are anxious about the future of the recipient of their care and their own futures, which are understandably difficult to separate as the above extract shows.

The following comment captures some of the elements of what this carer described as the “anxiety-centred” nature of being a carer:

There is the anxiety of “letting go” a vulnerable person into the community and letting them access public transport. There is the anxiety and humiliation of “begging” for employers to provide opportunities for work, even if on a volunteer basis. And, as both my adult-child and I age, there is overwhelming anxiety in finding/providing appropriate “independent” housing and support, well before I am past being able to care.

(ID 3447, original underline, carer of adult child, no specifics)

The final sentence in this excerpt reflects one of the most common kinds of anxieties expressed by carers – anxieties about what will happen when they are no longer able to care. The following comment also captures many of the anxieties carers feel about the future:

The future worries me so much...what will happen to my disabled adult...how to afford a ‘safe and happy’ life for her, where will she live, how can I afford her future, will I live long enough to do what I need to do, who will ‘care enough’???

(ID 3762, mother of disabled daughter, no specifics)

It was common for comments of this kind to illuminate the way in which a carer’s realisation of their own mortality influences their anxieties about the future of the person they care for. The emphasis given to “independent”, “safe and happy” and “care enough” in these comments also highlights the way in which carers are not merely worried about the availability of care in the future but the quality of the care on offer.

The following excerpts relate primarily to carers’ concerns about where a loved one will live in the future and, more specifically, the availability of appropriate accommodation:

My husband & I worry as to where our adult son will go to live if we both died or could not look after him anymore as we are coming up to retirement.

(ID 2286, carers of 35 year-old son with brain tumour, depression and epilepsy)

Our concern is the future welfare of our daughter when we can no longer care for her. We need supervised independent living accommodation. She is capable of living alone with supervision (essential).

(ID 2396, carer of daughter)

My biggest concern is the lack of fully supported accommodation for young-middle aged intellectually disabled adults. As we approach our 60s my husband and I are very worried as to who will look after our son when we are no longer able.

(ID 831, carer of adult child with an intellectual disability)

My husband and I are very positive about our life right now and feel that we will have a great future, however, one thing that worries me for the future is where my son will be living when he is older. I have heard many parents say that they had waited for 10 years or more before a placement in a group home is found.

(ID 3278, carer of son with Fragile X Syndrome)

As this final comment suggests, even for those parents who are able to express relatively positive feelings about the future, it is difficult to escape the inevitable anxieties about who will care, especially when they see the future flash before them in the form of the experiences of other carers.

Other carers' anxieties about who will care for their loved one in the future are more specifically related to being able to put plans for their care and accommodation in place while they are still able:

What happens to our son when I can no longer care for him? There is not enough group accommodation and seems to be no long term care plans in

place that we can tap into now, to ensure he is settled before his life is upturned by a change in our health or circumstances.

(ID 2375, carer of 19-year-old son with an intellectual impairment and mild motor dysfunction)

My main concern is I should be able to see my daughter settled before I go to the heavens!!

(ID 2329, 78-year-old carer of daughter, no specifics)

Other carers expressed a more general sense of anxiety about who will care, as in the following comments:

This is always a concern – “who will care for her when we are unable to?”

(ID 1965, cares for daughter no specifics)

As we approach our 60s my husband and I are very worried as to who will look after our son when we are no longer here.

(ID 831, mother of intellectually disabled adult son)

We are getting older and slower. We fear there will be a time when we will not be able to meet our daughter’s needs.

(ID 421, carers of daughter with an intellectual disability who is nonverbal)

My one worry is what happens to the person I care for if I become so incapacitated that I can no longer provide care or if I should suddenly pass away.

(ID 2963, carer, no specifics)

Other carers are concerned about not being able to meet the costs of future accommodation and care for their loved one:

I am also concerned as to who will care for my son when I am too old, too tired or dead. My other children love him, but do not fully understand the implications of caring for someone with a serious disability. It would be my preference for him to live in a group house for people like himself with full time

care. There is no way my husband and I will be able to provide for this. I understand getting funding for accommodation support is very limited. This is of great concern to us and plays on our minds constantly.

(ID 1593, carer of son who has high support needs)

For other carers it is their ability to provide financially for the person they care for in the future that is a cause of much stress:

We worry about providing for our son for the future and we are always discussing how to provide for him if he cannot bring in an income himself. This creates extra stress once again.

(ID 3619, carers of child with a disability, no specifics)

The author of the following comment expresses a more general concern about what she might have to contemplate if she is to become an elderly carer:

The thought of becoming an elderly carer is frightening. Will I have to put my husband into permanent residential care and will my son have to go and live in some 'cold' hostel?

(ID 582, carer of son with dual diagnosis of schizophrenia, developmental delay and alcohol/drug dependency, and husband, no specifics)

While most of the above concerns relate to the availability of accommodation, for other carers it is the lack of services available for the person they care for that is cause for concern:

My biggest concern is for my son once he finishes school as there are no services available for day care for older intellectually disabled persons in Darwin.

(ID 2074, carer of 11-year-old son with intellectual disability)

Carers' sense of anxiety about the future is aptly captured by the common sentiment of 'who will care when I am no longer able?' This was a widely voiced concern among elderly and ageing carers in particular, but it was also common for younger parents who foresaw a lack of supported accommodation facilities or care services

available for people with disabilities like those of their children. Also related to this was the fact that many people felt that their children ought to be living independently like other children their age; that they could not, because there are no suitable facilities available, was a source of sadness for parents of adult children. The large number of carers who expressed these kinds of anxieties suggests that there is a serious need both for more care services to be made available now but also for carers to be able to plan for the future care of a loved one while they are still able.

As these excerpts show, concerns about what will become of the person they care for are particularly common among ageing parents of children with some form of disability. Many of these carers have physical health problems of their own and, in addition to these, they are plagued emotionally with anxieties about the future living conditions of the child they have cared for their entire lives. It is often the case that their children are dependent on them and, in some cases, their carer provides their only link to the world and to other people. What clearly emerges from the above excerpts is that carers hold themselves responsible for the future of their loved one and, for many, being able to put in place a plan for their future would go some way toward relieving their anxieties. It would give them peace of mind, thereby adding to their quality of life, and it would also make for a less daunting transition for the care recipient. This is evident in the following comment:

The important issue is our aging and that fact that someone is going to have to take charge at some time and provide the care and oversight that is necessary. It makes sense to have that in place while we, as the ones who have provided care for so long, are able to monitor, assess and advise. With our daughter's poor hearing and lack of clarity in speech, communication is difficult for most people, and we know best how to interpret, explain and help her negotiate.

(ID 3797 parents and carers of adult child who is intellectually disabled and deaf)

Many of the anxieties about the future that are expressed in the above comments are strongly related to a carer's realisation that their caring potential is not limitless.

Apart from being concerned about the future of the person they care for, many carers are anxious about their own futures, particularly their financial capacity in the future and their ability to find work after being out of the workforce for extended periods of time as a result of fulfilling their caring role. Many carers do not have superannuation or any savings because of the huge and added costs that caring for someone brings. Many carers said that they will not be able to do the things they thought they would in their retirement and would be condemned to lives of poverty. As we have seen, caring can be both physically and emotionally demanding. The stresses and strains of being a carer (both physical and psychological) also mean that many carers are concerned about their health in the future, some implying that their role as carers has aged them before their time.

As has been discussed, many carers acknowledge that they fulfil an important role in the lives of their loved ones and speak positively about this, yet are still concerned about their own future:

I know the value of what I do and am very proud of the difference I make in the world BUT who cares for my future wellbeing – my health, happiness and heaven forbid, financial security. Maybe it is good that I don't have time to myself.

(ID 1195, original caps, no specifics)

In this comment it is possible to detect the sense of duty and responsibility felt by this carer as well as their anxieties and despair about the future. The final sentence is evocative of the potential risk that having too much time to contemplate the future may bring. Another person was particularly concerned about their ability to return to work:

Because I have been caring for someone for at least the last five years, I am very anxious about retraining, resume writing, interviews etc.

(ID 3426, carer of 88-year-old mother with dementia)

This was a common sentiment in many people's submissions and it relates closely to anxieties about their financial status now and in the future.

We have already seen that many carers believe that the role they perform is undervalued in society, particularly by government, and they argue this condemns them to lives of financial insecurity. This manifests itself in anxieties about their financial futures. The following excerpts highlight the various aspects of carers' financial insecurity and the broader consequences of this to their general health and wellbeing:

Lack of government funding is my main concern, I think it is appalling. Politicians don't seem to understand the lives that carers have to live, the isolation, the inability to be able to work full time forcing us to rely on welfare, giving us no opportunity to save for retirement.

(ID 1693, carer of son with high needs)

Superannuation is a huge concern. I have a very low earned income, with no superannuation contributions, and do not even qualify for the government's superannuation co-contribution. I strongly believe the government should address the issue of superannuation for people whose working capacity is severely limited by their caring role. Caring for someone with a disability is usually long-term, with the financial consequences lasting long after the caring role might end.

(ID 2407, carer of child with autism)

These comments highlight the fact that many carers sacrifice their prime working years (those years when they are most employable and have the most earning potential) to care for a loved one. As one carer comments, the consequences of this do not end if and when there is a change in the carer-care recipient relationship. The language used in the following comments is reminiscent of the previously discussed view among some carers that they are being punished for being carers:

We are condemned to a life of financial worry & a difficult time as we age because we are inadequately recompensed for what we do.

(ID 1896, carer of son for 28 years and husband for 15 years, no specifics)

Many of us are destined to a life of poverty, as we cannot work outside of our role as carers, and often also a life of loneliness and despair.

(ID 1119, carer of child with disability, no specifics)

In many people's comments financial insecurity was seen as a result of the fact that carers and the work they do is not valued highly enough in society, which is reflected in the limited financial assistance provided to carers by the government.

The final major theme to emerge in people's comments was frustration with government bureaucracy in general and Centrelink in particular. This frustration was commonly expressed in the form of accusations that the government is out of touch and/or its agencies are not designed and equipped to cater to the needs of carers and those who they care for.

3.5 Carers are frustrated with government bureaucracy

Closely related to the view that they are undervalued is the common view among carers that the government is out of touch with their needs. One person said this was reflected in the government's focus on facilities for older people, in which he said he would not want to place his daughter who needs 24 hour help:

The Federal government is particularly misguided and out of touch as to the needs in this area. Strategies put forward to help the disabled are merely 'stopgap/bandaid' solutions that a politician can take credit for one moment, then forget about the next.

(ID 1675, full time carer of wife who is a chronic migraine sufferer and 28-year-old daughter who suffered permanent ABI [Acquired Brain Injury] five years ago)

The following comment similarly suggests that the bureaucracy is more a hindrance than a help to carers:

Too often we carers come up against the limitations of the system which exists to support us and the persons for whom we care. Generally the support offered does not assist with our caring. We are offered respite in grandiose gestures but then we cannot have the respite because of all the conditions

attached. Some carer retreats and carer services are geared toward the agencies needs rather than the needs of the carers. We just make up their numbers for their funding.

(ID 3388, carer of sibling for nine years, no specifics)

There is also a perception among carers that money is not being spent in the right areas and that when it is spent, it is done to score political points rather than in recognition of and response to the needs of carers. These perceptions are evident in the following excerpts:

We don't have much money. My husband is classified as a low income earner. It annoys me no end that I need government handouts to get by. Having said that, I get really ticked off when there is an upcoming election and the government uses the carers to score votes. You know, they suddenly make available a one-off payment to carers. You gotta love the way they remember us when it's convenient to them. My son's disability isn't just for election times. We live it 24/7. Shove your money, Mr Howard. Actually, don't. We need it.....

(ID 7076, carer of 6 year old son with autism)

I wonder if you realise how cynical carers quickly become when some government spokesman announces extra funding for carers? We never seem to see any of it at grass-roots level, but I'm sure it creates another public service position or covers administrative costs.

(ID 1043, carer of wife, no specifics)

So more funding to the services to help our persons – funding not for office & managerial posts etc. For more respite & accommodation places.

(ID 3326, carer of intellectually disabled son with epilepsy)

One person offered a solution to the government and bureaucrats being out of touch with the realities of carers:

Just as the government's Treasurer needs to have prior experience with accountancy so policy makers in the portfolio of Health will be better fit for their understanding and decisions, after their own real life first hand personal

experience for a minimum of 6 months unsupported, unrelieved as sole 24X7 carer of a suicidal mentally ill active, fit young adult.

(ID 3476, elderly carer of adult son with a mental illness)

This person suggests that little effective change is likely to occur until policy makers gain this kind of experience. Similarly, another carer suggested that Centrelink needed to be educated about the carer experience:

Problems with Centrelink (but then what carer hasn't). They seem to think that one size fits all, they need some serious education from a Carers organisation as to the reality of what we do.

(ID 1043, full-time carer of wife for 9 years)

There was also the suggestion that agencies and organisations beholden to the government are unlikely to be able or willing to lobby for the changes that carers believe are needed:

It has been my experience that departments, and there are many, funded by Governments to supposedly help the people are not going to bite the hand that feeds them so they are impotent.

(ID 3492, carer of husband, carer of husband, no specifics)

Carer organisations are financially greased by governments, so they have to tow the party line. This is why, at that level, things won't change. They can only talk, and that talk has got them nowhere.

(ID 2591, carer of mother, no specifics)

Centrelink, as one of the agencies that carers have to deal with to access Carer Allowance as well as pensions and the like on behalf of the person they care for if they are unable to do so, is a source of frustration for many carers. The following are some common complaints:

When your child has a disability from birth – having to continually assure Centrelink that they haven't suddenly become 'normal' is another nightmare.

(ID 1058, mother who cares for daughter)

Increased Centrelink 'red tape' is also proving to be an added stress factor. Forms (for which I have the responsibility) are arriving every few weeks – even though our situation has not changed basically.

(ID 3451, carer of family members with mental illness, no specifics)

I am the children's nominee to administer all correspondence; it is all extra to the physical and emotional load I carry as carer. I have been brought to tears on more than one occasion advocating for myself and my children in what I thought was a system in place to help people like ourselves.

(ID 3587, carer of two adult children with CFS/ME and husband with Asperger's)

I feel like we don't fit into Centrelink's 'categories' very well. I was receiving Carers Allowance for my daughter when she was under 16, but have had to reapply recently when she turned 16. The application process is very difficult & off-putting & certainly makes me feel like giving up.

(ID 3665, carer of husband with ADHD and severe chronic fatigue, 18-year-old son with Asperger's and 16 year old daughter with ADHD, juvenile arthritis and type 1 diabetes)

Centrelink's requirement that carers must work 20 hours/week was another issue of concern for some people. In general, people seemed fed up with the paperwork, the one size fits all approach and the general lack of understanding.

3.6 Other notable, but not so common, comments

This section identifies issues that some people drew attention to but that were not prevalent across the corpus of carers' comments. The impact of Welfare to Work policy was a concern to two carers who were also sole parents; the plight of the aged carer and the need for eligibility requirements for Carer Payment to be widened was emphasised by people in this position, including one carer who said he had been lobbying governments on the issue; the plight of carers who have a mental illness was discussed by some carers, as was the need for information about available services to be improved, consolidated and more accessible, the need for training for carers, the lack of support for carers after the person being cared for moves to a home or dies,

and the experience of being abused and mistreated (verbally and physically) by the person they care for. This gives a sense of some of the other issues that carers emphasised and it is important to note that previous research has identified similar types of concerns among carers.

Although rare, some carers said they were happy with the respite services they have received, while on a more general level some carers mentioned the value of carer support groups as something of an antidote to the isolation of being a carer. One carer linked the importance of this kind of mutual support to their own health and wellbeing:

My fellow carers would second, that we go home, back to caring, feeling vitalised after sharing with our fellow carers. It is the only place where there is “true” understanding of where you may be coming from, understanding the issues you are confronting.

(ID 1264, carer, no specifics)

This comment is consistent with research into the personal gains carers receive from attending mutual aid groups, which include empathy, emotional coping, experiential knowledge, practical information and peer support/friendships (Munn-Giddings & McVicar, 2006). It also suggests that attending these kind of support groups stands the carer in good stead for coping when they return to their caring duties. Nonetheless, while carer support groups and carer counselling are a form of respite for some carers, as is having a loving and supportive family, many carers do not have a support network of any kind. Indeed, the number of carers who spoke of being alone in their role as a carer was striking; many did not have families living close by or if they did they were not interested in providing any assistance. Some people expressed feelings of resentment toward a spouse, sibling or another family member who was unwilling to share in the caring responsibility.

Some people described a feeling of being torn between providing care for an elderly parent or another family member while also meeting the needs of their spouse or their other children. On this latter point, some people referred to the “sandwich” generation to describe those people with the dual responsibility of caring for very young children

(because they have chosen to have children at a later age) and aging parents. This was seen as a growing problem and one that government's are going to have to address.

Some carers also took the opportunity to offer suggestions about things that would help them personally in their caring role and also things that would be of benefit to people in need of care. Having experienced an employer who was unresponsive to her needs, one carer suggested that employers needed to be more flexible in catering to the needs of carers by making provisions for job-sharing and part-time work. A recent report for Carers UK confirms that workplace cultures that are responsive to the needs of carers, many of whom wish to, or have to, combine paid employment with their caring responsibilities, benefit both employers and employees (Yeandle et al., 2006). It is clear from the comments of carers in Australia that are featured in this report that not being able to participate in paid employment is for many a source of great loss and social isolation. In this sense, developing carer friendly workplaces would benefit carers as well as employers by showing that they understand the importance of employment policies that encourage social inclusion.

Another carer suggested that education and training be provided to carers, particularly long term carers, and that this would stand them in good stead for finding employment after their caring role is complete:

The carers, if provided training, when the person they are caring is gone, will provide the carer a good experience which he/she can use for job seeking.

(ID 3919, former carer of husband who had bowel cancer and a stroke)

In a similar vein, one carer suggested that there ought to be a system in place to enable family carers to teach support services, based on the competencies they have developed over their career as carers. Such an approach would recognise that caring is a job that requires its own skills and competencies, many of which are also applicable to other types of work. These suggestions highlight the importance of carers continuing to develop skills while they are carers so that the transition back to or into work after their caring role is over is not so difficult.

The need for assistance in maintaining the house and garden was another issue raised by some carers, particularly older people who were no longer able to do this kind of work and who were not in a financial position to pay for a commercial gardening service. People were similarly disturbed by the lack of home help services available to assist them with household chores neglected as a consequence of the time and energy they devote to caring. Although these may seem like small things, combined with the other stresses and strains of being a carer they can compound the general malaise felt by many carers.

Some of the other notable submissions related to: strong criticism of David Richmond, author of the Richmond Report, which provided the impetus for the policy of 'community care' in Australia; the specific difficulties associated with caring for grandchildren; the need for more care and recognition to be given to the needs of carers of Vietnam war veterans and their children who have health problems and; a family's experience of adapting to their wife and mother's Multiple Personality Disorder. There was also a lengthy submission from a wife and carer about the mistreatment and inappropriate medication of her husband in an aged care facility.

4 Discussion

In addressing the question of what it is like to be a carer a number of key themes emerge from the data presented in this report. There is a strong feeling among carers that they are undervalued in society and that they are insufficiently recognised for the important work they do, the money they save the government and the sacrifices they make by choosing to care for their loved one. Some carers suggested that they actually felt as though they were being punished by the government and looked down upon by society for being carers. The lack of respite that many carers spoke of can also be seen to reinforce their perceptions that the work they do and the stresses and strains it entails are not fully appreciated.

While carers are a diverse group, it also seems that there are as many similarities as there are differences across their experiences. By far the most common feature of the caring experience was not having enough, if any, access to respite. This must in turn be seen within the broader context of lack of funding and financial assistance for carers and, more specifically, the undervalued role of carers in the community. These interlocking features of the caring experience mean that for many people being a carer is characterised by financial insecurity, loss of identity and anxieties about the future. The lack of time available to carers can also impact their physical and emotional health and wellbeing in a range of ways, both directly and indirectly. Taken together these factors point to a greater need for respite based on an understanding that the quality of care received by the care recipient will be a product of the quality of life, health and wellbeing of the carer.

As this report suggests, becoming a carer is a life changing experience. It brings with it responsibilities, expenses and potential risks that one would not otherwise have had. It can mean having more dealings with government bureaucracy than one would have otherwise, and feeling undervalued, tired, frustrated, lonely, unappreciated, invalidated and overwhelmed by a sense of loss and disappointment. For some people being a carer is a life enriching experience but for others it can be identity defining and, while these two experiences of caring are not mutually exclusive, many more people identified the ways in which being a carer has negatively impacted their health and wellbeing.

Being a carer is, for many people, a daily struggle that can be isolating and frustrating. The time that carers devote to caring for a loved one often leaves them with little time to care for themselves to any significant degree, which can be to the detriment of their physical and psychological health and wellbeing. Carers are anxious about the future of the person they care for and their own futures. The responsibility that comes with their caring role manifests itself in a strong sense of indebtedness to their loved one and their future care, lifestyle and general health and wellbeing. Many carers are acutely aware of their own mortality and are highly anxious and uncertain about what will happen to the person they care for when they are no longer able. While the extent of this anxiety differs depending on the specific needs of the person they care for, being worried about the future seems to be a common feature of the caring experience in general.

With regard to their own futures, many carers are anxious about not being able to adequately support themselves financially in the future. Financial insecurity is a common experience among carers; many are unable to work at all and some struggle to maintain the little paid work they do have, while juggling their responsibilities as carers. Without full-time paid employment many carers do not have superannuation or any prospect of saving for their own futures, let alone helping to establish/facilitate a future for their loved one. For those who had a career prior to becoming a full-time or otherwise primary carer, any savings they have are often spent on the added expenses associated with caring for a person with a disability or illness, some of which have been detailed in this report.

Many carers have had to give up work and career opportunities to take on the role of carer, and not being able to work is a source of loss for many. The loss is not only understood in financial terms but in terms of loss of self worth, belief and validation that comes with paid employment. This loss is exacerbated by the small amount of government financial assistance they receive for the full-time job of being a carer. Many carers vehemently believe that they are not adequately remunerated for the work they do as carers and the sacrifices they make in doing so. This leaves them gravely concerned about their ability to perform their caring role and *live* their lives at the same time. No amount of validation of a symbolic kind or tokenistic, one-off

payments will make up for the ongoing, and often lifelong, expenses associated with being a carer.

There is a feeling among many carers that the government is out of touch with the reality of the lives of carers, their needs and the needs of the people they care for. This manifests itself in a good deal of frustration being directed at the government and Centrelink as the agency many carers regrettably have to deal with in carrying out some of their duties as carers. Seemingly small things, such as having to fill out endless amounts of paperwork are, for many carers, evidence that the government and its agencies just do not understand or do not care about the pressures they are under. From the perspective of many carers, a one size fits all approach to providing assistance to carers is confirmation that the government is out of touch with their needs and the important work they do.

Being worried a lot of the time (about the future, the person they care for, their finances) does not bode well for a person's state of mind and sense of wellbeing. When this is combined with a lack of adequate respite and its consequences and general frustration with government and bureaucracy owing to feeling devalued, being a carer is not the most attractive-seeming career option. Nonetheless, being a carer is, for many people, a career. It is a full-time 24/7 job. But, unlike many jobs, it is not one that people can leave at the office – either physically or emotionally.

The findings presented in this report are consistent with previous research with carers, which shows that many struggle with anxieties about deciding on future actions and feel undervalued by government (Stoltz et al., 2006); experience loss on a number of levels when they become carers (Cheung & Hocking, 2004); have difficulties accessing suitable and quality respite, lack spontaneity in their lives and experience social and spatial isolation (Wiles, 2003; Yantzi et al., 2006); and often act to protect the self of the person they care for, even if this means not accepting respite (Caron & Bowers, 2003).

4.1 Limitations

It is important to acknowledge that the contents of this report reflect just some of the thoughts and concerns that were occupying the minds of carers at the time of completing the Carer Health and Wellbeing survey. The report has not been able to do justice to all of the comments made by carers in their submissions, particularly those lengthy comments that some people clearly took considerable time and energy to prepare. However, the attempt has been made to acknowledge the range of issues people raised. To the extent that carers' comments are anonymous it was not possible to seek validation from them as to the accuracy of the reading of their comments. This report is also limited in a number of other ways. It is lacking in any detail about the policy context that affects carers and care recipients. It also does not directly examine the payments and allowances available to carers and nor does it address the type of payments available to and received by people who are cared for. These questions are beyond the scope of this report and may therefore be deemed a limitation or a weakness of it. Notwithstanding these limitations, this report does achieve its primary aim of providing an insight into the lives of some carers in Australia. The following section identifies future research opportunities and methodological considerations.

4.2 Methodological considerations and future research

This report gives voice to the experiences of some carers as they interpreted it and chose to communicate at a particular moment in time and at a particular stage in their life as a carer. It is important to note that many respondents said that they would have answered the survey differently one or two years ago and others acknowledged that they would have answered the survey differently the previous day. It is in this context that the limitations of the method used and the constraints it imposes on the data obtained in this research must be recognised.

While open-ended survey questions provide participants with the freedom to decide what experiences and thoughts they wish to share, they have the disadvantage of not allowing researchers to probe participants further and to seek clarification. This can mean that some of the data they produce is difficult for researchers to interpret and analyse. Similarly, as suggested, this method is unable to provide an insight into the

experience of being a carer as it is lived by people in their daily lives. Future research in this area may, therefore, benefit from the use of ethnographic methods that enable the researcher to enter the world of the carer and care recipient in a more immediate way. People's additional comments were also suggestive of some other possibilities and opportunities for future research with carers. A number of carers said that they would be happy to talk further about their caring experience and one carer said that they would like to be involved in a focus group with other carers. In-depth interviews and focus groups certainly allow for the kind of probing that is absent in survey questionnaires and can facilitate the emergence of more detailed narratives about the carer experience.

This report offers a descriptive analysis of people's comments. Further analysis of the data obtained from this research would benefit from a more thorough exploration of previous research, an engagement with theoretical perspectives on caring and a more in-depth form of analysis. A discourse or narrative analysis would undoubtedly produce different and more complex readings of the data and may be a worthwhile avenue for future research. Future research might also investigate the claim by some carers that Australia is several years behind other developed countries in its treatment of carers. It is also important that future research distinguishes between different types of carer-care recipient relationship.

There are some further methodological considerations that need to be taken into account in the conduct of future research in this area. In particular, some carers commented on the short turnaround time between receiving the questionnaire and when they were required to return it. They asked that in future carers be given more time in recognition of the fact that many are time poor and under considerable stress as a result of their caring role. In planning and designing research with carers, researchers will need to be flexible and responsive to the time constraints on carers. Carers themselves should also have a key role in all aspects of the research so as to ensure that these considerations are fully appreciated and that research questions are grounded in the needs and values of carers themselves, rather than being imposed from above or outside.

5 Conclusion

It is important to restate that the data presented in this study is open to multiple interpretations. It will be left to the reader to determine if the inferences drawn resonate with their own experience of caring or their knowledge of caring more generally. It is important to recognise that no two carers share identical experiences. Carers, like the people they care for and like other members of society, are unique individuals. This means that each carer will understand their experience of caring and the experiences of carers generally in different ways. This report has attempted to give voice to the range of ways in which people understand the caring experience and the status of carers in society in general. It has not been the aim of the report to weigh up the different types of caring experiences and come to a conclusion about the type of carers that are struggling the most. What is important is that we recognise that carers are a diverse group of people whose needs are as diverse as those who they care for.

It is clear that many carers are not satisfied with the current systems in place to serve both them and those for whom they care. Improvements in funding and respite services would go some way toward sending a message to carers that they are valued. Carers must be given access to the kind of quality respite that will enable them to have an identity beyond that which revolves around caring, and a life in which they are able to enjoy some of the more enriching aspects of caring. Improving carers' access to respite is also undoubtedly likely to benefit the recipient of their care and cost the government less in healthcare costs in the future. To echo a 2006 report for Carers UK the costs of not supporting carers are worthy of serious contemplation by governments, employers and communities as a whole (Yeandle et al., 2006). As a society we must recognise the work that carers do and the sacrifices they make in doing it. If carers are not sufficiently remunerated, what is to become of the person they care for? This is a serious question and one that undoubtedly requires serious consideration by government lest we be responsible for perpetuating a cycle of poverty and pain in which social policy and social structures are a disabling, rather than an enabling, force in the lives of carers and those for whom they care. It is hoped that this report will contribute to a better understanding of the needs of carers and a fairer approach to supporting them in their role.

6 References

Arksey, H. (2003). People into employment: Supporting people with disabilities and carers into work. *Health and Social Care in the Community*, 11(3), 283-292.

Beeson, R. A. (2003). Loneliness and depression in spousal caregivers of those with Alzheimer's disease versus non-caring spouses. *Archives of Psychiatric Nursing*, 17(3), 135-143.

Caron, C. D. & Bowers, B. J. (2003). Deciding whether to continue, share, or relinquish caregiving: Caregiver views. *Qualitative Health Research*, 13(9), 1252-1271.

Chambers, M., Ryan, A. A. & Connor, S. L. (2001). Exploring the emotional support needs and coping strategies of family carers. *Journal of Psychiatric and Mental Health Nursing*, 8, 99-106.

Cheung, J. & Hocking, P. (2004). The experience of spousal carers of people with Multiple Sclerosis. *Qualitative Health Research*, 14(2), 153-166.

Denzin, N. K. & Lincoln, Y. S. (2000) (Eds.). Introduction: The discipline and practice of qualitative research. In *Handbook of Qualitative Research* (2nd Edition), (pp. 1-28). Thousand Oaks, California: Sage Publications.

Harding, R. & Higginson, I. J. (2003) What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliative Medicine*, 17, 63-74.

Hartrey, L. & Wells, J. S. G. (2003). The meaning of respite care to mothers of children with learning disabilities: Two Irish case studies. *Journal of Psychiatric and Mental Health Nursing*, 10, 335-342.

- Keith, L. (1992). Who cares wins? Women, caring and disability. *Disability, Handicap & Society*, 7(2), 167-175.
- Munn-Giddings, C. & McVicar, A. (2006). Self help groups as mutual support: What do carers value. *Health and Social Care in the Community*, 15(1), 26-34.
- Neufeld, A. & Harrison, M.J. (2003). Unfulfilled expectations and negative interactions: Nonsupport in the relationships of women caregivers. *Journal of Advanced Nursing*, 41(4), 323-331.
- Pusey, H. & Richards, D. (2001). A systematic review of the effectiveness of psychosocial interventions for carers of people with dementia. *Aging Mental Health*, 7(1), 7-14.
- Read, T. & Wuest, j. (2007). Daughters caring for dying parents: A process of relinquishing. *Qualitative Health Research*, 17(7), 932-944.
- Stoltz, P., Willman, A. & Udén, G. (2006). The meaning of support as narrated by family carers who care for ma senior relative at home. *Qualitative Health Research*, 16(5), 594-610.
- Wiles, J. (2003). Informal caregivers' experiences of formal support in a changing context. *Health and Social Care in the Community*, 11(3), 189-207.
- Yantzi, N. M., Rosenberg, M. W. & McKeever, P. (2006). Getting out of the house: The challenges mothers face when their children have long-term care needs, *Health and Social Care in the Community*, 15(1), 45-55.
- Yeandle, S., Bennett, C., Buckner, L., Shipton, L. & Suokas, A. (2006). *Who cares wins: The social and business benefits of working carers*. A report for Carers UK. Centre for Social Inclusion, Sheffield Hallam University.