

Health and Wellbeing

- 8.1 This chapter considers the impact of caring on the health and wellbeing of carers and their families. The chapter will consider issues associated with:
- the physical health of carers and options for assisting carers to maintain and improve their physical health;
 - the psychological and emotional wellbeing of carers and their families, and the importance of options for carers to have sufficient time out of the caring role and access to counselling support for carers and their families; and
 - social isolation experienced by many carers and consider options for increasing social inclusion.

The Impact of Caring on the Health and Wellbeing of Carers

- 8.2 A large number of submissions to the Inquiry have emphasised that the caring role potentially impacts significantly on all aspects of carers' lives, affecting carers' physical and psychological health, emotional wellbeing and social relationships. These assertions are well supported by the outcomes of recent research.
- 8.3 The 2003 Australian Bureau of Statistics Survey of Disability, Aging and Carers found that 29% of all primary carers reported a change to their overall physical and emotional wellbeing as a result of providing care. In addition, of the 64% of primary carers that reported no overall change in their health and wellbeing, approximately half reported experiencing at

least one specific negative effect such as frequently feeling worried or depressed.¹

8.4 The health and wellbeing of carers in Australia has also been the primary focus of two recent research projects; the 2007 Australian Unity Wellbeing Index Survey titled *The Wellbeing of Australians – Carer Health and Wellbeing* and the 2008 Australian Institute of Family Studies (AIFS) report titled *The Nature and Impact of Caring for Family Members with a Disability in Australia*.²

8.5 Key findings from the Australian Unity Wellbeing Index Survey include:

- carers have the lowest collective wellbeing of any population group yet discovered, with the wellbeing of carers who live with the person requiring care being the lowest ever recorded for a large group of people;
- carers have an average stress rating that is classified as moderate depression;
- carers are more likely to experience chronic pain than is normal and the wellbeing of carers is more vulnerable to pain;
- carers are highly likely to be carrying an injury; and
- wellbeing decreases linearly as the number of hours spent caring increases.³

8.6 The AIFS research, *The Nature and Impact of Caring for Family Members with a Disability in Australia* indicates that carers, in particular those under the age of 65 years, have significantly worse mental health and vitality and higher rates of depression than the general population. Key findings include:

- the risk of carers and family members experiencing a depressive episode of six months or more was greatest in the first year of caring;
- almost twice as many carers (29%) were in poor physical health than the general population (17%);

1 Australian Bureau of Statistics (2008), *A Profile of Carers in Australia*, 4448.0, p 38.

2 Australian Unity Wellbeing Index (2007), Survey 17.1, *The Wellbeing of Australians – Carer Health and Wellbeing*; Australian Institute of Family Studies (2008), *The Nature and Impact of Caring for Family Members with a Disability in Australia*, Research Report No 16.

3 Australian Unity Wellbeing Index (2007), Survey 17.1, *The Wellbeing of Australians – Carer Health and Wellbeing*, pp vi-vii.

- almost one in three female carers aged 50 years or less had separated or divorced since they started caring, while one in seven over the age of 50 years had separated or divorced since they started caring; and
- carers who had multiple care responsibilities or who were caring for children had worse mental health outcomes.⁴

8.7 A significant proportion of carers have reported suffering physical and psychological effects as a consequence of providing care. This was due to the relentless physical and emotional intensity of the caring role, exacerbated by financial hardship, a lack of respite and other supports, and the social isolation that they experience.⁵ Based on the feedback provided by carers on the negative physical and psychological impacts of caring, Carers ACT reported:

Of the total number of 259 surveys returned in the Carers ACT Territory Pre-Election Survey, 116 respondents (44%) provided additional written information to illustrate how they had been affected. Of this 116, 35 carers provided detail of how caring had negatively affected their physical health. Conditions discussed included: back or neck injuries, chronic conditions such as fibromyalgia, heart conditions, ulcers, arthritis, high blood pressure and cancer. In regard to psychological impact, 25 carers stated that they now suffered from depression, anxiety attacks or other stress related illness at a level requiring medication or other medical care. Another 56 participants provided information on how caring has impacted their general wellbeing, citing issues such as negative self-esteem, fatigue, anxiety, emotional and physical exhaustion, stress and severe social isolation.⁶

8.8 To a large extent the underlying causes of these types of adverse effects have been addressed through recommendations made by the Committee earlier in the report. These include recommendations to assist carers to access information and acquire necessary skills, to alleviate the financial disadvantages facing carers and their families, to improve access to

4 Australian Institute of Family Studies (2008), *The Nature and Impact of Caring for Family Members with a Disability in Australia*, Research Report No 16, p 98. See also: Australian Institute of Family Studies, Submission No 744, pp 2-8.

5 See for example: Ms D Osborne, Submission No 43, pp 1-2; Mr D Williams, Submission No 344, pp 1-2; Ms P Birch, Submission No 345, p 1; Mr R Sinclair, Transcript of Evidence, 13 August 2008, p 2.

6 Carers ACT, Submission No 702, p 28.

appropriate respite and other support services and to provide greater choice in relation to participation in employment and education. The importance of addressing these issues in order to improve the health and wellbeing of carers is illustrated by the Dodds family for whom one of the major frustrations of providing care for their son with a disability is:

Agencies telling you that you need counselling, when all we need is appropriate support, which in turn will reduce stress levels, depression and anxiety.⁷

8.9 In relation to the shortage of affordable respite options that allows carers to have time out of the caring role, Ms Laura Formosa asked:

How do you expect carers to maintain proper health and especially a healthy state of mind – a mind that does not fall into a depressed state? Chronic depression is often brought about by people not resting or having no time at all to themselves.⁸

8.10 As also explained by Ms Diane Vella, who provides care for her brother:

If there is no assistance given to the carer or help when they are trying to find supports for the person who they are looking after this puts extreme pressure on the carer. It is wise to remember that one can only take so [much] of this pressure before they break.⁹

8.11 Even with access to adequate supports and services, becoming a carer is inherently stressful as the role usually arises in conjunction with a traumatic and painful event that results in significant changes in the lives of carers and their families.¹⁰ As noted by Ms Thelma Camilleri, who provides care for her husband with a disability:

There are many different changes and losses carers experience; our lives may never be normal again.¹¹

8.12 Similarly, as explained by Ms Michela Cardomone, who has provided care for a member of her family with a mental illness:

Apart from the isolation and loneliness I was experiencing, like many carers I experienced anxiety and depression, trauma and grief as a direct result of the caring role. Whilst these conditions

7 Mr S Dodd & Ms H Dodd, Submission No 1196, p 1.

8 Ms L Formosa, Submission No 1296, p 2.

9 Ms D Vella, Submission No 273, p 2.

10 See for example: ARAFMI QLD, Submission No 574, pp 3-4; BrainLink Services, Submission No 690, pp 3-4; Ms J Steepe, Submission No 1023, p 10.

11 Ms T Camilleri, Submission No 48, p 1.

are considered mental illnesses in their own right, they are a fundamental part of the lived experience for carers.¹²

- 8.13 As a new carer whose child was diagnosed with a terminal medical condition also explained:

I am not ashamed to say that I am scared - about my ability to manage this, to stay strong for those around me, to come out the other end - and somehow to manage to smile on the way through. I can and do function as best as I can - and really try to stay positive and energetic for the kids, but the grief is always there. There's not an hour that goes by that I don't think about it. And this is emotionally and physically exhausting.¹³

- 8.14 As noted above, carers have been recorded as having the lowest collective wellbeing of any population group measured to date.¹⁴ The Committee's evidence corroborates the research and indicates that a combination of factors relating to the nature and demands of caring has ramifications for the wellbeing of carers. This chapter will explore in more detail the impact of caring on carers' physical health and psychological and emotional wellbeing and recommends specific measures to address their health needs.

Physical Health of Carers

- 8.15 Many carers have indicated that they suffer physically as a consequence of providing care. The physical demands of moving and lifting of care receivers who have limited mobility is an issue, with some carers reporting that they had sustained physical injury as a result.¹⁵ As noted in the submission from Special Kidz Special Needs:

Carers are often faced with lifting, twisting, and physical demands of enabling those they care for to sit, walk, bathe, toilet etc. This

12 Ms M Cardomone, Submission No 799, p 2.

13 Name withheld, Submission No 244, p 3.

14 Australian Unity Wellbeing Index (2007), Survey 17.1, *The Wellbeing of Australians – Carer Health and Wellbeing*, pp vi-vii.

15 See for example: Mr J Halford, Submission No 250, p 6; Mr R Regal, Submission No 335, p 4; Ms J Edwards, Submission No 564, p 1; Ms N Hughes, Submission No 830, p 1; Ms M Parnell, Submission No 849, pp 7-9; Mr L Hawksworth, Submission No 1018, p 1; Mr C Coleman, Transcript of Evidence, 12 August 2008, pp 29-30.

often leads to back pain and in the long term spinal subluxations (deformation) and arthritis.¹⁶

- 8.16 However, the physical impacts of providing care are broad ranging and are likely to increase as the carer ages, as the care receiver grows to adulthood or as a consequence of providing care over a prolonged period of time or at a high intensity. The following excerpts from carers' submissions illustrate the toll of caring:

Ms Leveina Belsham – carer for her 102 year old mother and for her husband (now deceased) following heart surgery and with cancer

... unfortunately the role of carer is very damaging to my health and body. Lifting both my husband and mother has caused damage to my back, knees and arms.¹⁷

Ms Janet Johnson – provides care with her husband for their two adult daughters in their late 40s and for a 15 year old grandson, each with varying degrees of intellectual impairment

We have spent most of our married life caring for them - lovingly, I hope with very little help from anyone. Consequently we are both suffering from elevated stress levels. We both have high blood pressure, digestion problems, back pain and a number of other stress related conditions including depression and anxiety.¹⁸

Name Withheld – carer for her son with cerebral palsy and mild autism

The problems I face day to day are physical health issues cast upon me due to caring. I have developed a stomach ulcer due to stress, fibromyalgia; muscle inflammation that prevents me from doing anything outside my caring role, a degenerative spine condition and depression which are all exacerbated because of caring.¹⁹

Ms Rosalie Quaife – carer for her two children, one with type 1 diabetes and the other with a mental illness

As a Carer I feel exhausted and that my quality of life has been greatly affected by my need to Care. This ultimately will result in

16 Special Kidz Special Needs, Submission No 567, p 18.

17 Ms L Belsham, Submission No 96, p 1.

18 Ms J Johnson, Submission No 16, p 1.

19 Name withheld, Submission No 650, p 1.

my state of health, physical and mental, negating my ability to care adequately. There is never a peaceful night of sleep.²⁰

Mr Noel Faint – primary carer for six people with various disabilities

I am overweight - suffer from sleep apnoea, blood pressure, stomach ulcer, bad kidneys, enlarged liver, depression, arthritis in the knees, ankles, elbow and wrists [and have] been waiting years for dental work. ... Unfortunately everybody needs come before mine but in all fairness that is my choice.²¹

Ms Jane Churchill – carer of her 16 year old son with a disability

Every day I have to wash due to my son's incontinence ... my health is deteriorating, I have arthritis, have had 2 hip operations in the last 10 years and I'm only 49. I have diabetes, chronic fatigue syndrome, scoliosis, lordosis and depression.²²

- 8.17 Despite experiencing poorer physical health, carers often reported that they had delayed attending to their own health needs. In some cases, carers indicated that the health needs of the care receiver were considered first and foremost, and with limited resources to the exclusion of considering their own health.²³ Other factors that restrict carers from addressing their own health needs include a lack of money and/or time.²⁴ For example, Ms Carolyn Paisley Dew, now a bereaved carer, stated:

I never had time (or money) to look after my own health. Since Matthew passed away, I have had a lot of really overdue work done on my teeth. I have also had two operations that each required a six-week period without lifting; each of these essential needs would have been impossible while he was alive.²⁵

Improving the Physical Health of Carers

- 8.18 Improving the physical health of carers will require a greater recognition of the importance of the carer's own health. To achieve this, the

20 Ms R Quaife, Submission No 1125, p 1.

21 Mr N Faint, Submission No 20, p 1.

22 Ms J Churchill, Submission No 66, p 1.

23 See for example: Ms M Nazzari, Submission No 100, p 1; Ms A Hewat, Submission No 866, p 8.

24 See for example: Ms L McIver, Submission No 191, p 3; Ms Y Wathen, Submission No 723, pp 1-2; Name withheld, Submission No 850, p 1; Ms D Le Cornu, Submission No 887, p 1.

25 Ms C Paisley-Dew, Submission No 826, p 4.

Committee believes that a preventive health approach based on support for measures which actively promote good health and reduce the incidence of injury and illness is crucial. Discussion earlier in the report has emphasised the need to provide carers with the skills, training and education to support them in their role. While the skills and training needs of individual carers will vary depending on the specifics of the caring situation, where appropriate this training should include safe manual handling practices and all carers should receive advice on looking after their own health.

- 8.19 Other preventative health measures that have been recommended to the Committee include the implementation of targeted health programs for carers, including the provision of free annual check-ups for carers.²⁶ For example, Carers ACT recommended:

That the government commit to providing a Primary Health Care Program for carers, including a free annual health check with a reminder system, a free annual Flu-vax, hepatitis vaccinations if needed, and a health care card.²⁷

- 8.20 In providing its support for the introduction of free annual check-ups for carers, the New South Wales Government observed:

Carers need to be encouraged not to ignore their own physical and mental health needs. General Practitioners could play a significant role in this area. The recently released UK carers strategy *Carers at the heart of 21st-century families and communities* is piloting annual health checks for carers.²⁸

- 8.21 Carers Australia pointed out that there are already a number of preventative health initiatives that target high risk groups:

There are precedents where the Federal Government has introduced health initiatives for specific population groups at risk of poor health, including Better Health Outcomes for Mental Health, the annual health checks for people aged 45-49 years with a health risk and, more recently, the Healthy Kids Check.²⁹

26 See for example: Ms J Harrison, Submission No 301, p 2; Ms S Durkin, Submission No 329, p 2; National Seniors Australia, Submission No 686, p 3; Palliative Care Australia, Submission No 688, p 10; Ms T Hayes, Submission No 933, p 4; Ms J Lehmann, Submission No 1258, p 5; Ms D Stewart, Transcript of Evidence, 13 August 2008, p 27.

27 Carers ACT, Submission No 702, p 4.

28 NSW Government, Submission No 1278, p 13.

29 Carers Australia, Submission No 699, p 21.

- 8.22 As carers experience very poor health and comparatively low levels of wellbeing, the Committee supports the introduction of a targeted preventative health program for carers. One approach to achieving this would be for the Enhanced Primary Care Program, a Department of Health and Ageing (DoHA) program which includes free health checks for at risk population groups (for example, people between the ages of 40 and 49, older Australians, Indigenous Australians and permanent residents of aged care homes) to be extended to include carers as an at risk group.³⁰ Eligibility for the program could be based on receipt of Carer Payment and/or Carer Allowance.

Recommendation 46

- 8.23 **That the Minister for Health and Ageing direct the Department of Health and Ageing to provide a preventative health care program targeted at carers. This could be achieved by extending the Enhanced Primary Care Program to include carers who receive Carers Payment and/or Carer Allowance as an at risk population group requiring intervention under this program.**
- 8.24 One issue that has been repeatedly raised by carers, relates to bulk billing by General Practitioners (GPs) and other health professionals. The Committee understands that the Australian Government already provides incentives under the Medicare Benefits Schedule (MBS) for GPs to bulk bill Pensioner Concession Card and Health Care Card holders, though the ultimate decision to bulk bill is at the doctor's discretion.³¹ However, submissions from carers indicate that finding GPs and other health professionals that are willing to bulk bill concession card holders is problematic.³²
- 8.25 To respond to these issues raised by carers, the Australian Government may wish to review the effectiveness of the MBS incentives offered to GPs to bulk bill concession card holders.

30 Australian Government, Department of Health and Ageing website, viewed 1 March 2009 at www.health.gov.au/epc.

31 Australian Government Departments (FaHSCIA, DoHA & DVA), Submission No 1109, p 23.

32 See for example: Ms C Phillips, Submission No 755, p 2; Mr A Skimin & Ms K Skimin, Submission No 810, p 2; Ms L Symons, Submission No 1043, p 2; Ms J Beattie, Submission No 1045, pp 3-4; Ms N Jensen, Submission No 1052, p 1.

The Psychological and Emotional Wellbeing of Carers

- 8.26 The evidence provided by hundreds of carers and organisations, emphasised that sustaining carers in a caring role and supporting their psychological and emotional wellbeing, means they must receive an adequate amount of 'time out' from the caring role and increased access to counselling and psychological services.
- 8.27 One carer described the interrelationship of stresses arising from the caring role, the lack of responsiveness of support services and the very real obstacles preventing carers attending to their own needs, in the following way:

In order to keep some sort of balance in life, we all need a little 'me' time on a regular basis. We Carers are people too, we need a break too. Just like everyone else, we like to feel the sunshine on our faces and wind in our hair, but do we get to do this as often as we should? No we don't. Why? Because we don't have anyone to take over the Care of our special people for us. So we seek out organisations to help us get some respite and help. What we get told is that there is nothing available due to lack of funding or you will be put on a waiting list or someone will call you back and our call just isn't returned. And if we are lucky enough to get put on a waiting list, do any of these people bother to check up on us to see if there is anything else they can do to help? No. Do any of these people refer us on to someone else who can help us? No. Do any of these people make some enquiries on our behalf because we are clearly in need of help and completely stressed out? No! A build-up of stress usually evolves and develops into depression, this might mean treatment such as counselling or intense therapy and or medication. This all costs time and money. This extra financial burden coupled with having to find the time to do the therapy all adds up to ... yep you guessed it ... more stress!!! And here we go stuck on that revolving door again!!!!³³

The Need for 'Time Out' in the Caring Role

- 8.28 A significant number of carers have reported experiencing extreme stress, anxiety and depression. The relentless intensity of the caring role and insufficient time for carers to attend to their own needs was identified as a

33 Ms D Etherington, Submission No 1204, p 1.

significant stress factor.³⁴ Many carers indicated that in the absence of sufficient 'time out' they were struggling to sustain their caring role. As explained in the submission from the National Carers Coalition:

If carers are not given timely breaks they risk burn-out. This is partly why carers have such high events of depression, physical conditions and illnesses.³⁵

8.29 The comments below are typical of those made by carers in relation to the impact of providing continuous care on their wellbeing and the importance of 'time out' or 'me time':

Ms Kerry Beamish - carer for her husband with kidney failure

The things that stress me about being a carer the most are that you have to be there all the time. There is no time for yourself, if you manage to fit in 'me' time it is for a very limited time.³⁶

Ms Judith Small - carer for her paraplegic husband since 1993 following removal of a brain tumour

I find it difficult to have the time and space for myself as we have had to move to a unit (as I could no longer maintain a home with a garden) and the TV is my husband's main interest at home with the consequence on me it is difficult for me to have time away by myself as he does not cope if I go away.³⁷

Ms Donna Etherington - carer for her son with a disability

I am susceptible to falling in and out of severe depression because of the mammoth stresses that a Caring role does bring. I am sure you would agree, dealing with depression is difficult for any individual, but it is amplified for those in a Caring role. As a Carer, you can't afford to get sick or unable to cope. If you can't be the 'Carer', then who is there to take over for you?³⁸

Name withheld - a new carer of a young child with a serious medical condition

At present, we rely on grandparents and paid babysitters for 'time

34 See for example: Ms M-J Galiazzo, Submission No 359, p 1; Ms C Franze, Submission No 622, p 3; Ms J Johnson, Submission No 1178, p 6; Ms M Anderson, Transcript of Evidence, 12 August 2008, p 44.

35 National Carers Coalition, Submission No 571, p 30.

36 Ms K Beamish, Submission No 55, p 1.

37 Ms J Small, Submission No 110, p 2.

38 Ms D Etherington, Submission No 1204, p 1.

out'. For busy working parents with the stress that this sort of diagnosis brings, this is essential. I can't imagine having to go through this without my husband's support - and it's so important that we do take time to be with each other. Without, we cannot support our family emotionally. However, respite care appears to be limited. Jamie's condition, chronic and terminal as it is, does not yet qualify us for any respite care service. I was told that he has to deteriorate further - not easy news to take.³⁹

8.30 While each individual's need for time away from the caring role will vary depending on the specifics of the caring situation, the consensus in evidence from carers is that the current respite provisions, both in-home and out-of home, are insufficient to meet demand.⁴⁰ The Committee has considered issues associated with respite earlier in the report and believes that its recommendations relating to improving access to quality respite services will assist carers gain their own time out.

8.31 In addition to the shortage of respite generally, a specific issue that has been raised by a number of carers relates to the maximum allowable allocation of 63 days per calendar year for the temporary cessation of care⁴¹ for recipients of Carer Payment or Carer Allowance. Some carers have questioned the rationale for the 63 day per year limit, arguing that it is insufficient and inequitable when compared to minimum conditions of employment. As explained by Ms Ellen Walker, a carer with over 14 years caring experience:

... currently carers can take off 63 days a year from their caring role - this does not even reflect usual working arrangements of a 37.5 hour week - indeed, carers do not even get the equivalent of weekends off in a year (104 days), let alone sick leave, holiday leave, personal leave.⁴²

39 Name withheld, Submission No 244, p 6.

40 See for example: Ms L Buckingham, Submission No 109, pp 1-2; Ms S Berardi, Submission No 550, p 1; Ms B Allen, Submission No 612, p 1; Ms G Esson, Submission No 647, p 3; Name withheld, Submission No 860, p 2; Ms D Galt, Submission No 861, p 1; Ms M Quinn, Submission No 867, p 1; Ms E Tielmann, Submission No 907, p 2; Ms G Hunter, Submission No 1090, pp 1-2; Ms D Etherington, Submission No 1204, p 2; Name withheld, Submission No 1304, p 1.

41 Temporary cessation of care provisions apply where the cessation of care is a 24 hour period. Part days do not count as temporary cessation of care.

42 Ms E Walker, Submission No 973, p 3. See also: Community Options (Dementia Respite Albury and District), Submission No 790, p 2; Ms N Hughes, Submission No 830, p 4; Mr M Tonissen & Ms R Tonissen, Submission No 1111, p 2.

- 8.32 Ms Anita Geach-Bennell, who provides care for her two daughters with high support needs, also questioned the 63 day temporary cessation of care limit, suggesting:

Remove the 63 day rule from CentreLink. My caring role of my daughters goes on during the night and day. WE SHOULD BE ABLE TO HAVE RESPITE WHEN WE NEED IT AND HOW WE NEED IT, AND NOT BE TOLD WHEN WE CAN HAVE IT.⁴³

- 8.33 An older carer, Ms Dorelle Purcell, also pointed out that the allowable 63 days of respite is often insufficient for older carers:

Whilst carers are permitted 63 days respite per year, if the carer becomes ill ... part of the 63 days must be used to avoid loss of benefits (to the carer). This is disgraceful, especially in the aged carer, as we need every one of those 63 days of respite in order to maintain our caring role.⁴⁴

- 8.34 Importantly, submissions from carers have brought the Committee's attention to the fact that, while an additional 63 day temporary cessation of care is available for periods where the care receiver is hospitalised, this is not the case where the carer temporarily ceases to provide care as a result of the carer's own hospitalisation or illness. As explained by one carer, Ms Lynn Walker:

Under Centrelink rules when a carer requires hospitalisation that time must be taken from the allowed respite days. I feel this is unfair as an ill carer would require both sick leave and respite days to regain health.⁴⁵

- 8.35 Ms Barbara Bale, who has provided care for her son for almost 37 years, explained how she had been required to use time from her 63 day 'respite' allowance to undergo treatment for cancer:

I was told to use my respite days when I was having a mastectomy, chemotherapy and Radiotherapy. This is wrong; respite is used to have a break, not to have treatment for cancer. This needs to be changed so that carers who do fall ill are supported and not told to use respite days.⁴⁶

43 Ms A Geach-Bennell, Submission No 1022, p 2.

44 Ms D Purcell, Submission No 2, p 1.

45 Ms L Walker, Submission No 470, p 1.

46 Ms B Bale, Submission No 930, p 1.

- 8.36 The Committee has already acknowledged the essential importance to carers of access to supports, particularly regular and adequate respite services, to allow them to have time out of their caring role to reduce the risk of carer burn out. The Committee also considers that the current social security provisions covering temporary cessation of care in respect of carers receiving Carer Payment and/or Carer Allowance, should be re-examined. It is the Committee's view that the allowable period of time for respite from the caring role be brought more in to line with community expectations for employment conditions, including time allowed for weekend breaks, recreational leave and sick leave entitlements.

Recommendation 47

- 8.37 **That the Minister for Families, Housing, Community Services and Indigenous Affairs direct the Department of Families, Housing, Community Services and Indigenous Affairs to review the temporary cessation of care requirements for Carer Payment and Carer Allowance recipients, particularly in relation to:**
- **the adequacy of the 63 days of respite per year particularly in comparison to minimum conditions of paid employment; and**
 - **the requirement of carers to use all or part of the allowable period of time to cover periods of time, when as a result of illness, they are unable to provide care.**

The Need for Psychological Support and Counselling

- 8.38 In addition to needing time away from the caring role to maintain a positive level of emotional wellbeing, many carers also identified the need for greater access to psychological support and counselling, both for themselves and for their families. This is particularly important during periods of transition and change, for example on commencement of caring, when the care receiver leaves school or employment, if there are significant changes in the level of care required, changes in accommodation or changes in family relationships and structures due to

separation or death.⁴⁷ As the Australian Institute of Health and Welfare explained:

Access to counselling, support and information is important for carers when they reach critical transition points: commencing or increasing caregiving (possibly involving decisions about paid employment) or ending care through death or institutionalisation.

Some carers may need help to re-engage with their community after a long period of caregiving.⁴⁸

8.39 The following comments from carers exemplify the views of many carers who raised the importance of psychological and emotional support at times of transition:

Ms Dulcie Sullivan - an older carer who cares for her 54 year old son

I particularly need help now I am 81 years old. I need to have transitional aid when relinquishing my role as a carer. This transitional period is confrontational.⁴⁹

Ms Annette McArthur - carer for her step-daughter for over 20 years and for her husband

One thing that would really help, is ready access to free counselling over the phone or in person at my own home. This would be great after a diagnosis, death or other crisis.⁵⁰

Mr Les Wheaton and Ms Judy Wheaton - cared for elderly parents in a rural community

Counselling available for carers to help them cope with all aspects of the caring role, especially transitions from one level of care to another when the carer may be dealing with feelings of guilt, anger, inadequacy etc.⁵¹

47 See for example: Ms W Bennett-Hall, Submission No 103, p 2; Ms A Dix, Submission No 431, p 2; Ms L McCulloch, Submission No 471, p 1; Ms A McArthur, Submission No 491, p 1; MND Australia, Submission No 568, p 25; Daughters in Demand, Submission No 611, p 2; Huntington's Australia, Submission No 670.2, p 1.

48 Australian Institute of Health and Welfare, Submission No 1033, p 5.

49 Ms D Sullivan, Submission No 126, p 6.

50 Ms A McArthur, Submission No 491, p 1.

51 Mr L Wheaton & Ms J Wheaton, Submission No 190, p 3. See also: Ms A Dix, Submission No 431, p 3.

- 8.40 From the evidence, it would appear that many carers are not accessing adequate counselling services to meet their needs. A number of carers have suggested that there is a need to increase the levels and affordability of emotional and psychological counselling available to carers.⁵²

The Impact on Other Members of the Family

- 8.41 The stress experienced by carers often also extends beyond the primary carer, affecting the whole family including spouses, siblings and other family members.⁵³ Relationship difficulties between siblings, is a particular area of concern identified by recent research.⁵⁴ The need for counselling services to ameliorate the impact of caring on the whole family was raised by many carers including:

Ms Beverley Tickner – carer for her adult son with mental illness

Most carers spend about 80% of their time catering to the needs of the child with the disability and 20% of time to children who are not disadvantaged. Therefore my caring role means that I have to devote a disproportionate amount of time to supervising the sick child/adult.⁵⁵

Ms Beverley Schulz – carer for her 22 year old daughter

My life revolves around my daughter instead of revolving around my husband and my family. My daughter's ill health has taken its toll on my health and I am suffering chronic pain. For the past 18 months she has suffered ill health and has had 3 stays in hospital, and had one major operation...I am approaching 50 and I need more time for me. I want to enjoy my life more but carers don't receive enough money or help to enable this to happen. My husband and I love our daughter; she is part of our family but the way things are going she will have to go into permanent care and that will cost the government more.⁵⁶

52 See for example: Ms A Silvey, Submission No 267, p 2; Ms J Wallent, Submission No 834, p 2; Ms T Hayes, Submission No 933, p 4; Ms M Hart & Mr R Hart, Submission No 1174, p 2;

53 See for example: Ms J Guilfoile, Submission No 160, p 2; Ms K Small, Submission No 165, p 1; Ms L Ruggiero, Transcript of Evidence, 12 August 2008, p 12; Ms S Gambin, Transcript of Evidence, 12 August 2008, pp 74-75; Ms V Cagliuso, Transcript of Evidence, 13 August 2008, p 21; Ms J Milburn, Transcript of Evidence, 13 August 2008, p 25; Ms K Strohm, Transcript of Evidence, 13 August 2008, pp 58-65.

54 Australian Institute of Family Studies, Submission No 744, p 5.

55 Ms B Tickner, Submission No 98, p 1.

56 Ms B Schulz, Submission No 286, p 1.

Ms Margaret Ingham – carer for her 15 year old son with Asperger's Syndrome, Oppositional Defiance Disorder, Tourettes, Depression and Attention Deficit Disorder

Our social life is virtually non-existent. My son's [Autism Spectrum Disorder] has alienated him from most of his family so we cannot visit them as a family, and some members are quite hostile towards us/him because of his bluntness and language. I can usually speak to my sisters on the telephone so to avoid confrontations. Because I side with him, (although I do not agree with him) this has caused much tension in family life.⁵⁷

Ms Alison Dix - carer for her daughter with Asperger's Syndrome and twin sons with Autism Spectrum Disorder

My husband and I also need to have marriage counselling because we are growing apart due to the responsibility and pressure of the situation. Separation has been a consideration when times get really tough and the children obviously suffer!⁵⁸

8.42 Carers frequently reported that the impact of stress on family relationships has contributed to marriage breakdown and family break up as a consequence of caring.⁵⁹ One such carer, Ms Lynne McCulloch, a long-term carer for her two sons described the impact of caring on her family in the following terms:

I feel that my role as carer for my disabled sons has cost me a lot in terms of health, friendships and marriage breakdown. ... My concern is that physically I won't be able to care for my son for too much longer as he is quite a lot taller and bigger than I am. My marriage broke down in 2003 because of a lot of the strain, both physically and emotionally.⁶⁰

8.43 Siblings Australia, an organisation which supports siblings of people with disability explained that the impact on siblings can be significant, not only as a secondary carer or through the need to take on childcare responsibilities, but also:

57 Ms M Ingham, Submission No 505, p 2.

58 Ms A Dix, Submission No 431, p 1. See also: Ms J Small, Submission No 110, p 2.

59 See for example: Name withheld, Submission No 22, p 1; Ms L Kschenka, Submission No 32, p 1; Ms C Polidano, Submission No 259, pp 2-3; Perth Carer Forum Group, Submission No 983, pp 5-6.

60 Ms L McCulloch, Submission No 471, p 1.

... because parents may be stressed and depressed and so not as available to them for support.⁶¹

- 8.44 The responsibilities taken on by siblings is eloquently explained at a hearing held in Perth by Ms Raynar Foldesi who described how she and her parents shared the responsibility for caring for her 'mentally and physically disabled' 19 year old brother and the impact on herself:

In our family, I guess like every family, we work as a team. Unlike some people, my brother, at the end of our mum's life and our dad's life, will have me as his carer. I will be his sole carer and he will be my dependant. On top of that, not only will he be part of my life but my life still has to continue also. I was lucky in that I did not have to completely stop schooling but I did miss a lot of school. I did not want to go to school; I had a lot of bullying. People, especially young kids, do not understand the difference. At the moment uni is quite tough. Even though my brother does go out and he does have carers coming in, there is always a chance that something might go wrong. Only yesterday our carer could not come in because she had a medical thing and was not able to look after my brother. Therefore I had to miss out on my training.⁶²

- 8.45 The overall evidence to the Inquiry supports the need for emotional and psychological support for primary carers as well as for other family members, including relationship counselling for spouses, siblings etc. As one carer commented:

Support for carers must include ongoing counselling & emotional support. The grief is raw with no closure, it is ongoing it effects & divides the whole family & social network.⁶³

Ending the Caring Role

- 8.46 Evidence also raises the importance of support to assist carers to transition out of the caring role and to reengage after long periods of social isolation. As one carer stated, she needed help with:

Rediscovering my own identity and support to regain mental and physical wellness again. I could well do with some life-coaching,

61 Siblings Australia, Submission No 701, p 1.

62 Ms R Foldesi, Transcript of Evidence, 23 July 2008, p 47.

63 Ms J Sykes, Submission No 237, p 1. See also: Ms J Small, Submission No 110, p 2; Ms A Dix, Submission No 431, p 1; Name withheld, Submission No 500, p 26.

personal training, help to join and play in a sports team: a mentor looking out for me.⁶⁴

- 8.47 Carers also stressed the importance of emotional and other forms of support for carers when a care receiver transitions to alternative accommodation and care. In this situation, the role of the carer may change but elements of the caring role may very well continue, as explained by the Carer Support Network of SA:

Carers whose loved one goes into residential care are in a unique position. Many still provide a high level of Caring yet they are excluded as a target group by the funding bodies – both State and Federal. This is a serious current anomaly and needs to be addressed. Carers who provide Care in this situation are providing meals, taking the Care Recipient on outings, doing washing, providing social support, helping to ensure the Care Recipient doesn't lose skills learnt at home, and so on.⁶⁵

- 8.48 The needs of bereaved carers are also an important consideration in relation to counselling and psychological support services for carers. Again, the Carer Support Network of SA commented:

... most Carers need a considerable time for re-adjustment once the Care Recipient has passed away. They have experienced social isolation, have usually left work, many have lost contact with previous friends and family. Their entire frame of reference to society has been through the needs of the person they have cared for. Carers in this situation need time and support to transition to another phase of their lives without Caring responsibilities. They need time to grieve, time to adjust, time to think about their futures, time to re-establish priorities.⁶⁶

- 8.49 An Indigenous carer also emphasised the importance of emotional support at times of transition or at the end of the caring role suggesting:

Assigning a Case Manager to an Indigenous Carer in a similar fashion to those assigned to the long-term unemployed which would greatly assist an Indigenous Carer in transitioning back to the work force because personal support may be required to

64 Ms J Guilfoile, Submission No 160, p 3.

65 Carer Support Network of SA, Submission No 675, p 12. See also: Ms N Tingey, Submission No 38, p 1; Ms H Parker, Submission No 1076, p 1; Ms S Gambin, Transcript of Evidence, 12 August 2008, p 72.

66 Carer Support Network of South Australia, Submission No 675, p 12.

address issues such as Grief and Loss, how to job search and retraining. Preferably the Case Manager position would be an identified position and filled by Indigenous staff.⁶⁷

Counselling for Carers

8.50 Telephone counselling can be a very successful intervention for carers in certain situations.⁶⁸ For example, the Life Goes On model of telephone counselling provides effective support for carers and family members facing a terminal or serious medical illness.⁶⁹ However, for others face-to-face counselling and support is more important. One such carer observed:

Carers need a support person to talk to about the stresses and demands of their role, preferable in person, not just via a telephone link-up, and opportunity to meet together away from the caring environment.⁷⁰

8.51 At the national level, counselling, emotional and psychological support for carers is provided through the network of Carers Associations which delivers the National Carer Counselling Program (NCCP) for DoHA. The program provides a range of services including, information, specialist advice and counselling services to carers in order to reduce carer stress, improve care coping skills and facilitate wherever possible, the continuation of the caring role.⁷¹

8.52 In addition to the NCCP, the Department of Families, Housing, Community Services and Indigenous Affairs administers the Family Relationships Service for Carers in each state and territory. The Family Relationship Service assists carers and families considering financial planning for the future care needs of a family member with a severe disability and provides mediation for families disagreeing over the future needs of a family member with a disability.⁷²

8.53 The national network of state and territory Carers Associations have recommended an expansion of the NCCP to meet a growing demand for

67 Name withheld, Submission No 1304, p 1.

68 Ms C Cornish, Submission No 1150, p 2.

69 Life Goes On, Submission No 257, pp 1-2.

70 Mr L Wheaton & Ms J Wheaton, Submission No 190, p 3.

71 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 26. See also: www.health.gov.au/internet/main/Publishing.nsf/Content/ageing-carers-nrcp.htm.

72 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 33. See also: [www.facsia.gov.au/internet/facsinternet.nsf/via/frsp/\\$file/FRSC_Brochure.pdf](http://www.facsia.gov.au/internet/facsinternet.nsf/via/frsp/$file/FRSC_Brochure.pdf).

this service.⁷³ Carers WA also recommends that an extended NCCP should encompass specific funding to support mobile services for families in rural and remote communities.⁷⁴

- 8.54 The Committee recommends an adequate provision of counselling and psychological support services targeted at carers as well as increasing the awareness of GPs about the vulnerability of carers and their families to mental health problems.
- 8.55 The Australian Government has recently established the Access to Allied Psychological Services (ATAPS) program which enables GPs to refer patients to allied health professionals, including psychologists, social workers, mental health nurses and other allied professionals.⁷⁵
- 8.56 The Committee understands that through ATAPS, patients are eligible for a maximum of 12 sessions per calendar year - six initial sessions with an option for a further six sessions following a mental health review by the referring GP. Sessions can be individual and/or group therapy sessions. In addition, the referring practitioner may consider that in exceptional circumstances the patient may require an additional six individual focussed psychological strategies above those already provided (up to a maximum total of 18 individual services per patient per calendar year).⁷⁶

Recommendation 48

- 8.57 **That the Minister for Health and Ageing expand the National Carers Counselling Program to better meet the demand for counselling services by carers.**

73 Carers WA, Submission No 566, pp 2, 22; Carers Victoria, Submission No 652, p 26.

74 Carers WA, Submission No 566, pp 6, 22.

75 Including occupational therapists and Aboriginal and Torres Strait Islander health workers with specific mental health qualifications. See Australian Government, Department of Health and Ageing website, viewed 16 March at www.health.gov.au/internet/main/publishing.nsf/Content/mental-boimhc-ataps.

76 Australian Government, Department of Health and Ageing website, viewed 16 March at www.health.gov.au/internet/main/publishing.nsf/Content/mental-boimhc-ataps.

Recommendation 49

- 8.58 **That the Minister for Health and Ageing direct the Department of Health and Ageing to raise awareness among General Practitioners of the high incidence of mental health problems among carers and their families and of the options available for support.**

Social Isolation

- 8.59 Many carers report social isolation resulting from their caring role and the evidence describes various reasons for this. Carers often describe self imposed isolation and circumstantial isolation resulting from a lack of available respite care as well as a lack of time, money or energy to socialise. Ms Judith Sykes, a carer with caring responsibilities for an adult daughter with mental illness and that daughter's 16 year old son, explained:

Caring creates barriers in social interaction in the following ways.

- I become too tired to socialise.
- I am worried & lack concentration.
- I am involved with the problems of caring
- I have to cancel social engagements.
- I suffer social anxiety & stress.⁷⁷

- 8.60 Explanations from carers about their limited or non existent social networks include the following examples:

Ms Deborah Edwards - carer of 20 years for her son with severe disability

Sadly, the total isolation we tend to live in prevents us from making and keeping acquaintances. We just don't get the chance to socialize and make friends, and our lives are so misunderstood and feared by people outside the disability sector that they tend to keep a distance, and not visit.⁷⁸

77 Ms J Sykes, Submission No 237, p 1.

78 Ms D Edwards, Submission No 159, p 3. See also: Ms S Hewett, Submission No 298, p 1.

Ms Julie Guilfoile - carer for her son with severe disability

Extended family and friendship networks often drop just as suddenly, as extended family and friends can't cope with the reality that this family now faces.⁷⁹

Mr Richard Morrison - carer for his 29 year old son

We find we are excluded from invitations to family and friends celebrations because of: 'we knew you could not come because you have to stay home to look after Christopher' when we really know they do not want our son there.⁸⁰

Ms Narelle Hughes - carer for her daughter with high care needs

Social Isolation is a part of most carer's lives. No matter how caring and understanding friends may be, the restrictions on carers of people with high support needs make it difficult to maintain close ties. Most of our friends are now in a position of relative freedom. Their children are grown, they are able to socialise without having to find a 'babysitter'. At fifty I still cannot go out for dinner without major planning for the care of my daughter, let alone holiday for a week or two. Even if I could organise care, how would I afford it? And I am one of the lucky one's who has a partner who works.⁸¹

Name Withheld - carer for her mother

The longing for friendship, someone to talk to, since one is not able to get out, is often overwhelming. Often one has to resort to impersonal telephone counselling.⁸²

- 8.61 In some situations the care receiver's circumstances, for example, limited mobility or challenging behaviours, may contribute to the isolation experienced by carers. For example:

Ms J Burke - a carer for her husband who has an acquired brain injury

My husband never wants to go anywhere with me. Most days are based around misunderstood conversations which turn into nasty fighting. Doesn't like me going out on my own, the feeling of

79 Ms J Guilfoile, Submission No 160, p 4.

80 Ms R Morrison, Submission No 40, p 1.

81 Ms N Hughes, Submission No 830, p 3.

82 Name withheld, Submission No 1087, p 5.

isolation, he never wants to socialise and spends most of his days when at home in his pyjamas.⁸³

Ms W Bennett – a carer with two children who have an autism spectrum disorder

Social opportunities are reduced as unpredictable behaviour makes it highly stressful for me and stressful for the children. My situation makes being able to consistently and reliably attend a paid job very tenuous.⁸⁴

Ms Joy Roze – sole parent/carer for twenty years for two sons with autism spectrum disorder

At one stage I was so socially isolated due to my son's behaviour that I could not risk leaving the house with him. I remained indoors only venturing out if it was completely unavoidable. I even resorted to doing my weekly grocery shopping online as a strategy to avoid public criticism as Jayden would tantrum severely in public every time I attempted to access the community with him. My only access to a social life at that stage was the internet and although accessing it caused a lot more financial strain it was my main connection with the outside world at that time.⁸⁵

Ms Alishya Purss – a young carer for her father who has depression and frontal lobe brain damage

My friends would not understand what I do as not every 19 year old does what I do. Socially, it is hard to go out on weekends and as I used to be an active volunteer in my region in regards to red shield appeals, salvation army door knock appeals and blood donations, I can no longer contribute to society as I could before.⁸⁶

- 8.62 As discussed in more detail earlier in the report, some carers report that the support and social connections made through self help or peer support groups is extremely valuable, in fact almost a lifeline, in an otherwise isolated and demanding situation. As one carer explained:

We managed the illness as much as we could and managed to earn our living though with Bi-Polar the moods are very high and low which is difficult to live with. I am a member of ARAFMI and

83 Ms J Burke, Submission No 99, p 1.

84 Ms W Bennett-Hall, Submission No 103, p 2.

85 Ms J Roze, Submission No 485, p 5.

86 Community Options, Dementia Respite Options, Albury & District, Submission No 790, p 6.

Queensland Carers Australia which gives me company and a will to keep going.⁸⁷

8.63 A number of recommendations made in the earlier chapters of the report, address some of the key underlying causes of isolation experienced by many carers. For example:

- increasing the recognition and understanding of the caring role by the Australian community;
- increasing services and supports to assist carers in their caring role;
- increasing respite or 'time out' from the caring role;
- increasing the choice for carers to participate in employment; and
- increasing financial assistance for carers.

8.64 The evidence before the Committee paints an overwhelming picture of social exclusion. Initiatives to promote greater social inclusion for carers have also been recommended as being fundamental to raising community awareness, knowledge and understanding of carers' roles.⁸⁸

8.65 The Committee notes that the Australian Government has announced a social inclusion agenda to:

... create a fair and inclusive society where all Australians have the opportunity to find meaningful employment, access services, connect with others, have their voice heard and deal effectively with the contingencies of life.⁸⁹

8.66 At the current time, the Australian Government has identified the following priorities for the agenda:

- homelessness;
- Indigenous disadvantage;
- employment for people with mental health and disability concerns;
- children at risk; and
- jobless families.⁹⁰

87 Ms V Thomson, Submission No 300, p 2.

88 Queensland Government, Department of the Premier and Cabinet, Submission No 1203, p 2. See also: Carers Australia, Submission No 699, p 18; Carers South Australia, Submission No 684, p 6; Aged and Community Services Australia, Submission No 1085, p 3.

89 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 44.

90 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 44.

- 8.67 To implement the social inclusion agenda, the Australian Government created a social inclusion committee of cabinet in February 2008; created the positions of Minister for Social Inclusion and Parliamentary Secretary for Social Inclusion and the Voluntary Sector; and established a Social Inclusion Unit in the Department of the Prime Minister and Cabinet. In May 2008, an Australian Social Inclusion Board was established to provide advice to the Australian Government on ways to achieve better outcomes for the most disadvantaged in the Australian community.⁹¹
- 8.68 The Committee believes that the degree of social alienation suffered by carers generally, warrants them being considered as a disadvantaged group for specific attention as an early priority on the Australian Government's social inclusion agenda.

Recommendation 50

- 8.69 **That the Minister for Social Inclusion nominate carers as an early priority for social inclusion on the social inclusion agenda and with the Australian Social Inclusion Board.**

Ms Annette Ellis MP
Chair

91 Australian Government Department of Prime Minister and Cabinet, Social Inclusion website, viewed 10 March 2009 at www.socialinclusion.gov.au/pmc_social_inclusion_unit.htm and <http://www.socialinclusion.gov.au/default>.

