



Proposal: Carer Card for NSW

Carers NSW
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1. Introduction

Carers NSW is the peak body representing family carers in NSW. We are proposing that a carer card be developed in this state. This is an initiative that we believe the NSW Government could adopt at minimal cost and great reward both for carers and for its own objectives.

The proposal is based on findings of scoping work carried out by Carers NSW, which examined the various models that currently exist or are being developed in other states of Australia and internationally. These included the Victorian Companion Card, the Seniors Card model and a number of international models of carer recreation cards (particularly in the UK).

The result of this initial scoping work was to propose a carer card based on the NSW Seniors Card model. This will be of greatest benefit to carers in their own right. Many of the other models, while providing benefits to carers, were dependent on them being with the person they usually support in order to receive the benefits.

This paper will outline the background information and work that has led to this proposal, the details of the proposal and it will make conclusions and recommendations for further action.

1.1 Who are carers?

Carers are family members or friends providing ongoing support in an unpaid capacity to a person with disability, mental illness/disorder, chronic condition or who is frail aged. There are estimated to be 750,000 carers in NSW, 150,000 of whom are primary carers, meaning they provide the majority of informal support to a family member¹.

Carers are as diverse as the general population in terms of age, cultural diversity, relationship type and gender. The tasks they carry out in their caring role can vary widely, from providing transport and supervision to providing high levels of personal care around the clock.

2. Background to the Proposal

Improving financial outcomes for carers is one of the top priorities for Carers NSW. We recognise that the state government is limited in what it can do in this regard. However the following proposal is one step that NSW can take towards improving financial outcomes for carers and increasing their ability to participate in community life.

The evidence supporting this proposal comes from carers themselves and current research on carers' needs and the impacts of being a carer.

Carers can feed their views to Carers NSW through a number of channels. These include:

- By contacting the Commonwealth Carer Resource Centre, located at Carers NSW;
- Through programs and projects that are run by Carers NSW (such as the Young Carer Project, the Mental Health Project);
- Through participation in events and research convened by Carers Associations; and

¹ ABS (2003) 'Ageing, Disability and Carers: Summary of Findings'

- By providing feedback in surveys of our membership, the most recent of which was conducted in 2004, through the Carers News monthly newsletter.

Comments about carer cards from these avenues indicate that carers feel a carer card could assist not only with improved access to the community, but also with the reduction of financial stress, access to services (both general and related to disability, ageing and carers) and increased recognition.

Therefore Carers NSW is proposing a Carer Card model which would:

1. Increase participation of carers in the community;
2. Give some financial benefits for carers; and
3. Improve recognition of carers across the community, government and health and disability sectors.

These three factors will be further considered here in light of the above-mentioned input from carers and current research on the impacts of caring.

2.1 Community participation of carers

In Australia over recent years the focus of policy for people with disability, mental illness and frail aged people has been to increase and facilitate community participation. Since the 1980s, and particularly with the signing of the 1991 Commonwealth-State Disability Agreement, the community care system has been developing with a focus on de-institutionalisation, community based services and community access and recreation services².

Family carers are pivotal to the emerging community care system as they provide the vast majority of support to Australians requiring assistance. They too require support through this system in their carer roles.

Figures on community participation from the Australian Bureau of Statistics (ABS) are only available for people with disability³ and frail aged people in Australia and not carers. Based on the data outlined below, however, some assumptions may be made that community participation for carers is restricted.

Low levels of community participation are likely to be related to the effects of caring on carers' health and well-being. Some of these effects on Australia's primary carers⁴ include:

- Sleep interruption (49% of carers);
- Weariness or lack of energy (34%); and
- Often feeling depressed or worried (29%).

The majority of primary carers (55%) spend more than 20 hours caring per week and many primary carers combine caring with part-time or full-time work⁵. For the significant proportion of carers who cannot access employment due to their caring responsibilities, significant opportunities for social engagement through participation are lost.

² AIHW 2003 'Australia's Welfare': 74.

³ The ABS definition of disability incorporates sensory, physical and intellectual disability as well as mental illness, emotional restrictions and chronic conditions.

⁴ ABS 2003 'Caring in the Community' Table 8.

⁵ ABS 2003 'Disability, Ageing and Carers: Summary of Findings', Australian Bureau of Statistics, Canberra.

An Australian study⁶ of older parent carers of adult children with intellectual disability reported that:

- 30% of participants found their social life was restricted by their caring role;
- 27% couldn't have a break or take a holiday; and
- 14% couldn't see friends as often as they would like to.

A recent report by the Social Policy Research Centre⁷ found that adults with caring responsibilities spend less time on their own personal care and have more restricted leisure time than other adults.

A carer card program such as the Seniors Card would increase community involvement of carers by providing not only financial assistance but also through providing information about community events.

2.2 Financial disadvantage of carers

Financial disadvantage is expected to be a significant contributor to low levels of participation of carers in the community. It is widely acknowledged that older people, people with disability and their carers are, overall, financially disadvantaged compared with the rest of the population⁸.

The need for a strategy to address the existing inequity is particularly significant and timely given the following information on financial disadvantage, coupled with the above data on levels of community participation of carers.

In NSW over half of all primary carers rely on a government pension or allowance as their principal source of income. Their median gross personal income is \$224 per week compared with \$401 for the total population⁹.

Low income for many carers results from the difficulty they have in accessing the labour force due to the demands of caring. Over three-quarters of primary carers in NSW are workforce age (18-64) and 64% are not in the labour force, compared with just 32% of people who don't have caring responsibilities. Of those who are in the labour force the rate of full time employment is much lower than that of non-carers (46% and 71% respectively)¹⁰.

These statistics support what Carers NSW often hears from carers themselves, that they need assistance and greater financial support. In the Carers News survey 2004¹¹, when asked what type of assistance respondents needed, 28% listed a form of financial assistance.

In addition to diminished earning and employment capacity, carers also face significant costs which result directly from caring. These may include transport costs, extra electricity due to

⁶ Llewellyn et al (2003) 'Invisible Carers Facing and Uncertain Future'

⁷ SPRC (2004) 'Identifying Isolated Carers: contacting carers with unmet needs for information and support', Social Policy Research Centre, NSW.

⁸ AIHW (2003) 'Australia's Welfare'; Schofield et al 1998 'Family Caregivers': 86; ABS 2003 'Disability, Ageing and Carers: Summary of Findings'.

⁹ ABS (2003) 'Disability, Ageing and Carers: Summary of Findings', Australian Bureau of Statistics, Canberra.

¹⁰ All primary carers aged 15 and over. ABS 2003, Disability, Ageing and Carers: Summary of Findings, NSW Tables.

¹¹ Can be accessed at www.carersnsw.asn.au

increased heating or cooling, washing (for instance if the person is incontinent) respite and other services, equipment, modifications etc. A number of Australian reports have shown that these costs are significantly higher than the Carers Allowance which many carers are eligible to receive¹².

2.3 Recognition of carers

Recognition means a range of things to carers. We do know that it is important. In a survey of Carers NSW members in 2002, carer recognition was identified as a high priority issue for the state government. In a subsequent survey in 2004, carers were asked what practical measures could be taken to improve recognition. One third of respondents answered financial assistance, of which one in four specified a carer card that offers discounts (like the Seniors Card), another form of identification or free travel and access to events.

3. Carer Card Proposal

The following proposal highlights the benefits to government, benefits to carers and other components of the proposed Carer Card including eligibility, limitations, scope and cost of the Carer Card.

3.1 Benefits to carers

The proposed carer card will provide a range of benefits that carers do not currently have access to in their carer capacity. If it reflects the benefits offered by the Seniors Card, carers will have access to:

- reduced fares on government and non-government run transport in NSW;
- discounts from various businesses providing goods and services and other leisure activities;
- discounts to events in NSW such as the Sydney Royal Easter Show;
- special rates for various galleries, restaurants, clubs and holiday venues; and
- discounted professional services including insurance and legal services

A Discount Directory will be mailed each year to members of the program with a range of discounts on goods and services in the following areas:

- Automotive
- Holiday and travel
- Leisure and lifestyle
- Professional services
- Shopping
- Information

Based on feedback from carers about what they want from a carer card¹³ there are several key things that should be included in the program. There are enquires every month to the NSW Commonwealth Carer Resource Centre about whether a card for carers is available. There are also specific requests for movie passes and discounts, access to leisure activities and identification as a carer when dealing with health professionals and service providers.

¹² Fisher D (1998) *Caring Costs: A Survey of Tax Issues and Health and Disability Related Costs for Family Carers*, Carers Association of Australia, Canberra and Taskforce on Care Costs (2005) *Creating Choice: Employment and the cost of care*.

¹³ Carers NSW (2005) *A Concession Card for Carers in NSW: Scoping Paper on Different Models* (unpublished)

3.2 Benefits to government

The NSW Government has much to gain from adopting this proposal for a carer card in NSW. Supporting people with disability, ageing people and their carers is a priority for the NSW Government as demonstrated in many policy documents. These include the 1999 Carers' Statement, the NSW Social Justice Budget Statement¹⁴ and the NSW Government Disability Policy Framework¹⁵, which stipulates community participation for people with disability and their carers as a high priority.

This year a significant step has been taken towards much needed improvement in recognition and support for carers in NSW. A commitment to review the 1999 Carers' Statement and develop a whole of government Carer Policy has been made. This is to be led by the NSW Department of Health in conjunction with the Department of Ageing, Disability and Home Care (DADHC). In this respect NSW is now demonstrating a commitment to carers that is equal to, or greater than, that of other Australian states.

The carer card we are proposing will demonstrate innovation and leadership in carer support and recognition of the barriers to community involvement faced by carers in their own right that has not yet been addressed at a government level in Australia.

By introducing a carer card the NSW Government will be providing carers with tangible recognition, not only by the government, but by the community, businesses, the health system and service providers, of their role as carers.

Given that most financial support for carers is provided by the Australian Government, this is also one of the few ways in which NSW can contribute to financial outcomes for carers at a minimal cost to government.

3.3 Eligibility

Carers NSW proposes that receipt of the Carer Payment or Carer Allowance could be used to provide entitlement to the carer card (see Appendix for entitlement criteria). We have some concerns with using these criteria and as a result propose some additional criteria. However, by using receipt of these payments as the core criteria, the Carer Card will reach those carers who are most financially disadvantaged, living on fixed incomes or require significant assistance with the costs of caring.

Discussing eligibility for such a scheme involves core questions about how a carer is defined, which carers are most in need and raises further questions around reaching hidden carers and the adequacy of the current payment system to carers in reaching all carers in need. These are important issues and should remain open for discussion and further consideration. These limitations will also be outlined in this proposal.

3.4 Additional considerations

There are a number of factors pertaining to the proposed eligibility criteria that require further consideration. The four areas are: ceasing the active caring role, renewal of the Carer Card, shared payments and changed financial circumstances of the carer.

A. Ceasing active caring role

If the person being supported dies, the carer should continue to have access to benefits of the carer card for fourteen weeks, in line with the Commonwealth Department of Family and

¹⁴ NSW Government *Social Justice Budget Statement 2003-04*, NSW Treasury, Sydney.

¹⁵ NSW Government *Disability Policy Framework*, viewed at www.dadhc.nsw.gov.au/NR/rdonlyres/898B1EC7-FFED-4F87-83F0-E7C25D504C61/278/dpf.pdf 9/12/04.

Community Services (FaCS) policy regarding bereavement payments for recipients of the Carer Payment¹⁶.

This fourteen-week payment also applies if the person receiving support moves into supported accommodation for people with disabilities or a nursing home. However in such circumstances a carer should continue to have access to benefits of the carer card beyond the fourteen week period in recognition of the significant amount of support a carer can continue to provide. Confirmation in writing by a General Practitioner, Health Professional such as Nursing Unit Manager of the nursing home, that they still provide a significant amount of support would be required.

B. Renewal of carer card

When a card is issued it should be valid for up to five years depending on ongoing receipt of the Carer Payment or Carer Allowance during that period. This is based on data showing that the majority of primary carers (53%) care for 2-10 years.

We propose that a letter be sent from the administering agency every five years requesting photocopied evidence of continued receipt of the Carer Payment or Carer Allowance. The evidence could include:

- Confirmation from Centrelink;
- A statutory declaration; or
- A letter from a GP or health professional stating a significant level of ongoing care.

A Justice of Peace would need to sign any photocopied evidence.

C. Shared payments

In some scenarios a Carer Allowance may be shared between two carers providing equal amounts of care to one individual. Where this is the case both parties should be eligible for a carer card.

D. Changed financial circumstances

If a carer's financial circumstances change making them ineligible for the Carer Payment we recommend that they continue to receive benefits for the carer card for a period of fourteen weeks.

3.6 Limitations

We recognise that there are limitations to tying the carer card eligibility to financial payments. There are many hidden carers, carers of people with mental illness and young carers for instance who are unable to access these payments. Carer Associations are lobbying for improvement of these payments to be inclusive of a wider group of carers.

The Carer Allowance and Carer Payment are only two types of government benefit that carers receive, along with the Disability Support Pension, the Age Pension and various Department of Veterans Affairs payments. The carer card may not benefit "hidden carers", those financially disadvantaged carers who do not identify as carers and therefore do not receive financial support from the government.

The eligibility criteria for the Carer Allowance and Carer Payment stipulating "constant care" may discriminate against carers of people with mental illness who might provide intermittent rather than constant care. The 2004 Carers News Survey highlighted the particular

¹⁶ Information viewed at www.facs.gov.au/guide/ssguide/36480.htm 12.09.05

importance of carer recognition, particularly by health professionals, for carers of people with mental illness.

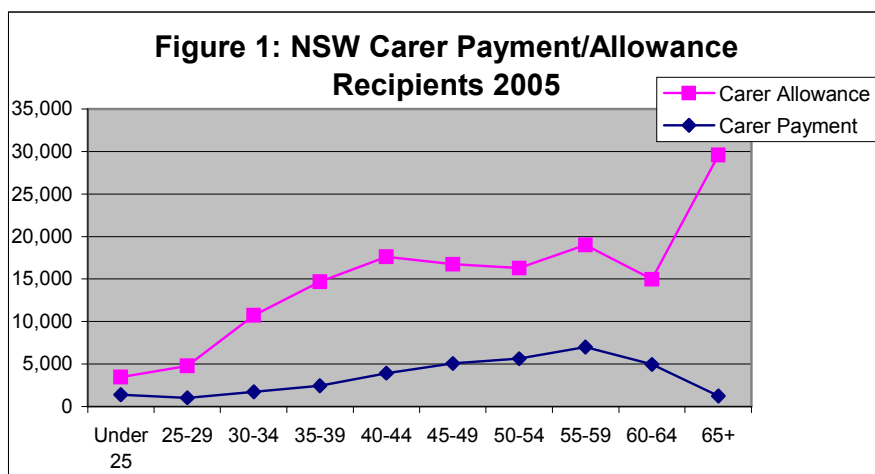
Current data shows that few young carers access the available Commonwealth payments for carers. In NSW under 5% of all Carer Payment recipients are aged under 26 and only 2% of Carer Allowance recipients are under 26 yet over 12% of all carers are in this age group¹⁷. There is significant evidence that a carer card program is needed for young carers¹⁸. Additional to barriers to community participation this group faces particular difficulties in gaining legitimacy in their caring role from government, the community and health and service providers.

It is important, therefore, that consideration be made for recognition and financial support of young carers particularly in regards to facilitating community involvement as it is known that many young carers do not access the same social activities as other people their age¹⁹.

These are general carer issues pertaining to the access to certain supports for carers from various population groups. Carers NSW works continuously to improve the access of these groups to services providing much needed assistance.

3.7 Scope

Based on the eligibility criteria that has been proposed, there would be an initial scope of less than 100,000 carers eligible for the carer card in NSW. This includes carers to the age of 60 (as people over 60 may be eligible for Seniors Card benefits). This is because there are:



Source: Centrelink unpublished data October 2005

- 34,421 people receiving the Carer Payment in NSW;
- Approximately 82% of all Carer Payment recipients are under 60;
- 113,394 people receive the Carer Allowance in NSW;
- Approximately 66% of all Carer Allowance recipients are under 60²⁰;
- 76% of Carer Payment recipients also receive the Carer Allowance²¹;

¹⁷ Data from Centrelink 'Superstar', September 2004, unpublished.

¹⁸ CA (2004) 'Young Carers Summit Report 04', Carers Australia

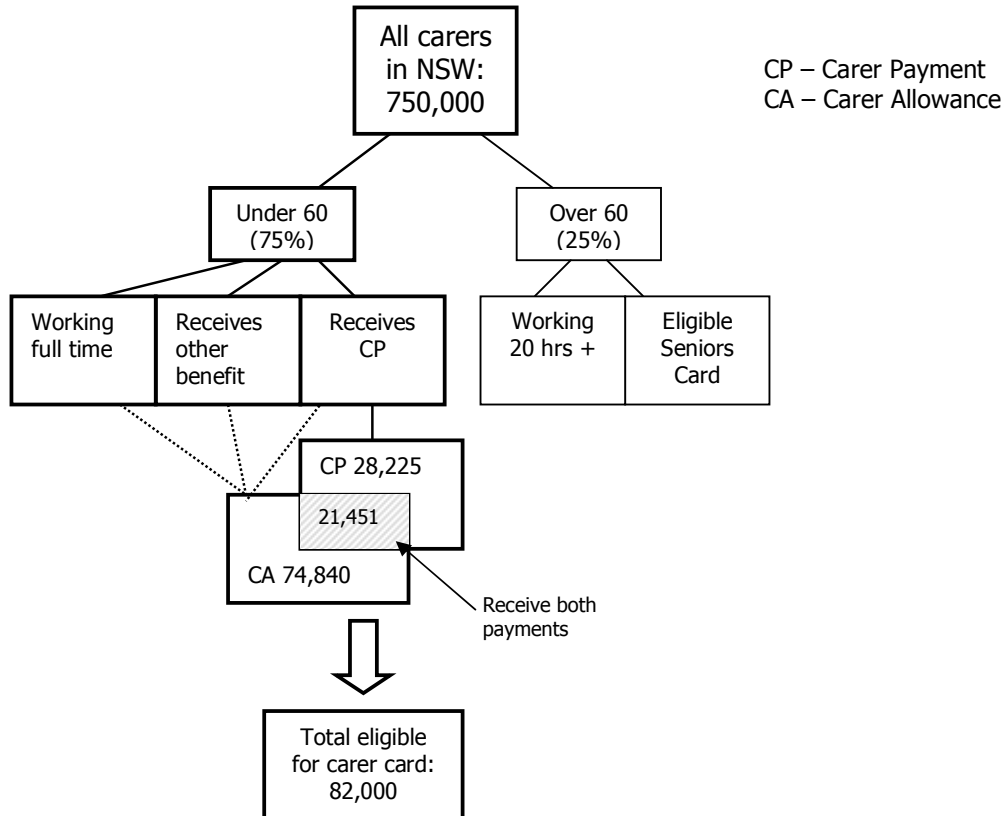
¹⁹ CA (2001) 'Young Carers Research Project Final Report' Carers Australia.

²⁰ Centrelink unpublished data, October 2005.

²¹ FaCS (2004) *Annual Report 2003-04*, Australian Department of Family and Community Services.

- Therefore approximately 82,000 people under 60 receive the Carer Payment, the Carer Allowance or both in NSW.
- A significant proportion of carers receiving both payments are aged over 60 as shown in Figure 1. This group would not require assistance under the carer card program as they would have access to the Seniors Card, although this does not take into account the recognition that a carer card could offer.

Figure 2: Eligibility for Proposed Carer Card



3.8 Cost

The following costing has been worked out based on the above scope of the Carer Card and approximate costs of the Seniors Card program, which is administered by DADHC. The Seniors Card program now has 890,000 members across NSW, which is 85% of all eligible seniors²². Therefore a Carer Card, with a potential initial scope of 80,000 would cost a fraction of the Seniors Card.

Cost relating to the Seniors Card program:

- \$1.7 million per annum including 4 staff members, outsourcing of data collection and production of annual publication that is sent to seniors.

²² Media release 'Businesses urged to access growing seniors market: NSW Seniors Card', accessed 3 May 2005 at www.seniorscard.nsw.gov.au/media/growing_market05.asp

- \$1 million revenue from advertisements in publication
- The total cost to government of transport concessions is high, around \$341 million for all concessions in 2003-04. The Seniors Card concessions would account for a small proportion of this cost²³.

With a smaller scope it can be assumed that the cost to government of a Carer Card would be significantly less than the cost of the Seniors Card.

We anticipate that the administrative costs of the carer card would include:

- 1 staff member (given the relative size of the program compared with the Seniors Program)
- outsourcing of data collection (as per Seniors Card program)
- outsourcing of publication (as per Seniors Card program)

While development of such a program is significant and can be costly, we suggest that some of this could 'piggyback' on the existing Seniors Card program.

Carers NSW believes that the carer card should be free to carers, in line with the Seniors card, so as not to deter carers from participating in the program.

Further to this there is some cross over between benefits offered by the proposed carer card and other benefits that carers receive, reducing the costs to government. These are outlined below.

3.9 Intersection of carer card with other benefits

Currently a person receiving the Carer Payment is also entitled to a Pensioner Concession Card (PCC) which allows them to receive various benefits from the Commonwealth and State governments. These include:

- A range of health and medical benefits including access to the PBS, Medicare Safety Net, hearing and dental services and NSW Ambulance;
- Concession rates for utilities including electricity, gas, water and telephone;
- Travel concessions;
- Vehicle registrations; and
- Various entertainment venues offering special rates for PCC holders.

As previously noted there are some benefits that carers can already receive through their PCC. Primarily this is the transport concession. In addition there may be some entertainment venues that would offer special rates for PCC holders and carer card members.

It is not anticipated that the carer card would entitle a carer without a PCC to concessions on utilities or vehicle registration or medical benefits (as this is not the case with the Seniors Card).

As 28,225 carers under 60 currently receive the Carer Payment in NSW many of these would already be entitled to transport concessions, therefore reducing the cost to government of

²³ Exact figures on the cost of the Seniors Card transport concessions are not known at this stage (advice from Ministry of Transport) and will not be known until end of 2005-06 financial year due to review of contractual arrangements with private bus operators.

providing further transport concessions to carers. It must be noted, however, that a carer card based on the Seniors Card model would offer a far greater range of benefits to carers than the PCC currently does.

4. Conclusion and Recommendations

Carers NSW proposes, based on a range of evidence and research, that a carer card be developed in NSW, modelled on the Seniors Card. We believe that this is a feasible, affordable and much needed strategy for improving carer support, carer recognition and carer finances in this state.

Based on this proposal there would currently be 82,000 carers eligible for the carer card. These would be carers under 60 who receive the Carer Payment and/or the Carer Allowance, the presumption being that most carers over 60 in receiving these payments would be eligible for the Seniors Card and would not require both.

We ask organisations that agree with and support this proposal to give their endorsement and that the NSW Government introduce a plan for developing a carer card in line with other strategies that are being developed for improving carer support and recognition in NSW.

Carers NSW recommends:

1. That the NSW Government investigates options for developing a carer card in NSW that is based on the Seniors Card model as a tangible way of improving support for carers in NSW.
2. That consideration be made of a carer card administered, in conjunction with the Seniors Card program, by the Department of Ageing, Disability and Home Care.

Appendix One - Entitlement Criteria for Carer Payment and Carer Allowance

People are currently entitled to the Carer Payment in Australia if they:

- Provide constant care in the home of a person aged 16 or over with a severe disability or medical condition, or an adult with moderate care needs and supervision of their dependent child if the child is:
 - under six years of age, or
 - between six and 16 years of age and attracts payment of Carer Allowance, or
 - a child under the age of 16 with a profound disability or medical condition, or
 - two or more children under the age of 16 with severe disabilities or medical conditions

A person must also meet the income and assets test and be an Australian resident or allowed to live in Australia permanently. They need a doctor's or health professional's report to help establish eligibility. The person they provide care for must also receive or be eligible for a pension and meet the income and assets limits.

A person is entitled to the Carer Allowance if they:

- Are looking after a child or an adult with a severe disability or medical condition who needs a lot of additional care and attention;
- Live with the child they are caring for, or provide care for an adult in either their home or the home of the person they care for; and
- The people they are caring for are Australian residents.

In addition:

- They need a doctor's or health professional's report to help establish eligibility.
- They can get Carer Allowance for more than one person.
- If they have two children with disabilities and the children do not individually qualify for Carer Allowance, but together create a substantial caring responsibility, they may still be entitled to a single rate of Carer Allowance.
- They can get Carer Allowance for up to two adults if both adults individually qualify.
- Two carers may share one payment of Carer Allowance, in certain circumstances, if together they are providing care.

The Adult Disability Assessment Tool and Child Disability Assessment Tool are used by Centrelink to assess medical eligibility for the Carer Allowance. For the Carer Payment the carer can work or study up to 25 hours per week and still receive the benefit. There is no means test for the Carer Allowance.

Entitlement to the Carer Payment and Carer Allowance specifies that a person must be providing "constant care". This must be confirmed by a health professional and entails the provision of frequent care or constant supervision. It must be daily care for at least 20 hours a week for an ongoing period of at least six months unless the person is supporting someone with a terminal illness.