



**Carers Australia**

**Submission to the Department of Social Services**

**Improved Assessment Process for Carer Payment and Carer Allowance**

**December 2015**

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a:

- disability,
- chronic condition,
- mental illness or disorder,
- drug or alcohol problem,
- terminal illness,
- or who are frail aged.

Carers Australia believes all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification or geographical location should have the same rights, choices and opportunities as other Australians.

They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

**For information contact:** Ara Cresswell  
Chief Executive Officer  
Carers Australia

Unit 1, 16 Napier Close  
DEAKIN ACT 2600  
Telephone: 02 6122 9900  
Facsimile: 02 6122 9999  
Email: [acresswell@carersaustralia.com.au](mailto:acresswell@carersaustralia.com.au)  
Website: [www.carersaustralia.com.au](http://www.carersaustralia.com.au)

## Introduction

Carers Australia welcomes the opportunity to provide input to the Department of Social Services' review for the 'Improved Assessment Process for Carer Payment and Carer Allowance'.

At the outset we should make it clear that we don't have definitive answers to many of the questions asked. A number of questions encapsulate too much diversity and complexity to respond definitively. In other cases we don't have the clinical expertise to respond.

We are aware that an objective of the Review is to reduce red tape and streamline assessment processes which, on the face of it, has many merits. However we are also concerned that too much standardisation and simplification may compromise the Department's ability to capture the diversity and complexity of individual of caring situations.

Our expectation is that this consultation will be the first in a round of public consultations based on discussion papers which will be increasingly refined as the review proceeds.

The responses below should be understood against this background.

## Discussion Questions

### **Q1. How could an assessment process measure care needed? & Q2. How could an assessment process measure care provided?**

#### **Consistency across 'fast-track' processes**

At present, there is a 'List of Recognised Disabilities'<sup>[1]</sup> for Carer Allowance (child) which automatically qualifies the carer for the allowance. There is also a list of medical conditions which can 'fast-track' applicants for the Disability Support Pension. However, no similar lists exist for either Carer Allowance (adult) or Carer Payment (child) or Carer Payment (adult).

Carers Australia believes there is value in developing a similar list for applicants of Carer Payment (adult and child) and Carer Allowance (adult) both in the interests of consistency and to help reduce the regulatory burden on both the Department and on applicants. For Carer Payment, conditions on the list would be those where it is clear that constant care is needed and that the condition is not going to improve. Degenerative conditions such as Motor Neurone Disease (MND) would be an example.

We do realise that maintaining such lists will be subject to occasional review as new conditions are identified for inclusion or as existing conditions can be alleviated as a result of medical breakthroughs. Such reviews may impose an extra administrative burden from time to time. It is a question of whether these costs outweigh the advantages of reducing the red tape involved in assessment for both the applicant and DHS in the normal course of events.

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<sup>[1]</sup> <https://www.dss.gov.au/our-responsibilities/disability-and-carers/benefits-payments/carers-allowance/guide-to-the-list-of-recognised-disabilities>

**Recommendation 1:** That the Review consider the feasibility and merits of developing a list of ‘recognised disabilities and conditions’ which would fast track applicants for Carer Payment (adult), Carer Payment (child) and Carer Allowance (adult).

#### **Maintaining a focus on functional impact**

In applying fast-track approaches, it is important that eligibility for both Carer Payment and Carer Allowance doesn’t shift to focus only on specific diagnosed conditions. While diagnosis is sometimes a clear indicator of care needed, this won’t always be the case. There should still be a place for assessment which focuses on functional impairment; not just what a person may be capable of doing, but what they actually do. For example, an individual with a psycho-social disability or an intellectual disability may be capable of showering, dressing and feeding themselves, but may not undertake and complete these tasks without considerable prompting and supervision.

**Recommendation 2:** That assessment for Carer Payment and Carer Allowance for those who care for someone who is not on a ‘List of Recognised Disabilities and Conditions’ applying to Carer Payment (Adult), Carer Allowance (Adult), Carer Payment (Child) and Carer Allowance (Child) be focused on the functional impact of that condition.

#### **Consistency in the definition of ‘permanent disability’**

While the objective of the Carer Payment is different to that of the Carer Allowance and therefore some aspects of eligibility differ, there are some inconsistencies between the two assessment processes that make less sense. For example, a successful applicant for the Carer Payment must care for someone who is likely to suffer from the condition or disability permanently or for an extended period of six months, whereas a successful applicant for the Carer Allowance must care for someone who is likely to suffer from the condition or disability permanently or for an extended period of at least 12 months. The Review should look at this inconsistency and consider reducing the definition of permanent disability for Carer Allowance to 6 months so that it is in-line with the definition for Carer Payment.

**Recommendation 3:** That the Review consider reducing the definition of permanent disability for Carer Allowance to 6 months to achieve consistency with the definition for Carer Payment.

#### **Ensuring the perspective and input of both health professionals and carers in assessment**

Carers Australia believes that the current process of having two questionnaires, one for the treating health professional (THP) and one for the carer, should be maintained. It is important that both sides of the caring relationship are captured as accurately as possible. While health professionals need to make a specialised/expert assessment of the functional impact of a disability, mental illness, or health condition on a person, they won’t necessarily have a full understanding of how that impairment translates into care provided - particularly when it comes to individuals with challenging behaviours. For example, a child with autism may be capable of completing many daily tasks associated with self-care, but the process of getting them to complete these activities may take considerable negotiation. Here the perspective of the carer is essential.

**Recommendation 4:** Any new assessment process for Carer Payment and Carer Allowance should maintain separate questionnaires for both treating health professionals and carers. We also

recommend that the list of health professionals be expanded for both Carer Payment (Adult) and Carer Allowance (Adult) to include appropriately registered social workers and psychologists as is the case for Carer Payment (child) and Carer Allowance (Child).

### **Options for simplification of the assessment questionnaires**

The current questionnaires are fairly comprehensive in their assessment of care needed, but there are improvements that could be made.

If the aim is to simplify and shorten the 'Assessment of care load questionnaire' for carers of children, there are some questions which could potentially be combined. For example, Questions 27 and 28 describe the child's need for assistance with dressing, distinguishing between assistance from the waist up versus from the waist down. The point is, the child needs assistance to dress. Also, Question 32 asks about the child's capacity to sit down and get up from the toilet or potty, while Question 33 asks about the child's capacity to sit down and get up from a chair or wheelchair. While there might be some differences between the care provided in each of these circumstances, there is also enough similarity to consider consolidating them.

### **Options to improve the comprehensiveness of some assessment questions**

Conversely, there are also areas of care need and care provided in the Adult Disability Assessment Tool (ADAT) that are considered by some not to be adequately captured in the current questionnaires. These relate to care which is not physically based, such as caring for someone with a mental illness. For example, Division C of the 'Professional questionnaire' asks whether the person shows signs of memory loss, but this doesn't fully capture those who need help to organise aspects of their daily life. Also, 'display aggression towards self or others' does not fully cover self-harm, which might be better described as 'needs supervision, vigilance or monitoring to ensure own safety or that of others'<sup>1</sup>. It is interesting to note that the Assessment of care load questionnaire of the Disability Care Load Assessment (Child) tool does include a specific question about whether the child has displayed suicidal behaviours, in addition to other questions about high-risk and harmful behaviours.

Division C of the 'Professional questionnaire' of the ADAT also asks whether the care recipient 'displays disinhibited behaviour'. This is fairly prescriptive and 'requires monitoring and strategies to help manage unusual behaviours' may better capture a variety of behaviours that require care and support.<sup>2</sup> Carers Australia recommends that the cognitive function component of the ADAT also be revised to include the common signs of psychosis.

**Recommendation 5:** That the Review considers the degree to which the current Adult Disability Assessment Tool (ADAT) adequately captures the care needs of people with a mental illness, including assessing the existence of symptoms of psychosis.

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<sup>1</sup> Carers Victoria 2013, *Invisible Care*

<sup>2</sup> Carers Victoria 2013, *Invisible Care*

### Q3. How can an assessment process recognise the varying frequencies of care activities and intensity of care?

#### Capturing the episodic nature of care

At present, applicants for Carer Payment and/or Carer Allowance Adult (and the treating health professionals who fill in the 'Professional questionnaire') are instructed that:

"If the condition is episodic or only apparent at certain times (LESS THAN ONCE A DAY), the carer and THP must respond as if the care recipient is NOT experiencing an episode or flare-up."<sup>3</sup>  
(Original emphasis).

The requirement for certain symptoms or behaviours to be present more than once a day in order to be considered in the assessment of care needed and care provided is particularly limiting. Individuals may have multiple symptoms or behaviours that are experienced less frequently than once a day, but which combined create a fairly high level of need. There is scope for the assessment to better capture the full impact of episodic conditions as well as the cumulative effect of a range of symptoms. For example, someone with epilepsy who has a grand mal seizure may require intense care and support for a couple of weeks after the event, especially if they have suffered physical harm – such as the breaking of bones - during the seizure.

All the factors identified above impact on the extent to which a caring role prevents the carer from engaging in "substantial paid employment"<sup>4</sup>. This really is the acid test.

**Recommendation 6:** That the review consider an assessment process that more adequately captures the cumulative effect of episodic symptoms, including the impact this has on the ability of the carer to engage in substantial paid employment (for applicants of Carer Payment).

#### Enabling easier transitions on and off Carer Payment

An assessment process which recognises 'varying frequencies of care activities and intensity of care' should also help to facilitate the transition of recipients on and off the Carer Payment when appropriate. The average duration on Carer Payment at June 2015 was 4.9 years, with 25.3 per cent of recipients on the payment for 5-10 years and a further 12.9 per cent on the payment for 10 years or more.<sup>5</sup>

The recent review of Australia's welfare system which released its final report in February 2015 concluded that the current social support system "does not have a coherent approach to supporting the significant transitions that affect an individual during their life".<sup>6</sup> For many carers, making the

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<sup>3</sup> Australian Government, Guide to Social Security Law, 3.6.9.70, *Answering the ADAT Questionnaire*  
<http://guides.dss.gov.au/guide-social-security-law/3/6/9/70>

<sup>4</sup> <http://www.humanservices.gov.au/customer/subjects/payments-for-carers>

<sup>5</sup> [www.data.gov.au](http://www.data.gov.au)

<sup>6</sup> Commonwealth of Australia 2015, *A New System for Better Employment and Social Outcomes*, Report of the Reference Group on Welfare Reform to the Minister for Social Services, 11 <https://www.dss.gov.au/about-the-department/news/2015/released-a-blueprint-for-welfare-reform>

'leap' from income support into the workforce when their caring role ceases or is reduced can be a daunting and stressful task with significant financial risk involved.

**Recommendation 7:** Carers Australia recommends that the review consider how the assessment process for Carer Payment can better enable recipients to engage in paid work when their caring role is reduced, and to transition back onto the payment smoothly if their caring role subsequently intensifies again.

#### **Q4. Are there differences between caring for adults and caring for children?**

##### **Comparing care provision**

Whether the age of the care recipient is a determinant in the level of care required will obviously depend on the individual circumstances of both the carer and the care recipient.

The care needs of the care recipient will vary depending on the nature of their disability or condition and its impact on their capacity to undertake activities of daily self-care, and whether they can complete these tasks without assistance, prompting or supervision. The age of the individual will often have a bearing on the degree to which they require support from someone, but not in all cases. Similarly, the impact of the caring role on the carer will depend on their own age in relation to the person they care for, and sometimes also their physical capability.

For example, a child with a mild intellectual disability may gradually gain greater independence as they get older through training which builds their capacity to undertake daily activities without assistance. In this circumstance the caring responsibilities required of the carer may diminish as the care recipient becomes an adult. In comparison, the caring role of someone who requires significant assistance with daily tasks such as bathing, dressing and feeding may become increasingly difficult as both the care recipient and the carer get older. The physical demands of moving an adult will be greater, particularly if the mobility of the carer is also diminishing with time.

##### **Access to replacement care**

As the Carer Payment is designed to support those whose caring responsibilities prevent them from undertaking substantial paid employment, the differences in access to replacement care will also play a factor in the differences between caring for an adult versus a child.

For example, while a child with disability may attend childcare or a specialist or mainstream school, the same options for replacement care may not be available when the care recipient turns 18 or is no longer at school.

##### **Comparing the Disability Care Load Assessment (Child) and the Adult Disability Assessment Determination**

There is understandably much over-lap between the carer and professional questionnaires for both the Disability Care Load Assessment (Child) Determination 2010 (DCLA Determination) and the Adult Disability Assessment Determination 1999 (ADAT Determination).

Carers Australia won't provide comment on the professional questionnaires as this is outside the parameters of our expertise. However, a comparison of the claimant/carer questionnaires of both the DCLA and the ADAT suggests that there would be scope for a consolidation of the two.

Currently, the 'Assessment of care load questionnaire' (to be filled out by the carer of a child) is considerably more comprehensive in covering a range of caring tasks than what is covered in the 'Claimant questionnaire' (to be filled out by the carer of an adult). For example, the DCLA asks the carer whether the child's ability to do everyday things is improving, becoming worse, relatively stable or fluctuating. Despite this also being relevant for carers of adults, the same question is not included in the 'Claimant questionnaire' of the ADAT. Other questions included in the DCLA which are not covered in the ADAT include provision of emergency first aid, carer attendance at appointments, carer involvement in physio and OT exercises, and the need for specialist replacement care. The level of detail and differentiation between a range of special care needs (such as different levels of assistance with breathing, eating, postural drainage, and suctioning) are also covered in the DCLA but not the ADAT.

If the goal was to develop a shorter version of the carer/claimant questionnaire, the current ADAT might provide a better template of how to bundle multiple questions about medical needs together. However, Carers Australia believes that the current DCLA provides carers with a greater opportunity to describe a broad range of caring tasks (and the opportunity for several open-ended questions). It would be preferable if such questions were maintained in any new version of the questionnaire/s.

#### **Q5. Are there situations when one care activity is needed, and therefore it is certain that another care activity would also be required?**

##### **Comment in relation to Q5.**

Undoubtedly there are numerous situations of this kind relating to different types of physical, intellectual and mental impairment. Rather than attempt to categorise these examples from a broad lay perspective, we would prefer to leave these questions to health professionals and organisations specialising in different kinds of disability and chronic illness to answer.

#### **Q6. What is the role of technology in reducing or increasing the caring role? How can we determine the right balance?**

It depends on a large range of factors.

- Some assistive technologies will help the person being cared for to do more for themselves than was previously the case. The extent to which this is true will vary across a vast range of disabilities and illnesses and will vary from case to case (even among individuals with the same condition) and the different physical environments in which they live.
- Other technologies may increase the caring role, especially in cases where treatment can now be provided in the home rather than in a clinical setting. Home dialysis, which requires a trained care partner and which can be time intensive on a weekly basis, can benefit both the person requiring dialysis and the carer (especially if it reduces the travel and waiting time involved in receiving treatment in a clinical facility and enables them to spend more time together). However, it also increases the caring role and dictates times when the carer must be present.

- There are a growing range of apps and other assistive telecare technologies which allow a carer to monitor the condition of the person they are caring for, communicate with them remotely and call quickly for emergency assistance if required. However the effectiveness of such technology will vary greatly from one caring situation to another. Even if it is practically effective, it will be of little benefit if the person being observed becomes lonely and frightened as a result.
- Most significantly, will carers and those they care for – particularly those of low means – be able to afford and access new technologies? When thinking of telecare, it is of note that the 2012 Survey of Disability, Ageing and Carers found that:
  - 337,500 carers (who lived in a private dwelling) did not have household access to a computer
  - 372,800 carers (who lived in a private dwelling) did not have household access to the internet

### **Comment in relation to Q6:**

Such generic questions make little sense in devising new CP/CA assessment procedures. If technologies are in place which impact on the caring role, their impact will be implicit in the description of what that role involves in each case.

### **Q7. What is a reasonable time, pattern of time and purpose to be away from caring?**

This question raises a number of issues in relation to the current rules.

#### **Pattern of Time Caring**

The current requirements to receive Carer Payment are:

“The care may be active, supervisory or monitoring. To provide care on a daily basis for a significant period, a carer should reasonably be expected to provide at least the equivalent of a normal working day in personal care, as the policy intent of providing [Carer Payment] is to recognise that the carer is not able to undertake substantial employment because of their caring responsibilities. This includes circumstances where the carer or care receiver are absent from the care situation for part of the day, but the intensity of the care required and provided during the remainder of any 24 hour period is such that it roughly equates to a normal working day.”<sup>7</sup>

### **Recommendation: 8**

It is Carers Australia’s view that the measurement of care should not only take into account the intensity of that care, but its frequency and timing. There are many circumstances in which a carer

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<sup>7</sup> Australian Government, Guide to Social Security Law, Version 1.213 2015, Carer Payment (CP) – Description, <http://guides.dss.gov.au/guide-social-security-law/1/1/c/310>

may only be required to perform particular caring tasks a few times a day, but the necessary timing of those tasks means that the carer is unable to gain or maintain paid employment. For example, a carer who is required to assist someone with PEG feeding several times a day may not be able to find work which accommodates the timing of these tasks. The unpredictability of some caring tasks may also make it difficult to gain or maintain employment.

### **Problems with the current rules applying to respite**

#### *Treatment of cessation of care in relation to illness of the carer and reasonable regular short breaks*

At present, a carer remains qualified for Carer Payment where they temporarily cease to provide the care receiver with constant care for up to 63 days in a calendar year<sup>8</sup>. These 63 days are considered to be respite from caring.

Key points:

- A carer who becomes too sick or injured to continue caring will be forced to use part of their 63 day allocation. This should not be considered as respite. It should be considered as sick leave.
- Daily care includes weekends. Most people in employment get time off for weekends or in lieu of weekends. If carers can find replacement care in order to take equivalent time off, why shouldn't they have the same entitlement without having to dip into their entitlement or be considered to have breached the condition of providing constant care?

**Recommendation 9:** That cessation of care due to sickness or the opportunity to take a break from caring equivalent to a weekend should not be treated as a cessation of care or counted against their entitlement.

#### *Inconsistency in the '63 days' temporary cessation of care*

A recipient of Carer Payment or Carer Allowance may take a break from caring for up to 63 days each calendar year without losing their qualification. In comparison, funding rules provide for 63 days aged care respite per financial year.

**Recommendation 10:** That the Review considers applying the same definition of a year for both aged care allocations of respite places and the allocation of 63 days temporary cessation of care for recipients of Carer Payment and Carer Allowance.

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<sup>8</sup> Australian Government, Guide to Social Security Law, 3.6.4.40, *Qualification for CP during Temporary Cessation of Care* <http://guides.dss.gov.au/guide-social-security-law/3/6/4/40>

## The Application of the '25 hour rule'

The current '25 hour rule' which prevents Carer Payment recipients from undertaking education, training or work for more than 25 hours a week (including the time taken to travel)<sup>9</sup> restricts the capacity of carers to remain engaged with the workforce or to update their skills while caring.

### Recommendation 11:

Carers Australia supports the following recommendations of the Australian Law Reform Commission:

- The *Guide to Social Security Law* should provide that a temporary cessation of constant care due to participation in paid employment, unpaid voluntary work, education or training that exceeds 25 hours per week:
  - (a) does not result in automatic cancellation of Carer Payment; and
  - (b) may, in some circumstances, be compatible with the constant care requirement for qualification for Carer Payment.<sup>10</sup>

Carers Australia considers that there are a range of ways the '25 hour rule' could be amended to improve the capacity of carers to remain connected to the workforce or to engage in education or training whilst caring. These include:

- Removing the inclusion of travel time in the '25 hours' so that those who are faced with longer travel times for geographical reasons are not unfairly penalised.
- Applying the 25 hour restriction only to paid employment, not to education and training. This would allow carers who have been out of the workforce for extended periods of time to gain new qualifications and skills which will improve their employment prospects when they cease caring. The change would also have a particular effect on young carers, who are currently unable to combine school with their caring role if they are in receipt of Carer Payment.

**Recommendation 12:** If recommendation 11 is not taken up, Carers Australia recommends the Review consider a range of other ways to amend the '25 hour rule' including removing the inclusion of travel time or applying the restriction only to paid employment, not to education and training.

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<sup>9</sup> Australian Government, Guide to Social Security Law, 3.6.4.70, *Changes to Carer Situation – Effect on CP Qualification* <http://guides.dss.gov.au/guide-social-security-law/3/6/4/70>

<sup>10</sup> Australian Law Reform Commission 2013, *Access All Ages: Older Workers & Commonwealth Laws*, 176