



**Australian Government
Department of Families, Housing,
Community Services and
Indigenous Affairs**

**A report on the payment review
experiences of Carer Payment and Carer
Allowance recipients**

July 2008

Table of contents

I.	Introduction.....	4
A.	Background.....	4
B.	Research objective	6
C.	Research methodology	6
D.	Profile of research participants	8
E.	Presentation of findings.....	10
II.	Overall awareness and understanding of Carer Payment and Carer Allowance.....	11
A.	About this chapter	11
B.	Awareness and sources of information about Carer Payment and Carer Allowance.....	11
C.	Purpose of Carer Allowance and Carer Payment.....	13
D.	Awareness and behaviours about reporting requirements for Carer Payment and Carer Allowance.....	13
III.	Awareness and understanding of review processes	15
A.	About this chapter	15
B.	Awareness and sources of information about review processes ...	15
C.	Purpose and acceptance of review processes	16
D.	Awareness of timing of review processes.....	17
E.	Awareness of appeals options	18
IV.	Experience of the review process.....	19
A.	About this chapter	19
B.	Recall of reviews.....	19
C.	Forward planning for the review.....	19
D.	Format of reviews	20
E.	Scheduling and spacing of reviews	20

F.	Centrelink customer service	21
G.	Income and assets reviews	22
H.	Circumstances reviews	22
I.	Medical reviews	22
J.	Review outcomes	24
V.	Caring situations and impact of the review process	26
A.	About this chapter	26
B.	Caring arrangements	26
C.	Carer health and wellbeing	27
D.	Impact of the review on the caring situation	28
VI.	Conclusions and possible improvements	29

Note: This is the full report with an amendment that removes all references to the locations in which the research was conducted and all direct quotes made by participants.

I. Introduction

A. Background

The Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) provides income support, income supplement payments and other forms of assistance to support carers of people with disability or a severe medical condition, or who are frail aged.

Carer Payment (CP) is an income support payment for people whose caring responsibilities prevent them from undertaking substantial workforce participation. Carer Payment is subject to income and assets tests and is paid at the same rate as other social security pensions.

Carers may receive either:

- ◆ Carer Payment (child) –for those caring for a child with a profound disability who has extremely high care needs
- ◆ Carer Payment (adult) – for those caring for someone with a disability, severe medical condition or who is frail aged

Carer Allowance (CA) is an income supplement available to people who provide daily care and attention at home to a person with disability or a severe medical condition. Carer Allowance is not taxable or income and assets tested. It can be paid in addition to a social security income support payment.

Carers may receive either:

- ◆ Carer Allowance (child) – for those who care for a child with a disability or severe medical condition at home
- ◆ Carer Allowance (adult) – for those who care for an adult with a disability, severe medical condition or who is frail aged at home

Both payments are subject to medical and circumstance reviews:

- ◆ Carer Allowance/Carer Payment medical reviews are paper-based mail reviews and are conducted every two years. Medical

reviews are not generally required where the person being cared for has a severe, permanent and non improving condition that results in high care needs.

- For Carer Allowance (child), medical reviews are scheduled at developmental milestones. Children with disabilities or medical conditions that appear on the Lists of Recognised Disabilities are subject to a simplified process of review. The reviews still occur at the developmental milestones but new medical information is not required. These reviews check to ensure that the child is still receiving care and attention in the family home. When the child reaches 15 years and 9 months customers is invited to test their eligibility for Carer Allowance - caring for a person 16 years or over.
- ◆ Carer Allowance/Carer Payment circumstance reviews occur every two years to check that care is still provided and that the caring situation has not changed. They are generally conducted by telephone, unless the carer is not able to be contacted. A mail-based review is then undertaken.
- ◆ Income and asset reviews are currently paper-based mail reviews and are usually conducted annually.

A new review regime is scheduled to be rolled out for Carer Allowance and Carer Payment recipients in the near future.

B. Research objective

This research project was undertaken to explore the payment review experiences of recipients of Carer Payment and Carer Allowance.

- ◆ It was similar in scope and approach to another project undertaken for the Department in 2005.

In preparation for the new review regime for Carer Allowance and Carer Payment recipients, the Department sought to determine if there are further areas for improving customer review outcomes prior to the commencement of the new review process.

The objective of the research was to obtain information on recipients':

- ◆ awareness and understanding of the payment review processes;
- ◆ experience of the range of reviews they had recently undergone; and
- ◆ opinions of the way the review was conducted.

The target audience for this research were recipients of Carer Payment and Carer Allowance who had undergone a recent review.

C. Research methodology

A purely qualitative research approach was adopted for this project, comprising:

- ◆ a series of mini focus groups conducted in and from 17 to 19 June 2008 (n=41); and
- ◆ in-depth telephone interviews with Carer Allowance and Carer Payment recipients in and (n=29).

A total sample of 70 people participated in the research according to the following research structure:

Type of research participant	Review type			Total
Mini focus groups				
Carer Allowance recipients caring for one or more children	Medical	1 (n=5)	-	1 (n=5)
	Care and attention	1 (n=5)	-	1 (n=5)
Carer Allowance recipients caring for an adult	Medical	1 (n=5)	-	1 (n=5)
	Care and attention	1 (n=5)	-	1 (n=5)
Carer Payment recipients caring for one or more children	Income-assets	1 (n=3)	-	1 (n=3)
Carer Payment recipients caring for an adult (and possibly also a child)	Medical	1 (n=4)	-	1 (n=4)
	Income-assets	1 (n=4)	-	1 (n=4)
Carer Allowance and Carer Payment recipients	Medical	-	1 (n=6)	1 (n=6)
Carer Allowance and Carer Payment recipients	Income-assets	-	1 (n=4)	1 (n=4)
In-depth telephone interviews				
Carer Allowance recipients caring for one or more children	Circumstances	1	1	2
	Medical	1	1	2
	Care and attention	1	2	3
Carer Allowance recipients caring for an adult	Circumstances	1	1	2
	Medical	2	1	3
	Care attention	2	2	4
Carer Payment recipients caring for one or more children	Circumstances	1	2	3
	Income-assets	1	1	2
Carer Payment recipients caring for an adult (and possibly also a child)	Circumstances	2	1	3
	Medical	1	2	3
	Income-assets	1	1	2
Total				n=70

A research issues guide (that was developed in conjunction with the FaHCSIA project team) was used to guide discussions in the mini focus groups and telephone interviews. Due to the exploratory nature of the research all discussions were flexible and only semi-structured, allowing research participants to raise issues they considered to be relevant.

Research participants were recruited from customer lists¹ provided by FaHCSIA. Prior to the research all clients on this sample list were sent a primary approach letter by the Department, advising of the purpose and nature of the research and allowing for potential participants to opt-out of the research process.

Participants were provided with a reimbursement in recognition of the time and expense—including possible respite costs—of taking part in the research session.

D. Profile of research participants

The demographic profile of research participants shows that people from a range of demographic characteristics participated in the research. The demographic profile of the research participants is presented below².

- ◆ Age:
 - 18-30 years – 3%
 - 31-45 years old – 27%
 - 46-60 years old – 51%
 - 61-75 years old – 19%
- ◆ Marital status:
 - Single – 14%
 - Married – 71%
 - Defacto/ Partnered – 3%
 - Divorced/separated – 11%

¹ Lists provided by FaHCSIA contained only limited customer contact details of people who had undergone a review in the last 6 months.

² Note that not all research participants completed a demographic questionnaire. The percentages represent the participants who answered the question on the demographic questionnaire. Percentages may not sum to 100% due to rounding.

-
- ◆ Gender:
 - Female – 77%
 - Male – 23%
 - ◆ Primarily cared for³:
 - Child/children – 45%
 - Spouse – 36%
 - Parent – 26%
 - Friend – 1%
 - ◆ Ages of person/people cared for⁴:
 - 1-9 years – 23%
 - 10-19 years – 13%
 - 20-39 years – 19%
 - 40-59 years – 19%
 - 60-84 years – 32%
 - 85 years and above – 12%
 - ◆ Centrelink payments received⁵:
 - Carer Allowance – 90%
 - Carer Payment – 60%
 - Parenting Payment – 4%
 - Newstart Allowance – 3%
 - Disability Support Pension – 1%
 - Age Pension – 1%
 - ◆ Annual household income:
 - Under \$30,000 – 57%
 - \$30-45,000 – 18%
 - \$46-60,000 – 10%
 - \$61-80,000 – 2%
 - \$81-100,000 – 10%
 - More than \$100,000 – 3%
 - ◆ Highest level of education completed:
 - Primary school – 9%
 - High school (Year 10 and under) – 33%
 - Year 11 – 13%
 - Year 12 – 13%
 - TAFE, Diploma, Certificate – 21%
 - University (under or post graduate) – 11%
 - ◆ Background:
 - A non-English speaking background – 22%
 - An Aboriginal or Torres Strait Islander background – 2%

³ This question allowed for multiple responses.

⁴ This question allowed for multiple responses.

⁵ This question allowed for multiple responses.

E. Presentation of findings

The research was qualitative in nature and hence the results and findings are presented in a qualitative manner. This research approach does not allow for the exact number of participants holding a particular view on individual issues to be measured. This report therefore provides an indication of themes, experiences and reactions among research participants rather than exact proportions of participants who felt a certain way.

The most common findings are reported except in certain situations where only a minority has raised particular issues, but these are nevertheless considered to be important and to have potentially wide-ranging implications/applications.

Findings for each target group have only been identified and discussed if there was a difference in results with the research participants overall.

Quotes have been provided throughout the report to support the main results or findings under discussion.

To facilitate readership, the term 'carer payments' has been used to refer to combined findings about Carer Payment and Carer Allowance throughout the report.

II. Overall awareness and understanding of Carer Payment and Carer Allowance

A. About this chapter

This chapter presents the research findings in relation to participants' awareness and understanding about Carer Payment and Carer Allowance—including their sources of information, understanding of the purpose of the payments, and awareness and behaviours in relation to reporting requirements.

B. Awareness and sources of information about Carer Payment and Carer Allowance

The research found that most participants were aware of the existence of two different payments available to carers. However, understanding of the eligibility requirements and purpose of the payments was mixed, as found in previous research⁶. A few participants were unaware that they could receive both payments - believing that they could only receive “one or the other”.

Participants who were receiving only Carer Allowance tended to have a lower awareness of the payments and their eligibility requirements than those who were receiving both Carer Allowance and Carer Payment. In general, participants caring for someone, or having a spouse, receiving another income support payment tended to be more aware of the parameters for carer payments – mainly because of their familiarity with Centrelink/ the welfare system.

When applying for Carer Allowance, many participants stated that they had been “surprised” to find that they were eligible. A few Carer Allowance participants remained unsure about the eligibility requirements for Carer Payment.

Several participants had been a carer for many years before learning about the carer payments and their eligibility for financial assistance. These participants felt “frustrated” by the fact that they had not been

⁶ Qualitative research on Carer Allowance and Carer Payment Review Experience conducted by ORIMA Research, 2005

made aware of the payments sooner.

- ◆ However, some were pleased that, once they applied for the payments, their payments were back-dated up to 2 years.

Most research participants had learned about the payments through “word-of-mouth” from their GP or other medical professional, or from friends and family members.

Only a few participants indicated that they found out about the carer payments directly through Centrelink—generally when they were applying for other assistance or support.

Some participants felt that Centrelink / “the Government” “deliberately” did not promote carer payments in order to “save money”.

- ◆ A few participants noted that other carers they knew who were on the Age Pension did not realise that they may be entitled to carer payments – which was believed to have additional benefits not covered by the Age Pension (e.g. bonus payment).

However, several participants also reported that once they made Centrelink aware of their caring role, staff were helpful in assisting them to receive their correct entitlements.

Most research participants were aware that eligibility for Carer Allowance was not based on income/means testing. Similarly, many were aware that Carer Payment was “like other pensions” - in that it was income tested. Several participants were also aware that receiving other income support payments (such as the Age Pension) excluded them from receiving Carer Payment.

The research found that Carer Payment participants generally had a reasonable awareness of the eligibility criteria for receiving Carer Payment. Specifically, participants were aware that:

- ◆ they had to be looking after “special needs” child(ren)/adult(s);
- ◆ their caring demands, in terms of time and effort, had to exceed the effort required for a “normal” child/adult;

- ◆ a doctor/specialist had to complete the relevant documentation to validate the condition of the care recipient and the amount of care required; and
- ◆ to receive Carer Payment, claimants had to satisfy the income/means testing requirements.

Several research participants stated that it was “much harder” to qualify for Carer Payment and that the medical conditions had to be “more serious”. Many also believed that the medical assessment process as well as the income and assets testing criteria were more “stringent” for Carer Payment.

C. Purpose of Carer Allowance and Carer Payment

The research found that participants broadly understood that Carer Allowance and Carer Payment were provided by the Government to:

- ◆ assist with the cost of caring for someone who has a disability/medical condition;
- ◆ assist with the costs of rehabilitation/treatment of the person with a disability/condition;
- ◆ facilitate caring at home and, indirectly, ease demand for places in hospitals and nursing homes; and
- ◆ (for Carer Payment) compensate for the carer’s loss of earnings/income as a result of their caring role.

However, many were unclear about whether Carer Payment and Carer Allowance had different purposes. Also, some participants were confused about which was the smaller payment and why this was so.

D. Awareness and behaviours about reporting requirements for Carer Payment and Carer Allowance

In comparison to the previous research conducted by ORIMA Research on this topic, this project identified improved levels of awareness of the types of

circumstance changes that need to be reported. Almost all research participants understood that they needed to inform/update Centrelink about changes, including:

- ◆ changes in personal details/information (e.g. address);
- ◆ changes in living conditions, arrangements and/or circumstances;
- ◆ changes in income / assets;
- ◆ changes in the amount/type of care being provided;
- ◆ changes in the condition of the care recipient (if they got better or the care was no longer required); and
- ◆ any period of time that the carer/care recipient goes overseas.

However, some participants were unsure about whether carers were required to notify Centrelink when the care recipient went into hospital or respite care for short periods of time.

A few carers who had claimed the payments several years ago appeared to be less sure about their detailed reporting requirements. They suggested that a “refresher” about the requirements would be useful for them.

Carers who had regular contact with Centrelink (due to a requirement to report their spouse’s income on fortnightly basis) tended to have the highest level of awareness of reporting requirements.

Carers who had regular/previous dealings and contact with Centrelink—via other income support payments or via the care recipients’ payments (e.g. DSP)—tended to be more aware of Carer Payment (and Carer Allowance) reporting requirements than those who were new to the system.

III. Awareness and understanding of review processes

A. About this chapter

This chapter presents the research findings in relation to participants' awareness and understanding of the review process, their acceptance of the need for periodic reviews and their awareness of the appeals process.

B. Awareness and sources of information about review processes

Only a few research participants recalled being told about the review process when they were claiming carer payments.

These few participants who were aware of the review process had expected to be reviewed by way of:

- ◆ a “medical update” on the care recipients' condition and the level of care required;
- ◆ a “check” of their circumstances and situation – “to see if anything had changed”; and
- ◆ an income / assets review.

Awareness of how often and when reviews would occur was quite limited among research participants.

While most of participants assumed that there would be some form of “checking” process, many were “surprised” when their first review “arrived in the mail” as they were not expecting it. They also reported that after their first review had occurred, they were “still not aware” of the frequency of future review cycles.

Consistent with previous research, awareness of review processes appeared to be higher amongst Carer Payment recipients than among Carer Allowance only recipients. Carer Payment participants tended to be more aware of review processes from their previous experiences of other income support payments (either for themselves or their care recipients).

C. Purpose and acceptance of review processes

Acceptance of the review process for carer payments appeared to be more widespread during this round of research than was the case in 2005. The research found that, overall, participants were satisfied with the review requirements—noting that the process was “fairly easy” to complete and it “didn’t have to be done very often”.

Most research participants agreed that review processes were required for carer payments:

- ◆ where the condition of the care recipient could change over time;
- ◆ to ensure that the same level of care was still being provided; and
- ◆ to check that people’s circumstances had not changed, particularly their income and assets.

A few participants also felt that review processes were necessary to prevent potential “cheats” and “abuse” of the payments.

Concern about the review processes related to the need for medical reviews. Nearly all participants felt that carers looking after people with permanent conditions—for example genetic conditions, terminal illness and conditions that progressively deteriorated with age—should be excluded from the review process. Research participants believed that such cases were not being excluded from the current medical review regime.

While having a recognised “list” of conditions in the medical form was seen as a “good idea” and as making the review process much easier, many participants felt that the list was too restrictive as it did not cover a sufficient number and range of conditions.

- ◆ However, some participants recognised that the conditions were periodically updated - with several carers noting that their care recipients’ condition had been “listed” between their previous and most recent reviews.

There was little awareness among research

participants that the doctor / medical specialist could alter the review regime by identifying the care recipients' condition as being permanent / unchanging.

In addition, medical reviews were perceived as being a lot of “hassle”, “effort” and “cost” for some participants. These participants indicated that making and attending medical appointments (particularly with medical specialists) to complete the review form was difficult due to:

- ◆ limited availability of specialist appointments—some noted that appointments had to be made “months in advance”;
- ◆ limited knowledge that the specialist had of the functionality of the care recipient as a result of minimal regular contact with the patient;
- ◆ the reluctance of care recipients' wanting to go to the doctor or “out of the house”;
- ◆ needing to organise additional help to “manage” / take the care recipient to the appointment; and
- ◆ transport availability—especially in the regional area.

A few participants commented that the cost and effort involved for medical reviews was “considerable” for those only receiving “a small amount” of Carer Allowance.

A few research participants questioned why the relative level of care being provided had to be continually assessed via the review. These participants felt that such an on-going assessment would only be justified if the rate of payment was linked to the level of care required and/or provided. They could not understand the need for regular care assessments in cases which were “not going to get better” as the payment rate was not variable or “on a sliding scale”.

D. Awareness of timing of review processes

Participants recalled wide variations in the timing of

their review processes—ranging from annual reviews to once every 2-4 years.

Overall, there was a lack of awareness about how often they should expect reviews to occur, and whether different types of reviews would occur at different intervals or at the same time.

Lack of knowledge of the timing of reviews generated concern and “worry” among some carers. These participants, who were unsure about when they would next be required to do a review, were concerned that they would “miss it in the mail” and have their “payments stopped”.

E. Awareness of appeals options

All research participants presumed that there would be some mechanism available to them to dispute a review decision that they disagreed with or perceived as unfair.

While the details of the appeals process were not widely known, most participants were confident that they would be able to source such information if they needed it—some recalled that they had “seen something on the back of a form”.

Participants agreed that detailed information about the appeals process was unnecessary prior to having an issue with a negative review outcome.

IV. Experience of the review process

A. About this chapter

This chapter presents the research findings in relation to participants' actual experiences of the review process. Initially the chapter presents some overall findings about the review process, and later in the chapter, specific findings about the different types of review experiences are covered.

B. Recall of reviews

Although the participants recruited for this research had been through a recent review process (within the last 6 months), recall of the latest review was varied.

Research participants tended to more easily recall:

- ◆ forms-based medical reviews, compared to telephone reviews and income and asset reviews; and
- ◆ reviews which they felt had been more “problematic” or “stressful processes”.

In addition, some participants found it difficult to distinguish between reviews for carer payments and those for income support or other assistance / payments being received by the care recipient.

C. Forward planning for the review

As already discussed, research participants said they did not know when their review would occur and had no sense of the timing for reviews—other than “every few years”. Therefore, participants reported that they were not able to plan or prepare for the review.

None of the participants recalled receiving any prior communications from Centrelink about their most recent review and all reviews (whether via phone or form) were reported as “coming out of the blue”.

While some participants reported that they did not need any advance notice of the review, others felt that prior awareness would be helpful. Those who preferred to receive advance notice of the review

process indicated that this was important because:

- ◆ they could start “pulling together any necessary documentation” / information;
- ◆ it would reduce the “surprise” and anxiety associated with the review; and
- ◆ it would assist in scheduling medical appointments.

A couple of participants noted that their last review form came just after they had completed “another round” of specialist/medical appointments (for ongoing health management reasons). This was reported as being “annoying” as they had to then make further appointments to complete the review form.

D. Format of reviews

The research indicated that, overall, participants had a preference for the “quickest” and simplest format for the review.

Telephone reviews were generally liked because they were fast, efficient and any concerns / questions could be addressed immediately. Contact with a Centrelink staff member was also seen as providing an opportunity to explain answers to review questions and ensure that the correct interpretation of the information was made.

Forms-based reviews were seen as necessary to collect some types of information but it was felt that the questions should be as minimal and stream-lined as possible.

Some carers looking after children or elderly people with high-needs felt that forms were a more convenient form of review, as they could complete them when they had the time / opportunity.

E. Scheduling and spacing of reviews

Overall there was no clear preference for the spacing of carer payment reviews—with different individuals preferring different options based on their individual circumstances and requirements.

Some said they liked carer and care recipient (e.g. DSP, Mobility Allowance) reviews to be as spaced apart as possible so that the effort involved could be spread over time. Others preferred reviews to come “all together” so that they could be “all done” and any similar information / documentation could be provided at one time.

F. Centrelink customer service

Overall, participants were satisfied with their interactions with Centrelink staff in the review process—saying that they were “helpful” and “understanding”.

However, a few participants reported experiencing a number of issues including:

- ◆ Centrelink (perceived to be sometimes repeatedly) losing forms or failing to transfer information between offices that were dealing with a single care situation.
- ◆ Centrelink cancelling payments—and therefore the loss of associated State Government entitlements—as a result of lost paperwork
- ◆ Having to deal with an individual staff member who had exhibited a lack of understanding and empathy about the caring role and / or disability / condition.

Although these incidents were rare, they had a substantial impact on the affected carer and led them to:

- ◆ provide more negative feedback about the review processes and Centrelink overall;
- ◆ feel unsure and anxious about further review processes;
- ◆ for some, seek to lodge all forms and information to Centrelink in person and insist on evidence of this—making the review process more onerous.

G. Income and assets reviews

Overall, income and assets reviews were found to be “quite straightforward” and understandable. As previously outlined, there was a high level of awareness and acceptance of the need for such reviews and the general type of information that would be collected.

A few participants felt that income and assets reviews were unnecessary because Centrelink already had all this information “on their computers” from their spouse’s income support payment.

There was some level of confusion amongst participants as to whether the review information should be posted to Centrelink or lodged in person - with many choosing to take it into an office “just to be sure” and / or to have it “stamped”.

The timeframe for income and assets reviews was felt to be appropriate.

H. Circumstances reviews

These reviews, by phone, were also found to be fairly simple and non-invasive.

Participants felt they were conducted appropriately and sensitively. There was also adequate scope for the review to be rescheduled if required.

Some participants said they would like to receive a follow-up letter in the mail after such reviews to confirm the information provided and the review outcome.

I. Medical reviews

As outlined previously, medical reviews were found to be the most difficult and time consuming for carers to complete.

Although the questions were relatively “straightforward” and easy to understand, the form was felt to be “long” to fill out, giving them “another thing to do”.

- ◆ NESB carers found the forms much more difficult to understand and complete. However, they were generally able to access help from family or Centrelink to complete the forms.

A few participants said that they received help from health professionals—such as hospital staff and mental health teams—in filling out and submitting (both parts of) the form and that this was “extremely helpful”.

Participants looking after care recipients with complex, uncommon, or undiagnosed conditions appeared to have some of the most significant problems and concerns in completing the medical review because:

- ◆ the conditions were not on the “list” so the whole form needed to be completed;
- ◆ the condition / care requirements could not be easily captured within the assessment tool—for example some more complex tasks / activities could be done while other simple ones were beyond the care recipients’ ability;
- ◆ carers felt that more time needed to be spent in providing detailed notes about the condition / care requirements; and
- ◆ carers were anxious that Centrelink staff would not understand the condition.

In general, carers in this situation felt quite anxious about whether they could complete the review “properly” to continue receiving payments.

In relation to the doctor / specialist’s review form, the research found that:

- ◆ participants sometimes found it “hard” to obtain specialists appointments within the review timeframe;
- ◆ travelling to doctors / specialists was difficult for some carers / care recipients, especially those in rural locations who had to “come into the city”;
- ◆ many carers felt uncomfortable taking the form to the doctor as they were aware that they did not like filling out the form;

- ◆ a couple of carers “pre-filled” the form for the doctor to simply check and sign, as the carer felt that they were in the best position to know the answers to the questions; and
- ◆ a few carers felt that it was difficult to “prove” the condition of some care recipients to the doctor as the care recipient could be “on their best behaviour” and “hiding” conditions, such as aggression and memory loss, while at the appointment.

Several participants suggested that it would be helpful if allied health professionals could fill out the doctors / specialists form because:

- ◆ these people knew the care recipient’s condition better from more frequent contact;
- ◆ they may be more willing or have more time to fill out the forms; and
- ◆ they were more accessible, particularly in non-metropolitan areas.

Several participants suggested that the medical review could be much more easily completed if they were asked to nominate any “changes” in the care recipients condition, rather than “starting from scratch” with each review. This was likened to the need to report changes in circumstances to Centrelink, and it was felt that it could be quite easily and quickly completed by doctors and carers.

The timeframe for medical reviews was felt to be sufficient and appropriate, with most participants recognising that they could seek an extension for special needs such as getting an appointment with a doctor who was unavailable within the timeframe.

J. Review outcomes

Only a few participants in this research round reported that they had received any follow up contact in relation to their review outcome—in all cases this was by letter.

However, a substantial number of participants said that they would have liked to be contacted about the outcome of their review, regardless of whether their

payment was continuing or not.

This was because many participants:

- ◆ wanted to know that Centrelink had received all the necessary forms / documentation and the review had been completed;
- ◆ otherwise had to rely on regularly checking their bank account to make sure their payment was continuing; and
- ◆ wanted to relieve their anxiety about the review outcome.

It was felt to be appropriate for the review outcome to be advised by mail, or by telephone if the review was successful.

There was also an indication that some carers would like information about the timeframe for their next review process to be provided at the completion of the current review. This was to help them in planning for the review and to reduce their anxiety about when it would next occur.

V. Caring situations and impact of the review process

A. About this chapter

This chapter aims to provide a contextual overview of the caring arrangements of the research participants, as well as a feel for their physical and emotional health status. It also outlines the findings about the impact of review processes on the caring role.

B. Caring arrangements

Most research participants were caring for one or more family members—elderly parent/s, a spouse, a sibling or child/ren. Just a few participants were caring for a friend.

A substantial proportion of the carers who took part in the research (16%) were providing care for more than one person, for example two parents, a spouse and child, or two children.

Primarily, the care was being provided in the carer's own home although those caring for a sibling or friend were doing so in the care recipient's dwelling.

Care recipients' disabilities included, but were not limited to, physical disabilities or injuries, learning difficulties, developmental delays, autism, genetic disorders / conditions, diabetes, epilepsy, mental illness, post-traumatic stress disorder, dementia, physical disabilities, heart conditions and other conditions of old age. Several participants noted that the person they cared for experienced multiple and compounding conditions.

The length of time spent caring spanned between 18 months and 24 years, but most research participants had been caring for a minimum of several years.

Most of the research participants were undertaking the caring role entirely alone or with very limited assistance from family, friends or professional services.

C. Carer health and wellbeing

All carers involved in the research reported adverse effects on their physical and emotional health as a result of the caring role. Many participants said that they gave their own health and wellbeing the lowest priority due to lack of time, energy and money.

Physical issues relating directly to the caring role and associated responsibilities were commonly reported as including:

- ◆ high blood pressure and associated heart conditions;
- ◆ physical demands in carrying, moving or restraining the care recipient;
- ◆ constant tiredness and fatigue as a result of poor sleeping patterns; and
- ◆ effects of a poor diet due to “eating for comfort” and “eating on the run”.

Psychological and mental health impacts of caring were seen to include stress, anxiety and depression.

In addition to these diagnosed / diagnosable conditions, the research also found that the carers commonly experienced:

- ◆ Issues of guilt—especially around asking for assistance in the caring role, and managing relationships with siblings of children being cared for and spouses.
- ◆ Constant feelings of uncertainty / anxiety—particularly around the ongoing health of the care recipient and making arrangements for children who would continue to require care as parents became elderly / incapacitated.
- ◆ Confusion and failing memory—particularly amongst older carers.
- ◆ A perceived sense of loss of patience / tolerance for the care recipient over time.

The carers who took part in the research typically reported being socially isolated, with many having no ongoing relationships other than with the care recipient and a small number of other family members.

Participants frequently noted they had “lost” friends and family due to being unable to engage in social activities, or others not understanding why they chose to take on the carer role. Some carers also noted that they faced social isolation due to the “shame” or “stigma” attached to certain situations—for example, children with disabilities, Vietnam veterans with post-traumatic stress.

Amongst the research participants there was very limited usage of respite care, and where respite was accessed it was generally only for a maximum of a few hours per week. Barriers to using respite care that were raised in this research included:

- ◆ lack of awareness of how to access respite care;
- ◆ limited respite services in the local area;
- ◆ concern about the trustworthiness / quality of respite carers / services; and
- ◆ unwillingness of the care recipient to accept another carer or someone in the home.

The few research participants who used respite care reported that it was very beneficial for themselves and the care recipient.

D. Impact of the review on the caring situation

A small number of research participants reported that the Carer Payment or Carer Allowance review process created additional difficulty in the caring situation.

A few participants reported that the review process increased the anxiety of the care recipient about the review process and possible outcome. This stress contributed to their condition becoming less stable and harder for the carer to manage.

In addition, travelling to, and keeping appointments with, doctors or specialists was difficult or troubling for some care recipients. This made it problematic for the carer to schedule and keep appointments and to manage the care needs of the recipient in the lead up to the appointment.

VI. Conclusions and possible improvements

Overall, the review process was accepted as being a necessary component of receiving financial assistance from the government.

The research indicated that the general review process was better accepted and perceived as being less difficult for carers than in the previous round of research in 2005.

It appears that this is most likely to be related to:

- ◆ Improvements to the process over this timeframe translating to a quicker or more straightforward recent review.
- ◆ Improved awareness about compliance requirements leading carers to be more accepting and knowledgeable about review requirements.

Circumstance and income and asset reviews were well understood—both in purpose and process—and were found to be relatively straightforward and efficient.

Telephone reviews were found to be convenient and helpful to payment recipients as they could be completed quickly and with minimal disruption to the caring role / routine.

Medical reviews required the greatest effort from carers with key reported difficulties being:

- ◆ making and attending medical appointments with the care recipient;
- ◆ accessing the medical specialist who best knows the care recipients' condition and needs; and
- ◆ answering the assessment tool questions to most appropriately reflect the care recipients' condition and requirements.

There continued to be confusion and a level of dismay in this research round about why carer payments were medically reviewed for care recipients

whose conditions were permanent and unchanging. While the Lists of Recognised Disabilities made the medical review process substantially easier for those dealing with relevant conditions, they were not felt to be as encompassing as necessary / possible.

- ◆ There was no expressed awareness in the research that the medical review requirements could be lessened through the doctor's identification of the condition as permanent and non-improving.

The research indicated that while the review process caused some inconvenience and effort for a short period of time while it was undertaken, the ongoing issues associated with review processes that also caused concern for carers were:

- ◆ lack of clarity about the purpose and timing of reviews;
- ◆ insufficient notice about reviews and advice about review outcomes; and
- ◆ impact of the review—feelings of uncertainty and anxiety—on the carer and care recipient.

Key strengths of the carer payments review process that appear to be working well and should be maintained include:

- ◆ the use of phone reviews wherever possible;
- ◆ relevant additions to the Lists of Recognised Disabilities over time;
- ◆ considered scheduling of multiple reviews (both for the carer and care recipient) to reduce the overall burden of the review processes;
- ◆ the automated prompting for carers to retest their eligibility for assistance when a child being cared for turns 15 years and 9 months, to support carers approaching this transition; and
- ◆ the neutral, business-like tone of communications about the review process.

This research project identified that potential improvements to the carer payments review process could include:

Improving awareness and understanding of the review process

1. Clarify the review purpose (both payment type and review type) in the covering letter sent with the review documentation.
2. At the conclusion of the review provide an estimate of the next review date and type of review (via letter outlined in improvement 9).
3. Continue to look at ways to provide carers with information about the nature and purpose of the payment being received to assist them in better understanding and accepting the context and nature of reviews.

Streamlining the review process

4. For medical reviews, send a personalised letter six weeks ahead of the review date advising of the upcoming review, and suggesting preparatory actions that could be taken including booking any necessary medical appointments.
5. For ongoing medical conditions and illnesses send out a prefilled form or record of the previous review information, asking the carer to advise if anything in the information has changed over the intervening period.
6. Allow completion of the medical review form by suitably qualified allied health professionals. If suitable, this approach could be piloted in regional areas where the burden of travelling to specialists is particularly substantial.
7. Identify possible options for reducing or removing the medical review process where the care recipient has a permanent illness or disability and high care needs—and/or make current options clearer to improve awareness and take-up.

Additional support for carers completing reviews

8. For review documentation lodged by mail, provide a personalised letter acknowledging receipt of documentation. This could be initiated through a check box on the form as

not all carers feel this is necessary.

9. For all reviews, provide a personalised letter advising of the review outcome and providing information about appeal options.
10. Before stopping payment, as a result of documentation not provided for a review, call the customer to check whether the documentation was provided.
11. Provide carers with the option of nominating whether they prefer separate reviews to be clumped or spread over time—including reviews associated with payments to the care recipient.

Other support for carers

12. Consider using payment statements and review communications as a vehicle for providing intermittent information about other services and payments for carers.
13. Consider introducing a short paragraph or strapline in review communications acknowledging the important role of carers in the community.