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CARERS ACT

THE COTTAGE FOCUS GROUP

*“...a gorgeous place where any of us would be happy
to spend the day.”*

JULY 2011

Carol Flynn & Associates Pty Ltd



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Executive Summary

The purpose of the program which funds The Cottage is to provide 'normalisation' in the lives of people with dementia, a Home from Home Respite Cottage. It is a totally different model to residential aged care facility respite. It demonstrates innovation, flexibility such as longer respite sessions during the day, group client mix as appropriate and is culturally and gender specific when needed. There are no limitations for clients accessing the service. Over the eight years of The Cottage program all the ministerial media releases hail The Cottage style respite as providing flexible, accessible and innovative respite options for Carers, particularly employed Carers, looking after a person with dementia.

The Cottage Focus Group of 15 Carers, who use or have used the services of The Cottage at Deakin, considered the following points:

- The difference between respite services available in residential aged care facilities compared to home from home respite at The Cottage.
- The reasons the group of Carers choose The Cottage over other respite options in the ACT. What does The Cottage offer that other facilities don't?
- What benefits do Carers and the Care Recipient gain from respite at The Cottage?
- What type of respite support (or replacement care) do working Carers need? How often do they need access to this type of respite?
- How do Community Care Packages (CACPs) support Carers who need to work and care for a person with dementia – what works and what doesn't.
- How does the level of fees influence Carers use of The Cottage?
- Can you suggest any improvements to The Cottage?

The Focus Group said that The Cottage demonstrates innovation, appropriate care by highly professional staff, flexibility and significant benefits for both Carers and Care Recipients.

- The Cottage is quite different to other respite services available in residential facilities. The model provides innovation in respite care for people with dementia
 - *"It is a special place and totally different to most institutions."*
 - *"The Cottage model must be duplicated in other areas because it is a world class example."*
 - *"The Cottage is an excellent facility providing a safe, secure and stimulating environment."*
 - *"I consider The Cottage absolute premium care for people with dementia."*
- The Cottage focuses on appropriate care with small groups of clients so the staff provide individual care with more activities and stimulation suitable for each client.
 - *"The staff keep people stimulated."*
 - *"(Staff) keep her active and mentally stimulated while I am at work."*
 - *"Reliable care with professional staff all day while I am at work."*

- *“Activities relevant to my partner’s ability.”*
- *“He is friends with them all, he gets personalised care.”*
- Staff at the Cottage implement the home from home model of care.
 - *“Each client is treated as a person.”*
 - *“The staff envelop them in affection.”*
 - *“Each staff member has their own special qualities and all are very caring. There is good staff consistency.”*
 - *“That she is cared for as I would care for her.”*
- The Cottage provides flexibility with longer hours of care and overnight care which is essential for all Carers, especially employed Carers
 - *“The Cottage has metaphorically saved my life as the Carer. It allows me a regular one night a week “off duty” and I have a consistent run of hours (i.e. a whole day).”*
 - *“I would not be able to do ANY work if not for The Cottage. It gives me some continuity and longer blocks of time. I could do more if it was open 7 days per week.”*
 - *“I would have to work shorter hours were it not for The Cottage as the other place I take mother shuts at 5.30pm.”*
 - *“Respite at The Cottage is not included in the 63 days of respite allowed.”*
- The benefits for the Carers and the Care Recipient are very significant personally and financially to the individuals and the government.
 - *“(My husband) benefits greatly from his twice weekly visits to The Cottage. The Cottage is unique in the fact that it differs from other Aged Care facilities; more personal care in a home atmosphere. The staff are wonderful and supportive of me too. In my circumstances (no immediate family in Canberra) and at my age (over 80), I don’t know how I will cope without this respite which I do appreciate it for all its excellent qualities.”*
 - *“I would have to reduce to part-time without The Cottage and lose income to pay the mortgage. I would also lose superannuation income when I retire.”*
 - *“In financial terms, the longer someone can go to The Cottage the longer they will stay out of residential care.”*
- Fees were not comparable *“because there is no comparable service to The Cottage.”*
- Improvements included:
 - open 7 days a week
 - more Cottages and
 - more stimulation.

Chapter One: Brief history of Carers ACT Cottage at Deakin

The *Home from Home Program* began with the aim of providing respite for Carers of people with Dementia in a familiar home – like setting. The program was particularly aimed at supporting those Carers whose needs were not being met by existing respite options.

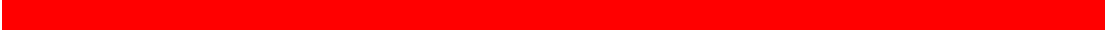
The program continues to operate from the Cottage, McKerrow House, Deakin, ACT. It has been running since October 2003 when the pilot program began and was opened officially by the Minister for Ageing, Ms Julie Bishop on 8 March 2004. The pilot was funded jointly by the Australian Government's Department of Health and Ageing, the Department of Veterans' Affairs and ACT Health. Subsequently the Cottage has been subject to nationally competitive tender processes and achieved recurrent funding from the Department of Health and Ageing. In fact the success of the program has meant that additional funding has been provided so that the opening hours have been able to be gradually increased over the years.

The Cottage is now open 6 days and nights per week. The program operates with flexible start and finish times to suit the Carers and clients. Planned activities are loosely organised into 3 sessions each day; morning, afternoon and overnight, with a maximum of 8 participants per day session and 3 for an overnight stay. The number of people in each session is also dependent on the needs of each individual. Those with more challenging behaviours may require a smaller session size so that the staff are able to successfully manage their behaviour in a way that doesn't impact on the other clients. The mix of clients in each session is planned to suit the individual needs of clients and enhance the group dynamic as much as is feasible whilst still attempting to accommodate last minute respite requests.

The atmosphere at the Cottage is homely. Clients are encouraged and assisted to participate in the life of the cottage which is very similar to those activities of an ordinary home. The Cottage has chickens, other birds, a dog and a garden to attend to. Breakfasts, lunches, dinners, snacks must be prepared with delicious cooking smells a part of the stimulation that is provided. Birthday celebrations, music, outings, chess, basketball, men's shed and high tea are an example of the activities that happen at the Cottage.

An evaluation of the Cottage was completed in December 2004. The results of this evaluation stated that the Cottage is highly valued by Carers as an effective environment which can provide them with respite from their caring role. The findings also stated that clients enjoy high quality care in a homelike environment attuned to their needs. Furthermore, staff consider that the Cottage and Carers ACT is an 'employer of choice'.

In the last financial year the Cottage provided 55 primary Carers with 15883 hours of respite during the day. An additional 6344 hours of overnight respite are provided to



26 of these Carers. The number of respite hours for the last 12 months is lower than the previous 12 months. However it should be noted that this is primarily due to accepting at least five care recipients with high care needs and challenging behaviours into the program this period as there was no alternative or appropriate respite support available in the region. This has meant the Cottage has had fewer day and overnight places available.



Chapter Two: The Focus Group on The Cottage

Dee McGrath, CEO Carers ACT, requested Carol Flynn & Associates to conduct a focus group of Carers who use The Cottage at Deakin to provide information about their experiences of:

- The difference between respite services available in residential facilities compared to home from home respite at The Cottage.
- The reasons the group of Carers choose The Cottage over other respite options in the ACT. What does The Cottage offer that other facilities don't?
- What benefits do Carers and the Care Recipient gain from respite at The Cottage?
- What type of respite support (or replacement care) do working Carers need? How often do they need access to this type of respite?
- How do Community Care Packages (CACPs) support Carers who need to work and care for a person with dementia – what works and what doesn't.
- How does the level of fees influence Carers use of The Cottage?
- Can you suggest any improvements to The Cottage?

The Cottage asked eighteen Carers, current and past users of The Cottage, to participate in the Focus Group. Fifteen Carers attended at the MS Society's meeting room in Deakin ACT from 3pm to 4.30pm on 18 July 2011.

The participants completed a form to gather quantitative and qualitative individual information and then took part in a group discussion focussed around the points above.

Carol Flynn conducted the focus group and Natasha Flores (Carers ACT) took notes from the whiteboard summaries made by Carol and included verbatim quotes from the participants.

The quantitative and qualitative information gathered and summarised on the form is at Attachment A and the qualitative information from the discussion is at Attachment B.

Chapter Three: Findings

The purpose of the program which funds The Cottage is to provide 'normalisation' in the lives of people with dementia, a Home from Home Respite Cottage. It is a totally different model to aged care facility respite.

The differences between respite services available in residential facilities compared to a small home from home Cottage Respite.

Responses on the individual form and during the group discussion underlined the totally different model of aged care dementia respite The Cottage represents. The Home from Home model of care at The Cottage was the major difference the group identified between The Cottage and other respite services in aged care residential facilities.

This is shown in the quantitative responses to the form question:

The aspects of The Cottage's services which influence your choice of respite for your Care Recipient are:

- **Homelike environment 100%**
- **Flexibility of access 93%**
- **Homelike activities e.g. cooking 87%**
- **Flexibility of individual care 87%**
- **Staffing ratios 80%**
- **Hours of respite 80%**
- **Same staff each visit 60%**
- **The fees 53%**
- **Management of difficult behaviours 27%**
- **Close to my workplace 7%**

It is also shown in the qualitative responses to the form question:

"Above (list) says it all. A friendly, caring and comfortable environment."

"It should continue in its special manner of service."

In the group discussion The Cottage was described as *"unique in the ACT and maybe Australia"*; a model to be replicated. Participants said The Cottage is:

"...a gorgeous place that any of us would be happy to spend the day."

"Home feel, lovely décor including photos of years gone by, double beds (not hospital beds), chairs not pushed to the sides of the room as in a nursing home, and age appropriate music playing."

"I consider the Cottage absolute premium care for people with dementia."

“Each client is treated as a person.”

“Homely activities take place in which the client can become involved such as cooking, chess, looking after the chooks and dog.”

“(x) invites her grandchildren to visit sometimes and it is lovely having different generations at the Cottage.”

“Good activities and food available (none of these things provided by other facilities).”

“It is important that the Cottage is a standalone building and not a wing of a nursing home. It can be distressing for both the Care Recipient and the Carer to look up the hall at the nursing home as you are going to respite. Psychologically it is a depressing signal that residential care is the next step.”

“There is much more staff interaction at the Cottage.”

“I will never forget when I went to pick her up (from the aged care facility respite), Mum was sitting by herself, hair all tussled and looking so miserable. I would never take her back to a facility, it was just too distressing”

“I would be happy to leave Mum in the Cottage overnight but couldn’t comprehend putting her in residential respite for a week. It would be too upsetting for us both.”

“I think that putting my wife in a facility would have knocked her back, more than just unhappiness while being there. The Cottage maintains her current level of functioning for longer.”

“The Cottage has less people so less potential infections and staff can provide more attention and possibly keep a better eye on the health of the clients.”

“The management are committed to the Cottage having a homely feel. Staff members who have not shared this ethos have had to leave.”

“We want our people to go to respite but we want them to go somewhere nice.”

The reasons the group of Carers choose The Cottage over other respite options in the ACT. What does The Cottage offer that other facilities don’t?

Responses on the individual form and in the group discussion identified the following reasons the group choose The Cottage over other respite options in the ACT.

- **Homelike environment: 100% (see above)**

“The Cottage is one of 3 places I take her (mother) to but it is the one I like the best. It’s got a homely feel; it’s different to the others which are more institutional.”

- **Professional staff providing safety, care, stimulation and activities: 87% (see above)**

“Carer knows that their person is safe, warm, cared for, has interaction, stimulation, outings.”

“The staff members each have their own special qualities and are very caring and there is good staff consistency.

“...comfortable, safe, secure, and enveloped with love and friendship...”

- **The Cottage’s 8am-6pm and overnight 8pm – 8am hours: Very important (80%), Important (13%)**

“The Cottages hours enable me to continue full time employment knowing my mother is expertly looked after and is happy and content at the Cottage.”

“Not easy to fit work in around respite program hours, for example some programs finish at 2 pm.”

“The Cottage does not provide respite to enable a full working day (9 -5) for a full working week. In fact there is nowhere in ACT that does..... “

- **Access and flexibility: 73% were very successful in gaining access to The Cottage when needed and 27% successful.**

“When needed no other places are available.”

“Bigger residential facilities require people to be in for at least a week or in some places 2 weeks, even if you only need a couple of nights. The Cottage doesn’t have this minimum stay requirement.”

“It’s flexible; my wife was in for six days whilst I had my operation.”

“The Cottage is more flexible then other places: The respite at the Cottage is not included in the 63 days of respite allowed.”

- **The Cottage’s ability to manage difficult behaviours: Very important (47%), Important (20%)**

“Understanding, yet firm when necessary. This knowledge is very assuring. Individual needs are met.”

“This isn’t really an issue for my mother, but the staff members are very good at dealing with clients who show such signs. Unmanaged difficult behaviours create stress for others.”

“Although Mum had dementia she did have some behavioural difficulties at times and staff at the Cottage met our needs to a high order”



What benefits do the Carer and the Care Recipient gain from respite?

The group listed benefits to the Carer and to the Care Recipient.

The benefits to the Carer included:

- High quality of care
- Home atmosphere
- Flexibility
- Small groups
- Safety
- Carer support

“Knowing (my husband) receives excellent care”

“I feel huge relief when I drop my husband off there.”

“Like in our own home.”

“I find large places impersonal and am unsure of how alert they are to my husband’s needs.”

“I can use the Cottage for 1-5 days respite if I need to go away for work.”

“Flexibility in capacity to care for Mum.”

“I feel she is safe.”

“Staff are very supportive of me.”

“Carer knows that their person is safe, warm, cared for, has interaction, stimulation, outings.”

The major benefits to the Care Recipient were:

- Homelike, small,
- Comfortable
- Friendly
- Familiarity
- Availability

“Homely and personal”

“In familiar homelike atmosphere”

“She is more comfortable at the Cottage than other institutions.”

“Feels safe and comfortable. Sometimes she doesn’t want to come home!”

“Lovely bedrooms.”

“Non institutionalised.”

“Familiar and skilled staff”

“Cared for with dignity and empathy with good humour.”

“Enjoys the activities and looks forward to his twice weekly visits.”

“Care which does not have any bad effects on her functioning.”

“Always came home happy.”

“A home is a familiar type of place (compared to a nursing home) which can help people with dementia feel more relaxed.”

What type of respite support (or replacement care) do working Carers need? How often do they need access to this type of respite?

All Carers in the group said they needed respite support of all types and at all times. 33% have multiple arrangements with various organisations which can be disruptive for their Care Recipient with dementia. In responding to the form question it is noticeable that, in addition to the types of care, all described the quality of care as of major concern.

For all Carers the types of respite care needed were:

- **All day care (regular or occasional or emergency) 60%**
- **Overnight care (regular or occasional or emergency) 53%**
- **Emergency day care 47%**
- **Weekend respite 13%**
- **Longer blocks of respite, up to 2 weeks 20%**

- **Respite that keeps the Care Recipient active and interested 40%**
- **Respite that is safe 33%**
- **Professional, caring staff 27%**
- **Help with housework etc 7%**

Responses from employed Carers showed they need respite support/care to enable them to continue in employment.

- **For employed Carers the types of respite care needed were:**
 - **Overnight care (regular or occasional or emergency) 100%**
 - **All day care while they were at work 100%**
 - **Emergency day care 100%**
 - **Weekend respite 40%**

“I would have to reduce to part-time without the Cottage and lose income to pay the mortgage, I would also lose superannuation income when I retire.”

“I would have difficulty holding down my job without the Cottage. Although my mother also attends programs at Alzheimer’s – this is only available, in certain programs, at particular times.”

"I would not be able to do any work if not for The Cottage. At gives me some continuity and longer blocks of time. I could do more if it was open 7 days per week."

"I would have to work shorter hours were it not for The Cottage as the other place I take my mother to shuts at 5:30pm."

"On the occasions that I need to be out of Canberra they assist."

"Important to ability to continue voluntary activity."

"Feel that it is unfair as employees get time off for the birth of a child but organisations do not recognise the responsibility of Caring to the same extent. "

The Cottage type respite was needed:

- **Twice a week 40%**
- **Once a week 20%**
- **Three times per week 13%**
- **Four times per week 7%**
- **Irregularly 33%, 27% in addition to regular respite**

The impact on employed Carers of the becoming the Carer of a person with dementia was very significant. The following information was gained from the form questions:

Of the 15 in the group, 33% were currently employed; 1 fulltime and 4 part-time for between 7 and 30 hours.

All the employed Carers and two of the unemployed Carers reported that caring had negative effects on their employment and personal lives. The most frequently mentioned effects were:

- **Career on hold and job/professional requirements not able to be met, leading to loss of opportunities. 100% plus 20% of currently unemployed**
- **Loss of income, entitlements (e.g. sick, long service leave) and superannuation. 100%**
- **Stress of working and Caring. 60%**
- **Loneliness and loss of peer group.60%**

Employed Carers had been in their current career or employment for

- **More than 20 years 40%**
- **10-20 years 20%**
- **5-10 years 40%**
- **The importance of their employment:**
 - **To their own wellbeing: very important 60%, important 20%, neutral 20%**
 - **To their families economic situation: very important 40%, important 60%**
 - **To their ability to provide care for the Care Recipient: very important 60%, important 40%**
- **The importance of The Cottage's services to their ability to stay in employment:**
 - **Very important 60% and important 40%**
- **The importance of flexibility in accessing and using The Cottage's services to continued employment:**
 - **Very important 80%**
 - **Important 20%**

“My employment gives me balance in my life. I became very sad when I was unemployed due to my caring role and consider myself very fortunate to have gained permanent part-time employment.”

“I need my research work to keep me sane, for my self-esteem; it has been my whole life (no children). I miss full-time work acutely; I am unable to do research trips or fieldwork.”

“Having to take time off work regularly and using up all my leave which I need for my own medical problems.”

Physical and mental exhaustion; because of exhaustion can't associate with people socially which then leads to isolation: the Hermit Syndrome.

“Limited opportunities to socialise with work colleagues which can impact on employment due to lost networking opportunities.”

“If you have a good work ethic it is not a good place to be if you can't give 100% to your work while you are there.”

“The stress of caring and working became too much, so I had to give up. Extremely stressful work and I was not able to give it my full attention.”

How do Community Care Packages (CACPs) support Carers who need to work and care for a person with dementia – what works and what doesn't.

60% of the group had CACPs while 40% did not. The reasons for those who did not have a package varied from not being eligible to choosing not to use it.

The following information was gained from the form questions

Number of hours in the Care Recipient's Care Package

- **20-50 hours per week 40%**
- **Less than 20 hours per week 20%**
- **No Care Package 40%**

The positives of CACPs were:

- **Help with housework**
- **Respite for Carer (me).**
- **Helps reduce my stress.**
- **May provide emotional support.**
- **Mature male carer gets on well with my husband.**

The negatives of CACPs were:

- **Inflexible**
- **Not happy with service**
- **Emphasises our disadvantage.**
- **Not enough subsidised hours.**
- **Too many different carers and arrangements.**

- **Lack of staff**

“I used to have a package to get someone to help bathe, but my mother was so hostile to the woman who came that I stopped her. Staff at the Cottage manage to bathe her –she is comfortable with them.”

The packages are not flexible in that they include components that you may not want, such as housekeeping, but you still have to pay even if you choose not to use that particular component. CACPs provide only shortish blocks of time and they require the Carer to timetable everything around them. Can be difficult for the Carer to remember who is coming when and to remember to cancel them when necessary.

“Don’t have a package. I buy in services at huge expense through desperation and I have people moonlighting for me.”

“My husband has become friends with his male carer provided by the package. They do things together which my husband enjoys, such as going to the art gallery.”

Several participants agreed that it is so difficult to find out what you can and can’t access under the CACPs and many are still unaware that they can access Carer payments, CACPs, etc. There needs to be a good source of broad information e.g. taxi vouchers, companion cards, incontinence pads, etc. Alzheimer’s Association, Carers ACT provide such information. One participant said the Social Worker at the hospital was a very good source of information.

Eligibility for a CACP can be difficult, in particular the requirement for an ACAT assessment for a younger person with dementia. Another participant had difficulty getting a doctor to sign the necessary paperwork and was put off trying again.

How does the level of fees influence your use of The Cottage?

The fees were seen as reasonable.

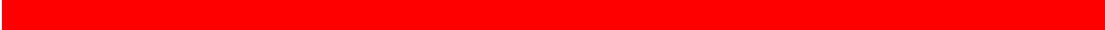
All the participants agreed that fees were not comparable as *“there is no comparable service to the Cottage”*.

All agreed that, in government budget financial terms, the longer someone can go to The Cottage the longer they will stay out of residential care.

Can you suggest any improvements to The Cottage?

The improvements participants agreed were:

- *Open seven days a week.*
- *The Cottage is wonderful. It should be a model that is applied Australia wide. But it needs to be small.*

- 
- *Have a north side Cottage. Important any new facility stays small so that it is not a nursing home.*
 - *The Cottage needs a few more mental activities including someone to talk to or play chess.*

“I really don’t know what I would have done or how I would have been able to manage without the Cottage’s help.”



Attachment A: Quantitative and qualitative information from the Form

Attachment A1: Summary of quantitative information

Attachment A2: Qualitative information

Attachment A3: Form

The summary of quantitative information gathered from 15 individual Carers through the form (Attachment A3) shows:

The participants

- The average number of years Carers cared for the Care Recipient was 7.6 years, with a range from 2 years to 42 years and a mode of 7 years.
- 8 Carers were between 50 and 65, 6 over 65 and 1 under 50.

Employment

Employed Carers

- 5 were currently employed, 1 fulltime and 4 part-time for between 7 and 30 hours.
- All the employed Carers and two of the unemployed Carers reported that caring had negative effects on their employment and personal lives.
- The most frequently mentioned effects were:
 - Career on hold and job/professional requirements not able to be met, leading to loss of opportunities. (100% plus 20% of currently unemployed)
 - Loss of income, entitlements (e.g. sick, long service leave) and superannuation. (100%)
 - Stress of working and Caring. (60%)
 - Loneliness and loss of peer group. (60%)
- For employed Carers the types of respite care needed were:
 - Overnight care (regular or occasional or emergency) (100%)
 - All day care while they were at work (100%)
 - Emergency day care (100%)
 - Weekend respite (40%)
- Employed Carers had been in their current career or employment for
 - More than 20 years (40%)
 - 10-20 years (20%)
 - 5-10 years (40%)
- The importance of their employment:
 - To their own wellbeing: very important 60%, important 20%, neutral 20%
 - To their families economic situation: very important 40%, important 60%
 - To their ability to provide care for the Care Recipient: very important 60%, important 40%
- The importance of The Cottage's services to their ability to stay in employment:
 - Very important 60% and important 40%
- The importance of flexibility in accessing and using The Cottage's services to continued employment:
 - Very important 80%
 - Important 20%

Carers not in current employment (10)

- 7 Carers were in employment when the Care Recipient was diagnosed with dementia.
- This number includes 2 currently employed
- 5 were not employed
- Some were retired

All Participants

For all Carers the types of respite care needed were:

- All day care (regular or occasional or emergency) (60%)
- Overnight care (regular or occasional or emergency) (53%)

- Emergency day care (47%)
- Weekend respite (13%)
- Longer blocks of respite, up to 2 weeks (20%)

- Respite that keeps the Care Recipient active and interested (40%)
- Respite that is safe (33%)
- Professional, caring staff (27%)
- Help with housework etc (27%)

The Cottage type respite was needed:

- Twice a week (40%)
- Once a week (20%)
- Three times per week (13%)
- Four times per week (7%)
- Irregularly (33%, 27% in addition to regular respite)

73% were very successful in gaining access to The Cottage when needed and 27% successful. The importance of The Cottage's ability to manage difficult behaviours to their choice of using The Cottage was:

- Very important (47%)
- Important (20%)
- Neutral (20%)
- Not important (7%)

The importance of The Cottage's 8am-6pm and overnight 8pm – 8am hours to their choice of The Cottage was:

- Very important (80%)
- Important (13%)
- Neutral (7%)

The Care Recipient

Number of hours in the Care Recipient's Care Package

- 20-50 hours per week (40%)
- Less than 20 hours per week (20%)
- No Care Package (40%)

Number of hours accessing The Cottage's services

- In an average week: the average was 17.2 hours, the range from 4.8 to 50 hours and the mode of 6, 8 and 16
- In a week of maximum use: the average was 44 hours, the range from 4 to 144 hours and the mode 16
- In a week of minimum use: the average was 12 hours, the range from 4 to 24 hours and the mode 4 hours

The aspects of The Cottage's services which influence their choice of respite for their Care Recipient are:

- Homelike environment 100%
- Flexibility of access 93%
- Homelike activities e.g. cooking 87%
- Flexibility of individual care 87%
- Staffing ratios 80%
- Hours of respite 80%
- Same staff each visit 60%
- The fees 53%
- Management of difficult behaviours 27%
- Close to my workplace 7%

The summary of qualitative information gathered from 15 individual Carers through the form (Attachment A3) shows:

ABOUT THE CARER

1. Are you currently employed?

5 yes, 10 No

a. Full-time: Yes/No (Circle one) **1(37.5hrs)**

b. Part-time: Yes/No (Circle one) **4**

Hours per week 7hrs, although officially on leave without pay for 12months, self-employed, 20hrs + sessional work, 30hrs

2. Has your employment status been effected by being a Carer? Yes/No (Circle one)

a. Briefly list the 3 most important effects (to you) on your employment

<ul style="list-style-type: none"> <input type="radio"/> Having to take time off work regularly and using up all my leave which I need for my own medical problems. <input type="radio"/> Not having any time to myself. <input type="radio"/> Unable to travel
<ul style="list-style-type: none"> <input type="radio"/> Have had to interrupt a major research grant at ANU. <input type="radio"/> Have lost momentum in research, publishing, writing and being in the thick of things <input type="radio"/> Have lost 12 months income and subsequent deleterious effect on my superannuation calculations and long service leave eligibility.
<ul style="list-style-type: none"> <input type="radio"/> Income <input type="radio"/> Professional Relationship <input type="radio"/> Loneliness
<ul style="list-style-type: none"> <input type="radio"/> From full-time work to part time, including a period of unemployment due to caring responsibilities. <input type="radio"/> Finding adequate support so that I can keep working and knowing that my mother is safe while I am at work. <input type="radio"/> Constant worry about being able to keep at the balls in the air and hold on to my employment
<ul style="list-style-type: none"> <input type="radio"/> Restricts ability to take opportunities <input type="radio"/> Travelling for work (not a major part of my job) is more difficult <input type="radio"/> Lower income/superannuation
<ul style="list-style-type: none"> <input type="radio"/>
<p>Two people who are not currently employed wrote:</p>
<ul style="list-style-type: none"> <input type="radio"/> Loss of shifts <input type="radio"/> Loss of knowledge <input type="radio"/> Reduction in peer group

- **Left work to care for my partner May 2010, career on hold**
- **Stress of working and Caring**
- **Unable to put effort into work that was required**

3. What types of respite support (or replacement care) do/did you as an employed Carer need? *List up to the 5 most important types of respite support or replacement care.*

<p>Someone to be with my mother all the time I am at work Someone to keep her active and mentally stimulated while I am at work Somewhere (i.e. the Cottage) for my mother to spend time in an emergency</p>
<p>Occasional days – i.e. short term Blocks of time to concentrate on work = Two week blocks Help with housework and laundry Longer blocks of time – week or two Needed relief at weekends</p>
<p>Care for wife to keep her interested and active Time for me to undertake home and work duties Respite from the never ending pressures and demands Travel to Capital Cities for work</p>
<p>Reliable care with professional staff – all day when at work Possible regular overnight in the future Emergency Respite</p>
<p>Daytime care for my mother Occasional overnight care for my mother Respite care (1 or 2 weeks normally)</p>
<p>People who are not currently employed (one person did not respond to this question):</p>
<p>Weekday respite Safety of my partner Opportunity for overnight Respite Activities relevant to my partners ability Emergency care</p>
<p>Day care that provided Activities suitable for someone aged 56 Secure overnight once a week Flexibility in case of emergency care</p>
<p>Respite for me (carer) Freedom to do normal things (shopping, medical appointments, etc)</p>
<p>Safe place Caring staff Emergency care Overnight stays</p>
<p>Overnight care for period when I was in hospital for operation (Another such need is likely in the future) Day care (regular one day per week) to enable me to keep up regular voluntary activity</p>
<p>Safe surrounding Knowledge that he will be understood Good care, needs met Regular respite</p>

Daytime Overnight Weekend Emergency
Safe, secure and stimulating environment Flexible hours Ability to stay overnight on occasions Emergency respite
a bit of a break (respite) from Caring for the consumers to be able to socialise with others for the carer to be able to attend to other important matters

How often do/did you as an employed Carer need The Cottage type respite support or replacement care? *(Circle one)*

- a. **Weekdays only, 1**
- b. **Weekends only, 2 (both ticked weekdays only as well)**
- c. **Five times per week, 0**
- d. **Four times per week, 1 (ticked 3 times per week)**
- e. **Three times per week, 2**
- f. **Twice a week, 6**
- g. **Once a week, 3**
- h. **Once every two weeks, 0**
- i. **Once every three weeks 1**
- j. **Once a month, 0**
- k. **Irregularly, 4 people ticked irregularly in addition to a regular time slot. One person wrote irregularly due to ill health, inability to cope, time out, holidays**

Some notes people made:

- **This person is one of the people who ticked weekdays and weekends only: My mother attends the cottage Weds and Sat, staying overnight on weds. She attends another centre on the other weekdays, and a third centre on some Sundays. The third centre is where she stays for a week or two at a time, and I saw that she looked frightened by it. Going on Sundays has helped familiarise her with it and she is a lot more comfortable now.**
- **Note if any of my mother's other care is taken away for any reason I would need the Cottage more (twice a week currently)**
- **Twice a week but this may escalate and other services or programs pull out. Some weekends would be useful as I also have full-time care of grandson.**

4. How successful are/were you in gaining access when you need/needed it? (Circle one)

Very successful 11	Successful 4	Neutral 0	Not successful 0	Not very successful 0
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Comment if you wish to

Those who ticked very successful:

- They were extremely accommodating and mostly met my needs.
- When I first started using it, demand seemed to be harder to get overnight stays. A few people have entered permanent care recently, so numbers have yet to build up.
- I seem to have been lucky gaining access – only once or twice not successful
- With the assistance of Alzheimer’s ACT
- Alzheimer’s ACT put this in place and it is the best thing for My husband (my husband) and myself. This took place about 5 years ago.
- I really don’t know what I would have done or how I would have been able to manage without the Cottage’s help.

Those who ticked successful

- They were personable and helpful
- At present there is a regular schedule- Mondays and Fridays
- Initially I was on a waiting list, but now I have been able to get extra in crisis times when other organisations have closed – e.g. school holidays when many programs close – e.g. Alzheimer’s programs.

5. How important is The Cottage’s ability to manage difficult behaviours to your choice of using The Cottage? (Circle one)

Very important 7	Important 3	Neutral 3	Not important 1	Not very important 0
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Comment if you wish to

One person did not select a response.

For those that ticked very important:

- Understanding, yet firm when necessary. This knowledge is very assuring. Individual needs are met.
- This isn’t really an issue for my mother, but the staff members are very good at dealing with clients who show such signs. Unmanaged difficult behaviours create stress for others.
- Although Mum had dementia she did have some behavioural difficulties at times and staff at the Cottage met our needs to a high order

For those who ticked important:

- The person I’m caring has sometimes have a mood swing!
- Keeps my mother safe from those who have difficult behaviour.

For those who ticked neutral:

- My husband not exhibiting difficult behaviours (so far)
- Behaviour has been contained and I assist her

For the person who ticked not important:

- My wife does not exhibit difficult behaviours – but no doubt ability to manage such in others is important to her.

6. How important are the 8am – 6pm and overnight 8pm – 8am hours to your choice of using The Cottage? (circle one)

Very important 12	Important 2	Neutral 1	Not important 0	Not very important 0
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Comment if you wish to add more information

For those who responded 'very important':

- **The Cottages hours enable me to continue full time employment and knowing my mother is expertly looked after and is happy and content at the cottage.**
- **I would also like to have weekends e.g. Fri – Mon**
- **It would be even more helpful to be a 7 day a week facility**
- **It is very assuring to know that this option is available. Has used it once.**
- **It would be great if funding was available for it to be open on Sundays.**
- **Was disappointed when Sunday care was withdrawn (due to cost)**
- **I think it it's important for the Cottage to be flexible in catering for the consumers (and Carers) needs.**
- **I use daily care, however I imagine a time in the future when overnight care on a regular basis would be positive for my mother to get used to it and myself to have a break.**

For those who responded 'important':

- **When needed no other places are available.**

7. How do Community Care Packages support Carers who work and care for a person with dementia? *List up to the three most positive aspects for employed Carers and list up to the three most negative aspects of Community Care Packages for employed Carers.*

Positive for employed Carers	Negative for employed Carers
For those carers who are employed:	
Assist with domestic requests Provide support in time off May provide emotional support	Expresses the disadvantage that you are in Places Chris and I in a Disadvantage Box.
Don't have a package currently. ACAT recently awaiting results.	
My mother doesn't have a package I used to have one to get someone to help bathe, but my mother was so hostile to the woman who came that I stopped her. Staff at the Cottage manage to bathe her – she is comfortable with them.	
Allows me to keep working full—time Helps reduce my stress Helps me to maintain my income.	Not enough subsidised hours.
Help with housework Mature male carer gets on well with my husband.	Short blocks of time Many different carers for client to remember. Have to remember to cancel

	arrangements if husband ill/ doctor appointment, etc.
For those that are not employed:	
Respite for Carer (me). Carer can attend other errands. Understand the consumer well.	Lack of staff by Community care. Short notice of change of care time.
Don't know much – had Goodwin EACH package – Not happy	
Not great flexibility	
Do not use a Community Care Package. Approved but decided not to use as not flexible.	

ABOUT THE CARER'S EMPLOYMENT (Number: 5)

If you are not currently employed, please go to Question 15

If you are currently employed, please complete Questions 11, 12, 13, and 14

8. How long have you been employed by your current employer or in your current career?
(Circle one)

- a. Under 1 year, 1 (this person also ticked more than 20 years for career)
- b. 2-5 years, 0
- c. 5-10 years, 2
- d. 10-20 years, 1
- e. More than 20 years, 2

9. How important is your employment to:

- a. Your own wellbeing (Circle one)

Very important, 3	Important, 1	Neutral, 1	Not important	Not very important
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- b. Your family's economic situation (Circle one)

Very important, 2	Important, 3	Neutral	Not important	Not very important
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- c. Your ability to provide care for the Care Recipient (Circle one)

Very important, 3	Important, 2	Neutral	Not important	Not very important
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Responses matched to comments:

(d) is a function of (b)
My employment gives me balance in my life. I became very sad when I was unemployed due to my caring role and consider myself very fortunate to have gained permanent part-time employment.
I need my research work to keep me sane, for my self – esteem; it has been my whole <u>life</u> (no children!). I miss full-time work acutely; I am unable to do research trips or fieldwork.

Other Comments by people not currently employed:

Left work in Dec 2010, currently negotiating to work two days to work in August 2011

My weekly voluntary activity is very important to my own well-being.

10. How important are The Cottage's services in your ability to stay in employment? *(Circle one)*

Very important, 3	Important, 2	Neutral	Not important	Not very important
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Comment if you wish to

For those that circled very important:

I would have to reduce to part-time without the Cottage and lose income to pay the mortgage, I would also lose superannuation income when I retire.

Would have difficulty holding down my job without the Cottage. Although my mother also attends, programs at Alzheimer's – this is only available, in certain programs, at particular times.

I would not be able to do any work if not for The Cottage. At gives me some continuity and longer blocks of time. I could do more if it was open 7 days per week.

I would have to work shorter hours were it not for The Cottage as the other place I take my mother to shuts at 5:30pm.

For those that circled important:

On the occasions that I need to be out of Canberra they assist.

Important to ability to continue voluntary activity.

11. How important is flexibility in accessing and using The Cottage's services to your continued employment? *(Circle one)*

Very important, 4	Important, 1	Neutral, 1	Not important	Not very important
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Comment if you wish to

For those who circled very important:

I have had to make last minute plans to get to work. I worry I will be inadequate as a worker.

For the person who circled important:

They make themselves available when needed.

If you are not in current employment please answer Question 15

12. Were you in employment when the Care Recipient was diagnosed with dementia?

Yes, 7 /No, 5 (Circle one). Including two people who are in current employment

If Yes please complete a. If No please complete b.

a. *If Yes, Briefly list the three most important factors (to you) which led to you leaving employment?*

My mother lived in Sydney. I had go down there and get diagnosis etc. This took 9 months.

My mother then agreed to move to ACT after much coming and going

Needed care and company

Ensured Valium medications are taken
Retirement (decided to retire anyway)
Unable to safely leave at home alone
Stressful and exacting work – needing extreme concentration
Chris required care to get ready in the morning.
Chris unable to catch buses on his own, so isolated
I was stressed working and caring
Became difficult to manage work and my partner

13. How important were The Cottage’s services in your decision to leave employment and/or its timing? *(Circle one)*

Very important	Important, 1	Neutral,3	Not important,1	Not very important
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Comment if you wish to add more information

For the person who circled important:
I already left employment before joining the Cottage.

For those who circled neutral:
I had already decided to retire anyway.
I was not using the Cottage services when I was at work. However I find that the respite at the Cottage now essential as disease progressed.
It has become obvious that I was not fully aware of all services available before I decided to leave work.

For the person who circled not important:
I did not use the Cottage until I had ceased employment.

For the person who just made a comment:
The Cottage has allowed me to take on a job when returning to the ACT. To find a job took some time – however was successful.

14. If No, What influence, if any, did The Cottage’s services have on your decision to remain out of the workforce. Briefly *list up to three most important influences* The Cottage’s services had on your decision.

Comment if you wish to

Retired long before my husband was diagnosed with Alzheimer’s
I had already retired.

ABOUT THE PERSON YOU CARE FOR

15. How many total hours respite does the person you care for receive under their Care Package? *(Circle one)* 6 people don’t have or decided not to use a package

- a. **More than 63 hours per week**
 - i. **Number of hours**
- b. **63 - 50 hours per week**
- c. **20-50 hours per week, 6**
- d. **Less than 20 hours per week, 3**

16. For how many of those hours do you choose to access The Cottage's services? (*Answer all*) Cottage hours are not part of Community Care Package
- No of hours in average week, 16, 16, 8, 6, 4,8, 50, 48 (2day/nights), 8, 5 (hope to increase), 6, 21**
 - No of hours in week of maximum use of The Cottage, 16, 144,4, 12, 72hrs (3day/nights), 16**
 - No of hours in week of minimum use of The Cottage,16,4,4, 1 (day/night)**
17. What aspects of the services offered by The Cottage influence your choice of respite at The Cottage for your Care Recipient? (*Circle all that apply*)
- Homelike environment, 15**
 - Staffing ratios, 12**
 - Management of difficult behaviours, 4**
 - Homelike activities e.g. cooking, 13**
 - Flexibility of access, 14**
 - Flexibility of care, 13**
 - Same staff each visit, 9**
 - Hours of respite 8am – 6pm and 8pm – 8am, 12**
 - The fees, 8**
 - Other, 1Close to my workplace – but still have difficulty getting person here**

Comment if you wish to

Above says it all. A friendly caring and comfortable environment. It should continue in its special manner of service.

18. Which other respite services do you access for your Care Recipient? *Circle all you access and note average hours for that facility per week in past 3 months.*

3 people responded N/A to this Question and 3 left it blank, One person said that their cared for person has been in Burrangiri in 2006, one person said that they used larger residential care facility for 8 day stay, one person said they used Goodwin Monash 2 weeks (7 years ago) but was not happy

Name	Average hours per week in past 3 months	<i>Comment if you wish to add more information</i>
Mirinjani		
Jindalee Aged Care Residence		
Day Break, Red Hill		
Burrangiri		
Villagio San Antonio	2	On longer period breaks
Other		
Mirinjani		
Jindalee Aged Care Residence		

Day Break, Red Hill		
Burrangiri		
Villagio San Antonio		
Other: Community Options Still Ticking Men Group	2 6 hours	Assisted Shopping HACC program
Mirinjani		
Jindalee Aged Care Residence		
Day Break, Red Hill		Have used this service, however Mum hated it- refused to go
Burrangiri		
Villagio San Antonio		Mum cried when I took her to look. She had to be taken out
Other Workers Program at Carers ACT		
Mirinjani		
Jindalee Aged Care Residence		
Day Break, Red Hill		
Burrangiri		
Villagio San Antonio		
Other	18	Visiting carers from Tandem and Community Options
Mirinjani		
Jindalee Aged Care Residence		
Day Break, Red Hill	32 (Mon, Tues, Thurs, Fri)	4 weekdays
Burrangiri		
Villagio San Antonio	8 (Sun)	Some Sundays and longer breaks
Other		

19. What are the differences between the respite care offered by these other respite services and those of The Cottage? *List up to the three most important differences to you and the person you care for.*

Important to Carer	Important to Care Recipient
Smaller group personal care Knowing that My husband receives excellent care. Staff are very supportive of me.	In familiar homelike atmosphere Comfortable and happy at the Cottage Enjoys the activities and looks forward to his twice weekly visits.
Safe, secure Familiar Flexible	Familiar Home from Home Friendly
Envelope them in affection She knows the Cottage and comes I feel she is safe	She is more comfortable at the Cottage then other institutions Emotionally and physically
Home feel Small numbers Get to know the staff Flexible care	Animals Home-cooking Lovely bedrooms
I feel huge relief when I drop my husband off there. I find large places impersonal and am unsure of how alert they are to my husband's needs. I can use Cottage for 1 -5 days respite if I need to go away for work.	Cottage is small and low-key Not-institutionalised Homely and personal
Confidence that Mum would be well cared for Flexibility in Capacity to take Care of Mum. Good activities and food available (none of these things provide by other facilities)	Cared for with dignity and empathy with a good humour. Comfortable in environment and with staff Interaction with other clients (but limited number)
In our own home Happy at home	in own home good comfort zone
Flexibility Home atmosphere Overnight stays are additional to 63 days a year	Hard to quantify this – the advantages relate to the atmosphere of the place.

20. What are the benefits of The Cottage's respite care to the person you care for? List up to the three most important benefits to the person you care for.

Available at most times She is familiar and happy there.
Homely Friendly staff (and helpful)
Safety, activities Not a nursing home Small facility
That she is cared for as I would care for her

Peace of Mind A place she enjoys coming to
He is quiet and relaxed at the Cottage. He participates in activities such as 'bingo' and basketball He enjoys outing , listening to music
Care which does not have any bad effects on her functioning
Always came home happy
Opportunity to go out of the house Knowledge that he is well cared for Made comfortable and welcome likes walking in the garden
Familiar surroundings Familiar and skilled staff Safe environment
He is comfortable there and safe He is friends with them all – he gets personalised care It is not overwhelming or threatening like a large residential facility is. He does not resist going there
Somewhere for my mother to go that she likes Lovely, homely environment Central location
Feels safe and comfortable – sometimes she doesn't want to come home She gets looked after Things to do

21. Any other comments you wish to make?

The Cottage is wonderful. It should be a model that is applied Australia wide. But needs to be small.

The Cottage is wonderful

The Cottage model must be duplicated in other areas because it is a world class example.

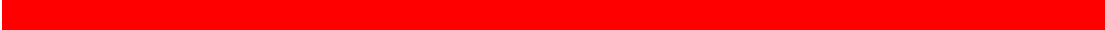
The Cottage has metaphorically 'saved' my life as the Carer. It allows me regular one night a week I can have completely 'off duty' and means I have a consistent run of hours (i.e. a whole day). It is efficient and well run and comfortable. I can always raise someone by phone. Staff alert me if any problem with my husband. Staff who interact more with clients more, activities for clients. 7 days weekly. Small – keep people stimulated.

My husband benefits greatly from his twice weekly visits to the Cottage. The Cottage is unique in the fact that it differs from other Aged Care facilities – more personal care home atmosphere. The staff are wonderful and supportive of me too. In my circumstances (no immediate family in Canberra) and at my age (over 80) I don't know how I will cope without this respite which I do appreciate for all its excellent qualities.

The Cottage is an excellent facility providing safe, secure and stimulating environment. 7 day a week care would be an advantage.

He finds the Cottage a peaceful and relaxing place, where the staff are caring and friendly.

Must be kept



I would be against any change in the current approach, management or thoroughfare of the Cottage. It is a special place and is totally different to most institutions.

Carers ACT

A FOCUS GROUP FOR CARERS ACCESSING SERVICES FROM THE COTTAGE AT DEAKIN

The Cottage at Deakin is part of the Employed Carers Program. The original intent of the Program, funded by the Commonwealth Department of Health and Ageing, was to provide a familiar home from home environment for people with dementia to enable the Carer to continue to be employed. The Cottage aims to meet Carers' need for flexibility in providing its services.

Thank you for attending this Focus Group. Your experiences with the services The Cottage provides will be part of Carers ACT's Funding Agreement discussions with the Department of Health and Ageing which is reviewing outputs of the Employed Carers Program.

The Focus Group is gathering information in two main ways:

- *Quantitative information on this form*
- *Qualitative information through the group discussion.*

All information you supply through this form and the group discussion will be anonymous and aggregated into a report for Carers ACT. No individual contribution will be identifiable. All forms will be destroyed once the report is finalised for Carers ACT.

INFORMATION ABOUT YOU (THE CARER) AND THE PERSON YOU CARE FOR

ABOUT THE CARER

1. How many years have you been the Carer of the person you care for?

.....years

2. To which age group do you belong? *(Circle one)*

- a. Under 40
- b. 40 – 50
- c. 50 – 60
- d. 60 – 65
- e. Over 65

3. Are you currently employed? Yes or No *(Circle one)*

a. *If Yes:*

i. Full-time: Yes or No *(Circle one)*

ii. Part-time: Yes or No *(Circle one)*

1. Hours per week

4. Has your employment status been affected by being a Carer? Yes or No (*Circle one*)

a. Briefly list the 3 most important effects (to you) on your employment

i. .

ii. .

iii. .

5. What types of respite support (or replacement care) do/did you as an employed Carer need? List up to the 5 most important types of respite support or replacement care.

a. .

b. .

c. .

d. .

e. .

6. How often do/did you as an employed Carer need The Cottage type respite support or replacement care? (*Circle one*)

a. Weekdays only

b. Weekends only

c. Five times per week

d. Four times per week

e. Three times per week

f. Twice a week

g. Once a week

h. Once every two weeks

i. Once every three weeks

j. Once a month

k. Irregularly due to

7. How successful are/were you in gaining access to the Cottage when you need/needed it? (*Circle one*)

Very successful	Successful	Neutral	Not successful	Not very successful
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Comment if you wish to add more information

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8. How important is The Cottage’s ability to manage difficult behaviours to your choice of using The Cottage? *(Circle one)*

Very important	Important	Neutral	Not important	Not very important
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Comment if you wish to add more information

9. How important are the 8am - 6pm and overnight 8pm - 8am hours to your choice of using The Cottage? *(Circle one)*

Very important	Important	Neutral	Not important	Not very important
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Comment if you wish to add more information

10. How do Community Care Packages support Carers who work and care for a person with dementia? *List up to the three most positive aspects for employed Carers and list up to the three most negative aspects of Community Care Packages for employed Carers.*

Positive for employed Carers	Negative for employed Carers
1.	1. .
2.	2. .
3.	3. .

ABOUT THE CARER’S EMPLOYMENT

If you are not currently employed, please go to Question 15

If you are currently employed, please complete Questions 11, 12, 13 and 14

11. How long have you been employed by your current employer or in your current career? *(Circle one)*



- a. Under 1 year
- b. 2-5 years
- c. 5-10 years
- d. 10-20 years
- e. More than 20 years

12. How important is your employment to:

a. Your own wellbeing *(Circle one)*

Very important	Important	Neutral	Not important	Not very important
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b. Your family's economic situation *(Circle one)*

Very important	Important	Neutral	Not important	Not very important
----------------	-----------	---------	---------------	--------------------

c.

d. Your ability to provide care for the person you care for *(Circle one)*

Very important	Important	Neutral	Not important	Not very important
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Comment if you wish to add more information

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13. How important are The Cottage's services in your ability to remain employed? *(Circle one)*

Very important	Important	Neutral	Not important	Not very important
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Comment if you wish to add more information

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14. How important is flexibility in accessing and using The Cottage's services to your continued employment? *(Circle one)*

Very important	Important	Neutral	Not important	Not very important
----------------	-----------	---------	---------------	--------------------

Comment if you wish to add more information

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If you are not currently employed please answer Question 15

15. Were you in employment when the person you care for was diagnosed with dementia?

Yes or No (*Circle one*).

If Yes, please complete a. If No, please complete b.

a. If Yes, *Briefly list up to three most important factors* (to you) which led to you leaving employment?

1. .

2. .

3. .

ii. How important were The Cottage’s services in your decision to leave employment and/or its timing? (*Circle one*)

Very important	Important	Neutral	Not important	Not very important
----------------	-----------	---------	---------------	--------------------

Comment if you wish to add more information

b. If No, What influence, if any, did The Cottage’s services have on your decision to remain out of the workforce. *Briefly list up to three most important influences* The Cottage’s services had on your decision.

1. .

2. .

3. .

Comment if you wish to add more information

ABOUT THE PERSON YOU CARE FOR

16. How many total hours respite does the person you care for receive under their Care Package? *(Circle one)*

- a. More than 63 hours per week
 - i. Number of hours
- b. 63 -50 hours per week
- c. 20-50 hours per week
- d. Less than 20 hours per week

17. For how many of those hours do you choose to access The Cottage’s services? *(Answer all)*

- a. No of hours in average week
- b. No of hours in week of maximum use of The Cottage
- c. No of hours in week of minimum use of The Cottage

18. What aspects of the services influence your choice of respite at The Cottage for the person you care for? *(Circle all that apply)*

- a. Home from home environment
- b. Staffing ratios
- c. Management of difficult behaviours
- d. Homelike activities e.g. cooking
- e. Flexibility of access
- f. Flexibility of care
- g. Same staff each visit
- h. Hours of respite 8am-6pm and 8pm-8am
- i. The fees
- j. Other

.....

Comment if you wish to add more information

19. Which other respite services do you access for the person you care for? *Circle all you access and note average hours for that facility per week in past 3 months.*

Facility	Average hours per week in past 3 months	Comment if you wish to add more information
Mirinjani		



Jindalee Aged Care Residence		
Day Break, Red Hill		
Burrangiri		
Villagio San Antonio		
Other		

20. What are the differences between the respite care offered by these other respite services and those of The Cottage? *List up to the three most important differences to you and to the person you care for.*

Important to Carer	Important to the person you care for
a. .	a. .
b. .	b. .
c. .	c. .

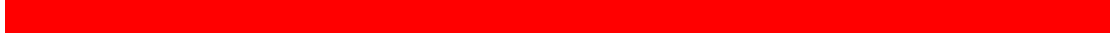
21. What are the benefits of The Cottage’s respite care to the person you care for? *List up to the three most important benefits to the person you care for.*

a. b. . c. .

22. Any other comments you wish to make?

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Thank you for participating in The Cottage focus group.



Attachment B: Notes from Focus Group

Notes from Focus Group - 18th July 2011

Attended by 15 Carers who use or have used the Cottage for Respite

Introduction:

- **The focus group is about the Cottage versus other forms of respite.**
- **Initial anxiety expressed by some participants that the focus group was actually the beginning of a process to close the Cottage down. Carol reassured them that there were no plans to shut the Cottage down.**

Some quotes from people as they introduced themselves:

"The Cottage is unique in the ACT, maybe Australia."

"...a gorgeous place that any of us would be happy to spend the day."

"I consider the Cottage absolute premium care for people with dementia."

"I don't know how I would manage without respite."

"The Cottage is a 'reason' for my husband to get up and dress up, otherwise he would just stay in bed"

"My wife is very hard to please but she is quite happy to come to the Cottage."

"The Cottage is one of 3 places I take her (mother) to but it is the one I like the best. It's got a homely feel; it's different to the others which are more institutional."

"We tried some of the other facilities in ACT. In one she (mother) just burst into tears and we had a bad experience at another too. She will come to the Cottage."

"Gobsmacked when I first looked at the place"

"...comfortable, safe, secure, and enveloped with love and friendship..."

"It's flexible; my wife was in for six days whilst I had my operation."

"Sometimes she resists but seems to enjoy it once she gets there."

Q1. How has your employment been effected by becoming a Carer?

It has been totally devastating: I was in the middle of a 5 year research grant at the ANU, at the peak of my career, and I've had to put that on hold. I'm an anthropologist and I need to travel to research, which I can't do now that I am caring. I don't have help from other family members.

I had to reduce work hours from full time to one day a week. Income loss too. Loss of superannuation and eligibility for long service leave. Loss of identity because had I have devoted my life to research

Had to give up work because I could no longer leave the person I care for alone in order to go to work

The stress of caring and working became too much and so I had to give up.

- **Rushing in the morning to get everyone ready**
- **Rushing in the evening to get dinner ready, housework and getting everyone into bed**
- **Worrying at work including getting phone calls from or about care recipient at work**
- **Extremely stressful work and was not able to give it my full attention.**

“If you have a good work ethic it’s not a good place to be if you can’t give 100% to your work while you’re there.”

Not easy to fit work in around respite program hours, for example some programs finish at 2 pm

Interstate meetings are impossible – inevitably something happens to care recipient just as your about to get on the plane and the whole thing is scrubbed.

Working and then having to work from home to catch –up, leading to extreme tiredness.

Physical and mental exhaustion; because of exhaustion can’t associate with people socially which then leads to isolation – “Hermit Syndrome”

Limited opportunities to socialise with work colleagues, which can also impact on employment due to lost networking opportunities.

Other important opportunities such as presenting at conferences and workshops are lost because as a Carer it is impossible to make a commitment to be available in the future as the health and needs of the person you care for are to a large extent outside your control.

Unable to ‘act up’ if asked to at work or aim for promotion due to Caring responsibility.

Employers expectations are high and may include emailing after hours and working on weekends (not possible if you are Caring after work).

Feel that it is unfair as employees get time off for the birth of a child but organisations do not recognise the responsibly of Caring to the same extent.

The Cottage does not provide respite to enable a full working day (9 -5) for a full working week. In fact there is nowhere in ACT that does.....

Even if not employed – weeks are filled up with appointments can’t do things you want to.

Q2. What does the Cottage offer that others don’t?



Each client is treated as a person

Home feel, lovely décor including photos of years gone by, double beds (not hospital beds), chairs not pushed to the sides of the room as in a nursing home, and age appropriate music playing.

A home is a familiar type of place compared to a nursing home which can help people with dementia feel more relaxed.

Homely activities take place which the client can become involved in such as cooking, chess, looking after the chooks and dog.

The staff members each have their own special qualities and are very caring and good staff consistency.

Pam invites her grandchildren to visit sometimes and it is lovely having different generations at the Cottage.

It is important that the Cottage is a standalone building and not a wing of a nursing home. It can be distressing for both the care recipient and the Carer to look up the hall at the nursing home as you are going to respite. Psychologically it is a depressing signal that residential care is the next step.

The management are committed to the Cottage having a homely feel. Staff members who have not shared this ethos have had to leave.

“I took Mum to a facility and she cried and cried. I took her there for a few days but she hated it. At the cottage it still is taking her a while but she is learning to like it. It takes a person with dementia six months to a year to warm up and get used to a place.”

There is much more staff interaction at the Cottage

Cottage has outings for those that are able.


Carer knows that their person is safe, warm, cared for, has interaction, stimulation, outings.

We want our people to go to respite but we want them to go somewhere nice.

The Cottage is more flexible than other places:

The respite at the Cottage is not included in the 63 days of respite allowed.

Bigger residential facilities require people to be in for at least a week or in some places 2 weeks, even if you only need a couple of nights. The Cottage doesn't have this minimum stay requirement.



“I will never forget when I went to pick her up, Mum was sitting by herself, hair all tussled and looking so miserable. I would never take her back to a facility, it was just too distressing”

“I would be happy to leave Mum in the Cottage overnight but couldn’t comprehend putting her in residential respite for a week. It would be too upsetting for us both.”

“I think that putting my wife in a facility would have knocked her back, more than just unhappiness while being there. The Cottage maintains her current level of functioning for longer.”

The Cottage has less people so less potential infections and staff can provide more attention and possibly keep a better eye on the health of the clients.

Mum went through a stage of being a bit difficult and they (the Cottage) handled it really well. They seem to be able to manage disruptive behaviour to an extent so that it does not impact on other clients.

Q3. What are the positives and negatives of Community Care Packages?

Several participants agreed that it is so difficult to find out what you can and can’t access. There are still many Carers who are not aware that they can access Carer payment, CACP’s etc.

Alzheimer’s Association and Carers ACT are good sources of information. One participant said that the social worker at the hospital was very good source, better than Alzheimer’s and Carers put together.

There needs to be a good source of broad information i.e. taxi vouchers, CACP’s, companion cards, incontinence pads, everything. (It’s taken two years to get on top of all the information).


Eligibility for a CACP can be difficult in particular the requirement for an ACAT assessment for a younger person with dementia.

Somebody else said that Low care ACAT’s are now valid for two years instead of just one.

Another participant had difficulty getting a doctor to sign the necessary paperwork and was put off trying again.

The packages themselves provide only shortish blocks of time and they require the Carer to timetable everything around them. Can be difficult for the Carer to remember whose coming when and to remember to cancel them when necessary.

The package are not flexible in that they include components that you may not want such as housekeeping but you still have to pay even if you choose not to use that particular component.



There is a flat rate of charge for CACP, EACH and EACH D even though they are different hours (CACP subsidise the extra hours of the EACH's).

Feel at the mercy of the amount of packages available

Husband has become friends with his male carer provide by the package. They do things together which my husband enjoys such as going to the art gallery.

Packages can provide a variety of services i.e., housework, outings, personal care, companionship.

Don't have a package. I buy in services at huge expense through desperation and I have people moonlighting for me.

Q4. How does the level of fees influence your use of the Cottage?

"Fees are extraordinarily low – I think." "...don't say that, they will put them up."

"Can't compare the fees because there is no comparable service to the cottage"

"Fees are reasonable."

In financial terms, the longer someone can go to the Cottage the longer they will stay out of residential care.

Q5. Can you suggest any improvements to the Cottage?

Open seven days a week

Have a north side Cottage. Important that any new facility stays small so that it is not a nursing home.

Stimulation for clients is very important and at the moment stimulation is not as high as it was with (x).

"Cottage needs a few more mental activities including someone to talk too or play chess"