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Submission No. 904
(Inq into better support for carers)

3 July 2008

Secretary
Inquiry into Better Support for Carers
Standing Committee on Family, Community, Housing & Youth
P O Box 6021
House of Representatives, Parliament House
CANBERRA ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community Housing and Youth's Inquiry into better support for carers.

In my submission I address the following issues I have experienced as a carer. in accordance with the third Term of Reference namely:

"The practical measures required to better support carers including key priorities for action".

- Availability and ready access to information.
- Respite Care
- Inhome Care Packages
- Legislation relating to Assets Assessments

Summaries:

- Information on respite / inhome care
Difficult and time consuming to obtain the information as service providers are not forthcoming with such information until they have secured a package.
- Respite Care
Insufficient available beds for respite due to lack of funding, number of beds in facilities to cater for low, high and dementia specific categories and long waiting lists.
- Inhome Care
Lack of flexibility in combining aspects of different packages to tailor a package to client's specific needs.
- Assets Assessment – Family Home
Apparent discrimination against a child who has been a live-in carer in the family home for at least five years or more but who continues to work full time. Example: A son who is 55, working full time on a salary of \$55,000, caring for his father or mother or both, lives in the family home and does not have any other property or investment.

I **attach** my submission for consideration.

I was only able to put forward my views as I found out about the Inquiry through a casual conversation and am concerned there may be many carers out there who are not aware of this Inquiry whose input may be of value. . Information about this Inquiry doesn't appear to have been widely distributed to carers and I trust the submissions received are totally reflective of carers' concerns in general.

Thank you for taking my views into consideration as part of the committee's inquiry. I look forward to reviewing the recommendations you make in order to improve support for carers.

Should you require clarification on any of the content please do not hesitate to contact me at the above address or telephone number.

Yours sincerely

Carer

SUBMISSION

AVAILABILITY / ACCESS TO RELEVANT INFORMATION

Service providers appear inclined to keep querists "in the dark" as to what packages are generally available and what these packages can provide until an ACAT Assessment has been done and a provider appointed. This precludes a querist from having any knowledge of where they may be heading until they are actually on the track to a particular package.

I live with my mother who is a 88 year old war widow and I am her prime carer. I have been caring for her over the past 20 years since she became unwell and over the years has slowly become progressively worse. As I work fulltime it has been extremely difficult over the years to combine work and care. To enable me to continue to care for her in her own home I need all the support available to me. As my family are unreliable in supporting me I have had to resort to putting my Mum into respite care to enable me to get a break. I have found it extremely difficult and time consuming to obtain information on care and what is available. I appreciate that there are associations like Carers Queensland who handle respite and they have been helpful but the situation became difficult when I then tried to put their information into practice. I started to hit brick walls especially as far as respite and inhome care were concerned.

It would be great if there was a one stop website showing you where to go for the relevant information/services and easy links to all information. I have had to spend many hours just trying to understand what is available and where to get the information from. I have found suppliers tend to say "you don't need to know what is available, just tell us what your requirements are and we will work it out from there. It's a mine field for us and it is too complex to explain". Or when you finally get an ACAT assessment and recommended package you then have to wait a long time for a package to become available and when you try to find out what you can do in the mean time no-one really wants to assist and they are inclined to tell you there are waiting lists and when your package comes up we can discuss it then. When you finally get to talk in interview it then works out you can't get what you need anyway because none of the packages actually suit the requirement. It would be good to know beforehand what is available so that when the interview comes up you have an idea of what your options may be.

Recommendation

One website showing what is available for carers as far as packages are concerned, what they represent, who is eligible and what suppliers have these packages available, whether they are State or Federal. This would greatly reduce the time spent having to go to different websites and search for the information or be told conflicting information from agencies or suppliers. The carer would know what is available so when it came time for the assessment they would have an idea of what package would suit them and then be able to discuss how they could best utilise the package when a supplier makes contact. The website could have links to where the relevant information is. As it is now it takes a long time once you get to the correct or appropriate website to then have to search through that material to get to the information you want.

I have focussed on respite and packages here but there are many other areas that could be linked on the website.

RESPITE CARE

As stated above I am the carer for my mother and as I work fulltime it has been difficult to manage both care and work without the family support. I have found that there is a long waiting list (sometimes 12 months or longer) for respite beds in facilities that do provide respite and this makes it difficult for a carer to get respite and also restricts when they can take it. If they want to go on a holiday or plan a trip they almost always have to fit in with the availability of a respite bed – not when the carer needs the break.

Example:

I wanted to get some respite and I had a considerable amount of trouble finding a facility that had a single room respite bed for high care. When I finally found a facility that had a high care respite bed I was informed that there was a long waiting list of around 12 months. To date I have found three newer complexes that cater for high care respite (not dementia specific) having one single room and they all have quite a long waiting list for that room. Others have a bed but in a shared ward and others are in very old complexes. It has been suggested that I make sure I book well in advance if I want respite– like book now for next year, which may not suit my requirements or work commitments.

Another reason there is a shortage of single respite rooms is that I have been told nursing homes or facilities are getting rid of their respite beds for permanent beds because of lack of funding and they need that room or bed for a permanent person. This in turn makes it more difficult to get a room. Carers are then restricted to when they can obtain respite depending on what is available and when. To plan a holiday you have to book respite first and then work out where you want to go. Working commitments also make it even more difficult. So if they start to cut down on respite beds/rooms it will make it extremely hard for carers to take a break, especially if family members don't help out.

I am aware that there is emergency respite available, however this doesn't always provide a facility of choice and may have a negative effect on the person going into respite if the standard of care and facility isn't at the same level as previous respite placements. For example: Shared ward as opposed to single room, high care bed is in dementia ward etc. and this may impact on the person negatively resulting in reluctance to accept further respite in the future. This could then put the carer in a position where they may not be able to avail themselves of future respite.

As I live at home and care for my mum I see my role as carer a very important one in giving her a specific quality of life by remaining in her own home that she wouldn't necessarily have if she was in a care facility, assisting the government and facilities /complexes to enable others to avail themselves of their care as there are long waiting lists. Therefore it is imperative to have the respite facility there and available for carers.

Another point is that many of the homes are very old and whilst there is accreditation in place to keep to a standard of care I have found a lot of them still require upgrading. I realise this is slowly taking place as older homes are being redeveloped but they need government funding to make them more attractive and especially as there is going to be a greater need in the future. When new facilities are developed and built it would be good if they included respite rooms for high, low and dementia specific care.

I was wondering if would be feasible to have say one big respite centre in each capital city in the future. I don't know if there is a demand for it but it would be good to have a centre that had the three levels of care because there are older folks who are at the lower end of high care that have to go into dementia specific high care where people aren't coherent or can't communicate very well and this is also a distressing factor when considering respite.

My role as carer affects my life insofar as I don't have any time for myself, to go out or away apart from when I go to work. It is very hard for me to get away and that is why respite is so valuable to me. On the other hand for my mum when she is going into respite its much better if she can go into a room of her own and somewhere which has pleasant surroundings.

It is important for the Government to keep funding Aged Care facilities for respite beds both in high and low care. It has been my experience that a lot of facilities only have a respite bed in low care and nothing for high care. This makes it extremely difficult for a carer to get a break and limits the choice of facility for respite beds.

It is important for carers to be able to take the breaks they require to enable them to continue to provide the care so necessary to keep people in their homes for as long as they can whether it be high or low care. My experience is I have found it quite hard to find an appropriate facility to cater for the lower end of high care and getting a single room. I would encourage funding for new establishments to provide single respite rooms especially in high care.

I realise with high care a majority of the community would more than likely already be in care, but if they are assessed as being at the lower end of high care then I am sure that there are people out there being cared for in their own homes until such time as it is impossible to continue care in the home and these are the ones that need respite in a high care facility.

Summary

- There is a lack of respite beds both for low and high care especially in a single room.
- There is a long waiting list for respite beds restricting carers from taking a break when they need a break.
- Suppliers are getting rid of respite beds because of the demand for permanent placements and funding costs for beds associated with permanent/respite beds.
- New facilities need to take respite bed/room into account when building complexes.
- The demand for respite will become greater the longer people want to stay in their homes with a carer whether they be high or low care.

Recommendation:

The Government support facilities / suppliers / nursing homes with more funding for respite beds especially in high care. By high care I do not mean "dementia specific". There are facilities which have a respite bed in dementia wings but no respite bed in a high care wing. Therefore if a person is classified as high care but not suffering dementia they would have to go into a dementia wing because that's where the bed is situated. This is not appropriate. Facilities need to have respite beds available in low, high and dementia.

INHOME CARE PACKAGES

As funding is provided for quite a number of packages to assist carers or people to stay in their own homes it would be of benefit if perhaps some of these packages could be flexible in providing the care. For example VHC only provides hygiene for 3 days a week unless given special consideration for 5.

However if the person then wants to go to an outing or an appointment they can't do this under VHC they would have to take a CAPS package. There is nothing in between these two packages apart from a COPS package and this doesn't necessarily give enough hours unless you combine them so that the person can be given the assistance they need to stay in their own home. You may not need all these hours to accommodate your requirements but you have to pay for them if you don't use them anyway.

However if you could interchange packages say : HACC with VHC or COPS then this could be tailored to accommodate the requirements needed. This would also free up the CAPS package for someone who is in more need of the extra hours and as there are long waiting lists for all packages.

Recommendation:

Is it possible to make the packages more flexible so the suppliers can adapt them to the needs of the person rather than have to take a package that has too many hours and not utilised fully.

It seems a waste for the person needing care to have pay out for additional hours that they don't require and utilise a package that someone else could be using fully because there isn't the flexibility to streamline between packages enough to cater for one's requirements. Perhaps be flexible with say a HACC package with VHC or parts thereof. I realise that is mixing State and Federal funding and this may not be feasible. So that for example if a person required 5 showers a week and an outing or appointment these could be joined together rather than have to take up a CAPS package. A COPS package doesn't have enough hours to do this either and a CAPS package has too much that isn't needed, and with CAPS you have to pay for the hours even though you may not need to utilise them.

LEGISLATION

Presently there are accommodation bonds for low care. It seems the government may be looking at the same for high care. I would like to put forward a proposal for a further exemption in both cases for family carers who are living in the home. At the moment the family home is specifically excluded for low care from the assets if:

- You have a spouse, de facto partner or dependent child still living in the family home;
- A close family member has lived in the family home for at least five years, and is eligible for an income support payments (e.g. the aged pension, carer payment, or newstart allowance);
- A carer has lived in the family home for at least two years and is eligible for an income support payment.

I would like to put forward for consideration a further exemption to be added to the Assets assessment in relation to the family home for:

A child who is a carer, has lived in the family home which is their principal place of residence for at least 5 years or more, has the prime responsibility of care for the parent or parents and does not own any other residential property, is not in receipt of a Centrelink Income Support payment and works full time.

The reason I say this is that if a child has lived in the family home for this period of time or all of their life and becomes the prime carer for a parent or parents but is still working and not receiving a Centrelink Income Support payment, it puts that child in a very difficult position if the home then has to be sold to pay for an accommodation bond. It leaves that person without a home (unless they have an investment property or the like, in which case they would not be exempt), to then find rental accommodation.

This is becoming extremely difficult and costly with the growth in population across the capital cities and would certainly cause hardship for some.

It may be the case that if they could remain in the home they could pay rent or a charge to the homeowner who then passes it onto the facility. By allowing the carer/child to remain in the home they could then still continue to provide care for the parent who has gone into a facility. Otherwise with the relocation of the carer they may not be able to provide the ongoing support to the parent because of financial or location difficulties.

This situation may only affect a small percentage of the community but it does have a huge financial and emotional impact on the person who has been caring for a parent or parents to have to sell the home and then find alternate accommodation after years of dedication and assisting the government by caring for someone in their own home whilst continuing to work and pay taxes which in turn support the government to implement strategies and systems to assist the community.

Example:

A child has lived in the family home all their life. Since one of their parents passed away 15 years ago they have been the prime carer for the other parent. Over the past ten years the care for that parent has become more demanding due to increasing health problems. The child works and gets assistance in to help out with her care. They are not on any Centrelink benefits only the carer's allowance. As the parent's health continues to deteriorate it may become necessary for them to go into care. If they are assessed as low care she would have to pay an accommodation bond.

Presently under the guidelines the family home would be taken into consideration as an asset. If the home was to be sold to pay the accommodation bond that would then leave the child in a situation where they had nowhere to live having lived with their parents. This would then cause them hardship as they would have to find a rental property. With the population increasing it has become very difficult to acquire rental property and rents are expensive. In order to keep up the support for their parent whilst in care, it would be beneficial for the child to be able to remain in the home to provide such support and be able to bring the parent back to their home for visits. If the property was made exempt from the assets assessment under these circumstances it would assist the child and the parent or parents if the child could remain in the home until the parent was deceased.

If high care is going to attract an accommodation bond then it is suggested the same exemption should apply to the assets assessment.

IN CONCLUSION – GENERAL COMMENT

As a carer I have experienced that what government agencies or staff are telling you is not exactly what the suppliers tell you, and have ended up entirely confused about what is correct. It then can become time consuming and frustrating to have to go back and forth searching websites and contacting people for documentation to be sent so that a carer can find out accurate details in relation to the information sought.

Therefore it is critical that information and documentation is easily accessible, user friendly and accurately conveyed.

Carer