SUBMISSION RE CONFUSING RESPITE RULES

My comments are based on personal experience as the 76 y.o. carer of my husband who will be 92 years of age in September 2010. We have been in receipt of a CACPs package since February 2009.

When my husband goes into residential care, he has been assured that he is not eligible to attend his twice weekly specialised physio conducted exercise group because his respite is funded by DVA and the exercise group has its funding from DVA. As he is totally deaf he is isolated in the respite facility and misses his exercise group. FOR WHAT PURPOSE? No-one else can take up his place for the week or even two weeks when he is in respite.

I must stress that the exercise group staff are sympathetic to his cause and the commonsense solution of allowing him to continue to attend, but they cannot permit it. Apparently it is “double dipping” and the respite facility will provide exercises anyway. They do, but they are footling compared to the specialised strengthening and maintenance program he usually undertakes.

If we are paying for his respite care apparently after much enquiry he could attend the exercise group, but by the time he pays for a taxi each way and full cost recovery for the exercise session the cost would be prohibitive.

I am sure DVA would not want this situation to prevail as that Department is so generous and considerate of old veterans.

The above situation that I quote it is a case of loss all around. My husband loses his exercise opportunity twice in one week, the service loses its target by two places and two fees of $7.00 each, the government department loses the opportunity to provide a service and the service provider loses staff time discussing such a trifling matter.

Curiouser, and curiouser when my husband is in Commonwealth funded respite, or respite that we pay for ourselves, he is still able to receive his CACPS package services, which are provided to keep him out of residential care!!! I could understand if this were stopped. But then would we still pay for the CACPS package which we currently do when he is in respite residential care.

We are of course very grateful that this 3hours of CACPs “respite” care is available when he is in residential care because we use for the usual paid carer to take my husband to hydrotherapy twice a week as usual.

What would help me is instead of “tooing” and “froing” with many phone calls between service providers in these different organisations, would be if there was a phone number to call where a person had authority to sort out and give a decision on these small anomalies. An approval number could be given to safeguard the service provider from sanction. The calls could be randomly audited to ensure that the approvals were appropriate and also to pinpoint faults and unhelpful application or framing of rules.

SUBMISSION CACPs and EACH PACKAGES

My comments are based on personal experience as the carer (aged 76) of my husband who will be 92 years of age in September 2010. We have been in receipt of a CACPs package since February 2009.

I have submitted a response on CACPs.

CACPs packages provide around 5-6 hours of direct assistance per week. EACH packages provide between 15-20 hours of assistance.

I do not find the CACPs quite enough assistance, but it does not seem logical to jump from 5-6 hours of care and then to suddenly seek 15-20 hours. Deterioration is often a slow process. I think what really happens is that carers really struggle for too long on the CACPs package.

I realize that one does not have to take up the full 15-20 hours of assistance, but what concerns me is if as a carer I am struggling with 5-6 hours of assistance. Concerned about failing in the caring role and my husband going into residential care, I may be tempted to discourage my husband from the slow procedure of showering, and dressing himself and thus qualify for a higher level of care.

At assessment I may give the worst case scenario of the bouts of incontinence. I would be tempted to mention the burden of daily shaving, the special food preparation, the monitoring of medications, the disturbed night's sleep, my own aches and pains, so that we would qualify for the higher level of care. This is counterproductive to the encouragement of independence of the care recipient and encouraging support of the carer. Not much help to the couple or carer/caree relationship either.

I understand that Linkages packages give a slightly higher level of care than CACPs but they are not widely available.

I believe it would make more sense to have a gradual as needed "step up" in CACPs packages to say 10 hours per week, then leading on to 15-20 hours in an EACH package as the need arises. Except in the case of sudden illness or accident, care needs do not double overnight. So why is the service designed to give this huge leap in amount of service available.

Of course while CACPs packages are little enough what really concerns me is that with costs of providing these services rising that the 1.7% increase in funding recently announced can only mean the packages will be even smaller in the future. Hardly above what a HACC eligible person would receive in homecare, certainly nowhere near what was intended when the packages were created which was to support at home a person assessed as requiring low level residential care.

SUBMISSION RE CACPS PACKAGES

My comments are based on personal experience as the carer (aged 76) of my husband who will be 92 years of age in September 2010.

We are in receipt of a CACPs package, which gives us 90 minutes of house cleaning per fortnight, and 3 hours per week of care labelled "respite". The service is that a carer takes my husband twice a week to an indoor hydrotherapy pool where he does exercises specified some time ago by his physiotherapist. This is a task I could not manage to do.

We became eligible for this package in February 2009. It is really only on the last few months that the service provided, which may be a little unusual, is really what we want.

The reason for this is I believe that there appears to be a tendency to offer personal care, showering, shopping and the like. We tried these services and they really did not help me as a carer. This was because my husband's main problem is severe and continual pain in the inner ear as a result of shingles in the middle ear three years ago. Services such as help with showering did not relieve us of any stress because he needs to be showered when he feels up to it. After cancelling the help with showering he has learned to do this safely for himself which is a better outcome as he has maintained a higher level of independence.

I prefer to do the shopping myself although the shopping was an outing for him it really did not save me any effort and was a considerable effort on his part. So initially the package did not really help either of us.

I want to put on record that all the staff, case managers and paid care workers are respectful of older people and their home. They are neat, equipped and competent to do their tasks.

What would have improved the whole process for us would have been if we had been joined as in a "partnership" from the beginning. For example the CACPs package was never explained in terms of how many hours or how much money was available to be spent per week or per month. I was surprised to see CACPs shown as 5-6 hours per week in your document.

As carer I am a well person. I participated in the workplace for over 55 years. I have run several businesses and qualified as a social worker in 1981. I practiced in that role for over 25 years. I would much rather know what resources are in the package and deploy them through recognised provider agencies to suit our needs. This would involve fewer phone calls for me, more choice, flexibility and a sense of control. The required 6 weekly visit by the case manager is hard to fit in around dental, physio, doctor's appointments for us both and not necessary in our case.

I am sure that the case manager's role is appreciated by many carers. But I am not one of them. Surely it would be good practice to give carers and packages recipients the choice of self management with oversight by CACPs of service providers used and full accountability of funds expended.

SUBMISSION RE RESPITE.

My comments are based on personal experience as the carer (aged 76) of my husband who will be 92 in September 2010. We are in receipt of a CACPs package, which gives us 90 minutes of house cleaning per fortnight, and 3 hours per week of care labelled "respite". The service is that a carer takes my husband twice a week to an indoor hydrotherapy pool where he does exercises specified some time ago by his physiotherapist. This is a task I could not manage.

I have submitted a response on CACPs and on CACPs and EACH packages.

The respite service I use is through Commonwealth Respite and Carelink Centre, Southern Region in Victoria. I use this service mostly in the evenings so that I can attend the theatre and other functions about once a fortnight.

It is a wonderful service. The co-ordinators are competent and efficient. The carers sent have all been extremely pleasant, helpful and I have full confidence in leaving my husband with them knowing that they will heat and serve his meal and provide whatever level of company he requires. The carers have always arrived right on time so I have no anxiety about my plans being disrupted.

This service makes all the difference to me as a carer. It helps me maintain a positive view to my caring role. I am not tied to the house and I am able to join in with my friends on planned outings.

The other respite we access is residential respite. This is mostly of a high standard and sometimes just an adequate standard. The worst feature is availability. Bookings have to be made far in advance. Many of the best places are booked up over a year ahead. I like to take a week's respite when I am tired and just want a break and I cannot realistically plan that effectively a year ahead.

Emergency residential respite I am sure would be hard to provide, but it can be needed. Recently I was suddenly very ill, particularly over a weekend. We staggered through but I was really just needing to stay in bed all day and night myself, which was impossible. I was very fed up with caring. In home respite could have been organised, but as a carer who was ill I did not feel up to organising the care and then showing a person where everything was or trying to set up a room for an overnight carer. I began to think that my husband must go into permanent residential care.

On recovery I phoned around to see what would have been available had I been up to the task of trying to access emergency residential care.

I was dismayed to hear from a commonwealth funded hostel that they do have unplanned respite beds for emergencies but they do not do admissions on Saturday or Sunday. I understand the constraints of administration staff on weekends but surely there needs to be some system to cope with this eventuality.

What would have helped me would have been if I could have made one phone call and set in motion the admission of my husband to one of the unplanned respite beds. Admission documentation appears standard. Saturday and Sunday telephone access to a qualified person to take the admission details over the phone, make the care plan, record the medication information, find a bed and dispatch a care worker to pack up some clothes, take the person and their medications to the residential while emailing the admissions information to a residential facility should be possible.