

Committee Secretary
Standing Committee on Family, Community,
Housing and Youth
PO 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.

As the primary Carer of my husband who is a quadriplegic and has been high maintenance for many years I strongly feel that my role is extremely demanding and undervalued by government. And to ensure there is a clear understanding by the Committee of what my care responsibility is to my husband it is also important to explain what this carer role entails especially on a 24 hour a day, 7 day a week basis so that the Committee knows how this impacts and restricts my own quality of life. It is also worth noting that I am the only person who is available to provide this care and should I not be around to do this my husband would have to be admitted (not his choice at his age) into a nursing home.

As a Quadriplegic his care needs involve all his personal care, showering, dressing, meal preparation and assistance with some feeding, putting to bed and night turns, transfers into and out of his wheelchair and the car, assistance with pushing his manual wheelchair especially over long distances. Whilst my husband receives an Aged Care Package that only provides 1.5 hours during week days and 1 hour on weekends and public holidays. In addition to my husband's age care package I receive the Carers Allowance.

My husband's income is from a self funded superannuation pension and I am due to retire in July this year also on a superannuation pension. The decision to retire is heavily weighted toward my husband's continued deterioration in his condition. The decision to retire will see a significant decline in our income. As pensioners we will also have to reduce our lifestyle and become more frugal with our money because the "Cost of Disability" is increasing inline with my husband's disability and these extra costs are not fully accounted for or funded in his age care package.

Although we own our home we also have the expenses of the various charges for water, electricity, land rates, telephone, gas, motor vehicle registration and licence, house and contents insurance and private health insurance (a special high priority need in our case because of my husband's medical needs). Even though we are both

seniors we receive no discounts for any of these payments. In addition to these cost we have to pay tradesman for home maintenance and gardening. Increases in petrol and food over recent times will further diminish our ability to meet these payments on my retirement and further deplete our small savings. And yet the government's Utilities Allowance is not available to us.

We own and use a 10 year old motor vehicle because public transport is not fully accessible at this time to wheelchair users and to a level that it can be relied upon for all of my husband's transport needs to doctor's appointments or social activities etc. We are in no financial position to upgrade to either a more economical or an adapted vehicle that is easier to transport my husband in either his manual or power wheelchair.

Other cost factors include the need to now have access to the internet to research government, disability and aged care information including plus communication to these groups. Our current computer is over 5 years old and together with the limitations on internet down-loads the service provider costs need to be closely watched by us to prevent cost over runs. Again, and with a 16 year old house we now need the house painted and soon will need to replace the hot water system and cook top all on tight and limited joint fortnightly pensions.

ABOUT MY HUSBAND'S CARE PACKAGE:

In 2005 my husband was in hospital for a long period and assessed by the Aged Care Assessment Team as needing a CACP Package. Following further deterioration and in an endeavour to assist me as his primary carer this was upgraded to an EACH Package as I was then working full-time. At the time and even now it is very difficult to get the Guidelines or get an indication from his provider what these packages cover, what the daily rate is and how the income test determines what care recipient pays.

Whilst it is appreciated and necessary to have these aged care assistance packages they come with a significant trade off to your lifestyle if you allow the provider to totally control how they run the care. Providers appear not to understand that the care should be minimal on the basis that families don't want large numbers of different carers taking over our lives at times that suit the provider. While the carers themselves seem to recognise this when raised it is often overlooked by the provider administrators and can be viewed by them as an issue that appears to cloud their decisions if raised.

Over time my husband has had quite a number of carer changes mainly due to people leaving. Although my husband is quite flexible as to who provides his care last year he got quite concerned with these constant changes as he not only had to retrain carers in his special care needs he never knew who was due to turn up. It got to a point that he demanded that his provider always only send the same 4 cares each week and this was not deemed acceptable by the provider. This was only agreed to by the Provider on the basis that should any of the 4 be absent for what ever reason and providing I was rung and told of the change he agreed to accept their choice of replacement.

This brings into the question the provider's management ability together with their empathy with the care needs. Over the last few months and what I suspect is the constant office staff changes they have forgotten to send a carer altogether on one occasion and not been able to offer carers on 4 other occasions. The time no carer appeared I was at work and unaware of the no show and was not due to return home until after 4.30pm that day. It placed my husband at great risk because he was left in bed without food or water, the inability to turn himself or go to the toilet and without a communication device. I am not aware if the provider has a back up system to check if all clients are given their daily care as required.

With my husband's package we previously paid \$197.38 each month being the care recipient contribution by us and this increased from 1st of June 2008 to \$200.75. Although he is due for an aged care review in July 2008 there is little prospect of any reduction in our payment. This last increase by the Provider in the care recipient contribution means that I now retain only 45 cents from the Carer's Allowance of \$201.20 a month for the 23 hours each day I provide my husband's care.

Whilst we are aware and accept that we must contribute toward my husband's care package there appears to be no option to claim back the daily fee paid by us when no care is provide on any given day due to staff shortages and I do all that care on those days. We also accept that we must pay the daily contribution when we go on holiday and the care is provided interstate by another provider. And yet there is no indication by the care provider that they recognise or will accept the out of pocket "Cost of Disability" payments we make in calculating our contribution to reduce our monthly care recipient payment.

We also have the sense with the care provider that if we make a complaint about any situation regarding his care we could loose my husband's care package all together. The lack of documentation that clearly explains or indicates that my husband has rights with the care package being provided or what those rights may be further prevents a good working relationship with the provider. It is also difficult to manage my husband's care with the constant staff and administrative or policy changes in the provider's office. Up until mid last year the organisation had a very popular newsletter that kept staff, clients and nursing home residents informed of changes and happenings. For some reason never given to clients this has been discontinued in its printed format and only available on the provider's website and it discriminates against those care recipients that don't have internet access.

It has come to our attention that my husband's package will fund certain items he requires for personal care and incontinence and it may well consider funding for wheelchairs and a shower/commode. We have been advised by the provider that if it was to be considered it would be at the discretion of the Chief Executive Officer and it would only be for a standard and not a more suitable or appropriate wheelchair that best suit's my husband's disability. As we don't have access to any list of equipment the package will purchase or cover it is therefore difficult to ask for equipment that my husband purchases annually out of his pension to help manage his disability. Last year it was in the order of \$8,000 and what is referred to in this document as the "Cost of Disability".

Whilst the former government's program of aged care in home support is in our view a good one, it seems to be still in the development stage and at the same time endeavouring to meet the aged care needs of recipients. From our own experience it appears to have particular shortcomings in that information to clients clearly spelling out in an understandable way on nearly all its aspects is not readily provided to those it is trying to provide care. It may also be a reason why our provider is not as competent in providing the high level of care so necessary to better assist us carers.

I contribute to Australian society by providing long hours as a primary carer and giving an individual (in my case my husband) a quality of life that would not be available in a nursing home. This contribution saves the taxpayer and the government a very significant amount of money. Such a significant contribution is at a huge personal cost in time to have my own life of my choosing and that would enable me to do the things I personally enjoy. The workload also is tiring and restricts my ability to have quality time with my partner to do the many things we previously did as a married couple. This is a further worry in that my future health will suffer with the constant demand to do this heavy work. I could be selfish and just walk away from this situation and that would shift the responsibility onto taxpayers and the government.

Previously I mentioned some of the financial costs of my husband's care. To my husband's credit he recognised his work limitations relative to his disability and the ability to generate significant extra income that could be saved over time to maintain a good lifestyle in retirement. He endeavoured to maximise not only our savings and also our superannuation but the rules restricting these past opportunities now see us struggling financially. It has the added disadvantage in the future as we become more reliant on government support for our aged care needs that our quality of life will not be good – and that's a worry. This is further exacerbated by that fact that I am at an age where going back to full or part-time paid work is not an option not only because of my age but also as a result of my husband's increased care needs.

As parents who consciously worked hard at trying to provide a future inheritance for our son these current demands of my husband's care and those of the future are rapidly diminishing that possible inheritance. This will be further curtailed with my own aged care needs in the future and with out any opportunity or ability of either of us to address this in the future it becomes a bigger problem unless there are some restrictions on the constant increases in the application of the user-pays-principal.

My concerns with the aged care system are the packages and the lack of things that are not clearly articulated by the care provider administering my husband's package. There is often presented a view that these packages have guidelines but these guidelines are for the administrators and not care recipients. We are told that certain equipment items can be provided but to know what these are is difficult to find out. There is no advice given on what the basic care package is or what can be provided. The whole package revolves around a care plan designed by the provider in so-called-consultation with the care recipient and one's family that seems to be used to seek a level of funding from the government. This level of funding appears to be a secretive figure that recipients are not allowed to either know or for fear that they may ask for more care which in-turn will restrict profit generation by providers.

IN SUMMARY:

It is my considered opinion Carers needs the following changes and inclusions in the care packages to assist them in their care responsibility.

- There needs to be a significant increase in the Carer Allowance above the current \$200 a month.
- A cap needs to be placed on Recipient Contributions.
- This cap should restrict care providers taking the full Carer Allowance as the case will be after the 1st of June 2008 increase to \$200.75 by the provider.
- There needs to be a balance in care provision that does not see numerous care provider organisations taking over care responsibilities in a manner that is restrictive to a carer and one's family life style.
- This balance must address the fundamental need of people needing the care and being in control of their lives without lifestyle restrictions.
- The Centrelink system is so complex that it scares people and fails to simply address needs and issues in a manner that is clear and unambiguous. It should not be as I believe so complex that it is used as a mechanism to reduce welfare.
- Award wages for care workers need increasing to a level that will assist organisations to better recruit and retain staff both in the nursing home and community home care setting.
- Guidelines for In-Home Care Services need to be finalised.
- The Guidelines need to be crafted or worded in a manor that focuses more on the Carer and Care recipient and less on the provider.
- In should be mandatory that the Guidelines be provided to Carers and Care Recipients when the ACAT recommends the care.
- Any Guidelines must include a full list of all equipment that any of the CACP, EACH and EACHD package will fund.
- It must also list the level of funding and if a client contribution is necessary.
- A Charter of Rights for Carers and Care Recipient needs to be developed and provided to those receiving the care.

Thank you for taking my views into consideration as part of the Committee's Inquiry and my husband and I would also like the opportunity to address or speak to the Committee. I also look forward to reviewing any recommendations you make to improve life for Carers and care recipients in Australia.

Yours sincerely

M D T

12 June 2008