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Linda

Secretary
Inquiry into Better Support for Carers
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600
fchy.reps@aph.gov.au

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.

My name is Linda . My husband is an ex-RAAF veteran retired TPI (Totally & Permanently Incapacitated) pensioner with Department of Veteran's Affairs (DVA). He is currently 45 years of age & since he did not have overseas service, we do not receive the Service Pension. He was retired primarily due to psychologic problems but has arthritis in his ankles & some other physical injuries.

I am one of less than 10 carers still attached to DVA & receiving Carer's Payment through DVA because transferring me to CentreLink would adversely affect us. I also receive Carer's Allowance from CentreLink.

My husband's income is from DFRB (Defence Force Retirement Benefits) – his RAAF Superannuation, DVA TPI & DVA DFISA (Defence Force Income Support Allowance) linked through CentreLink Disability Support Pension (to receive a Pensioner Concession Card but no income).

CentreLink Problems.

If someone wishes to telephone CentreLink, the contact system is centralised & the local office cannot be telephoned, unless the direct contact number for a specific staff member is known. Central telephone answering staff are often not very knowledgeable & it is very difficult to find anyone with knowledge about issues that may affect both DVA & CentreLink. Contacting a local staff member familiar with your case history is likely to save a lot of stress & wasted time.

If my husband feels well enough to work, the TPI rules allow him to work up to 8 hours a week. He likes to do some work to maintain his trade skills & for the social interaction & improved self esteem.

The number of work hours he is capable of doing can vary considerably. This causes CentreLink problems because they wish to estimate his earnings, for future calculations. Because his earnings vary continually, they make constant adjustments to my income as a result. One staff member even wished him to submit a weekly or fortnightly report of the hours he worked. Thankfully other staff have allowed less frequent reporting because otherwise he would probably simply stop any work activities because of the associated stress & frustration.

Multi Agency Problems.

We find that we have problems because we are serviced through both CentreLink & DVA. Often the same information needs to be supplied to both agencies & it is sometimes difficult to remember, or even work out what belongs to each agency. It is very upsetting to be accused of not supplying information when, in fact, you have been supplying it, but it has been passed on to just the one agency – even though you supply it to the same local counter staff for both agencies.

An example of the problems of Government Agencies not working together was when a scheme called DFISA (Defence Force Income Support Allowance) was introduced. TPI's not receiving the Service Pension were not entitled to a Pensioner Concession Card (PCC) or other benefits, even though they had significantly lower income, because they had no "means tested" government income.

CentreLink had my husband apply for a Disability Support Pension (DSP) for the purposes of applying DFISA (Through DFISA, the DSP could give him the PCC & benefits but no income). They could access all of the financial & personal data residing on DVA's computer system, but would not accept any of that data for their own purposes, & sent us to get original financial statements etc. Despite being TPI, my husband had to have two medicals, & we spent approximately 20 hours with CentreLink staff & the same amount of our own time simply doing all the paperwork. For the two of us, this was extremely stressful, & I have spoken to people who simply could not face it.

Medical Treatment Service Availability.

It is getting very difficult to even source medical practitioners, & next to impossible to find private practitioners that will bulk bill. Many medical practitioners are now reaching retirement age, further adding to the problem. There is a short supply of Public Service practitioners with a large turnover, so getting appointments from that sector is very difficult & appointment durations are kept short. The large turnover also means that they are rarely familiar with your case & the limited time available prevents you from describing problems in any depth, or acquainting them with your case history. Often psychiatric appointments do little more than review medication.

The time that it takes familiarising a practitioner, & problems with getting an appointment in an emergency, are major reasons that we ensure that we keep periodic appointments booked well into the future. Continually repeating & reliving your medical history & associated problems is frustrating & stressful & further depresses my husband.

Medical Treatment Problems - Special Case.

My husband has a major phobia with hospitals resulting from his initial treatment in a rather infamous psychiatric facility. As a result of this he has nightmares if he is hospitalised & can even lose control of bodily functions.

He is often psychologically dependent on me, & can become extremely nervous & fearful if we become separated.

There is no allowance for carers who may need to be close by their charges when they are hospitalised, or for transport required as a result of your charge. I have the opposite problem as well. Local surgeons have refused to treat me (because of my husband's mental health) & state that treatment in Townsville is necessary so that my husband may be close to psychiatric support. This means that transport for me & my husband is necessary due to my HUSBAND's condition, as well as accommodation either just for him or for both of us.

In addition, there really isn't any facility to keep my husband under psychiatric observation but out of hospital - & hospitalisation would cause his condition to deteriorate & normally leads to self harm problems that can last for a considerable time, even after the event is over. We have been told by advocates that there are many ex-service veterans with hospital phobias & that is a reason that many of them have stopped receiving any medical treatment.

When depressed, my husband often feels threatened by enclosed spaces as well. He had one appointment at the new Townsville hospital psychiatric centre & will not go there again because the waiting area is so small. The psychiatrist that he mentioned that to stated that that was how the building was designed & that patients who didn't like it could just stop coming there!! I am sure that some have.

Privacy Legislation & Enduring Power of Attorney.

I have an Enduring Power of Attorney for my husband's affairs. A common problem is that Government Departments, Banks & Financial Agencies, & other businesses & organisations do not seem to have made any allowance for Carers or for persons having Enduring Power of Attorney. Privacy concerns are used as an excuse for not allowing access to information - often even if an Enduring Power of Attorney is shown to them. Privacy is also the excuse given for not placing on file any information about a Carer being given permission to access information. This causes problems with speed of service as well as unnecessary stress for both me & my husband.

Fragmented Approaches to Carer Services.

It is often difficult to find the various services that exist to assist carers (or their charges). They are scattered & there is no single directory or point of contact to enable finding them. Carers regularly tell each other services that they have found & sometimes will often mention services that could have been of great assistance if known about earlier.

There needs to be a basic minimum standard of assistance for all carers, because currently services are often funded purely with a strict focus on a specific group, which can leave others in similar need without any service at all.

Lack of continuity of service once a charge reaches some particular criteria such as ability or age is also a problem. Funding for many services is also limited to a specific time period making finding the service initially a problem & then leaving carers to try to find another service once it is gone.

Seniors Card, Aged Pensioners & Concessions

The publicity of the plight of Aged Pensioners & the introduction of the Seniors Card has caused a major erosion in benefits for Carers & their charges that are not aged pensioners because many now state that concessions are for Aged Pensioners only & do not accept the Pensioner Concession Card.

TPI's have had a similar erosion of benefits since DVA extended the Gold Card free medical treatment to all Vietnam Veteran's & other groups. The Gold Card was used as TPI identification by many Councils, Transport Companies etc to give special concessions, but many of them were simply stopped when the Gold Card was given to a wider group.

The federal government has stated that it will address the lack of reciprocity of public transport concessions between the states as well as some other concessions, but they have stated that this will only apply to Aged Pensioner Users, so we will still be adversely affected.

Asset Value & Future Planning

Whilst it may be unusual for a carer & charge, my husband & I both own houses. I owned a house before we were married & he was entitled to a low interest rate Defence Home Loan when he was medically retired. The continual rise in valuations & rates is a major concern to us.

His house was used when we got married & was kept to retire to when we got older & unable to handle our current hilly property. Neighbourhood changes make that area now less suitable for our retirement requirements. We would be willing to sell one house & invest in another better suited to our future needs, but the sudden income would cause a major problem if we were unable to reinvest it immediately.

We are often quite frugal & it is frustrating to be told that we should spend our money rather than save it. It is also very difficult to work out how to plan for our future retirement. It is difficult to find anyone who knows all three necessary areas - DVA, DFRB (Defence Force Retirement Benefits - my husband's RAAF Superannuation) & CentreLink legislation. That our situation will change when we reach Aged Pension age is also a problem that is hard to plan for.

Until recently, my Husband's incomes were only indexed to CPI & not to the greater of MTAW & CPI as most other payments are, so we also had erosion of value through that as well.

Letters regarding Incapacity causing Disputes.

My mother has been in a nursing home for several years because of dementia as well as age-linked restrictions. The dementia has progressively become worse so that she seldom talks now, & we suspect that we are only recognised by her because of our frequent visits & not that we are her children.

Because of a local Council election, it came to our attention that my Mum had not been removed from the electoral roll. She had been removed from one Electoral Roll but not another. I thought that had been attended to years ago. I was advised by the electoral roll staff to complete a form & to submit it with a doctor's medical certificate to validate the reason for her removal from the electoral roll.

I was surprised & grieved that a letter outlining our actions was sent to my Mum. While she no longer recognises or responds to such outside stimuli, her dementia had initially led to severe paranoia &, if she had read the letter just a few years ago, she would have been extremely upset & outraged with me for doing so (even though she would not have been legally responsible for making decisions).

I realise there are legal requirements & avenues that need to be adhered to, but surely the evidence given by a medical practitioner should, at least in certain cases, allow the unnecessary breakdown of harmony to be avoided.

This type of problem could occur with any paperwork advising Removal from Electoral Rolls, Limitations in Capacity, or Transferred Responsibilities due to any form of Incapacity.

I am aware of another case similar to mine at the moment. Her charge was sent a similar letter, & although he is medically unable to make legal decisions, he was so furious with her, that she is still having enormous complications trying to organise his daily needs because of the "red tape" that has invaded her life. She has had to go to court with the backing of the Legal Guardian to legally remove her charge from all access to his finances purely because of that letter.

Technological Challenges.

Internet access is now an essential item for self help & government information access as well as for email. We currently use a dial up connection but may soon be moving to broadband simply because larger file sizes & increased graphics usage of web sites has made it almost impossible to do without it. A recent operating system update was more than 30 hours downloading on our dial up connection & had to be restarted a number of times due to file corruption.

I am fortunate that my husband enjoys playing with the computer & is fairly computer literate. Even though he ensures that our system is kept up to date with operating system & defences against virus & malware (spyware etc), it still takes him a lot of time to source information & fix problems caused by a few virus & malware attacks that have been successful. I would find it very hard to do such things myself & wouldn't know where to get training. As a result it would cost me a great deal of time & money to fix those problems.

Broadband access is expensive & although we use free protection products, training information on installing & using those products & on web security would be valuable. It would also be helpful to have a central system to report scams to help reduce their number & severity. We have looked at the TADAust Connect developed by Technical Aid to the Disabled (www.tadaustconnect.org.au) to give pensioner internet access but wouldn't use it because, until recently, it had excess usage charges & not speed reduction when the allowed maximum data usage was reached.

Carers Queensland Exercise, Health & Companionship Initiatives.

My husband suffers from depression & I suffer from it a little as well. When he gets depressed & withdraws & doesn't feel like doing anything, I can find myself lacking the enthusiasm & drive to do things as well. That can form a vicious cycle.

Carers Queensland has been providing assistance to carers in the form of supporting exercise initiatives like Aqua Aerobics & Tai Chi as well as outings. Importantly they allow the Carers to take their charges as otherwise many would be unable to attend.

This form of structured exercise & outings cuts through depressive inertia & procrastination & provides much needed incentives to get out & do something as well as the helpful social interactions.

Disability Perceptions.

Because many of my husband's disabilities are psychological, we have found that many people including Government agencies seem to have the view that he must be lacking in intellectual capacity. Quite the opposite is true, he has a very high IQ & his aptitude scores when he was recruited by the defence force enabled him to perform all of the tests for both the RAAF & RAN (Navy) in the one day & get accepted by both for electronics technical training. We have had responses in the past that if he was capable of such high quality paperwork submissions then he could not be TPI.

There needs to be better government staff training about psychologic disabilities & depression.

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to re viewing the recommendations you make in order to improve support for carers.

Yours sincerely,
Linda