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ROC 28/7/08

Vicki

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 to Better Support Carers.

I care for my husband (not my partner); he has lga nephritis, caused by an undiagnosed childhood illness. He is one of about 52,000 Australians who have severely damaged kidneys requiring dialysis. There is very little support for carers of these people.

I feel that my role is to assist my husband to live a healthy life on home hemodialysis. To fulfil this role I feel compelled to be present for the complete time of his dialysis treatment. Each treatment session takes approximately 7 hours if during the day and longer if overnight. This includes the actual treatment of daytime 5.5 hours, another 2 hours to set up the machine, the coming off the procedure and cleaning of machine.

I contribute to Australian society by more than halving the cost of the delivery of hemodialysis to my husband. He does not have to attend a dialysis unit feeing up a place for someone who does not have help at home.

I face the following problems:

- Limits put on the time away from the home and the inability to plan for long term for work or social life. My husband has dialysis every second day, however from time to time this can change to fit in medical appointments with specialists, nurses or technicians and some social events.
- My husband finds it difficult to accept people visiting him during his treatment, this means I feel is necessary to be present all the time. During his treatment he usually has a full meal and a snack including medication and a drink. Hemodialysis requires the patient to be attached to the machine by two bloodlines, attached through a cannula in the arm, the patient cannot move

from the bed or chair. Therefore he is unable to get himself food or drinks and any hot food or drinks go cold unless used as soon as they are prepared.

- On different occasions I have tried to arrange for relatives or paid workers to visit and prepare meals for him but he has either refused to cooperate with paid workers or contacted relatives and cancelled my arrangements.

I can't fully participate in social life because it is difficult to arrange social activities around my husband's hemodialysis treatment and the affect his illness and treatment has on him.

My husband's fluid intake is restricted to approximately 300 mls in 24 hours. This makes it difficult for him to mix at social events because he is always aware of his fluid intake. Even going out for a cup of coffee or an ice cream has to be worked into the day's intake.

I feel guilty attending social functions without my husband because he is having treatment or does not want to attend. At the same time if I arrange activities for us around his treatment I am putting him under extra stress.

Holidays are difficult to arrange and for people on hemodialysis you must have private health insurance or pay approximately \$250 per treatment, that means an extra \$750 per week in expenses. A medical certificate from my husbands nephrologist and copies of his blood tests have to be sent to each dialysis unit he will be attending and we have to carry needles and cannulas with us.

There are very few holiday "beds" available in dialysis units. To go to Western Australia we have booked 2 weeks of treatment in Perth for October. We also want to go to the southern areas of WA while we are on the other side of the country but at this time are unable to book further treatment in Bunbury and Albany. As these units do not have designated holiday "beds" they will not take a booking at this time and have suggested we contact them about 6 weeks before our holiday to see if they have a vacancy.

We cannot take advantage of early bookings for airfares and accommodation, as we don't know if my husband can get treatment before or after the two weeks we have booked in Perth. Air travel is the only way to go because travel has to arrange between dialysis treatments.

When on holiday my husband will spend 3 days a week (usually Tuesday, Thursday and Saturday) having treatment. This limits how far we can travel in the time we are at a destination and makes it very lonely for the carer. Some financial assistance to set up support for carers either using paid or volunteer workers would be wonderful.

We have tried to go away for a "weekend" by starting his treatment about 6.00am and finishing at around 1.00 pm leaving straight away. Travelling for about 4 hours arriving at around 5.00 pm. We have the next day away and have to leave the following day by 10.00 am at the latest to return home for him to do dialysis that day, finishing dialysis around 9.00 pm. Then back to work the next day.

The things that stress me the most about being a carer are:

Lack of training for carers:

- To give my husband his Aranesp injection I was shown once.
- When my husband was trained to do his dialysis at home he has six weeks of training. In that time I was shown how to take his blood samples once, then a month later I had to do it. I was never shown how to fill in the pathology laboratory form. Over the next few months I felt the staff at the pathology laboratory had great delight in pointing out my mistakes in filling out the form. No one bothered to take the time to explain the form to me.
- I now know:
 - Get my husband to sign the form.
 - Fill it out in black ink. THEY scan it and blue ink doesn't show up very well.
 - Put all the patients medication on the list
 - Put the time you take the blood on the tubes
 - No you can't do labels on the computer you have to hand write every tube.
 - Put the tubes in the plastic bag and the form in the flap on the outside
 - etc
- It took about six months to get the procedure right, so that I still feel what are they going to come up with this time.
- I find the nurses and doctors are usually patient and explain procedures to patients and carers but the office workers need some training in people and communication skills.
- When my husband had to go into hospital for day surgery unexpectedly it was scheduled on a day I had to work. I phoned the surgeon's rooms to ask if he would have to stay in hospital half or all day. The person answering the phone could not give me a satisfactory answer; she kept repeating a set answer that did not address my question. I asked what I felt was a simple question "would my husband be there a half day or full day" the answer to this question would help me work out how to get my husband to the hospital and pick him up myself or have someone else do it. I did not get an answer to the question from her. I had to ring another hospital to get a general answer. On the day this lack of knowledge made a simple procedure extremely stressful for my husband and me.

The Carers Allowance and Payment form is totally useless to cover people on treatment like dialysis. Complete renal failure requires dialysis or kidney transplant for the patient to survive.

On the Medical Report Q5. Does the person require help on a daily basis because of their disability and/or medical condition(s) to carry out routine personal activities OR because they may be at risk to themselves or to others? And Q7Is this care required for a significant period each day (at least the equivalent of a normal working day)?

If the patient is on dialysis they are suffering a terminal illness. Peritoneal Dialysis is a daily treatment, while haemodialysis is either at home usually every second day or in a hospital unit usually 3 times a week.

Therefore if the person is on home haemodialysis the answer would be no, because it is possible for the patient to perform these tasks around the dialysis treatment.

Part C on the Carer's Allowance application form "**About the care you give**", it is very difficult to fit the questions or answers to dialysis patients.

1. Move around the house?	Most people on dialysis can move around the house unaided except while having dialysis treatment then they are unable to move during the treatment
2. Fall over indoors or outdoors (or from wheelchair)?	No
3. Move to and from bed, chair, wheelchair and walking aids?	Same as one
4. Have difficulty hearing others?	Hearing loss is not usually caused by kidney failure
5. Have difficulty seeing clearly?	Not usually a problem for people suffering from nephritis
6. Need help or attention during the night?	Depends on the time and type of dialysis. People doing Automated Peritoneal Dialysis can require attention during the night. Also those doing haemodialysis during the night. Both machines are noisy and can disturb the carer's sleep.
7. Have loss of bladder and/or bowel control	People on dialysis pass very little urine. Controlling their fluid intake is a bigger problem but there is no where to record this unless you could put it under behaviour (8 have unusual, inappropriate or repetitive behaviours? The person drinks too much fluid and puts themselves at risk)
8. Use continence aids or equipment	Does not even mention dialysis machine. If it takes the place of the kidney is it not a continence aid.
9. Use toilet	Without help when not on the machine. With help to recirculate if during treatment. This will add approximately half an hour to the treatment.
10. Eat his/her food	If it is appropriately prepared and can be eaten with one hand or is cut up.
11. Shower or bathe him/herself?	Without help but must be fitted around treatment

12. Dress him/herself?	As above
13. Look after his/her grooming?	As above
14. Take care of his/her own medication	Is this where I put in the stock take? Ordering, rotation and packing away of supplies, both fluid and consumable? They have to be ordered at different times. The fluids are delivered on two different days and the consumables on another day. Each of the up to 20 boxes a delivery weigh at least 12 kilos, so it is best to be home when the stock is delivered so the carer does not have to bring it inside.
15. Take care of his/her own treatment?	With a lot of help

In other words all day-to-day needs have to fit in between the haemodialysis treatment and do not count towards the carer getting the Allowance or Payment.

Q17 Behaviour—for each statement please tick the box which best describes the person's usual state.

Does the person:

Show signs of depression?	Of course the person will show some signs of depression. The person is connected to a machine for 7 hours for haemodialysis. For Continuous Ambulatory Peritoneal Dialysis (CAPD) 4 x 45 minute treatments a day. For Automated Peritoneal Dialysis (APD) takes 8-10 hours overnight
Show signs of memory loss?	Just normal ageing, unless they also suffer from dementia or due to depression
Withdraw from social contact	Sometimes Fluid intake is drastically restricted, so taking part in many Australian style social activities is not much fun. The time it takes for the treatment limits opportunity for social contact.
4 Display aggression towards self or others?	Not usually
5 Display disinhibited behaviour?	What does this mean?

Assisting with eating and drinking does not include meal preparation or cooking and shopping for food and spending time with them while they eat their meal.

For many carers diet and food preparation is changed radically from their previous meal preparation. For a person on dialysis their diet has usually changed in the months prior to going on dialysis when a low protein diet has been used to lengthen the time before starting dialysis to assist the kidneys to continue functioning.

Haemodialysis requires one type of diet and peritoneal dialysis requires a different diet. My husband has been on all three of these treatments over the past three years. It has made my shopping take a lot longer. Food labelling is a nightmare; you just about need a magnifying glass to read some. Few have the potassium levels on them. High potassium levels can result in the cared for person needing hospitalisation.

Trying to come up with meals that can be eaten using only one hand is another process again.

The person is isolated on a machine for 4 to 6 hours and a carer cannot count the time spent eating a meal with them. Remember the person cannot move.

Unlike diabetics people on dialysis through nephritis are just about on their own when it comes to education about diet and food preparation. When my husband went on hemodialysis the first time around the dietician visited him during his treatment session. My husband is in his sixties and no SNAG, food comes from the kitchen prepared, the only thing he remembered from the talk was that he did not have to restrict his protein any more. If asked by friends if he is on a diet my husband answers no. My answer to the same question is we work on his diet at home so that he can **enjoy** a normal meal when we are out and if visiting friends they do not have to worry out his diet. Our friends have already had to arrange for our visit to fit in with his treatment.

I work 16 hours per week in a job that required me to work different days each week to perform my duties; I found the position before my husband-required dialysis. I would not be able to work in a paid position in most other jobs.

For many carers physical help with shopping, transport, housework and tasks of daily living meet their needs. In my situation illness specific knowledge is my main need. The Renal Resource Centre and Kidney Foundation have a lot of information but lack the staff and resources to get the message out. Telephone information to reassure carers when their person is unwell, the common cold, flu and gastric infections can cause sudden increase in blood pressure that are frightening, someone to talk to at these times can make all the difference. Don't reinvent the wheel there is organizations available they just need to be better resourced don't fragment and confuse the issue.

I hope this will give the Committee some insight into the needs of carers in Australia; we are working hard to save the country many dollars. All we ask is for some of the savings to be used to help us.

Yours sincerely

VICKI