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Submission No. 981
(Inq into better support for carers)

Submission
To
Parliamentary Inquiry

BETTER CARE FOR OUR CARERS

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Covering letter

My name is Janet and before becoming a carer, some years ago, my professional career was in the field of welfare. In the late seventies after having done mostly nursing, I became a foster parent and went from there. My last position before becoming a carer was Youth Services Coordinator for Bourke Shire. My career ended there, too soon.

My role now is carer to my hubby and my mum, both high needs people. It is a 24/7 position, with no days off for good behavior, like prisoners; no free weekends as it is not a forty hour week with overtime and penalties.

I WOULD NOT TRADE IT FOR THE WORLD!

I do find that at times the needs I have don't fit any existing services, leaving me at times lost and feeling more alone. I moved to this town as a carer and therefore have not had the luxury of going out and making friends and the little I did have, my writing group, I can no longer attend as mum needs me 24/7. Don't get me wrong, I know a lot of people but for close friends, no, that is not part of my life. If I really need to talk to someone, I see my counselor and we talk things over. Acquaintances, are not friends and as time has gone by, my social network has diminished to mainly the professional angels who come and help me keep this house running.

In any one 24 hour period (I work nights to), I can wear 6-8 different hats, from repairing skin tear at 2am when mum has a fall to re assuring my hubby about his abilities, he is starting to notice the loss from his last stroke. I run the finances and my hubby has an obsession with food and spends his entire pension on food that I have to throw out and he has no comprehension that I struggle to pay the bills. He now shows love with food, that's how it is. He calls me mum or mummy and that took some getting used to.

Every day is constant care for mum. Take her to the toilet pulling her pants down and up, dress and undress her, clean her teeth and put her hearing aid in, guide her wherever she wants to go in the house, explain her food position and cut it as she is unable to see it. She is never more than three feet away from me all her waking hours. This does not leave me much time to do what has to be done to run a house and garden.

When I should be resting I run about trying to get my daily chores done and then I'm back to sitting with mum and tending to all her needs. She is a WWII veteran, with extreme disabilities and I refuse to put her in a nursing home.

Mum is going into respite for the first time and I dread the thought. I have a tumor in my throat that needs to come out and I was unable to get help in for that period of time and so my only option was a nursing home a long way from me, when I have had surgery on my throat and I am the only driver in the house. Hubby is having carers come in till I come home and then its back to work, so to speak, two days after surgery.

My life is our ¼ acre and what happens in it. I really don't have time to pursue any of my wants as there are just not enough hours in the day. I juggle appointments to doctors, visiting professionals like nurses and physiotherapists, Home Care and Ex Services.

On Saturday and Sunday I get to laze and not be dressed; and most weekends I don't even make the beds and it does break the seven day ritual and give me a little of the relaxation time I used to have. I don't get to always read my paper, but I still have my pajamas on, Ha! Ha!

I believe I have given you a snap shot of what my life is like, just scratching the surface. The one thing I have that gets us through is a sense of humor. We have fun just talking, they both love talking about their pasts. I can never forget these memories, I hear them often.

I would never trade kissing my mum good night and telling her I love her and snuggling into my hubby's back when he is asleep and remember how it used to be. Besides calling me mum, he tells me at least 50-60 times a day he loves me. At those times their frustrating behaviors evaporate and there is love exchanged. Who could ask for more?

As for when my caring role is over, I have contemplated many choices and although I would love to do something, I will be well and truly burnt out and I am 56 years old now, who would employ me when I am 63-65?

I hope you will accept my submission and consider the suggestions enclosed and I look forward to hearing from you in the future.

Yours Sincerely,

Janet

Introduction

I welcome the opportunity to present my views as a carer in the community. There are not many forums where we are able to be heard.

I pondered the list of points of reference and personally thought point three would have been better placed point one. Do any of you know what it is like to fall into bed exhausted and then be aware of a monitor? Not for a baby, for an 86 year old who is likely to snap at you in the middle of the night because that's just how it is, or has fallen and there is an eight inch skin tear to be repaired and dressed at 2am. Then to be woken early as your hubby wants to start cooking tea and starts talking non stop as soon as he has your eyes open?

The stress for a mother caring for her disabled child must be far worse. Will I live long enough to care for my child all of its life? What arrangements do I need to make, how much will it cost, will we lose the house and the list goes on. One blessing caring for the aged is that they have had a life where as the children have had no or a very little restricted life.

As I am no longer a professional, this presentation may not be professionally presented; it does however contain insight and some suggestions worth listening to.

Over my many years of experience and training in welfare, I believe have given me insights I would otherwise not have developed. My submission is simple in presentation, due to lack of time. It does not lack much thought as to what would make lives for carers just a little better.

Points of reference

- The role and contribution of carers in society and how this should be recognised

To me personally, this would be at the end and not the beginning. We need support and that will lead on to recognition. As support is offered and it is exposed in the media, would this not raise the level of acceptance of our role and what we contribute to the community, as well as what we save the government.

To me there are many things that need to go before this public recognition of what most of us would do anyway.

One way I personally would like to see our silent army recognized, is a badge, sold once a year and the money raised to build a place for worn out primary carers when they have finished their caring role can go for rest and recuperation. From a personal point of view, when I escape to the shop for five minutes for milk; it would warm my heart to see someone wearing a badge that said they supported what I do.

Another way could be to let the community know we are isolated and if some one knows a carer, go have a cuppa with them. I am not sure how that might work in reality. You could have carers inundated and not coping further, anyway it is an idea, for you to ponder.

Start a carer's column in the local newspapers, or perhaps in the Sunday paper, where carers can write in and share funny stories or ask for advice. A column just for them, they have them for just about everyone else.

Another suggestion I can think of is long service for primary carers, who have done so for ten years or more. Surely the ten years of providing primary care has saved the government money and it could afford to give them a holiday at no cost, or even ask them what they would like (within reason), it could be to pay something off their mortgage. Again an idea I believe deserves discussion.

- The barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or continue employment;

When I first became a carer, I was gainfully employed in Bourke and needed no support as I was not at that stage, a primary carer. As the situation changed it became evident that I was not able to keep running home to John each time he called and so I resigned and we moved to Iluka.

Perhaps if we had not moved I would have had more support as we had friends there but as we owned the house in Iluka, John said come with me or I'll leave you behind. He was suffering deep depression after he smashed his back in a roof and his building career was cut short. What choice did I have abandon the man I loved or move and care for him, I chose the latter.

There is a lot of pressure from caree's to get the carer to do what they want. I have seen it not only here, in other settings and forums and they all have that ability, particularly if the person needing care is older. My mum finds it so hard to accept that her daughter is caring for her," that is a mum's role" she says and I put my counselor hat on and talk it through and we end up with a laugh.

There are a lot of family emotional barriers, which are one of the hardest. Then there's a social barrier; there is no way a primary carer can even plan a coffee at a particular time with someone and know you'll get there.

Employment is almost impossible. Who would employ a carer, say one day a week knowing that if something went wrong you'd have to leave and who looks after the carees; would the cost would outweigh the benefits. Getting out and working even one day a week, mixing with sane adults having meaningful conversation and socialization sounds fantastic. Where do you draw a weekly carer from while you work? As far as I am aware I receive the amount of assistance I do, because I am a primary carer, would that change if I worked one day a week?

- The practical measures required to better support carers, including key priorities for action;

One of the key priorities is carer health. I am not the only carer I know with medical problems made worse by caring. There should be a priority for us to access the medical assistance we need to continue in our roles. There are days where I take 8 panadine forte just to walk the day and be able to care for mum and John.

Another is access to things such as community transport to get to and from either medical procedures or if they are going for surgery. I am unable to get community transport as I am able bodied and can drive, although I am on a disability pension. So because my hubby has lost his license and I am the only driver, I have to pay to get to Grafton hospital for a tumor removal and pay to get them to bring me home.

Medical assistance should be free for carers. Many carers put off having the medical examinations due to cost. The longer they ignore their health the more it ends up costing the government to care for carer and caree for longer periods as the carer's health has deteriorated to a level requiring much more intervention and more cost.

Easier and quicker access to mental and emotional support. There are more issues than can be mentioned here that carers are left to sort out for themselves. Particularly if you are isolated and have no support network, that alone raises issues for carers and that on top of this on top of something certainly leaves people feeling isolated and alone, particularly if they do not avail themselves of the services already offered. I know of many such situations here in Iluka.

Train those who deal with us that we have the daily knowledge to assist. Within the area we live I am treated with respect by professionals who have dealings with me. I have had an occasion where I was out of area and not treated with the same respect. I was just the carer and they were the professionals and knew best.

- Strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future

This I believe should have been first!

All my years of experience in the welfare field and the changes I saw over my twenty something years, I honestly believe Case Management is the most effective way to support, manage and be cost effective. It is an effective way to give people more choices; more input and have access through the case manager the choices that can be individualized to compliment the care of the caree by the carer.

The parameter; the cost factor that the government already spends in this area, including all areas; hospitalization, respite, pensions and allowances paid to us (including our one off payments), cost of ongoing inquiries and the cost of other government agencies, like Centerlink to administer pensions, the cost of contracting any other agencies to administer services.

No two situations, no two carers have the same ability to cope, no two carees needs are the same. Yet up to now we have all been put in the one basket, with the exception of ACAT evaluation which deems whether someone is low or high care. Then that is the box you stay in and receive whatever is in that package. Also most carees, if they are cared for at home are not ACAT assessed and therefore are they getting the appropriate assistance.

I would introduce case management to all non primary carers first, so if they have some form of employment the government assists them to continue. At the same time I would introduce it to all new carers coming onto your books and lastly to the primary carers, like myself.

Case Management with teeth given to it by the government. I am sure the government knows how much each case costs it per year and it is my belief that it could be better used and perhaps reduced if money and services were on a needs basis, not just because someone is in a low or high care basket.

The government could also make it like the army reserves; that employers cannot refuse the time off required by a carer and employers can claim financial restitution within guidelines, again set by the government.

There would be the expense of setting it up or contracting it out. My personal choice would be to have it as a government department as my familiarity of contracting out is that each contractor puts just a little difference to it and it ends up not being, as it started.

Also those working as case managers need to be trained in the manner I was (with Juvenile Justice) competency based training, with daily assessment of what was taught. Intense but from where I stand effective. Those who couldn't cut it didn't make it and didn't graduate.

It is a hard training which is in the long run cost effective. You don't have incompetent people making decisions with people's lives and government money who have not learned their role to be empathic and stay distanced enough to advise objectively and professionally, with a win/win scenario. The most cost effective solution to the problem so that the client is happy and the government has spent money wisely.

This way carers would have competent case managers to facilitate the maze of options and paperwork and support the carer come to terms with the situation. Most carers come into this role by 'accident' shall we say rather than by choice. Mothers don't plan to have disabled children and I certainly didn't plan to kiss my hubby good night and wake up to someone else (as a result of his fifth stroke), I am alone yet he is not dead.

Promotion of effective case management ability would encourage more people to plan to care at home rather than in residential units. If there was an effective support system in place, perhaps it would make it more attractive to those considering caring for a relative. More so if they were able to maintain some of their life and not be in my position, for a lot longer.

At the moment other than what you can find out for yourself or what different agencies you have to deal with each have a little piece of information and if you are skilled you can work your way through. Most carers would love an advocate, manager and someone who understood their plight and also have the skills and knowledge to put in place the support package most suited to meet the need of the situation.

Conclusion

I hope that you take on board my crude way of getting my point across, due to lack of time. If your committee takes up one idea then I have done something for carers.

It is good that this process has started; my only critic would be that there wasn't enough publicity for more carers to be able to reply. I know that an organization has knowledge of circumstances of many families and perhaps can report on what carers and carees have told them as well as present statistics to back up their point, is that really hearing from the people on the ground, us.

The one thing I would not like to see is a group of professionals making decisions that impact on our lives, without including carers. We are the ones on the ground, we are the ones who live our role, there's no going home at the end of the day or the end of Parliament sitting and Christmas holidays.

For knowledge of the impact of caring, ask a carer; the professionals go home at the end of the day and they have an emotional break from responsibility, carers don't. I wanted to learn from our indigenous people, I didn't read a book I went and lived with them.

I am not suggesting you come and live with carers, though having a day with a family and then asking the carer to write a nightly journal for a week, you would get a better idea, perhaps than you have now of the daily dilemmas that occur and one person, the carer has to deal with it all.

I would like to write more but I have time constraints and mum in hospital. I implore you to see past the crudeness of this submission and think about its substance.