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Submission No. 953
(Inq into better support for carers)

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

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 role as a carer has involved caring for my mother for the last 15 years. Over this time mum has faced many physical, emotional and mental challenges but more recently they include open heart surgery, breast cancer, numerous TIAs, a stroke, diabetes, hypertension, an aneurysm, numerous falls resulting in bruising, bumps and shock, to hairline fractures of the pelvis, permanent indwelling catheters, suprapubic catheter, the list goes on. Over riding all of this mum suffers from Bi-Polar Depression which at times can be more challenging and debilitating than some of her medical challenges.

I have been there each time she has needed me and for as long as it takes to get her back to functioning by herself and into society again. I have been there when medications are incorrect, when staff at hospitals leave her to fend for herself to eat when she can not get the spoon from the plate to her mouth. When she has been upset and needed someone to listen to what she is saying. Listen, understand and to be her voice when she can't speak up or when she is too sick to be able to.

I have monitored her medications, taken her to her many doctors appointments, specialists appointments, kept track of these and followed up on further recommendations and suggestions. I have taken her to hospital or been there at admissions to give the correct information and then take her home again and settled her in. Kept track of her medical claims and bills and ensured she has enough money to live on, including

enough to keep up with her medical bills and private health insurance.

I have take her into my home to care for her when the hospitals and doctors tell her she has to go home, yet she isn't even able to make herself a cup of tea. I get the physios or other services organized to help her when needed, to learn to walk each time she has been bed ridden or medications have sedated her for any length of time. I am her advocate. I am her friend I am her daughter and I am her carer.

I believe my role is very important. If I was not doing what I do everyday mum would have to rely more on the health services and health system that is already spread so thin. Many services have to be contacted constantly to get what has been promised or recommended and Mum does not have the ability to do this, nor do so many others. Mums vast health needs would not be monitored consistently by the one individual which is so vital to optimum overall health. Mums hospital stays would be much longer or her recovery much more difficult. OR truth has it, mum would be another one of those individuals who has to battle on by themselves, struggling to understand the health system or the nature of their illness, especially those suffering with mental health challenges. I see it all the time, people left to look after themselves, especially the elderly, because they have no family or their family is too busy, or live too far away to be with them at times when they need someone who loves and cares for them, to give them a hand. We all need a hand at times and one of the most important times is when we are not well. Many elderly people, especially those suffering from depression or painful illnesses do not want to continue to live, they are suffering and some suffer all the more because their family, the ones they love the most are not with them or even call or visit.

As our population ages, many people cannot cope with the many challenges life now presents their parents or grandparents. Many can not cope with seeing them age, or they don't have the patience, the time or the understanding to be with them. I think it is truly sad to see how many visitors the parents and grandparents who now live in nursing homes actually get. What does the next generation have to look forward to? So many of us have lives that are so busy just getting through day to day necessities, caring for our own family or going to work to make ends meet. We don't have the extra hour or two to pop in to see how mum, dad granddad or grandma are doing. In most cases we need mum and dad to help us get through our week. I am not in that boat I have two elderly parents Mum is 79 and Dad is 84. Both suffer physical and mental illnesses. My heart breaks as I can no longer support and care for my dad as I use to as mums challenges have become too much. I can not visit him as much as I would like or want to as I have to prioritize who I can help or assist the most and who needs it the most. Is it my husband, it is one of my three children, is it my mum, is it my dad? This is a decision I have to make everyday.

I believe the government has to look seriously at this issue. My mum is frail and elderly, she has a physical disability and has a mental illness.

I know from experience by being the main carer for my mother it has truly proved to be the best way to care for her overall needs. There are so many different services or suggestions but no one to help co-ordinate the lot from beginning to end and still be there next time they are needed. When I am able to be involved with mum's care it places so much less stress on her and gives her stability, trust and assurance that she will have someone who loves and cares for her wholeheartedly around when she needs it the most.

The government needs to look seriously at this as a very important role and be supporting those who choose to care, support and be advocates for their loved ones.

Originally I had a choice to help mum or not. I choose to help and as the years go on so does the extra time and effort needed to maintain that support. But the experience and knowledge I have gained could never be taught any other way. I have attended seminars, read books, spoken to specialists and other health workers. I have put my heart and soul into understanding mum's health issues and what could be the best for her. I now know a lot about hospitals, aged care facilities, certain illnesses and I know and understand mum a whole lot more. I am still learning and will continue to learn and stand up for what is best for mum.

The government needs to understand the commitment and dedication that is needed to care for people with vast health needs. By being able to care for someone you love, you learn some of the most rewarding and natural skills in life. Caring, supporting and being responsible for someone else. Society or the government puts little value on this any more, even being a mother and staying at home to care for your baby or child is not seen as a worthy cause so how are we going to find enough people to care, truly care for the other end of the spectrum, our elderly or disadvantaged, especially as our population ages. One of the greatest joys our elderly can have is to see their children or grandchildren or great grandchildren. How do we teach love, patience, understanding and caring unless we show it ourselves. We as a society need to put more value on those who do truly care, the government needs to value the commitment of those who put their lives on hold to care for someone they love.

Not many people understands how time consuming, exhausting and frustrating caring for someone else with extra needs is, unless they themselves are in the same boat. Feeling worthy, feeling valued, having a sense of pride that I am caring for another person should be a privilege, it is in some ways and in others its a huge sacrifice, a sacrifice not only for myself, but my children and my husband and our lively hood.

When mum is really unwell everything is put on hold. At times I am with her day and night to get the correct help, understand what's going on and

make the decisions I have to make. Bi-Polar depression is the unseen reason I chose to carefully monitor mums health situation. If this is monitored well, we can get through most other situations as well as anyone else. A lot of people, including professional health workers do not understand mental health and by being with mum as much as possible during these times, a lot of confusion, stress and anxiety can be avoided which is best for everyone involved.

Unfortunately with mums health issues increasing the time I spend supporting her is putting undue stress on our home life. We are finding it increasingly difficult emotionally, physically and financially. My husband and I have done this all our married life, now with 3 young children and a small business, we find it difficult to find the time or finances to keep doing what we are doing. We have asked for help, but no one understands the enormous extra work load we have on our plate. We find it too hard to keep explaining and too hard to keep asking. We end up deciding is quicker and less stress at times to keep on doing it ourselves. But in the end we still have to find the time and the resources and it affects us, our kids and our business and our marriage.

What choice do we have ?

Mum was recently assessed high care, so my role of carer and supporter is suppose to be finished as she enters high care nursing home. Maybe I can get my life back on track and be able to be there more for my children and my husband. Even get a job to help out financially. Unfortunately not in this case. No available beds in our home town of Toowoomba has meant mum has been transferred to another town, 40 minutes away. She knows no one in this town. Mum has had to change doctors and being able to be there to support her has been a huge commitment. Monitoring mums health especially her mental health has been extremely difficult. Mum had to leave her home of 12 years with not even a goodbye to her neighbors and friends. I can no longer pop in to check on her and see how she is going or take her grandchildren in to see her on our way home from school. Her friends find it hard to afford to ring her very often as it costs \$2.50 each time they ring. I can really only see her once a week and a large part of this time is spent at meetings and discussions as I try to help the staff to understand mums physical ailments let alone that of her mental health. The stress and medication changes has brought on another manic episode. Mum has not suffered this badly for nearly 10 years. I was there everyday and sometimes at night when mum refused to take her medications and certain things were done or said by those around mum that unknowingly aggravated the situation. Mum could not go through to the mental health unit as no beds were available straight away. Not many people understand mental health, it has such a stigma and yet if you manage it correctly, understand the illness and the person, you can prevent enormous turmoil, not only to the sufferer but those around who care and an enormous

financial cost to our health system and to society.

Right now I do not know what to do about mums situation. She has been in care for 5 months. It has been an exhausting and difficult time. If a high care bed becomes available back in Toowoomba it may make some things a lot easier but emotionally and mentally I don't know if mum could cope with another change.

As of today mum has 5 specialists appointments back in Toowoomba over the next 4 weeks. Each one of these appointments takes me all day to get mum to and from. I need to ensure someone can look after my children when they finish school and financially we have to find the money to do this and the time. Alternatively mum can get an ambulance to transfer her but an escort or volunteer has to accompany her, and again it can take all day to do as no times can be given on a return trip. To try to move mum back to Toowoomba or closer to us if and when a bed becomes available could be too much stress for her (and myself) as new staff and situations could trigger another manic episode.

The other alternative would be to walk away from my responsibilities and commitment to mum and hope she'll be ok. I know the answer to this as past history usually repeats itself and instead of visiting mum in an aged care facility we visit her in a mental health unit. I know which one I prefer and I know which one mum prefers and I know that I can, in most cases prevent such an event happening.

Caring for mum is a huge responsibility but if I don't who else can take over from the years of experience, knowledge and understanding that I now have and know about mum. My commitment has meant a lot to Mum and I just want some help, assistance and support, emotionally and financially to keep on doing what time has proven, to be the most efficient and best way to help mum obtain the best overall health she can have, including her mental health.

Please listen, please try to understand and please put yourself into the shoes of someone who is a carer. Think what you would do if someone you love was needing your help, your support and your commitment.

Thank you for giving me the opportunity to voice my concerns.

Please give all carers a voice so we can be heard and valued.

Show us you care - for those who care.

With Thanks,

from Sonia
(SONIA)