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Dear Secretary

My name is **Helen** and 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.

I am a 'petite' 45yo wife to my wonderful husband Peter and the mother of two beautiful boys aged 17yo and 14yo. I am also the daughter of a very special gentleman, my 79yo father. I live in rural **Victoria** in a town called **Traralgon**.

Firstly, before sharing my situation, I would like to congratulate the Rudd Government in providing this 'opportunity of a lifetime' to share my caring situation with the House of Representatives Standing Committee.

I trust my situation, together with all the Carers stories and submissions received from the inquiry will be sincerely and respectfully considered with an assurance of positive solutions and outcomes. Attention to adequate '**individualised**' support and **reformed service systems MUST be introduced**, to give myself, my family and all Carers much needed **piece of mind**. Necessary changes **MUST** be made to make a holistic difference to my life, ensuring my future role as a Carer is enjoyable, satisfying and sustainable and not lead me to financial desperation, physical exhaustion or emotional breakdown.

**I am hoping this inquiry will bring REAL change together with a HUMANE recognition for all Carers across Australia. Finally, I am anticipating a committed guarantee from the Rudd government that increased, appropriate and equitable financial assistance, services and supports will be provided to me, my family and all Carers to ensure our caring role is an adequate sustainable role in all areas.**

**CARERS UNDERVALUED:**

At the moment I feel my role as a Carer to my 14yo son and my 79yo father is definitely undervalued. I know if I wasn't able to care any longer, the service system (whether state or federal) would be forced to provide funding of over \$125,000 per year each = \$250,000 plus for both my father and son.

Financially, what do I get as a Carer? I receive \$100.60 x 2 each fortnight. I currently receive a non-guaranteed Carers bonus of \$600 x 2 (which is very much appreciated and needed) and until my son is 16 (which is in 1.5yrs) I receive a Disability Assistance Package of \$1000. I also receive a funded Linkages package from the State Government of around \$6500 which of course I am also extremely grateful. We utilize this funding to purchase in home support, in home respite, assistance to purchase some equipment and to purchase continence products. However, I see myself as one of the lucky ones. As I am a 'squeaky wheel'. Whilst there are many families across Australia who receive minimal financial assistance. It is not 'rocket science' when you do the math's, that in my caring role, providing the care to my son and my father, I am actually 'financially' saving the government and Australia's taxpayers, millions of dollars over my lifetime, therefore I believe we as Carers are very deserving of necessary support, services and funds to assist in our caring roles.

However the Standing Committee needs to ask themselves and today's government, 'is this current financial situation truly ethical for Carers? Is it right? Is it fair? Is Australia really recognizing and supporting (in government's words) the 'unsung heroes'?' With its billions of dollars of surplus funds, is it not able to truly provide adequate and equitable financial support to many Carers who are Australians and more importantly Human Beings who are truly financially struggling? Is it not able to provide appropriate, flexible and adequate service provision to support Carers and those for whom we are providing the care to?

### **MULTIPLE CARING**

I am a wife, a mother and daughter, however I am also forced to 'label' myself as a CARER. My caring role is a **Multiple Caring** situation where I have more than one caring responsibility. I care for my 14yo son Ben who has an extremely rare syndrome named Rubinstein-Taybi Syndrome (approx 600 in the world) plus at 4yo he was diagnosed as severely Autistic. So he is now classed as having a 'dual diagnosis' and his disabilities put him in the category of a child who is profound and severely disabled. Although it is extremely hard work caring for Ben, he brings so much joy to myself, my husband, my older son and my father, Ben's grandfather. Ben is a beautiful individual with an infectious smile, a cute giggle and a wicked sense of humour.

The other person I care for is my father, who has lived with us for over 3 years now and suffers Chronic Obstructive Airways Disease, where he now has less than 20% lung capacity, requiring full-time oxygen, numerous medications and various levels of ongoing support with minimal independence.

### **INEQUITY between government supports**

As I mentioned my caring role is a 'multiple care responsibility' however I would like government to be aware that I may be, and hope, I will be caring for my son for a long time. Perhaps the whole of my lifetime. However, due to my father's debilitating disease, one can assume, care for my father will be for a shorter time. Yet there is so much more funding available to those who are ageing and support for their Carers in comparison to parents and/or Carers who are caring for children and young adults with a disability for a greater length of time. Often for their whole parenting life. Where is the equity here? I am certainly not suggesting funding needs to be reduced for those funded by Health and Ageing. What I am suggesting is that the financial support needs to be

increased for those caring for a child/adult with a disability at the same level of funding as the aged. Perhaps the whole portfolio needs to be called 'Health, Ageing, Disability and Carers (HADC) portfolio. This will bring responsibility at a commonwealth level and hopefully a positive outcome for some of the most vulnerable members of the Australian community. The unsung heroes.

As you are aware, because my father is over 65yo he is funded under the Commonwealth portfolio of Health and Ageing which appears to be a very 'wealthy' portfolio. I make this statement as my father has been very fortunate to start out with a Community Aged Care Package (CACP) and as he has become more dependent he is now receiving an EACH (Extended Aged Care at Home) package. I am not sure if you are aware, but I believe this EACH package brings an allocation of funds of approximately \$45K which is an adequate amount of funding to support my father and provide support to myself and my family as his Carers. He has services such as Personal Care, Home Care, District Nursing, Podiatry, Oxygen Costs, Equipment costs and the list goes on.

#### HOWEVER:

My son Ben, now 14yo (15 in October) who was not expected to live past 10yo, however, thankfully we continue to be blessed with his life today, requires **much greater care and has significant higher care needs** than my father, as he is much more dependent than my father and requires an enormous amount of support and care 24/7. Yet I am unable to secure a funding package anywhere close to the EACH package which is what my father receives. Currently the Victorian State Government is kind enough to provide us with a 'Linkages funding Package' where after brokerage dollars (as this package must have a case manager attached to it) we receive approximately \$6.5K. This is so much less than the amount of financial support my father receives and yet my son has greater care needs and costs. Ben's care will continue to be more complicated and difficult as he grows bigger and gets older. Does this make sense?

#### SOLUTION:

A holistic approach needs to occur. The simple questions need to be asked: 'What do you and your family need to assist you in your caring role and assist the person (or persons) you care for?' 'How can we (generic and specialist services) make your life easier?' 'What can we do for you?' 'What do you need from government?'. All these questions should be answered with sincere actions, results and real outcomes.

**WE NEED: 1. Choices of flexible services 2. Immediate access to necessary services (ie: Flexible and regular in home supports, regular access and choices of flexible respite, access to behaviour specialists and programs, toileting specialists, allied health/therapy services, OH&S training to protect our own health and physical stability as carers, instant availability of funded equipment, available funds to purchase a fully funded modified vehicle, access to funds for modified housing etc.) 3. Immediate increase to financial supports according to the need 4. Choices of creative and flexible supported accommodation models 5. A Carer superannuation scheme 6. Opportunities to plan for the future ....and the list goes on.**

A **whole of government approach** needs to be initiated. Remove the blame game. Rid opportunity for statements such as, 'that's the state's responsibility' or 'that's the commonwealth's responsibility!' As Carers, we don't care who is responsible, who pays

the money or where it comes from. So long as it is providing the services and supports we need both within our homes and out of our homes in the wider community sector.

Government needs to **honor their commitment of 'lifetime planning' and 'access to supports for all people with a disability and their Carers'**, then choices will begin to evolve and positive outcomes will begin to evolve.

### **SUPPORT & SERVICES**

Supports and services are required to not just look at the person with a disability or who is frail and ageing but a 'whole family system' needs to be considered when policy and frameworks are being developed to respond to multiple and individual needs. Maximum choice, flexible and creative services and supports need to exist for all families and carers in all situations.

### **CONTINENCE PRODUCTS and COSTS:**

One huge cost in our lives is the costs of continence products. I currently hold an invoice for the past financial year 2007-2008, from a continence supplier where I purchase most of my son's continence products, showing the total cost of continence products purchased last financial year was **\$3500**. I am prepared to produce this summary invoice at the public hearing in Melbourne or fax this through at any time. It needs to be noted that this is only the amount totaling continence products I purchased through this supplier. There was probably \$500+ of products purchased from various other suppliers, chemists, supermarkets etc. As Ben is getting older and growing bigger this cost will continue to rise. I acknowledge and we are extremely grateful the state provides funding support of \$470 until Ben is 16yo and the federal government also provides funding up to \$470 which equals \$940 for another 1.5yrs however, once Ben turns 16yo we will only have access to the federal government scheme which just isn't enough! Where will the other \$3000 come from, that we will be forced to pay out of our already financially stretched pockets?

The Committee needs to be aware as my son (and others) grow older and become larger, the continence products required will need to increase in size and as the continence products increase in size the products become more expensive and we actually receive less products in each packet purchased.

### **GST: WHY ARE CARERS FORCED TO PAY GST?**

A further issue is that I am also required to purchase surgical gloves for daily enema's, wipes for hygiene and cleanliness, inserts into the disposable 'jocks' to reduce leakage, specialized plastic pants specifically made to Ben's size to go over his disposable jocks, washing detergent to wash all soiled bedding and clothing etc however each and every one of these products I am forced to **pay GST**.

My question to the committee is **WHY are Carers paying GST? Why is government taking money and making money from those who are saving the government money?** This is an urgent area which needs to be seriously considered. Our role as Carers is already financially destructive therefore why is government forcing us to pay GST on items which are a necessity and we have NO option but to purchase in our caring roles.

**SOLUTION:**

GST should be exempt for all CARERS. Carers currently pay GST on our power, water, gas, telephone, rates, vehicle registration and the list goes on. Often many of us are forced to utilize utilities at a greater capacity in comparison to others who are not caring. ie: Excessive washing, bathing, heating, specialized equipment requiring power etc.

**CARERS SHOULD BE EXEMPT FROM PAYING GST**

WHY aren't we exempt from paying GST? If we can provide proof of caring we should be able to claim this GST back through our taxes? For those who are unable to work and don't pay taxes due to their caring role there should also be a way that they can claim back GST at the end of each financial year OR be exempt from paying GST. **This is one area which could be seriously considered to help reduce the financial burden of caring.** I urge government to consider this option for all Carers who are living with and providing substantial 'one on one' care. Often initiatives are introduced to those who are accessing welfare payments. However this initiative needs to include ALL Carers, including those who are working and those Carers in receipt of welfare support. It needs to be recognized, even though there are some Carers who are working F/Time or P/Time, they should not be disadvantaged by not being able to claim back GST or receive necessary supports. Afterall, like typical people and families, as workers, we have a right to get ahead, however if we are not eligible to access GST rebates or funds for necessary supports, services and equipment, then we will continue to remain severely affected financially.

**FINANCIAL SOLUTION/S:**

As suggested in the Taskforce on Care Costs (TOCC) made recommendations to the Federal Government to fund a 50% reimbursement, up to \$10000 each year, for disability and aged care costs as a tax rebate as a measure to support workforce participation of Carers and family caring. This would then obviously free up some of the dollars within the welfare systems enabling more funds to be available to those who are unable to work and pay taxes due to their caring role. It may also encourage Carers to seek opportunities to work as they will know not only will they be receiving an income but they will be partly re-imbursed via the tax system for some caring costs incurred.

**HIGH INCOME EARNERS**

Government needs to seriously address the issues of those fortunate Australians who receive an income in excess of \$150,000. Consideration should be given once income exceeds \$150K a .5% levy tax should be introduced and government should be directing this .5% levy specifically towards carers and the people they care for.

Another idea, could be when a person's income reaches \$300,000, then a 1% levy (tax) should be directed towards carers and the person or people they care for.

Also, for those Australians earning more than \$500,000, under tax law, should be obligated to make a substantial yearly donation ie: \$20K or more, to a charity of their choice. Donation amounts should increase as the income increases. This will help create much needed financial support to local community charities.

### **MY CARER STORY: The Diagnosis Years**

I can still vividly remember how desperate and sad I felt during those early years when Ben was first born. I recall the overwhelming fear that lay deep within my heart when his life was at risk on so many occasions. In those early years I felt continually heart broken and always questioning how and why this situation has happened to my child, to our family and to me as his mother. There were days that I truly did not know if I could go on and whether I would get through the day without thoughts of ending it all.

I look back over the years and now realize that I suffered a severe depression but somehow managed to get through the long dark tunnel of grief. Believe me, there are still days now where I find myself back in that tunnel of darkness and despair wondering when, if and how I will get through to other side. But we manage and find a way.

Life for our family and other families across Australia who are caring for their child with a disability is truly difficult. **It is emotionally and mentally draining, physically exhausting and financially destructive.** So many life changes have to occur, plans put on hold and so often without choice.

### **SOLUTION/S:**

Adequately funded organisations that provide information, support, advice and advocacy services. Information resources must exist for all Carers according to their need and the level of care they are required to provide. Recognition to Carers that our situation is tough and inform carers of the value of counseling and how it can be seen as re-charging their batteries. Readily available access to a place for parents / carers can meet together, share their caring situation with others, share resources and help each other identify solutions to various issues they are confronted with in their daily caring lives. It has to be acknowledged that our situation is 'big stuff' and for some, we can't possibly get through this 'new world of caring' on our own. We need opportunities to socialize with others who are living similar situations. Choices of various supports are needed.

In the earlier days, it would have been so beneficial if I was nominated a 'support person' who was someone to help 'walk with me and walk me through those earlier years' when I felt so alone, so isolated, so afraid and so naïve to this world of caring for my seriously ill child who, if he lived was going to have this rare syndrome which caused a profound and severe disability. I might as well have been on Mars and told my son was an alien and we now had to live in a different world, without knowing the language, without a road map to find our way and without being able to make any plans for our future. We were continually told (and still told to this day) to take things slowly and take each day as it comes. It is important that every carer is given an information resource package providing a suite of various information and resources which would be immediately available (ie: NO waiting lists) when carers decided the time was right to begin accessing supports and services. My own experiences in those earlier years, I believe I would have appreciated and benefited enormously, if a person visited me to deliver an '**Information Resource Pack**' filled with:

- ~ Various local, state and national information and resources including financial options information services who provide support, telephone contacts who you can speak with such as the Association for Children with a Disability or Carers Victoria.
- ~ Access to 'time-out' options which was flexible and creative respite choices
- ~ FREE Counselling opportunities with acknowledgement that the overwhelming fear and

depression you feel is 'normal' and part of the process of what you have been confronted with. Once again a choice in the styles of counseling ie: in home, telephone, internet, email or face-to-face counseling in a place nominated by me.

- ~Employment protection (as I had to leave my job I suffered a great deal of grief and financial uncertainty as we had a mortgage to pay)
- ~Education and training about: Early Childhood Intervention services, school-specialist educational settings, beyond school – training and adult centre's, Advocacy and how to be an Advocate, Explanation of various therapy programs to access and what they do ie: O/T, Speech, Psychology, What to expect from hospitals, your entitlements including access to specific medical training rather than being sent home and having to work it all out for ourselves. Also training should be offered to the whole family and surrounding support people who were prepared to assist me in my caring role – especially considering Ben had a colostomy bag for 3 years and numerous medical complications as very few people offered to assist as I believe they were afraid of the unknown just as we were. Another very important and necessary area of training is OH&S to ensure we as carers remain physically safe in our caring role.
- ~Access to a service to assist in planning for our Financial Security and the Financial Security for the person we care for especially if they are a child.

### **PLANNING FOR THE FUTURE**

This is another area which concerns me. The lack of opportunity to **plan for the future**. I want to retire just like you, like my parents, like my family members and like my friends, work colleagues and neighbours. However because of our situation caring for our son, and the lack of choices and options, I may never have the opportunity to retire.

### **SOLUTION/S:**

Opportunities for parents to sit down with someone and firstly look at what financial options we have available within our own means to create a sustainable future for our child with a disability when he turns 18, 21, 25 or whatever age we as their parents choose to formally retire from our caring role.

### **SUPPORTED ACCOMMODATION**

Parents also need to know there will be creative choices and options for our adult extremely dependent child in regards to supported accommodation and a choice of accommodation models should be made available to consider. Personally, whilst I am able to provide the physical care, when the time comes, I would like to retire and be able to travel whilst someone moves into my home and supports my son on a 'one-on-one' basis. This person would need to be fully trained to know Ben's needs and be trusted to run the house in my absence. I would even be prepared to allow another 'compatible' person with a disability, who perhaps didn't have as high care needs and was more independent than Ben, to also stay in my home. Enabling other parents to have a much needed respite break as well. I believe this model does not currently exist and if my husband and I chose to travel now, Ben would be forced into a Community Respite House. There are so many respite strategies and solutions that families could initiate if given the opportunity. Of course, if I physically was not able to care for Ben any longer, once again, I would like a F/T person living with us to support Ben in his own environment, whilst remaining in our care and in our home. However if I was no longer on this earth, then I would also like the opportunity to begin making plans now and know exactly what the service system will provide and what care options would be available to

Ben to give me surety of his happiness, safety and well being when I am no longer alive. I urge government to please help parents/Carers to begin **developing sustainable and strategic supported accommodation** plans for our **dependent children with profound and severe disabilities**. To date there is a great deal of effort and advocacy given to those who are semi-dependent and encouragement is made to ensure these people with disabilities have the opportunity to move out of home, away from their ageing parents and to live supported in a community inclusive environment. I applaud this model however for those people, like my son, who have a severe and profound disability requiring one on one 24/7 care, there is minimal advocacy and/or planning for various supported accommodation options to enable these people to move out of home and be fully supported in a community inclusive environment. Once again where is the equity? Yes we are aware that these people with highly dependent severe and profound disabilities do cost a great deal more to be fully supported in various supported accommodation models, but don't they have just as equal rights as the person who has a lesser disability and are more independent? This is truly a question of rights. Rights for the person with a disability (no matter how severe) and rights for the parents and carers.

#### **SUPERANUATION:**

Before having Ben I was a Bank Accountant with Westpac. Of course I had every intention to return to work however due to Ben's high care needs and complex medical situation, this was not possible. Therefore, without work I was not able to contribute to Superannuation towards my retirement. I am now fortunate to be working 2.5 days a week however our 'planned' superannuation target is no longer possible. I also wish the committee to consider the many Carers across Australia who are in receipt of a Carers Payment and are unable to work therefore they do not have an option for a Superannuation Scheme. Or in my case, when my son or my father become unwell, I have to cease work, which in turn effects my contribution to superannuation, hence my retirement options are severely affected.

#### **SOLUTION:**

A Carer Superannuation Scheme to eliminate Carers financial insecurity is urgently needed.

#### **WORKFORCE PARTICIPATION:**

Caring responsibilities have reduced my workforce participation dramatically. I am grateful when I can work and I applaud my employers for their understanding and flexibility to my situation. However when I am unable to work, the lack of income significantly impacts on our household budget especially at a time when costs are so high.

#### **SOLUTION:**

A National Carer Insurance Scheme or a National Disability Insurance Scheme – OR BOTH! Such scheme/s will provide a guaranteed mechanism of support and eliminate the financial insecurity when a Carer is unable to or no longer able to work due to their caring role. Also employers need to be encouraged and supported to have flexible, carer friendly work environments.



**MORE ABOUT BEN and his CARE NEEDS:**

Ben's syndrome has caused severe intellectual disability, he is non verbal, is incontinent, has complex medical problems and is physically challenged in his every day life.

Over the past 14 years Ben has had over 23 surgical procedures and we have lost count of how many specialist visits have been required at the RCH. He has a portfolio comprising of over 20 specialists most of whom are based at the Royal Children's Hospital in Melbourne. This hospital is over 160km away from our family home. Can you imagine the financial costs we have incurred to access this specialist facility on a regular basis?

Ben has had a surgical procedure on almost every part of his body. from the tear ducts at the top right down to his big toe at the bottom. Some surgical procedures were called 'dual surgeries' as often a surgical team would operate at one end of his little body whilst another team were down at the other end. This was to save him from having to endure extra anesthetics which always set him back.

On numerous occasion I was forced to take matters in my own hands when I knew Ben's care in the hospital environment was not being monitored appropriately or mistakes were being made ie: wrong size gastric tubing inserted down his throat, too much fluid being given intravenously, incorrect decisions made, appropriate x-rays (if any) not being performed and often people within the medical system were just not prepared to listen to me or my concerns.

I would also like to mention, in 1998 my mother also died in a major Melbourne hospital from a terrible medical blunder which led to a 2 day Coronial Inquiry. My trust in the medical system is now destroyed and you can imagine the overwhelming anxiety that overcomes us whenever Ben is required to have surgery?

**SOLUTION:**

For all Carers and parents to be listened to. To be consulted and recognized as a major participant and partner in health and community care – across hospitals and community health, disability, aged care, mental health, palliative care and community care service systems. We are a valuable resource as we know the people we care for and we must be collaboratively involved in all decision making processes.

**CARING IS EXHAUSTING AND EMOTIONAL:**

The emotional ups and downs we have experienced in Ben's lifetime have been enormous. The overwhelming grief of not knowing what tomorrow is going to bring has been very difficult to deal with on a daily basis. At times it is truly difficult to raise the head from the pillow and get out of bed. Especially if you have been up half the night supporting the person (or persons) you care for. It is exhausting both in a physical sense and in an emotional sense. Carers need all the support they can get.

**ONGOING COMPLICATIONS**

Earlier this year we had further anxieties thrown upon us when we were summoned to attend a geneticist clinic, to be advised, that confirmed research has shown many boys with Rubinstein-Taybi Syndrome have been prone to Leukemia up until the age of 16yo. Therefore we are now having regular visits with more specialists to keep a watchful eye for any signs of Leukemia. It truly is never ending!!

### **SLEEP DEPRIVATION**

Ben has a severe sleeping disorder and wakes frequently throughout the night. We have had to purchase a bed with side walls for his safety as he does not understand danger and he would be at high risk if he slept in a normal bed. He cannot have blankets as he continually places them over his head and twists them until they are tight around his neck. Therefore on cooler nights we have a thermostat controlled heater in his room. He also suffers from bi-lateral lymphodemia which causes his extremities to be continually cold. Another reason for the heater which as you can imagine is a cost to run. Also we have to run a monitor all night so we can hear if is in distress, thumping his head, restless or if he is unwell as he is unable to call out due to his inability to speak.

Ben likes to sleep sitting up and loves to 'head bang'. If he lies down, he rocks constantly from side to side throughout the night. He also enjoys the thrill of self mutilation. Therefore we have to dress him in a full piece body suit under his pyjamas to prevent his fingers from wondering into parts of his body which are not built for fingers. We also have to tape his socks to his legs OR he will put his fingers deep down into his socks and scratch the skin from the sole of his feet.

On numerous occasions when I enter his room in the early hours of the morning to check him or to encourage him to lie still, it is not unusual for me to find blood from one end of his bed to the other as he puts his fingers so far up his nostrils, he causes severe nose bleeds. He then chooses to finger paint the blood on any slippery for flat surface he can find.

### **24/7 SUPPORT**

Ben is unable to support himself with any personal care needs. ie: bathing, undress/dress, clean his teeth, wash his face, comb his hair, tend to his own toileting needs, put his shoes on or take them off, independently get himself something to eat or drink, go for a walk without support or supervision and this list goes on and on. This is something we do for him each and every day of his life. With consideration that often several clothing changes are required due to his bladder/bowel incontinence and /or food/drink spills.

### **CONTINENCE CARE**

As he is incontinent, regular occasions in the morning and at times throughout the night we are forced to change his bed due to wet sheets. Even though we put him to bed dressed in an armour of continence products such as a pull-up, a padded insert inside the pull up, followed by an adult disposable jock (nappy) over the top of his pull up AND as previously mentioned he has specially made protective plastic pants which come from Sydney, which go over the top as well AND YET somehow the urine flood gates regularly open.

When Ben was 3 days old we were told his bowel was deformed therefore surgeons supposedly had no option but to give him a colostomy bag. It was extremely rare for a baby so young to have a colostomy bag. That bag was an absolute nightmare for 3 long years. Finally after 3 years we had a decision to make, as to whether we keep the colostomy or to allow the surgeons to completely reconstruct Ben's bowel in the hope of him having overall continence.

We were advised by the medical team that it was 'life threatening' surgery. Therefore we decided to seek a second opinion. Luckily we did, as we were informed by another paediatric surgeon that there was nothing wrong with Ben's bowel and that he should never have been given a colostomy in the first place. After several testing operations his colostomy was then reversed. Unfortunately a few months after the surgery we discovered his bowel muscles had diminished from lack of use. You may appreciate from this experience our faith in the medical system became seriously challenged.

Because of Ben's bowel situation we are now required to give him a daily enema which takes up to and sometimes over an hour every night. These circumstances severely hinder our opportunities of overnight respite as only qualified medical people are permitted to apply internal medical treatments. We were also confronted with issues of changing & toileting Ben. Due to Occ Health and Safety reasons, to enable us to have respite, we had to install a change table and have it attached to the wall near the toilet, a larger than normal toileting area was required and specialized toileting equipment is also needed. Which all lead to MORE costs!

Ben has severe sensory issues which I believe is a side kick from his Autism. He does not like people touching him and he will only allow a hug or kiss if it is on his terms. These sensory issues also affect his eating and drinking. We are required to puree/mash most of his food as he won't eat any food that is hard or lumpy. I'm telling you now we are the world's best pureeing team... You name it, we puree it.

Ben can and will only drink from a straw cup and it has to be a specific cup which makes life difficult if you go out and you forget his cup... Recently we have managed to encourage him to accept and drink a McDonalds Thickshake or a Boost Juice which has been helpful when out and about.

Ben is completely non verbal. He is unable to explain his frustrations, sadness, fears, if he is in pain or if he is feeling unwell. Ongoing efforts and many years of persistence and perseverance, Ben has finally learnt how to use his \$5000 specialized electronic communication device called the MACAW. He will now use his 'buttons' when he wants a drink, something to eat OR when he wants a different video... Which is often!

Ben is physically challenged and suffers from scoliosis and collapsing bones in his ankles. Therefore he currently requires a wheelchair for long distances and general everyday shopping or community activities. However with Ben's degenerative condition it will come to a point that life threatening surgery will be required to help rectify Ben's numerous medical issues relating to his physical wellbeing.

## **EQUIPMENT**

For many families throughout Australia there are huge issues relating to obtaining **funding for equipment** such as their child's **wheelchair** as well as a **modified vehicle** to enable transportation of their child with the wheelchair. This situation needs to be **URGENTLY** addressed.

**MODIFIED VEHICLE**

The Victorian Government need to be congratulated as they, along with WA, are the first state across the nation to formerly introduce a new initiative within the Victorian Aids and Equipment Program, for families to access 'some' funding for a modified vehicle. However, families will still be required to find top-up funding of approximately \$10,000 from somewhere. Not to mention gather enough funds to purchase the larger vehicle to start with to enable transportation of a wheelchair within the vehicle. This is an URGENT situation which the **Federal government** needs to address to ensure equitable and consistent access to enable Carers to purchase a modified vehicle which is a necessity to enable access and community inclusiveness.

**SOLUTION:** Funding grants to be made available across the nation (similar to Vic initiative) and an Interest Free Loan for the rest of the funds to purchase a modified vehicle.

**MODIFICATIONS to homes:**

This is another issue where minimal and insufficient funding is allocated to families/carers to assist them with the ongoing care needs of the person they care for.

**SOLUTION:** Funding grants to be made available across the nation and Interest Free Loans to enable modifications to homes to take place.

**OCCUPATIONAL HEALTH & SAFETY**

As identified in the work place for workers there are also many issues (if not more issues) relating to OH&S for Carers when supporting and caring for a child/young person/adult with a disability or who is frail and aged. As workers are provided with training and safety equipment and/or modifications in the workplace, this exact model should be considered for Carers, and urgent consideration needs to be addressed for CARERS in their workplace ie: their family home. Training, information, advice and access to appropriate equipment and home modifications is paramount to eliminate injury of the Carer!

**Various and recent research has shown many Carers are among the poorest most disadvantaged people in our community and yet the cost of caring is significant and continues to rise.**

Families, like mine who are supporting their child/adult with a disability and for some, like my family, have a **multiple caring role** and are also supporting their ageing parent, need appropriate assistance that enables us to sustain their caring responsibilities, maintain their health and wellbeing and have an equal opportunity to participate in family, social and community life, employment and education.

**CARE NEEDS of my father:**

As I have mentioned my father is on Full-Time oxygen. When he first came to live with us over 3 years ago it took 6 months for an assessment to take place from the Aged Care Assessment Team. Then it took another 3 months before a Community Aged Care Package (CACP) became available. During this time Dad was very unwell and had several hospital admissions. He was also forced to receive a catheter due to urology

concerns. Of course this created numerous amount of problems and a great deal of extra work. But of course assistance could not be provided as he was on a waiting list for support.

When he was finally funded for a CACP package his package was unable to fund the oxygen due to him receiving Commonwealth financial assistance via the CACP and the oxygen was a state funded program through the Victorian Aids and Equipment Program (V&EP). I advocated strongly against this issue, visiting state and federal politicians and having regular dialogue with bureaucrats within the state government. Since Dad has now gone over to an EACH package I believe this decision has now been reversed and access to the VA&EP is now possible. Common sense unveiled!

Currently Dad receives Personal Care (showering) three times a week as instructed by the 'system'. He is required to take medication 4 hourly via a nebulizer along with other various medications on a daily basis. He requires assistance with his personal care and his every day activities.

He is unable to prepare his own meals and lately is no longer able to even carry a cup of tea due to his weakness. He also requires assistance throughout the night as often he is breathless, becomes quite anxious, requires assistance with his medication and just needs someone to sit with him until he begins to feel OK. Due to his medical condition he has minimal mobility. His situation is very frustrating as he really wants to walk, his mind is telling him to walk but his lungs do not allow any physical activity. We have recently secured some funding to enable someone to come and check on him in the middle of the day and to have a chat. This is something he values and it has made the world of difference to him. Someone different to converse with and someone who he can chat with who will truly listen to anything and everything he chooses to talk about. We are all grateful for this service as a noticeable change in my fathers personality occurs when he knows one of his 'girls' are coming for the hourly chat. We are all very grateful for this service.

**Unless you are 'walking in our shoes' and living the life of a 'carer' or a parent of a child with a disability, there is no way ANYONE can possibly grasp the ongoing 'struggle' and lack of supports, services and financial assistance which is so glaringly obvious in this world or caring. As many have stated, there is enough evidence and research available which the Senate Committee could view and study to confirm my situation as a carer and parent of a child with a disability, and all carers and parents throughout Australia.**

**I will endeavour to continue with my caring role of both my precious son and father. However I urge the Senate Committee and the Rudd government to seriously consider all ideas and solutions being presented during this inquiry to ensure my life and the life of 2.6million other carers across Australia (many with varying degrees of care needs) are given the opportunity to live a lifestyle of dignity. A surety that my life and the life of my family does not lead to financial destruction, physical exhaustion and/or emotion breakdown.**

Thank you for taking my views into consideration as part of the Committee's Inquiry. I am more than willing to attend and have the opportunity to appear as a witness at the public hearings that are scheduled in Melbourne for August 12 and 13 2008.

If I can further assist with this inquiry please do not hesitate to contact me.

I anxiously anticipate the recommendations the Committee will make to improve life for ALL Carers across Australia.

Yours sincerely

Helen