Inquiry into Disability and
Care and Support

13/6/2010

To Whom It May Concern,

My name is Gary Allsop and I am a quadriplegic due to an accident playing Australian Rules football for Warrandyte on April 29, 1989 and to say this changed my life would be a gross understatement. Having been in a wheelchair for over 21 years now I have experienced every little setback and disadvantage that people in similar positions like me have to contend with every day. It is one thing to have catastrophic loss of personal physicality and independence, but only people close to someone living with quadriplegia would know what we have to go through on a daily basis. I once was an active sports person, but now rely on carers and my wonderful parents to do lot of my more basic and personal needs for me. I write to convey some extremely important information in the hope that the government can help the plight of the many thousands of people in my position living with spinal cord injuries in Australia.

I would like to let you into my world and inform you of some of the many medical things that people living with quadriplegia have to face 24/7. Pressure areas, urinary tract infections, Blood clots, Incontinence, bowel and bladder problems, shortness of breath, Osteoporosis, temperature regulation, severe sweating, muscle atrophy, kidney and bladder stones, severe chronic nerve pain and Hypereflexia whereby the bladder over-fills and there is a possibility of stroke.

Add to this poor body image, loss of independence and dignity, loss of sexual function and the ability to have children, breakdowns of relationships, fear of never meeting a partner, loss of career, future life plans and direction, loss of friends, loss of self-esteem and confidence, added pressure on families, depression and in extreme cases suicide. This only highlights what a spinally injured person has to deal with every day. So you can see why it is a lot to cope with and if you gave only one aspect of the aforementioned to an able-bodied person it would change their life significantly.

I was not compensated for my accident and I live on a disability pension. For the past 21 years I believe I have often fallen through the cracks of funding eligibility that is not currently recognised by state and federal governments. For example I firmly believe I am under-funded for incontinence aids collectively from the State government allowance and the Federal government CAAS allowance which I find absolutely abhorrent. I think as an Australian citizen who has had a catastrophic injury it should be my human right to go to the toilet each day for free like everyone else, something that everyone else takes for granted. The mere fact that our State and Federal government does not give me enough allowance to supply adequate amount of equipment for medical procedures to take place so that I can do so is simply just not good enough.

I have found over the 21 years I have been in a wheelchair that there is a drastic imbalance in the levels of care depending on how you had your injury in the first place. For example if you had a car accident or work accident you are completely covered by the likes of TAC or Workcare and very importantly that means for changes to your home, additional equipment, how many care hours you are entitled to and incontinence aids, for life. In my case I was not compensated for my accident and like many fall through the cracks of funding for equipment, I am only funded for limited amounts of care hours and only partially funded for incontinence aids through the State government Aids and Equipment scheme and the Federal government CAAS scheme, soon to become the CAPS scheme which is nowhere near enough. It seems to me a form of discrimination and the lack of equal opportunity that some people in Australia who may have the same injury as a result of a different accident are not cared for equally in the same way. It is very much a system that does not practice equality for everybody.

As long as I have been in my wheelchair I have decided that I would stand up for issues that mattered and for a long time now I have been a patient advocate for the vast amount of people living with spinal cord injuries in many different circles within the community, be it a local council, hospital or even a government issue. Along the way I have been able to change many things in the community that people might not necessarily think about because they are not living their life in a wheelchair and don't look at things from where we sit. Here in Melbourne in my major role as an Honorary Director of Spinal Cure Australia I have been able to successfully negotiate with the Victorian State government in particular on the subject of spinal cord research after I met with the then Treasurer John Brumby in 2004. As a result of that meeting $63 million was secured into spinal Cord injury and acquired brain injury research establishing the Victorian Neurotrauma Initiative in 2005. Here in Melbourne I am now a patient advocate for the State government on the subject of spinal cord research and I am more than happy to speak out particularly for people with spinal injuries when it comes to any of these vital issues. I say this not to brag but to highlight that this whole experience over the last 21 years living with a spinal injury has taught me that one small voice can make a difference in the community and by speaking to someone in authority within government and letting them know what it is actually like to live with a disability and as a result what greatness can be achieved. Every time I have done this I have managed to open up that person's eyes and their mind and brilliant things have resulted for the benefit of disabled people within the Australian community who deserve basic needs just like everybody else, so I will continue to speak out in order for change for the better to occur.

I have met with many other politicians in my 21 years including Robert Doyle, Steve Bracks, Timothy Holding, Kirstie Marshall, Tony Robinson, Gavin Jennings, Lisa Neville, Mike Symons, Bill Shorten and Deputy Prime Minister Julia Gillard, all who have either directly or indirectly opened up doors for improvement for people with spinal cord injuries after speaking with me. I am more than happy to represent on behalf of people with spinal injuries when it comes to this vital issue and also that of care in the home. If you are seriously looking at ways to improve community care programs such as CAAS and care for people with disabilities in their home then you definitely would benefit by talking to me, because it is the harsh reality that exists in the Australian disabled community that the government needs to hear about and needs to put well overdue and urgent policies into place immediately to fix the system.

In the past year or so I have met twice with Bill Shorten, whereby we discussed these issues at length along with the subject of funding for spinal cord research. I explained my situation to Bill that I had an accident through no fault of my own and became disabled for the rest of my life, with no compensation and exist on a disability pension. I put it to him that it should be everyone's human right to go to the toilet free of charge, particularly when they are no longer physically able to and that it should be the government of the day's moral responsibility to look after people in my situation and cover all the costs of incontinence aids, not just part of, to which he agreed. Bill was extremely sympathetic to my argument that CAAS does not go far enough in assessing an individual's needs according to the disability and the importance of those supplies for people's health and survival. I pointed out to him it is one thing to become incontinent and still be able-bodied and just rely on a little bit of assistance but being in my position and needing incontinence aids as a matter of life or death is a whole different level. For example having an intermittent catheter inserted into your bladder twice daily, my mother does this procedure, is a medical procedure and all equipment associated with that procedure, I believe, should be fully covered by the Federal government through the Medicare scheme.

Bill told me on the day that I had made a significant impact on him meeting me face-to-face and that he had a whole new appreciation of what it was like to live with a spinal injury and how the medical procedure using incontinence aids was vitally important for my health. As a result of that meeting Bill told me that he would forward the information that I had expressed to him to the health Minister Nicola Roxon and asked me to provide some information about this issue and about spinal cord research online that would go to a government committee within FAHCSIA, which I did the next day. He also made me aware that he was just a small cog in the government wheel and whilst he wished he could put things right immediately these matters sometimes take a long time to be fixed through government circles.

Let me outline to this committee, as I did to Tony Abbott, Nicola Roxon, Mike Symons, Bill Shorten and in a recent letter to Prime Minister Kevin Rudd. The medical procedures that I need to have daily in order to survive and the usage of the incontinence supplies so you can have a better understanding why this matter needs your government's urgent attention. In my case because my bladder does not function like a normal person I need to wear a condom or sheath drainage connected to a bag strapped to my leg, otherwise obviously automatic urination would occur. Additionally to that I have to have the medical procedure of catheterisation done twice daily. This involves inserting a catheter into the bladder to drain excess urine from the bladder to avoid bladder reflux (where the urine can infect the kidneys); if this is not done regularly it could be very dangerous to my health. Also if you just left the urine sitting in the bladder this would only add further dangers of urinary tract infections (UTI), which can be very dangerous for people with spinal cord injuries. These are basic needs to avoid health problems and embarrassment and keep reasonable dignity.

I think it is inadequate to simply say the aim is to help people meet part of the cost not all of it. That may be so for someone who has adequate income streams whereby the allowance helps them to meet the cost, but someone in my position who relies on certain medical procedures to be done to exist and only receives a pension it is another level again, there has to be some flexibility (horses for courses). You cannot simply put everyone under the same umbrella and expect them to get by, particularly in my case as it can be very detrimental to my health without adequate supplies. Things need to be assessed on a needs basis based on the disability and the extenuating circumstances that might be involved with that particular disability from a medical point of view; this is where CAAS falls down. This scheme definitely needs fixing and if the government is not going to address it then people like me are going to continually struggle, because the price of the supplies continue to rise yet the allowance has not had as CPI rise since it was introduced in 1992. We cannot be expected to afford this equipment along with all of the other essential items that have risen in price. I am not suggesting for one moment that everyone who receives money from the scheme should have all their incontinence supplies paid for, but perhaps may I suggest, there should be some criteria that if you do not have adequate supplies to perform those vital life-threatening medical procedures within the allowance you can make a special application to CAAS signed off by an experienced medical doctor. CAAS is in urgent need of reform particularly for people like me that fall through the cracks of compensation and need adequate supplies to perform sterile medical procedures in order to maintain good health.

Please bear in mind that my circumstances are somewhat mild compared to others that may need even more supplies due to heavier regimes according to their bladder health. Some people I know have cut down the amount of catheters they are supposed to be doing putting themselves at severe health risk just because they cannot afford the equipment needed. Is the government going to take responsibility if someone cutting down on procedures due to not having enough supplies dies because of complications? If these procedures are not done at the designated times and frequency, which are specifically trained that way from day one in hospital, then further dangerous health problems can occur. If the bladder is not emptied correctly a person can suffer a condition called hype-reflexia. This is where the bladder is full, cannot empty in a normal way and immediately a person breaks out in a sweat and receives a very severe headache. If the bladder is not emptied immediately it can render a person unconscious, can possibly lead to stroke and even death. Also in particular urinary tract infections (UTI) are far more common for people with spinal injuries because the bladder is emptied less frequently and bugs get into your bloodstream that is why it is vital that the bladder is emptied in this way. These urinary tract infections often require hospitalisation and if left untreated have killed many people in wheelchairs. Many people, because they cannot afford the incontinence supplies, use catheters more than once, sometimes using one catheter for up to a week. This procedure is definitely not recommended by experienced spinal doctors, because of the risk of introducing infection is far greater. In a hospital situation when they are training your bladder to function it is a one catheter per procedure and then they are thrown away, that is the way it should be in the home, a sterile medical procedure, anything less than that is putting anyone's health at risk and sometimes require them to be back in hospital. It seems to me a no-brainer and false economy that if the correct amount of incontinence aids were supplied in the first place there would be less hospital admissions, costing less to the community, but more importantly less risk on people's lives. It is extremely detrimental for your health to have been trained one-way to empty your bladder in hospital then have to risk your health by reducing the amount of procedures because you can't afford the incontinence aids supplies.

For your information the scheme was introduced in 1992 for any people who received incontinence aids assistance from State and Territory governments and since that time has had hardly any CPI rises and has only risen $19.95 since 1992. My argument to the current and previous governments is that if there had been a 4% CPI rise since 1992 given every year this is how it would have worked out:

$470	1992
$498.8	1993
$518.75	1994
$539.50	1995
$561.06	1996
$583.50	1997
$606.84	1998
$631.11	1999
$656.35	2000
$682.50	2001
$709.80	2002
$738.20	2003
$767.73	2004
$798.44	2005
$830.38	2006
$863.60	2007
$898.14	2008
$934.07	2009
$970 .43	2010

If this CPI rise had been given every year I probably wouldn't be complaining about it as it wouldn't be an issue as I and many others would probably be covered. Also if I had been compensated for my accident and didn't have to exist on a disability pension, I would not be raising this issue again. Surely any government can't expect especially invalid pensioners to go on affording this essential equipment especially when the cost of this vital equipment keeps going up but the allowance doesn't. Every year at very least the allowance should have a CPI rise. We cannot be expected to afford this equipment along with all of the other essential items that have risen in price since 1992.

I do understand that the Department of Health and Ageing is currently developing a national consistent approach to strengthen and improve community care programs, including the home and community care program. With the greatest of respect, this sort of talk about reviewing the CAAS situation has been going on for over 10 years and still nothing gets done about it. It is becoming a very tired argument and let's face it actions speak much louder than words. This solution could be quite simple if only people making the decisions like your good self could talk directly with people like myself to get the real picture of what is actually happening in the community from the people with the disability and the real costs that are involved where I believe they would have a whole new appreciation of what is required. The CAAS is in urgent need of reform particularly for people like me that fall through the cracks of compensation and need adequate supplies to perform sterile medical procedures in order to maintain good health. A person injured in a car accident is totally covered by TAC for incontinence aids supplies for life, but for a person in my situation this shortfall is very difficult to cover and we are left to battle on. This is where the government could be very helpful in making up the total expenditure of incontinence aids supplies for people under certain criteria, as I suggested above. In these cases perhaps your government could at very least match the allowance of the State government Aids and Equipment of $1200.

I now understand from correspondence I have received that you are updating the CAAS scheme to the newly named **Continence Aids Payment Scheme (CAPS)** 1 July 2010 and it will be distributed through Medicare and paid directly into your bank account. This is actually a good initiative as it enables people to buy from different sources and hopefully get some better prices. But the scheme still does not address people on their merits as I have already stated above and again the allowance has not gone up at all, unless the allowance is increased not a lot has changed and your initiatives have not gone far enough in my opinion.

Let me give you a comparison. I am currently on a drug by the name of Neurontin which is a pain control drug for nerve pain and it is funded by the Federal government pharmaceuticals scheme. I need this drug every day to ease the nerve pain that I suffer every day. Now I'm sure the government would not fund it for only nine months of the year and leave me hanging for the rest of the time? That's what seems to be happening with incontinence supplies, I am being funded for part of equipment which I have explained are used for the most important vital medical procedure that takes place twice daily and left hanging for the rest, this seems ridiculously inhumane.

On the other side of the coin if you happen to be lucky enough to be a TAC patient all of the above said incontinence aids equipment is supplied free of charge for the rest of your life. This certainly takes away any unnecessary risks of not having enough equipment and a sizable financial burden. Also under TAC if you need any other sort of equipment like wheelchairs, exercise equipment, alterations to your house, hoists, vehicle modifications and specialised furniture, again this is all covered. Unlike people in my position if I want to buy anything like this it would have to come out of my own pocket. It seems to me to be a ridiculously unfair and antiquated system that the nature of your accident determines what you are compensated for, for the rest of your life and how that might determine how much longer you live. Let's face it TAC is a government body that compensates anyone in a car accident and Workcare compensates people if they have an accident at work. It begs the question for instance in my case why doesn't the Ministry of sport compensate people who have sporting accident? The whole question of compensation for No Fault catastrophic injury system for everybody in Australia needs immediate attention and a much fairer system agreed upon.

Australia could well take a leaf out of New Zealand's Accident Compensation Commission that looks after any New Zealand resident or visitor to their country, no matter what accident or injury they have, in terms of rehabilitation and costs involved in their life thereafter. For further information about the New Zealand Accident Compensation Commission here is their website http://www.acc.co.nz/index.htm . I have been involved with a group of people with spinal cord injuries here in Victoria along with the TAC and the Victorian Spinal Cord Service endeavouring to find ways to make it fairer for people with a spinal injury to be compensated or looked after for the rest of their life regardless of how their spinal cord was damaged. This New Zealand model has been cited as one of the best in the world and sets the standard for the rest of the world. This is a model Australia would do well to adapt, surely if New Zealand's economy can have such a great policy in place Australia can do likewise, I know Bill Shorten is very aware of it.

I see recently in the media that your government is looking at funding lap-band surgery for obese people. I am not against it, but surely if a medical procedure such as that can be funded, because it is seen as dangerous for people to be morbidly obese, then why can't someone with a spinal injury like mine that was not my fault, wasn’t compensated for my accident and exists on a pension be funded for all incontinence aids and other equipment that is needed on a daily basis for vital medical procedures for my long-term survival? I hope you can see an inconsistency here?

I think it is most important for all politicians and bureaucrats within government to consider what it might be like to live with such disabilities where you cannot go to the toilet like every able-bodied person does. I think it is definitely something that we all take for granted until you are in a situation like mine and many others, where you need assistance from a carer and with equipment to allow a vital medical procedure to take place and monetary support from the government. Should people with disabilities be made to pay for such an inconvenience, especially those on a pension? I would certainly hope that your answer to that question would be no!

NO ONE in this day and age living in Australia with the lifestyles that we are afforded should be made to pay to have a toilet procedure done that every other Australian citizen can do for free under normal circumstances. Sufficient funding from the government for the appropriate incontinence aids supplies and other necessary equipment would allow this to happen, but currently this is not the situation and should be rectified immediately. It needs to be pointed out in no uncertain terms to government that this is a real situation that people in Australia are living with, a situation that no able-bodied person would like to live or cope with. The time to act is now, regardless of budgets, human beings with disabilities and their needs should be taken care of first and foremost on the government's list of priorities and ultimately carried out immediately. Whilst $489.95 may seem a generous allowance, it goes nowhere near the amount needed for people with such disabilities as mine and our requirements.

I strongly urge the politicians and bureaucrats to for one moment put themselves in my position, as this matter is far too long overdue in being dealt with by government. I sincerely hope that you will address the issues I have raised and set about putting policies in place immediately to greatly assist people like myself according to people's needs. If people like me living with a disability are unable to get through to the powers that be by pouring my heart out in detail writing submissions like this then I don't think anyone ever will and things will never ever improve and I may as well give up representing and speaking on behalf of other people in my position because we feel let down by the government over many years and that no one seems to be listening. We strongly feel we are left in a vulnerable position that we should never be in the first place through no fault of our own after many years of government neglect of people with disabilities. Currently the way some people with disabilities are treated in Australia is disgraceful and a sad indictment on previous and current government policies.

After writing several letters to Nicola Roxon and calling her office many times over the past three years requesting a meeting with her and her declining to meet me, I recently finally got to meet with one of her advisers Chris Picton at her Maribyrnong office to discuss this vital subject. I was given a very fair hearing and assured that he would report back to her with my deep concerns about this system and get back to me. I only hope that what I had to say to him is taken on board by Nicola Roxon and the government and does not fall on deaf ears.

Another very important issue to me personally and many others is as follows. Currently I live with my parents and I have carers come and help me with my personal care. What is uncertain is my future living arrangements when my parents pass away in terms of what sort of carer hours both day and night I would receive to continue to be able to live on my own safely in the same house and not be a burden on the community. I would like to continue to live in my current home when my parents do pass away and not be forced to live in a nursing home or shared accommodation, as I am sure many people in the community would like to stay independent. In stark comparison a TAC patient would be fully covered for carer hours day and night for the rest of their lives, so you can see it’s not a fair system for everybody. Considering my parents have filled that void for the past 21 years I feel that I am entitled to the exact same cover of hours to look after me in my own home for the rest of my life as any TAC patient would be. I am sure a system like this for everybody can be implemented fairly with eligibility by application and assessed by the needs of that particular disability.

By having to employ more carers in the community the impact on the workforce would be that it certainly would create a lot of employment and funding for this additional employment as well as full cover of incontinence aids for eligible people, mentioned above, could certainly come from the likes of speeding fine, petrol tax or poker machine revenue for example. It seems to me that the government always seems to be able to find money when they need it, for example the soccer World Cup bid for 2022 is costing millions of dollars. If that sum of money can be found for such an event then it should be absolutely more important that it can be found to look after people with disabilities in the community on a year-to-year basis, basic human rights for people living in such an affluent country like Australia.

I do understand and believe that the Prime Minister is trying to do something about this along with Bill Shorten and Jenny Macklin with the National Disabilities Strategy along with the State and Territory governments. I applaud them all on this initiative because the range of issues that this will cover and hopefully improve is a revelation and a long time coming for people with disabilities. Now is the time for the government to seriously change the system for people with catastrophic disabilities in Australia because it is the harsh reality that exists in the Australian disabled community that the government needs to hear about and needs to put well overdue and urgent policies into place immediately to fix the system. Please bear in mind when you are scheduling public hearings. People with disabilities quite often have their carers come in the morning to do their personal care, so it would be appreciated if the public hearings were not early in the morning, perhaps late morning or early afternoon so that people with disabilities can attend and give their opinions.

I did not ask for my accident to happen and neither did many others in the Australian community that have suffered a no fault catastrophic injury and we are now crying out for well overdue help. I only hope that government forums such as this asking for our input are not all talk and no action?

Yours sincerely

Gary Allsop