Where to start, our journey has been short in comparison to many people that we have met so far but already we have uncovered so many aspects of life as a disabled person.

Almost to the day 12 months ago my wife became ill and within a matter of hours a C1 tetraplegic, the highest level of disability. From that day till now our journey has been a struggle, even finding the time to submit this has been difficult. Right now my wife is fighting for her life in hospital yet I find myself compelled to make a submission so that one day life may become easier for those that have to follow a similar path.

My wife is a 32 year old woman with a husband (me) and a 13 month old baby. She has no sensation or movement from the neck down, this also includes the use of a permanent ventilator for breathing. She is an educated professional woman who is adjusting to the significant and devastating changes to her independence, lifestyle, social and family situation. She is a determined, strong willed individual and has made the decision to try to make the most of what is an overwhelming situation.

She is cognitively intact and fully aware of her health situation while remaining optimistic and determined to live her life to the full. She is now (when not in hospital) permanently living in accommodation under the guidance of Yooralla that can meet her health and care needs, and importantly maintain family relationships with me and her daughter.

We find ourselves frustrated with so many aspects of the current health support system that I find it very difficult to pick out where to start, let’s try funding

FUNDING...

When our sole focus should be on spending quality time with my wife, we find most of our days are battling with the current Aids and Equipment Program and raising much needed funds for vital equipment for her. Take the wheelchair for example, due to the high level of disability my wife has, the costs are significant as we need to get a highly customised chair so she can drive it with her chin. Under the current funding scheme, we can get around $8000 in funding, great, the chair costs around $26,000. Not many people I know have $18,000 sitting around to just hand over. Under the current funding scheme I’ve said every day, the higher the injury, the higher the cost and the worse of you are. And then you receive a letter saying that by accepting $8000 you are permanently loaning the chair even though you have to cover the remaining amount. Don’t get me wrong, if we don’t need the chair we would love for it to go to someone who needs it, they deserve a break.

Many of the specialists we have met have mentioned that if only you were a road accident victim, TAC would be covering all of this. It has never felt right that I should be wishing that we were in a road accident to get where we are today, why isn’t there a system in place that covers the community for those that are just “unlucky”. My suggestion would be to template what TAC does for road accident victims and apply that to the rest of the Australian health system for those under duress and suffering from a disability.

Strangely I would like to have my wife home with myself and my daughter, while this seems like a dream I believe it would help her recovery and help us deal with the situation a little better. Even if she has limited time left, wouldn’t it be better for her to be home than living in some nursing home. So now I’ve started a list that disgusts me every time I look at it. The funding for every single piece of equipment is inadequate, and not just slightly off the mark, most funding is for less than a third of the price. Clearly this funding scheme (A&EP) is in need of a major overhaul, and should be done so on a regular basis to move with the market for devices. Let's see if I can show you a few major things on the list -

	Cost	Funding avail	Gap
Bed - Pressure Care	$30,000	$5,000	$25,000
Hoist - Mounted	$10,000	$3,600	$6,400
Hoist - Portable	$7,000	$2,600	$4,400
Wheel Chair	$26,000	$8,000	$18,000
Ramps - Portable	$1,000	$400	$600
Car	$60,000	$10,000	$50,000
Lounge Chair	$4,500	$1,000	$3,500
Home Renovations	$50,000	$4,400	$45,600

Total GAP in funding = $153,500

This isn't everything, I didn't even include the costs of her accommodation right now on top of our normal living expenses, but where am I supposed to come up with $153,000. So my family, friends, relatives and people they all know are trying to help. We are looking at fundraising, why should we have to? We pay our taxes, and we have the top level of cover with Private Health Insurance. My wife is a very private person, and now is the time when she needs her privacy more than ever. Lots of people have suggested going on TV shows to get our story across and see if someone can help, believe me this is the last thing we want to do but what choice do we have. It is shattering to think that I may have to put my wife on TV to be able to get her home, I know she doesn't want this. I didn't include the funding of carers as the figure totally blows out the numbers above and I wanted to make a point about the equipment funding, carer funding is a whole new topic.

Please fix the funding, come up a system that is fair and just, and offers people the opportunity to bring their loved ones home....

PRIVATE HEALTH INSURANCE

This may be completely irrelevant but we have always been encouraged to take out private health insurance, but when it comes to you becoming critically ill they can offer nothing. Surely private health insurance should have the cover similar to TAC to look after someone who is a paying customer and their health is significantly affected. We have the top level of care but can offer nothing above what Medicare does. Sure if you want a massage you can get some money back, but that's a slap in the face for us right now. Private Health Insurance needs a complete overhaul, this could be a very justifiable solution to fixing the funding gaps, but of course it's private and we have no control over it. So it appears the only reason I have Private health insurance is so I don't get the Medicare levy surcharge?

OTHER ISSUES

When my wife became ill, it is not just her that is affected. Myself, our daughter, her parents and many of our family stopped working to stay by her side. Slowly many of them have returned to work but me, her mother and father have been by her side every day.

Funding not just a carer allowance, but some sort of compassionate family allowance is almost necessary. Her mother, I and her father to a smaller extent have all given up work to support my wife. Better people than me could help decide on eligibility but this certainly has a place in their entire scheme. Most of us have suffered with our health and well being during this time.

While my wife was recovering in hospital we spent countless hours/days/weeks/months negotiating with other hospitals to try to get her into a rehab program. As she was both a spinal and ventilated patient there was only one hospital with 3 beds that was even willing to consider taking care of her and this took months to find. Why are there not adequate support systems in place to deal with patients with high level spinal injuries? We found it devastating that there was a very real chance that she would remain in ICU for the remainder of her life as we couldn't get her into adequate facilities due to demand. Surely we should be considering training our specialist spinal units to be able to care for patients that are dependent on ventilators, this is a problem that many spinal patients suffer from and yet we only have 3 beds available in Victoria, why?

Every person that suffers from a disability should be given every chance to live, to try everything possible to improve their quality of life and choose their future. There are inadequate resources available to you under the current health system for occupational therapists, speech pathologists and especially physical therapists. My wife requires weekly if not daily access to these specialists, but you guessed it, we have to pay for it. Are we supposed to spend the remainder of our hard earned savings to access these, why isn't this covered under the current medical system for disabled persons. There is still some hope that she may be able to speak one day, or even move a limb but as soon as you leave hospital, and end up at a care facility the access to these resources disappear and you are left to fend for yourself. And what happens when all of our money runs out?

Centrelink is brutal, there should be dedicated channels for family and the disabled person to discuss your needs and eligibility rather than fill in forms, sit in queues then be degraded by someone stamping the papers with no compassion, only to receive a rejection letter. I've wasted countless hours with Centrelink for absolutely nothing and don't even bother anymore.

Fighting for accommodation over other people with similar disabilities, why is there not more suitable accommodation? Or why wouldn't you fund people to get home, surely this would reduce the strain on hospitals and accommodation, increase jobs for carers and nurses in the community and give the affected person some independence, sense of self worth and the ability to live as "normal" as possible.

I guess the general theme of my notes above is more questions than solutions, but that's the reality of the situation, no one seems to be able to answer them so the questions remain. So I'll submit this and head back into hospital to be by my wife's side. By the time this commission is finished with its findings I fear that it will have no impact on us, but we hope that families that end up in the same situation in the future will find the systems supports them rather than fights them every step of the way. Fix the funding, find a way to support families during the hardest times of their lives, help the disabled rediscover life and believe there is a future worth fighting for. Give us hope...