A.O.C. 30/6/08

Submission No. 244

(Inq into better support for carers)

Summary

Thank you for the opportunity to tell our story. As members of this Committee, I'm sure that you will hear many heartwrenching stories of grief, bravery and love. These are stories that are quietly unfolding in homes all over Australia – they need to be heard, understood and managed intelligently and sensitively at a public policy level. Most importantly, this is not about partisan politics or short term political gains. You never know when these stories will become your story – and most of them will be about grief, bravery and love that will endure far longer than any electoral cycle.

My story is that of a reluctant new carer. At the beginning of this year, I knew little about caring outside of my own family, nothing more than the odd kids' cold. We were proudly healthy and self sufficient and had the hopes and dreams of many Australian families for a full and fun family life. This all changed on 12 January this year when my younger son, Jamie, was diagnosed with Duchenne's muscular dystrophy.

It's been a crash course in the meaning of life – and death. Things that mattered no longer matter and things that didn't matter, or we took for granted – have taken on new meaning. No parent should have to watch their child die – we've been given about 10 years' notice to do exactly that. This is our journey and observations so far. Much of it is very personal, but my hope is that this helps you understand our mindset and some of our needs as carers at this time. My apologies for the length; it has been a therapeutic way for me to stabilise many swirling thoughts. I have included some highlighted thoughts and suggestions throughout for ease of reference.

Jamie's life will be short, but we're determined that it'll be as happy and fun as any child could want for. In the meantime, we're hoping to learn to enjoy the journey, rather than fear it, for the sake of our sons, my stepdaughters and our own relationship and sanity.

About Jamie

Jamie is three and a half now. We first suspected that something wasn't quite right when he was about two and a half but it took a while to work through the various assessments and finally get an unexpected life sentence.

Duchenne's muscular dystrophy (DMD) in a nutshell is caused by the deletion of various receptors on a gene that would otherwise produce a protein that is necessary for muscle health. Without it, his muscles will waste away, starting with the legs and ending with the heart or lungs. The average life expectancy is 18 years and there is no cure. In our case, results show that the condition is a result of spontaneous mutation, the odds being 1:12 000.

Jamie is a happy and loving child, but as a result of his condition, also has mild developmental delays and is currently exhibiting behavioural difficulties. He will always have difficulty with numbers and abstract concepts including spelling etc, so will require integrated supported education.

At the moment, Jamie is not toilet trained and we are seeing more stumbles and trips by the week. He requires help with most daily activities including dressing, bathing, eating, getting into the car, playing outside etc. This level of assistance will increase as the condition progresses.

About Us

We are a pretty typical "working family" and more fortunate than many. We are both postgraduate educated professionals on above average incomes. We are IT savvy and mostly, pretty resourceful and determined. We have our own home, with a mortgage and financially support two older girls (away from home) and Jamie's older brother (6 years).

We have small and supportive group of friends locally as well as limited assistance from one set of grandparents. We have a strong relationship – my husband plays a very active role in the kids' upbringing and is a good emotional communicator (unlike many males !). We can afford to have a babysitter every two weeks for "date nights" – and we consider this a valuable investment.

We have top level health insurance and have rarely had to call upon it. We have for many years supported local charities and events, including Cancerians, Camp Quality and Red Cross. We felt that the world was "our oyster" - only late last year, we were contemplating a move to Asia to take up an executive position.

We have had no history of illness in our family so this came completely "out of the blue". 12 January changed everything. I changed, almost overnight, from an energetic professional mother with an internal age 10 years younger than my actual age to someone who felt unbearably raw, vulnerable but somehow more part of the human race and sympathetic to our weaknesses. My husband suffered from claustrophobia and couldn't sleep for many nights. The tears erupted volcanically for weeks. I've now got it down to every two weeks or so, but I never know what going to set it off.

My older son has had to watch all this. We have decided that the best way to help him is to be open and honest about it and ensure that he builds a strong group of friends and interests outside the home to help cushion the blows as they inevitably will come. It is humbling being told by a six year old – "don't cry Mummy, he's not dead yet". Thankfully, he's a smart boy with a love of David Attenborough and understands that there is no life without death. If only more kids and adults alike were prepared to accept that too.

Information about DMD

There is plenty of information available on DMD from hospital and association websites. In reality, I am too scared to read some of it. I'm not ready. And in time, I'm sure that much of the most useful information will come from those that have been there before us.

Suggestion: It is important to ensure that carers have reasonable IT access and skills to enable them to access information and online support groups. My experience is that it is important to be able to

New Carer Support

The malignant sadness has been cushioned to some extent by a broad range of support that we've found in the Canberra community. If there's one good thing that's come out of this, it's some of the wonderful people that we may not have otherwise met.

Our family and friends have been supportive. However, most are working families with younger children of their own, very limited time and like many Australian families, our family and friends are dispersed throughout the world, with many in Europe and elsewhere in Australia. For this reason, we have relied heavily on the phone and e-mail.

Suggestion: Ensure that carers have reliable affordable communication and the skills to enable use.

We have also started writing a regular newsletter to family and friends to give them news of Jamie and ourselves. Many people are reluctant to ask, in case it is too painful and as a carer, it is time consuming and emotionally exhausting repeating the same information to all that are interested. Quite selfishly, it is also a means of building and maintaining a support group that I know that we will need to rely on heavily later on. Our first newsletter was very well received and we will maintain this on a six monthly basis.

Suggestion: I have seen a US based website where carers can provide information on their caree's progress etc. I thought this was a wonderful idea. It is expensive, time consuming and technically complex for most carers to set up a website, but perhaps some thought could be given to offering a free website for carers to update within a template themselves. An option should be offered so that access can be either open or password limited to closed communities of the carer's choosing.

The broader Canberra community has also been very supportive, both people that we know through community fundraising efforts, parents at the school, friends of friends etc. It's very Canberra where everyone knows everyone. Through this, we have found many that are willing to help in all sorts of ways. As noted above, we are inherently proudly self sufficient, but will have to learn to reach out and ask. What is wonderful is that there are so many out there willing and this really has buoyed my sense of pride in the local community.

Suggestion: Carers need to be encouraged to have the confidence to talk about their needs. If you don't ask, you don't get. Reach out to those that may not have the strength to do so.

My older son's school has been supportive. I spoke with the relevant teachers, counsellor and Principal about the condition and possible impact on my son shortly after we received the news. As a result, the counsellor has talked with the class generally about illness and disability and they know that they can talk with her. I know that my older son has the confidence to talk about Jamie's condition openly and that his friends always welcome Jamie. This is a huge relief to me. I also asked the school about the extent to which resilience and dealing with death and illness are integrated into their learning. The answer from one teacher – we would address that at Easter – was less than satisfactory to me.

access information when you feel ready for it and privately. We have received good and reliable information from both Sydney Children's Hospital and the Muscular Dystrophy Association, so please do not limit their resources that enable this in the future. It is valuable.

Emotional Issues

It is hard to describe the overwhelming feeling of grief, loss and depression that comes with this diagnosis. I can tell within minutes of talking to someone whether they understand grief and loss. Many are just too scared to talk about it. It is not like a sudden death, which awful as is, is finite. Eventually, you can close the chapter and move on. It's not like old age, when you can rationalise it to some extent. It's not like a condition that offers some hope for cure or remission, however small. A condition like this brings loss after loss, after loss, not just for Jamie, but for those of us around him. Jamie will lose his physical abilities, to enjoy what he sees his peers doing, his expectation of a "normal" childhood and eventually, his life. His brother will also lose his right to a normal childhood – we will not be able to do some of the things that we would have liked to, particularly more of the outdoor, sporting and adventure activities that form such an integral part of the Australian psyche. He will lose the company of a sibling in life once we have moved on. And we lose the opportunity to see our little boy grow up and the opportunity to offer him the life that we envisaged for him, not to mention the many "life choice" and financial sacrifices that will have to be made along the way.

I am not ashamed to say that I am scared – about my ability to manage this, to stay strong for those around me, to come out the other end – and somehow to manage to smile on the way through. I can and do function as best as I can – and really try to stay positive and energetic for the kids, but the grief is always there. There's not an hour that goes by that I don't think about it. And this is emotionally and physically exhausting.

We have been offered the opportunity to talk to social workers. There are social workers available to us through Therapy ACT, through the Sydney Children's Hospital, my son's school, at work, through Carer's Australia and there are social workers amongst my family and friends. But there is nothing that can be said that will take the pain away and nothing that I can say to them that I can't say to friends. I understand the importance of not burdening friends too much with personal grief, however, I also know that they understand me, my son and my family better than any stranger can. And often, all I need is someone to say, yes, it sucks, let's go watch a movie or a well timed call to say, you need a G&T ! Having said that, we may find that we want to talk later and certainly understand that the path of grief is very different for everyone.

Suggestion: It is comforting to know that there are social workers available to us should we wish to discuss our concerns or seek their assistance in obtaining services. We would suggest that this level of support be maintained. New carers who are more socially isolated than us will need them.

At present, we rely on grandparents and paid babysitters for "time out". For busy working parents with the stress that this sort of diagnosis brings, this is essential. I can't imagine having to go through this without my husband's support – and it's so important that we do take time to be with each other. Without, we cannot support our family emotionally. However, respite care appears to be limited. Jamie's condition, chronic and terminal as it is, does not yet qualify us for any respite care service. I was told that he has to deteriorate further – not easy news to take.

Suggestion: Respite care is essential to patients and their families in providing time out to recharge emotionally, draw breath and regain perspective. This is particularly important for families like ourselves where our older son also needs one on one time with his parents and after Jamie has gone, we need to be able to continue functioning. Please consider extending resourcing for valuable services, such as FABRIC. For the patient (and our sake), it is also important that these services be able to offer respite carers that can form a longer term relationship with the patient. For a child like Jamie, building relationships will be important to his happiness.

I know that many people turn to religion after a diagnosis such as ours. And certainly, there may be a role for religion in offering meaning and supportive community for some. However, it's not for everyone. I am a firm believer in evolutionary science – that we come from the earth and return to the earth and that "god" is simply the moral conscience that every human has, but chooses to listen and be guided by it to different extents. The beach is my church. The reason that this is worth mentioning is that (a) whilst religion may be a source of comfort and community to some, is not to others; (b) it can be annoying when people try to comfort you by offering prayers and telling you that god must have a greater plan. How could an apparently all hearing benevolent being (with a communication system that any country would want to implement) do this to an innocent child ? In my view, there is no great plan, it is simply an unfortunate quirk of nature – and the sooner people realise this, perhaps we can get on with focussing on research to address the condition. There is so much beyond our understanding, we should not allow religion to be an excuse for failing to explore that which can help us without breaching decent moral values.

Suggestion: Religion is a source of comfort for some and annoyance for others. At a political level, it can also be used as a reason to pursue or not pursue a particular line of research. Such decisions should be based on the broader moral conscience and not influenced by a vocal minority. It would be a tragedy if stem cell research that could hold the key to a cure for conditions such as DMD were hampered. Certainly, have a full and informed debate, but please be mindful that for kids like Jamie, these decisions will likely determine whether they will be the last generation to die or the first to live.

Medical Support

The level of medical support that we have received so far for Jamie has been excellent. The Sydney Children's Hospital neuromuscular team visit Canberra each six months to assess their patients as part a full clinic, which saves us the additional time, cost and stress of travelling to Sydney. They have also made themselves available to us for other questions and needs between visits. Over the

Suggestion: Kids should not be sheltered from death and illness. This more recent trend towards "cotton wool-ing" kids is unhealthy and leaves them unable to adequately deal with – or be empathetic to - tragic events when they occur. It can also make them more blasé about the value of health and life, both for themselves and the broader community. It should not be taken for granted. In the "old days" and more traditional cultures, death and illness were part of life, talked about more openly and kids were permitted to participate. I would like to see schools and the broader community address death and illness in a more open, braver way and allow children to be involved in a manner that is age appropriate.

Therapy ACT has provided me with excellent support in terms of physiotherapy services, occupational therapy advice and more informal links to other people and services. Whilst Jamie's condition will deteriorate, at least I know that I am doing everything that can be done to maintain his current level of skills and can "bounce" ideas with people who have a wealth of experience.

Suggestion: Maintain the current level of funding support for Therapy ACT and similar government services. It is very valuable to both patients and their carers. The wealth of experience of the more mature employees is fabulous. Ensure that these people are not lost through poor or uncompetitive employment conditions. That would be a tragedy.

I have deliberately chosen to return to work on a part time basis as a means of not losing myself in sadness and maintaining some confidence and sense of self. Like most mothers, there is an element of guilt with not spending every spare moment with my dying child. However, I have found that I am much better able to cope with the situation by working and am happier in the time that I have with my kids. I realise that this is not for everyone, but it works for me.

Suggestion: I am very fortunate to have an employer that has given me the hours that I want, flexible leave arrangements and even access to a social worker should I want it. More employers should be encouraged to do so – and those that do, should be recognised accordingly. My experience is the part time mums work very hard and achieve good results because they have to manage their time (and guilt) very effectively !

One of the things that I've had to give up is going to the gym and any real form of exercise. I simply don't have the time. This is important both emotionally and physically. First, carers need time out and exercising is a productive and positive means of using this time. You return more refreshed and able to deal positively with what life has thrown at you. Secondly, with Jamie's condition and needs, I need to be physically strong and have the energy to manage his needs. If my back goes out (again), I simply can't care for him and we don't have any fall back arrangement available to us at present.

Suggestion: Time is the key issue, which can only be addressed through respite care. However, cost is also an issue for many, so the government might consider how carers can access gym facilities more easily eg. Carer's Australia member discount at nominated gyms, tax rebate on fees and/or limited sporting equipment for registered carers. This used to be provided by private health insurers, but seems to have been removed in recent years.

Services (for Jamie)

When Jamie was found to have a developmental delay before the final diagnosis, he was quickly lined up for enrolment in the ACT Department of Education Early Intervention Program managed by Malkara Early Childhood Centre (MECC). This has been wonderful. Jamie participates in preschool with a high carer/student ratio and has an individual learning program (ILP) tailored to his specific needs. He cannot wait to get out of the door on these two mornings per week and always seems more relaxed when he returns. This program is benefiting Jamie (emotionally and behaviourally) as well as us, knowing that he is receiving excellent care that is helping with his behaviour, which we have found difficult to cope with in the situation.

Suggestion: The continuation of this program should be assured and if it is not offered in all states, this is a successful model upon which to base new programs.

Jamie also attends an ABC learning centre for three days a week, where the support has been patchy depending on the skills of individual carers. One older carer with special needs experience was excellent and formed a wonderful bond with Jamie, as well as being a support for us in the lead up to the diagnosis. Many of the others are very young and don't appear to have the emotional maturity to connect with the children and parents in the same way.

ABC (with our encouragement) have sought and received approval for appointment of a dedicated teacher's aide for a certain number of hours per week, but despite advertising for two months or so, have not been able to appoint anyone to date. This is disappointing. We need to know that Jamie is receiving good care whilst I work, particularly when he is at such a young and impressionable age.

Suggestion: There appears to be a serious lack of qualified childcare workers, particularly older carers who have skills and expertise that can only be gained with experience and maturity. Measures should be considered to encourage more people into childcare positions, ensure that they are paid at a level that provides them with a career path (not just a part time uni job or "turnstile" position) and encourage retired workers back to the childcare workforce, even on a part time basis.

Jamie has started riding horses at Pegasus Riding School this term, an activity primarily aimed at improving his core muscle strength and balance. It also gives him a special activity that is "his own". This has been excellent. He is sitting straighter already, a sign of confidence, but also good for his posture given that scoliosis can be an issue for many kids with DMD. Many wonderful volunteer assistants are involved and the program receives widespread recognition throughout the Canberra community. However, funding is inevitably an issue.

Suggestion: Pegasus is a wonderful and positive program for people with disabilities. It should continue to be supported in every way possible and may also provide a model for similar programs elsewhere.

We have recently become active in the local Scouts group. Whilst only our older son is old enough to participate at this stage, we are keen for Jamie to become involved when he's eligible. Scouts is an years, we have paid very high taxes and it is wonderful to see that they're being used well in this instance.

Suggestion: Please don't change resourcing priorities to reduce the current level of service. It is highly valued by us.

The level of medical support available locally is not as impressive. Kids with DMD will have more falls as a result of their condition and colds and flus can be life threatening given their reduced heart and lung strength. We need to be able to access GPs quickly before any seemingly minor complaint deteriorates. We have a nice GP here, but typically have to wait several days for an appointment.

Suggestion: There is a desperate need for readily accessible GP's in Canberra. For some, this is a matter of great frustration – for us, it is closer to a matter of life and death.

I hear a lot about research for cancer and there's not a day that goes by without seeing an advertisement or fundraising pin, pen etc etc for diabetes, MS etc. I am wondering where muscular dystrophy features in all this ? Many people have no idea what it is or what it means. We were sufficiently naive as to ask the diagnosing paediatrician what kind of life Jamie could expect when he's an adult, only to be told that he's unlikely to make it that far. One parent suggested that I use homeopathic remedies !

Suggestion: We need to consider how best to raise the profile of muscular dystrophy in the broader community in the interests of encouraging greater funding. This is a role that can in part be played by the relevant association and I will get involved. However, there is perhaps a role for government to consider whether DMD is deserving of more focussed research assistance. If DMD is not in the public conscience, it is hard to ensure that receives the attention that it deserves. I don't want my son's death and our pain to be in vain. If we can help prevent this from happening to another family, we will.

I will not address medical costs separately here. To date, we are adequately covered by Medicare, private health cover and Jamie's health card. I have no doubt that our expenses will mount as Jamie's condition deteriorates, but can't anticipate his needs at this time.

The final issue that I wanted to raise here is controversial - voluntary euthanasia. Our objective for Jamie is for him to have as happy a life as any child can. When we get to the point of no return, I don't want him to suffer needlessly. If you failed to put a pet out of its misery, it would be considered negligence and cruel. But you are required to treat a child that you love in this way. Why can we treat our pets better than our children ? This condition has forced us to accept that a short happy life is better than a longer life of suffering. I am not so selfish as to want Jamie to suffer when his time is up, but the law requires me to allow it.

Suggestion: This debate has not been settled. I am sick of hearing objections from vocal (sometimes religious) wowsers. Ensure that you reach out to those who live with this every day and often too busy or scared to make their opinion known.

Suggestion: The various muscular dystrophy associations around Australia might consider combining nationally with state based branches to better utilise the limited resources and provide better services to their members, who have a common cause and needs, wherever they are. As someone who worked in an association for many years, I am willing to get involved to the extent that my existing commitments allow. However, the government might consider providing some tied support to facilitate any agreed transition to a national association.

We have also joined our local Carers Australia branch and have been impressed with the services that they offer locally, but particularly the advocacy role that they play. As a member, I know that they are effectively reaching out to members and seeking their views, a difficult role given the limited time that carers have to dedicate to helping themselves and their carees.

Suggestion: Carers Australia are playing a valued role on behalf of their members. Please engage with them fully and give their suggestions due consideration. These suggestions come from those "at the coalface".

We have also investigated participation in Siblings Australia for the benefit of our son. They appear to offer some good resources, information sessions and networking opportunities for both parents and siblings. My son does not feel that he needs this involvement at this stage, so we will reconsider if and when he does. Nevertheless, good to know that it's there.

Financial Issues

Recurrent Costs

So far, the financial impact of Jamie's condition is reasonably limited. He is still in nappies ($30 per week), we do spend more time at home (additional cost of electricitiy, heating etc) and we've bought some new recreational items that would otherwise have been handed down from his brother, such as a bike attachment ($200 or so), a safe swing ($60) and an enclosed trampoline to encourage supported jumping and balance ($1000 or so).

Specialised Equipment

The real costs are still to come. There are costs directly associated with Jamie's condition - we will need equipment (manual and eventually, power wheelchair), adapted bed and hoists etc. We will need to buy a car that can accommodate a wheelchair. And we need to adapt the house (or move) to enable wheelchair access and an appropriately fitted out bedroom and bathroom.

Medical Costs - Jamie

See above.

Medical Costs - Other

We have already incurred medical costs that would not have arisen had it not been for Jamie's condition. Most are fairly minor, such as a script for sleeping medication and a general health check inclusive organisation that offers many activities that Jamie will be able to participate in, and the groups are sufficiently flexible and small so as to be able to accommodate his needs as they escalate. We know of kids with DMD who were very involved previously and they are widely reputed to have "lived a full and fun" life, in large part, owing to their involvement in Scouts.

Suggestion: As a committee member, I know that local Scout groups run "on the smell of an oily rag", but offer their members a wonderful range of experiences, many of which benefit the members as well as the local community. Consideration might be given to supporting those groups that have special needs members, to assist them accommodate any additional requirements arising from those needs. Eg. we know of one instance where members built a sedan chair for a bush walk and took turns to carry their fellow member !

Whilst we have generally been pleased with the level and range of services available to us as carers, we are very frustrated by the residential prerequisites for some of them. We will need to either renovate extensively or move house to accommodate Jamie's future need for wheelchair access. A few months back, we found a house in Jerrabomberra (over the border in NSW) that met our requirements perfectly – it was large, single level and affordable. However, before making an offer, I called around and was told that we would not be eligible for many of the Canberra based services that we currently receive for Jamie. We have lived in Canberra for many years now, we work (and pay significant taxes) in Canberra, our son goes to a Canberra school, we pay for Canberra based medical services and we buy from Canberra businesses. Yet a move across the border to a house that would be more suitable for Jamie and not place undue financial stress on us, was ruled out on the basis of a border. This was extremely disappointing to us, when we are simply trying to accommodate the changed needs of our family.

Suggestion: Serious consideration needs to be given to cross border eligibility for services and, I assume, the cross border funding arrangements that flow from them.

The Role of Associations

As a new carer faced with a horrific diagnosis, I felt alone, grief stricken and somewhat at a loss to know how to proceed. This is where associations can play a significant role in providing information, networking opportunities with people in similar positions and providing a channel for positive efforts such as fundraising for medical research.

I was given the details of Muscular Dystrophy Australia (NSW) and ACT at the clinic and followed up with them quickly. MDA (NSW) provided some useful information, distributes a newsletter and runs some events, mostly in Sydney. MDA (ACT) has been a wasted call and I gather that it may soon be defunct. This means that those of us in Canberra (DMD occurs in 1:3200 population so a simple calculation would suggest that there are at least 100 people with DMD - and their families), are reliant on a limited Sydney based association (or an active, but distant Victorian association). As noted above, it is extremely frustrating for me as a carer to see red noses, pins, pens, car raffles and charity balls etc for every cause under the sun, with the notable absence of DMD.

Comment: I am very fortunate to have an employer who offers me part time work, family friendly and flexible conditions and interesting work. This has helped me cope with Jamie's diagnosis. Carers can and should be encouraged to work where they want to. Employers should be encouraged to offer flexible arrangements wherever possible, including part time, working from home and 48/52 leave arrangements.

Government Support

We have been grateful for the government assistance that we receive by means of carer's allowance and other minor schemes such as the interstate transport and accommodation scheme (for medical visits to Sydney). However, they do little to offset the very considerable costs long term that we are facing, as outlined above. Please consider whether additional assistance might be given through tax measures.

The special needs parking pass has also been useful. However, we have found that some people without passes park in designated areas, so suggest that inspectors/rangers pay particular attention to these.

Concluding Comments

Thank you for considering the suggestions made in the various submissions to the Committee, including my own. My view is that of a new carer to a child – I am sure that my needs and perspectives are different from others to some extent, but perhaps there is also much in common with others, including the many that do not have the time or strength to express their views.

Please note that I have provided a copy of this submission to several of the organisations referenced above for their reference.

I am happy to provide further information to the Committee as the hearings progress, in writing or in person and look forward to hearing the outcomes of your deliberations.

END.

for myself, particularly following some heart pain shortly after receiving the diagnosis. Others will likely be recurrent costs. I have put my back out several times whilst assisting Jamie, resulting in regular trips to the chiropractor and remedial massage. Whilst both are partially covered by health insurance, I am out of pocket by $50 – 60 per 6 weeks.

House Modifications

Given that we currently live on a steep block in a two storey house, we also need to consider putting in a lift (the stairs are too narrow) and an inclinator for the driveway. Doorways need to be widened, the bathroom modified and rails added in various places. We are considering the merits of putting in a pool, given that this would give Jamie much needed supported therapy later, whilst minimising travel and maximising family involvement. We understand that the cost of an elevator can be in the order of $60 000 - $100 000. A pool may well be in the order of $ 50 000 given the topography of our block. These are considerable costs and ones that are not likely to be fully recouped on later sale of the property. We love our current place and have recently renovated here, but realistically, it may not be practical to stay.

Our other alternative is to move house. Inevitably, we will need a larger house to accommodate a wheelchair and it needs to be single level (see also comments above). A larger house in the same area will cost more. It will cost to move (stamp duty, agents fees and removalists etc). And in the current climate, our existing mortgage and interest will escalate considerably. I am concerned about adding more (financial) stress to an already stressful situation. But Jamie is already having trouble getting up the stairs here and falls regularly, so we have to decide quickly.

Suggestion: The government may already have some schemes to assist with necessary house modifications. I am sure this is valued by those that can adapt their current home. However, we would appreciate tax relief (stamp duty, mortgage) on the costs of moving to a more suitable house, given that that may be our only real alternative.

Employment

One of the most significant costs to us is loss of income and career path. Until last year, I worked full time and earned a 6 figure salary. Clearly, it wasn't viable to continue in our new situation. I have accepted a more flexible part role and now earn less than half of what I was on previously. Moreover, my career prospects will be curtailed as a result. As someone who enjoys and takes pride in working, this has forced a difficult change of identity and is yet another loss. The current part time arrangement gives me valuable "respite" time away from my family/carer role, allows me to continue in the workforce and brings in some useful income.

My husband's career options are also now more limited. Last year, we were looking at moving interstate or overseas for an exciting executive position. Now, our needs have changed and there is some merit in him continuing in a local role where he does not have to prove himself anew and has accrued leave benefits etc. This is, in part, a positive recognition of the support that we receive in Canberra, but emotionally and financially, it represents yet another loss.