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Committee Secretary
Inquiry into Better Support For Carers
House of Representatives Standing Committee on Family, Community, Housing and Youth
PO Box 6021
Parliament House
CANBERRA ACT 2600

Dear Secretary,

I wish to make a submission to the House Of Representatives standing committee on Family, Community, Housing & Youth's Inquiry into Better Support for Carers.

Can I start by saying that I welcome and appreciate the opportunity for my voice to be heard. I also think it is important to note that the fact you are hearing from me is an achievement in itself. Whilst I am a capable letterwriter, I simply do not have ANY spare time and I suspect my situation would be echoed by thousands of other carers.

Just because you do not hear from all of them does not mean they don't exist, don't care or are not suffering, it probably just means they had higher priorities!

We do appreciate that you want to take the time to read and understand our concerns and issues.

Our Story

I married my wife, Julia in 1988 after getting engaged 3 weeks after we met in 1986. We built our first home in the leadup to our wedding and moved in together after the wedding. We delayed our honeymoon because of the financial commitments of the house and the wedding. To our great delight our first child, Jessica, was born in March 1992. Just before Jessica's first birthday Julia was diagnosed with MS. At that time the effects were relatively minor and whilst it was a bombshell, we really had no appreciation of what was to come. Our second child, a son Dale, was born in early 1994 and it quickly became apparent that our original home would be too small for the 4 of us. We set about building our second and current home with little special consideration other than not making it 2 storey. We were naive and had no concept of how much our lives would change in the few short years after. Julia was unable to continue work past 1997 due to her worsening health. She stabilised for some periods of time but rode a roller-coaster between attacks where she would suffer from serious fatigue and other mobility issues because of the MS.

By 2002, she had begun an irreversible transition into secondary, progressive MS. The roller-coaster had stopped and it was now a steady, slow decline.

I have been employed by the same company in the IT industry for the past 25 years and have held several positions of responsibility managing up to a dozen people and being in charge of large budgets. By early-2004, the situation at home had become very difficult and I was on the verge of a complete breakdown. I was working hard during normal hours, coming home and performing many domestic tasks and then burning the midnight oil on work tasks until early hours. Whilst I was in the office, there were a number of occasions when Julia had nasty falls and personal safety issues at home.

It got to the stage where I was so distressed about leaving her on her own that I sent an open email to my management team explaining the situation and I had personal discussions with several of them about cutting back to part time and working from home.

We were not in a financial position to do this but I felt I had no choice. My Employer was very understanding and accommodating and in mid-2004, I switched to part-time working from home. Although it is difficult, I maintain that business relationship to this day.

The necessary change in the work-dynamic has not been a particularly positive one for me. I am quite a gregarious, talkative and humorous person by nature but I now feel very disconnected. Many friends have fallen by the wayside.

I can't say whether it is directly-related to the MS but we don't experience the normal social lifestyle that most in our community do. We aren't heavily involved in any sporting clubs and the normal social circles that develop from that and our lives are very much insular. Social contacts are rare and limited to some close friends and occasional family. Money is always an issue. Despite several support payments (DSP & Carer Payment), a single part-time wage supporting a family of 4 means sacrifice and discipline. I am sure my kids think I am the "tightest of tightarses" but this is only because I have to focus on the basics – paying the mortgage, paying the bills and putting food on the table. There is little time or money left for leisure or pleasure.

As Julia's disease enters an escalated phase, we now face more severe mobility issues, personal relationship issues, 2 normal teenage children (not their fault!), a static part-time income and spiralling costs of food, utilities, transport & education.

On top of this, the house that we thought was reasonably well-equipped to suit Julia's (at that time "future") needs, requires extensive modifications and we are battling beauracracy to get assistance with that project (yes, I understand it's a state funding issue!). The works required are in the vicinity of \$15,000 and the funding available under VAEP is only \$4000. Just another thing to stress about!

I have some health issues of my own (which I choose mostly to ignore because I can't afford to address them – either financially or because of the impact to work and family).

I do not sleep well because I worry about everything. I am not a worrier by nature but I genuinely despair that we will run out of money and be unable to cope either financially or emotionally with day-to-day life or that the favourable employment situation I currently enjoy might change unexpectedly.

My Role as a Carer:

I feel that my role as a carer is a Dual-role. As the primary breadwinner, I was always responsible for making ends meet and ensuring that there was always food on the table and that the mortgage and bills were paid. In addition, I now need to ensure that my wife is safe and secure, that her personal, mobility and medical needs are met, that her personal safety is assured and that she is fed, clothed and housed.

On top of this, I also fulfil many of the organisational, parental and homemaker tasks that Julia would traditionally have performed as a "non-working" housewife (not intended to be a derogatory term). I wash dishes, clothes, taxi kids, clean the house, take the garbage out, do the grocery shopping, pay the bills, do the banking, trips to the chemist/specialists/doctors, attend parent meetings at schools, take kids to sport, etc.)

My attempts to maintain a part-time work strategy are increasingly difficult. Whilst my employer has been very flexible in allowing me to work from home, I still have a regular need to attend the office for meetings (typically 1 day per week/fortnight). The need is irregular and dependant upon others schedules and is therefore not something I can plan ahead for. There is no access to short-notice, in-home (or otherwise), respite care for Julia so I have no choice other than to leave her on her own and hope to god nothing happens while I'm at work. A situation which creates additional stress as I'm sure you'd understand.

At the end of the day, there is very little time left for me.

What could the government help with?

There are so many issues to deal with as a carer it is difficult to know where to start. Many cannot really be impacted by Government but there are 3 big issues where I believe the government could assist –

1. **Transportation** - We really have no option other than our own vehicle. Where we live the public transport options are extremely limited and difficult to access. Taxi costs (even with a TaxiCard) are highly-prohibitive and the heavy reliance we have on our car has many flowthrough impacts. Sharp rises in fuel costs & vehicle maintenance take a heavy toll. The government could assist with additional registration/TAC rebates (or even bonuses!) for carers and they could offer tax rebates on fuel. How hard would it be for the fuel chains to swipe your PCC card (or some other purpose-issued card) to deduct a portion of the govt tax take for my fuel purchase? We are about to get an electric wheelchair for Julia and this changing need will probably mean we will need to replace our perfectly good car. Maybe an waiving of stamp duty in this scenario would be appropriate (Yes, I know it's a state responsibility).
2. **Time** - As a carer your time is critical. Tight budgets mean rushing from shop to shop to pick up the week's bargains in bulk and picking up every "reduced" or "not quite right" special that you can. When you couple these time-sponges with endless hospital and doctors trips, home-maintenance, caring responsibilities and normal parental duties, there just aren't enough hours in the day. Any assistance with gardening, house-cleaning, handymen/tradesmen and the like would be a huge benefit. Subsidised or free Metlink cards for the kids would be a huge help in reducing their dependence/reliance on me and free up time.
3. **Beauracracy** - The Centrelink file in my filing cabinet is the biggest file in the cabinet. Our situation has not fundamentally changed in the last 5 years and I do not expect it will change significantly in the next 5. I have one income stream and it has not essentially changed in 5 years - It is very simple. Yet not a week goes by that Julia or myself do not receive some sort of correspondence from Centrelink. It gets to saturation point where half the time I don't even read them because it looks like exactly the same letter I got last week. Firstly, there should be a recognition that as the carer, I am the one who actually deals with ALL the correspondence for both of us and consolidate it accordingly. Secondly, a single point of reference (case manager?) within Centrelink for all contact (be it FTB, DSP, Carer, etc) so that the PERSON is managed rather than the PAYMENT. As a long-term disability support client of Centrelink, it doesn't make sense that we are treated the same as a transient, teenage job-seeker.

Thank you for taking the time to read my submission and for taking my views into consideration. I am proudly and passionately Australian and I am convinced we live in the greatest country on this planet. I appreciate the fact that you want to improve the situation for carers in Australia and I welcome any questions or further clarification you might seek.

Yours Sincerely

Craig