Submission No 39

THE PROGRAM OF APPLIANCES FOR DISABLED PEOPLE (PADP)

Name:

Supressed

Date received:

3/09/2008



To:
The Hon Robyn Parker MLC.
Chair of the Legislative Council's General Purpose Standing Committee No. 2 (PADP)

Dear Madam,

My wife, Diana suffers from Multiple Sclerosis (MS). She was diagnosed as having the disease over twenty five years ago. My wife's condition has steadily deteriorated over the last ten years – from a walking (unsteadily at times) hard working mother to the current day where she is considered a quadriplegic – having some voluntary movement in her left arm only. I am her husband and full time personal carer. My life has changed markedly over this period. The company that has employed me for the last twenty three years has been generous to allow me to continue working from home. Of course, my salary was reduced drastically (over 60%). This has left us with many financial challenges including the housing mortgage and bringing up two daughters, now in their early twenties.

The previous paragraph is a brief summary of my family's involvement with MS. When this opportunity to write to the inquiry/committee about "The Program of Appliances for Disabled People" (PADP) arose, I felt compelled to relate our involvement with PADP – both the frustrations and great benefits.

Before I became my wife's full time carer, my income allowed us to purchase such essential products as wheelchairs and even a motorized scooter. When I began working from home, any major purchase of equipment or aids became financially impossible. This is where schemes such as PADP worked wonderfully. Over the last five to ten years, PADP has purchased disability aids such as commode chair, bathing chair and even an electric hoist. I don't know if you would understand the joy my wife expressed when simple tasks such as bathing and toileting became so much easier using this equipment. Whenever the occupational therapist deemed a piece of equipment necessary, it was delivered within a week to our home.

When my wife's condition deteriorated even further, a motorized wheelchair (which she still uses today) was deemed necessary. The freedom and flexibility the new wheelchair gave her was astonishing. The cost of this chair (over \$20,000) would never have been achieved without the help of this scheme. There was a considerable delay in its delivery (over 4 months) but this was expected as the wheelchair had to be customized to my wife's specific needs by the manufacturing company in USA.

This is where frustration enters this story – simple repairs which I cannot perform can take weeks to be approved and rendered. The current process is to telephone the PADP department and gain approval for the repair. Then telephone and book the appropriate company to perform the repair. Please note that there have been occasions where this process has all been done on the same day. At the moment my wife is suffering back pains and strains due to her seating (being seated in her chair over twelve hours a day). To overcome this situation as best we can, a stocking full of foam rubber is stuffed into the back of the wheelchair seat to give my wife the extra support needed. The solution is to purchase a new cushion for her wheelchair. Unfortunately, PADP is currently under-funded and the waiting list is accordingly long. I must stress this cushion is a gel based moulded seat which costs over \$4,000. This is an item which I can no longer afford. The PADP system appears to be currently under stress. I don't know whether extra funding would alleviate the situation or just delay its collapse.

I understand my wife is a severe case and her needs are greater than most MS sufferers, but there must be a better and more timely way to aid people in such situations.

Could a grant (similar to the once a year \$1,000 pension scheme) or a tax scheme to allow the total return of such expenses, be made available for disabled people to use to purchase essential equipment and aids? Based on one's level of disability, the grant/tax return could be scaled and allowed to be accumulated over years so that large purchases such as motorized wheelchairs could be achieved on an individual basis.

I await with great anticipation the inquiry's conclusions. My wife's situation must improve!

If this letter is used in publication or made public, could you please ensure that my private details are kept confidential.

Also if there are any details or clarification necessary, please do not hesitate to contact me. I would be available to attend the inquiry and relate my experiences personally if needed.

Yours sincerely,