

I am a 36 year old female and I am writing this submission based wholly on my own personal experience of living with a disability that has been caused by a chronic lung disease and antibody deficiency. I have approximately 20% lung function left and require home and portable oxygen.

I had to resign from my full-time employment in July 2007. Before this time, I was lucky enough to have never had to deal with any disability services. As my condition has worsened, I have become reliant on various community and government services.

### **Problem 1 — Centrelink**

I currently think that the biggest barrier to those of us with a disability is dealing with the rules and regulations of Centrelink. I try to work on a casual basis when I'm well enough, and I've also created my own home based business to earn income. Under Centrelink's rules, I am not allowed to work more than 15 hours per week or I am no longer classified as disabled and my disability pension will be cut off.

Whether I'm well enough to work 15 or 20 hours in a particular week and then zero hours the next week doesn't change the fact that I can't breathe. It only changes the amount of income that I can earn. I should be allowed to try to earn as much as I can, while I still can, so that I can then report it to Centrelink and they can reduce my payments accordingly. I'm trying not to rely on handouts from taxpayers money, but what choice do I have?

### **Problem 2 — Disabled Parking / Cost of relying on having a car**

Public transport is not accessible for all of those persons with a disability, so a car can become a lifeline to remaining independent.

In simplified terms, there are currently two types of Disabled Parking Permits available:

Category One — For those with a physical impairment, where an extra wide space is necessary to allow for physical aids. These permits allow the holder to park in a disabled bay for the allotted time, or to park for double the amount of time in a normal parking bay.

Category Two — These permits **do not** allow the permit holder to park in a disabled bay. They only allow parking for double the amount of time in a normal parking bay.

### **Problems with the current scheme:**

- Parking in a metered parking bay — Parking meters only allow for the normal allotted time to be paid for, and therefore the extra time that should be available via the permit scheme is unavailable.
- The current scheme does not take into account those persons with disabilities that do not require an extra wide space, but do require a space that may be close to the entrance of a shop / government building / park / art gallery etc.
- The amount of Disabled Parking spaces available seems inversely proportional to the number of permits issued. Permit holders find it very difficult to find a vacant disabled parking bay to park in.
- Disabled Parking permits are issued via local Councils instead of a centralized organization.

Running a car is extremely expensive — the purchase price, maintenance and servicing, registration, insurance, petrol. A disability pension does not take into account whether someone can use public transport or whether they must have a car.

### **Problem 3 — Home Care Services (Cleaning)**

Home care services are stretched to the limit. The service only provides the absolute basics — vacuum carpet, mop tiles, clean bathroom, change bed linen.

There are so many other areas of people homes that do not get cleaned — kitchens, ovens, windows, skirting boards, walls, etc. A person with a disability should not be expected to live in a dirty home just because they are unable to do their own cleaning.

Also, if a scheduled cleaning day happens to be on a public holiday, then it automatically gets cancelled, but not re-scheduled, meaning that I have four weeks in-between cleaning, where my shower and toilet do not get cleaned, and my bed linen does not get changed.

Considering my medical condition, I should not have to live in an unhygienic home.

#### **Problem 4 — The cost of having a Chronic Medical Condition**

Persons with a chronic medical condition which has caused a disability tend to be forgotten and not catered for in any sort of disability categories.

There are many large costs such as medical equipment (oxygen concentrators, nebulisers, wheelchairs), prescription medicines, non-prescription medicines (which do not attract a concession), disposable oxygen and nebuliser equipment, petrol to travel to hospital and medical appointments, parking fees at hospital appointments (some hospitals don't even offer concession parking rates), out of pocket doctor expenses not covered by medicare, extra electricity costs to power medical equipment.

There's also just the extra utilities cost of being at home all day rather than at work.

#### **Problem 5 — Education / Aids & Equipment**

There is a severe shortage of education programs for young adults with disabilities. With a combination of education, and aids & equipment, a more independant lifestyle can be maintained.

#### **Problem 6 — Becoming a burden / Mental Health**

I wake up every day knowing that in my current medical state, I am a burden to my family (particularly my sister), and I'm now also a burden to the welfare system. I'm university educated and this is not what I'd planned for my life.

One of the biggest failures of our current medical system, is the complete lack of resources to deal with mental health issues that can arise from chronic medical conditions. I've been dealing with this condition since the age of 15 (more than 21 years), and I've never been given any counselling to help cope with my disability.

#### **Conclusion**

Under the new scheme, I'd like to see more support for young and middle aged adults with chronic medical conditions. Particularly, more support to remain at home independently for as long as possible. More support to remain productive members of society. More support to find and keep employment (without the fear of losing Centrelink entitlements).

More access to community services such as home hygiene, gardening, and maintenance.