

**I am an individual providing unpaid support for my disabled son. He has ongoing needs and as his carer, I think it is high time some of my needs as well those of my family are met.**

We know that we fulfil a vital role as carers but we are running out of steam. All over Australia a network of carers are sharing information. We are able to do this with the assistance of the Internet. Carers are fully aware that things have been getting progressively worse and they will no longer accept this fact. They are socially isolated, have chronic health conditions, suffer depression and many are also struggling financially. They have little or no respite and no real hope of obtaining permanent care for their disabled children. They also fear that the siblings of their disabled child will be forced into relinquishing their lives to take on this role, the role which has devastated and destroyed their parent's lives. No, we won't let that happen, not at all.

**What can be done to assist the carers?**

We need more respite and we need it now.

We also need to know that there will be suitable supported accommodation in our area for our disabled children before we die. We would like to help them to settle whilst we are still able. We do not want them to lose both their home and their parents at once; this would be cruel and can be avoided by doing something now. We are ready for the transition out of caring. We are ready to effectively plan for what little future we have left, and we are ready to do this now.

I am a carer, like so many other carers, caring has become my life's work; in fact it is my life. I do not have a life as such. I have no choice but to forego actually 'living' Devotion is one thing, but surely we are entitled to some 'life' are we not?

**My son is now turning 30.**

He is intellectually disabled, he has epilepsy, behaviour problems and some autistic behaviours. He takes a powerful cocktail of 3 different anticonvulsants, as well as antipsychotics and antidepressants.

This week, he is relatively happy and therefore, so are we.

Up until the time when my son had his first seizures, at 18 months of age, I was lucky enough to be a 'normal' mum.

But many lives changed the day his disabilities began. 28 years ago...

My husband now has chronic back, knee and hip problems; He has had a dangerous heart condition. He also suffers from depression and some

anxiety. He works part time for two reasons: To care for our son at home and also to earn money for our future. Unfortunately, my husband's ill health will not let him work more than part time now. Caring for a person with disabilities has taken its toll.

I also have chronic abdominal and back problems, depression, migraines and recurring anxiety. I too work part time both to care for our son and also because of my own ill health. But ultimately we both need to earn some money.

Our son's Paternal Grandmother has now passed away, she was able to assist us somewhat when she was alive. It took its toll on her too.

Our daughter is very successful in her chosen profession, but due to emotional issues in her upbringing, she now finds her marriage of less than five years has broken down. She too is suffering depression and anxiety attacks.

This family needs some time to heal, some time to live as a 'normal' family might do. To see our son safe and settled, now, in an environment with his peers in the local area, in an Intentional Community, a Cluster Development in this neighbourhood. This would enable this family to take the remaining years of our lives and live them. Just that, we could actually 'live' for a time.

Lynette