

Inquiry into better support for carers

Background to our personal Caring role

My husband and I are Carers for our 7 year old daughter who has a physical disability, being paralysed below armpit level. The paralysis renders her 'floppy' below armpit level. She uses a manual wheelchair (strapped in firmly at chest level and over her shoulders) and requires 6 tube-feeds and 6 catheterisations per day. She also requires many medications and one ½- to 1-hour bowel procedure per day. Our daughter requires assistance to get into and out of her wheelchair, to the floor, to her bed, standing frame, change-table, commode chair, bath/shower, into and out of the car etc. She also requires constant supervision as she is subject to life-threatening complications due to aspiration pneumonia, an inability to regulate her body temperature, and a condition called autonomic dysreflexia. Autonomic dysreflexia can be brought on by a simple ingrown toenail or an over-full bladder.

Our daughter attends a mainstream primary school and has community nursing visits each day whilst at school. She also has the support of a Special Teachers Assistant (STA). Both her teacher and STA's are aware of her life-threatening conditions and phone us if there is anything untoward occurring regarding Angela's health – so that when our daughter is at school we need to be nearby and 'on-call' (turning our mobile off is not an option).

As she is prone to constant urinary tract infections and chest infections (which can quickly lead to pneumonia) she misses a lot of school. For example in 2007 she missed over a term of school due to illnesses, including a month in hospital due to a severe pneumonia.

Areas for improvement in supporting Carers:

Our disabled daughter, together with our 2 other daughters (7 and 9), are beautiful children and are very loved and cherished. Raising a daughter with a disability has included times of fear and sadness as well as times of great joy and happiness. The danger for carers is that the negative feelings can begin to seep into our everyday lives. Caring is not just something we do, but something we are – but we don't want to be defined purely by this role as we are people with dreams beyond Caring. There are particular areas where we feel Carers could be much better supported, thereby making our caring role an easier and more fulfilling one. These include:

- An awareness in the general public that Carers have not chosen this occupation as their life's choice, they are thrust into it and as such make do in the best way they can. A lot of dreams and aspirations held by Carers are gone, unlike the rest of the general population. The Caring role many families undertake saves our Government a lot of money – if the Carers were not there, the Government would have to provide accommodation, health care, nursing support, medicine and

full-time support staff to look after the cared-for person. Of course families are most often willing to Care for their loved one, this is not the question. Carers just need to feel recognised for what they do, their lost dreams, and to be supported fully in their caring role and helped to again live at least part of their dream for their future.

- Greater financial assistance for Carers caring for people with high equipment needs including: home modifications, vehicle modifications, medical equipment (feeding pumps/catheters/nappies/feeding tubes/syringes etc), medication, feeding supplies etc. For example we have just completed some major renovations to make our home wheelchair accessible and increase accessibility, but this has left us financially vulnerable. We still need to find money to buy our daughter a larger wheelchair and to fund modifications to a vehicle so that our daughter can travel in her wheelchair. Modifications to a vehicle cost around \$25,000 and a new wheelchair will cost upwards of \$7,500. Private health cover and Medicare cover none of the equipment or home modifications our daughter needs, and we are made to feel like beggars asking for help from charities (which can only support a certain number of requests).
- Greater support for quality respite care and support workers. We try to have a few hours each Thursday evening where my husband and I have respite care. We leave the house while a support worker comes in to look after the children. Over the past several years we have had some fantastic support workers. We have trained these workers in the needs of our daughter and organised a nursing visit to complete a catheterisation and tube feed while we are out. Whilst this respite service is so very necessary we are often extremely frustrated at the lack of reliability of these workers due to; illness, studies, or moving on to permanent, better paid jobs. This frustration is amplified (for us and our children) when we have to meet and train new support workers on a regular basis. Support workers are paid a relatively low wage and often use this work as a 'second job' or a way of earning money while they are at Uni. Support workers are not seen as 'valuable' in our society today and yet for Carers their support worker can be their one lifeline to a regular break from Caring.
- Knowledge that the cared-for person will be looked after by our Government once they become young adults, for example helping to find suitable accommodation and care arrangements, jobs, training etc. In essence recognising that the cared for person is an adult and should be independent from their Carers. Too often Carers are left with no security that their loved one will be looked after.
- Greater assistance for carers who are couples to have 'time-out' together. My husband and I perhaps once a year give each other a few nights 'away', so that one person looks after our daughters while the other gets away for a short break. While this does help to refresh the person going away, the person who has been at home coping alone is often more stressed than before, and needs a break themselves. It is also not a great way to be strengthening the 'couples' relationship. So much time and energy is spent on the cared-for person that there is often little time spent in nurturing the couples relationship. If this

primary relationship breaks down, financial and emotional stress on the family is increased dramatically, thereby placing more stress on the Government in increased family support payments, health payments etc.

In summary, if the Government can spend the time to get things right for carers, they will be getting things right for the Government. The bottom line is that **if Australia looks after her Carers it will save Australia money.**