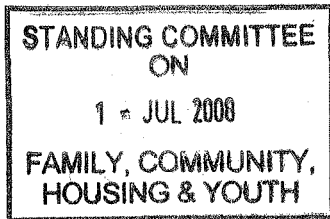


27 06 08



Submission No. 635

(Inq into better support for carers)

A.O.C. 8/7/08

To: Committee Secretary
Standing Committee on family, Community, Housing & Youth
House of Representatives
Parliament House

Dear Secretary,

I wish to make a submission to the Standing Committee re the Inquiry into better support for Carers.

I am the Carer for my daughter who will be 49 in August. As a result of having Meningitis as a 6-year-old, my daughter is intellectually disabled. Medication for the illness caused deafness, stunted her growth and, as we learnt about 5 years ago, also damaged her kidneys, eventually causing her to have a transplant in December 2004. She was fortunate that her father was able to donate a kidney, though 73 at the time. I had two patients for some months after that!

Our lives, and the lives of our two sons, both younger than our daughter, were dramatically changed by her childhood illness, the boys not receiving the attention that had previously been available for them, though this does not seem to have resulted in long term effect. One thing that has also become very obvious to my husband & myself is the strain her disability caused in our relationship as the years went by. Others of our age had freedom to be a couple as their children matured. That has not been so for us and, as our daughter's health deteriorated more as her kidneys failed, the demands upon me became even more. The care and medical needs since the transplant are far more than we ever imagined.

Not only are our daughter's needs quite high, but she is also competent enough to know that she has limitations. That, at times, makes her very frustrated, and quite demanding of me in her desire to do extra things which need guidance. This adds extra stress. The provision of respite care, which began some years ago, has proved valuable in giving my husband & I time together, though we often just stay at home to have that time together, and I endeavour to 'catch up with things', even sometimes managing to have visitors come for a meal.

The deterioration in our daughter's health has meant many, many trips to doctors, to hospitals, pathology etc, and our so-called retirement contains more demands than in previous years. (My husband is 77.) Because of the complications of her care since the transplant, our daughter's medical regime etc make it difficult for her to stay with relatives, even for a short time, such as a weekend. Her care includes diet, and insulin injections, for diabetes, triggered some months after the transplant by extreme illness due to a virus, then the onset of a massive bacterial infection which she contracted during her 7 weeks' hospitalisation.

Respite is great, and staff have learnt to manage our daughter's needs, which is vital, but it requires so much organisation that it's often stressful in days that are already full. We actually managed a few weeks' holiday away by ourselves last year, only our second holiday alone since we married almost 50 years ago. That planning etc proved extremely stressful, I found, and it took a while to recover so that I could enjoy our time together. A few weeks after that time away I must admit that I was ready for another 'break away'. I have since realised very clearly how necessary it is for us to have time to be ourselves as a couple.

Having naturally associated with the families of many of our daughter's friends, I see many in stress, particularly where a spouse has died, or has been unable to cope and has left the family. The problem is that those who suffer stress are more likely to develop health problems themselves, thereby also becoming in need of care. Some couples have simply committed so much of their lives to the care of a dependent 'child' that they have little life outside that care.

It makes sense to me to put in as much assistance as possible for carers, thereby enabling happier, healthier, families, and hopefully assisting relationships for those in the caring role. The cost must surely be worth the resultant health, etc costs where there is not enough support. To expect the wider family to contribute to care is often not feasible, particularly as the dependent person ages, and siblings marry and have their own young families to care for, or may have moved too far away to be available to assist.

We find ourselves often frustrated in having little time to assist others, yet at the same time are very aware of our daughter's vulnerability and need for care, affection and affirmation. It's complex! Participation in social life can be complex at times, too, though our daughter is much loved by many people, and some are able to communicate with her reasonably well, which is affirming for her.

We are fortunate that, after around 10 years of planning, a home may be available for our daughter and two friends within the next year. This is vital as we, and she, become older. Our desire is to see a home set up that will cater for all needs of each girl: health, happiness, fulfilment, security, etc. To have this established while we are able to oversee and ensure that all needs are met, is vital for each girl's well-being. Community support has been of great assistance in this.

As I look at the needs, considering others as well as ourselves, I feel that it is necessary to consider so many aspects of the care needs for the dependent person, as well as the carer, because the care for one enables the well-being of the other. All is entwined.

As said previously, respite has been a wonderful, actually sanity-saving & relationship-saving, aid to my/our caring role. This only works well when those staffing respite places are competent. I feel that there is a great need to recognise the value of those who work in respite facilities. This means, of course, the choice of appropriate people, the provision of good training, appropriate expectations of staff, and value in the wages that are paid these folk who take on great responsibility. There should also be, of course, ways of ensuring that any staff who prove unsuitable are not retained in that particular service. Here I must say that we have been very impressed with most who have cared for our daughter, and have had no concern for her well-being while in respite.

Ongoing support through Support Workers from Centacare has been a real boost, too. Just a couple of hours twice a week, but it gives me 'space' and also a great deal of pleasure to our daughter, who is enabled to do things that "Mum doesn't want to do" and, more importantly, she feels that she has real friends of her own, people she is comfortable with and can trust. I've heard similar comments from others, and feel that this particular provision is of great value, too.

Both respite and support work have been invaluable in giving our daughter confidence in the care of other people, and that is tremendously important to a dependent person with limited understanding and capability.

One further aspect of care & provision is in the area of holidays. Our daughter loves to get away but, as we age, this has not been as available to her as she would like - and needs. Some holiday provisions are available, but mostly to those needing less specific care. Consideration of extra provision for this aspect of life for a disabled person with higher needs, would be much appreciated.

Thank you for your endeavours to consider the need for providing quality of life to disabled people and their carers.

Yours sincerely,

Jackie