

5th June, 2008.

BETTER CARE FOR OUR CARERS - new parliamentary inquiry announced

IN THE BEGINNING

My name is Lynette
[REDACTED], for almost 30 years.

I have been a carer for my son, [REDACTED]

When my son was first born, I was married to his father, [REDACTED]. [REDACTED] was born in Blacktown Hospital on 29th June, 1978. The morning after he was born, whilst I was looking at him in his humid crib (as he was 5 weeks premature) I was asked to wait around as the Pediatrician wanted to see me and discuss with me about my baby. At this time I did not know there was anything wrong. When he came to the Special Nursery, he asked me if I had noticed if there was anything wrong with my baby. All I had noticed was that his feet looked funny. He then started to rattle off a whole lot of stuff that I could not possibly take in. He then left me to explain what he had said to my husband. How could I possibly explain what I could not understand myself?

This was the beginning of the end for our marriage. I believe that if there had been a Social Worker or some other person available to talk to both of us about the situation, things may not have happened as they did! Every hospital should have a professional person available to talk to mothers and fathers (together) of the problems that they are facing, and to explain in great detail about their situation. This person should also be versed in counseling, so that they could inform the parents in a caring way as to what is going on, and what options are available for them from the Government. Also, this should be an ongoing thing with the parents so that both feel that they can communicate with someone about what they are feeling, and advice can be offered right at the beginning, and not when it is too late.

Advice also needs to be given as to Physiotherapy, Occupational Therapy, Speech Therapy, Specialists, etc. etc. These professionals need to be with the clients right from the beginning, and to continue caring for them right till the end.

TREATMENT.

I found that when my son was being given Physiotherapy at Westmead Children's Hospital, it was the policy of the hospital to rotate their staff so that the staff get experience in different types of conditions. However, my son's condition was so complex, that he needed to have the same person. It would take him ages to trust the person for starters, and it would also take ages for the person to learn exactly what was needed. By then the staff would be rotated, and a new person would then be involved and the whole process would have to be started again. I tried to explain this in a letter to the Medical Superintendent, but he was not interested in my son, only in his staff's experience. He did not see that some clients are not the same, and needed special help.

P.A.D.P.

I have found that the staff who works for the P.A.D.P. thought of themselves as experts in the needs for my child. I had to almost beg to get the equipment that I needed to allow my son to stay at home and be able to go to school. These people need to be trained to treat carers as special people, as we are very sensitive to how we are treated. I, for one, do not like to beg and feel that my son and I are a burden on society. You are made to feel like a second class person, and are helped only by what they feel you should have. These people are only clerical staff, and not experts on your child's condition or their needs.

MONEY

Because of my son's condition, I was not able to work (except as a volunteer in the school he went to - as I had to be there anyway for him). At one stage I was being paid, but that did not last for long. I did not wish to be there for one thing as I had far too much to do at home as I was his only carer. When I married my second husband, I was not financially better off as my ex-husband than decided that he did not have to give me any money for my son's maintenance.

At the time I believe I was getting \$40 a fortnight for caring for my son. My husband and I have not been able to save any money for the whole time I have been caring for my son.

Now my son is being cared for 24 hours a day in our home. We had to make a bedroom larger to allow there to be more room for the carers to be able to look after him. My husband and I had to get a loan to extend the room, and my son put some of his pension towards it. Earlier, we had to buy a van so that he could be transported around. Again my husband had to get a loan for that also, plus the lift at the back.

Why doesn't the government at least give out loans with no interest? Even to get work done by T.A.D. it costs money. We are constantly paying off loans. Not just one loan.

HELP FOR MY SON

The only way I did get help was when my son had a brain hemorrhage; he had to be admitted to ICU at Nepean Hospital. I stayed with him for 3 months whilst he was there. The nurses there were of little use because they would not listen to me when I told them that they had to be trained in how to look after my son with suctioning and physiotherapy. They were not interested as it would take too long to explain and they were only there for a shift and then a new nurse would come on. They made me feel like I was stupid for staying there and constantly told me to go home. After 3 days of staying there, they finally found me a cot and allowed me to have a shower. I looked after him 24 hours a day for 3 months, and felt like killing myself. The only thing that kept me alive was the fact that there was no-one else who could look after him, other than myself.

When the Specialist said that he was well enough to go home, I said no. I knew I could not go on looking after him 24 hours a day. So they had a meeting, and now I have 24 hour help. You see, it cost more for him to stay in I.C.U., then it did to give me equipment and 24 hour help. They did try to send him to other wards, and other hospitals, but no-one wanted him because he was ventilated!

WORK FOR ME

I wanted to go back to work after a while, as I had trained the staff adequately to look after my son, and I knew I could take some of the pressure off my husband by helping him with the payments. I used to be a Stenographer for the Department of Health at various hospitals, taking care of the Mangers. I would have loved to go back to being a Typist/Receptionist, but I found that when staff are sick, or on leave, who is left to look after my son? Only me, that's who! When there is no one else, who else can the Agency call on? So I had to get a job with the Agency, and am now caring for the sick, aged and disabled. I am good at this, but my love is for typing, filing, etc. etc.

I cannot work full-time, as I still have to take care of the needs of my son, such as washing, ironing, cleaning, cooking, etc. So here I am working part-time, but find it difficult to come home to doing the housework and cooking, as I do that at work also.

MY HEALTH.

I suffer from osteoarthritis, and cannot see me doing this for the rest of my life. I am now 57, going on 58, and am feeling my age. I am on anti-depressants, and probably will be for the rest of my life, and I take blood pressure tablets, and migraine tablets. This will not change. I know my health has been compromised by taking care of my son all those years.

MY SON'S HEALTH

Another problem, dealing with health, is that when my son was sick I could not take him to the doctors, nor would the doctor do home visits. This was in Rooty Hill when I lived

there. So I had to work out what was wrong with him, and then get a script from whoever would give me one.

TURNING 18

Another problem was with the Children's Hospital. When my son turned 18, he was no longer a child, so they dropped us like a hotcake, took all the equipment off us, supplied us with new equipment, but did not supply us with any support or backup. So there we were, on our own, and when something went wrong with the equipment (which was usually in the wee hours of the morning), we had to ring and try to get backup equipment from any hospital that had it. Guess what, no hospital had his equipment except the children's hospital. So we would then have to beg for help from whoever was on call. They were afraid of getting into trouble. My son, my husband, and myself would stay up and beg some more. If we were lucky we sometimes got help. This was before my son required 24 hour ventilation.

HOLIDAYS AND SAVING

Now that I am working, most of my money goes towards us having a holiday. We never went out or had a holiday for most of our married life. We have been married 22 years now, and it has only been in the last 2 years that we have been able to enjoy some freedom. However, even now that depends on whether all the shifts are covered or not.

I could go on and on about life as a carer, but I think I have given you enough to help you with your committee. People do not understand what it can be like. For some it may not be as hard, but it is hard, no matter how hard it is. Caring for someone takes away your feeling good about yourself. You do not feel worthwhile, as you are treated as less than a person who works. You are not paid for the work you do. What is a measly \$100 a fortnight going to do for you? Is that all you are worth?

I have suffered for 30 years, it has taken its toll on me. My son has suffered for 30 years, it is still taking its toll on him. My husband and ex-husband have suffered. I have felt that no-one cares about us so many times. Things have gotten better, yes, but they will never be right for any of us. We have lost our youth, and that cannot be restored. I can only look forward to my enjoyment of my work, which is not what I want to do, and my time away with my husband. It's the only time we are alone!

If you are able to help others before it is too late, please do. I beg you to help them as no one helped us!

Yours faithfully,

Lynette

