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Tasmania
Saturday 17th May 2003

To the Submissions of Discrimination.

To begin with, until our son had such a tragic accident, I knew nothing about people with disabilities. I can assure you I know a lot more now.

Not everything, but a whole lot more than some nurses, doctors, wards-men, and the general public.

When our son was alive, he did not want a fuss made of the times in which he was discriminated against, but to save others from the same acts I would like to bring to your attention the facts of that time.

He was a triplegic, and at that time December 1993 until May 1999, there was many an occasion that was blatant discrimination.

People who have anything to do with anyone with disability, should learn all they can about -: the patient, their sensitivities, their feelings, and most important their needs.

I would even go so far as to suggest that all doctors, nurses, wards-men and carers who wish to work with spinal patients be made have three spinal blocks. One in the lumbar region, one in the thorax region and one in the cervical region, for just one hour in the different areas. This would make them understand how the person they are looking after feel.

Taxis -: Only one was able to take our son. We were told to book ahead of the time when it was needed. We did, but only once did he ever have the use of it. The taxis did not operate after 8pm. So if a person in a chair was to go out at night, say to the cinema, dinner, or party, they had to leave before 8pm.

Hospitals -: At that time hospital staff knew **nothing** of paraplegia, quadriplegia (I am sure) and most definitely nothing at all about triplegia. (Maybe one or two persons who worked there at the time did.)

In the first hospital our son was left laying (Except from the times he was in theatre) for ten days - with out being turned. When he was turned in the next hospital, he was thrown into the air and it was hoped by the wards-men that he would land back onto the bed.

P.S. When I came back from Melbourne and went to this second hospital, I wanted to tell the wards-men how to turn patients as they do in the Austin Hospital. The wards-man I spoke to said quote – We are not allowed to touch patients. – unquote.

So until they change their ways there will be patients in pain unnecessarily or discriminated against.

There were nurses who would go mad at him for putting his leg in the way (Spasms caused this), while they were doing dressing on his pressure areas, (which also were caused through lack of knowledge,) or again him being discriminated against because he was doped up to his eyeballs – because he was above average build – and because we knew nothing of the importance of being moved every two – four hours.

There was one nurse in particular (Agency nurse) who put him onto a commode and began to push him toward the shower. The chair did not move but she kept pushing, when she looked to see why it wouldn't move, our son's foot was on the floor in the way of the wheel. That nurse(???) had the cheek to say, 'Why didn't you lift your foot out of the way' when our son said he didn't know it was there, her reply was "Well why didn't you tell me?" and the time he was left in the bathroom, outside the shower recess, without a towel and dripping wet for three-quarters of an hour, because the nurse had forgotten the towel. When we arrived he was shivering, the nurse asked -Why he didn't get himself back to the ward – he could have rung the bell – which by the way was not within his reach either.

His meals, when he was allowed to eat in ICU, out of his reach or on the wrong side for him to be able to feed himself. Nurses told him to sit up and get it, they did not have the time to feed him. ------- How do you think you would feel if you were told that? Why he did not want complaints made ? *The nursing staff took it out on him when we were not there.*

THESE ARE BUT A FEW.

Re- Hab -: Nurses who did not know how, and were not interested in learning to do bowel regime. (Most made it up as they went along, to our son's and probably other's discomfort)

The nurse who, when asked to rub Dencor Rub on his shoulder, rubbed it on what used to be his pressure areas, and could have burned the skin from them.

Complete and Incomplete

I feel I must define 'complete' and 'incomplete'.

A complete paraplegic or quadriplegic is one who has COMPLETE spinal cord break.

When this happens there is no way, at the moment, the spinal cord can be repaired.

An incomplete para or quad is when the cord is NOT severed, and the person can walk again, can use their bowels or bladder without help, can feel if there is any pressure on sensitive areas. Plus loads more.

It <u>hurts</u> people with 'complete' breaks, and their relatives, when some article in a news paper or magazine reads-: ---They have over come their spinal cord injury and have worked hard to learn to walk again. ---

IF that person who had 'overcome' their disability and learned to walk again had a COMPLETE break, they would NEVER walk again.

As anyone, who knows about spinal cord injuries, knows above the complete break in a spinal cord, the person becomes more sensitive. That is where they are coldest, in winter. That is where they are hottest in summer. That is where they feel pain ten times as much as anyone else.

The <u>occupational therapist</u> who, on many occasions let him down.

He came from Melbourne's re-hab for one weekend in late September 1994.

The occupational therapist was told half way through August he was coming home. A ramp had been approved for our home, but it could not be done until the O.T. had measured up. She actually got here (after a call every two days) on the last day of August. But there was still three weeks plus until, our son arrived. We thought there was still plenty of time to have a ramp put in.
He came over on the 24th September 1994, and because of her (what I would call) discrimination against our son, he could NOT get into our home. It was a cold day, and we had to have him outside. He had to go elsewhere to sleep. FACT.
He left on the Sunday night to go back to Melbourne, on the Monday morning a chap came. When I told him he was too late, he said he could not believe we had to have our son outside in the cold. I asked him if he was calling me a liar. His reply -: There is no way that would happen. ----- Believe me -- it did.
I know I should have reported both of them, but did not want to stir up any trouble at that time I wanted our son back in Tasmania.
This is just a few times discrimination was against *our son*, how many more times has it happened to others who do not have relatives to help them?

I wrote this article to the MAIB, and did not send it off until after we lost our beloved son. For the simple reason he asked me not to at that time, his words were -: until the time is right.

This is how I thought people with spinal cord breaks would feel. I asked my son to read it, and he said that is exactly what it is like.
So when next you see some one with a severed spinal cord, or with a disability, look twice, and think how lucky you are to be able to walk, to be able to go to the toilet (without help), reach up into a cupboard, climb the stairs, feel the water and sand on your toes, jump over rocks and puddles all the things we, as NOT having spinal cord damage, take for granted.

If you can imagine ---- your head is sitting on your shoulders, but, below the break in your spinal cord there is a bit of meat just hanging there, like meat hanging on a butcher's hook.
You have no control over your bowels or your bladder.
You cannot go on holiday without a lot of preparation.
It is difficult to get on a 'plane.
When you book the disabled cabin on the Spirit of Tasmania, you must be sure you get there VERY early, otherwise you have to stay in the hospital ward, or stay

up all night. Because the cabin you booked has been given to some one who got to the boat before you.

You have to stay at 'special' motels, which are wheel chair friendly, IF you can find one.

When ***you*** get into bed at night - if ***you*** get thirsty, ***you*** can hop out of bed to get a drink, a para or quad can't.

Imagine you are wanting your favourite meal and you haven't got an essential ingredient, you cannot hop in your car and go to the shop, you have to go without.

Simple little things to the able bodied, become a big chore for a para or quad.

People in general, don't realise how much trouble it is for some disabled persons.

Remember also, the able bodied can -: walk on the beach – feel sand and water underfoot – go running over rocks – go fishing at your favourite spot – go wading through the water spearing flounder – swim – go to the toilet any time throughout the day - have a bath or shower when you want one – stop of at the shop for an ice cream or drink.

I do hope this is of some help and will help in some small way to stop discrimination against people with disabilities.

Regards

Jean C Bailey