

EPILEPSY ASSOCIATION OF WESTERN AUSTRALIA — RACHEL FIELDING

Statement

HON SALLY TALBOT (South West) [5.40 pm]: I have never met John Fielding and I did not know his 18-year-old daughter, Rachel Fielding, but I came across their story the other day through the Epilepsy Association of Western Australia. It is a really remarkable story and one that I will share with honourable members tonight. John Fielding recently presented the Epilepsy Association of Western Australia with a donation of \$625, which had been raised by the Perth-Bayswater Rugby Union Football Club. The money had been raised in memory of Rachel who, at the age of 18, passed away on 31 May this year. John, in presenting the money to the Epilepsy Association, sent it a copy of a speech that he made when he presented a trophy in memory of his daughter to the Perth-Bayswater Rugby Union Football Club. He forwarded a copy of the speech, which he asked to be made public on its Facebook page. I have subsequently checked that everybody concerned is happy for me to read this into the record tonight. Much of this story is told in Rachel's own words in something that she wrote to try to explain what it was like to suffer from this particular form of epilepsy. It reads as follows —

My name is Rachel Fielding and I have refractory Epilepsy. I had my first seizure when I was 14 and I am now in my second year of Uni about to turn 19.

Her father interjects —

(In that 4 and half year period Rachel had about 100 full on seizures.)

Rachel continues —

I would really like it if the people around me knew more about what I was going through rather than appearing scared of me once they find out. I think there is a stigma about epilepsy but that is only because so little is known about it.

- “I am one of the 50 million people around the world that have Epilepsy.
- The two types I have are tonic-clonic (the ones you shake a lot and go unconscious) and absence (When you just phase out for a while), but there are actually around 40 different types of seizures.
- It feels like I have been on at least 20 different medications and then mixes of medication and the side effects really suck. Some make me tired, some depressed, some really hungry and most don't even work. I even got Kidney Stones from one of them which were very painful
- Only 70% of people get seizure control with medication and the other 30% of us just have to be really careful.
- Obviously it's not safe to have seizures I have hurt myself many times. My tongue has been a major casualty as it gets in the way of my teeth. Loads of scabbed knees and elbows, numerous black eyes, a broken nose, chipped teeth and some really bad burns.
- I am still learning to live with my seizures but I have not yet mastered it. Turning 18 has added problems to do with trying to be an adult and be independent and go out. It is so hard to live with seizures as there is ALWAYS a part of my life that I am not in control of. I've had to accept that there are some things that I can't do because it's too dangerous for me and other people, but at the same time I have to make sure I'm not using the epilepsy as an excuse, to not live my life! I just wish that more people understood how complex this is.

Her father continues the story —

Shortly after writing this Rachel came home one day very excited and announced that she had been talking to a friend at Uni, and she had decided she was going to play Rugby, and training was tonight could I give her a lift. (All in one breath) She had obviously decided that Rugby was one of those things that was not too dangerous)

My heart goes out to this man. As a parent, I can imagine what it must have been like to have his child come home and make that announcement. He continues —

At first I was anti the idea as not only did Rachel have Epilepsy but she had only recently gone through double knee surgery to stop her knees from dislocating.

But I could see the excitement in her eyes. She battered her eyelids to suck me in and before I knew it I was driving down Beaufort street taking her to training.

After that Rugby was all she would talk about. She skipped lectures at uni so she could go to training and timetabled her study time so it did not clash. She started taking her lunch to Uni so she could use the Rugby Lunch box she had been given. Rugby had ignited a passion in her that I had not seen for a long time,

Her first game arrived and there was much excitement in the house. We had to go out and buy new boots and she took great pride in pulling on the uniform for the first time. Rachel said she did not want my wife and I to come and watch until at least she knew some of the rules. We gave her, her space as we realised she was doing something off her own back and we wanted her to find her own way.

However instead of her 1st game being one to remember for all the right reasons unfortunately Rachel had a seizure after the game. She fell from a 1 meter lime stone wall straight on to her face and as a result lost two of her front teeth and smashed up her face quite badly.

On the way out to the Fremantle hospital that night I said to my wife well that might be the end of her Rugby career. After just one game. How wrong I was. A few days later with a head bandaged like a mummy and missing teeth she was determined to go to training and not let her epilepsy dictate her life. I told her that she will scare the living daylights out of her coach and team mates showing up like that but she was determined to go.

I think this young lady had also scared the living daylights out of her parents —

So once again I found myself driving down Beaufort Street taking her to training. We finally convinced her that she would have to miss at least one game before she returned and she reluctantly agreed.

It wasn't until after her come back game when I realised how much this sport of Rugby had taken her in. Rachel still did not want us to come and watch. So when I picked her up after the game I asked her how the game went. There was silence for a moment and then she just started crying. After some cajoling she explained to me that they had a full team that week and the coach didn't put her on not even for 5 minutes. She knew the coach was probably just trying to protect her but she didn't want sympathy she just wanted to fit in and be part of the team, not some freak sitting on the side line.

Once again I thought well that may be the last straw and this will surely be the end of her Rugby Career. But she was not to be deterred, she showed up for training the next week as if nothing had happened determined to work her way back into the side.

I don't know what she said to the coach but the next week after the purchase of a helmet she was back playing.

For Rachel the challenge was not to be the best player in the team or to make that unbelievable Tri. For Rachel the struggle was to just make the team, to be part of something where she felt she belonged. I truly believe she found that place right here with this club and for that I thank you all.

It must be remembered that this is Rachel's father talking to the club members. He then goes on to present the trophy, during which he says —

... I hope she will be remembered as the person who never stopped climbing that hill, remembered for all the road blocks she had to jump over, remembered for all the sacrifices she had to make just to take the field and finally remembered for the perseverance she showed just to play the game she had come to love.

Rachel died on 31 May this year, as I said. She had struggled with epilepsy for five years. Her condition did not respond to medication. Again I quote her father —

Following a seizure she fell in such a way as to block her airway whilst she was unconscious and it unfortunately took her life. As you can imagine there was a huge reaction from her family and friends to our loss and their support has been amazing. Some of Rachel's friends have subsequently involved themselves in a number of activities to increase awareness of her condition and to raise funds for various Epilepsy organisations.

I think this young woman and, indeed, her family are truly an example of the fact that epilepsy is what a person has, not what a person is. A person is not an epileptic; they are a person with epilepsy. I hope honourable members appreciate the chance to hear Rachel's story in her own words and in the words of her father. They are obviously exceptional people.