



Janis Cottee, speaking on behalf of tide at UK Dementia Congress.

"Good Morning. I am here on behalf of tide, or 'together in dementia everyday.'

I am Janis and I cared for Richard my husband, who I met when I was 14 and he was 15. We married when I was 21. One thing I must tell you though...at the age of 14 I only dated him from Friday to Tuesday and then I packed him up when he had run out of money, a fact I'm not proud of now!

We were married for 45 years and have two children and two grandsons. I love this guy.

Today I'd like to talk about human rights, especially the right to dignity, respect and not to be treated in a degrading manner

Richard developed symptoms at 58. I knew there was something wrong and asked if it could be Early onset Alzheimer's, because of the symptoms, but I was repeatedly told it was depression, PTSD, anything else.

Eventually, after a three-year battle, he was diagnosed. The brain damage showed quite clearly on his brain scan.

I want to talk to you today about one day in Richard's and my life. New Year's Day 2013.

He was admitted to the care home 9 months earlier, amongst many misgivings on my part, but I was told no other home would take him and I had 24 hours to check the home out and get him there myself. Would you all try to remember he weighed 11 stone on admission.

We hit quite a few problems with the home as I felt they were unable to meet Richard's needs and he would become extremely agitated at times. I supplied the home with Richard's Life Story book, which contained everything they needed to know about him, on day one. It told them what his job had been, who his family are, what he liked and disliked, even the fact he liked two sugars in his tea. It was never used. I had found him locked in his room, he was constantly fed purée, as they couldn't get him to eat, yet I could. They also never gave him time to understand what they were going to do when it came to personal care.

They had never had a person in the home with Early onset Alzheimer's, and I was constantly being told if I removed him from that home he would deteriorate, so they even played the guilt card!

On 1st January 2013, we hit a crisis.

He had developed a water infection and had become very agitated and was lashing out. I arrived at 9.30 that morning and was told they had called an ambulance. He wasn't washed or dressed, he stank of urine, was extremely agitated and unusually for him, he wouldn't even let me near him. I coerced him into the quiet room where I managed to carry out some personal care. He gradually settled and fell asleep in the chair.

The door suddenly opened and two paramedics and two policemen walked in. I was expecting the paramedics but not the policemen. When I asked why the police were there I was told they had been told Richard was very violent and they had arrived to restrain him. I explained to the police officers that Richard had early onset Alzheimer's and was, by then, a frail sixty four year old man who weighed six and a half stone and he had some sort of infection which was causing some agitated behaviour. The police officers understood, empathised and left.

We had to wait for 8 hours for his GP to give him an injection so he could be safely transferred to hospital as it was New Year's Day and the home also refused to make the call until a shift change.

In all that time, I was left to cope on my own as no one offered to clean or change Richard. When we arrived at the general hospital. We were immediately put in a police detention room as they had nowhere else available. My daughter joined us at this stage. Yet again nothing was offered in terms of personal care or refreshments. They eventually did some blood tests and many hours later he was transferred to Goodmayes Mental Hospital, in the early hours of the morning. The staff immediately told Richard they were going to make him a bit more comfortable, and took him away. Less than ten minutes later he was returned to the visitor's room where we were waiting, showered and changed from head to foot. They also brought in some tea and some sandwiches. Despite the fact Richard was supposed to be on a soft diet, he ate three egg mayo sandwiches straight away!

After 17 hours with little or no respect shown to us, that was the first time I had seen good care in practice. They understood he was ill, not disruptive, or bloody minded. He was with them for some time and although he still became agitated when he was unwell, he was well liked there, very well cared for, and on the whole much calmer.

He never went back to that care home, because I insisted he didn't. By the time he was discharged, I knew what he needed in the way of care, and I wouldn't settle for less.

I loved Richard and if he was happy, so was I. If he was treated badly it affected me badly. No-one at the care home understood that. The ambulance staff, the policemen and the hospital all understood, so why couldn't they?

Richard was taken to his new home weighing two stone heavier. On arrival his Life Story book was being read to staff and residents by the ward manager and he settled happily there from day one! He also gained another half a stone. He had two happy years there. Lots of hugs and kisses.

We danced... We drank beer in the garden, and I discovered he could still hum along to music!

Sadly, he died on the 28th July last year aged 66. During that awful day in January 2013, if Richard had been treated with respect and dignity and had not been subjected to degrading treatment, not only his but my human rights would have been respected.

One in four of us will develop dementia. If Richard was your relative wouldn't you want them treated with respect and dignity?

Being a member of TIDE has not only given me a voice but also gives me the opportunity to talk about my Richard and hopefully help people understand that we were a team, and when his human rights weren't recognised and respected neither were mine.