

Ann's Story:

Where do I start to say how PSP has changed the life of not only my husband but also our whole family?

My husband was wrongly diagnosed as having Parkinson's disease in February 2003. Gradually his movements became stiffer, falls started happening, his voice became softer, his hand-writing was a small scribble, he lost interest in doing things that he used to enjoy, his facial expression changed, his swallowing changed and bladder problems started. During this time he was also told he wasn't allowed to drive anymore – this was very hard for him to take, but for those of us who had seen his driving it was a blessing.

I was used to being with people with Parkinson's disease, as my mother and uncle have it. My husband's symptoms were different to their symptoms, so it didn't make sense.

Things really started to get worse in August 2007. After a fall my husband was in hospital with a bad infection in his leg resulting in three operations and five weeks in hospital. Then followed many weeks in rehabilitation. In February 2008 he fell again, dislocating his shoulder and breaking his arm. After two operations and a stay in rehabilitation he also had cataracts removed from his eyes. Then his worst fall happened in May - he broke his neck and split his head open – this really scared us. Another rehabilitation stay followed. During all of this he never once complained! In the end I had to ask for some help taking care of him; I found nothing was offered until I said I couldn't do it anymore.

Then his eyes started closing and he would just sit there listening to the T.V. and even closed his eyes when going out with friends. He hardly ever participated in the conversation. They thought he wasn't interested or was tired and I kept asking him to open his eyes. He then also started to collapse for no apparent reason, even falling out of his chair. He started having trouble getting his breath if he laughed, ate or was drinking, going bright red and giving us all a fright. After many talks with his neurologist over 12 months he couldn't give a reason. He asked if we would like to participate in a trial of a new Parkinson's drug. We agreed to try anything and went along to see someone else in March 2009. **What a shock we got:** we were told he didn't have Parkinson's disease but Progressive Supranuclear Palsy. We were told to go home and look it up on the internet. We were in shock. We felt devastated, but also relieved to know what was the problem was. It had taken 6 years to get the right diagnosis.

Since then we have had to do bathroom renovations, install ramps, get a lift-chair and a wheelchair. We already had a hospital bed as he has to sleep on an incline to stop the saliva building up in his throat. My husband is slowly getting worse in his movements, swallowing and bladder control. He doesn't talk very much unless asked a question and his eyes are closed most of the day (although he has had Botox injections to try and keep them open). He can no longer shower or dress himself. I have changed his diet so that everything is soft and his drinks are thickened. At night I have to help him into bed.

He can still go to his gentle exercise and balance classes once a week. He also goes to a daily activity centre once a week (providing they are staying at the centre as he is now classed as 'high dependency' and cannot go on outings). He looks forward to these days even though he doesn't talk much but listens to what is going on around him. We have a male Carer on a Friday for 4 hours now. He is taking my husband out somewhere different each week and they have a meal together. I think this is good for my husband as he is in the company of another male instead of being surrounded by females all the time. He doesn't talk much, but that doesn't matter and our Carer understands. During his activity group or on a Friday I try to do something for myself, either catching up with friends or even having a massage.

Our life has totally changed and at times I feel very lonely and sad. I look at my husband just sitting there for hours on end with his eyes closed and my heart breaks. This terrible disease has taken away the man I married and I know he must hate being totally dependant on people to do everything for him. I know things are going to get worse and luckily I have family and friends close by. I have to keep telling myself to take one day at a time and be happy when we have a good day together.