

My story

Sylvia Benham

Sylvia Benham aged 61 years, lives in Berkshire and celebrated her ruby wedding anniversary with husband Derek in 2007. Here, Sylvie tells of her battle with Meige syndrome.



● Derek & Sylvia Benham

"It started in 1999, not with dystonia but when I was diagnosed with an overactive thyroid in a form called Graves's disease, which made my eyes protrude," she said, "and in 2004, I was persuaded to have an operation to lower my eyelids with the aim of protecting my eyeballs. It wasn't a total success, it left one eyelid lower than the other and was probably the worse thing I had done. Then in May 2006 after a holiday in Portugal, my eyes suddenly began to act quite strangely. My eyelids were going lower and I found it difficult to focus" added Sylvia.

In June, Sylvia was referred back to the eye clinic of the Royal Berkshire Hospital, though it took another 3 months before she saw the consultant. Meanwhile, she stopped driving, was given sick leave from her job and gave up helping at the Stroke Club. Her eyes were now clamping shut. "The consultant told me that I needed a second eyelid operation to correct the imbalance but that I should have botulinum toxin injections to prevent eyelid spasms during surgery. The doctors still saw this as a surgical problem not a neurological one."

By the end of October 2006, the dystonia had spread to Sylvia's mouth and food started falling from it. She could not understand what was happening to her body. Sylvia found it increasingly difficult to leave the house on her own and had to resign from her job at the school. "Even eating in restaurants was out. It became a bit of an embarrassment," she said. "I needed to ask for small spoons as I couldn't get larger ones in my mouth and I was reduced to soups. I lost all confidence in myself", said Sylvia.

"Thanks to counselling I feel more positive about myself."

Sylvia's weight reduced dramatically from a healthy nine and half stones to about 7 stones. As an act of desperation, Sylvia and Derek sought a private consultation with Professor Gregory, who told them within five minutes that her condition was called *Meige syndrome*. One week later, Professor Gregory started Sylvia on botulinum toxin injections round her eyes. With a definitive diagnosis, Sylvia's GP gave her substantial support, arranging home visit by nutritionists, food supplements, the telephone number of the Dystonia Society's Helpline support service, and later counselling sessions. Dr Gregory continued to see her at ten weekly intervals but this did not help the solid food rejection problem.

"Sometimes, chewing gum ended up shooting across the other side of the floor because of my jaw spasms. It happened one time in clinic when a lozenge was propelled like a bullet across the corridor," said Sylvia. Because of this problem, she was referred to Dr Catania at the National Hospital who performed injections every three months into Sylvia's jaw and around her eyes. "Dr Catania says I have a naughty tongue," said Sylvia.

Now, Sylvia liquidises every meal and separates even a Sunday roast. Meat is first, followed by vegetables ("liquidised parsnips taste nice," she said, "and baked beans liquidise wonderfully") and then roast or jacket potatoes separately. "Derek is a brilliant sauce maker," she added. "Fish and cauliflower liquidise well with a separate sauce. Indian meals contain a lot of liquid and help me to regain some of the lost weight."

Sylvia still has counselling once a month and believes it is the best move she has ever made. "Thanks to counselling I feel more positive about myself," she said. In the past, I got the impression that people were deliberately sitting away from me because of how my face looked. At my lowest point, I felt hopeless, that I had no future. Now I am more confident; I have returned to help at the Stroke Club, I attend evening church services again. We started to attend the Oxford support group meetings which Derek found fascinating. We also belong to the Berkshire group which started last year. Both have been a great support."