

Case study

Mary Buck



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It is an incredible twist of fate that had Mary Buck contract her dystonia at age 60. Instead of looking forward to an eagerly anticipated retirement, Mary was about to embark on a totally different journey. Not only was she going to call on reserves of strength and fortitude to fight one form of dystonia, Mary was also going to be struck by a second dystonia, three years after the first.

The first, laryngeal dystonia, initially manifested itself in 1990 but it wasn't correctly diagnosed until 2005. By that time the second dystonia, writer's cramp, was also adding to Mary's challenge.

Mary's ability to speak, make herself understood, very quickly suffered, a seemingly irreversible deterioration that has left her today frustrated and angry but not unbowed, using her skills as a linguist to make herself enunciate as clearly as she can.

Like so many people with dystonia, the medical professionals Mary saw had little or no idea of dystonia. In Mary's case her strangled, breathy voice was a symptom of almost everything but laryngeal dystonia. Endless consultations with specialists over a depressingly long 15-year period finally ended when a speech therapist suspected Parkinson's Disease and recommended a brain scan. It resulted in verifying that all this time Mary had been suffering from dystonia.

As for the writer's cramp, Mary went through operations on both wrists, to no avail, endless blood tests, and a mis-diagnosis of benign essential tremor. But once the laryngeal dystonia was correctly diagnosed, the specialists were quick to pin down the problems with Mary's wrists as dystonic writer's cramp.

"Treatment for both is injections," commented Mary, "I receive two injections every four months for each dystonia. Two go into my larynx, and two into my forearms. Both sets of injections are effective to a degree.

"Roughly two weeks after the laryngeal injections the breathiness diminishes and the quality of my voice improves gradually with a peak at about the twelfth week. It then slowly deteriorates and the injections begin again around week sixteen.

"Similarly, my ability to write, hold a cup without spilling its contents, use a knife and fork, walk my dog on a lead, improve then tail off again. I still cannot speak clearly and my hand tremor is such I cannot now write a letter nor wear shoes with laces, clothes with buttons, nor pour from a kettle or bottle without spilling."

Fortunately, arriving after retirement, the dystonias did not harm Mary's career as Education Advisor and Inspector in Modern Languages, although she is no longer able to lecture or travel alone thanks to the lack of clear speech and ability to write a legible hand.

Says Mary, "I socialise to a degree but only with small groups since I can no longer cope with a room full of people. I still entertain but my Cordon Bleu level has slipped!"

Socialising means theatre and cinema visits with friends, attending lectures and enjoying restaurants. Mary has two daughters, one living half the year in France with her husband, the other principal of her own busy veterinary practice, both leading very demanding lives with very little free time. "They bring my grandson regularly and he is amazingly patient with my attempts at conversation!"

But Mary is not down or negative. As she observes, "I have an excellent circle of friends. I am determined not to allow the dystonia to make me a hermit, and to find ways round the problems it throws up. I enjoy my membership of our UA3 Book Group, typing my critique of the monthly book for the group to discuss, and our U3A Writers' Group where a friend reads my contribution for me.

"And I still have my car, enjoy driving and walking my dog, a black Labrador cross lurcher, once a sad, uncontrollable dog, now a rescued, happy and much loved companion."

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