

My story

Trip to the spa changed my life...

By Lisa Todd

I was only 42, a busy working mum, always planning getaways and trips to the theatre with friends and family. Then dystonia took away my spontaneity, crushed my social life and left me frightened of even shaking hands with someone in case it set off the spasms. Worse of all, I now live in terror of being hugged, even by my own family.

It happened one Wednesday in October, four and a half years ago. A girlfriend and I had decided to treat ourselves to a day at a luxury spa, warding off the winter blues with a float in the Dead Sea pool. After lunch we retired to the poolside for a pot of tea in our dressing gowns. I laid my head back for a snooze, only for the chair I was sitting on to collapse, throwing me backwards so that my head hit the ground and I was left winded and crying. I had sat down on a broken chair.

Invisible dog collar

Within 24 hours my head had started pulling to the left as if my neck was in an invisible dog collar and someone was yanking on the lead every other second. I couldn't keep still for a moment. But I assumed I'd just pulled a muscle and it would heal soon enough.



● Lisa Todd with her daughter Olivia at their home in Windsor

A few days later, I took the train to Bath with my daughter Olivia to visit her grandmother. As soon as she saw me, my mum said 'what on earth's happened to you?' My head was still twitching uncontrollably and the spasms contorted my face with the searing pain. I was terrified.

The next day I went to see a physiotherapist at the Bath Clinic. Puzzled, she sent me to see a rheumatologist and then the tour of specialists began. They all drew a blank.

At first I had no idea of the seriousness or permanence of the situation and did not want to pursue compensation because of the stress; all I wanted to do was get better! As the treatment bills mounted and the suffering continued, I did want to sue the pants off them and at least have some recompense for the devastation!

Meanwhile for nine weeks I struggled from rheumatologist to osteopath to physiotherapist in a desperate attempt to find out what had happened to me. None of the health professionals knew what the problem was although there are at least 40,000 known sufferers of dystonia in the UK. Dystonia is almost an unheard of condition, with both diagnosis and the on-going day to day challenges, remaining hurdles to be overcome.

During this time my neck pulled ferociously and I could not stand still, sit still or walk in a straight line. My neck muscles pulled in searing, painful spasms, my head contorted onto my left

shoulder. In bed I had to lie on my side and hold the pillow to stop my head from pulling me over. I lay on the couch when friends visited and couldn't hold my head up. I couldn't drive my daughter to school, cook a meal or keep my head still in the bath. It was how you imagine Chinese water torture to be and I felt suicidal for the first time in my life.

'Dystonia is an almost unheard of condition, with both diagnosis and the on-going day to day challenges, remaining hurdles to be overcome.'

My story *continued*

by Lisa Todd

I was given the number of a neurologist and was told I would need botulinum toxin. Two days later I was in a neurologist's waiting room unable to sit still. As he approached he took one glance and said I had spasmodic torticollis and need botulinum toxin injections.

After two sets of injections and with Christmas approaching, I was unable to lift my head off the couch. I was also being spoon fed M&S cottage pie by my husband and was unable to write a card or wrap a present for my little girl. In between (and many tears later) I co-ordinated my own programme of rehabilitation determined not to be beaten by this monster that had inhabited my body.



● *Walking in our garden*

Alternative therapies

I had cranial osteopathy, massage, acupuncture, remedial pilates and lots of gentle work in the swimming pool. (None of these treatments were available on the NHS and our financial resources soon became strained.) Cranial osteopathy rebalances the cranial fluids and helps improve the head position with the objective being to feedback to the brain that a straight head position is normal and the muscles do not need to fight. Acupuncture works by releasing the endorphins and therefore lifting the mood making it easier to cope and also provides relief from pain and stiffness in the muscles.

My injections followed at 3 monthly intervals. Botulinum toxin injections receive lots of media coverage mainly to do with cosmetic enhancement. The drug provides relief by temporarily paralysing the nerve endings which helps to calm the spasms. It is not administered in pin pricks, as for wrinkles, but in larger doses depending on the type of dystonia.

I was terrified each time I attended the clinic for further injections and suffered from the side effects. I would certainly rather have tried other 'non drug' therapies but could not have survived without it.

With more osteopathy, acupuncture and healing, together with huge support from my family, it is now nine months since I had the last injections and I am apparently in mild remission. In reality I can't get in or out of a bath, am unable to drive, go to the dentist, hairdresser, do the school run, go to the pictures, get on a plane, go to Waitrose unaccompanied, or wear high heels!

On the positive side I have started a painting course at my local college and it is fantastic to be out with other people doing something creative. I try to swim three times a week. After three years I can now turn my head to breathe when swimming, having progressed from doggie paddle to using one arm whilst needing to stop to breathe – a huge feeling of achievement. I love water and it provides great therapy. I have had some Shaw technique lessons which concentrate on taking the strain off the neck whilst swimming. Dystonia does nothing for your confidence, self esteem or sex appeal (you so feel like the world is looking at you with your crooked head) and there are many activities that are on my wish list – driving is number one!

The chance of remission is small but even mild remission is infinitely better than nothing! The injections have helped to manage my dystonia and I believe the complementary therapies and exercise have significantly improved my outlook for a better future.

Cervical dystonia

dystonia affecting the muscles of the neck (includes torticollis, antecollis, retrocollis or laterocollis)

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The **dystonia** society

To obtain the above leaflet about cervical dystonia, including information about spasmodic torticollis, or if you have any other questions about dystonia, please visit our website: www.dystonia.org.uk or call our helpline: **0845 458 6322**