Dystonia matters!

‘Tea on the terrace’

100 guests gather for Lords treat
Society news page 5

Also in this special issue...

Cycling for dystonia back cover

Marathon tally tops £10k inside back cover
The Dystonia Society exists to support people who have any form of the neurological movement disorder known as dystonia, and their families, through the promotion of awareness, research and welfare.

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FOUNDER
The late Joan Young

Disability Awareness Day
Come and support us at the Disability Awareness Day in Warrington on Sunday 6 July. If members require further information, please call 01925 240064 or visit our website www.disabilityawarenessday.org.uk Thanks to member, Jane Hewerton, for her special efforts in organising our presence at this important venue.

Good luck Jessica!
Jessica Spall has left the Society after providing support to callers to our Helpline for over six years. We thank her for all her great efforts and wish her all the very best for the future. Her son Dilon, who arrived in 2007, has spent a number of months in Great Ormond Street Hospital but is now happily living at home with mum, dad and his two brothers.

Society news
New Role...
We are delighted to welcome Angie Brown who joins the Society as our new Helpline and Support Manager.

She comes from ChildLine where she spent 16 years, rising to the position of Senior ChildLine Service Manager of the London 24 hour helpline for children and young people. The development of the Dystonia Helpline is her first priority. Recruitment of a Helpline Officer is underway at the moment.

She will then concentrate on developing the One-to-One peer support service ensuring that the service is offered in a safe and effective way for all concerned. Later, in September, Angie will take forward the training of Helpline volunteers.

Angie Brown

QUESTIONNAIRE
Thanks to those members who returned a pilot questionnaire that allowed us to fine-tune the final version. The questionnaire will go to all members before the end of June. Please do take the 10 minutes needed to complete it. We look forward to hearing your views about how you want the Society to develop.

Disability Awareness Day
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Welcome to the Summer newsletter

Well done to everyone involved in the Awareness Week in May. Many members did a great job of raising awareness via articles in their local papers or in raising money through sponsored activities like the Rutland bike ride. Thanks to your efforts, the Society is really making progress. See the reports and pictures later in this issue.

This is a special year for the Society – our 25th anniversary. We are thus delighted that our Royal Patron, HRH Princess Alexandra, has just confirmed that she can attend a Reception to mark this event on 29 October. It is just a shame that attendance at the Reception will have to be limited to 100 people when so many more individuals have made significant contributions over the years.

Colleagues and I are excited that, at last, with three year funding in place and with Angie Brown’s appointment, we are now able to move ahead in developing our new ‘One-to-One’ support service. This service will offer interested members the chance to make contact with others in similar circumstances, either via telephone contact or through email contact, to share experiences and gain support.

The next issue of Dystonia matters! will feature tardive dystonia (dystonia caused by particular drugs). If you have anything you would like to contribute to this important subject, please send it to the Editor by the end of June.

Philip Eckstein Chief Executive

Society news

Thanks to the A teams

We’d like to say thank you to two fantastic husband and wife teams who are retiring from vital roles in the running of two of our best established groups.

Larry and Faith McKeever were Chairman and Secretary respectively of the Oxford group for the majority of twelve years. Eve and Allan Monnox have been involved with the Bristol group for over twenty years, where along with Patricia Cane, Phil and Sylvia Williams and Geoff and Marjorie Hemmings, they have done so much to establish one of the longest-running groups in the Society.

Frank Bound (8 Dec 1915 – 5 Nov 2007)

Frank was a very dear and valued member of the Bristol group. Both Frank and Joan his wife (who died in May 2007), worked tirelessly for the Dystonia Society, especially in the 1990’s raising thousands of pounds by organising the lottery from their sitting room. They never missed an opportunity to raise the profile of Dystonia. He requested donations to The Dystonia Society rather than flowers at his funeral. Two great friends of the Society.

GROUP FORUMS

Following successful meetings in Cambridge and Birmingham for volunteers connected with groups based in the local areas, we are pleased to announce further group forums to be held in Preston on 7 June, followed by one in Brighton on 28 June and one in London on 19 July meeting at a venue in central London.

SCOTTISH ANNUAL CONFERENCE

This was held in Aberdeen in May, and 44 members and friends attended. There were interesting sessions including Running a Botulinum Toxin Clinic from Dr Carl Counsell. A session on Hand Exercises for Tai Chi that can be performed seated went down very well with delegates. Dorothy Chisholm organised a raffle and the members ensured the event was a great success.

DIARY DATES

Three free ‘Living with Dystonia’ days will be held later this year:
6 Sept ● Nottingham
20 Sept ● Liverpool December ● Gatwick (near London)

Details and application forms of the September conferences will be sent to all members living in the regions at the end of June.

1 Nov ● Annual conference & AGM (at the Wellcome Centre, London, NW1 as last year). All are welcome.

We are very grateful to Ipsen Ltd for their generosity in providing a significant, unrestricted grant to support the newsletter.

Philip Eckstein Chief Executive
Society news

Tea on the Terrace

Around 100 guests, including fundraisers, corporate and trust sponsors, together with leading medical experts, were invited by our patron, Lord Macdonald of Tradeston, to a splendid tea on the terrace of the House of Lords during Awareness Week.

Our media-savvy members have AGAIN come up trumps for this year’s Awareness Week.

Judging from the cuttings we have already received – and they are still coming in daily – a growing number of members are using their local (and national) media to spread the message. Here is a snapshot of some of our successes so far...

- Top fundraisers, Deborah and Vicci Livingstone
- Right: Nigel Homer Business Unit Director, Ipsen Ltd
- Below: One guest, Helen Barber also met Ronan Keating and other members of Boyzone at the hotel where she and her sister were staying
- Above right: Lord Macdonald with Henry and Clare McRory who raised over £16,000 from a golf day at Enniskillen
- Professor Kailash Bhatia (left) Dr Katy Hayward, medical advisor for Eisai and Stuart Rose, managing director, Merz
- Above: Maddy and Felicity Boardman (see inside back cover)
- Vivenne Holstead featured in the Yorkshire Post, Wetherby News, the Daily Mirror, Yorkshire TV’s Calendar News and a live interview on BBC Radio 5 Live.
- The Brighton Argus and BBC South East News highlighted Jackie Sloper’s campaign with her local health trust
- An article on Keith Hall’s dystonia and his sponsored sky dive appeared in the Healthy Living supplement of the Sheffield Star.
- The Gazette, covering South Gloucestershire, carried a news story on Barbara Adams.
- The success of Kate Forsyth from Somerset in gaining an Open University degree, together with featuring Awareness Week, appeared in the Western Gazette and the Chard News.
- Pauline Johnson from Bangor, Northern Ireland told her story in her local Spectator newsletter.
- An interview outlining dystonia by our Service Development Manager, Val Wells, was broadcast by over 40 local radio stations.
- Wilma Williams and West of Scotland Coordinator, Dorothy Chisholm, were interviewed on Govan Radio. Dorothy was also asked to help produce a jingle on behalf of the Society.
Cervical dystonia

The big picture

Europe’s largest centre for the treatment of cervical dystonia (dystonia of the neck muscles) is the National Hospital for Neurology in Queen Square, London.

Professor Kailash Bhatia is responsible for this clinic which currently treats over 450 patients with cervical dystonia. Here Professor Bhatia highlights some of the important issues.

The figure of 40,000 is usually quoted as the total incidence of dystonia in the UK but Professor Bhatia believes this may be an understatement. “This figure is too low. I believe the true figure is closer to three times this value,” he says. Cervical dystonia (often referred to as spasmodic torticollis) is the most common form of dystonia. It accounts for around two thirds of the total number of cases of dystonia in the UK – in other words, 25,000 people are affected by cervical dystonia.

To the Professor’s dismay, it is still a very under-recognised condition. Patients are still reporting that it can take up to three or four years before a diagnosis is made and they are finally seen by a neurologist. “Unfortunately there is still misdiagnosis at the primary care level,” he says. “People are often sent to see a rheumatologist, osteopath or physiotherapist or even psychiatrist. It is only after doing the rounds, there will eventually be a diagnosis of dystonia and people come to the clinic. We need to raise the awareness of dystonia amongst all these specialists, particularly as there is an effective treatment available through botulinum toxin injections,” he says.

“It is important to identify people affected by cervical dystonia early on. The pain and the strong spasms resulting from the dystonia are not necessary. These symptoms can be effectively dealt with by regular botulinum toxin injections. As these symptoms can cause anxiety and depression, cervical dystonia can have a big effect on the quality of a person’s life,” he adds.

Botulinum toxin as a therapy for dystonia has been around in the UK for over twenty years. “We were the first centre to start injections back in 1987. These were done under Professor Marsden. I still treat patients who attended the very first clinics and who are still finding the treatment effective,” the Professor comments.

He acknowledges that in medical terms this is a relatively short time interval. However, the treatment has by now been used by thousands of people throughout the world and is safe. “There has not been any suggestion in the medical literature that people who have been having this treatment for focal dystonia over eight or ten years have had any long-term negative effects. It is a safe treatment though there is still a need to research any long-term effects.” As regards the recent reports of generalised weakness resulting from botulinum toxin injections, he is keen to point out that these may be related to its use in children with spasticity with high doses – quite a different usage to that in adults with dystonia.

Some Society members have raised questions about the way that botulinum toxin appears to ‘thin’ muscles. Professor Bhatia reassures: “As the injections are stopped, so the muscles will start to fill out. It’s very unlikely that after you stop the injections they will remain thin forever.”

As with all types of dystonia, people with torticollis can find their dystonia goes into remission. “The ball park figure in our experience is about one in ten cases go into remission. It’s more common for this to happen in the cases of younger onset – people under 40 years old. However, we do know of this happening to people in their 50’s and 60’s,” comments Professor Bhatia. “Unfortunately, for most people the dystonia will reoccur after five years. Permanent remission rates are much lower – well under 5%.”

In most cases cervical dystonia settles down after two or three years to being a stable condition without much change in the muscles affected. It is only in the first few years that it is likely to spread. “If you’re anxious, tired, depressed, it can temporarily get worse but it will normally settle down again after the stress is removed,” he says.
Cervical dystonia
The big picture continued

There has been a belief that if your head turns to one side, you should try to develop the muscles on the other side. “I personally don’t think there is good scientific evidence to show that is beneficial but graded physiotherapy exercises along with botulinum toxin injections could be useful. There is no rule that works for everyone. There is a need for much more research into this area,” comments Professor Bhatia. A number of puzzles remain concerning cervical dystonia. For instance, as with most other types of dystonia, it is more common in women than men (by a ratio of 3:1 in the case of cervical dystonia). Torticollis is more common pulling to the left than to the right. The likeliest time for people to report cervical dystonia is in their 50’s. Why does it affect people in the 50-70’s age range frequently? Why is it that when you are young you get generalised dystonia but, when you’re older, dystonia tends to be restricted to certain areas such as the neck? These questions amongst others await some answers in the future.

What causes cervical dystonia? This is still a mystery. The scientific community still has no clear idea of the mechanisms underlying the condition. However, Professor Bhatia and his colleagues have a hunch: they believe that there are actually a number of ‘cervical dystonias’. Various pieces of their research already point to the fact that people with cervical dystonia are not a homogenous group so that although people with cervical dystonia all have similar symptoms, the underlying causes are likely to be varied due to a mix of environmental and genetic factors.

Professor Bhatia and colleagues are currently formulating an exciting project that could provide some very important answers to this question by potentially finding genes associated with each type of cervical dystonia. Then the way will be open to producing individualised treatments that could cure the problem at a cellular level, rather than just masking the symptoms as is currently the case.

Research update
Mechanisms of childhood dystonia

Dystonia that starts in childhood can be one of the most severe and disabling forms. Recently the Society made an award of £25,000 towards continuing the important work of Dr Tom Warner and his team. This work is shedding light on the mechanisms that cause malfunctioning in the cells controlling the movement of affected children.

Childhood dystonia is often caused by a genetic change (mutation) in the DYT1 gene. This gene encodes a protein called torsinA, which is found in most cells, especially those in our brains. By understanding how this gene and the associated protein work in healthy children and how they differ in children with dystonia, Dr Warner’s team are gaining important insights into why the dystonic movements arise. It is hoped that in the future this research may identify novel treatment strategies for this incurable condition. In addition, the study of the DYT1 gene is also relevant to the more common forms of focal dystonia appearing in adulthood (such as cervical dystonia and blepharospasm), as work has shown that this gene can act to increase the susceptibility of some people to develop these forms of dystonia.

The team has investigated the way in which mutant torsinA causes dystonia in nerve cell models and has identified a novel protein that is directly associated with it. This protein, called snapin, is involved in the release cycle of the packets of chemical messengers (called synaptic vesicles) which allow our nerve cells to communicate to each other and ultimately make the brain work. The team has also found that the normal torsinA protein is involved in regulating this release process, a function which is lost by the mutant form. These findings are of great significance as, for the first time, they provide a link between the mutated DYT1 gene and abnormal nerve cell signalling which leads to dystonic movements.
Cervical dystonia

DBS for Cervical dystonia?

Deep Brain Stimulation (DBS) is widely known as a potentially successful treatment in cases of generalised dystonia, but does it have a role in cervical dystonia?

Mr Jeremy Rowe, consultant neurosurgeon at the Royal Hallamshire Hospital in Sheffield talks to Dystonia matters! about the potential uses of DBS for this form of dystonia.

We take our neck movements for granted and do not even think about them when they are normal. To manage even basic functions such as swallowing or eating requires neck control. Therefore it is important when considering treatments for cervical dystonia to look at the impact of the condition on all aspects of the lives of those affected.

The appropriateness of DBS for cervical dystonia will depend on how effective the existing treatments are for the individual patient, the extent of the muscle groups being affected by the dystonia and, of course, the impact that this has in terms of the activities of daily living.

Patients with spasmodic torticollis would most likely be treated in the early stages with botulinum toxin to manage their symptoms. It can work very well particularly if the affected the muscles are in a limited area. However the more extensive the dystonia is, then the harder it can be to get adequate symptom control with botulinum toxin. In addition with time there can be a loss of efficacy or resistance, or more rarely adverse reactions to the botulinum toxin.

Mr Rowe said: “Patients would only come to me to consider neurosurgery when they have failed in the conventional medical management of drugs and botulinum toxin.”

When talking to patients about surgery, Mr Rowe always talks about the risks. “I would divide those risks up in different ways”, he says. “The most significant risk is the risk of causing a bleed or a stroke when inserting the electrodes in the initial DBS operation. This risk is small and is usually cited at around 1%, but it is real,” he says. There are also potentially less important risks related to equipment malfunction etc which may require further surgery.

Should a patient decide to go ahead there is a very rigorous assessment to ensure that they and their symptoms are suitable for DBS. The tests are extensive and involve MRI scans of the head and neck both for planning surgery and to ensure the dystonia has not caused too much degeneration in the spine. There is also a battery of neuro-psychology tests that are undertaken. As part of the assessment a patient will also see a specialist movement disorder nurse and will be video recorded and assessed using the standard disease rating scales to provide a baseline.

One of the rewards of Mr Rowe’s work is the interaction and relationship between his multi-disciplinary colleagues. He says “It is not a neurosurgeon operating in isolation. DBS needs strong backup from the movement disorder nursing team, neurology services team, neuro-psychology and the radiological imaging group, amongst others.

How does DBS contrast with selective denervation?

Mr Rowe points out some of the differences: DBS is different from selective denervation in that it does not involve destructive surgery. Electrodes are inserted into the brain without destroying the neural connections and these electrodes can be taken out without having caused permanent changes. With selective denervation the aim is to cut nerves permanently. Cervical denervation can be attractive because it offers a one-off permanent solution. However sometimes further operations are required as muscles that were initially denervated grow back at a later stage. “We must also recognise that following the initial operation for DBS further operations may be required when the battery needs replacing, though rechargeable batteries are in development,” he concluded.

(See interview with Mr James Palmer about this treatment.)
Selective Denervation
for torticollis

Mr James Palmer, Consultant Neurosurgeon and Medical Director at Derriford Hospital in Plymouth, is the principal surgeon in the UK carrying out this procedure. Dystonia matters! asks the questions.

What is Selective Denervation (SD)?
This is a surgical operation to cut the nerves controlling the overactive muscles that are causing the symptoms of dystonia. The aim of the operation is to introduce a permanent paralysis to the muscles causing the problems.

When should people consider surgery?
People normally consider SD when botulinum toxin treatment has been tried and has failed or is starting to fail. It is important to see patients early after the failure of previous treatments, not years later. If patients are referred early then results can be really good and offer a chance of providing a permanent fix for their cervical dystonia. Unfortunately, patients who are referred to me after many years often don’t do well: the constant twisting of torticollis will have caused destruction of the joints in the neck over the years. However, even in these cases the procedure can often reduce pain and improve head position though it is difficult to return the neck to having a good range of movement once the bones have been damaged.

When is surgery not appropriate?
If the cervical dystonia involves too many muscle groups, SD may not be feasible because it would involve trying to cut too many nerves. Some nerve pathways always need to be maintained to preserve neck movement. Some types of torticollis are easier to treat than others. The best results are usually obtained in cases of a rotation or twist of the neck. The hardest examples to treat are cases where the neck is pulled up and backwards because there are so many muscles involved. This wouldn’t necessarily preclude the operation taking place, but I would have to advise the patient that the chances of success were less.

What are the benefits of this surgery?
For the right patient, there is a very reasonable chance (maybe 40%) of eradicating the effects of dystonia. Even in other cases there should be marked – and permanent – improvement in position and body image which for me is one of the most rewarding reasons for carrying out this procedure. Following surgery, a neurophysiologist or a physiotherapist are on hand to teach the patient exercises to build up the strength of their neck muscles. This is important.

What are the disadvantages?
In a few cases there is a risk of incurring temporary swallowing problems. In extremely rare cases this can become permanent. As in the case of botulinum toxin, swallowing problems may follow injections but the symptoms do ease. Surgery can certainly leave you with several numb patches at the back of the head because some of the sensation nerves have to be removed. However it is an operation involving muscles which usually heals very well and there aren’t many risks involved in this type of surgery.

Is it difficult to get funding for this type of surgery?
Because it’s approved by the National Institute for Clinical Excellence (NICE) and has a tariff, our hospital is quite happy to operate and provide treatment. It’s free for every member of the NHS. I’ve not had a problem getting funding so far.

Why are there so few neurosurgeons performing this type of operation?
More are not needed! When I first started, I worked out there were about 400 patients in the UK who might benefit from this operation. One surgeon can probably treat all 400 in their career. The technique is very different from other types of neurosurgery. I’m sure as I get older I will need to make sure another surgeon is trained to take over. You only need one or two surgeons in the UK to do this procedure as it needs particular expertise.
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.

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.

‘Dystonia is an almost 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.
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.

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.
## Case notes
### Mrs Caroline Minger

**Condition:** Cervical dystonia  
**Age:** 44  
**Address:** Lives in Rainham, Essex with husband Pierre and has three children, Natasha (22), Francesca (18) and Mark (12)

**Patient notes:**
“I started with tremors in my neck and head. This made simple tasks become more difficult, like putting on makeup. It was hard to keep my head still and my family couldn’t understand. ‘Don’t be so nervous,’ they said. But I couldn’t help it. My head just wouldn’t keep still. This went on for a few years and I was prescribed with anti-depressants. I knew there was something else wrong and eventually I was referred to the Queen’s Hospital in Romford under Professor Findley. I’d never heard of the condition before when I was told I may have dystonia. I started on botulinum toxin injections about three years ago, these are repeated every 2 to 3 months. The injections do help tremendously. I started seeing Liz about the same time as commencing the injections. First it was home visits and then to the nurse-led clinic. I really appreciate the help and support I receive from Liz on a regular basis.”

Liz Edmonds RGN works for Havering Primary Care Trust as a motor neurone disease and dystonia nurse specialist and operates her nurse-led clinic from the Disablement Services Centre at Harold Wood hospital.

**Diagnosis:** The great thing about Caroline is that she is very receptive to education about her condition and she is aware of when support is necessary and where it should come from. She has had to cope with problems other than cervical dystonia which have been very hard because she is a sensitive person. She is coping because she knows the support is on-going which I think is highly important for her well-being.

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### Dystonia Society
**Information leaflets available:**

- Dystonia explained
- Blepharospasm
- Hemifacial spasm
- Writer’s cramp
- Myoclonus dystonia
- Paroxysmal dystonia
- Dystonia & genetics
- Laryngeal dystonia  
  *(Spasmodic or spastic dysphonia)*
- Oromandibular dystonia
- Cervical dystonia  
  *(Spasmodic torticollis)*
- Online resources (other websites)
- What you need to know about my condition (care information)
- Your starter for ten (for telling people about dystonia)
- Access to Disability Living Allowance
- Ptosis eyelid props / lundie loops
- Access to the Blue Badge Scheme
- Blepharospasm Sight Impairment services available
- Blepharospasm or facial dystonia exercises
- Coping strategies for oromandibular dystonia
- Coping strategies for blepharospasm
- Coping strategies for paroxysmal dystonia
- Coping strategies for myoclonus
- Driving & dystonia
- How to find a therapist
- Self-help techniques
- Sensory tricks & dystonia
- What special educational equipment is available
- Getting the best from neurological services
- Graded neck exercises
- Cranial dystonia  
  *(Meige’s syndrome)*
- Tardive dystonia / dyskinesia
- Dopa responsive dystonia
- Generalised dystonia
- Facial relaxation exercises for blepharospasm
- Deep brain stimulation (DBS)
- Botulinum toxin treatment
- Statutory benefits
- Dystonia Guidebook for Kids (8–12 yrs)
- A Guidebook for Young Adults who have dystonia (18–30 yrs)

We also have a selection of videos, DVD’s and books that can be bought or borrowed. Please call our office number on 0845 458 6211 or our Helpline 0845 458 6322 for more information. Or you can visit our website [www.dystonia.org.uk](http://www.dystonia.org.uk)
Notice board

Coping with cervical dystonia

Tips from members:

- I go swimming and take part in Pilates classes. These are gentle exercises, they help to relieve stress and I feel good afterwards.

  “Pilates develops the body uniformly, corrects wrong postures, restores physical vitality, invigorates the mind and elevates the spirit.” Joseph Pilates

- I avoid anything that jolts the neck and shoulders such as lifting heavy weights above the head as I find it causes more spasms and pain afterwards.

- I enjoy listening to music and watching TV as it helps me to relax. When I am relaxed the pain and spasms are easier to cope with.

- I put a newspaper down the back of my jumper to help with driving! It seems to support the neck and shoulders.

- When I am in a lot of pain or discomfort I use heated wheat packs to relieve it.

- I find that gentle massage is really helpful as it seems to relax me and makes the pain and stiffness easier.

- Having physiotherapy really helps but it is important to have a therapist that knows about dystonia and how it affects you.

- I use relaxation and meditation techniques, they seem to make the dystonia less active.

- I know that avoiding getting stressed and anxious makes my dystonia better.

- I have found that if I avoid lots of tea and coffee and other caffeine drinks, my dystonia seems to be less troublesome.

- I find that I need to eat a healthy diet regularly, otherwise I get really tired which makes the dystonia worse.

- I use a variety of high backed chairs or seats to provide head support, which reduces the discomfort I get from my dystonia.

- I touch the right hand side of my head or face which seems to realign the head and neck and stops my head turning.

- I have trained myself to use my PC mouse with the left hand so that if I need to, I can support my head with the right hand.

- I now drive an automatic car so that I can support my head with my right hand if I need to.

- I try to keep people on my left hand side as it is much easier to see and/or speak to them without straining.

- I have an excellent pillow on my bed which provides good support. Mine is a Tempura foam one but there are others you can buy.

- A neuro-physiotherapist has given me graded neck exercises which I do every morning. (A video providing graded neck exercises is available from UK Office.)

- A trainer at my gym has developed a fitness programme incorporating several exercises for my neck, shoulders and upper back which I do regularly.

The above is feedback from others with dystonia and may be called sensory tricks. We have no clinical evidence that they will work universally, and therefore it is up to yourself if you want to try them out. Please do feedback anything you try and find works for you.
Cervical dystonia

Treatment centres

Map shows clinics offering treatment for cervical dystonia

(Note of caution: These are the centres we are aware of. Please do call the Helpline on 0845 458 6322 if you notice any omissions or if you would like further information.)
## Cervical dystonia List of clinics

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<th>HOSPITAL NAME / CITY</th>
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**Dystonia matters!**

HELPLINE ● 0845 458 6322
Your Questions & Answers...

Q. I am considering Deep Brain Stimulation (DBS) but I am not sure if it would be suitable for me because I have heard it works best on one specific area of the body and I have generalised dystonia.

Actually DBS works very well for more widespread dystonia, possibly better than for focal dystonia (located in one part of the body). The selection of patients for DBS is done very carefully at each of the 15 centres in the UK so you should be confident that if you are selected for the procedure there is a good chance of a response.

Q. I have a 5 year old son who has a rare metabolic condition and symptomatic epilepsy and dystonia. He is prescribed Levodopa in the form of Sinemet suspension every 6 hours. I would like to change his medication times for the purpose of convenience and would like to know if it is necessary to keep to the 6 hourly intervals for the Sinemet? Could it still be administered to him safely at 12 hourly intervals?

The suspension form of Levodopa has a relatively short half life which is why it needs to be taken more often. There is a slow release version of Levodopa that can be taken 12 hourly but this is only available in tablet form so it is probably not helpful. Dr Warner would suggest that if you feel Levodopa is working and helping your son’s symptoms, then it is worth keeping to 6 hourly intervals.

Q. Do you have any experience or knowledge of dystonia affecting the bladder and causing an overactive bladder. If so, what treatments might be worth trying?

Dystonia itself does not affect the bladder muscles. If the dystonia is part of another neurological condition which has additional symptoms, then bladder symptoms can be seen, particularly if they involve the pathways in the spinal cord that control it. In these cases, there can be a number of different symptoms and there are different treatments for these. It would be worth asking to see a continence advisory nurse in the first instance and sometimes if the symptoms are bad, a urologist.

Q. Can you suggest a clinic or consultant that specialises in Dopa Responsive Dystonia (DRD)? I live Northern Ireland, but would be willing to travel to England or Scotland.

Most movement disorder specialists should be able to deal with this matter. As for individuals with a particular interest in DRD, in London both Professor Kailash Bhatia at the National Hospital for Neurology and Neurosurgery and Dr Warner at the Royal Free have an interest in DRD. In Sheffield, Dr Oliver Bandmann also has an interest in DRD.

Q. A member has just found out that her grandson has dyspraxia and is concerned that there may be a correlation between this and her dystonia?

Our Medical Adviser writes that he is not aware of any study that shows an association.

Q. I have secondary cranial and cervical dystonia as a result of a car accident. I have been receiving physiotherapy as a result of the whiplash. It has recently been suggested to me that I have botulinum toxin injections. I suffer from hypermobility. Does this mean that injections would not be effective?

You would need assessing by a neurologist regarding botulinum toxin injections to decide whether they might help. If any significant spinal problems are suspected you may need an x-ray or MRI scan.

Q. I would like to know if botulinum toxin injections can lower the immune system to viruses such as flu and colds.

Our Medical Adviser writes that there is no evidence to support this view.

Q. I was diagnosed with cervical dystonia and have been referred for botulinum toxin injections and to a pain clinic. I will have to wait six months for the clinic so in the meantime I has been offered cortisone injections for my neck. Is this an appropriate treatment?

Presumably the cortisone injections are for pain. Whilst there is no obvious interaction with botulinum toxin, it may be
that some of the pain is connected to your cervical dystonia and that the toxin can help. Steroid injections are sometimes used when there is evidence of either facet joint pain in the spine or if it is felt the pain relates to irritation of a nerve root in the neck. Therefore it seems sensible not to try both treatments together as if matters improve it will not be clear which one worked.

Q. Is there a connection between autism and dystonia? I have a friend who says that he has autistic dystonia?

• Our medical adviser writes that he is not aware of a diagnosis of autistic dystonia or of any particular link between the two conditions.

Q. I have a dent in my neck where I have received botulinum toxin injections for the past two years. When I queried the nurse about this I was told that the botulinum toxin injections are causing the muscle to deteriorate. Can you give me any information about botulinum toxin and muscle deterioration and the potential danger of this?

• Botulinum toxin is injected into the overactive muscles as part of the correct treatment.

Untreated the muscles hypertrophy (get bulkier) because they are constantly active, in the same way you can build up muscle bulk by specific exercises such as in body building. When these muscles are injected, this temporarily weakens them and with time they atrophy (get smaller because they are now less active). Shrinkage of the muscle is not a complication but usually a sign that the treatment is working. After a period of treatment, the dose of botulinum toxin may be reduced by your physician. This is a clinical decision made according to the symptoms and activity of the muscles.

Q. I am a mother of a fifteen year old daughter who has just been diagnosed with blepharospasm. I would like to know whether it is unusual to have this condition at such a young age and whether there are any studies that you could recommend to her? I am a qualified nurse and keen to research as much as possible.

• There is no evidence to support this, unless it is discomfort from dystonia that causes the inability to go to sleep. Dystonia actually goes away during sleep.

Q. I have had primary cervical dystonia for over thirty years and have always had really bad insomnia. Recently, I saw a neuro-psychiatrist in Toronto, Canada and he suggested that some of my insomnia may be due to my cervical dystonia, given the relationship between cervical dystonia and the basal ganglia. Do you think this is possible?

• There is no evidence to support this, unless it is discomfort from dystonia that causes the inability to go to sleep. Dystonia actually goes away during sleep.

Q. I have been having regular botulinum toxin injections which have worked effectively to manage my dystonia. However recently I have developed rheumatoid arthritis for which I am going to be prescribed the immunosuppressant called methotrexate. Will this have an effect on botulinum toxin? Can I still have the injections?

• Methotrexate should not have a specific effect on the use of botulinum toxin and you should still be able to have your botulinum toxin injections.

Q. My mother has recently had a probable diagnosis of Motor Neurone Disease. Her symptoms also seem to fit with the symptoms of dystonia. Do you know of any cases where people are diagnosed with Motor Neurone Disease when in actual fact they have dystonia?

• There really should not be any confusion between dystonia and MND. They are quite separate conditions with very different symptoms and prognoses. MND can easily be distinguished by an experienced neurologist using their clinical knowledge and a number of established tests.

Q. How common is dystonia?

• Dystonia is not a rare condition. The widely accepted figure for the incidence of dystonia in the UK is 40,000 people. However, many experienced physicians believe that dystonia is under-diagnosed and that the incidence is actually much higher. Professor Bhatia of the Institute of Neurology, London, believes it could be as high as 120,000 – the same incidence as Parkinson’s disease.
Reader’s letters
Have your say...

Ian Astbury, Somerset

Delay
I will probably have to wait until August for my next botulinum toxin injection at the National Hospital in London. This will be about six months after the last injection in early February.

I have been told that my previous ENT consultant is no longer taking these clinics and is to be replaced by another consultant who will start running the clinics from July onwards. It will mean many patients who are being treated for laryngeal dystonia are having to wait an extra few months (most normally attend every four months for injections) before they can get their treatment. This represents a terrible situation for everyone affected. What can we do?

Val Wells, Service Development Manager comments: ‘We have been aware of this problem for some months now and have been trying to work with management at the National Hospital to try and resolve it. However, to date they seem to be reluctant to work with us and to inform people about what is happening. We are currently reviewing how we can involve the media in order to raise awareness of the issue. For those of you affected by this problem, please contact me at the UK office where I can provide you with information about other sources of treatment.

Irene Davison, Derbyshire

Fantastic support
I developed dystonia over seven years ago; it started with blepharospasm and other facial symptoms which I now know to be Meige’s syndrome and over time it has become a more generalised dystonia. I also developed the wobbly head! Until I was diagnosed and received the first injection around my eyes, I was virtually blind – all this on top of suffering from ME in varying degrees of severity!

But, hey, with the fantastic support network that I have from my family, the Dystonia Society, the Sheffield ME group and the wonderful specialists and nursing staff at the Royal Hallamshire in Sheffield, not forgetting my GPs and our lovely caring group of friends, I get through.

Margaret Parkes, Cornwall

Cranial Osteopathy
I have had blepharospasm for twenty years and have trouble reading. Your newsletter is one of the few I can read thanks to the dark, big print and this is much appreciated.

For about thirteen of those years, I had botulinum toxin injections which were good. Then I went to a cranial osteopath in Truro. I still attend every six weeks. For a long time I haven’t needed injections as my eyes keep open nearly all the time and never tightly close.

I wonder if a trial can be conducted on this form of treatment? I go to the Walsingham Clinic in Truro. If it works for me, surely it can help others with this condition.

Editor’s note: We would be interested in hearing from you if you have had a similar experience to Margaret’s.

Kate Forsyth, Somerset

DBS Group?
I had deep brain stimulation (DBS) last November and wonder if anyone would be interested, under the auspices of the Society, in creating a group for those who have had or are about to have this type of surgery? This procedure has an excellent track record of success.

However, I feel that once you have had DBS you almost become a different breed of dystonia patient – left much in control of your symptoms but still feeling a little overwhelmed. I would be most interested to hear from others with a view to creating such a group that would provide feedback and support from those who have been through it.

There are probably not that many of us and I understand that much contact these days is ‘virtual’ (via email and the web). But if it stops people feeling isolated or alone then that has got to be a good idea.

Editor’s note: Angie Brown at UK office would be interested to hear from anyone who may wish to join a DBS group (angie@dystonia.org.uk)

PS. I forgot to mention that the feature on blepharospasm in the last issue was fascinating, yet familiar in its content. It always makes me feel more normal when reading about others with similar problems and symptoms. Also the magazine design and layout is fabulous; very manageable and readable, even with weakened limbs. Thank you.

Irene Davison, Derbyshire

Delay
I will probably have to wait until August for my next botulinum toxin injection at the National Hospital in London. This will be about six months after the last injection in early February.

I have been told that my previous ENT consultant is no longer taking these clinics and is to be replaced by another consultant who will start running the clinics from July onwards. It will mean many patients who are being treated for laryngeal dystonia are having to wait an extra few months (most normally attend every four months for injections) before they can get their treatment. This represents a terrible situation for everyone affected. What can we do?

Angie Brown at UK office would be interested to hear from anyone who may wish to join a DBS group (angie@dystonia.org.uk)
Reader’s letters... (continued)

PLEASE NOTE: The views and opinions expressed in Reader’s Letters are not necessarily those held by the Dystonia Society.

• Nina Murray, via email
Can you help?
I don’t seem to be able to get answers here in Australia about my dystonia. It’s always the same scenario: ‘We know you have some sort of dystonia but we’re not too sure what type’. It is just driving me to distraction. If I can find a physician who understands my dystonia, it will be something. To this end, I am coming to the UK to see Professor Kailash Bhatia. My problem now is to locate some accommodation in the UK, before I can make an appointment or even book flights. If someone is able to accommodate me, I would be willing to pay a reasonable price for a bedsit or available room. Anywhere would be fine for me, just as long as it is near a bus stop!

Editor’s note: To respond to Nina, please contact Angie Brown at the UK office.

• Christine Carr, Midlothian
No mention
I have looked at your website for quite some time and it’s really good and straight forward to navigate. However, I notice no mention is made of torsion/generalised dystonia. I have this condition and, although rarer than other forms of dystonia, perhaps some information on this is required. Thanks to all who work tirelessly for the Society. I definitely appreciated your support when I was first diagnosed in 1987 after 15 years of being labelled as a crack pot.

Editor’s note: Thank you for your suggestion. We are in the process of producing a leaflet about generalised dystonia which will be ready in a few months.

• Sharon Cattermole, Essex
Shiatsu
I attended the Herts group meeting and one of the members, Elizabeth McKay, gave a talk on how shiatsu has helped with her dystonia and I volunteered for a ten minute treatment.

At that time, I was only six days away from my next three-monthly injection and my spasmodic torticollis was at its worse. After the session, during which time I lay on cushions on the floor whilst Elizabeth stretched my arms and worked on the pressure points for the gall bladder, I had some immediate relief. My neck felt much looser and not so painful. I was able to turn my head and I had a restful nights sleep.

I believe that students who are studying shiatsu (or any type of massage) often require volunteers to practise their techniques and this may be an avenue to pursue for anyone who wishes to try out a treatment without financial outlay.

• Nikki Parkin, Herts

Group forum
The Cambridge Forum for group coordinators in April proved to be an extremely interesting day. It was a great way of getting people together from other areas (in this case, south east) who may not otherwise meet up.

I feel that the forums are an excellent way to get people together and exchange ideas on treatments or, as was the case with this forum, to discuss ways of raising the profile and awareness of dystonia; how to set up a local group and ideas on how best to welcome new people to a local group.

Kathryn Haigh and Una Rennard did a great job in setting everything up and both are great motivators, encouraging the group to work together as a team.

• Barry Fagg, Norfolk
Twisted
Your readers may be interested to know that there is a film on dystonia called ‘Twisted’ and from observations on US dystonia websites it has met with some acclaim. By chance it has come to my attention that this film (released last year) has been screened on television in the UK. Unfortunately, it is on Sky – Real Lives Channel 253. It was screened several times earlier this year and looks like it is repeated frequently.

Editor’s note: We have a copy of the DVD that we would be happy to loan out to interested members.

We are always interested in hearing from you. Please send your letter to the Editor, Dystoniamatters!, Dystonia Society 1st Floor, 89 Albert Embankment, London, SE1 7TP

HELPLINE • 0845 458 6322
Fundraising news

Congratulations!

We are always extremely grateful to those who ask guests at a special occasion to make donations in lieu of gifts...

Sir Gordon Jewkes, a former governor of the Falkland Islands and Lady Jewkes asked guests at their wedding for donations to the Society and in return we received over £2,000.

Sir Gordon & Lady Jewkes

Mr and Mrs Fred Pulman of Windsor did the same at their 40th wedding anniversary and as a result of their guest’s generosity we received donations totalling £425.

Nifty knitter

You may recall that Win Gladding from Oakham raised over £500 by knitting and selling scarves over the Christmas period. She has now sent us another £200 which she raised by knitting Easter chicks. She tells us that she is running out of ideas for things to knit in future for us. So if anyone has any good ideas, please let us know.

Sharon Nobbs has been one of the leading lights that led to law firm, Burges Salmon, her employers, raising just under £4,000 towards the Living with Dystonia Day in Bristol earlier this year. The inspiration to Sharon’s sterling work for the Dystonia Society has been her 81 year old grandmother, Ruby Russell, who has had dystonia since the age of 22 years. “My grandmother suffers with generalised dystonia affecting the whole body and her sister has the same, although not quite so bad,” says Sharon. “I find her absolutely amazing and a credit. Despite everything, she has never let this illness beat her down. I am so proud of her and proud she is my grandmother, a woman who I look up to in so many ways.”

Good neighbours

A garden party was held at the home of Marlene Presswood in Chesterfield which raised £363 towards Mansfield cyclist Alan Foreman’s sponsorship in the Rutland cycle ride in May.

HYDE PARK CHALLENGE

Each year we have a stalwart band of runners, led by Coral Datta, who run the Adidas Women’s 5K Challenge in Hyde Park, London, to raise funds and awareness for the Society. This year’s event will take place on Sunday 7 September in London, Birmingham and Liverpool. There will be one of our new t-shirts free for everyone taking part.

To find out more please check www.womenschallenge.co.uk or telephone Joy Bourne on 020 7793 3654.
The Sydney and Phyllis Goldberg Memorial Charitable Trust have once again supported our work by making a donation of £13,500. We would not have reached the milestone of our 25th anniversary without the loyal and generous support of the many trusts and foundations such as the above.

Fundraising and events...

The Marshall clan from Blyton, near Gainsborough have organised several fundraising events which raised over £800. A successful coffee morning, with a raffle and tombola stall, was followed by Ben Barley, the fiancé of Gillian Marshall’s niece, running on our behalf in the Lincoln 10K run in March.

Glasgow run

Lynne McAulay (pictured on the right) took part in the Glasgow 10K run on our behalf and raised over £500 with more, hopefully, to follow. A fantastic effort!

PAINTBALL anyone?

A company that runs paintball centres over the UK has donated 100 booklets of Priority Pass tickets worth £49.95 each which can be used as raffle prizes at future fundraising events. Paintball Days are said to be very popular with people of all ages. All you have to pay for is the paintballs. If you are interested, please contact Joy Bourne on 020 7793 3654.

Dystonia Matters! HELpline 0845 458 6322

Fundraising news

Dystonia Dynamos

Congratulations to Gill Jepson and her team of around 50 walkers, all kitted out with our new t-shirts, who took part in the 40 mile Keswick to Barrow walk in May. All but two of the Dystonia Dynamos team completed the trek in what Gill describes as ‘appallingly hot’ weather conditions. The team finished 10th fastest and two of the walkers featured on BBC North West news over that weekend. Gill is already planning a team for next year’s walk!

Excellent Essex

Well done to the Essex group who have recently organised two successful fundraising events. A fundraising dinner in Benfleet raised a whopping £212 and recently Sharon Cattermole of Leigh on Sea held a wine tasting which raised a further £145.

Trust gift

The Sydney and Phyllis Goldberg Memorial Charitable Trust have once again supported our work by making a donation of £13,500. We would not have reached the milestone of our 25th anniversary without the loyal and generous support of the many trusts and foundations such as the above.
**A day in the life...**

**Liz Edmonds**

Liz Edmonds is a dystonia nurse specialist at the Disablement Services Centre at Harold Wood in Essex. The first nurse-led clinic in Barking and Dagenham was established late last year and this one at Harold Wood was set up earlier this year. It has increased from once to twice monthly for half-hour consultations.

- **Why have you set up the nurse-led clinic for dystonia patients?**
  These are in addition to the clinic for botulinum toxin injections, as a need has been identified for separate specialist consultations to provide support on a one-to-one, face-to-face basis to discuss how their condition may be interfering with daily living, together with the psychological care to help them discuss what impact their dystonia has on them and their family.

- **How does the clinic work?**
  The patients living in the area I cover and who are on my case load are contacted by letter or telephone. They attend a clinic at an agreed appointment time, although a home visit can sometimes be arranged if necessary. At the end of that consultation they will have an appointment to attend another nurse-led clinic at an agreed date and time.

- **How long do you envisage continuing with this support?**
  For some people, this may need to be monthly; for others it could be two monthly or longer. It depends on what arises out of that consultation and also my assessment of them as to how they are coping.

  If somebody has depression, it can make them feel rejected and contributes to very low self-esteem. If that’s not supported and dealt with, it can lead to further depression and they end up requiring anti-depressant therapies. Other people’s attitudes towards them doesn’t help.

The impact dystonia has on their daily activities such as the simple things we all take for granted, like putting on make-up or inserting contact lenses, can exacerbate the abnormal movements caused by dystonia.

- **You talked about attitudes. Is that the people with dystonia or their family and friends?**
  It’s the attitudes of the people they meet. Patients often talk about people appearing to laugh at them or they’ve been told that there is something emotionally wrong with them and there is a degree of negative attitude towards them. They feel a prejudice directed towards them and they’re not understood. Some patients have said people thought they were drunk and this upset them. Others have said that they felt people had avoided them because they hadn’t had the decency to come over and ask them what was wrong. People shut themselves away and that makes them feel isolated.

- **You talked about two clinics that you’ve been running this nurse-led service. How long have they been running?**
  The first clinic in Barking and Dagenham was set up in December last year and these clinics here in Harold Wood have been set up since January. They’ve increased from one to twice a month for half-hour sessions. You can do home visits if required although we’ve been encouraged to cut down on home visits and see people in the nurse-led clinics. I try to encourage patients to take what support is offered to them to enable them to cope and, hopefully, this will increase their resilience.
In my opinion...
by Janet Baird

“It’s psychological, you need a psychiatrist,” said the NHS. “You are in some self-inflicted personal hell,” said a friend who had changed into a hippy, dippy psychobablist.

No, I was not the local head case, just a woman who was living with undiagnosed oromandibular dystonia...

Finally in 1991, I met a doctor who told me about a physical condition called dystonia. At last it had a name and I was not a nutcase.

At my lowest point I was feeling suicidal due to other people’s ignorance and their cruel remarks (rather than the disease itself). It was then that I went on a course to study iridology which is the examination of the iris of the eye to determine factors that are important in the prevention and treatment of disease. The reason for my dystonia was staring me in the eye, if you will forgive the pun. On the left side of my mouth was an old mercury filling which had been leaking into my mouth for many years.

Following the removal of the filling by a mercury free dentist who used the correct procedure to protect the patient (any other method is dangerous) and chelation treatment to remove the mercury from my body, I am now 95% cured. I am not suggesting that everyone who has mercury fillings and dystonia should rush to have their fillings removed or that this is the cause of their dystonia. But anyone who has any metal in their mouth should at least consider that this may be the cause.

Recently a dystonia ‘expert’ said the only way to find out if mercury causes dystonia is to pull out everyone’s teeth, ha ha! There is a much less traumatic way – ask your GP for a blood test for heavy metals.

Editor’s note: We would endorse Janet’s comments and confirm that the British Dental Association recommends that you don’t have your fillings removed unless they need to be renewed.

Dystonia Society
Marathon tally tops £10k

Our four intrepid runners, Madeline Boardman, Beth Scorer, Stephen Killick and Paul Kendall, all successfully completed the Flora London Marathon in April in what were truly appallingly cold and rainy weather conditions.

First home, in an astonishing 3.15 hours, was Maddy which enabled her to finish in the top 1% of women competitors and the top 7% overall. Maddy said: “I undertook this run because my sister, Felicity, has generalised dystonia. When I hit the wall at 22 miles, my body was screaming at me to stop but I knew that no matter how bad it felt, it’s nothing compared to what she and others with dystonia must endure. Their pain doesn’t end when they cross the finish line in the Mall.”

Beth’s mum, Toni Scorer, a primary school teacher who has dystonia, organised a ‘tracksuit and trainers day’ at her school to help raise money for Beth’s run.

Grateful thanks to Stephen and Pauline Killick for a wonderful team effort – he did the running and she helped raise a massive £4,079 in sponsorship. Pauline is operations manager for Merz and the company agreed to match whatever the Killicks raised by making a donation to ADDER. All in all, the fundraising was phenomenal and with Gift Aid, the final total should be around £10,000.

See also Maddy and Felicity on page 5.
Cycling for dystonia
*Rutland Water cycle ride*

- Right: Tony Rudge & his daughter
- Left: Professional belly dancers, Katherine Caddick, Sarah Hodgson & Elinor Jackson with Nikki Parkin, Cara Eckstein & Philip Eckstein
- Below: Team members from Tribal Group

- Above: The couple that finished first!

- Left: Francesca Isherwood from BBC Children’s TV ‘Roman Mysteries’
- Right: Christine Chapman & family

**WELL DONE!** Jan Ferguson from Nantwich, Cheshire raised **£940** in sponsorship

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The dystonia society