

NEURO KEY

An Alliance supporting people
with neurological conditions

DYSTONIA

‘Unlocking minds and opening doors’

Open Door series by Neuro Key



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Foreword

Since inception Neuro Key, the working name of the Charity, Tees Valley, Durham and North Yorkshire Neurological Alliance, has harnessed lived experience as an educational tool to improve service delivery and professional understanding of not only the common threads between neurological conditions but also the complexities. From enabling participants to take part in research, delivering lived experience seminars, making sure people can respond to surveys and strategic consultations or supporting people to lead the operational direction of the Charity, we are passionate about our social purpose.

We promote a culture of mutual exchange to broker common purpose across all neurological conditions. More importantly, we do not define by the deficits a condition may impose on people's lives. We concentrate on the value of lived experience to professional knowledge and skill, the contribution to the evidence base and for people themselves to share and learn from each other. By supporting people to be more confident in knowledge sharing and cooperation across social divides we sustain a well-informed neuro community to improve self-management skills, neuro-literacy and social capital.

We foster collaborative working partnerships to respond, support and sustain a high customer service focus to encourage creative problem-solving and efficiencies by reducing risk and crisis. We strive for excellence with agreed standards and outcomes.

Our **Open Door** series of booklets has been developed to acknowledge the challenges of living with a neurological condition that is misunderstood, subject to media-driven or political myths and is neither prevalent nor the focus of national publicity campaigns.

Dystonia is a neurological movement disorder, the 3rd most common movement disorder behind Parkinson's and essential tremor. There are about 100,000 people with Dystonia in the UK who live with uncontrollable muscle spasms triggered by incorrect signals from the brain, which can be very painful. Dystonia can affect any region of the body including the eyelids, face, jaw, vocal cords, torso, limbs, hands and feet. Depending on the region of the body affected, each type of Dystonia has a separate clinical name.

One of the motives for this booklet is that Dystonia is life long and there is no cure.

The following stories are all real life narratives written by people living with Dystonia and contributing to their communities. We have adopted fictional names to protect their identities.

NEURO KEY

February 2022

Grace's Dystonia

When I was around 45 I had a really busy life, I worked full-time as a chartered engineer, I ran a Beaver Scout group and had a husband and two teenage sons.

I was the sort of person who needed 8 days in a week!

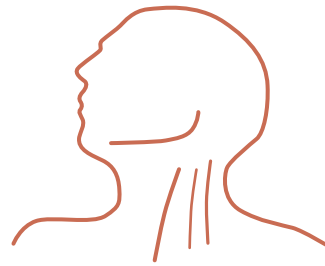
I first began to suspect something was wrong with my health when my eyes became ultra-sensitive to light. I had my eyes tested, bought new sunglasses and was forever putting the visor down on my car windscreen, even on a dull day.

After a few weeks my eyelids began to clamp shut and the only way I could open them was to prise them open with my fingers. I became what I now know is called 'functionally blind'. There was nothing wrong with my eye sight but I couldn't see through closed eyelids. I had to take time off work and of course visited my GP. I was fortunate in that my GP recognised the symptoms immediately and referred me to a neurologist who instantly diagnosed Dystonia, in particular my type was called Blepharospasm.

This was a difficult time for me and my family, I had always been outgoing, enjoyed doing things with my family, enjoyed my work (most of the time) and socialising. I very quickly became almost housebound and certainly couldn't be employed. I couldn't go out of the house alone. I couldn't read, watch TV, use a computer or drive, all the things I had taken for granted my whole life. I felt like the life I knew was over, I don't mean that I wanted to die, but that my WAY of life was over.

Over the next few months my symptoms got worse and spread to my jaw and neck. Eventually, after about 18 months I had fully developed dystonia in my eyelids, jaw, neck and shoulders, known as Meiges syndrome. I had begun to go out on my own but it was very difficult, I had to hold one eyelid open with my fingers (using the other hand to carry bags etc), but the spasms were so strong that my eyelid would still close and of course having my hand so close to my eye restricted my vision when my lids were open. At home I regularly bumped into doors or furniture (Graphic courtesy Dystonia Europe) and also cut and burned myself while trying to cook.

Apart from the occasional bad day I tried my best to remain positive and I had a great deal of support from my husband, sons, extended family and my friends, which helped me a great deal.



Graphic - Dystonia Europe

I was receiving treatment of botulinum toxin injections, the most common treatment for dystonia to help restrict the muscle spasms and I would typically have around 20 injections every 12 weeks. However, they were doing nothing for me.

In fact sometimes the side effects were making me worse.

...almost housebound and certainly couldn't be employed. I couldn't go out of the house alone. I couldn't read, watch TV, use a computer or drive...

My consultant suggested I have the nerves to my eyelids severed and after a great deal of thought I agreed. The operation came and went and while the spasms were not so severe, I still could not open my eyes naturally. Around this time I realised that I had to just accept that my dystonia was not going to go away and was not going to be relieved by treatment.

That was when I began to get my life back again. I began to socialise again, go out more often on my own, I got the bus wherever I needed to go, when out shopping. I just took my time and tried not to bump into anyone.

About 18 months after my surgery I realised my eyes were staying open for several minutes at a time. This slowly increased until a few weeks later my eyes were behaving normally. That was almost 11 years ago and my eyes are still

I did warn you that each type of dystonia has its own name.

behaving normally. If this had been as a result of my surgery it would have happened instantly and would only have lasted about 2 years.

My consultant was confident in telling me that

my eyelids were in remission, hooray!

I do still have dystonia in my jaw, neck and shoulders which is called Oromandibular dystonia.

I did warn you that each type of dystonia has its own name.

So, I still get botulinum toxin injections every 12 weeks and I usually get around 20-24 injections each time. My dystonia is about as good as it is going to get. I don't get complete relief, my spasms never really go away but the toxin does reduce them a little which in turn reduces the pain level.

I have had complications associated with having dystonia in my neck. Mainly, I occasionally get a spasm in my larynx, unfortunately for me my larynx closes which means I can't breathe. This was terrifying the first time it happened. When I told my consultant about it he told me not to worry, the worst that could happen is that I will pass out at which point my muscles will relax and I will begin to breathe again, easy for him to say!

During all this time, I resigned from my job which was a huge decision for me and my family to make...

I do try to follow his advice and so far have only been hospitalised with it once. Sadly, the first hospital I was taken to didn't have a clue about dystonia and in the emergency room the only thing I was offered was a cough sweet. I was then transferred to another hospital and taken straight

DYSTONIA EUROPE

to the resuscitation room where my condition was treated appropriately.

During all this time, I resigned from my job which was a huge decision for me and my family to make, but honestly it has been one of the best decisions we have made. As I said earlier I was a very busy person, like most people are these days, but giving up work gave me time to relax, think about my family and my future.

I also became involved with a local charity which supports people with dystonia called Action for Dystonia, Diagnosis, Education and Research (ADDER) and I have met lots of people who also have dystonia in various forms, there are a lot of types of dystonia!

I began to volunteer with ADDER and quickly became involved with talking to medical students, educating them about dystonia. This is something I really enjoy and I find it very satisfying each time a young medical student stays after the lecture in order to ask more questions, especially if he or she tells me they would like to treat dystonia in the future.

There aren't many dystonia clinics in the UK and many patients have to travel long distances to get their treatment.

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The story is much the same across Europe and I am now on the board of directors for a charity called Dystonia Europe, I was recently elected into the post of secretary.

My life now is as busy as it was before Dystonia hit me, I still volunteer with ADDER and I am secretary, treasurer and administrator for the Charity. In my role as secretary for Dystonia Europe, I undertake some travel around Europe and I am also the UK Ambassador for an app that Dystonia Europe has developed called MyDystonia.

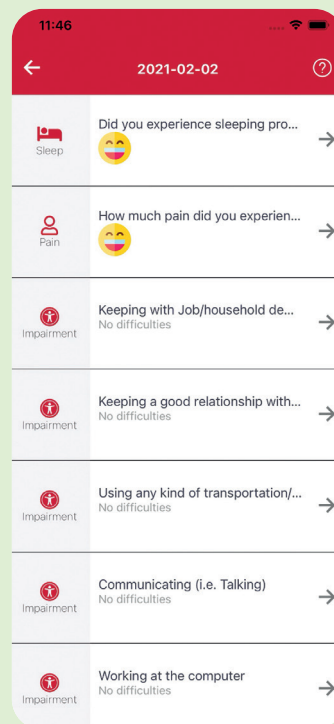
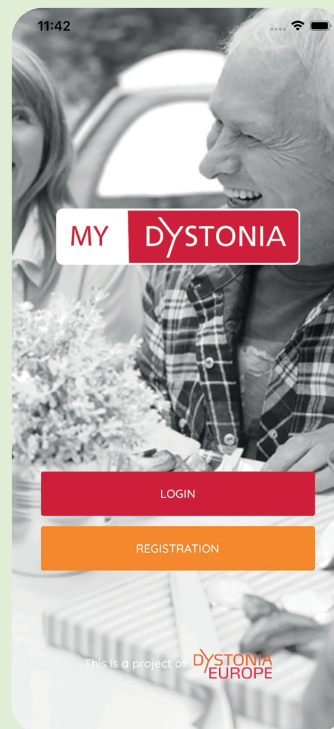
The app is an electronic symptoms diary, patients record their symptoms daily, weekly or at intervals to suite themselves, the app then produces graphs of their symptoms which they can show to their consultant. I do this myself and my consultant finds it very easy to understand how I've been in the 12 weeks since my previous appointment.

Aside from my 'dystonia' work I also help with the care of my 2 beautiful granddaughters while their parents are working and I give support and care to my elderly mother.

I am also a member of the Patient Participation Group at my GP practice and have recently done voluntary work at their Covid 19 vaccine clinics.

As well as all that I love being creative, and find that while I am making something my dystonia fades into the background. I do a lot of knitting and in fact, I cannot watch television without knitting. If I try, my dystonia makes my head shake so much and so severely that I can't actually see the screen.

I also enjoy time as a silversmith and I am a member of group of amateur silversmiths who meet in a studio once a month to make jewellery and help each other with tips and ideas. I also enjoy making greeting cards for birthdays and Christmas. Almost forgot to say, my social life is as busy as it ever was, thank goodness!



Jeanette's Journey with Dystonia

I first noticed that I had a problem with my neck, seventeen years ago when I was aged 43 years. The main difficulty was trying to turn my neck especially when crossing the road, the situation very quickly worsened in that my neck was turning to the right. At the time I was working as a financial adviser and I noticed when talking to clients that my neck was turning and making it difficult to do my job on a daily basis.

Not having any luck with my own doctor, I then made an appointment with a local chiropractor...

My first thought was to make an appointment with my doctor. I did mention to her that my mum and various other members of my family had what had been diagnosed as a 'Familial Tremor'. At first, she dismissed this and thought I had maybe pulled a muscle. Not having any luck with my own doctor, I

then made an appointment with a local chiropractor, asking me to make appointments with him twice a week until it was sorted out. After about a month he then said that he thought it might be a problem with my jaw, at which point I lost faith in him as I knew that was not the problem.

Realising that I had an ongoing problem and I was getting very frustrated, my father recommended that I made an appointment with a physiotherapist at the local Nuffield Hospital. At the appointment I again mentioned the problem that my mum and various members of my family were having. Well into the appointment, the physiotherapist recommended that I make another appointment with my GP and ask for a referral to the local Neurology department.

Eventually I received my referral to the Hospital and the consultant immediately diagnosed me with Cervical Dystonia, also called Spasmodic Torticollis, a painful condition in which neck muscles contract involuntarily, causing the neck to twist or turn to one side, which in turn causes involuntary movements and neck spasms. He referred me to a neurologist

at a rehabilitation centre where they could give me botulin toxin (Botox) in my neck to help with the spasms and the twisting.

Whilst a bit of a "roller-coaster", with good days and bad days, Botox did help to a certain degree for a number of years. However, within the last three years the effectiveness of the Botox started to reduce and my symptoms have worsened. I was in a lot more pain. The doctor suggested that she did a test to see if my body was building up antibodies to the Botox which can happen when injections are given over a number of years and the results showed that this was the case. It was suggested that I should have a period without Botox injections and this went on for a very difficult year. The next stage was to try different toxins but although this did help symptoms slightly, there was no significant change and the spasms worsened and continued in a lot of pain.

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Within my Dystonia support group a number of friends have had the Deep Brain Stimulation (DBS) operation. This is a neurosurgical procedure involving the placement of a device called a Neurostimulator which sends electrical impulses, through electrodes placed to specific targets deep

into the brain. This is connected to a relatively small, long-life, rechargeable battery placed under the skin in the chest, the frequency of the impulses controlled by a device similar to a television remote. The low-level electrical impulses interfere or can block the random impulses caused through Dystonia and reduce or even stop the involuntary movement spasms. I discussed this operation with the doctor at the Centre and decided that I had nothing to lose in looking further into it.

She referred me to the Neurosurgeon to see if I would be a suitable candidate.

Unfortunately, my first appointment with the Neurosurgeon had to be a telephone appointment as we were in the throes of the first lockdown due to Covid-19. As I described my symptoms and the impact they had on everyday activities, she definitely thought the operation would help me. My next appointment was a face-to-face meeting with a specialist nurse who was extremely thorough. He too thought that the operation would make a big difference. The operation does not cure the disease but would hopefully help with my tremor, turning of my neck and the spasms.

I decided to proceed with the operation and had a face-to-face appointment with the Neurosurgeon around Christmas time 2020. Unfortunately, she told me that operations were being delayed due to Covid-19 and the strain of the virus on the hospital as a whole. However, she hoped I would be operated on before the end of summer 2021.

The operation does not cure the disease but would hopefully help with my tremor, turning of my neck and the spasms.

Then the good news arrived, the specialist nurse rang me in May 2021 to say that they were able to go ahead with my operation in 10 days. I was so grateful and the short period of time gave me very little time to think about it or get too anxious.

All went well with the operation – I went in at 7.30 am and was home by early afternoon the next day. In order to first recover from the operation, the device was not switched on for the first few weeks. At my first post-operation appointment with the specialist nurse, he switched the device on and set it up so that I could increase the stimulator myself to a certain degree. In the first few weeks I saw very little difference and then all of a sudden, I got to a point where the stimulator was set at a level where the difference was dramatic.



Suddenly, I was able to turn my head from left to right, walk without holding my head and even the pain has disappeared. I really feel as though I have been reborn and given a second chance to enjoy life. In fact my husband would go as far as saying that the operation has been like a 'magic wand'. The

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relatively small cuts on my scalp healed remarkably quickly and the speed in which my hair grew back was amazing. The battery in my chest is not noticeable under my clothes and seven months on the scar is fading fast.

I am so grateful to the neurosurgeon and specialist nurse who have really performed a miracle.

Tammy's story

It is due to my mam and dad that I am here today. Having toxemia my mam was told she needed a C section, but she wouldn't as I may not have survived. She then went into early labour. She was very weak and forceps were used to deliver me without being warmed beforehand. Dad was then told it was very unlikely that either of us would survive, but we did. Shortly after I was diagnosed as having Cerebral Palsy and only time would tell as to how it would affect me, but it would be highly unlikely that I would be able to walk and would be in a wheelchair the rest of my life and my ability to do anything for myself was doubtful.

How wrong they all were. I was walking at 15 months and doing most things a toddler should be doing when they were expected. When mam was doing the tea, dad would make a game of the exercises they were giving by the hospital, playing wheelbarrow races with me and my sisters, me being the wheelbarrow where I had to keep my hand flat on the floor and not use my wrist. Another game he did was pretend together, we were a bear and push my leg to move with his knee and chase my sisters.

I couldn't keep the calipers on no matter how many extra straps they put on...

of the spasms I had constantly. I couldn't keep the calipers on no matter how many extra straps they put on to try and secure them. I hated school. I was shy, conscious that I was different as I was the only child with a disability. I never saw one other disabled child in the school environment until my last year at school and was always being made fun of by the other kids.

At home, it was so different the kids in the street didn't seem to

They had to challenge the authorities to allow me to attend mainstream school and I was only told a few days before the start of term. I lost a lot of school as I always seemed to be in plasters before being fitted with calipers which never worked because

notice although at times I did and when I thought I couldn't do anything I would wander off and sit away from them, but my mam wouldn't have it she would pull me back amongst them to play and wouldn't hear the word 'can't'. She stayed outside with me till I was able to do things.

Even though I would be in tears she taught me to play 2 balls one handed (you all probably don't even know what I'm talking about) and in the end I could juggle 3 balls. She helped me to learn to play skips by literally dragging me in to the ropes to jump for my life. I think at times it caused a bit of disagreement between my mam and dad as I remember walking in on them having an almighty row when dad was saying that mam was being too hard on me and shouldn't push me the way she did. Her response was 'I'm not going to sit back. If she doesn't try she will never know what she can achieve on her own'.

At the age of 7 or 8 my walking deteriorated that badly they thought I would have ended up in a wheelchair. I used to see a consultant at the regional hospital and saw a neurosurgeon who suggested that I may benefit from a new

operation that was in the trial stages which could possibly help keep me on my feet and may even help me get some control of my hand. I had the surgery and after the op the consultant brought mam and dad to the side of my bed and ask me to show them my bad hand, but mam thought it was my good one as it was so straight and said, "No love your

...my mam wouldn't have it she would pull me back amongst them to play and wouldn't hear the word 'can't'.

I'm not going to sit back. If she doesn't try she will never know what she can achieve on her own'.

Mam never knew just how low I got but after a while I gave myself a good talking to and got on with things.

so many falls and, hand on heart, I believe helped me lead a normal life. I still had bad spells as the spasms still affected me, especially in my hand. I was offered the op again in the hope it would help the functions in my arm/hand but as they could not guarantee it wouldn't effect my walking I said no. In my way of thinking I never had much use of my hand so would have to start to learn to use it but the risks were too great, if my walking deteriorated I may have ended up in a wheelchair.

...helped me get over the anxiety I had and indeed still have from time to time.

prescribed. Mam never knew just how low I got but after a while I gave myself a good talking to and got on with things. I think being 1 of 7 children and having support from the parents I have, helped me get through that dark time.

In contrast to my time at school I had a great time when I left. Having left school with no qualifications the Careers services decided the only work I could do was on an assembly line in a factory that employed disabled adults. Again, due to my mam's persistence they eventually found me a place at a

other one." Then, broke down in tears when she realised it was my bad hand. I can't remember this and unfortunately it never happened again.

My walking however was greatly improved so we deemed it to be a great success as for years after I didn't have

When things got too much, I was given various meds which never worked, only made me sick. I had periods where I got so depressed especially in senior school and at one point took a lot more tablets than I was

rehab centre. It was arranged for me to attend a college for the disabled in Surrey. I went there to train as a telephonist but also had the opportunity to train as a punch card operator.

I grew in confidence and am proud to say that despite leaving school with no qualifications from the age of 17 to 60 I have been employed only taking a couple of years out when my boys came along. My career has always revolved around administration with various organisations and plenty of opportunities for promotions. I was the last man/women standing in a company who employed over 20 admin staff when one company went into receivership and once a new company took it over I helped its growth and re-employed several of the staff who were made redundant.

My final job has given me the biggest pleasure as it was supporting people with disabilities gain and sustain their employment. I started off as receptionist but ended as a regional admin/finance manager with 12 branches though the north of England. This was a very challenging and demanding role having to travel up and down the country but one I thoroughly enjoyed and helped me get over the anxiety I had and indeed still have from time to time.

My social life was good, in fact, I was never in.

The spasms were not too bad for a time. I was even able to wear platform shoes (which were the fashion back then) against my dad's approval and looking back he was right as I often fell but I wouldn't give them up, I didn't want to be different. I spent lots of my spare time going to keep fit and playing squash and badminton 2 or 3 times a week.

I met my husband at 19 and married 10 months later. I cannot

I broke a bone in my foot twice the first which I ignored thinking it was the spasms acting up and affecting my mobility.

thank him enough for standing by me as my condition started to really deteriorate. When I was about 32 and over a couple of years I broke a few bones, one being the knee on my good leg which I thought was just fluid on the knee so ignored for some months and it had started to heal before I went to get it looked at. Then I broke a bone in my foot twice the first which I ignored thinking it was the spasms acting up and affecting my mobility. The second break happened just by my foot not clearing a gap in the pavement. I was in so much pain it was unbearable I and could not stop crying.

When the doctor saw me, he said I wasn't helping myself it wasn't broken and I was overweight. My sister who was with me at the time wiped the floor with him and made him prescribe Valium to help me relax and relieve the spasm. It was the next day when she took me to hospital and they saw the new break and the scarring of the first one. That was in the June.

They decided to put me in plaster which despite me telling them it wouldn't work as when my foot is restricted the spasms go mad, after 3 hours or so they plastered me up gave me Valium to take home to try and keep me relaxed. Every time I went back they repeated the exercise as the break hadn't healed.

In the November they decided I needed an operation to put a pin in and that I should stay in plaster till then. I had been putting too much pressure on my husband, was worrying my small sons to bits so I said, "No way was I going to have any more plasters, just leave it alone until the surgery".

After one surgery date was cancelled when I was actually on the ward ready to go down for the procedure, I eventually went down a few weeks later to wake up and be told the

bone had started to heal by itself so they decided to let it continue healing itself.

I never really got back to how I was before having another stress fracture some years later. I was upset for a long time as I found it very difficult to accept that my mobility was deteriorating so much I was told I had to see a psychiatrist

because I was always crying every time I went to the doctors. I eventually agreed but only to shut the doctor up. I went to one and refused to go back as he just wanted to talk about my relationship with my husband which despite us having gone through so much was good. After a lot of persuasion from my new doctor I went back to see a second and had a good meeting. He understood that the only problem I had was I was sad and in a way grieving over the loss of the life I had till things started to go wrong with my disability which is exactly how I was feeling.

I learned to drive to help me get around, eventually accepted having to use a stick and in recent years a wheelchair at times, although I hate to be pushed and wherever possible use my electric chair.

Although I don't work now, there is life in this old dog yet and after getting over yet another wobble, I am now a volunteer for the Samaritans, a listening volunteer and currently am the Director of the local branch.

I think the moral of my story is, don't judge a book by the cover and please don't pigeon hole those you may meet in your future careers. Don't just do a tick box exercise, look, listen and learn from all you meet in the future as I am still doing.

Thank you for reading.

Don't just do a tick box exercise, look, listen and learn from all you meet in the future as I am still doing.

Colin's Story

Most people who are living with dystonia can relate to a certain period in their lives when they experienced a trigger point, as to when their dystonia first occurred, I am no different.

I was working at home, long before home working was advised by the government, because of fears of spreading the deadly Covid virus. I was self-employed, working as a typesetter/proof reader, when my head suddenly jerked severely to the right. This was a frightening experience and one which worried me about it happening again, although it didn't occur again. Over the coming months, my head would very slowly move to the right on its own accord and at first I ignored it, thinking it was maybe down to my working as a proof reader. Little did I know how much my life would change.

I was self-employed, working as a typesetter/proof reader, when my head suddenly jerked severely to the right...

I know the medical profession do not approve of patients using the Internet to look for answers, for the fear of finding certain conditions, which may frighten patients into thinking they have serious conditions, which most of the time are unfounded. Hence, I still went ahead, and I looked at many Internet web sites before I self-diagnosed

in having dystonia (some people wait years before they are diagnosed correctly). I was used to working with computers, so it was not a problem looking at various sites, before I came across dystonia. I immediately showed my wife, a retired nurse and at first she was not convinced, but I was certain. I made an appointment with my GP and requested an appointment with a specialist, whom I saw at the regional hospital. This would have been in approximately 2006 and he confirmed my suspicions, that I did indeed have dystonia with the most common type of dystonia, known as cervical spasmodic

torticollis. He referred me to a different hospital but I had not heard of this hospital before. I was given an appointment with a Professor who started giving me Botulinum Toxin injections along with a Nurse Practitioner who specialised in dystonia. These injections were administered into my neck, 5 or 6 at a time. All told, I had these injections every 10 to 12 weeks and not one of them was successful. I had in the region of 70 injections and even different types of Botulinum Toxin. Apparently, the lack of success was down to me having strong anti-bodies.

It was about this time when I first met the late Dr Butler and his wife. I immediately warmed to them and they assured me that I was not an isolated case, far from it. Although it is still a rare condition, the number of people who have been diagnosed is growing, in fact Dr Butler had been

compiling new cases through his epidemiology study, when he tragically passed away. They were the co-founders of a charity called Action for Dystonia, Diagnosis, Education and Research, (A.D.D.E.R), which I became involved with, along with a few other people. By joining the committee, all of us give our time voluntarily. I am now the Chairman, edit the magazine (The A.D.D.E.R. Mag.) and organise the runners who raise funds by getting sponsorship for competing in the Great North Run, which is our main source of income.

As my condition deteriorated, I had to reluctantly give up work. I then qualified for sickness benefit and had to stop taking my wife to her place of work as she couldn't drive. The car was laid up for about three or four years. If I needed to go anywhere, I had to use public transport during this period, as my dystonia worsened. I thought everybody was staring at me, which is a common misconception!

I did indeed have dystonia with the most common type of dystonia, known as cervical spasmodic torticollis.

As my condition deteriorated, I had to reluctantly give up work.

and he asked me if I had considered the DBS (Deep Brain Stimulation) operation, which his wife had a number of years ago. I was interested to learn more, so back onto the Internet, where I found a lot of information about the DBS operation.

I had the first operation in 2009, whereby a static battery was fitted, which only lasted about 18 months, which was a big disappointment for me, so I asked if I could have a rechargeable one fitted, which was granted immediately. I had a second operation to have the rechargeable battery fitted in 2010. This device has a lead going from my chest wall, up near my collar bone, then passing the back of my ear, through the top of my head, deep into my brain. I attend the hospital every year for check-ups and so far, this second operation has proved successful, with the battery still

...I have certain medication which I take daily, which in conjunction with having the DBS, has changed my life for the better...

I am happy to say that I am now driving again and have been for a good few years. This came about because I was talking with Dr Butler at one of our committee meetings

and he asked me if I had considered the DBS (Deep Brain Stimulation) operation, which his wife had a number of years ago. I was interested to learn more, so back onto the Internet, where I found a lot of information about the DBS operation.

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Whilst I have to recharge the battery almost on a daily basis, I have certain medication which I take daily, which in conjunction with having the DBS, has changed my life for the better, as at this moment in time, there is no cure for dystonia.

If there is one thing that I am grateful for, is the fact that I didn't have this condition when I was young, as it would have meant possible financial hardship, as I would have had to give up working a lot sooner than I did.

At present, I now also have dystonia in my feet, which results in my toes curling as I walk, and sometimes when I am sitting down.

Learning outcomes

	Be able to;	Relevant for
1	Listen, have a willingness to learn, encourage a positive outlook and understand there are no quick fixes or cure	Primary care - GP's and staff NHS personnel
2	Refer to a neurologist at the earliest opportunity, early treatment is vital for prognosis and should be modified appropriately	Primary care - GP's and staff NHS personnel
3	Signpost to peer support to consider options, sustain self-management, employment and mental well-being	Primary care - GP's and staff Voluntary sector Neuropsychology
4	Provide consistency to care pathways to enable confidence, reduce isolation and fear	Primary care - GP's and staff Neurologists Voluntary sector
5	Consider the impact of Dystonia, low mood, low self-esteem, mobility or dexterity difficulties, loss of aspiration, self-conscious in social settings	Primary care - GP's and staff Neuropsychology Physiotherapists Occupational Therapists Employers
6	Reflect on points of deterioration, review care pathways regularly, encourage interaction and questions to support confidence building and resilience	Primary care Secondary Care Neuropsychology Neurorehabilitation
7	Identify ability and mitigate self-management to avoid isolation by diagnosis or disability	Primary care Physiotherapists Occupational Therapists Employers
8	Take an adaptive approach to movement disorders which can vary day-to-day and person to person but are debilitating and disabling	Primary care Public sector

What can we learn from these narratives?

How can services respond more appropriately?

Acknowledgements

Our Open Door series is only possible with the commitment from the people, happy to tell their story. The contributors offer the learning outcomes to benefit the care of others in the future. We are very grateful for the collaboration with Gill Ainsley from ADDER to coordinate these narratives and Dystonia Europe for use of the graphics. We hope these narratives can provide inspiration to improve understanding of Dystonia and the challenges people have to overcome.

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NEURO KEY

An Alliance supporting people
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Our Open Door series is collectively created to share our expertise and ultimately, benefit the whole neuro community. However, we need to sustain this Charity. If this resource has been useful for you, we would appreciate a donation to help keep the work going.

Scan the QR code with a smartphone and go to the donation page on our website.



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