Take Control hits north-east England

Epilepsy Action has launched phase two of the Take Control campaign in the north-east of England. The campaign is a development of the original Take Control and, if it is successful, the plan is to roll it out nationwide.

About 80,000 people in the UK still have seizures because they are simply not receiving the best treatment for their epilepsy. This could mean they have not had their anti-epileptic medication reviewed recently, and are continuing to take drugs which may not offer them the best seizure control.

Take Control aims to help people with epilepsy to assess their own quality of life and encourage discussion with their GP to ensure that they are receiving the best treatment options available.

If you live in north-east England and would like to register for the campaign and receive your free epilepsy diary, please visit www.takecontroluk.org or call the Epilepsy Helpline freephone 0808 800 50 50.

Take Control is supported by an education grant from UCB Pharma.

Matthew’s Friends to hold information day

Matthew’s Friends, the charity set up to provide information on the ketogenic diet, is holding an information day and annual conference at Alder Hey Hospital in Liverpool on 8 July.

The topics covered will include a beginner’s guide to the diet, as well as information on drug weaning while on the diet, problems with the diet and drug interactions with the diet.

For further information and an application form, please visit www.matthewsfriends.org or write to Matthew’s Friends, PO Box 191, Oxted, Surrey, RH8 0WL.

Amish children provide key to genetics of newly discovered childhood seizure disorder

Scientists have discovered a new childhood disorder that has severe epilepsy and autistic traits as its symptoms. They have also found out its genetic cause, according to a report published in the New England Journal of Medicine.

Cortical dysplasia-focal epilepsy syndrome (CDFE) was discovered in a group of closely related Old Order Amish children from Pennsylvania, USA.

All the affected children grew up in a relatively ordinary way at first, but they began to have frequent difficult-to-control seizures in early childhood. The children then lost some of their language skills and showed other signs of autism. The gene causing CDFE may also be a cause of autism in other children.

Doctors at the Clinic for Special Children in Strasburg, Pennsylvania took DNA from four of the children and their six parents. With help from the Translational Genomics Research Institute, they identified a mutation in the gene for a protein called CASPR2.

The protein has a well-known role in the contact between brain and nerve cells and other cells in adults’ nervous systems. Researchers claim this is the first evidence that CASPR2 is also important in the early development of the brain.

Dr Holmes Morton, medical director of the clinic, said: “The identification of the mutation in CASPR2 in our Amish patients has already allowed us to recognise affected babies before we see symptoms. We hope that early treatment and prevention of prolonged seizures in these infants will reduce the effects of CDFE upon the lives of children and their families.”

Imaging technology reduces surgery risk

Researchers have developed a technique to reduce the risk of damage to the memory and language skills of people with epilepsy who have brain surgery.

Neurologists working for the National Society for Epilepsy (NSE) used tests called EEG-fMRI (electroencephalogram-functional magnetic resonance imaging) and MRT (magnetic resonance tractography). These allow doctors to get a clear picture of which brain areas are involved in language and memory and how these connect to other parts of the brain. They can now find out which parts of the brain remember words, faces and pictures. This helps to reduce the risks to patients considering surgery.

NSE researcher Dr Rob Powell said: “These advances in scanning are providing us with a more detailed picture of how the brain works and increasing the number of people suitable for surgery. Operating on the brain will never be free of risk but this breakthrough is improving the outcome for many people.”
There is no reason why someone who has epilepsy should be refused any kind of beauty treatment. Treatments from electrolysis and laser treatment to an ordinary facial are all suitable for people with epilepsy, who should not be prevented from having them.

This is not always the case, however: there are many reports of beauticians who have refused to treat people just because they have epilepsy, or have asked people to get a doctor’s note before they can have the treatment.

The mention of epilepsy and the thought that someone might have a seizure while undergoing treatment seems to throw many beauty therapists into complete panic. I contacted some beauty salons to enquire about treatments; when I mentioned epilepsy to them and asked whether this would be a problem, the answers I received varied greatly.

Some refused to treat me, some said I should consult my doctor first and some, thankfully, said having epilepsy was not a problem and that I could go ahead with the treatment.

Why the conflicting advice? When it comes to treating people with epilepsy, there appears to be quite a lot of confusion among beauty professionals. A lot of this seems to be a result of the stigma and lack of awareness that still surrounds epilepsy. Several times I was told that the electrical impulses and laser lighting that is used in some of the treatments would trigger a seizure. This, so I was told, meant I wouldn’t be able to have the treatment.

When I explained that I didn’t have photosensitive epilepsy, I was told that I would need to speak to my doctor and get a note before the salon was prepared to go ahead with the treatment.

There’s no telling some people
When I suggested that I didn’t need to get a doctor’s note and told staff that I didn’t have uncontrolled seizures, that the treatments wouldn’t bring on a seizure and that I was quite happy to go ahead with the treatment, some still refused to treat me.

“The treatments could stimulate a fit,” one beautician told me. “Epilepsy is a contraindication. It’s the same with any beauty treatment – they could trigger a fit. You need to be careful. The doctor’s note is safety for us as well as for you.”

This beautician was certainly misinformed, but her attitude meant that anyone who revealed they had epilepsy could not
The beautician was obviously concerned that she would be blamed if anyone did have a seizure during treatment. She didn’t know anything about epilepsy and safety was her main concern – but she should not have refused to treat me. Other beauticians in the area were more than happy to see me without getting a doctor’s note.

Rosanna Burrill from Epilepsy Action says: “You can understand why some beauticians are concerned. I certainly wouldn’t want to have a tonic-clonic seizure while I was having electrolysis treatment, in case of injury or scarring. If you are having regular seizures you might want to speak to your beauty consultant about how your epilepsy affects you, but you should not be prevented from having treatments because of your condition.

“In some cases it might be appropriate to seek your doctor’s advice before having certain treatments, for instance if you have frequent seizures; but in many cases it will be an unnecessary inconvenience, not to mention expense, as doctors often charge to provide such letters.”

What rights do you have?

If you have epilepsy and live in the UK, you are covered by the Disability Discrimination Act (DDA). This means that organisations including colleges or beauty salons must not treat you less favourably than other people because you have epilepsy. Under the DDA, organisations must not place blanket restrictions on people because they have epilepsy, but must consider each person’s case individually. Saying that no one with epilepsy can have a certain treatment, or that everyone with epilepsy needs a letter from their doctor before they can have treatment, could be seen as blanket restrictions.

Unless every person who wants to have treatment has to produce a letter from their doctor, it may be discriminatory only to ask people with epilepsy to provide one. The DDA also means that service providers must try to make reasonable adjustments for disabled people, such as providing extra help or making changes to the way they deliver services. This could include making staff aware what to do if someone has a seizure during beauty treatment.

What can you do if you are refused treatment?

If you are refused treatment, the first thing to do is find out why you have been refused treatment or told that you must have a doctor’s letter. It is not enough simply to be told that it is because you have epilepsy. Is it because of a misconception that light or electricity involved in the treatment may cause you to have a seizure? Or is it because of concerns about what staff should do if you have a seizure during the treatment? Is it because the salon is not prepared to train staff in epilepsy awareness or first aid?

Try to talk to the beautician first to resolve any problems. If this fails and you feel that you may have been discriminated against by being refused beauty treatment, you can contact the Disability Rights Commission (DRC) for advice. The DRC is an independent body set up to prevent discrimination and promote equality of opportunity for disabled people. In a small number of cases, the DRC supports individual people in seeking their rights under the Disability Discrimination Act, and helps to solve problems. The DRC runs a Disability Conciliation Service that aims to help people resolve disputes about goods and services without going to court. To find out if your case has a legal basis, contact the DRC helpline.

If you can’t resolve your dispute with your beauty provider, and the DRC is unable to help you, you may wish to contact a solicitor such as Russell Jones & Walker – a firm of solicitors that offers a free assessment service for people who feel they may have been discriminated against by a goods or service provider. If the company feels that your case has a legal basis, you will have to pay for any further legal advice, but the initial assessment is free.

Additional work on this article was carried out by Amy Perry.

See page 12 for information on specific treatments.

Who to talk to

- Disability Rights Commission
  Helpline: 08457 622 633
  www.drc-gb.org

- Russell Jones & Walker Solicitors
  Swinton House
  324 Gray’s Inn Road
  London WC1X 8DH
  www.rjw.co.uk
Face facts

For some people with epilepsy, beauty treatments are very important – a side-effect of some anti-epileptic medication is excess hair, for instance. Below, we look at some of the treatments available. If your epilepsy is uncontrolled, it is useful to talk to the beautician to find out what risks, if any, would result from a seizure during the treatment. By Amy Perry

Treatments involving light

Sun beds
Just because sun beds and laser hair removal involve light, many people think that they are not suitable for people with epilepsy. These warnings are often based on the misconception that all people with epilepsy have seizures triggered by flickering or flashing light. In reality, fewer than five per cent of people with epilepsy have photosensitive epilepsy.

Most people with this type of epilepsy are only sensitive to light that flickers 16 to 25 times a second, although some people may be sensitive to other ranges. Because the light in the sun beds does not flicker, it would not trigger a seizure if you have photosensitive epilepsy. In theory, if the lights in the sun beds became faulty and started to flicker within the problem range for people with photosensitive epilepsy, this could trigger a seizure, although Epilepsy Action has never heard of this happening. If you have photosensitive epilepsy and want to use a sun bed, you could ask staff at the tanning centre to make sure that the lights are working properly before you go in.

Laser hair removal
This involves a laser beam targeted at hair follicles to prevent new growth. Intense pulsed light therapy (IPL) is a similar treatment, except that the laser beams used are more concentrated. Although neither treatment can permanently remove all hair completely, both methods can reduce it. You might be refused treatment because of fears that the laser will cause a seizure. Flickering lights are only a possible seizure trigger if you have photosensitive epilepsy; and the beam of light used in these treatments is very small, and does not flicker.

Laser skin resurfacing
In this type of treatment, laser or intense pulsed light is used to reduce acne scars, birthmarks, sun damage, facial thread veins and other skin blemishes. The laser or IPL removes the top layer of the skin. When the skin heals and grows back it should do so without the blemishes, wrinkles or scars. A local anaesthetic may be used for the treatment and your eyes must be protected with specially designed goggles.

Treatments involving electricity

Electrolysis
People with epilepsy are sometimes warned against using certain beauty treatments involving electricity, including electrolysis or electrical products such as abdominal toning belts. There is no evidence to suggest that electricity can trigger epileptic seizures – the fact that a treatment uses electricity should not prevent you from having these beauty treatments.

In electrolysis, a special needle is inserted into hair follicles. A tiny electrical impulse is sent through the needle to the hair root. This helps to destroy the follicle from which the unwanted hair grows. With several treatments of electrolysis over time, hair growth can be permanently stopped. Epilepsy Action recommends you speak with the beautician about the potential risks if you had a seizure during treatment. Would there be any scarring if you had a seizure and moved suddenly during the treatment?

Electrical body toning products
These usually consist of a battery-powered belt, designed to be worn while exercising. Most of the products produce muscle contractions by stimulating the nerves that control your muscles. Your muscles should contract smoothly, hold themselves in a tensed position for a few seconds and gently relax again. Some manufacturers say their electrical body toning products are not suitable for use by people with epilepsy but, Epilepsy Action is not aware of any reason why you should not use these products.

Foot spas
Some products carry a warning not to use them if you have epilepsy – this is probably because of the misconception that electricity can trigger a seizure. There is no reason why people with epilepsy can’t use them.

Rotary epilators
Rotary epilators are similar to electric razors, but instead of a cutting blade on a rotary head, they have rows of tweezers that pull hairs out by the root. There is no reason why people with epilepsy can’t use them.

Beauty treatments for relaxation

Massage
Massage usually involves aromatherapy oils and certain oils can trigger seizures. If you have epilepsy you should avoid these – they include rosemary, sage, hyssop, fennel and wormwood. Most other oils are safe to use.

Some people with the condition are warned against having massage in case this triggers a seizure. This is unlikely for most people. Some people with epilepsy may have seizures if they become very relaxed but this is extremely uncommon. For most people with epilepsy, relaxation can reduce seizure frequency.

If you do have frequent seizures, there is a chance you could have one during the massage, but providing the person doing the massage knows the appropriate first aid, there should be no danger. The same applies if you would like an Indian head massage. People might think that massaging the head may trigger a seizure by stimulating the brain, but this is untrue.

Further information about epilepsy and beauty treatments is available from the Epilepsy Helpline, freephone 0808 800 5050.
My employer, one of the biggest in the UK public sector, follows a mantra about “managing attendance” and asks line managers to follow all sorts of complicated procedures if an employee has more than eight days off sick a year. My line managers have filled filing cabinets with forms about me, and a couple of years ago the personnel department sent me to an occupational health specialist, asking him to predict how many days I would have off sick in a year because of my epilepsy.

Although I hadn’t had a seizure for 20 years, the occupational health specialist refused, as he isn’t a clairvoyant. He also asked why I had been sent to see him, pointing out that the consultation caused a great deal of unnecessary stress. But as I was there, we had a pleasant chat about my employer, which probably didn’t come into his remit. We also discussed epilepsy management and agreed on the need for a holistic approach and a good work-life balance.

It was just as well the occupational health specialist had refused to forecast my future sick leave patterns, because one afternoon not long afterwards I had such a disabling sequence of complex partial seizures that I was paralysed down my left side for 12 hours. I spent 24 hours in hospital, and came home, mostly reassured by the neurologist telling me that it was a “one-off.” As it turned out, it wasn’t a one-off at all and it took nearly 15 months before my epilepsy was controlled again.

Reading about employment-related issues on forum4e and in Epilepsy Today, I realise I have been very lucky at work. Once management realised I was covered by the Disability Discrimination Act, they did their best to support me through a difficult and upsetting period.

Fortunately, I’ve only had one mega-seizure at work, and several smaller ones. I remember the big seizure through the filter of complex partial altered consciousness, which is quite impossible to explain to anyone who hasn’t been there: intense colours, changed perspective, a heightened awareness of bystanders’ emotions, muddled chronology and lots of gaps. I remember being desperate for reassurance that I was OK, and that I was valued and cared about. I needed to know that all my colleagues were OK too. Actually, some of them must have been pretty frightened themselves: there I was, talking gibberish and lying on the floor unable to move, for what I was later told was nearly two hours.

Like my children, my colleagues have an intuitive sense of what I need mid-seizure. Someone held me all the time, and when I panicked about the apparent silence, someone spoke to me. We work in a public-facing environment, but they kept the public away. They called my husband and an ambulance. I have a dream-like recall of one of the paramedics telling me how lucky I was to have such lovely friends.

I have had more seizures at work, but I have become better at recognising the auras, and getting myself to the tea-room in time. I know, but don’t remember, that someone always drives me home, and waits with me until my husband or one of my older children gets home. Sometimes I have found the drug side-effects more disabling than the seizures themselves, particularly the double vision I experienced on high doses of Tegretol.

I was having an especially ghastly time with my double vision when Mary, my Sapphire Nurse (a specialist epilepsy nurse).
came to the office to give staff training. She talked about epilepsy in general, and about coping with my type of complex partial seizures, which sometimes develop into generalised seizures, in particular. Mary’s visit was suggested by my neurologist, and was a good way of supporting my colleagues, who at the time were putting up with a lot because of all my problems.

That year I had about three months off sick. When I went back to work, I benefited from a scheme that enabled me to return part-time on medical grounds, building my hours up each week until I got back to my 37 and a half. At about the same time, I applied to work part-time permanently, and now I work only four days a week. I think this has contributed to my improved seizure-control, because I am more rested, and have more time for my family and myself.

I was 50 at the beginning of March. A time for reflection, and all that. I’ve been wondering how much of my working life has been affected by my epilepsy. Quite a lot I think, because of the driving issue, the unacknowledged seizures and the general dopiness and lack of spark caused by the anti-epileptic drugs. There is never any point in indulging in “what if...?”, but when I’m feeling depressed I do think about my career in terms of “what if I hadn’t had epilepsy?” Has epilepsy been my personal glass ceiling, preventing me from writing a blockbusting novel, editing a broadsheet newspaper or managing an industrial conglomerate? Who knows?

I was diagnosed with temporal lobe epilepsy when I was 14, and although I was officially seizure-free from my late teens until my mid-20s, and for another 20 years until recently, I’ve always had a sense I shouldn’t drive. From time to time my perception goes weird. I can cope with it in the ordinary way, but I think twice about crossing the road when I feel like that. At those times I know I’m much too dangerous to control a fast-moving lump of metal. Perhaps it is no coincidence it took me seven goes to pass my driving test!

Not driving was a difficulty for me when I first started serious career-type work, three years after I graduated. I joined IPC Business Press as a trainee journalist in 1980, working on food titles such as Catering Times and Supermarketing. My failure to drive was one issue, and when I started having seizures again in my 20s it was another. Rather than waiting for an NHS appointment, IPC sent me to a private consultant, which delayed finding suitable medication for about a year. The company also threatened to move me to an administrative job. Rather than face up to this, I moved on into public relations. I wasn’t much good at that, because I wouldn’t flirt with clients or wear the sort of 1980s power clothes required of me. It seems quite astonishing now, but I was actually asked to leave one company because I refused to wear make-up! I wasn’t happy anyway – I wanted to write.

By now I was married, and I spent a few years as a freelance writer, mostly for food titles, and some public relations companies, before the children were born. This was great, with no issues about driving because I worked from home. If I needed to interview someone, I used the phone.

In 1993 I decided to train as an early years teacher, doing a year-long postgraduate course. I can’t remember how many job applications I filled in, but I do remember that they asked about health and medication. I always had a long debate with myself about this one, but decided on balance I’d better declare my epilepsy and Tegretol. I had job interviews, but was frequently asked about my epilepsy. If you’re reading this, you know all about the ignorance and stigma, and I’m afraid school governors are not immune. My epilepsy, combined with the fact I have old-fashioned views about primary-school education meant I never got a job, except for a maternity leave cover and some supply work.

So it was back to freelancing, writing pieces for management titles. This time I had even less need of a car; the internet had arrived. Sure, it was very clunky in those early days, and horrendously slow, but it made my job even easier. I didn’t have to talk to people during working hours; I could interview by email, and get a feel for different industrial sectors by researching on the web.

I would probably be writing those boardroom articles still, but for two things. One is the expense of teenage children: it became obvious that I needed a more reliable source of income. The other was the horrific day we have come to know as 9/11. That Tuesday, I finished an article in the morning, had a row with my editor about how much he was expecting me to do, and then turned the television on. You probably remember those images as vividly as I do; but what happened next was an immediate slump in the advertising revenue of the magazines I was working on. In fact, one folded altogether. So my work dried up and I was stuck. I was getting a few poems published, but as it is said even the Poet Laureate, Andrew Motion, can’t live on the money he makes from his poetry, there wasn’t much hope for me.

So, in my mid-40s I was in the job market with no skills to speak of except the ability to put a string of sentences together, although I reckoned I had plenty of life skills. I couldn’t even go back into supply teaching, because there had been too many changes to the National Curriculum since I had last been in the classroom. I tried the local employment agencies, which held out no hope for me as I refused to travel very far, and I was rubbish at data input, although I can type extremely fast.

But, like I said, I hit lucky. I did find an employer, to which I declared my epilepsy, and as things turned out it is just as well I did. Senior management seems to operate on the blunderbuss model, but it does abide by the Disability Discrimination Act. My local managers have been very supportive through the difficulties caused by my epilepsy, and I have the best bunch of colleagues I’ve known in nearly 30 working years. My office is five minutes walk away from my house. What more could I ask for?
Photography Competition

Images challenging stigma by showing the world seen through the eyes of young people with epilepsy

If you are under 18, love taking photos and would like to be part of In Focus, please contact Elizabeth Anderson on 0113 210 8800 or email: eanderson@epilepsy.org.uk