It’s in the genes
Breakthrough research
by Dr Sameer Zuberi

Doing things differently
Cognitive Behavioural
Therapy for epilepsy

Teens talk
Life with epilepsy in Ghana and Scotland

Putting occupational health into practice
Unique epilepsy guide for employers
Any questions about epilepsy?

Text us on:
07786 209 501

Facebook.com/epilepsy.scotland
Twitter.com/epilepsy_scot

Epilepsy Scotland was built on sound principles; improving the quality of life for those living with epilepsy, being a positive force for change, providing quality services and being respected as a professional and informed contributor to policy making.

These solid foundations combined with your continued support will ensure our future and continuing success.
IN TOUCH
Helpline & Information

Our busy helpline takes calls from people looking for information or who simply need to talk. People ask us about many different things. Often, callers have just been diagnosed, some face difficulties at work, others need information on benefits or how to access the bus pass scheme. Enquiries vary day to day. Lots of parents call for support to cope with their children’s epilepsy. Many people use the chance to air their worries.

A wide range of professionals call us too, from GPs and employers to teachers and Occupational Health doctors. We never know what challenges the next call may hold! But people don’t just contact us by phone, they can also email, text or write in. We even have enquiries via Twitter and Facebook.

Accurate and clear information is so important. Over 20 different publications are available online, all checked by medical professionals to ensure you can trust the information they contain. We produce simple fact sheets as well in response to popular topics that callers ask us about.

Our information guides are appreciated by epilepsy organisations in other countries. In Australia, the Epilepsy Association of Victoria is developing a programme for teachers and employers based on these guides. In return they have made a donation for using our words and artwork. We are very proud that our publications also help people with epilepsy half-way around the globe!

Our team helps update what appears on Epilepsy Scotland’s new-look website. We want to make sure it meets your needs and is as accessible as possible. All of our publications and fact sheets are there to view and download for free.

So whatever you want to know about epilepsy, remember we’re here to help. Call 0808 800 2200
email: enquiries@epilepsyscotland.org.uk
text 07786 209 501 or visit www.epilepsyscotland.org.uk

PUBLICATIONS
Teen guide

Our new ‘Guide to getting on with your life’ is written by and for 13-19 year olds. Many in the Edinburgh Youth Group shared their ideas and helped us create this eye-catching, magazine-style guide. It has loads of information about epilepsy, whether you’ve had it for a while or have just been diagnosed. There are brilliant illustrations with tips from other teenagers with epilepsy and links to useful resources. Even better, the guide’s own micro website will be going live shortly. Meantime you can download the pdf from the microsite at www.getonwithyourlife.org or from www.epilepsyscotland.org.uk.

IN TOUCH
Young ones

Epilepsy West Lothian has received a grant from Epilepsy Action’s Diamond Project to employ two new members of staff for their new youth project. They will raise epilepsy awareness with visits to local high schools and by running teen workshops.

www.epilepsywestlothian.co.uk
FEATURE

Putting occupational health into practice

When Epilepsy Scotland launched the UK’s first occupational health guide to epilepsy, several speakers at our Holyrood reception commented how this new resource will help employers. The unique guide was compiled by Epilepsy Scotland and occupational health professionals from the voluntary, public and private sector. Here are some highlights from the launch.

Parliament Reception Host, Alasdair Allan MSP

“This guide fills an important gap in the understanding of employers about how to deal with the issue of epilepsy. It also provides a good foundation for the rights of people with epilepsy in the workplace as well.

“My own experience has been mixed. I can remember a summer job where I had a seizure and it was made very plain to me by my employer, possibly for reasons unrelated to my seizure, that he had concerns about my mental health. It showed a certain lack of understanding about what epilepsy was.

“A happier experience was when I arrived for an interview with the then SNP Chief Executive, Mike Russell. In the midst of my job interview I had a seizure. Mike Russell was under the belief initially that I had died. I am happy to say I did get the job. I hope more and more employers are understanding about epilepsy and will show a greater willingness to learn where they are perhaps lacking in information.”

Epilepsy Scotland Chief Executive, Lesslie Young

“This document will go a long way to help reduce the challenges that are often experienced by people with epilepsy in the workplace and ensure they are given every opportunity to enjoy a fulfilling work life. We hope it will furnish employers, employees and HR professionals alike with all the information they need to ensure that employees with epilepsy are supported and guided towards a positive solution to the difficulties they may be experiencing in the workplace. I thank the Deputy First Minister for her continued support and Eisai for funding the publication.”

Serco Occupational Physician, Dr Freddie Westbrook

“Diagnostic labels like epilepsy can come with associated preconceptions and ideas, and sometimes a degree of prejudice that actually influence people’s impressions of things like risk and health effects.

“One of our tasks really should be trying to optimise the employment potential of people with epilepsy. Now I believe access to specialist occupational health advice has an important part in achieving that goal. Now I would say that, wouldn’t I? However, real success in accomplishing that goal is only going to be achieved when all of the stakeholders involved in the system actually get together to put all the pieces in place to make that work; sharing good practice of what has actually worked in organisations which can be adopted and adapted into other organisations.”
Fife Constabulary Chief Inspector, Ross Bennet

“I’ve had epilepsy since my mid 20’s. I don’t see myself as disabled. My current role is the Operational Head of three stations and I absolutely adore my work.

“My employers were very understanding and catered for my non driving, hospital appointments and any medication side effects. You are the same person but, in truth, you do not always appreciate this. You need all the support you can get particularly in the early stages. I was treated as the individual I am, which allowed me to grow as a person. My employers, for example, subsidised my further education to MBA level and facilitated additional IT equipment at my work station.

“I spent a period in Human Resources where, encouraged by those around me, I made it my business to assist in pushing the traditional boundaries of staff health and occupational health. If you want to bring out the best in people, you have to cater for any issues whether as a consequence of epilepsy or any other condition. Occupational health is, for me, the ethical balance to ensure that everyone is treated fairly. Without this, not only could I not be standing here before you as a Chief Inspector but I may not even be in employment.”

Society of Occupational Medicine Chief Executive, Hilary Todd

“This new booklet is going to be a valuable tool for occupational health doctors to give to employers. It sets out a useful framework to help that wherever possible people with epilepsy can be employed, remain in work and be safe at work. More importantly, I believe this new booklet will be a useful communication tool for open discussions with the person with epilepsy. No two people are the same, so asking questions about the person’s seizure type and any trigger they may have can be really useful. Occupational health doctors, with the help of this booklet, can ensure some of these basic but vital conversations take place.”

Cabinet Minister for Health and Wellbeing, Nicola Sturgeon

“I want to give a very warm welcome to this extremely practical document that tells employers what they need to know about epilepsy and the workplace. I’m sure it will succeed in its aim of helping not just them, but also those working for them who have epilepsy, to get the most out of occupational health. We all know that epilepsy is no longer a valid reason for being excluded from or discriminated against in the job market. This novel guide moves even beyond that position into a new era where the focus is on providing the best possible support for someone with epilepsy in the working environment.”

The full speeches will shortly be available to view on YouTube and Epilepsy Scotland’s website www.epilepsyscotland.org.uk
The Epilepsy Challenge

Epilepsy Scotland has issued an Epilepsy Challenge to all councillors and MSPs following the May elections. We have four priorities which they can help with:

- Tackle the treatment gap for epilepsy and save lives
- More epilepsy specialist nurses
- Develop joint council/NHS transition services for young people
- Run national schools/public awareness programmes

Our Epilepsy Challenge spells out the benefits of epilepsy care so that 70% of people instead of 52% become seizure free. Future savings will outweigh costs and may prevent around 40 deaths a year. Why not ask your councillors and MSPs to support this Epilepsy Challenge? You can download a copy from our website.

Thanks to funding from JEC (Joint Epilepsy Council of the UK and Ireland) we briefed senior shadow ministers and researchers of three political parties before the election. Scottish New Labour, the Scottish Liberal Democrats and Scottish Conservatives were in agreement to maintain the number of specialist nurses. All these parties favoured joint transition services and also recognised the importance of epilepsy and schools awareness training.

Kenneth Gibson MSP led a parliamentary debate to have student teachers learn about epilepsy. For details of the Epilepsy Challenge and the debate visit www.epilepsyscotland.org.uk

The colour purple

Customers saw purple when they visited some west of Scotland Vodaphone stores on Saturday 26 March. Staff dressed up in a fun way to celebrate Purple Day and raise public awareness while fundraising for Epilepsy Scotland.

Purple Day gives people the chance to think and talk about epilepsy. Founded in 2008 by nine year-old Canadian Cassidy Megan with the Epilepsy Association of Nova Scotia, this global awareness day now has a wide appeal in Scotland with school children, businesses, MSPs and celebrities like Lorraine Kelly taking part.

28 MSPs backed a Purple Day motion by Richard Simpson MSP which invited parliamentary staff and candidates to wear shades of purple and send their photos to Epilepsy Scotland’s website. Schools including St Ninians in Fife ran purple-themed activities. Community fundraising events across Scotland included a dance in the Spey Valley, a raffle in South Queensferry and the sale of purple glitter cakes in Hamilton. Epilepsy Scotland’s staff also held a wearing purple competition!

Many people enjoy social networking so twitter users added our purple “twibbon” to messages while facebook fans gave their profile picture a purple hue. All the money raised helps run services available to over 40,000 people with epilepsy in Scotland.
IN TOUCH
Service users get involved

The service user forum has gathered momentum. The forum has now been held in our Glasgow and Edinburgh offices. It has been a great opportunity for people who use our services to meet and discuss their views and share this with other service users. The forum decides the agenda and has already discussed Epilepsy Scotland’s services and information. The next topic for discussion will be about benefits. The forum has invited a guest speaker from a Citizens Advice Bureau office to give an update on benefits at their next event, which will take place on 3 June at our Glasgow office.

It has been all go at Govan Road will the new Lighthouse Activities group. This is an opportunity for service users to take part in a wide variety of activities, ranging from arts and crafts, creative writing, holistic therapies and even massage. More details from Debbie or Kenny: 0141 427 4911 or dmackinnon@epilepsyscotland.org.uk

CALENDAR
What’s ahead

Here are dates for your diary plus some events we are taking part in:

15-21 May – National Epilepsy Week
22 May – Edinburgh Marathon Festival
5 June – Walk for Scotland and Run for Scotland
15 June – Cross-Party Group on Epilepsy reception, Edinburgh
16 June – MSPs Garden Lobby photo call, Edinburgh
28 August - 1 September – IBE/ILAE Epilepsy Congress, Rome
4 September – Great Scottish Run 10k and Half Marathon
9 September – Bigharted Scotland awards dinner, Grand Central Hotel, Glasgow
September tbc – Cross-Party Group on Epilepsy, Edinburgh
3 October – Baxter’s Loch Ness Marathon
16 December – Christmas Concert, St Mary’s Cathedral, Edinburgh

Please contact our fundraising team for details of our community events on 0141 427 4911 or check our website.

We are planning information events and awareness talks. For details about your area please contact 0141 427 4911, email enquiries@epilepsyscotland.org.uk or visit www.epilepsyscotland.org.uk
IN TOUCH
Making changes in Dumfries and Galloway!

Katie Russell leads the Dumfries and Galloway Epilepsy Group. This small but determined group is working hard to attract more members and supporters. Over the last year they have gained political backing from local MPs and MSPs as well as getting press and media coverage. Katie describes some challenges they face.

“Dumfries and Galloway is a huge area, many parts are very remote, which can affect people being able to meet regularly in a central location. Politicians like Alex Fergusson have come to the group and listened to our concerns about the lack of permanent specialist neurologists in Dumfries. Also the region has no epilepsy specialist nurse. We have tried hard to get a venue in Dumfries. We do, however, have a free venue in Castle Douglas, but some members struggle to get transport there for meetings.

“Last year an important member of our group, Kenny Hall, died from a fatal seizure. His partner Sally Gillies, who always attended meetings with Kenny, helped arrange a tribute gig with his fellow musicians, the Dangleberries, supported by other local bands. Kenny was a drummer in the Dangleberries. The loss of Kenny cannot be put into words.

“A lot of people expressed shock at the lack of help in the NHS for those with epilepsy and their carers. We contacted all GP surgeries and discovered that not all of them had information on epilepsy available for patients. This is really worrying.

“Getting support is difficult for a number of reasons. People still feel awkward talking about the condition and some do not want to be involved in a support group. This is something we respect. More people get support online now, but there are still those who don’t have or can’t use the internet. People unable to drive and who do not receive information can end up feeling very isolated. Our group offers a chance to keep up to date and to suggest ways that make changes to services in our area.

“We plan to continue to meet as regularly as we can and new members are very welcome – the more members, the more success the group can have.”

Contact Katie Russell on: 01556 502985 or email tulipsrussell@googlemail.com

AWARDS

Herald scoop

Lesley Quinn’s exclusive Herald feature won Epilepsy Scotland’s Journalist of the Year award for highlighting how Scotland International and Celtic player Julie Ferguson uses her condition to raise public awareness. Nearly 200 guests at our Edinburgh Wags fundraising dinner saw Lesley receive her trophy and £500 prize.

This year’s judges included novelists Lin Anderson, Des Dillon and Alexander McCall Smith, with Scottish National Union of Journalists Secretary Paul Holleran and BBC Scotland’s Head of News and Current Affairs, Atholl Duncan. Award runners up included Jane Gregory (Sunday Mirror) and Joan McFadden (Herald).

You can read the winning article on www.epilepsyscotland.org.uk
University Challenge

An audit of UK university websites by the Epilepsy Society has found that 239 out of 305 universities have no information about epilepsy. Just four universities give any detailed information about epilepsy and the support which they could offer. Only 13 websites provide links to epilepsy organisations which can fill in the gaps when it comes to support, treatment and basic information. Epilepsy did appear in the disability section of 49 websites without further details about getting support during studying. Following this audit, Epilepsy Scotland’s helpline is being given to anyone looking for further information at Scottish universities. For details of the audit visit: www.epilepsysociety.org.uk
Epilepsy Scotland has links with Basic-Needs Ghana. This African organisation supports people living with epilepsy. Ghana is on the west coast of Africa and has a population of 21 million people. Epilepsy Scotland and BasicNeeds recently discussed the impact epilepsy has on young people in Scotland and Ghana. We thought we would compare how epilepsy affects young people in two very different countries.

Mariam and Jamie are both 13, they both have epilepsy and live with their families at home. Jamie lives in Edinburgh and Mariam lives in the City of Tamale in Northern Ghana. We asked Jamie and Mariam to tell us what it is like to live with epilepsy and the results were really interesting.

When asked how their friends respond to their condition Jamie mentioned that his friends are quite confused by it and that he has to explain it to them. But on the whole they accept it. Mariam stated that some of her friends became quite indifferent towards her when her seizures were particularly bad due to a shortage of medication. But now her seizures are controlled, she enjoys friendship and support from her friends. Both Mariam and Jamie’s friends did not understand their condition due to a general lack of awareness of epilepsy across the world.

Jamie and Mariam both find epilepsy restricts their daily life. Mariam is not allowed to light the fire, cook, fetch water or help her mum at work. She commented that she is unable to live a free life. Jamie really enjoys swimming but cannot go without his mum attending. Both Jamie and Mariam commented that epilepsy makes them feel different – and this makes them feel sad.

Jamie takes time to think about things alone and feels better after taking time out to do this. He also has a loving family who “look out for me and help me stay positive.” Mariam copes with these feelings through her faith and support from her family.

The biggest challenge for both Mariam and Jamie was remembering to take their medication every day. Both teenagers get support from their families in taking their medication. Both teens also try and stay positive to overcome any challenges. Mariam says “I try not to worry about my illness and the things I am unable to do.” Jamie commented that he just gets on with it.

Mariam and Jamie both get care and treatment from specialists. Mariam is lucky to live near the Specialist Unit in Tamale where she gets her medications. Most people in Ghana do not live near specialist services and as a result do not get any treatment. Jamie lives in Edinburgh and has regular contact with a Specialist Nurse. In Scotland there are only 30 Specialist Nurses to support 40,000 people with epilepsy therefore not everyone can access this service.

Finally, Jamie and Mariam have something else in common. They are both supported by the voluntary sector in their respective countries. Jamie attends the Epilepsy Scotland Lighthouse youth group where he meets more teens with epilepsy and makes friends along the way. Mariam is supported by BasicNeeds Ghana who ensure that her medications are available.

Both teens also have some great advice for any newly diagnosed young people across the world.
“Don’t worry too much – if you get depressed it doesn’t help. You have to remember to take your medication and go to your friends and family for support.” Jamie

“My advice to others is to seek treatment and stick to medical advice. The medication I receive has been very good for me and I no longer experience severe seizures – I don’t even remember the last time I had a seizure!” Mariam

Our special thanks to Jamie and to Mariam and Ben Alando, Knowledge and Communications Officer, BasicNeeds Ghana for this interview. More details at: www.basicneeds.org.uk

AWARDS

Good fella

Professor Martin J Brodie from Glasgow Western Infirmary’s Epilepsy Unit has been honoured by his peers at the Bournemouth ILAE (International League Against Epilepsy) conference.

In recognition of his outstanding contribution to epilepsy he received the epilepsy lifetime service award.

CAMPAIGNS

Transition: a testing time

Transition is a term used to describe the journey we all take from one phase of our life to another. It is a key issue for many young people with epilepsy and other support needs. During childhood support needs are provided by local authority schools across Scotland. But when a child reaches ‘adulthood’ (this can be any age between 16 and 21 depending on the local authority area) the young person’s support and development must come from other areas such as social care, voluntary sector or supported employment.

Many young people, and their families/carers, face difficult times when leaving school and moving on to the next phase in their life. This is because ‘transition’ requires input and planning from many different agencies including: families, education, health, social care, employers and, most importantly, the young person with additional support needs. Epilepsy Scotland is keen to find out about you or your son / daughters transition experience. Did it run smoothly or were there challenges along the way? What were those challenges and what do you think would make a ‘good transition’ for a young person about to embark on the journey?

We would love to hear your story. Please email atonberg@epilepsyscotland.org.uk and tell us what you think about transition services. We would like to work to ensure that everyone in Scotland who has epilepsy and other support needs navigates the transition process with ease. We will feedback your stories (in confidence and with your consent) to the people who can help to make things better.

SERVICES

Epilepsy Training

Epilepsy Scotland can provide epilepsy training to suit your needs. From awareness talks to administering emergency medication, we can deliver training sessions specifically tailored for you. Contact our friendly and helpful training team on: 0141 427 4911, kshearer@epilepsyscotland.org.uk, or lcushen@epilepsyscotland.org.uk

You can also fill in the web inquiry form at www.epilepsyscotland.org.uk/training/enquiries/
Edel Dewhurst is a specialist psychotherapist based at Sheffield Teaching Hospital. The Neurology Psychotherapy Service offers a range of therapeutic approaches, with the team seeing and caring for people with epilepsy and associated psychological problems as well as non-epileptic seizures. Her article explains how the use of CBT (Cognitive Behavioural Therapy) for epilepsy has been relevant and cost effective.

**A Case Study**

Anne, a 19 year old unemployed woman has been referred by one of the Specialist Nurses. She was diagnosed with epilepsy at the age of 13 years. At assessment she tells me that her parents divorced when she was six years old. She was an only child until her mother re-married and had two more daughters. She has excellent relationships with her father and her half sisters. She moved out of her mother’s home into a flat a few minutes away when she was 17. This is so that she can call on her mother at anytime and especially when she has seizures. She has lived alone since this time.

Anne missed a lot of school on account of her seizures. She has few friends. She explains that she is afraid to go out alone in case of having a seizure. She began a college course and worked as a nursery nurse but did not complete her studies or continue in her job because she believed it was too demanding for her. She took a taxi to the hospital and explained that when she travelled alone by bus before, she lost her way and panicked, resulting in her mother leaving work to come and collect her.

Anne’s story is not uncommon. The inhibiting factors in her life are regularly present in our epilepsy patients.

“The Epilepsy Psychotherapy Service in Sheffield was set up in October 2007 in response to a perceived need for extra support for patients with epilepsy post-surgery, although all patients with a diagnosis of epilepsy with associated psychological problems may be referred. Since there was already a psychotherapy service for functional neurological symptoms in place, it was relatively straightforward to introduce the service for epilepsy within the Neurology Department. Over 60 people a year are referred to the Epilepsy Psychotherapy Service with an average of 47 being seen for individual therapy. Referrals come through Consultants and Epilepsy Nurse Specialists.

“We are operating a Stepped Care Model in which patients with less severe problems receive targeted support from our Epilepsy Nurse Specialists (e.g. encouraging activity, practising relaxation techniques and teaching diaphragmatic breathing) and patients with epilepsy with more significant psychological or emotional problems see a psychotherapist.

“At present referrals are made to the Joint Neuro-Psychology/Psychotherapy Service for assessment where the Consultant Neuro-Psychologist and the Psychotherapist discuss the most appropriate service for the patient. This model is presently being developed. It is hoped we will eventually organise referral meetings where referrals are discussed between all, so that patients get the best support possible and are referred to appropriate services.
CBT
“It has often become clear that some patients may best be supported from within their community as opposed to attending the psychotherapy service at the hospital. Once the patient has been assessed by either service it may become clear that further assessment by the other service may also be required. If psychotherapy seems the best way forward the patient will be offered CBT. Depending on where they live they may decide to attend on a weekly or fortnightly basis. As is evident from Anne’s story people with epilepsy can get stuck in disabling and sometimes dependent cycles.

“Their perception of their lives can be due to a number of influences, e.g. attitudes of family and others, medical perceptions and practices, the type of epilepsy and frequency of seizures and generally living with a chronic illness. Of course this affects how they live. CBT is a psychotherapeutic approach which seeks to enable a person like Anne to recognise the relationship between her thoughts, behaviours, physical symptoms (health) and emotions.

“ACT (Acceptance and Commitment Therapy) which is part of the wider CBT tradition parts ways with traditional CBT, in that the aim is less about changing thoughts in order to alleviate suffering but more about changing our relationship to the events of our lives and subsequently creating greater psychological flexibility. The patient is encouraged to move in the direction of their values which can involve change and/or acceptance.

“Patients complete the DASS (Depression, Anxiety and Stress Scale) at the beginning, midway and at the end of therapy along with completing diaries to monitor activity and thoughts. Keeping seizure diaries is also encouraged so that patients recognise seizure triggers. Most patients find they learn from diary-keeping and report improvement in self awareness as a result.

“While initially we evaluated the service by asking patients to complete a short questionnaire about their experience of therapy, we now monitor the effectiveness of our Psychotherapy Service by asking patients to complete self-report questionnaires before and after therapy.

“This incorporates the areas of their general health, self-esteem, work and social adjustment, anxiety and risk. We will use these as part of our research.

“Some people using the service have commented that it’s ‘very effective, didn’t take long for therapy to change my behaviour and thoughts, made me think in a different way’ or ‘the feelings, thoughts and actions I was displaying were overwhelming and I had no-one to turn to. This service gave me answers and understanding.’ Key outcomes include a 36% reduction in seizure frequency and 66% of patients were confident of sustained effects.

“The service has secured funding through different means. Originally this was through the Sheffield Teaching Hospitals Neurosciences Directorate through the PBR (Payment by Results tariff system). Now with the support of our local commissioners and the expansion of the psychotherapy service we are entering a new level of funding and being commissioned directly by the PCT (Primary Care Trust).

Handbook
“For many people with epilepsy medication is the mainstay of their management. However we have identified that other approaches such as CBT are important also. As is evident, this service for epilepsy in Sheffield is evolving. We are presently working on a CBT handbook of supportive and beneficial materials to assist people with epilepsy. The handbook will target such problems as adjustment, depression, anxiety and memory problems. With research in progress it is hoped that we will continue to improve our psychotherapy service for people with epilepsy and disseminate our knowledge and findings to a wider group.”

Contact Edel.Dewhurst@sth.nhs.uk

Back Row (L to R): Dr Richard Grunewald, Consultant Neurologist, Carina Mack, Clinical Manager, Edel Dewhurst, Specialist Psychotherapist. Front Row (L to R) Rebecca Mayor, Research Assistant in Psychological Therapies, Stephanie Howlett, Specialist Psychotherapist, Dr Markus Reuber, Consultant Neurologist.
FEATURE

Everyday life and epilepsy

PhD student Niall Smith conducts a social study on epilepsy

“Many readers have recently completed a questionnaire about daily life with epilepsy. This is the first part of my PhD research project (between the University of Glasgow and Epilepsy Scotland) which runs until December 2012. I’m researching ‘The Social Geographies of Living with Epilepsy’ which means I look at the impact epilepsy has on peoples’ everyday lives.

“Lots of studies examine the medical side of epilepsy. Fewer address how people cope with the challenges of daily life. Research like this can be used by policy-makers and epilepsy organisations to ensure people receive the information and care they need. I received 144 completed surveys from members, which was about a third of the people contacted. The survey questions mainly asked about:

  * the physical effects of epilepsy
  * whether people change or plan their daily routines in order to cope better
  * whether epilepsy interferes with their everyday activities
  * how people feel about the reactions of others who witness their seizures, or who they tell about having epilepsy
  * if and how people access support.

For most people, the main physical effects of epilepsy included the side-effects of anti-epilepsy drugs (AEDs), especially tiredness and injuries caused by seizures. Apart from taking AEDs, the most common way people tried to control seizures was by keeping to a routine to prevent stress and tiredness.

“The majority (56%) of individuals cared where they have a seizure. Many people felt unsafe having a seizure in the street (50%), on a bus (41%), in a shopping centre (38%), a car (38%), or venues like pubs, clubs and leisure centres (35%). Although seizures can be unpredictable, 54% of people said they did not attempt to control where seizures might occur.

“However, many people said that where and when they go to different places often depends on whether they are accompanied by a companion. Ultimately, peoples’ levels of anxiety about having seizures seemed to vary from place to place and their individual circumstances.

Stigma

“Respondents felt more comfortable talking to friends and family about their epilepsy than having them witness a seizure. While 41% of people in employment were ‘very confident’ talking with colleagues about epilepsy, almost a third were ‘not at all comfortable’ with colleagues witnessing seizures. Nearly half (48%) of respondents had experienced discrimination and many revealed that their problems were linked to the workplace. In spite of potential stigma, 60% had never tried to hide that they have epilepsy in order to avoid peoples’ reactions.

“Most people (77%) received information about epilepsy from a hospital doctor, followed by epilepsy charities (63%). Only 27% had received information from other people with epilepsy. The majority of respondents did not attend support groups, though many said that they might, given the right circumstances. Nearly one in four (38%) had been involved in public activities, many by joining campaigns run by Epilepsy Scotland. There was disagreement over whether epilepsy was a ‘disability’: 37% said yes it is, 31% said no and 32% felt it was sometimes a disability.
“Information about everyday lives was analysed against factors like age and seizure type. Several factors contributed to peoples’ concerns. Seizure frequency seemed to be the most important influence on peoples’ experiences of epilepsy. This was followed by their age, how old they were when epilepsy was diagnosed and what kind of seizures they have.

“The most significant non-medical issue was how epilepsy impacts work. This was followed by the effect of epilepsy on socialising and the experience of discrimination.

“The social effect of epilepsy also varied according to the types of seizure people have, their gender, current age and age at diagnosis. The impact was linked to how much everyday plans and routines were affected. Whether or not someone seeks support appeared to be related to seizure frequency and age. These results will provide the ‘bedrock’ for my research, and there are many fascinating aspects to investigate in the coming months.

“I want to thank everyone who participated in the questionnaire – without your valuable input this research would not be possible.

“I will soon be contacting several members interested in giving follow-up interviews to help me explore what epilepsy means for peoples’ everyday lives.

“The questionnaire results report will shortly appear on Epilepsy Scotland’s website. Information from the whole research project, including interviews, will be released towards the end of 2012.

“All these findings, including the stories of people whose lives have been affected in many different ways, will be showcased on the web and coincide with a special launch at Glasgow University, hosted by Epilepsy Scotland.”

HEALTHCARE

New form of medical ID

Sam Docherty’s new Press Don’t Panic audio button may be a useful tool for people who could have a seizure when they’re out and about. Mr Docherty, who has epilepsy following surgery for a brain tumour, developed the audio button when he couldn’t find just the right product to alert people if he had a seizure. This small device pre-records a personal message which explains what to do - and just as importantly what not to do - in the event of an emergency.

While lecturing at Edinburgh’s Stevenson College, Mr Docherty came up with the idea for an alarm that speaks when he can’t. He said: “The audio button was a product of necessity. There was nothing else out there which would convey personalised information about my condition, and how to help me in an emergency; both audibly and instantly. I truly believe that Press Don’t Panic can bring other people the same peace of mind it has brought to me and those that care about me.”

Mr Docherty has spent four years creating the audio button which is worn on outer clothing. He believes it could assist with other life-threatening or health-related conditions like speech disorders, anxieties, phobias and developmental disabilities such as autism.

When those assisting in an emergency press the green cross on the front of the device, the recording tells them how to help and who to contact. It can include clear directions about any emergency procedure to follow and this essential medical information can be played back whenever the wearer requires assistance. Its manufacturers have started a public awareness campaign so that people recognise the device and know to push the first aid button to play the message if someone is in difficulties. No-one needs training to use the alarm - just push the button and hear how to help.

For details call 01721 730311 or visit www.pressdontpanic.com
Paediatric consultant neurologist Sameer Zuberi explains how new genetic research in Scotland is helping families to deal with epilepsy.

“The Glasgow Epilepsy Genetics Service was established in December 2005 after the Muir Maxwell Trust, at our request, purchased a genetic sequencer which is housed in the Duncan Guthrie Institute of Medical Genetics in Yorkhill. The first gene we tested is called SCN1A. Changes (mutations) in this gene can cause several epilepsy syndromes. As an established centre, we now get hundreds of samples every year from the UK and all round the world. Our laboratory has found more than 350 genetic changes for a particular condition called Dravet syndrome. We have now tested more than 1,500 children and helped doctors make more than 350 diagnoses.

“Genetic testing is new in epilepsy and we are only just beginning to understand how it can help patients. Our research has shown that families find genetic testing exceedingly beneficial. For many it has given them a diagnosis after waiting sometimes 10 or 20 years. It has helped them understand why their child has a very difficult to control epilepsy. It has helped them reappraise their goals for the child. It has helped them realise that doing other tests, scans or other metabolic investigations are no longer necessary now they have the reason for their child’s epilepsy.

Better seizure control
“Interestingly, a specific diagnosis has given many families access to more services in the community, although this isn’t the way it should be. Children should be given services based on their need for appropriate respite, physiotherapy and other educational support. However, the primary benefit is that many of these children have had their medication changed as a result of the genetic test. In more than half their seizures were controlled better. We have shown for the first time that genetic testing in certain epilepsy syndromes can actually influence medical management.

Expanding services
“There are now several genes we test in Yorkhill for the UK, Ireland and overseas. We have expanded our service to include a gene called PCDH19. This gene is very important because it can present in girls with a very difficult epilepsy in the first year of life. Sometimes this gene can be inherited from the father’s side of the family when the father is completely well. Making the diagnosis is important for genetic counselling as if the father does carry the gene there is a risk of other girls in the family being affected. We can make this diagnosis in infants in 2011 and have been able to go back to test children and adults seen at Yorkhill over the last ten to twenty years, and make a diagnosis finally and offer genetic counselling.

“In addition we test for a gene called SLC2A1 which is related to a disorder in which glucose is not transported normally into the brain. This disorder can mean the brain is deprived of energy and one of the resulting symptoms is epileptic seizures. More recently certain types of epilepsy such as early onset absence epilepsy in childhood are being associated with SLC2A1. Finding a change in this gene and making the diagnosis is very important because there is a specific treatment for this condition which is the Ketogenic diet. Genetic testing can potentially help many of these individuals to get the appropriate treatment, including people who have had epilepsy that’s not been well controlled or is made worse by anti-epileptic medication.

“We are expanding the portfolio of genes even further to epilepsies presenting in the newborn period. One example is the Ohtahara syndrome which can cause children to have a very difficult to control epilepsy and profound learning problems. Again finding the STXBP1 gene is important for families and doctors to understand the cause, hopefully leading to further research, better understanding and better treatments in the future.
Genetic counselling

“It’s important for a family to have genetic counselling because often knowing what’s happened with their child can give families confidence to go on and have other children. When we find a genetic change, we issue a report to the family’s doctor in which we strongly suggest a family referral to a clinical genetics department. In Yorkhill, Dr John Tolmie and I run the epilepsy genetics clinic where we discuss the implications of the report and what it means for the family. We tell them more about the changes that we found. I talk about the medical significance and treatment significance while Dr Tolmie explains the genetic basis of the condition and discusses the risk of other children being affected in future pregnancies.

“For some of these conditions the child may have significant disabilities and is not likely to have a family. However, many children we know will have a gene identified and many of them will have children of their own. We explain to parents about inherited genes. For some of the older teenagers, we talk individually about the risk. We are opening up this clinic to adult referrals made by other specialist services.

They can examine the genetic code for a particular gene in a genetic sequencer and using computer programmes, and their own skills and analysing results, they are able to tell whether there is a change in the genetic code.

“If you think of a genetic code as a series of letters, sometimes those letters are substituted in the code and that particular gene does not work properly. Genes help make proteins in the body so the lab looks at those genes which make proteins that help control electrical activity or provide glucose to the brain. If these aren’t working properly you can have seizures. As genetic information is so valuable and so important, the test gets double checked and triple checked to make sure it is accurate before a report is issued. Since I work very closely with the lab scientists our report includes both scientific findings and what it might mean for the actual epilepsy the child has. This is very important because as we have learned more about genetics we have found that there is tremendous variation between different people in their genes. We have to work out using the results of the test and the type of epilepsy whether any change we find is natural variation or and epilepsy causing change.

“As an NHS lab we always have to provide a report within 8 weeks. Genetic testing is very complex and that may seem a long time. At the moment, from samples arriving to issuing lab reports is just a few weeks.

Funding

“If samples come from England, Wales or Northern Ireland, there is a fee for each test which is paid by the local hospital. There is no charge to hospitals in Scotland. Sometimes we will test samples without charge on a compassionate basis when families in poorer, developing countries can’t afford it.

“New genes are being discovered all the time and we focus on the ones we think are going to help the patient most. The most satisfying times are when you make a diagnosis in a patient or know that a new finding will be really important for a family you have followed for many years. The important thing is that genetics must always be linked to helping the actual problems of the individual.”

More details: sameer.zuberi@nhs.net
IN TOUCH
Q & A

I have read that lots of benefits are being cut. How will this affect me?

Big changes are being made to the benefits system and a lot of people are worried. Each case is different so it is important that you get advice on your own situation. The government is still deciding what changes they will make. They have published a Welfare Reform Bill that explains what they are considering. Key benefits affected include the Disability Living Allowance and Incapacity Benefit.

For some people, new rules mean that you might be asked for a medical assessment. If this happens and you are unhappy with the result, you can appeal. Contact your local Citizens Advice Bureau for more information, or call their helpline on 0844 848 9600.

Some council areas also have Welfare Rights Officers who will be able to help. Contact your local social work department for more details.

RESEARCH
Predict & prevent seizures

Scientists at Aalborg University in Denmark have moved one step closer to understanding how the left vagus nerve works in the brain. Findings from their initial study may allow them to develop a new vagus nerve stimulation (VNS) device which can predict a seizure. The device would then send electrical stimulation to the left vagus nerve just before a seizure, hopefully preventing the seizure completely. If successful, this development may lead to more effective epilepsy treatment in future.

FUNDING
Newlife grants

Funding is available from BDF Newlife for equipment where a child has epilepsy. You can also get professional advice and support from their nurse-led helpline if a child has a disability, a long term health condition, a learning difficulty or a life-limiting condition. Call 0800 902 0095 or visit www.newlifecharity.co.uk

RESEARCH
Exciting Scottish research

Scientists from Edinburgh University and the Wellcome Trust Sanger Institute in Hinxton, Cambridgeshire have for the first time identified 1,461 proteins in our brains. These proteins account for more than 130 diseases and conditions that affect the brain including epilepsy, Alzheimers and autism.

Each of these proteins is encoded by a different gene. Each gene is located in the points where neurons connect (synapses). Neurons are important because they are responsible for transmitting information via electrical signals in our brain.

The researchers were able to identify which conditions are linked to which mutated gene and have created a ‘roadmap’ of this. Findings from this research will allow further exploration of all the conditions that affect the human brain. In future, this may lead to new and more effective epilepsy treatments.

RESEARCH
Why surgery fails?

About one third of people with epilepsy don’t respond to anti-epileptic drugs (AEDs). Brain surgery may then be considered to treat seizures. Two thirds of people who have surgery become seizure free. New research into why surgery sometimes fails has made some interesting findings. In temporal lobe epilepsy, a protein called P-glycoprotein (Pgp) might be involved. Pgp transports chemicals between the blood and the brain. Findings suggest if there are too many Pgp transporters in the brain, AEDs may be less effective. High levels of Pgp have been found in people whose brain surgery has not been successful. If further research supports these findings people with temporal lobe epilepsy could be screened first for Pgp levels, helping to avoid unnecessary surgery.
Community pharmacies are providing a new service for people with long-term conditions. Alison Strath at the Chief Pharmacist's office explains how it works.

What is the Chronic Medication Service?
The Chronic Medication Service is a new NHS service for patients with long-term conditions such as epilepsy and asthma. It is available at any community pharmacy (chemist) in Scotland. There are three main parts to the service: registration; a review of how you use your medicines to identify any problems you may have; and a care plan to help you with your medicines where you have problems. In the future you may also be able to get serial prescriptions from your doctor. These are different from normal repeat prescriptions and allow you to go directly to your pharmacy for repeat medicines.

What will the service do for me?
The service will help you manage the medicines you take for your condition. Your pharmacist is an expert in medicines and will talk to you about any concerns you have about your medicines and help you get the most benefit from them.

How do I access it?
If you are registered with a doctor's surgery in Scotland and get regular prescriptions to treat a long-term condition(s) you can register at your local pharmacy for this service. It's a good idea to register with the pharmacy you normally go to for your medicines as your pharmacist will know what medicines you take. You will have to sign a registration form and your doctor will be told that you have registered for the service.

When will the pharmacist review the use of my medicines?
After you have registered for the service, your pharmacist will look at how you use your medicines. They will ask you about the medicines you take to treat your condition(s) and if you have any problems with them. Your pharmacist may do this when you register, or when you next need one of your medicines, or at another time that suits you.

What happens if I do have problems with my medicines?
If your pharmacist thinks that you do have problems, then they will develop a care plan to help you with your medicines.

What is a care plan?
A care plan is a record of:
- any problems you are having with your medicines, for example difficulty swallowing tablets;
- what you and your pharmacist would like to do about the problems;
- any actions you and your pharmacist both agree are required to solve the problems and who should do them, for example, speaking to your doctor about changing your tablets to easy-to-swallow capsules; and
- noting the date when a problem has been solved.

What happens when I have a care plan?
You and your pharmacist will jointly review and update your care plan regularly.

Where is my care plan stored?
Care plans are held safely and securely on the pharmacy computer which is part of the secure NHS system. Only your pharmacist can look at your care plan and they have a legal duty to keep information about you confidential. Your pharmacist will also give you a paper copy of your care plan.

What is a serial prescription and when will they be available?
A serial prescription looks like a normal prescription but lasts for 24- or 48-weeks. Your doctor decides if a serial prescription is suitable for you and how often you should collect the medicines on your serial prescription, for example every four or eight weeks. Your pharmacist, where you are registered for the service, will keep your serial prescription in the pharmacy and should have it ready for you when you need it. This part of the service is currently being tested and should be available during 2012.
FUNDRAISING
A tribute to Kenny Hall

A tribute night was held in Dumfries, in memory of one of our members Kenny Hall, who died last November.

Kenny was one of the drummers in the kilt clan band called The Dangleberries. This Dumfries and Galloway-based band play traditional bagpipe music but with a twist - their unique brand of drums and guitars and not forgetting the tambourine!

In memory of Kenny, the band decided to donate all profits from ticket sales to Epilepsy Scotland from the gig. Fellow bands Novante and Room 16 featured too. It was a great night fully supported by the local community, Kenny’s family and friends.

A fantastic £3,425 was raised from the gig. To honour Kenny’s memory further, the money will go towards designing a tartan which is unique to Epilepsy Scotland.

The new tartan colours include purple and blue from our charity logo. Look out for our new tartan range of merchandise which will be coming soon!

To read the Dangleberries own tribute to Kenny go to: www.thedangleberries.com

Our warmest thanks go to all the band members and to Kenny’s girlfriend Sally for this ongoing support.

FUNDRAISING
Legacies – a lasting impact

Leaving Epilepsy Scotland a gift in your will can help us to survive and continue our work.

Epilepsy is not decreasing. In fact more people are developing this common condition and the demand for our services continues to grow each year. Your legacy can help us to plan for the future and carry on our work in your memory.

If you are planning to leave a gift in your will or need more information on how to do this please call 0141 427 4911, in confidence. We can thank you personally and let you know how your legacy will help.

IN TOUCH
Epilepsy champion

Epilepsy Scotland is honoured that Glasgow Warriors player and Scotland rugby internationalist Graeme Morrison is our latest ambassador for epilepsy. Graeme’s younger brother James developed seizures at 19 while studying at London University. We are delighted that Graeme wants to do all he can do to help us raise public awareness. We are also grateful to James for sharing his experiences to attract a wider interest in epilepsy.

Graeme explained: “James took a seizure a few years ago and it was like a bolt from the blue. It came as a complete shock to him and our family. Like me, James enjoyed playing rugby. He had to give up playing for a year while his medication was adjusted. He left London University and returned to Scotland. Today his seizures are well controlled and James is studying law at Edinburgh University. As a family we feel people don’t know enough about epilepsy.

It’s a privilege to become Epilepsy Scotland’s ambassador and promote what the charity is doing to help families like mine.”
FUNDRAISING
Donations in memory

Thank you to everyone for their kindness in making a donation in memory of their loved ones:

Mhairi and Ishbel raised £30 in memory of loved family members by busking in Peebles

£1,052 raised by Forfar Academy pupils on Purple Day in memory of their friend Christina Ilia

£196.37 in memory of Mr Henry Matheson

£300 was collected by Desmond Neve at the funeral of his son Andrew

£567.76 received in loving memory of Hugh Higney

£20 in memory of a beloved son from an anonymous donor

£893.20 from the funeral collection of Epilepsy Scotland member Kenny Hall

£100 in memory of Scott McRobbie who passed away 6 years ago, from his mother Shirley Gregory and family

£90 in memory of the late Mr George Wood

£458 in memory of Miss Carol Anne Mackenzie

£500 in memory of Mrs Walker’s late mother

£198.61 funeral collection in memory of Mr William Norman

£719.58 funeral collection in memory of Epilepsy Scotland member Raymond McAllister

£441.95 funeral collection of Mrs June Wilson

£395.90 in memory of Lorna Stoddart

£806.93 in memory of Rick Miller, raised by Tiffany his daughter and partner Lynn

£4,347 received to date in memory of Natalie Hughes by her loving family and friends

£1,083.61 received from Mr and Mrs Stenhouse collected at the funeral of their daughter Sylvia Stenhouse

£410 raised in memory of Paul MacFadyen by his colleagues at HMRC who organised a bake sale and raffle.
Christine Robertson from Inverness explains how her daredevil fundraising adventures are raising awareness of epilepsy.

“Two of my three sons were diagnosed with epilepsy at the age of 16. Teenage years were traumatic enough without the complication of a condition we knew little about.

“The priority for our boys was to manage epilepsy and live full and active lives. One is now a scientist and the other is a pilot/technician. Both attained black belts in Tae Kwon-Do and one is a Scotland International kick boxer.

“In 2008, the death of a young family friend filled me with a sense of needing to do something to promote awareness of epilepsy. I decided to raise money for Epilepsy Scotland by doing an overseas challenge and ended up climbing Mount Kilimanjaro!

“My brother convinced me that anything is achievable as long as the training is broken down into stages. My first Munro was the longest and hardest because of the winter weather conditions and my lack of fitness. By the summer we achieved an amazing six or seven Munros in a few days.

“Alongside training, I began fundraising and was totally overwhelmed by the generosity of so many people. Running two busy restaurants gave me an opportunity to talk about this challenge and Epilepsy Scotland’s work.

“Climbing Mount Kilimanjaro was fantastic. I remember the beauty of Tanzania, the warmth and support of the guides and porters, the team spirit of our group, most of which had never met before and the sense of achievement at the summit - many unforgettable and sometimes emotional moments.

“CS Lewis said you are never too old to set a new goal or dream a new dream. I’ve never really cycled before so this November I’m doing 266 miles through the Nevada Desert. Two friends are coming on this Death Valley Extreme Cycle Challenge, Alistair Davidson and John Macrae, and their support and commitment to training has really pushed me on to achieve goals I never thought possible.

“We are again raising money for Epilepsy Scotland as I believe their work is a vital support to any family that finds themselves in a situation like ours.”

You can click on “Find a friend” and enter Christine Robertson. Visit: www.virginmoneygiving.com/giving/
FUNDRAISING
Run For Us

With summer looming and the Olympic Games just around the corner Epilepsy Scotland would like to invite you to GET OUT and GET FIT!

There are hundreds of events to choose from, so whether you are a dedicated marathon expert, a fast paced 10k hero or merely enjoy a 5k here and there, we have an event for you! Have a look at these fantastic events happening across Scotland:

Women’s 10k - 8 May 2011

Edinburgh Marathon Festival – 22 May 2011

Walk for Scotland and Run for Scotland – 5 June 2011

Men’s 10k – 19 June 2011

Great Scottish Run 10k and Half Marathon – 4 September 2011

Baxter’s Loch Ness Marathon – 3 October 2011

The Big Fun Run Scotland – September and October 2011

Make it your personal goal to GET OUT, GET FIT and COMPLETE A 5K!

Epilepsy Scotland understands that not everyone is an Olympic athlete or has the confidence to go running alone. But with the help of our fantastic weekly training sessions you can wipe the cobwebs off your running shoes and race across the finish line this summer.

This year we are looking for new recruits to tackle a series of training sessions in Glasgow which will have you completing a 5k run in just six short weeks.

With the help of our fully qualified Jog Scotland Jog Leader you will GET OUT, GET FIT and COMPLETE A 5K with ease!

Contact Rachel on 0141 427 4911 to reserve your running team place.
FUNDRAISING

Make a one-off donation

☐ I have enclosed a cheque / Postal Order (payable to Epilepsy Scotland) for £ _______

OR ☐ Please debit £____ from my card as a donation

Card No. □□□□ □□□□ □□□□ □□□□ □□□□

Valid from □□/□□ Expiry date □□/□□ Issue No.□□

3 digit security code □□□

Please tick if you do not require a letter of thanks ☐

Gift Aid it! If you are a UK taxpayer you can make your donation worth more at no extra cost to you.

For every £1 you give we can reclaim an additional 25p of tax.

☐ Yes, I want Epilepsy Scotland to treat all the donations I have made in the last 4 years and all future donations I make from the date of this declaration as Gift Aid donations.

Signature(s) ............................ Date ..... / ...... / ......

You must pay at least as much UK tax (Income Tax and/or Capital Gains Tax) in each tax year at least equal to the tax that Epilepsy Scotland will claim from the Government on your Gift Aid donations. A Please advise us if your change your name or address or if you are no longer pay sufficient tax to qualify for Gift Aid. B You can cancel this declaration at any time by notifying us.

Please return your completed donation form to:

Epilepsy Scotland  Freepost SCO 2178  48 Govan Road  Glasgow  G51 1BR

Thank you!

By supporting us you are helping to make a positive difference to people living with epilepsy every day of their lives.

Scottish Charity SC000067