Welcome to Epilepsy

Epilepsy is the most common serious disorder that affects the brain. One person in 20 will have an epileptic seizure sometime in their lifetime and 50 per 100,000 people develop epilepsy every year. In the UK, this translates to 450,000 having epilepsy at the present and 30,000 developing it every year. Whilst two thirds of those who develop epilepsy have the condition controlled with medication, the remainder do not do so well and continue to have seizures.

Our ability to understand the causes of epilepsy has come a long way in the last decade as a result of sophisticated imaging with magnetic resonance imaging (MRI), that visualises not only the structure of the brain in exquisite detail, but also the function of the brain: both normal functions such as language and memory, and abnormal activity that gives rise to epileptic seizures. These data are vital for planning potentially curative surgical treatment for those in whom medications are not successful at controlling their epilepsy.

With the mapping of the human genetic code, much current effort is going into understanding how variations in the genetic make-up of individual people causes them to be at high or low risk of developing different types of epileptic seizures. Of even more importance is the understanding of how individual genetic make-up determines whether particular medications are likely to be effective or not, and whether they are likely to have adverse effects or not. The combination of sophisticated brain imaging and genetic analysis, with the traditional tools of a detailed clinical history, video recording of seizures and study of the brain’s electrical rhythms with the electroencephalogram (EEG) are now allowing us to individualise therapy for each person so they have the best possible chance of control of their epilepsy without side-effects from treatment.

Epilepsy remains a condition that is serious, common and misunderstood by many. With the advances in understanding and treatment that are being made, however, the future has never been brighter for those who develop epilepsy. A wider understanding of epilepsy by the public at large is also needed to eliminate the stigma that many still feel and this report will go a long way towards achieving that goal.

The National Society for Epilepsy (NSE) is the UK’s largest epilepsy charity, offering the broadest range of services of any charity working in this field. Services include residential, respite and domiciliary care; medical services including outpatient clinics and inpatient assessment, diagnosis and treatment; information, support and training services, including a confidential epilepsy helpline.

Working in collaboration with the National Hospital for Neurology and Neurosurgery, part of University College London Hospitals Trust, NSE’s consultants run the largest epilepsy outpatient clinics in the country seeing more than 3,000 patients every year. The Sir William Gowers Centre, also at Chalfont St Peter, admits around 400 in-patients every year for a detailed assessment of their diagnosis and treatment. Patients are referred through the NHS.

NSE’s research is renowned throughout the world. Much of the research centres on the quest to develop new and improved methods of imaging the brain using magnetic resonance imaging techniques. The charity runs a powerful 3-Tesla MRI scanner, housed at it’s Chalfont headquarters, which is used for both clinical and research scans. Visiting researchers come to NSE’s Chalfont Centre from all over the globe to share in the research programmes. NSE is also becoming increasingly involved in research into the genetics of epilepsy, unravelling the DNA code to discover the causes and implications of epilepsy with a goal of developing personalised treatments for each individual with the condition.

The charity has been providing treatment and care for people with epilepsy for more than 110 years. It was founded to offer a safe home and employment. Specific information packages are available for people with learning disabilities. Information resources also include videos and DVDs.

The epilepsy helpline is a caller-led, confidential helpline. It is open each weekday from 10am to 4pm. Call 01494-601 400
Experts in epilepsy

The most common serious neurological condition, epilepsy directly affects almost half a million people in the UK, and touches the lives of many more.

It can strike anyone, at any time.

The National Society for Epilepsy is seeking a seizure free life for everyone through:

- Pioneering research
- Promoting awareness
- Providing expert care

To support us in our important work make a donation today. Log on at www.epilepsynse.org.uk/donate, call 01494 601 414, or send a cheque made payable to ‘NSE’ to the FREEPOST address below.

Seahorse Appeal

seeking a seizure free life for everyone

Helpline 01494 601 400

www.epilepsynse.org.uk
An individual condition

Epilepsy is one of the oldest medical conditions known to man. Aristotle, Socrates and, later, Julius Caesar, were among the earliest great people who are said to have had epilepsy. Through the ages the condition has been much misunderstood.

In the middle ages theories abounded that epilepsy is caused by evil spirits, and in the Victorian era people with epilepsy were often condemned to asylums in the mistaken belief that epilepsy is a mental condition.

But epilepsy is a physical condition that can affect anyone, of any age, background and race. It may be caused by anything that affects the brain, including a genetic defect, a malfunction in the development of the brain, or may be the result of physical trauma or an illness such as stroke, meningitis or a tumour. In some people there will be no evident cause.

People with epilepsy will have seizures that arise when there is an abnormal electrical discharge of the nerve cells in the brain. Whilst many people may have a single seizure at some time in their life, a person with epilepsy will have recurrent seizures.

Epileptic seizures can take many forms. Some attacks may be quite short and people were said to either have ‘grand mal’ or ‘petit mal’ seizures. These terms are now outdated, particularly as they do not, in any way, convey the complexity and multiplicity of the different seizure types. While most people will experience the stereotypical falling to the ground, jerking and foaming at the mouth, most seizure types do not involve convulsions.

Different types of seizures

Seizures can be divided into two groups: partial seizures and generalised seizures, although a partial seizure can spread throughout the brain to become a secondarily generalised seizure.

Partial seizures always start in just one hemisphere of the brain, sometimes involving the whole hemisphere or possibly just a small area within one of the lobes. There are three types of partial seizure.

Partial seizures

In a simple partial seizure only a small part of the brain is affected. The person will be totally conscious and may recognise that they are having a seizure. Signs of the seizure may include twitching of a limb or part of a limb, or the individual may just experience an unusual smell or taste, or a tingling like pins and needles. These symptoms are sometimes referred to as aura.

Complex partial seizures will involve a greater portion of the brain and the person will be in a state of altered consciousness, possibly wandering about, fiddling with clothes and other objects, sometimes mumbling or making other noises, chewing or smacking their lips. The behaviour will often seem bizarre to others, especially as the individual may react when another person speaks to them – but may not understand or properly hear what is being said. People experiencing complex partial seizures may often be mistaken for being drunk or under the influence of drugs, or they may find themselves being compromised by their actions during the seizure.

Sally Goernsall, a mother of two from Newark, experienced complex partial seizures for many years before having successful surgery. She said: “I would come out of the seizure not knowing where I was or where I had been, only to see the faces of other people looking at me as if I was drunk or just simply weird. One time I had a complex partial seizure on a station platform. I fell onto the railway line, yet no one came forward to help me. I guess because they were ignorant of what was happening.”

Both simple partial and complex partial seizures can spread across the brain into a secondarily generalised seizure with total loss of consciousness, sometimes spreading so quickly that the partial phase may not even be noticed.

Generalised seizures

Generalised seizures involve the whole brain from the outset and often happen with no warning whatsoever. The individual will be totally unconscious for the duration of the seizure. Such seizures include the tonic clonic – convulsive – seizure in which the muscles will tighten and relax rhythmically making the body jerk or shake; if standing, the person will fall to the ground, their breathing may stop or become difficult, their skin colour may change turning blue-grey, they may cry out at the start of the seizure, may bite their tongue or cheek and may be incontinent. This is the seizure type that used to be known as ‘grand mal’.

Common triggers for people with photosensitive epilepsy include:

- Watching television, playing computer games or looking at other computer graphics
- Watching a faulty television or other computer graphics
- Strobe lights

Tips which might help people with photosensitive epilepsy include:

- Identify trigger factors such as tiredness, stress or heavy drinking that may bring on a seizure and avoid them.
- Keep fit and relax – many enjoyable activities help to lower stress and improve seizure control.

Healthy tips

- Take anti-epileptic medication regularly and at the required times.
- Check with your doctor or pharmacist before using any other medication as some treatments may interact with anti-epileptic medication and may cause seizures to occur.
- Take simple safety precautions to reduce risk of injury during a seizure.
- Identify trigger factors such as tiredness, stress or heavy drinking that may bring on a seizure and avoid them.
- Keep fit and relax – many enjoyable activities help to lower stress and improve seizure control.

Photosensitive epilepsy

Epileptic seizures can sometimes be triggered by flashing or flickering lights or by some geometric shapes or patterns. Contrary to popular belief, photosensitive epilepsy is rare and only affects between three and five per cent of people with epilepsy. It is more common in children and young people.

Common triggers for people with photosensitive epilepsy include:

- Watching television, playing computer games or looking at other computer graphics
- Watching a faulty television or other light source that flickers slowly
- Strobe lights

Embarrassment following the seizure can be one of the worst effects – knowing you have been completely out of control and unconscious yet having no knowledge of what you have done during the seizure. It’s the loss of dignity – and the indignation on other people’s faces – that can be so hard to cope with.

At the other end of the spectrum, generalised seizures are the absence seizure, formerly known as ‘petit mal’. During an absence seizure the person is briefly unconscious and unresponsive, possibly staring blankly for a few seconds or with the eyelids flickering. Such seizures may be so brief that they go unnoticed. Other generalised seizures include tonic seizures in which the muscles suddenly stiffen, tonic seizures in which the muscles suddenly relax, and myoclonic seizures which involve sudden jerking of a limb or limbs.

Between these seizure types are many variations. Epilepsy is very much an individual condition. No two people’s experiences will be exactly the same and some people may experience just one seizure type while others may experience a varied mix.
Finally seizure free

Top London lawyer and legal advisor to many celebrities, Mark Stephens has lived with epilepsy for most of his life.

Throughout his childhood he experienced dozens of small absences, which went unnoticed, and he learned to cope with. He was finally diagnosed with epilepsy as a teenager following a dramatic tonic clonic seizure shortly after passing his motorcycle test.

Now in his 40s, Mark has been prescribed most of the anti-epileptic drugs available.

Mark said: “I had mixed feelings when my diagnosis was confirmed. I suppose that there was a sense of relief that there was a reason for what had happened to me. At the same time I felt really vulnerable. I had just started at university and despite medication my epilepsy wasn’t controlled. I felt I would stand out from everyone else if I had a seizure when all I really wanted to do was blend in. I found myself facing the dilemma, who should I tell and when should I tell them.”

Eventually Mark told his university friends and was reassured by their reaction. He said: “Despite that, I did go through a period of rebelling against the condition. I did all the dangerous things I’d been told not to do and went through a period of refusing to take the medication.”

As Mark’s professional career flourished, he struggled to gain control of his seizures. He experienced 20 to 30 seizures a day and tried almost every anti-epileptic drug available. “It was as if the neurologists were playing a game of battleships with pharmacology, making guesses as to which drug might work best.”

Then five years ago a new drug turned his life around. He is now seizure free, is able to drive and no longer needs to employ coping strategies to help keep him at the top of his profession.

He said: “There needs to be a greater awareness of epilepsy and its complexities. I was honest with my colleagues and clients about how epilepsy affected me and they were understanding. Epilepsy is so common, and yet there is still a stigma attached to it. I just hope that by telling my story it will help raise awareness.”

UCB - dedicated to epilepsy

UCB are committed to improving the lives of people with epilepsy. As one of the world’s leading biopharmaceutical companies, we market and develop innovative treatments for epilepsy which exploit the very latest scientific discoveries.

But we are doing much more than this, the patient is always at the forefront of our research. We aren’t just developing the most effective treatments for epilepsy, we want to make a meaningful difference to the epilepsy community: to patients and their families, and to the doctors, nurses and all those who care for them. From laboratory bench to bedside, the patient comes first.

Epilepsy affects over 450,000 people in the UK (that’s one in every 131 people). But an estimated 70% of patients could be free of seizures if they had the right treatment for their particular epilepsy. Over the past 12 months, we at UCB have made significant progress in developing a portfolio of medicines to ensure that more people can get the treatment they need for their type of epilepsy.

Our planned acquisition of Schwarz Pharma – an innovative pharmaceutical company with a pipeline of exciting new medicines which complements our own – will enable us further to expand our capabilities and investment in treatments for brain and nervous system diseases, and to become a global leader in the field.

But our work does not end when our products leave the building.

At UCB, we believe that more people need to understand what epilepsy is – and what it isn’t. We want to spread the word that, around the world, millions of people with epilepsy are leading happy, healthy fulfilling lives. That is why we are supporting educational initiatives that aim to broaden both medical and public awareness and understanding of epilepsy.

We are focusing on empowerment. Through the ‘Take Control’ initiative, established by Epilepsy Action, we support efforts to reach out to those who are disengaged from the health care system and to encourage them to become more involved in the treatment process and the management of their own condition.

We also support a number of projects from the National Society for Epilepsy. One of these – the Epilepsy Information Network (EIN) – helps patients to access information about epilepsy and provides volunteers who offer valuable help and support to patients at hospitals across the UK.

We work with health care specialists on the best ways to help patients live with epilepsy. Our Epilepsy Masterclass programme helps doctors and nurses who care for people with epilepsy to keep up to date with the latest advances. Our Epilepsy Ambassador scheme enables people with epilepsy to talk about their experiences to both medical and non medical audiences, thus improving understanding of the needs of patients, and the challenges of living with epilepsy. We also support the Epilepsy Action Sapphire nurse programme, which pump primes the specialist nurse positions that are critical to creating a personalised, effective treatment programme for patients.

UCB is not just a biopharmaceutical company. We are a company committed to developing holistic, innovative solutions to diseases of the brain and nervous system, such as epilepsy. From our dedication to cutting-edge research, to our commitment to education and training, to our engagement with our partners in the field of epilepsy, we are improving the lives of patients here in the UK and further abroad. It is this ‘patient-centred’ ethos that is at the core of our culture.

The ketogenic diet

The Ketogenic diet is a high fat, low carbohydrate, adequate protein diet, which has been shown to dramatically end or reduce seizures in children. It may be used as an alternative to, or in conjunction with, AEDs. It can be a difficult diet to follow but may be effective in a significant number of children with epilepsy, though not all. Trials are on-going at Great Ormond Street Hospital.

The diet was first developed in the early part of the last century. It works by mimicking the effects of starvation. When fasting or starving, your body first uses up glucose and glycogen before burning up stored body fat. In the absence of glucose it produces chemicals called ketones which provide energy. The diet alters the body’s metabolism by replacing glucose with fats as a major energy source. The broken down fat produces ketone bodies that help to alleviate seizures in some people.

Calories and proportions of nutrients on the diet are carefully controlled. Weight gain can sometimes be a problem if the prescribed amounts are exceeded, but in most cases this does not happen as the child’s weight is carefully monitored and the dietary prescription altered as necessary. Close partnership working between the child’s family or carers and the clinical team is vital.

Some children’s seizures respond very quickly to the diet; others can take up to three months and some will not respond at all. How long a child stays on the diet will depend on how much they seem to be benefiting. If the child is seizure free for two years, most doctors would suggest a trial of slowly returning to a normal diet.

For more information, contact Matthews Friends 0788 4054811

For more information on the Take Control initiative please visit: www.takecontroluk.org
Diagnosis

Epilepsy can be very difficult to diagnose and misdiagnosis rates are high. About 50 per cent of newly diagnosed or suspected epileptic seizures at primary care level will, after appropriate assessment, turn out not to be epileptic in nature. Similarly, between 20 and 30 per cent of people diagnosed with chronic epilepsy at secondary care level, when later fully diagnosed at a tertiary referral centre, are found not to have epilepsy.

A person is diagnosed as having epilepsy if they have repeated seizures that start in the brain. Anyone can have a single seizure at some point in their life but a one-off seizure is not epilepsy.

There are more than 50 different types of epilepsy. Many only last a short time whilst others are life long.

The National Institute for Health and Clinical Excellence (NICE) guidelines state that any person who has had a possible epileptic seizure should be seen within two weeks by a specialist practitioner with training and expertise in epilepsy. This specialist should have an open mind in making the initial diagnosis, which may involve specialist tests (see adjacent). Where required, these tests should be available within four weeks of a specialist asking for them, says NICE.

Key to diagnosis is an eye witness account of the seizure and the circumstances leading up to the seizure. However possible any witness should attend the specialist appointment with the patient. If this is not possible attempts should be made to talk to the witness or to obtain a written account. If a number of episodes take place, video footage can be very helpful.

The specialist will want to know what events took place in the lead up to the seizure, if there was a change in mood, if the individual experienced any unusual sensations such as an odd smell or taste, or if they had any warning that the seizure was going to happen.

Part of the diagnosis will also include looking at a person’s medical history and any other medical conditions they may have.

The specialist may arrange for tests to be done. These might include a blood test, to rule out other possible causes of the seizure such as low blood sugar or an electrocardiogram (ECG) to check the way the heart is working.

Reactions to a diagnosis

People react in many different ways to a diagnosis of epilepsy. Often there is a feeling of shock. Others may react to the loss in independence and the restrictions imposed on their life such as having to surrender a driving licence.

Information

Information is vitally important in coming to terms with a diagnosis of epilepsy. The NICE guidelines state that information should be available so that the individual is empowered to manage their condition as well as possible and be fully involved with their specialist or GP as a partner in all decisions about healthcare and lifestyle.

Once a diagnosis of epilepsy is established medical professionals will assess how much information should be given, or indeed how much can be assimilated by the individual. The professional needs to choose carefully the right time to deliver the right information for that person.

Access to voluntary groups is important as they can provide additional information and support. Their details should be made known to all people with epilepsy.

Specific tests for epilepsy:

Electroencephalograms (EEG)

An EEG is used to record the electrical activity of the brain by picking up the electrical signals from the brain cells, via electrodes on the head. The electrodes only record electrical activity. When someone has an epileptic seizure, their brain activity changes. However, unless a seizure occurs during the recording process, the test may just show as normal.

An EEG test normally lasts about half an hour but if activity of the brain needs to be monitored for longer, an ambulatory EEG might be undertaken. During this type of EEG the electrodes are attached to a small recording machine worn around the waist. This allows brain activity to be recorded for hours, days or weeks.

Video telemetry

This test is done in hospital over a few days. As well as having an ambulatory EEG, a video camera records what the person is doing. This test means that the electrical activity of the brain can be compared with what the person does during a seizure. This can help to work out what type of seizures the person has.

Magnetic Resonance Imaging (MRI) scans

MRI produces high quality images of the brain. MRI is based on the principles of nuclear magnetic resonance (NMR) to obtain microscopic chemical and physical information about molecules. This information is then processed through a computer and images are produced. As science advances and stronger magnetic fields are utilised the effect on the molecules in the brain is more obvious. Images are clearer, more detailed and with greater contrast. They can show scarring, damage or tumours which may be the cause of epilepsy.

Computerised Axial Tomography (CT or CAT) scans

CT scans use x rays to produce pictures of the brain. The pictures might show an obvious physical cause for the seizures.
Epilepsy in children and young people

Epilepsy is not a single condition; there are many possible causes of epilepsy. Some factors will affect how the condition progresses. A single seizure does not mean a child has epilepsy and a diagnosis will only be made on the evidence presented by more than one seizure. Equally, while five per cent of children will have febrile seizures in the pre-school years this does not mean that they have, or will develop epilepsy.

Seizure types
Seizures will vary from one child to another in their pattern, type and intensity. A child may experience one type of seizure or a combination. In some children, as in adults, seizures will only occur at night, while in others they may arise at any time. Seizures range from ‘absences’ in which there is a brief lapse of consciousness, through to ‘tonic clonic’ seizures which are typified by convulsions. Between these extremes are many other seizure types, not all of which involve total loss of consciousness.

Absences occur in around 30 percent of children with epilepsy and may be undiagnosed for many years. These brief lapses in consciousness are often very fleeting and very frequent. If undiagnosed they can be mistakes for daydreaming. Undetected absences can have a profound effect on a child’s ability to learn.

A known trigger of seizures is photosensitivity, although it is very rare – in only around five per cent of people with the condition are seizures triggered by flashing or flickering lights. Most children with epilepsy can use computers and watch television without any problem.

Diagnosis
If there is a possibility that a child has epilepsy they will usually be referred to a paediatrician for diagnosis. Often the paediatrician makes the diagnosis using an eyewitness description of the seizure and other information about the child’s medical history. However, to help with diagnosis a number of tests may be used. These tests are described in the box to the left, and are usually painless but younger children or children with learning disabilities may be given a light anaesthetic to help them relax and stay still. Normal results from these tests do not rule out a diagnosis of epilepsy.

Syndromes
If a child has been diagnosed with an epileptic syndrome their seizures have a particular group of characteristics that occur together. Seizures classified within a syndrome have a typical pattern, a typical age when they start and produce specific EEG recordings. The syndrome may also follow a definite pattern of progression. Around 75 percent of epileptic syndromes start in childhood.

Dosages are usually based on the child’s body weight. The dose will gradually be increased until the seizures are controlled or unacceptable side effects develop. If side effects do occur another drug may be substituted or added to the first (polytherapy). Gaining good seizure control can sometimes take a long time. Keeping a diary of the child’s seizures can help the specialist identify any patterns that are emerging and help determine the best treatment plan for the child.

Most AEDs usually have at least two names, a chemical or generic name and a trade or brand name given by the manufacturer. For anyone with epilepsy it is advisable to take the same manufactured preparation all the time as preparations can vary slightly which could have an effect on seizure control or the development of side effects.

How does the medication work?
Different drugs work on different parts of the brain and each drug is selected according to the type of seizure a child has. Having each drug has a slightly different way of acting, they all act on the brain to suppress seizures. They do not treat the underlying cause and do not ‘cure’ epilepsy.

AEDs do have to be taken regularly as prescribed. Most AEDs are available in various forms to make them more palatable for children. Some tablets may be chewed, sprinkled on food, crushed or dissolved.

Epilepsy and education
Epilepsy can affect children in different ways and it is important that the school is aware of the extra support each child may need. Staff may need to take extra care in supervising some activities to make sure the child and others are not put at risk.

An individual healthcare plan can help staff identify the necessary safety measures to support a child with epilepsy. This may include information such as side effects of medication, what action to take in an emergency, what not to do in the event of an emergency and who to contact. An individual care plan including all this information should be agreed between the parent, the teacher and appropriate professionals for every child with epilepsy. This should also include information on how to manage seizures, determining if, or at what stage, an ambulance needs to be called.

Generally calling an ambulance will not be necessary. Most seizures will take their natural course and the child will recover and be able to continue with school activities. Sometimes the child will feel drowsy and this needs to be taken account of.

However, occasionally, seizures may not follow the anticipated pattern and a situation known as status epilepticus may develop. This is when the seizure continues or one seizure follows another. Medical intervention will be necessary.

Some children may need to take their medication during a school day. The school should have a medicines policy in place which should cover procedures such as managing prescription medicines in school and on trips and outings, a clear statement on the role and responsibility for administering or supervising the administration of medicines, and a clear statement on parental responsibilities in respect of their child’s medical needs.

If a child is having seizures, others in the classroom may think he is strange or may even be afraid. Knowledge and understanding are key to breaking down fears and the teacher has an important role to play in ‘normalising’ both the child and the situation.

Epilepsy and learning disabilities
Epilepsy itself does not cause learning difficulties, though as the cause is often underlying brain damage this may result in learning difficulties. However there is evidence that a significant number of children with epilepsy in particular have certain subject problems. Problems in reading and, to a greater extent, in spelling and arithmetic are common. Learning capacity may be affected, as can planning ability and reasoning. Some AEDs may reduce the child’s ability to concentrate. Disturbed sleep patterns, the effects of high levels of medication and the likelihood of more absenteeism also give rise to potential for underachievement.

With all of the above taken into consideration, it is important to remember that children with epilepsy should be able to participate in all school activities, extra curricular activities and have as normal as possible a childhood.
Epilepsy in women

There are aspects of epilepsy and its treatment which are particular to women only. Hormonal changes can affect the way epilepsy progresses.

Although epilepsy can occur at any time in a person’s life, research has shown a link between hormones and seizures. This means that there can be times in a woman’s life when epilepsy is more likely to start or seizures are more likely to happen, such as hormonal changes during the menstrual cycle and throughout pregnancy.

The two female hormones, oestrogen and progesterone, stimulate or slow down brain cells. This can lower or raise a person’s level of resistance to seizures (seizure threshold). When oestrogen levels are high and progesterone levels fall, women are more likely to have a seizure. As changes in hormone levels occur during puberty, this can be a common time for epilepsy to start.

One in three women with epilepsy finds that their menstrual cycle affects their seizure pattern. Although they may have seizures at any time, some women find they are more frequent before and during their period or regularly occur at another stage during their menstrual cycle such as ovulation. Some women have seizures only during their period and at no other time.

Polycystic Ovary Syndrome (PCOS), which can give rise to irregular or infrequent periods is thought to be more common in women with epilepsy and those taking the anti-epileptic drug sodium valproate.

Contraception

There are many methods of contraception and some may not be as effective in preventing pregnancy for women taking AEDs. There is no evidence to suggest that taking the contraceptive pill affects epilepsy, although it may affect the efficacy of the AED itself.

AEDs can be divided into two groups, enzyme inducing and non enzyme inducing drugs. Enzyme inducing drugs result in the hormones in the oral contraceptive pill being broken down more quickly in the liver, making this method of contraceptive less effective. Even if the dose of the pill is increased it will still be less reliable than if enzyme inducing drugs were not being taken. The morning after pill dose would need to be increased by 50 per cent if an enzyme inducing drug was being taken.

Non enzyme inducing AEDs do not affect any type of contraceptive method and women can use any method of contraception.

Contraception should always be discussed with your GP or epilepsy specialist.

Conception and preconception counselling

Between 1,800 and 2,400 children are born every year to women who have epilepsy and their babies need to be monitored. Women affected by epilepsy during pregnancy are more likely to have a seizure. As changes in hormone levels occur during puberty, this can be a common time for epilepsy to start.

Seizure patterns

Most women with epilepsy do not see any change in their seizure frequency during pregnancy. For those who see an increase in seizures, it is normally associated with not taking AEDs as prescribed, vomiting within an hour of taking medication, sleep deprivation or reduced drug levels. Some women have better controlled seizures during pregnancy.

The menopause

Some women may develop epilepsy during a phase in their life cycle such as the menopause. Others may find that their seizure control improves or their seizures stop completely.

Hormone Replacement Therapy (HRT) does not usually cause any problems for women with epilepsy. The development of face, limbs and some AEDs could carry greater risks than others.

Seizures during pregnancy

For any woman having a child there is a three per cent risk that the baby may be born with a malformation. Taking AEDs during pregnancy may increase this risk, and some AEDs could carry greater risks than others.

The developmental abnormalities associated with AEDs may include cleft lip and palate and malformation of face, limbs and internal organs.

The dangers to the baby and the mother herself from not taking medication are usually greater than those associated with taking AEDs.

Some women have better controlled seizures during pregnancy.

The dangers to the baby and the mother herself from not taking medication are usually greater than those associated with taking AEDs.

Pregnancy

- Women taking AEDs who are planning a pregnancy are recommended to take higher supplement of folic acid (5 mg per day) as research shows this to reduce the risk of neural tube defects.
- Women who are likely to still have seizures during pregnancy need to continue taking AEDs although their specialist may adjust the dose.
- The dangers to the baby and the mother herself from not taking medication are usually greater than those associated with taking AEDs.
- For any woman having a child there is a three per cent risk that the baby may be born with a malformation. Taking AEDs during pregnancy may increase this risk, and some AEDs could carry greater risks than others.
- The developmental abnormalities associated with AEDs may include cleft lip and palate and malformation of face, limbs and internal organs.
- During pregnancy the body uses more AEDs, and the levels of the drug in the blood may fall. Monitoring blood levels can give a good indication if medication needs increasing. Women affected by morning sickness may need to change the time of taking their AEDs.
- Just as for all pregnant women, ultrasound scans at intervals during pregnancy are useful to monitor a baby’s development.

Polycystic Ovary Syndrome (PCOS), which can give rise to irregular or infrequent periods is thought to be more common in women with epilepsy and those taking the anti-epileptic drug sodium valproate.

Contraception

There are many methods of contraception and some may not be as effective in preventing pregnancy for women taking AEDs. There is no evidence to suggest that taking the contraceptive pill affects epilepsy, although it may affect the efficacy of the AED itself.

AEDs can be divided into two groups, enzyme inducing and non enzyme inducing drugs. Enzyme inducing drugs result in the hormones in the oral contraceptive pill being broken down more quickly in the liver, making this method of contraceptive less effective. Even if the dose of the pill is increased it will still be less reliable than if enzyme inducing drugs were not being taken. The morning after pill dose would need to be increased by 50 per cent if an enzyme inducing drug was being taken.

Non enzyme inducing AEDs do not affect any type of contraceptive method and women can use any method of contraception.

Contraception should always be discussed with your GP or epilepsy specialist.

Conception and preconception counselling

Between 1,800 and 2,400 children are born every year to women who have epilepsy and their babies need to be monitored. Women affected by epilepsy during pregnancy are more likely to have a seizure. As changes in hormone levels occur during puberty, this can be a common time for epilepsy to start.

Seizure patterns

Most women with epilepsy do not see any change in their seizure frequency during pregnancy. For those who see an increase in seizures, it is normally associated with not taking AEDs as prescribed, vomiting within an hour of taking medication, sleep deprivation or reduced drug levels. Some women have better controlled seizures during pregnancy.

The menopause

Some women may develop epilepsy during a phase in their life cycle such as the menopause. Others may find that their seizure control improves or their seizures stop completely.

Hormone Replacement Therapy (HRT) does not usually cause any problems for women with epilepsy. The development of face, limbs and some AEDs could carry greater risks than others.

Seizures during pregnancy

For any woman having a child there is a three per cent risk that the baby may be born with a malformation. Taking AEDs during pregnancy may increase this risk, and some AEDs could carry greater risks than others.

The developmental abnormalities associated with AEDs may include cleft lip and palate and malformation of face, limbs and internal organs.

The dangers to the baby and the mother herself from not taking medication are usually greater than those associated with taking AEDs.

Pregnancy

- Women taking AEDs who are planning a pregnancy are recommended to take higher supplement of folic acid (5 mg per day) as research shows this to reduce the risk of neural tube defects.
- Women who are likely to still have seizures during pregnancy need to continue taking AEDs although their specialist may adjust the dose.
- The dangers to the baby and the mother herself from not taking medication are usually greater than those associated with taking AEDs.
- For any woman having a child there is a three per cent risk that the baby may be born with a malformation. Taking AEDs during pregnancy may increase this risk, and some AEDs could carry greater risks than others.
- The developmental abnormalities associated with AEDs may include cleft lip and palate and malformation of face, limbs and internal organs.
- During pregnancy the body uses more AEDs, and the levels of the drug in the blood may fall. Monitoring blood levels can give a good indication if medication needs increasing. Women affected by morning sickness may need to change the time of taking their AEDs.
- Just as for all pregnant women, ultrasound scans at intervals during pregnancy are useful to monitor a baby’s development.
Living with epilepsy

A diagnosis of epilepsy should not prevent someone from living a full and active life.

Epilepsy is a very individual condition so choices about what activities to participate in and how to live life need to be made on an individual basis, depending on the type and frequency of seizures and the level of control with medication.

What effect epilepsy has on your life depends on what your seizures are like and how well the medication works. Most people carry on a normal life.

However you may feel you don’t want to go out or do the things you would normally do in case you have a seizure.

It may help to find out more about epilepsy, think about some simple safety measures or find out what support there is. Finding ways of doing what you would like to do and keeping as mentally and physically active as you can might help to make epilepsy just part of your life and not the most dominant part.

When you are diagnosed with epilepsy the reaction of family and friends can vary. They may feel concerned and want to offer help and support. Some may not understand what epilepsy is like or may become overprotective. Helping them to understand more about the condition and how it affects you may help.

Employment

Nearly all jobs are open to people with epilepsy and having epilepsy does not necessarily prevent people from working in the job they choose.

Epilepsy is a condition covered by the Disability Discrimination Act. The type of work you can do will depend on whether you still have seizures, what they are like and how often they happen. However jobs in the armed services can still be restricted by law to people with epilepsy. Other professions may have their own specific health regulations if a person’s epilepsy could present a risk to safety.

The point when someone tells their current or future employers that they have epilepsy is a personal choice. If you develop epilepsy or if your epilepsy changes and starts to cause difficulties at work, your employer is expected to make reasonable adjustments so that you can continue to work.

Driving

For many people one immediate effect of having a seizure is that they have to stop driving. There is a legal obligation for anyone to inform the DVLA of any medical condition which may affect their ability to drive. This responsibility lies with the person themselves.

DVLA regulations say you must stop driving for a period of one year from the date of your last seizure. If you have no further seizures for 12 months you can apply to the DVLA for a new licence.

The DVLA recommends that anyone who is changing or stopping their medication should stop driving while they are doing this and for six months afterwards.

Under the Disability Discrimination Act, motor insurance companies should not add a premium to insurance just because a person has epilepsy.

Air travel

Having epilepsy does not usually stop people from being able to travel by air. However, some people find that their seizures are triggered by extreme tiredness such as jet lag, excitement or anxiety, all of which can be caused by travelling or flying.

Risk assessment

People who have seizures may have little or no warning when they will happen and may be at risk of injury during or after a seizure. The risk depends very much on the type and number of seizures. Looking at ways of lowering risk can help people to do the things they enjoy and be as independent as they would like.

There are some simple measures which people with epilepsy can take to make the home a safer place. These include taking a shower rather than bath and using a microwave rather than a cooker.

Leisure

The way in which we spend our leisure time is important and individual to us all, regardless of whether or not we have epilepsy. Most leisure activities can be made safer by adopting simple safety measures to help minimise any potential risk.

Watersport activities are often those which people with epilepsy often have concerns about. Choices need not be restrictive – just realistic.

For example, when swimming it is a good idea to go with someone who knows about the type of seizures you have and how to deal with them, and to inform a lifeguard.

Water sports such as windsurfing, sailing and canoeing are popular and need not be a problem to someone with epilepsy providing there is someone on hand to manage a seizure if necessary.

Scuba diving, however, is really not recommended for people with epilepsy. People taking AEDs are more likely to experience ‘nitrogen narcosis’ – a condition which affects rational thinking.

Having and living with epilepsy will affect different people in different ways. What they all have in common is the ability to ensure appropriate precautions are taken, allowing them to lead their lives to the fullest possible extent.

Epilepsy in the elderly

Epilepsy can affect anyone at any time of life. However, it is more common in people under the age of 20 or over the age of 60. One in four people who develop epilepsy is over the age of 60. There are many causes of epilepsy, and some are more common in later life. As we get older our bodies start to change. For example, the blood vessels that supply blood to the brain sometimes become narrower and harder, which can affect the flow of blood to the brain. This is often the cause of seizures in later life.

There are other medical conditions that can look like seizures, so as part of the diagnosis a specialist may look at other possible causes besides epilepsy.

For example, your specialist may try and rule out causes like diabetes, fainting, heart problems or a cerebrovascular (CV) condition which affects the blood vessels of the brain. They may ask you to have a blood test, check your heart, blood pressure and cholesterol levels. By doing tests for other conditions, your specialist may be able to avoid any future problems such as finding a CV condition at an early stage.

Treatment

Once a positive diagnosis of epilepsy has been made, your specialist will start treatment. The choice of anti-epileptic drug (AED) is important, particularly if you are taking drugs for other medical conditions. Some drugs interact and affect how well other drugs work. Other AEDs may affect memory and the ability to think quickly. Some AEDs may increase your risk of osteoporosis. These are all points that have to be considered by the specialist when prescribing medication.

If you are taking several drugs for different conditions it may be useful to use a chart, pill box or drug wallet to remind you which tablets to take and when. Your specialist or GP will also be able to help by putting together a treatment plan which might include a way of taking your AEDs at a time to suit you.
Brain imaging & epilepsy

Epilepsy arises in the brain as an electrical disturbance and may have many causes. Only for the last 30 years has it been possible to take images of the brain in life and thereby be able to visualise the many causes of epilepsy and also their consequences.

BY PROFESSOR JOHN DUNCAN, HEAD OF THE DEPT OF CLINICAL AND EXPERIMENTAL EPILEPSY, INSTITUTE OF NEUROLOGY UCL. ALSO MEDICAL DIRECTOR OF THE NATIONAL SOCIETY FOR EPILEPSY

X-ray CT scans came into clinical use in the mid 1970s and for the first time showed the structure of the brain. Large abnormalities such as tumours, blood clots, strokes and abscesses could be demonstrated. In addition to leading to a better understanding about the causes of epilepsy, this also underpinned the development of epilepsy surgery, that is surgery to remove the cause of the epilepsy with the hope of stopping the occurrence of epileptic seizures.

In the subsequent years, magnetic resonance imaging was invented in Nottingham and the first reports of MRI in individuals with epilepsy appeared in 1984. It rapidly became apparent that MRI provided much better definition and identification of subtle abnormalities in the brain than did X-ray CT. Over the last 20 years, MRI has become more and more sophisticated as a result of many technological advances, not only in the design of the magnets and instruments, but also in the computing equipment required to programme the scanner to take images in different ways and to analyse the enormous amounts of data that are now produced by an MRI scan.

The core of the MRI scanner is the magnet with the strength of the magnet being measured in Tesla. The first MRI scanners had magnet strengths of 0.3 Tesla. The current state-of-the-art standard for clinical MRI scanning is 3 Tesla. Current MRI scans show the structure of the brain in exquisite detail, showing the details of the grey matter and the white matter and the precise folding of the brain, with the ability to show structures and abnormalities no more than a few millimetres across. Increasingly we are able to see subtle malformations of parts of the brain in addition to small areas of scarring that commonly give rise to epilepsy.

Imaging methods

There are many new ways of acquiring scans that give more information in addition to the standard scans in which the images are essentially based on the concentration of water in different parts of the brain tissue. For example, magnetisation transfer images reveal the interaction and binding of water with large molecules, particularly proteins, in the brain. Diffusion tensor imaging visualises the movement of water within the brain. If an area of brain is damaged or disorganised there will commonly be more space between the individual nerve cells and so water is more mobile and this can be visualised with a diffusion scan.

Increasingly we are able to see subtle malformations of parts of the brain in addition to small areas of scarring that commonly give rise to epilepsy.

The nerve fibres in the brain are arranged like small tubes. Water may move along these tubes much more easily than it may move from side to side. The analogy would be that water might move up and down a stick of celery much more easily than it can move sideways. With the visualisation of the movement of water within these nerve fibres, the nerve fibre connections within the brain can be picked out, using the technique known as tractography. This is giving us dramatic new insights into how one part of the brain is connected with other parts and how these interact with each other. For example, we have been able to show that the connections in the brain between the part of the brain that understands language and the part that generates words on the left-hand side of the brain is reduced in those with epilepsy arising in this area.

We have also recently been able to show, for the first time, the connections in the brain that appear to carry the spread of epileptic activity from one part of the brain to another. This information is beginning to be extremely useful in the planning of surgical treatments. In addition to predicting the risks of surgery, the information can be made available to the surgeon so that an operation may be planned to minimise the risk of damage to the important connections. The analogy in day-to-day life would be that the grey matter of the brain is the city and towns and the connections between the areas of the brain are the motorways joining up the cities and tractography demonstrates these motorways.

Functional MRI

Over the last 10 years what is known as Functional MRI has been invented and put into practice. Essentially in this process, the MRI scanner is tuned into the delivery of blood to various parts of the brain. If the activity of the part of the brain is increased, the flow of blood increases and this can be picked up by the scanner. This may be used to visualise the parts of the brain involved in normal functions for example moving a right hand will cause an increase in blood flow to the middle outside part of the brain on the left-hand side. Similarly, more complicated tasks such as memory, thinking of words, looking at a fearful face as opposed to a neutral face will all result in activation of the relevant parts of the brain.

If the activity of the part of the brain is increased, the flow of blood increases and this can be picked up by the scanner.

Thus, functional MRI can be used for seeing which part of the brain carries out functions and how the different parts of the brain interact and work with each other. We are beginning to understand, using this technique, how epilepsy arising in different parts of the brain may affect memory and cognitive processes. For example, in those with epilepsy arising in the temporal lobe on the left, trying to remember new words, which normally would activate the left temporal lobe, is much reduced. By recording the electrical brainwaves and epileptic activity during such a functional MRI scan, we can now map where in the brain epileptic activity is occurring. By combining this with functional MRI and examining the white matter tracts we can assemble a 3-dimensional map of areas of the brain that are functioning abnormally and normally and use this to plan the best treatment approach.

Spectroscopy

In addition to looking at the structure of the brain, the MR scanner can be used to measure the concentration of different brain chemicals such as glutamate and gamma-amino butyric acid (GABA). Glutamate is crucial to the working of the brain, is released by nerve cells and makes other nerve cells fire off. When present in excess, in the wrong area at the wrong time, an epileptic seizure may occur. In contrast, GABA (also produced by nerve cells) makes other nerve cells quieten down. The measurement of these chemicals in the brain using MR spectroscopy is giving us vital new insights into the chemical process for brain activity and how this may go wrong in conditions such as epilepsy.
Difficult diagnosis simplified by hi-tech MRI

MRI, or Magnetic Resonance Imaging, is used to help in the diagnosis of many types of neurological disorders. Typically, standard MRI scans, which take between 15 and 30 minutes, require patients to lie absolutely still. Any movement and the resulting image may not be clear enough for doctors to make an accurate diagnosis.

The stark fact is, up to one in 10 people need re-scanning because motion causes blurred images, making their MRI scans impossible to read. With MRI scanning costs at around £360 per hour, the expense of uncontrolled movement soon mounts up. The prospect of an MRI brain scan to investigate a suspected neurological disorder can be upsetting enough. In people with suspected epilepsy, an MRI scan may be used to look for scar tissue, tumours or physical damage that may be causing seizures. For a patient who may already be a little nervous, the prospect of a re-scan if they cannot hold still is of little comfort.

For some, the answer has been sedation. However, one in six children does not respond adequately to the sedation used during such scans, and one in four does not respond at all. Adult sedation or general anaesthesia services are not generally available in MRI suites. Now a technological breakthrough from GE Healthcare is revolutionising the use of MRI in neurology by using a software sequence to dramatically freeze patient motion.

GE Healthcare has produced the world’s first high definition magnetic resonance system. Its PROPELLER High Definition technology now gives doctors unprecedented image clarity even if patients move. This is critical in epilepsy research, because looking at lesions in the hippocampus of epileptic patients requires very high resolution images with good tissue contrast to see the internal structures. It is also of immense benefit in all sorts of clinical settings, from imaging in restless children to patients with Parkinson’s Disease, Alzheimer’s and other conditions that cause involuntary movement.

“Studies with our clinical partners show that even if patients rock their heads from side to side continuously during a scan, doctors using our system still get good quality images to aid in diagnosis. It’s remarkable, saving time and money,” says Nigel Mason, Country Manager at GE Healthcare UK. PROPELLER benefits anyone having an MRI brain scan by improving the quality and resolution of images by allowing more data to be acquired, and removing many other causes of image degradation. It presents the highest quality images possible to help with an effective diagnosis, making life easier for patients and doctors alike.

Professor John Duncan, Medical Director at the National Society for Epilepsy, says: “The use of the PROPELLER method of acquiring MRI scans is a major step forward as the blurring of images that result from even minute movement is taken out. This gives greater clarity of images in everyone, as no one can stay completely motionless during a scan. Further, it is now possible to get good images of the brain in those who are restless and have difficulty in keeping still.”

Ongoing epilepsy care

The National Institute for Health and Clinical Excellence (NICE) guidelines state that:

- Adults with epilepsy should have a review at least once a year by their GP or specialist. Those who continue to have seizures or side effects or need particular advice, such as women planning a pregnancy, should be referred to a specialist by their GP.
- Children should be reviewed by a specialist at least once a year, or more often if necessary.

People with difficult to manage epilepsy should be referred to a specialist centre if:

- Their epilepsy is not controlled with medication within two years
- Their epilepsy is not controlled with medication after two drugs have been tried
- They are experiencing, or at risk of, unacceptable side effects from medication
- Their epilepsy is associated with a psychological or psychiatric condition
- There is a possible doubt over the diagnosis of the seizures or syndrome

The specialist service should include a multi-disciplinary team who are experienced in the assessment of people with complex epilepsy and have access to investigations and both medical and surgical treatment. Individuals with controlled epilepsy but with concerns about specific issues such as pregnancy should also have access to this service.

The treatment gap

Although anti-epileptic drugs have the potential to stop seizures in around 70 per cent of people, in reality only around 52 per cent of people achieve control with these drugs due to lack of optimal services. This equates to around 82,000 people with epilepsy having seizures when they could be seizure free.

It would cost around £130 million a year to improve epilepsy healthcare and reduce the number of people falling into this treatment gap. The payback would be a saving in excess of the figure by reducing the cost of misdiagnosis, estimated to be more than £160 million, and disability living allowance.
The role of genetics

Two thousand years ago Hippocrates recognised that inheritance, or genetics, plays a role in epilepsy. Today we know that there are many different types of epilepsy, and have identified over 12 different genes’ mutations which cause epilepsies that run in families. Sometimes this allows us to identify the genetic change that is responsible for the condition, giving us insights into how epilepsy occurs and how it might best be treated. There are however also cases where people with epilepsy have no family history of the condition, but also turn out to have mutations in some of these same genes.

BY DR SANJAY SISODIYA

Most of these genes encode proteins that act as controllable pores in the walls of brain cells, or neurons. The activity of these pores is usually closely coordinated and controlled and is responsible for the firing of neurons and thus eventually for much of the activity – normal and abnormal – of the brain. Mutations in the genes that encode these pores often lead to disruption of their function, and eventually to seizures and epilepsy.

Genetic research into rare epilepsies, more common epilepsies, and into responses to treatment, is helping us achieve a fundamental understanding of the very basis of the epilepsies, and to think in new ways in the search for better treatments for them.

In my own research group at the National Society for Epilepsy, working in partnership with the Institute of Neurology and Duke University in the USA, we are running the largest epilepsy genetics project of its type in the world to date, in more than three thousand patients. Amongst other milestones, we have identified genetic variations that influence the dose of certain anti-epileptic drugs. Hopefully, this type of research will provide important information on how genetics influences epilepsy in many people with the condition.

Such research is also likely to produce tests that will guide treatment with anti-epileptic drugs, perhaps allowing us to make better choices of which drug, and how much, to use in which patient, and what adverse reactions we might expect – or prevent. It is predicted that relatively soon, genetic profiling, based on analysis of a single blood sample, may significantly improve the lives of people with epilepsy. In the longer term, genetic research may direct the design of new treatments, and perhaps even begin to generate rational cures and preventions.

The genetic code – a blueprint

Each person’s genetic code might be considered a blueprint or manuscript just as a manuscript for a play guides the actors who make it an entity with life, character and individuality. Manuscripts that have been around for centuries often come in slightly different versions. In the same way every person has the same basic set of genes, or manuscript.

However as a result of changes accrued by generations over millennia, each of us has our own, unique, individual version inherited from our parents, distinguished by slight differences between individuals at several points throughout our individual manuscripts. The manuscript is the “genome”.

Broadly speaking, the human genome contains some 30,000 genes, each of which encodes a protein – which might be considered the actors in the play. Variations in genes come in several different forms, of which the most well-studied, and probably the most common, are called “single nucleotide polymorphisms”, or SNPs. Currently, we believe SNPs underlie many of the inherited differences people have in a range of characteristics. Such characteristics encompass not only normal attributes, such as height, but also traits such as susceptibility to various diseases and responses to the drugs used in their treatment.

Most SNPs are comparatively common. Some variations in the genome, however, are rare or very rare. Such mutations may be harmful to those that bear them, causing rare, often serious, diseases. Familiar examples are Down’s Syndrome, usually caused by an extra copy of an entire part of the genome bearing several genes, known as a chromosome, and haemophilia, at least one type of which is caused by a genetic mutation, usually inherited, in a gene that encodes a protein essential for the clotting of blood.

These enormous strides in our knowledge of the human genome, and in our ability to examine large numbers of SNPs in large groups of people with epilepsy, have enabled us to identify how epilepsy occurs and how it might best be treated. In the longer term, genetic research may direct the design of new treatments, and perhaps even begin to generate rational cures and preventions.

For more information, see www.epilepsynse.org.uk/genetics

I would like to become a Research Associate Member

Name: ___________________________________________________________
Address: _______________________________________________________
Postcode: _______________________________________________________
Phone: _______________________________________________________
Email: _______________________________________________________

Payment: I wish to pay by: Cheque (payable to NSE) [ ] Credit/Debit card [ ] Direct Debit [ ] (a form will be sent to you)
Card number: ___________________________
Expire: / / Valid from / / Issue no. (Switch only): ________________
Last 3 security numbers (on the back of the card): __________________

* I would like to add a donation of: £ _________________________
Annual membership payment: £ 50
Total amount: £ _________________________

Please return to: Associate Membership Office, FREEPOST SL766, Gerrards Cross, SL9 7BR

www.epilepsynse.org.uk/research

NSE: Leaders in epilepsy research

The National Society for Epilepsy (NSE) is at the cutting edge of world research into the UK’s most common serious neurological condition.

Its pioneering research programmes are advancing epilepsy knowledge across the globe and giving hope to hundreds of thousands of people with poorly controlled epilepsy.

You can make a personal contribution to NSE’s world-leading research programme by becoming a Research Associate Member for a minimum annual payment of £50.

Registered Charity No. 206186
A global perspective on epilepsy

Epilepsy is a global condition, respecting no geographical borders and potentially affecting anyone, irrespective of race. A lot is known about potential risk factors for epilepsy in the so-called developed world although it is fair to say that even today, with the benefit of sophisticated diagnostic tests, the causes of epilepsy for a significant minority of people remain unclear.

BY PROFESSION L EY SANDER, NICE PROFESSOR OF NEUROLOGY & CLINICAL EPILEPSY AND HEAD OF THE WHO COLLABORATIVE CENTRE FOR RESEARCH & TRAINING IN NEUROSCIENCES, LONDON UK

The great majority of patients with epilepsy, are not in rich countries but in resource-poor countries where less is known about the possible causes of epilepsy. Over 80% of the world’s population lives in resource-poor countries and therefore it is no surprise that well over 80% of people with epilepsy live in such countries. Indeed, it is often said that people in poor societies are more likely to develop epilepsy than those in wealthier populations. The reasons are not fully understood but are likely to be associated with lower standards of living and poorer sanitation and hygiene.

Different causes of epilepsy

Some causes of epilepsy, including diseases of brain blood vessels and head injuries, exist throughout the world. Some causes, however, such as viral, viral, fungal and parasitic infections, are more frequent in resource-poor countries. A large number of people who develop epilepsy in the tropical world do so due to potentially avoidable causes – from diseases, infections and parasites. These could be avoided with better sanitation, hygiene and nutrition, and by better healthcare. Unfortunately, in resource-poor countries healthcare is sometimes non-existent and diseases are often widespread.

Some of the most preventable causes of epilepsy include infections such as malaria and neurocysticercosis. A study of children in Kenya who survived cerebral malaria found that many went on to develop epilepsy. This is also likely to be happening in other regions in which malaria is endemic. It is not surprising to know that the World Health Organisation (WHO) has declared the eradication of malaria as one of its main priorities. Malaria can kill but also has the potential to cause suffering many years later if the person survives.

Neurocysticercosis is another infection which is now being treated in some parts of India and Latin America. Neurocysticercosis is caused by the pork tapeworm infection. The worm sits in the human intestine and releases eggs which are passed in stools. If these eggs are eaten by a pig, they develop into cysts within the muscles. If people eat these cysts in undercooked or raw pork, they can get tapeworms, but not neurocysticercosis. However, if humans ingest the eggs through contaminated water or food then they may develop neurocysticercosis. In humans the cysts often develop in the brain rather than in muscles. Once in the brain a cyst may cause inflammation and swelling which in turn may trigger epileptic seizures. Improving sanitation, so that pigs and humans do not come into contact with human waste, could help reduce dramatically the risk of this disease and consequently the burden of epilepsy.

It is interesting that not everyone who develops these brain infections goes on to develop epilepsy. Part of the answer may lie in the person’s genetic makeup. Certain specific genes between genetic factors and environmental factors such as poor sanitation, poor diet and poor healthcare systems are not known. Many people are likely to play an important part in the risk of developing epilepsy. This is an area in which further studies are urgently needed to decrease the global burden of epilepsy.

The treatment gap in resource-poor countries

In developed societies up to 70% of people with epilepsy may have their seizures fully controlled with appropriate medication and the majority of people can achieve seizure-freedom. But the treatment of epilepsy is a costly one and even in the developed world many people do not receive adequate treatment in the form of anti-epileptic drugs. However, in the poorer countries the great majority of people receive no treatment and suffer as a result. The WHO has established that over 80% of people in resource-poor countries receive no attention, medical or otherwise, for their epilepsy. In many of these countries epilepsy is often not considered a priority. Often anti-epileptic drugs are not available. Coupled with a lack of expertise in epilepsy, this makes diagnosing and treating epilepsy very difficult.

In some countries there is also strong stigma surrounding epilepsy; people may prefer not to disclose having the condition, or the person may be hidden away from society. In some cultures epilepsy is not seen as a medical or neurological condition but as a spiritual one, as possession by evil spirits. In parts of Africa many people with epilepsy are cast out. Managing epilepsy as we do in the UK would not necessarily work everywhere. When it comes to developing and providing services for epilepsy, we need to take into account the local structures for healthcare and people’s belief systems, and provide services tailored to each individual country.

Bringing epilepsy out of the shadows

The WHO, in collaboration with a number of non-governmental organisations in the field of epilepsy, launched a programme called the Global Campaign against Epilepsy aiming at increasing awareness and decreasing the treatment gap. Initiatives have been developed in several countries with various degrees of success. Projects in Brazil and China have been particularly successful. In Brazil, the project served as the embryo of a national epilepsy programme which is now being implemented. In China, epilepsy treatment has reached rural areas and the Chinese Government is now taking programmes into 16 provinces, reaching thousands of people. Much remains to be done to increase global understanding of epilepsy, its diagnosis, treatment and management. Only then will it be possible to get it out of the shadows – but a first step has been taken.

Epilepsy related deaths

Many people, often including healthcare professionals, mistakenly think that epilepsy is a benign condition. It is not. There are at least three seizure related deaths every day in the UK. Sudden Unexpected Death in Epilepsy (SUDEP) accounts for just over half of these deaths, with young adults most affected.

BY JANE HANNA, DIRECTOR, EPILEPSY BEREAVED

When SUDEP occurs families and carers often experience bewilderment, isolation and prolonged distress because they do not realise that a seizure can be fatal; the death usually occurs during sleep and is wholly unexpected. Although the mechanisms are not fully understood, research shows that a seizure can trigger a person’s breathing to stop, or cause a fatal heart rhythm. Preliminary research has identified that some SUDEP deaths may be prevented through the use of a pacemaker in people with epilepsy who experience seizure-related cardiac events. Night seizure monitors are also being researched for their effectiveness in alerting other members of the family or professional carers to a night-time seizure.

Just because someone has a diagnosis of epilepsy does not mean that they are at risk of SUDEP so it is important that people with epilepsy access accurate individualised information from the clinician or nurse responsible for managing their epilepsy. Like other chronic conditions such as asthma it is then important for there to be discussion on the different options for managing any risk. Tailored information on SUDEP is part of the general package of essential information that people with epilepsy need so that they can make relevant treatment decisions and lifestyle choices.

Surprisingly, given the statistics, although SUDEP can affect any age it is much rarer in children and more common in young adults. The most significant risk factor for SUDEP is the occurrence of seizures with studies reporting a 23-fold increased risk of SUDEP for people who have not been seizure free during the preceding year compared to people with fully controlled seizures. Generalised tonic-clonic seizures and night-time seizures are the types of seizures most associated with SUDEP, yet there are some types of seizures carrying little or no risk. National guidelines on the epilepsies state that the risk of SUDEP is much lower if a person’s seizures are being controlled and people with epilepsy and their carers are alert to the risks of night-time seizures.

The good news is that for every 10 patients with epilepsy, 7 can be seizure-free on the right medication. Seizure-freedom is the major factor in improving quality of life for people with epilepsy, but it is also the most important step in reducing the most significant risk factor for fatalities in epilepsy.

The problem is that many people with epilepsy do not have the choice of accessing a specialist epilepsy service offering prompt and accurate investigation, diagnosis and treatment. We know that four out of 10 patients in every GP Practice could be seizure free, but are not.

In 2002 a UK government funded report on epilepsy deaths led by Epilepsy Bereaved, a network of people who have lost someone to epilepsy, and the Royal Colleges found that up to 4,000 epilepsy deaths were potentially avoidable. Some deaths occurred whilst patients were on long waiting lists to see a doctor with expertise in epilepsy. For many patients, the nature and frequency of the seizures were not being monitored by GPs and, if they were, action was not always taken to refer to specialist services. Most did not access epilepsy specialist nurse services and many of those who might have benefited from epilepsy surgery to stop their seizures had not been considered. There was a total lack of information on managing the risks of fatality from a seizure for those who did not know they were at risk.

The numbers of deaths from epilepsy have not fallen since 2002. Proposals for new legal powers for GPs and the NHS to insist on a report from a hospital or general practitioner on preventable deaths may provide a valuable legal challenge to drive improvements to service provision, but there remains an urgent need for political action by government to tackle the low priority afforded to epilepsy.

Whilst bereaved families wait for action, NICE recommends that when SUDEP occurs health professionals should offer information on SUDEP support services. Epilepsy Bereaved offers a confidential SUDEP service for anyone affected by a bereavement through epilepsy and an opportunity for bereaved families to be active in the SUDEP campaign.
Bio-feedback – consciously controlling activity in the brain

Bio-feedback is a technique which may be helpful for people who experience partial seizures or secondarily generalised seizures that begin with some kind of warning or aura. Over time some people can learn skills to help to consciously control activity in the brain. In some people this may help stop the seizure spreading. Furthermore, the technique may increase a person’s self-esteem by giving them a sense of control over their epilepsy. This therapy is not widely used, as it requires a lot of input from the therapist, and much practice and time on the part of the patient to achieve results. Biofeedback may be offered to adults and young people in clinical psychology departments in some hospitals.

Complementary therapies

Research into the use of complementary therapies in epilepsy is currently limited. Although there is growing interest and more work is being carried out, there is currently little scientific evidence as to the effectiveness of many of complementary treatments, and the outcome is often variable.

Complementary therapies are often referred to as alternative therapies. In the case of epilepsy they should not be considered an alternative to anti-epileptic drugs. They can, however, sometimes be used as a complement to conventional medicine, to help improve wellbeing and give people a sense of taking control of their own bodies and their lives. However, while some people may find complementary therapies beneficial, others may find they interfere with seizure control.

Relaxation therapies, such as massage, acupuncture or reflexology, can be helpful for those people who find they have more seizures at times of stress or anxiety, but great care needs to be taken with aromatherapy. Although certain aromatherapy oils such as jasmine, ylang ylang, camomile and lavender have a calming effect and may be helpful in improving seizure control, other oils such as hyssop, rosemary, sweet fennel and sage are thought to have an alerting effect on the brain and may trigger seizures in people with epilepsy.

Some herbal medicines may interfere with seizure control. In particular Ayurvedic medicines may aggravate epilepsy and may best be avoided. Ayurveda is an ancient Indian branch of medicine which uses herbal remedies and other therapies.

There are different views concerning the safety of St John’s Wort. A review of 30 patients at Birmingham University Seizure Clinic has so far shown no evidence of any significant increase in seizures in people taking anti-epileptic medication and St John’s Wort. However, other research suggests that St John’s Wort may affect the blood levels of many types of medication including anti-epileptic drugs. The Committee on Safety of Medicines recommends that people taking anti-epileptic drugs do not take St John’s Wort, and that anyone already taking this herbal remedy see their doctor to discuss the possibility of withdrawing it. It is important to speak to the doctor first if considering stopping St John’s Wort, as the dose of anti-epileptic medication may need to be altered to prevent side effects.

When considering any area of complementary therapies, it can be helpful for the person to discuss the possible effect this may have on their seizure control with their GP or epilepsy specialist, and with a qualified practitioner in that particular field of complementary medicine.

AEDs – the potential to control seizures

Epileptic seizures can have a major impact on every aspect of a person’s life and, in some cases, are potentially life threatening. The highest risk factor in having epilepsy comes from the seizures themselves and the goal of treatment must be to give complete seizure freedom as soon as possible after the onset of seizures. It has been said that one seizure, once in a while, is one seizure too many.

Most people with a diagnosis of epilepsy will be prescribed anti-epileptic drugs (AEDs). These have the potential to control seizures in around 70 per cent of cases. However, starting treatment with an AED is a major event for a patient and should not be undertaken without a careful evaluation of all relevant factors and until a diagnosis has been established beyond any doubt.

AEDs act by suppressing seizures and are not curative. Once treatment has begun the therapy is likely to be long term – sometimes, depending on the circumstances, for life. The drugs are powerful and adverse side effects are common. Possible side effects include drowsiness, weight loss or weight gain, and allergic reactions such as skin rash.

More than 20 different AEDs are currently licensed throughout the world. The choice of drug prescribed is influenced by the type of seizure or epileptic syndrome. The selection is largely empirical rather than rational, with the prescriber selecting the drug based on the experience of what is likely to work best for the particular seizure type, rather than being able to predict precisely, at the outset, which drug will be effective.

Treatment is usually started with a single drug at a small dose. Dosage is gradually increased, if necessary, until the seizures are brought under control. The key is to start low and go slow. If the first drug is not successful, a second drug may be tried and the first may be gradually withdrawn. This process may continue until the right regime is established. Around 47 per cent of individuals will respond successfully to the first drug they try, 32 per cent of the remainder to the second and nine per cent of the remainder to a third.

Some individuals will need to take two or more drugs in combination (polytherapy), but the ideal result is to achieve seizure freedom with a single drug (monotherapy) in the lowest possible dosage, with the fewest side effects. Even within a particular seizure type, one individual will respond well to a particular drug whereas another might not; also one patient may experience adverse side effects and another may not.

Twelve new AEDs have been introduced in the UK in the last 20 years – three have already been dropped because of adverse side effects and even the best of these new drugs have only increased the potential for seizure freedom by around 10–20 per cent. The quest for new drugs is therefore on-going as is the need to improve existing drugs for first line use (monotherapy), in terms of their efficacy, safety, pharmacokinetics (metabolism of the drug) and their cost effectiveness.

The National Institute for Health and Clinical Excellence (NICE) undertook an appraisal of the newer AEDs, reporting on their clinical and cost effectiveness in 2004. They looked at seven drugs that were licensed in the UK between 1989 and 2000. They noted that almost all studies comparing the older drugs with the newer found no statistically significant difference in seizure outcomes. Also, while it is generally believed that the newer AEDs carry fewer side effects, and are better tolerated than the older drugs, the appraisal committee determined there was, at the time, insufficient evidence to support this.

Particular consideration was given to the teratogenicity – potential to cause defect in the unborn child – of AEDs. All the older AEDs have been associated with malformations and the risk is higher among those taking more than one drug. But the committee found there was insufficient data...
Helen Hollis felt she had been thrown a lifeline when she was offered surgery in May 2005. Although she still experiences the occasional seizure, she feels her life has been turned around.

She speaks candidly about her epilepsy, and her thoughts prior to, and after surgery.

The mother of two was 19 when she had her first tonic clonic seizure at her grandfather's funeral. It took another five years for her epilepsy to be diagnosed, during which time Helen felt ‘detached from reality’.

She said: “The diagnosis was almost a relief, it gave an explanation for my experiences. But in spite of the diagnosis I struggled to gain control of my seizures. The medication made me tired and slowed down my thinking. My confidence suffered and there were times when my dignity was bruised.”

Helen regrets that her children, now aged 12 and 9, have never known their mum ‘without epilepsy’. She said: “When I had a series of seizures it must have affected them and their school life. They dealt with the situation admirably and I am very proud of them. It can’t be easy for them and I regret things like not being able to run them about in the car like other mums.”

In a typical day Helen would experience up to eight complex partial seizures. In her words: “These are the type of seizures where I was aware of what was happening but my consciousness was altered. I often felt as though it might progress to a generalised seizure and it was very frightening. I did not want to lose consciousness and I was anxious about what my family might have to cope with. At these times my confidence was rock bottom.”

“I would have to go in to town with mum when I was having a bad day. Mum had to watch me like a child. I dared not go anywhere alone as I was worried about putting down cash or credit cards and losing them.”

In 2005 Helen was referred to the National Hospital in London and underwent tests at the NSE’s Assessment Centre in Buckinghamshire to see if she was a potential candidate for surgery.

She said: “The tests showed my seizures stemmed from the right hippocampus which meant that surgery was an option. I was thrilled and excited! I did worry about the risk I was taking but the medical staff were wonderful. They explained the risks and benefits and were very reassuring.”

A few weeks later, Helen underwent surgery and her life turned around. That was almost two years ago. Although she still experiences the very occasional seizure, Helen realises that surgery has released her independence. “I looked at an old seizure diary the other day and there were so many seizures recorded in it every week. I have to remember just how frequent and severe they were before the operation. I am vastly better off. I have had just three seizures since my operation. My confidence has grown. I have travelled on a train alone. I go into town alone. Liberation is great!”

Surgery

Surgery is a treatment option for some people whose epilepsy is proving resistant to anti-epileptic drugs (AEDs). It will only be considered if the part of the brain from which the seizures are arising (the focal point) is clearly identifiable, is accessible to the surgeon, and if it can be assessed that removal of that part of the brain will not adversely compromise the patient.

Epilepsy surgery usually involves the resection of the damaged or abnormal part of the brain. This may be a small amount of tissue such as a lesion on the brain, or, in extreme cases when there is a lot of damage to one half of the brain, may involve the removal of the complete hemisphere. The other strategy for surgical treatment is palliative, either to interrupt pathways of seizure spread by disconnecting the area of the brain that is causing seizures, or vagal nerve stimulation.

Success rates are high and some procedures, such as the removal of part of the brain known as the hippocampus, located in the temporal lobe, can result in complete seizure freedom in more than 70 per cent of cases. But even in those patients who do not achieve complete seizure freedom, the surgery can result in far fewer seizures and a greatly improved quality of life. In children, surgery can also lead to improved developmental outcomes.

Before the decision to go for surgery is finally made, the patient will undergo many tests to pinpoint precisely the epileptogenic tissue and any potential adverse effects, and to establish the individual’s suitability for surgery. A multi-disciplinary approach should be undertaken in this pre-surgical assessment, including the neurologist, neurosurgeon, psychologist, psychiatrist, neurophysiologist and radiologist.

Tests will include a thorough review of the clinical history and seizure pattern, MRI and, in some cases, other imaging techniques such as PET and SPECT (see article on brain imaging). Scalp electroencephalogram (EEG) will be included, as may EEG-video telemetry in which video recordings of the patient having seizures are compared with the EEG traces of electrical activity within the brain to give a clearer correlation between the way the seizures are presenting and the electrical activity that is taking place.

In some cases, a decision will be made to undertake intracranial EEG, a surgical procedure using subdural and depth electrodes. Psychometric assessments will also be carried out to establish that cognitive skills will not be impaired and psychiatric assessments will also be undertaken. Equally, it is essential that the patient, families and carers, are fully informed and counselled before any decision to go ahead with surgery is taken.

Currently around three per cent of people with intractable epilepsy will be considered eligible for surgery, totalling around 500 cases a year. However, it is thought that there are between 750 to 1,500 people each year in the UK who could have epilepsy surgery. This is perhaps because many patients could be eligible but may not be referred to specialist centres and therefore remain under-investigated.

With advances in brain imaging techniques, it is hoped that more people can be identified who may be able to have this form of surgery.

AEDs act by suppressing seizures and are not curative.
Vagus nerve stimulation

Vagus nerve stimulation (VNS) involves mild electrical stimulation of the left vagus nerve as it passes through the neck. It is used to treat epilepsy as well as depression.

The vagus nerve is a major communication link between the body and the brain. VNS Therapy works by sending mild electrical signals to the brain via the nerve, disrupting the abnormal electrical activity that can cause seizures. It may reduce the number and intensity of seizures in some people, but it is unlikely to completely stop the seizures happening so anti-epileptic drugs will usually still be prescribed. VNS Therapy may also reduce the length of the recovery time after seizures, and some people find that it has a positive effect on their quality of life. It has been suggested that VNS Therapy enhances the mood, memory and alertness for some people. Also, after findings showing that it has a positive effect on individuals suffering from depression, VNS is also indicated for the treatment of chronic or recurrent depression.

In epilepsy treatment, a stimulator, a little like a heart pacemaker, is implanted under the skin in the person’s upper chest. Electrodes are connected to the stimulator at one end and are coiled around the left vagus nerve in the neck at the other end. The stimulator is programmed to transmit regular electrical signals to the nerve, usually giving 30 seconds of stimulation every five minutes during the day and night. These signals travel up into the brain, spreading out widely through the nerve fibres.

The signal can be boosted by passing a magnet over the stimulator. This can be helpful for people who have an aura or a warning that a seizure is about to happen as it may prevent the aura from developing into another type of seizure, or may reduce the length of the subsequent seizure or the recovery time. If the person has no warning before their seizures, someone else could use the magnet for them when a seizure happens, potentially reducing the seizure length or the recovery time. The magnet is usually worn on the wrist like a watch. It is not clear who will respond best to VNS therapy and it is usually considered if a number of anti-epileptic drugs have failed to fully control seizures. It may also be used for people who are not suitable for, or who do not want to have brain surgery.

Side effects can include discomfort in the throat, a cough, difficulty swallowing and hoarseness of the voice, though these usually only happen when the vagus nerve is being stimulated. These effects may reduce with time or the person may get used to them.

The effects of VNS improve over time and full effect is usually seen 12–18 months after the implant. If after 18–24 months there is no improvement in seizures, the person may choose to have the stimulator switched off or removed.

VNS Therapy

NICE Clinical guidelines state that VNS Therapy is indicated for use as an adjunctive therapy in reducing the frequency of seizures in patients whose epileptic disorder is dominated by partial seizures (with or without secondary generalisation) or generalised seizures.

To date approximately 35,000 patients worldwide have been implanted with the VNS Therapy System and the UK figure amounts to 1,800 patients.

The American Academy of Neurology has concluded that: “Insufficient evidence exists to rate VNS Therapy for epilepsy as effective and safe based on a preponderance of Class 1 evidence” of intractable partial epilepsy.

In addition to having a positive impact on seizure control, VNS Therapy can enhance alertness, mood, memory retention and reduce daytime sleepiness.

Memory loss

It is not unusual for people who have epilepsy to have difficulties with their memory.

Any type of epileptic seizure has the potential to affect a person’s memory – and the more seizures an individual has the more frequently memory difficulties may occur.

The location of the seizures within the brain may influence the type of memory loss a person may encounter. For example, seizures in the frontal lobe of the brain may give rise to problems in remembering what to do in the future as this part of the brain is responsible for prospective memory. Seizures arising in the temporal lobe may present difficulties in remembering things, as this lobe is responsible for new learning. And people whose seizures start in the left side of the brain may have problems remembering words and get stuck in mid-conversation, because the left side of the brain is usually the side that controls language and words.

Some people experience post-ictal confusion, ie in the period immediately after a seizure, and have difficulty recalling any sort of information. This will usually go away once the person has had a chance to recover from the seizure, though it will vary from one person to another and some people may find their memory is permanently affected after a seizure.

The side effects of taking anti-epileptic drugs (AEDs), such as drowsiness or attention problems, can have an effect on short-term memory and may make it difficult to learn and store new information, although when AEDs bring seizures under control this can help to improve memory. This improvement is probably not due directly to the AEDs, but is more likely due to the cessation of the seizures.

Surgery may have an impact on a person’s memory, if the part of the brain that has been operated on is important in memory function – but for some people a reduction in their memory may be a price worth paying if the surgery successfully stops or reduces their seizures.

There are several techniques and aids-memoires. A psychologist can advise on ways to manage memory difficulties, and can also undertake a memory assessment to determine the extent and impact of the difficulties. Referrals for a memory assessment are usually made from a person’s GP or from their specialist.
Government Initiatives

Over the last twenty years, a number of government reports highlighted the poor quality of epilepsy care in the UK and a clinical standards audit (CSAG) published in 2000 even suggested ways of changing the way that epilepsy care was provided.

BY DR W HENRY SMITHSON, GP ESCRICK NORTH YORKSHIRE, CHAIR EPILEPSIES GUIDELINES GROUP AT NICE, HON SEN.

CLINICAL LECTURER HULL YORK MEDICAL SCHOOL.

Frustratingly, health strategists largely ignored these reports until the publication of a Department of Health funded report on epilepsy related deaths. It is estimated that perhaps a thousand people a year die of epilepsy related causes of which half are sudden and unexpected; this report published in 2002 showed that about half the number of sudden unexpected deaths might have been avoided if epilepsy care was improved.

The Chief Medical Officer for England promised an action plan and this was launched in 2003. This suggested several initiatives to improve care.

The Action plan was broadly welcomed by the epilepsy charities, but their fear of effective improvement in care being restricted by lack of ringfenced funding and poorly defined objectives was indeed proved correct with the restricted impact of the NSF for long term conditions.4

However, four developments have had a positive effect for people with epilepsy. The first was a professionally driven independent non-government initiative and the other three driven by the Department of Health.

The first was the development and growth of Epilepsy Specialist Nurses. This was an independent initiative and had nothing to do with government. It came about as an improvement identified and driven by doctors and nurses working in the NHS. This service gap was initially identified by a GP working in Doncaster whose daughter had epilepsy. His group worked with the voluntary sector and the Pharma industry to address the suboptimal care and the paucity of specialists by becoming the first GP with a special interest in epilepsy and training 2 specialist nurses to work alongside him and develop a satellite service under the supervision of a neurologist in Sheffield.

This was found to be clinically and cost effective and so the charity Epilepsy Action funded an increasing number of ‘sapphire nurses’ to commemorate its fortieth birthday. The number of specialist nurses grew to about a thousand but are now being cut back because of the financial difficulties of the ‘modernised NHS’.

The second was the publication of guidelines (by SIGN in Scotland and NICE in England and Wales). Both guidelines are based on best clinical evidence but the NICE document also considered cost effective data. These guidelines were developed to set out how epilepsy could be better managed. They are slowly being adopted.

The third was the inclusion of epilepsy in the new GP contract as part of the Qualities and Outcomes Framework (QOF) and set out minimum ‘targets’ for epilepsy care in general practice. This QOF framework has some drawbacks but at least brings epilepsy into the NHS radar. People with epilepsy are now invited for an annual review of their condition. There are toolkits and guidelines to assist clinicians in providing better care and these can be interested professionals in both primary and secondary care.

The final service development is the post of ‘GP with a Special Interest’ in epilepsy (GPSIE). Some PCTs up and down the country have embraced this idea and identified and trained GPs to spend some of their time working with the Primary Care Trust (PCT) to supplement specialist care. Arrangements about how to structure a GPSIE service are worked out locally. Of course not all PCTs feel the need for GPSIE and so if anyone with epilepsy feels their condition is not well managed they should put pressure on their PCT to consider improving services with either specialist GPs or nurses. This service can support and inform patients, families, friends and carers and reduces the stigma and impact of the condition. Regrettably service development is currently under financial pressure in many areas.

Economic burden

It is estimated that there are around 456,000 people with epilepsy in the UK – this is the equivalent of one person in 131. Of these, 42,000 (one in 279) are children under 16, and one in 91 are over 65 years of age.

Approximately 131,000 are women of ‘child-bearing age’, i.e between 12 and 50. Around one in five people with epilepsy will have a degree of learning disability or impairment. The number of new cases diagnosed every day in the UK is around 75.

Misdiagnosis rates, where a diagnosis of epilepsy is wrongly made, are estimated between 20 and 31 per cent. At an assumed midway rate of 23 per cent misdiagnosis, this equates to 105,000 people having a diagnosis and receiving anti-epileptic drugs even though they do not have epilepsy.

The Clinical Guidelines for the management of the epilepsy, published in 2004 by the National Institute for Health and Clinical Excellence (NICE) reported that the medical cost of treating people with epilepsy in England alone was over £23 million, rising to almost £28 million across the whole of the UK. The non medical costs are significantly higher at more than £111 million in England (over £132 million across the UK), bringing the combined costs across the UK to in excess of £160 million. In addition it is estimated that 58,900 people with epilepsy are claiming Disability Living Allowance at a cost of £184 million per year.

It will cost £15 billion to treat the total current UK population of children with epilepsy during their lifetimes. This figure does not include social services and educational costs. This is equivalent to 0.5 billion per annum to treat children with epilepsy.

Despite this economic burden, epilepsy attracts very little government funding. In 2002/03, only one per cent (£3.78 million) of the grant from the UK government’s medical research council went to fund epilepsy research and only 1.4 per cent of the total overall grants given by UK neurological funding bodies went to fund epilepsy research.

All the information provided in this article is taken from the Joint Epilepsy Council’s report Epilepsy Prevalence, Incidence and Other Statistics, published in 2005. The Joint Epilepsy Council is an umbrella body representing more than 20 epilepsy organisations throughout the UK and the Republic of Ireland.

EPILEPSY

Therapy Development

PROJECT

Advancing New Therapies for People Living With Epilepsy

Please join us at the upcoming AED IX conference March 21-23, 2007 in Sunny Isles, Florida or the 2nd Eilat International Educational Course September 2-9, 2007 in Eilat, Israel!

Find out more about our grants, programs, and conferences at epilepsy.com and epilepsytdep.org
Who looks after your epilepsy?

The best answer is that you do! Individuals living with long term conditions have to make personal decisions about their health and their treatment and how to manage that condition. Doctors, nurses and other health professionals who help in management must remember that epilepsy is a poorly understood label that encompasses a wide range of potential seizure activity and brings with it a feeling of stigma, of loss of control, restrictions on driving, leisure, education and employment.

Who looks after your epilepsy?

The crucial thing is to find a professional who understands you and your condition.

The Medical Specialist: the doctor with an interest and expertise in the condition and is usually trained in neurology but psychiatrists, general physicians and elderly medicine specialists may all have the necessary experience to run a specialist epilepsy service. Your GP will know the best person in your part of the country.

The Epilepsy Specialist Nurse: has the same role as their paediatric counterparts.

The GP with a Special Interest in Epilepsy: some PCTs have appointed and trained a few GPs to have a more extensive knowledge of epilepsy. This GPSI service is yet to be standardised but these specialists may well work with neurologists to diagnose and treat more complex epilepsies. Of course, you may find that your own practice has a GP or nurse with a particular interest in the condition.

Epilepsy: a complex and challenging condition. It is estimated that 50 million people are affected worldwide. In the UK, around 100,000 children and young people have epilepsy as their main health problem.

Epilepsy Action is currently campaigning to save the jobs of the many epilepsy specialist nurses who have been threatened with redundancy, reduced working hours, or spending less time on specialist epilepsy duties due to cuts in NHS funding.

Epilepsy Action campaigns to save epilepsy specialist nurses

The All-Party Parliamentary Group on Epilepsy (APPG) met on 4 December 2006 to discuss the threats to epilepsy specialist nurses and to specialist nurses in other neurological conditions. Since then, John Battle MP has tabled an Early Day Motion (no. 541) in Parliament to gather signatures from MPs to show their support for a particular issue.

The response to the campaign from Epilepsy Action members and MPs has been fantastic. The post of an epilepsy specialist nurse in Ipswich has been saved through media work and the publicity that was generated. The post of an epilepsy specialist nurse in Leeds is no longer at risk.

Quite an array of talent! But the crucial thing is to find a professional who understands you and your condition so you can all work together to manage it better.
Epilepsy resources

The Joint Epilepsy Council is the representative body of the UK’s main epilepsy organisations.

JEC Members
- Joint Epilepsy Council
  www.jecc.org
  01943 871852
- National Society for Epilepsy
  www.epilepsy.org.uk
  01494 601 300
- Brainwave: The Irish Epilepsy Association
  www.epilepsy.ie
  +353 1455 7500
- Enlighten
  www.enlighten.org.uk
  0131 226 5458
- David Lewis Centre
  www.davidlewis.org.uk
  01565 640000
- Epilepsy Action
  www.epilepsy.org.uk
  0113 210 8800
  helpline 0808 800 5050
- Epilepsy Bereaved
  www.sudep.org
  01235 772850
- Epilepsy Research Foundation
  www.erf.org.uk
  020 8459 4781
- Epilepsy Scotland
  www.epilepsyscotland.org.uk
  0141 427 4931
  helpline 0808 800 2200
- Epilepsy Specialist Nurses Association
  www.esna-online.org.uk
  0114 2712186
- Epilepsy Wales
  www.epilepsy-wales.co.uk
  Helpline 08457 413774
- Epilepsy West Lothian
  www.epilepsywestlothian.co.uk
  01506 464446
- Fund for Epilepsy
  www.fundepilepsy.org.uk
  020 7592 3270
- Gravesend Epilepsy Network
  01474 351 673
- Gwent Epilepsy Group
  01495 763 131
- International League Against Epilepsy (ILAE)
  www.ilae-uk.org.uk
- Meath EPILEPSY Trust
  www.meath.org.uk
  01483 415 095
- Mersey Region Epilepsy Association
  www.epilepsymersey.org.uk
  0151 298 2666
- National Centre for Young People with Epilepsy (NCYPE)
  www.ncype.org.uk
  01342 832 243
- Organisation for Anti-Convulsant Syndrome
  www.oacs-uk.co.uk
  01253 790022
- Quarrers
  www.quarrers.org.uk
  01505 612224
- St Elizabeth’s Centre
  www.stelizabeths.org.uk
  01279 843 451
- Euclidean
  www.euclidean.org
  0208 995 4781
- Epilepsy Bereaved
  www.epilepsy-wales.co.uk
  Helpline 08457 413774

THE EPILEPSY INFORMATION NETWORK

The EIN is an innovative service developed by the National Society for Epilepsy (NSE) in response to the 1999 Clinical Standards Advisory Group report to Government which highlighted the need for quality information to be available at a local level to support people with epilepsy. The importance of information provision for all people with epilepsy was further highlighted in the NICE clinical guidelines, 2004.

The EIN primarily provides epilepsy information services in healthcare settings, working alongside healthcare professionals. The services are manned by trained volunteers, who are supported by regional managers.

Today there are more than 100 such services in hospitals and clinics throughout England with more in development.

The service is regularly evaluated by NSE and the neurologists and specialists it works with. In the most recent survey, all who responded said the EIN complemented the services they already offered and 95 per cent said their patients benefited from speaking to an EIN volunteer during their hospital visit.

The EIN is showcased in a Good Practice guidance document supporting the Government’s National Service Framework for long term conditions, as a model of good practice for its innovative services.

The EIN has latterly expanded to schools with a programme to make pupils more aware about epilepsy and how to respond to someone having a seizure. Developed by NSE and delivered by EIN volunteers, the Schools Awareness Programme ties in with the national curriculum at Key Stage three.

For more information, contact the National Society for Epilepsy

Would you like there to be a cure for epilepsy?
You are not alone.

“I can’t think of anyone better to support than the Epilepsy Research Foundation because more research into epilepsy can only be a good thing.”
Damian Cronshaw

- Epilepsy affects over 450,000 people in the UK alone.
- Every day 75 people are diagnosed with the condition in the UK.
  Even with control of seizures, quality of life for people with epilepsy can be poor.
  However, new research offers the very real possibility of developing therapies that could transform the lives of those affected.
  The Epilepsy Research Foundation is a national charity at the forefront of these research developments. We identify and fund promising research at its earliest stages and our track record is excellent.
- Over the past five years every pound of Foundation funding has led to a further two pounds being allocated to epilepsy research by organisations such as the Medical Research Council.
  The Foundation is also very efficiently run.
- Last year 87 pence in every pound was spent on research and associated charitable activity.
  Great progress in understanding the causes of epilepsy has been made in recent years, but there is still much to be done.

Other useful contacts
- Brain Injury Rehabilitation Trust
  www.birt.co.uk
  01924 896100
- Epilepsy imaging Group
  www.ioan.ucl.ac.uk
  020 7391 8905
- FABLE (VNS)
  www.fable.org.uk
  helpline 0800 521 629
- Global epilepsy campaign
  www.who.int/mental_health/neurology
- Headway: the brain injury association
  www.headway.org.uk
  helpline 0808 800 2244
- Hemihelp: Info & Support for Children with Hemiplegia
  www.hemihelp.org.uk
  helpline 0845 123 2372
- Matthews Friends (the ketogenic diet)
  www.matthewsfriends.org
  0788 405 4811
- The Muir Maxwell Trust
  www.muirmaxwelltrust.com
  0131 454 0606
- Neurosupport
  www.neurosupport.org.uk
  0151 298 2999
- Support Dogs
  www.support-dogs.org.uk
  0870 609 3476
- UK Epilepsy & Pregnancy Register
  www.epilepsyandpregnancy.co.uk
- Voluntary Organisations Disability Group
  www.vodg.org.uk
  07857 886 134
- Po Box 3004, London, W4 4XT

To make a donation today visit:
www.erf.org.uk/givenow.htm
call 0208 995 4781
or send a cheque made payable to Epilepsy Research Foundation to:
Epilepsy Research Foundation
PO Box 3004, London, W4 4XT
Please Support Us

Every year 1,000 people die as a result of epilepsy.
Imagine living with the fear of an attack that can strike at any time without warning.
Imagine not being able to prepare or cook a meal, not being able to take a bath or to cross the road in safety.
Now imagine having a best friend who can alert you to an imminent seizure ... my name is Dougal.

Support Dogs is a unique UK charity dedicated to improving the quality of life for people with epilepsy by training dogs like Dougal.

By giving a warning up to 45 minutes prior to an attack, these dogs enable epilepsy sufferers to live as full a life as possible and take away many of the dangers of everyday life.

As the only organisation in the United Kingdom to train Seizure Alert Dogs®, the demand for our dogs is increasing, but Support Dogs receives no government funding and is reliant entirely upon donations to continue its work.

Each dog costs in the region of £12,000 to train.

Please help us to train more of these amazing animals by making a donation. Corporate sponsorship is also welcome.

For further information or to donate please contact:

supportdogs

21 Jessops Riverside,
Brightside Lane,
Sheffield, S9 2RX
Telephone: 0870 609 3476
Email: supportdogs@btconnect.com
Website: www.support-dogs.org.uk