



Scargill – Children and Families Weekend 2005



The 23 – 25 September saw this year's weekend away in the Yorkshire Dales for Children and Families affected by Encephalitis.

The weekend took place at Scargill House, a large rambling building, set in its own 98 acres of woodland and nestled into the hills of the Yorkshire Dales. 14 families attended along with a professional staff of child carers and staff from the Society. The weekend enabled opportunities for enjoying the countryside, making new friendships and 'time out' opportunities. The days were interspersed with workshops on a variety of subjects, including benefits, behaviour challenges, educational issues, getting the best from professional services. The children had a full schedule throughout, including nature trails, entertainment show, drawing and artwork, etc. On the Saturday evening we opened a few bottles of wine and beer, and settled down together to enjoy Sally's family quiz and magic, and a wonderful impromptu musical gala which included chamber music from Mary and Liam Smith, Lorna Brooksbank singing Ronan Keating, Stephanie Currie singing White Flag by Dido and all the kids in an Amarillo Finale!

Moving Media, the film company who are helping us to produce our Information DVD came along and captured loads of magnificent footage by filming and interviewing staff and families, alike.

Continued on back page

Lots of examples of fun ways to raise money are given here. The Society can send you a Fundraising pack with ideas, sponsor forms and details of how to use the Just Giving www.justgiving.com internet based site. This site enables you to set up your own Internet sponsor page – no charge – with details of your event. The site will collect your sponsorship for you and claim Gift Aid tax back from the Treasury increasing your total raised considerably. The site can also be used for In Memorium funds.

Our stalwart fundraising families across the UK keep up the momentum

The Allsorts Variety Show raised £1186 from a cabaret night, this is a new venture for the Allsorts and proved so popular that it is set to become an annual event. The other annual event from our fundraising team in Nuneaton – the Race Night - raised £933. The Mitchell family, our fundraising team in Cornwall, had a quiet year after their marathon efforts last year but still managed to send in a cheque. The Dunham family also continued their long standing support through events at their two holiday parks raising over £2,500; and the family of Jonathan Oates raised almost £400 from a Swimathon challenge at the local Physical Fitness Club and sponsorship by work colleagues for Michael Oates's run in the Bristol Half marathon. Gwen Makel, her granddaughter Amy, Katie Lauren and friends raised £300 from their annual cake stall in Blackpool. Staff at the Encephalitis Society also did their annual stint, manning a drinks station on the Great Yorkshire Bike Ride resulting in a donation of £1359.

James Pratt and his family persuaded his local pub the New Inn at Leamington Spa to organise a Quiz night which raised £500 and the Society was nominated to benefit from a “dress down” day at Peoples Insurance Services with staff donating £136. Bernie and Benny Grainger celebrated their 25th Wedding Anniversary and asked for donations to the Society in lieu of presents resulting in donations totalling £1,150.

Collecting Boxes

We have a supply of collecting boxes, please send for them to put in local shops and businesses. Mr Piercy collected £94 and Mrs Royal £170 with their boxes.

Running, walking and riding for Funds

Congratulations to Felicity Holt and the Cooper family who took part in the British 10k raising over £400. ***We have 6 places available in next year's 10k if you are feeling fit!***

Mark Bentley walked along Hadrian's wall and raised £706 from sponsorship whilst Craig Roberts raised £380 and Christine Currie raised £251 also by undertaking sponsored walks.

Donations

Thank you to all who have sent in donations – too many to mention – your support of the Society is very much appreciated.

In Memorium

It is sad to receive money in memory of people who have died as a result of encephalitis but their families can be assured that the funds will be used to tackle the cause and effects of what we all know is a devastating illness. We have received funds in memory of Alf Moona, Ronald Frederick Leach, Ruth McLeish, Mary Monica McDonald, Geoffrey Packer and Jeanette Rice.

Companies and Trusts

Schroder Charity Trust donated £500 towards the cost of responding to enquiries and Sovereign Health Care donated £500 towards the cost of IT upgrade. MBNA's community campaign “People for People” continue their support and have donated a further £500.



The Cooper family, father and sons, competing in the British 10k

Funding Ways and Means

The Society relies on fundraising and donations to continue its work. If you would like to put the *fun* in *fundraising* send for a fundraising pack and join the club. You can also put *challenge* and *excitement* into fundraising through Charity Challenge.

Charity Challenge

Charity Challenge is the UK's leading adventure travel company specialising exclusively in the organisation, leadership and administration of inspirational fundraising expeditions. They operate more than 100 challenges each year for around 2,000 participants, and have so far helped to raise somewhere in the region of £15million for over 550 charities.

Their expeditions include treks, mountain bike rides, mountain climbs, white water rafting, sailing, horse riding & Community Challenges. The expeditions take place in Africa, the Caribbean, Asia, Europe, the Americas and the Middle East. They cover four different difficulty levels, ensuring there really is something for everyone.

Charity Challenge are renowned for their professional conduct and concern for participants' safety at every step of the adventure. They offer comprehensive advice during the booking process and provide a full support package including notes on fitness training, travel tips, vaccinations needed, visa information, high altitude info, responsible travel guidance and fundraising ideas.



Next year 2 of our members are joining a Charity Challenge trek raising funds for the Encephalitis Society in the process. Alex Thompson is making a "lava trek" in Iceland and Dan Clarke is cycling from Ho Chi Minh (Saigon) in Vietnam to the lost temples of Angkor Wat in Cambodia. Each has a web page on the Just Giving site giving more information at:

www.justgiving.com/alexthompson

www.justgiving.com/dan-nam2cam

We hope that the Charity Challenge website www.charitychallenge.com will inspire you and that in the not too distant future you will reflect on having completed a momentous challenge, and have the satisfaction of having raised thousands of pounds for the Encephalitis Society.

10k British Road Race

Each year the Society purchases places in the 10K British Road race held in London in July. The route passes famous land marks and at 10k (about 6 miles) is a much more achievable distance for many people than a marathon. Contact Jon in the office for details.

Do you work for a Company?

Many companies have charitable policies and respond well to appeals from their own staff. Some companies will match any funds raised by employees. Other companies may be interested in sponsoring an event such as a regional meeting, a Family weekend or the weekend Retreat; an edition of the newsletter or a page on the web site. Who better to approach them than the person who has a personal interest. Contact Jon in the office if you need help in making the approach.

The Expert Patient Programme (EPP)



The Expert Patients Programme (EPP) is a NHS-based training programme that provides opportunities to people who live with long-term chronic conditions to develop new skills to manage their condition better on a day-to-day basis. Set up in April 2002, it is based on research from the US and UK over the last two decades which shows that people living with chronic illnesses are often in the best position to know what they need in managing their own condition. Provided with the necessary 'self-management' skills, they can make

a tangible impact on their disease and quality of life more generally.

The EPP is one among a range of new policies and initiatives to modernise the NHS to emphasise the importance of the patient in the design and delivery of services. Fundamental changes are taking place to empower patients, recognise that patients and professionals each have their own area of knowledge and expertise and need to work together.

Patient self-management or 'Expert Patient' Programmes are not simply about educating patients about their condition or giving them relevant information - they are based on developing patients' confidence and motivation to use their own skills, information and professional services to take effective control over life with a chronic condition.

Features of the EPP training course

The Chronic Disease Self Management Programme (CDSMP) recognises that people with all kinds of long-term conditions are dealing with similar issues on a daily basis. These include pain management, stress, low self-image and the development of coping skills. The programme has been used in Australasia, Europe, USA and by a number of patient bodies in the UK.

The course is run over six consecutive weekly sessions of 2.5 hours each week. Each week, two volunteer tutors lead 8-16 participants through structured course material delivered from a scripted manual covering topics such as relaxation, diet, exercise, fatigue, breaking the symptom cycle, managing pain and medication, and communication with health care professionals.

Participants on the course use a course manual called ***Living a healthy life with chronic conditions***, based on a book used at Stanford University. It has been adapted for use in England.

For more information or to locate your nearest course check out <http://www.expertpatients.nhs.uk> or contact your local Primary Care Trust.



Learning for Living

Learning for Living is an online learning course accompanied by an optional accredited qualification called the 'The Certificate in Personal Development and Learning for Unpaid Carers'.

The course aims to provide carers with an opportunity for self development, confidence building and preparation for other roles and choices in their lives by transferring the skills acquired in the caring role.

City and Guilds worked closely with carers charities such as Carers UK to develop the course. If you are interested in attending a free web-conference briefing session or would like to receive further information about Learning for Living please visit www.learning-for-living.co.uk/contact or Tel: 020 7294 8217 e-mail: carers@city-and-guilds.co.uk.

Barrie's Story

In November 2002 I was struck down by viral encephalitis. I was 69 at the time and spent the next three months in hospital, I remember nothing of that period of my life.

I had never been in hospital in my life and I was playing golf at least twice a week and competitive tennis at least 2 or 3 times a week and felt exceptionally fit for my age! However, a few weeks before I was diagnosed with encephalitis I started to have headaches (something I had never suffered from), was aware of lack of concentration, was forgetful and had lack of coordination when playing sport. Over the next week my condition deteriorated, I developed a very high temperature and flu-like symptoms, became very confused, confined to bed and delirious. I was



admitted to hospital and encephalitis was diagnosed immediately and confirmed by MRI brain scan. My wife was told that I would be in hospital for 3 months and the doctors could not give her any prognosis as to what recovery I would make. I do not remember anything about hospital until the end of January when I asked what date it was to which my wife replied that it was January 26th and I asked what had happened to Christmas! (Apparently 10 days earlier the Neurologist had asked me 10 questions and the only thing I knew was that the person standing at the end of my bed was my wife and her name. I did not know where I was or what was wrong with me or what day or year it was!)

I came out of Hospital in February 2003 and for the next 12 months had a very quiet time. I gradually started to go for walks, joined a fitness gym, then started playing a few holes of golf. Finally, after a year, I started to play tennis and put back the 3 stones in weight that I had lost. I am now back to playing golf and tennis twice a week and my wife and I went to Australia for 6 weeks in January 2005. Before my illness I was a Governor of a prominent School, Chairman of a Home for the Elderly Trust and President of the local rugby club but unfortunately I had to give these positions up as I had been out of touch too long. I do miss these interests.

I am writing this letter to give encouragement to other people and their families affected by this vicious illness. Some factors which have helped me to make such a remarkable recovery are:

1. For my age I was very fit and when told I had had a virus which had attacked my brain the doctors said I was very positive that I was going to "beat it".
2. I was very fortunate in having a loving wife and family - they had been told to expect the worst. A host of great friends supported my wife through and when I "came round", I had four long-standing friends who came to visit me and talk on a one-to-one basis.
3. The care I received in hospital and follow-up with physiotherapy (I had lost 3 stone in weight and was unable to walk), speech therapist, occupational therapist and neuro-psychologist who continued with my treatment after I returned home.

Has the illness changed my outlook? The answer is "yes". I will be 72 in a few weeks time and do admit to being more forgetful, but the Consultant told me that my memory would be in slow decline at my age anyway. I get great pleasure from things in the present and remembering events, places and people of many years ago. I also get great pleasure in looking forward to events in the future but no longer assume automatically that these events will happen. I was a great optimist in my earlier years and still am, but I do tend to worry about little things.

I, my wife, daughters and all our friends appreciate that I have been very fortunate to make such a remarkable recovery - Miracles do happen!

Barrie Appleyard

Helen's Story

My first memory of the illness is fidgeting around in the hospital bed and my husband telling me to keep still because he had something to tell me. I was pregnant. It didn't seem like a big surprise to me but it was definitely news. I spent three weeks in hospital but most of it is blank. I remember asking Abdul, my husband, if he had telephoned work for me. He told me I didn't have a job, I thought this was a bit weird then discovered that I'd been made redundant a few months before.

Abdul spent the whole time I was in hospital off work. When I was discharged, he gradually told me what had happened. He had come home from work one night at his usual time 11pm. I went to bed and woke up about 2am, asked Abdul who he was and then asked him where my brother was, then went back to sleep again. I woke up about 7am and again asked Abdul who he was - we'd been together for over eight years but he was a stranger to me. He showed me lots of photos from our past - holidays, days out and our wedding but I still didn't believe he was my husband. He called the NHS helpline for advice and was told to get me to hospital. The first hospital I was taken to couldn't diagnose me so I was sent to a second. This is where I spent the next three weeks.

When discharged, my mum took me up to Leeds to be with her and my dad for a few weeks so that Abdul could go back to work. I don't remember much of the time there in Leeds. My mum told me I got out of a cab outside the house I grew up in and asked where we were. Back in London, I didn't recognise my life. So I wished I wasn't pregnant. It was something I never got used to in the five months I had left. Abdul mentioned my studies to me. I vaguely remembered an 'A' level I'd started so assumed he was referring to this. He told me I'd finished this and had started a diploma. This is something I still have no memory of at all. Most memories of the last five years plus are faded but not blank.

My other after effect of the illness was no sense of smell and limited sense of taste – no sense of sweetness at all. Also I was not as squeamish as I used to be and because of that, after nearly 20 years, I'm no longer a vegetarian.

My baby was born, a lovely boy. The first few months of being a Mum just seemed to add to all the confusion of not recognising my life. But after a few months we managed to get into a routine which did help. During that year I also had the odd memory coming back and I got back into the habit of reading, something I'd not done since before everything had happened.

Recently, I have noticed more memory loss – events from a few weeks before are never clear. This affects my reading – I picked up a book, one day, was halfway through and didn't have a clue what I had read. A psychologist I briefly saw recommended keeping a daily diary. This is something I have done since and reading back definitely helps.

I have also been diagnosed with epilepsy since Abdul witnessed one whilst I was asleep. Another effect I recently noticed comes from teaching my son what colour things are. Often I look at something that is red, for example, and tell him it's green. I mentioned this at my last hospital appointment and the doctor confirmed that it is, yet another, after effect of encephalitis.

It's now been nearly 2½ years. To start with things seemed to get better, then followed the odd step back but overall my moods have improved so much. I read about other people who had encephalitis and cannot help thinking I did have it pretty mildly.

Helen Berroukech



Have Wheelchair - will travel!!

I had encephalitis in September 2001 and have been in a wheelchair ever since. I came out of hospital unable to do a lot for myself, not knowing what the future would hold for myself, my husband, Andy, or my two teenage sons, David and Christopher. Before the illness I was working as a Nursery Nurse with ten pairs of eyes, boundless energy and running a home as well as working. Suddenly, I needed a carer every day and physiotherapy every week. The house had to be adapted and our lives, and those of the boys, changed. Soon, everything seemed easier, we got used to our new lifestyle, David started medical school, Christopher finished his GCSE's. Then unfortunately, I had a relapse, some sort of infection which caused me to lose use of my left side. Now I am no longer able to propel my wheelchair myself, but I tell myself each day, with Gods help, "Tomorrow is a New Day, Dust Yourself Down and start again". And it works.

My Uncle from America rang me regularly every Tuesday asking "How are you?" My ambition was to go to New York and say in person "Here's how I am". After three years of nagging, asking my GP and neurologist, paying a fortune for travel insurance, my ambition was finally fulfilled in January this year.

I have to be honest at this point and admit, that the only reason Andy gave in was because he travels a lot on business and had managed to collect enough Airmiles to take us both business class. This meant we could have lie-down beds for the 8 hour journey!! We flew from Heathrow and the staff were extremely helpful, they were very discreet onboard with my needs, and this made us both relax and enjoy the flight.

We arrived at New York, and the only thing I found a little demoralising was waiting to be taken off the plane on the little chair they have to use. Again though, my fears were unfounded as the staff did their utmost to laugh with me as the American staff waited at the end with my own wheelchair to take me to their customs officers. It was all worth it, my Uncle was delighted to see us. We spent the first two days relaxing and catching up on family news, sleep, food, sleep, talk and on, and on...

My Uncle's house is in Stamford, Connecticut, approximately 30 - 40 minutes by train from New York City. We were with him for only two weeks, but managed to make the trip to New York City three times. It was minus 10 - 18 most days so we tended to look for indoor activities. Fortunately, I bought lined trousers, thermal hat and gloves before leaving the UK and believe me sitting in my wheelchair, they were a Godsend! There was no way I was using the blanket my Uncle kept offering. Whilst in New York City we visited Rockefeller Centre, dined in the restaurant and watched the Ice Skaters, sat outside a closed United Nations, toured the Metropolitan Museum of Art, Macys, FAO Schwartz Toy Shop, Times Square, Broadway, 5th Avenue, Madison Avenue and too many more to mention. My husband Andy walked miles pushing my wheelchair (NY subway is not at all wheelchair friendly) - what a hero!!

The rest of the holiday was spent in Connecticut. My cousin is a Senator and he took us on an official tour of the State Capitol Building. By this time we were starting to see the snow and by the end of our holiday, we had almost 2 feet. I was stuck in the hotel for two days, I did ask for skis for my wheelchair, but no-one would take me seriously - they obviously don't know me!. Andy did manage to go for a walk in the snow and take some photos for me. On the Saturday we were packed and ready to go, Goodbyes said, when Andy's mobile phone rang. It was the airline. JFK airport had come to a standstill, and we wouldn't be able to fly until Monday. Disaster, I was due to go into the National Hospital for Neurology in London on the Tuesday for extensive tests.

We arrived at Heathrow first thing in the morning, left the airport, collected the car and arrived at my sisters in south London for a cup of tea at 1.30pm. By 3.30pm I was in a bed at the National Hospital! No more New York. Suddenly I was institutionalised. Two and a half weeks later I was still there. The high of New York was well gone. I had all the usual tests everyone has when they are first diagnosed with encephalitis, only this time I knew exactly what they were doing, what was going on, and why. I was put through the MRI machine, blood tests, physio, lumbar puncture etc. Then I was told they couldn't really tell me much more than I already know. They did however say, that I appear to have a very POSITIVE approach to what had happened and even though, I hadn't gained anything, I hadn't lost anything either. Who knows what will happen in years to come. The National Hospital in London are more than likely the best in the world, and if they say the best approach to encephalitis or any brain injury, is POSITIVITY, then my philosophy of TOMORROW IS A NEW DAY - DUST YOURSELF DOWN AND START AGAIN! will continue.

If you haven't ventured out there on holiday, with your husband/wife/partner/friend - now is the time.

Cath Agnew



Ethan's story

Ethan was born the 4th September 1999. He was a beautiful baby. He was clever too. By the time he was two, Ethan could swim fifty metres unaided, sing any song he had heard once, and bake wonderful cakes! This is no exaggeration. I have the certificates to prove it. And the photos. And the memories. I never thought all those things that meant to make you smile later on in life could hurt so much.

On the 19th January, 2003 at the age of 3.5, Ethan fell into a six week coma after a very high temperature. The night before, I believed he was having those high temperatures toddlers get. The next day he did tell me his legs felt funny and I told him it was pins and needles because he had been sitting on them. How these little

details torture me, and will do so for evermore. I took him to hospital when his temperature reached 106.2 and they sent us home saying it was probably a virus. At two in the afternoon his temperature dropped to normal, but he was drifting in and out of sleep. Then at eight he took a deep breath and lost control of his bowels. His fists clenched and he was grinding his teeth, I screamed. It was on a Sunday night and therefore no radiologist, no nothing. The private hospital didn't have an ICU. The paediatrician got out of bed and said it was a febrile convulsion. I said that those occur when a temperature is high. Ethan hadn't had one since two pm.

Dad was away on business. I was hysterical. Two hours later a spinal tap and a brain scan revealed nothing. The doctor went to bed. But Ethan was still having seizures. At 3am, I screamed in desperation and the doctors finally agreed to transfer Ethan to a hospital with an ICU. Meanwhile, Dad had landed at his destination only to hear my message, then waited in terror at the airport for the next flight back, five hours later.

After 48 hours of believing that our son had Reyes syndrome, an eventual MRI revealed widespread brain damage. They did not call it inflammation. During this revelation, the students and consultants forgot that dad was in the MRI, and that he was hearing what they were saying. They talked as if he was not there. It was only his outburst of tears that made them silent. I, Ethan's mum had not even had the courage to go into the MRI. That hour was a long one. And I took one look at my husband's face and without anyone saying what it was I threw myself on the ground shouting, "no please no!" over and over

An hour later the neurologist spoke to us and told to prepare ourselves. She felt that Ethan's one chance of survival was to give him a very large dose of steroids. We had been told only eight hours earlier that such a dose could be lethal. We had no choice. It saved his life. But Ethan remained in a coma.

During the next six weeks there were many more scares, from heart failure to malnutrition. As the days went by, I lost hope. There were small improvements but nothing close to the Ethan that I knew. But I loved him fiercely. I abandoned my other children and could not leave Ethan's bedside. I hated myself for not seeing the signs; why did I say that he had pins and needles for goodness sake!. "Dear God" I prayed, "please do not punish Ethan for all the wrong that I have ever done" for I could not believe that God would make such a beautiful innocent child suffer for no reason.

Gradually, Ethan awoke. His whole body was contorted, his eyes pointed in opposite directions and he did not respond to me. But by this time I had no hope. I had heard the words 'PVS' (permanent vegetative state and believed our son had reached it.

Ethan was always a strong willed but loving child. I'm glad to tell you that he still is. His stubbornness has carried him to where he is now. Two years later, Ethan is walking albeit not far, not for long and not without a limp. But he is walking and after a year of not speaking (we had all learnt to sign) Ethan spoke! His speech is clear but slow. We were told that the worst damage was to the brainstem and that meant that Ethan would always have poor fine and gross motor skills.

But the days are long. There are still a million hospital appointments, and lots of therapy. There's a 'normal' life to try to get back to, although that seems like a million miles away. I didn't see my other children for six months, and when



it was time to leave Great Ormond Street Hospital, I was too scared to go. I had grown dependent on their love and attention. I never realised just how difficult disabled people and their carers have it in this world. It seems an endless battle now that I'm fighting for the rights of a special child. Who is going to fight for his corner when I am gone? Please God let the world's attitudes change before then.

There is nothing more painful in life than to watch the ones you love suffer pain. Ethan does not remember pain, and so it is my own selfish pain that has caused me to hide in the dark for so long. Ethan has forgiven, and therefore I too must learn to forgive. If he can love with life as a special person, then I too must learn to accept his limitations. What I cannot accept is the world's limitations.

Thank you to the Encephalitis Society for reaching out to us. There is still so much to do. Let's help them to do it. Let's start by educating the medical world, so that they can spot Encephalitis before it takes another victim.

Jojo Southwell, Ethan's mum.

Ruth McLeish

Earlier this year we were saddened to hear of the death of Ruth McLeish. Ruth was the wife of one of the Society's Trustees Martin McLeish. She became ill with encephalitis whilst on holiday, was left with severe memory problems but enjoyed a good quality of life cared for by her family.

Earlier this year Ruth went into hospital after two weeks of a chest infection. The progress of her illness was, blow for blow, the same as what happened to George Best; except that her immune system had been compromised by encephalitis and not by transplant drugs. She spent two weeks in an isolation room where attempts were made to curb the infection but had to be moved to the ICU as she was so distressed by the treatments and could not accept a breathing machine mask. In ICU she was sedated and put on a ventilator whilst the medical staff tried to fight the infection with various levels of drugs; to which she did not respond. Ruth developed more and more infections and her organs began to fail. After two weeks of trying, it was agreed that there was no hope for her to make any recovery and the artificial life support was removed. A few hours later, on 15th June, Ruth died peacefully.

Ruth's husband, Martin, has put together a photographic memorial to her on www.martinsphotosite.com where people could see pictures of her in happy times, both before and after encephalitis.



Caring for your brain after encephalitis

Your brain consists of neurons (brain nerves) connected together in a network (neural network). In all types of encephalitis the inflammation can cause damage to neurons and their connections resulting in disrupted neural networks.

Neural networks can be likened to a road network and the inflammation likened to a terrorist attack. Visualise a road map and imagine that the neural networks in your brain is like the road network on the map. Now imagine a terrorist attack destroying roads in the network, this is like the inflammation destroying neurons.

The terrorist attack / inflammation may cause only minor damage to local roads / neurons resulting in only a little local disruption. A more serious attack may result in the loss of major roads/ neurons affecting more than one area. In severe cases the damage can be widespread – resulting in severe loss of functions.

Neural networks in your brain are being constantly repaired and upgraded in response to stimulation, exactly like road networks are in response to traffic. So after encephalitis your brain does have some ability to make repairs: however the repair takes time, needs a plentiful supply of materials and may be less than perfect.

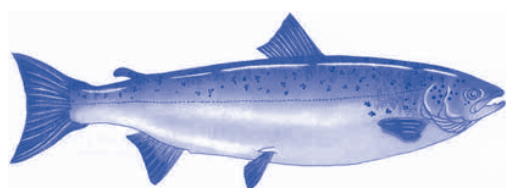
Stop before you get tired and take a break.

Just as repairs to roads is quicker and easier if there is less traffic on the road, so the repair to your neurons and neural networks is helped if you rest. Rest is ideally lying down in a quiet dark room – but sitting quietly with your eyes shut can also be beneficial. New pathways and connections can be created to get around the neurons that are damaged beyond repair. This can be likened to a motorist taking a minor road to avoid a traffic accident on their intended route. However taking these roundabout routes can be tiring. Imagine going from York to Scarborough using minor roads and without a map, by the time you get there you will be bad tempered, frustrated and exhausted – a state that people affected by encephalitis will be all too familiar with!

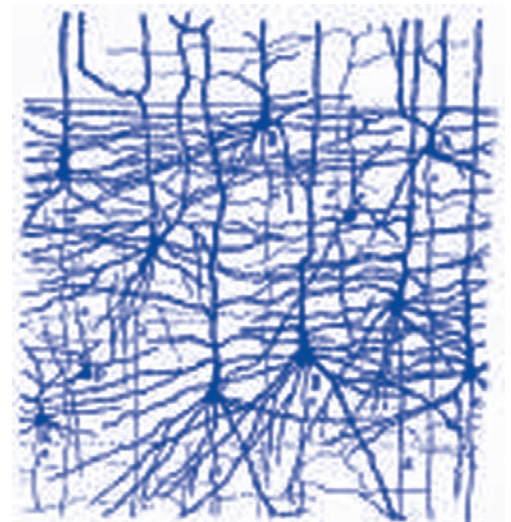
You can't afford *not* to eat a healthy diet.

Repairing nerves and maintaining them in the best possible condition requires essential nutrients. You should eat a healthy diet, high in antioxidants – found in fresh fruit and vegetables, and omega 3's – found in fish oils.

Antioxidants protect your nerves from everyday damage. All our cells at all times are bombarded by substances called "free radicals". Free radicals are produced during normal metabolism (energy production in cells) but are produced in greater quantity during infection. They are extremely destructive substances and are kept under control by antioxidants. Following encephalitis you cannot afford to let your fragile nerves fall into disrepair so keep them healthy by eating 5 portions of fruit and vegetables each day.



Omega 3 is an essential ingredient of myelin the covering of nerves. Covering nerves with myelin can be likened to covering a road with tarmac, traffic flows much easier and quicker down a tarmac covered road. Omega 3 is found in fatty fish (such as salmon, tuna and sardines), Flax (linseed) oil and can be taken as an oil capsule.



Exercise is also important.

Exercise improves blood flow through the brain, bringing the essential nutrients needed for repair and maintenance. Exercise may even spur the growth of new brain cells and prolong the life of existing ones. Studies at Princeton University, the Salk Institute for Biological Studies, the University of Illinois and other places have shown that exercise increases the number of brain cells in the hippocampus, the part of the brain essential for learning and memory. A little fresh air can even improve your mood. Exercise doesn't have to be time consuming or expensive, a short walk round the block 3 times a day will give your brain that boost it needs.

Keep your stress levels down.

A common concern following encephalitis is an apparent return of symptoms. Recurrence of encephalitis is extremely rare and the most likely cause of symptoms is an overload of repaired neural networks. These repaired networks may work fine under optimal conditions but under stress they can fail. "Stress" may be physical stress such as tiredness or too much physical exertion; emotional stress such as a row within the family or moving house; or it can be as a result of fighting an infection. If stress is unavoidable consider complementary therapies or a change of lifestyle.

Listen to your brain

Treat your brain gently, do not overload it with too many tasks, be aware of its new limitations. Following encephalitis your brain will be more fragile than it was before and less flexible, less able to cope with multi-tasking. It will react to being over taxed by shutting down – and many of you will be familiar with the "gridlock" syndrome when overtired.

If you have a headache, are unusually irritable, or confused, your brain is telling you it needs some time out. Listen to it. If it had been an arm that you had broken and it began to ache you would rest it, support it.

Learn to take frequent rest periods and to remove yourself from stressful situations.

Be truthful and tell those around you that your brain is damaged and does not function as it should especially when you are tired – explain that your neural networks become "gridlocked" and your brain "shuts down".

Build yourself a better brain

Image Copyrights

Neural network is from an original drawing of cortical neurons by Cajal (1900)

Road network courtesy of www.multimap.com

Fruit and vegetables image from www.chefmalta.com

Salmon drawing provided courtesy of the 'Maine Department of Marine Resources Recreational Fisheries program' and the Maine Outdoor Heritage Fund.

Elizabeth Finn Care

Elizabeth Finn Care (EFC) is a charity that provides practical and financial support to people from a wide range of career backgrounds - people who have slipped into poverty due to, or made worse by, physical or mental illness, family breakdown, bereavement or redundancy. Established over a century ago by social entrepreneur Elizabeth Finn, the charity provides grants and support to over 2,000 people who are struggling to make ends meet and who often feel isolated and neglected.

We work to provide practical and effective solutions after listening carefully to each individual's particular circumstances. This can include providing a weekly allowance to alleviate the worry of not being able to pay the bills or awarding one-off grants for essential household repairs, for instance. In some situations, if we are unable to offer financial help, we work to find an alternative organisation for people to get help from. EFC aims to reach as many people in need as it can and encourages them to come forward for help.

We also provide care and individual attention through contact with our well-trained, understanding and experienced caseworkers and volunteer visitors. This enables our beneficiaries - who often lack supportive family or social networks - to feel valued and cared for once again.

<http://www.elizabethfinncare.org.uk>



Scargill – Children and Families Weekend 2005

During the weekend we were accompanied by 2 staff from Scargill throughout who kept us fed and watered and directed us as needed. We felt the nature, success and impact of these weekends was captured in a letter we subsequently received from them. This is copied below.



www.power-health.co.uk

Power Health Based in Pocklington near York are offering readers a 10% discount on their products and will give the Encephalitis Society an extra 10% on profits from Omega 3 liquid and capsules and Power ACE from sales to readers. A form is included with the newsletter or contact the Encephalitis Society office.

