

Below is the first in a new series of articles on personal experiences of disease. In this issue, I am enormously grateful to Claire Rytina (a patient of mine) who eloquently describes the consequences of the herpes simplex encephalitis that struck her back in 2004. Claire was admitted to our hospital in May 2004 with a three day history of nausea, vomiting, headache and increasing confusion with difficulty recognising her

children. On admission she was able to follow commands with a GCS of 14 and no focal neurology. Her CT scan that showed some swelling of the right temporal lobe, with an MRI scan that confirmed this with involvement of the adjacent insula and basal ganglia and subtle changes in the left temporal lobe. A presumptive diagnosis of HSE was made and she was started on acyclovir. Her CSF showed 32 white cells,

a raised protein, normal glucose and subsequently PCR confirmed HSV. She improved, but from the outset had major problems with facial recognition. She remained in hospital for almost three months and subsequently has been involved with an active rehabilitation programme through the Oliver Zangwill Centre in Ely. This is her account of this illness and how it has affected her.

*Roger Barker, Editor.*

## My Life Post Hse

The first I knew of my illness with herpes simplex encephalitis was being told I had been in hospital for six and a half weeks. I am told that I had a gastro-intestinal upset, was off work, felt depressed and had unusual dreams for a few days. Apparently I then became confused and was taken to hospital. My daughter tells me I called my husband Stephanie. The MRI scan reported a high signal intensity in the right mesial temporal lobe extending into the adjacent basal ganglia, insular and inferior frontal lobe. There was limited high signal change in the left temporal lobe.

I awoke, very lost, confused and disorientated in my surroundings. I know it was a while later before I realised that I was not recognising people, or being able to place their identity. I am told that the first time I recognised someone was at five and a half weeks, when my son spoke to me from behind the bed where I was unable to see him, but I must have recognised his voice and said his name. They must all have been so delighted and relieved. And so special that it was him that I recognised. I still find now that some people's voices are very familiar and I can make correct guesses at who they might be. The weeks between then and my discharge home, at eleven weeks, are mostly unrecorded in my memory. I am told about all the kind people who came to visit me, having no memory of this I find very saddening. I still have cards and presents, now two and a half years later, that I cannot bring myself to look at as I feel so upset that "I" was not there to thank them for caring so much about me. I feel absent from such an important time in my life.

The illness has affected me in many ways: I have lost a bank of factual information, semantic memory, and consequently confidence. I have prosopagnosia, have had a seizure and have lost the ability to recognise both taste and smell. I have verbal communication misunderstandings leading to low self-confidence and emotional anxiety.

These difficulties leave me with a huge loss of identity and feelings of low self-worth. I don't trust myself to live life and react to the world around me appropriately. My continuous state of anxiety gives me headaches, back, shoulder and neck ache a great deal of the time and I am nervy and jump at the slightest noise. I am constantly anxious about times gone and times to come so that I have sleep difficulties leading to overtiredness and less ability to feel any confidence to manage.

I was discharged home and had to believe that my husband was the right person, but I had no sense of certainty about him. Although I could not recognise our children I did have the belief that they were mine. I have memories of that time which are very frightening and upsetting. I had no sense of belonging to this family who I was told was mine. I remember feeling very frightened about the identity of my husband in particular and very separate from a unit of individuals who seemed so intense and confident together. I remember coming home to a house I could not find my way around and being helped to go to the right rooms. I am told that I struggled to believe that it was the home that I lived in, even that some of my clothing belonged to me. I do remember not wanting to wear any of it, denying that it had anything to do with me. I know I bagged some items up to hide

them away from myself and many things have never been found. My husband thinks I disposed of most of the items which were previously my favourites, ones I suppose which identified more with the person I had lost. For some time I was unable to stop crying and continued to be confused.

In my life prior to illness I had a good education, nurse training and twenty-seven years experience working for the NHS. I found myself unable even to name plants and animals, also panicking not knowing where to go just two doors from home. I had had access to a huge bank of knowledge, most of which like anybody I just took for granted, and find myself at a loss to grasp most of it. It has left me feeling very anxious and confused and unable to trust myself to manage everyday situations.

Deep in my heart I have a huge need to be caring for others and I now feel a dismal failure. I misunderstand the needs of my children and frequently make them upset by behaving in a way they can't possibly understand and this has led to tensions within our relationships. Our family set-up has had to change with roles which worked before my illness being adjusted. I have been so confused within my "self" and how and where I fit in, that these changes have given me much grief in so many ways. How difficult to readjust my lack of self-worth when told "we managed perfectly well when you were in hospital." This of course was meant to make me feel better and that I shouldn't worry.

After two and a half years, I am now able to recognise my own family at home if they are the only ones there. I struggle to pick them out when they are in their friendship groups. I regularly rely on clothing to help me identify people once I know who they are, which helps me mind out for my children or keep with a friend while we are out.

People are told that I am home now but suffering a loss of facial recognition. That makes them feel that I will know who they are and all about them when they give me their name. They are so pleased to be telling me they are "Linda!" and I then feel so desperate to snatch at something to jog my memory of who on earth this person can be – just something so I can react appropriately, understand them, know them. But they don't realise I don't know them and start talking to me as if they have met me before, telling me about this person, that person, events that I would have known about which they expect me to know about. They are so pleased to see me and have no idea that they feel like a complete stranger to me. They are someone who knows so much more about the person that was me, than "I" do. As if the meeting isn't bad enough, then comes that terrible question: "How are you?" Do I just lie and say: "Okay thanks" or "Fine" and hope that's the end of it or do I set about telling them that I am struggling to adjust myself to a new life, a life where all the parameters have changed, leading to confusion, disappointment, low self-esteem and huge anxiety? Just "I'm not me" is probably the answer. I have come to a point now that I have felt so much at a loss when meeting people and so guilty about not being able to care for them in any meaningful way, that I feel I have become very unsociable. I choose not to join in with sociable occasions,



Claire Rytina

keep in a back seat if I do and make sure I never make eye contact with anyone in case they start to speak to me. Expecting I'll fail again.

I feel very oddly separated from the idea of 'myself' so that I can't feel I properly belong to any group anymore. I don't feel like I am the wife, the mum, the nurse, the friend that I believe I was before. I am fearful that I will never fit into these roles again.

I struggle to understand what people are telling me and feel very anxious about misunderstanding what is happening, what is expected of me and how I will manage. I can't concentrate for very long on things which need me to think and work things through in a logical meaningful way. I get very tired just trying to manage simple everyday things. I am my own worst enemy for helping myself relax. I don't do stop. I've led a busy working and home life in which relaxing had very little part, and nor did I want it to. I struggle to make the new myself do it, and can't wind down because I'm anxious about all the things I'm not doing.

I feel very sad most of the time, and even when I'm not tired, anxious or stressed and I should relax and have some enjoyment, I just can't. My family are fun-loving in a full-on way and I can't relax enough to have much enjoyment even with them. They do tease me to try and make me laugh, and sometimes I don't recognise this, so it upsets me. More and more now I am able to recognise the repeated teasing for what it is, just fun, and react more normally. I don't manage to relax and have fun very much, especially when out with special friends as their expectations of me to be the 'me' they made friends with feel threatening to the mixed up feelings I have about myself. I find it a lot easier to talk to people and be 'myself?' if I have never met them before and they have no expectations of who I am, they just take me for the person that I appear to be. In that situation I can relax and almost feel okay about the person that I am now. I can still be sociable, polite, helpful, even enjoy a bit of a joke. I can relax and not feel threatened by the muddle of who I was. It's like I'm starting again, as the new me, and it feels okay. This has made it a lot easier for me to take friendship and support from the other people with brain difficulties, and the therapists whom I have met along the way. It has been easier for me to spend time with them and feel like a person accepted for who I am.

I feel completely separate from the world I think I used to live in, I suppose I just carried on with life; wife, mother to four children, nurse, close friend, a person known, loved and valued by so many people. I feel now that I am no more the person I was and I have a huge difficulty feeling any sense of belonging in this new world.

I know I am not the same person that I was before my illness and that my life has changed completely. I have to take ten deep breaths before I venture out into the village in case someone speaks to me, I avoid meeting up with my close friends and keep a low profile when I do, and I struggle hugely emotionally with my family. Since having my illness I have found social contact much easier to manage by emails. I don't need any facial recognition and I have time to

think about what to say, and reply, without any body language or facial nuances to try to understand. I am able to re-read post messages to jog my memory and then write and say as much or as little as I like at that time. I can even change my mind about what I have said which is easy to do and doesn't involve a whole lot of shock and guilt, laughing or teasing. I can take those three deep breaths, and choose a moment when I am calm and able to manage the communication positively and properly. None of these are possible at the village post office or when answering the phone. I never answer the phone unless I have to.

I have been encouraged by my rehabilitation therapists to use relaxation methods: specific CD to listen quietly to, using breathing techniques and taking proper rest time.

I have had support to help me face the difficulty of asking people who they are; polite and practical methods of trying to know who they are and ways of explaining my difficulties to them. It feels so rude and un-caring to have to ask. Many people now just come straight up to my face and announce their name with great pleasure and I do get lots of hugs.

I have always said, "I was born a nurse" and have worked my heart out for the NHS for 27 years, so recently having my contract terminated on ill-health grounds has broken my heart. I know I can't do the job I did because of my memory and confidence problems but the one thing that has kept me going was the Occupational Health Consultant saying to me "I'm not saying that you can't do anything".

My poor family have had to live with me throughout my illness, struggling hugely with my sense of negativity and my loss of any feelings of belonging, even to them. All our interactions are complicated both practically and emotionally and as much as they have tried to help me, I have misunderstood and felt rejected, pushed out by losing my own sense of any worth. I feel my husband organises the family and that the children refer to him for everything, quite fairly as I feel I can't be trusted to give the correct answer – even down to the basic question "When's tea?"

I am feeling almost like I am one of the children at times. I have been unable to drive for the last year, following a tonic-clonic seizure, and don't do any of the household shopping, but I can do household jobs and cooking – now even without a timing list, so I am improving. I can even do a roast dinner now, let alone dippy eggs using a timer. I have even coped recently with my husband teasing me, and calling me "a housewife" which I not only recognised as fun, but I managed to tell myself should feel positive, not negative.

I do need to remember that, although my life has turned upside down, it has also been a huge emotional upset for my family. The sooner I accept that going backwards isn't going to help, the more positive I will feel about going forwards. My family have always been there to help me, even when it hasn't quite felt like it, and I am a very privileged and thankful person. I want to relax and enjoy life again, enjoy being with them and I have been very lucky to have the support of specialist people to help not just me, but all the family to support us managing. I know that I have to face what has happened and try to move

forwards and not dwell on my difficulties. I need to do this for myself and all my family and friends.

I have recently accepted the idea that rehabilitation is not synonymous with recovery – and that I can't expect to get back to be the person I was before the illness. I will do my best to use the strategies I have been given to continue to help myself to become a new happy, meaningful, belonging, valued and loving person, caring and sharing. A year ago I had never heard of a strategy application, let alone cognitive thinking! I know there are things which may never mend – like the part of my brain which tells me the truth about taste and smell and that I may never taste chocolate again or be able to smell roses. But I do know that brains are good at learning and I am busy teaching mine about who I know and how I know them, what paths in our lives have crossed. I get great pleasure from writing a friendship book where I write information down to re-read. I use face-on photographs with names. I make photo-scrapbooks and watch old home videos with my family to help me improve my sense of belonging. My husband and children enjoyed these and I became able to relax and laugh at their pleasure shouting out "There's you Mum!!" "We had a storm that night!!" Many bits of memory were happily jogged so that I coped with the bits missing without too much heartache.

My brain has been taught to use a Filofax and not to scribble on millions of scraps of old paper and then lose them. And I have learnt not to hide any more official letters or documents so they can never be found – and I keep my clothing.

Right from coming home from hospital I have used a pack of cards to gain some relaxation and feel like I am getting my head together. I have recently read about Clive Wearing and was amazed that I am playing patience almost addictively, rather like he did. I pester others to play card games with me and have played on many train journeys to pass the time and reduce agitation and worry about the journey and what the day may have in store. I have been lucky to travel with other clients to our centre for rehabilitation but strangers on the train have often joined in a card game very happily. It's an easy type of social communication which I cope well with and feel enjoyment and sharing out of.

Over a long period of wonderful rehabilitation I have realised that we only have one life, and that I should live it. They have helped me to form strategies to do this. They can't do it for me. No-one can. I have to do it for myself. No-one can mend my brain.

How lucky I am to be able to say that my heart is in the right place, even if my head isn't.

I give huge thanks to the heads and hearts of my family, my friends and all the caring therapists who have helped me so much throughout my illness and who still give me understanding, caring and a more positive outlook for my future.

*Claire Rytina,  
December 2006.*