

THE PATIENTS VOICE AT THE MILLENNIUM

How I took epilepsy on board

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INTRODUCTION

As a person with epilepsy I will be focusing on my social life in this paper, and one of my hobbies, namely windsurfing, is reflected in the title. My main reason for choosing to focus on social life has been influenced by events that have occurred, and also my work as a psychiatric nurse where I feel a patient's social life is not awarded sufficient priority in health care. By doing so I hope to raise the awareness of the readers to the importance of this area of health care. I will describe a variety of issues related to my experiences of having epilepsy and its interrelationships with my social life. It should be noted that I will focus upon how epilepsy affected my social life and how my social life affected my epilepsy including positive as well as negative issues. Due to the word limit placed on this paper I will not be able to cover all aspects that could be included, but relevant points related also to other aspects of my life will also be incorporated where appropriate. I will begin by giving a brief medical history. I will then describe various events that occurred throughout my life, and discuss their effect on my development as a person. I consider the term 'social life' in a broad sense which encompasses the effect of my epilepsy on my relationships with friends, boyfriends, potential partners, my strategies for disclosure of epilepsy and the subsequent results will also be included where relevant. Throughout the paper I will include relevant references. I will conclude by summing up the main points and what it has taught me.

I developed epilepsy at the age of 12 years with the first seizures taking the form of absences which incorporated me standing and rocking for a short period of time and then being confused for a few minutes before complete recovery (classified as petit mal, now classified as generalized absences). My mother was a psychiatric nurse and she took me to my GP who referred me to the neurologist at the local hospital where the necessary investigations were done. After approximately 18 months the seizures just occurred when I

was asleep (classified as grand mal). At the age of 16 years the seizures stopped for 2 years, reasons for this will be discussed in detail later.

When the seizures resumed they occurred in my sleep, and were a gentler version of the tonic-clonic seizures described earlier, with no headaches or tongue biting. During my twenties I experienced two tonic-clonic seizures whilst awake due to an accumulation of several stressful events, but then they resumed to occurring only during my sleep. In my early thirties a stressful event caused me to experience several simple partial seizures which took the form of either a facial tic, or a tingling sensation down one arm, neither occurring with any loss of consciousness. Due to my consultant neurologist doing nothing to assist or explain reasons for no action despite an obvious change in the form the seizures occurred, I changed consultants and with a change in medication and an event that boosted my confidence, the seizures ceased and I have not experienced any since September 1985. At this time I was diagnosed as having temporal lobe epilepsy. The interrelationships between these events and my social life has fascinated me and they will now be discussed.

Following the initial investigations I received the diagnosis, but was puzzled because I had not experienced or seen any evidence of my behaviour during or after the seizures and initially did not want to accept the diagnosis. The diagnosis led to prescription of medication and a banning from my favourite hobbies which included cycling, ice-skating and swimming.

I quickly adapted to taking medication regularly, but the aspect I found most awkward was having to leave my school friends during lunch and go to collect tablets from the school secretary. Having established this as a routine I adapted to it and due a change in the frequency and occurrence of seizures, eventually the midday dose was stopped.

The ban on swimming was hard to handle as I learnt to swim when I was 5 years old and represented my Brownie pack at the district swimming galas, gain-

ing several wins. Having joined the Girl Guides at the age of 11 years I was included in the teams representing our company at the district swimming galas, again with favourable results. The ban on swimming made me feel embarrassed and resentful of those who were allowed to continue to take part.

Another reason why this ban was hard was because the seizures were detected in the summer holidays just prior to my starting my second year at secondary school. We had been told in the first year that swimming was being introduced into the school curriculum as part of the second and third year timetable, and were eagerly awaiting this. I was informed by the school games teacher that when my friends were going swimming I would join another class and play netball or tennis, according to the season. I was bitterly disappointed, but the teachers handled it well and included me in the netball and tennis teams representing our school in matches, due to my skill at these sports.

Prior to the diagnosis, my mother gave me her bicycle, which I was not allowed to use after I had been labelled as having epilepsy. The phrase that was constantly used when any restrictions were imposed was 'just in case'. This phrase has remained with me ever since, but not just in a negative way (see the sections concerning issues about disclosure).

Luckily, the neurologist I initially saw was very good, and treated me as a member of the team, he asked me to keep records of my menstrual cycle, and also when seizures took place to determine whether there was a link. I developed a system for myself which I still carry out and this showed that the seizures were not related to menstruation, and that, after 18 months, they had settled to occurring just when I was asleep.

I felt better for being allowed to be an active and valuable member of the team, even though I could not always describe the form the seizures took. Because of the seizures occurring whilst I was asleep my neurologist said that I could resume my hobbies as long as there was always someone present who knew about my epilepsy. I duly took on the responsibility of ensuring that I adhered to this condition. I feel that being given this responsibility facilitated me not denying my epilepsy, allowing me to identify ways of adapting situations so that it was catered for.

However, due to the stopping of the hobbies mentioned I concentrated on other activities such as music and having been playing a violin since junior school, soon passed exams and gained a scholarship awarded by the Royal Academy of Music allowing me free piano lessons. I was included in the school orchestra and allowed to play solo at school concerts, which made me feel that I was not inferior to my schoolmates. After some persuasion by my mother, the teachers allowed me to go swimming with the rest of my class

and I gained the Bronze and Silver Awards for long distance swimming, but had I been allowed to start with my friends I am sure I could have also got the Gold Award.

I was also allowed to represent my Guide company at district swimming galas and still have the certificates I won. I felt one of the crowd again, but the seizures' after effects affected my social life.

As stated earlier, when the seizures started to occur at night they also became more severe and I used to wake with a headache and a bitten tongue. These effects lasted long after the seizures as the area of my tongue that I had bitten inevitably developed into ulcers which took at least 10 days to heal, were painful and resulted in my speech being slurred, a factor I was self-conscious of. The headaches usually wore off during the day without the use of medication. The general effects were not as bad as those described by McLean (1996)⁴, but still affected my social life, due to the problems of communicating without sounding slurred and dreading a seizure to occur a few days before a school music concert where I would be singing a solo.

Other aspects of my social life during my teens proved to be significant in how my epilepsy developed. One involved boyfriends and strategies that I developed to cope with disclosure of my epilepsy to them. I deliberately did not initially inform them of my epilepsy as I was convinced that they would not want to go out with me due to ignorance about the different types of epilepsy. I held this view because in those days the different types of epilepsy just consisted of grand mal and petit mal, unlike now where the International League Against Epilepsy's (ILAE) classification of seizures has been adopted by the World Health Organisation (WHO) (British Epilepsy Association (BEA) 1997)¹.

Another reason for this view was because when I was 5 years old I had encountered the stigma associated with epilepsy. I had befriended a girl at the church and had been told by an adult member of the congregation to stay away from her because she had epilepsy, which influenced my feelings of how people would treat me, and is a classic example of 'enacted stigma' as outlined by Scambler (1984)⁵.

When I went home and told my mother about the incident she assured me that I would not 'catch' it and that there was no reason for me not to remain friends with her. I remained friends with her for a further 15 years, and never once saw her having a seizure. I feel that this incident illustrates the stereotypical view that people have of epilepsy.

Having a variable (i.e. epilepsy), that was not apparent unless I was asleep implies that my stigmatizing factor classifies me as 'discreditable' as defined by Goffman (1963)³. This suggests that for people to be aware of this factor they need to be told about it.

My strategy for coping with epilepsy when acquainting myself with a potential boyfriend was simple. I merely went out with him, and if he showed a potential for being a likeable acquaintance, on our third date I would say 'I need to inform you that I have a type of epilepsy', I would then describe that they occurred in my sleep, emphasize that I was only informing them 'just in case', and then would say 'But if you do not want to go out with me because of my epilepsy I won't hold it against you. Do you want to see me again?' None of them refused, and more often than not it was me who would break off the relationship when someone else came along!

I realize that by developing this strategy I prevented unnecessary stress and increased my self-esteem having noticed a letter on the page of an agony aunt by a girl who did not know how to broach the subject and was convinced she would never get a boyfriend. I have always made an effort to plan how to disclose my epilepsy, adapting methods to suit different situations.

A major event during my teens involved my attendance at my local youth club. Due to my diligence in keeping records of my seizures it became apparent that seizures were occurring every Sunday night, after the youth club meeting. At the youth club, the organizer spent most of his time engaging in activities with the same group of members and several of us were left to entertain ourselves. I wondered if I was one of the 'out' group because of my epilepsy. This caused me stress and it had been established that stress was a triggering factor in my case. I wondered if there was a connection, left the youth club for 6 months and did not have any seizures. I returned to the youth club and on my second week of attendance had another seizure in my sleep. I left the youth club and no more occurred. I told my neurologist who verified that I had identified a major factor. I have since considered this situation and am convinced that the stress caused by the youth club leader's lack of organizational skills was the main factor influencing the frequency of seizures, the reasons for this are in Table 1.

Table 1: Indicators of why my seizures were triggered by the youth club leader's lack of organizational skills.

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- (1) I attended this venue on the same day at a different time, continuing to do so when I left the youth club and did not experience seizures.
 - (2) I attended the same venue at the same time on a different day (Girl Guide meetings), for group meetings which were organized differently, and did not experience seizures.
 - (3) I attended meetings at the same venue with the same people, whilst still a member of the youth club, for different purposes (youth club concerts) and did not experience seizures.
 - (4) When I temporarily left the youth club the seizures ceased.
 - (5) When I rejoined the youth club they started again.
 - (6) When I permanently left the youth club the seizures ceased.
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I studied for GCE O'levels and A'levels and did not experience seizures during these stressful events, although whilst studying for O'levels I was also attending the youth club. This helped to verify that it was the youth club that caused me to experience sufficient stress to trigger seizures.

Another aspect of my social life involved pocket money. When I was 17 I looked for ways to earn extra spending money and began work as a waitress with a catering company owned by a family with whom my mother was friends. I enjoyed going out on Saturdays and participating in a wide variety of social occasions. However, a friend offered me a lift home after one of the jobs and a drunken driver caused an accident resulting in me being flung through the windscreen. My brain was not damaged but the trauma caused my seizures to resume. This was disappointing as I was on the verge of being taken off medication. In addition to coping with the physical scars I found myself having to cope with the flashbacks of the accident and the emotional scars of the accident and the return of the seizures. I clung to the positive thoughts about the form that the seizures took which, as described earlier, were less severe and did not cause extensive after effects.

This event occurred at a particularly crucial time in my career development. I had started to train as a primary school teacher and the accident happened just before my first teaching practice. I lost interest in teaching and eventually sought a different career path. I started a fulfilling career as a psychiatric nurse, which was not without its problems, most of which can be attributed to my epilepsy. However, this proved to be a turning point in how inferior I was feeling at that time, and my exposure to patients who had been

in institutions for longer than I had been alive was an eye opener for me.

Another positive aspect of my epilepsy occurred during the 1960s when, as a teenager, I had seen the advent of drug taking as a recreational activity. I resented the fact that people were taking barbiturates through choice where I was forced to take them. I had no sympathy for drug addicts, but I think that my strong feelings about drug taking helped me to resist excessive consumption of alcohol and/or other recreational drugs. My friends appreciated my refusal to drink more than a half pint of shandy at social gatherings, and I did not find cigarettes pleasant or relaxing, so I never got addicted.

Driving was becoming popular and I gained a driving licence when the law changed. My epilepsy has not affected my driving but insurance is high and, with my short-term licence, I experienced discrimination if I tried to obtain a courtesy car when mine was being serviced. I did not own a car until I became a community psychiatric nurse (CPN), and by that time I had the confidence to express my disgust. I wrote to the insurance company but did not get a reply. I had to get my insurance company to fax a statement that they would insure me while I drove the hired car. On returning the car I insisted that the staff member inspect the condition of the car's bodywork and the engine, and made him sign a statement to the effect that 'an epileptic' had driven the car without damaging it before I returned the keys. I was popular the next time I had the car serviced there, when the staff proudly told me that insurance would not be a problem as they had changed companies.

Being able to drive has had an effect on recreational activities I could undertake, particularly where the ease of transporting equipment is a major factor. Windsurfing requires me being able to transport a board, rig and wetsuit from my home to the sailing location. When I could not drive, I relied on my husband for transport, and if he had not also been interested in windsurfing, or was unwilling to drive to the sailing location I would not have been able to pursue this sport. In my twenties I married, and my husband has been a great support and source of comfort during bad times. He is the one who has experienced my seizures, as it is him who has to tell me when one occurs and describe the form it takes.

The event described earlier concerning the youth club had a positive effect on my work. It made me more aware of the effect of leisure pursuits on a person's health, and consequently helped me identify a gap in our services. Recreation has not received much priority in health care but I have found it to be very therapeutic, and have attempted to include interventions which facilitate clients making use of community resources as part of treatment programmes.

An activity that I became addicted to in my thirties has proved relevant to my work in a variety of ways. I tried windsurfing on holiday and enjoyed it. My husband and I both like it, but I wondered if I would be accepted with my epilepsy. I was never refused training, hire of equipment or membership of a sailing club and always informed people of my epilepsy. I became competent, patients showed interest and after an enjoyable session with patients at a Royal Yachting Association (RYA) approved windsurfing centre I enquired about training as an instructor from the RYA Windsurfing establishment. The person I spoke with was realistic and advised me to contact trainers and centre principals to see if they would employ me as an instructor with epilepsy. Nobody refused me, and I am now a Level 2 (Improvers) Instructor. I have responsibility for vulnerable people and must be constantly aware of each learner's whereabouts, frequently operating rescue cover. I have arranged sessions for several types of client groups, and have also had articles published in windsurfing instructor newsletters and leisure studies journals about windsurfing and epilepsy.

Access, is not a term that is not immediately considered a problem for people with epilepsy because it is not visual, but it is a process that begins in the brochures produced by the leisure companies. I campaigned for the rights of people with epilepsy by scouring windsurfing holiday brochures, having noticed the wording in a well-known company's brochure which stated 'windsurfing exposes you to particular risks and we recommend that people with asthma, epilepsy or heart problems do not try it'. I suggested changes in wording about health issues and these were taken notice of. However, when the company was taken over by a larger company the wording reverted to the original version. I again wrote to the company and explained the effects that this discrimination could have on people, including not disclosing conditions 'contraindicated', the letter I received acknowledged my views and stated 'we are sorry that you feel sufficiently aggrieved that you had to write to us', but they adjusted the brochure the next year in line with my recommendations which included:

- (a) Stating first and in bold print that having these conditions would not necessarily exclude people from being eligible to take a holiday with the company.
- (b) Inviting people to get medical approval before booking a holiday.
- (c) Requesting that people inform them of the condition that they feel the instructors should know about.
- (d) Informing people of the lack of medical cover matching that provided in this country.

I deliberately state my epilepsy in writing when booking a windsurfing holiday and check whether instructors at the resorts are aware of my condition. So far, this information is not passed on and the centre principals express gratitude when I tell them. I have also been invited to seminars arranged for teaching RYA instructors about issues related to epilepsy and participation in the sport.

Another way that my epilepsy has benefited my patients resulted from me writing an article for the Leisure Studies Association where I defined the concepts of impairment, disability and handicap and used epilepsy as an example to illustrate points made. I included a rough estimate of the time I had spent in each of these states. I used the definitions of each concept as defined by the World Health Organisation (WHO as cited in Donaldson and Donaldson (1987)²). Impairment is defined as a dysfunction which I interpret as my above-average predisposition to having epileptic seizures. Disability is defined as being unable to perform a task within a range considered normal, due to the impairment, which I interpret as occurring when I am having a seizure or coping with immediate after effects. Handicap is defined as being unable to undertake tasks due to the attitude of the patient or others to the impairment. It occurred that some attempt to quantify these concepts would help to place them in perspective. I made a rough estimate of my life and the results are shown in Table 2.

Table 2: Time in states of impairment, disability and handicap as defined by WHO cited in Donaldson and Donaldson (1987).²

Concept	Time in this state
Impairment	36 years
Disability (total time)	6.25 days
Disability whilst asleep	5.95 days
Disability whilst awake	8 hours
Handicap	36 years

As can be seen from Table 2, the amount of time spent in a state of disability is very small in comparison with the states of impairment or handicap. I have used this technique with patients who, like me, experience a state of disability intermittently, and it has proved useful in helping them to put their own conditions into perspective. Had I not become a windsurfer, and eventually a windsurfing instructor I may not have found this technique for helping patients, some of whom have found it comforting to talk to a nurse with long-term health problems.

The fact that I am a qualified RYA windsurfing instructor relates directly to my work, where the interest shown by patients prompted me to investigate the possibility of becoming an instructor so that I could discuss theoretical issues more accurately. I also know

that I am not the only person with epilepsy who is a RYA windsurfing instructor and have met some of them.

Other people who have found my experiences interesting are people with epilepsy. I have been invited to some self-help groups, initially as a nurse with epilepsy and then as a RYA windsurfing instructor with epilepsy. People express appreciation at being able to speak with a health professional with epilepsy about epilepsy. They are often surprised at my hobby of windsurfing, and I have taken the opportunity to stress the considerations I took into account before trying it. These are based on the responsibility I developed as described earlier.

I could give countless examples from my social life. My musical abilities, resulting from the withdrawal from some sports, remain with me and I have earned the nickname of the 'singing nurse', where on wards with patients suffering from severe dementia I organized musical sessions and gave them some enjoyment. Long-term rehabilitation patients were amused at ways that I adjusted the wording of songs and some had a try themselves which resulted in a song about our local speedway team being played at the stadium, with the local fans joining in the easy chorus, much to the patients' delight who I had encouraged to attend matches. A medical colleague is keen on light operatics and belongs to an operatic society. He invited a group of us to see a show, and I remarked afterwards on how much fun they must be to make. He invited me to try and I am now a member. Although nervous, the stress has never caused me to have a seizure on stage. People remark on how full my life is treading the boards.

Areas that I have not mentioned because of the limited words permitted include my sexual life, my education, training, work and family relations. These issues would each in themselves merit a paper, and colleagues have suggested that I write a book about my experiences, although I do not consider myself any more unique than the next person with epilepsy.

It can be seen from the events described that I have experienced several types of epileptic seizures. How generalizable this is requires research, but that they have occupied a relatively short period of my life, occurring somewhat intermittently. However, the after effects took up more time, but overall still occupied a comparatively small amount of time. The medication caused me a relatively minor problem of adjustment, the problem occurring now is ensuring that I have sufficient to allow me take it as prescribed. The only fault is with the accuracy of dosage marked on the bottle, but as I have had to take medication for such a long time I am aware of the dosage.

My social life cannot be separated from my epilepsy and they are interrelated, as shown in the events de-

scribed. Both my epilepsy and my social life has had an effect on other aspects of my life, such as my work, my married life and friendships. The unpredictability of my seizures proved to be a very influential factor regarding freedom in my social life, determining whether I am or have been in a state of impairment or handicap, with the times I was in a state of disability having a very small, direct result. The ignorance about the variety of forms of epilepsy and the high level of control available is still prevalent, and people need to be educated. One reason why I chose to describe my epilepsy in relation to my social life is because I do not feel that health-care professionals give this aspect of life sufficient priority when treating patients. As can be seen from just my account, a person's social life can have a direct effect on their health.

Although I am a health-care professional I have written this paper as a person with epilepsy, although the two variables cannot be separated. I have also

learned that having epilepsy need not be a totally negative experience, and as in my case, it can be an asset. I have had the opportunity to have articles published which focus on issues related to recreational activities and epilepsy, and also psychiatric nursing. I feel that I would not have been as aware of the importance of a person's social life and its effects on their health if I had not developed epilepsy.

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How Epilepsy Is Treated. By Reza Shouri, MD. | Medically reviewed by a board-certified physician | Updated May 02, 2019. [Read More.](#)

Epilepsy. Epilepsy is usually treated with prescription drugs to control seizures, but it may also involve surgery, nerve stimulation devices, or special diets, depending on your situation and how well your seizures are controlled with medication. Multiple new epilepsy treatments are on the horizon, as well. It can take some trial and error to find the best drug and dosage with the fewest side effects for you. Some side effects may go away after you've been on the medication for a week or two and your body has had a chance to adjust. If they don't taper off, or if they're severe or bothersome, talk to your doctor right away. [Epilepsy Doctor Discussion Guide.](#) WHO fact sheet on epilepsy, a chronic noncommunicable disorder of the brain that affects people of all ages. The fact sheet includes key facts, signs and symptoms, causes, treatment, prevention, social and economic impacts, human rights and WHO response. Epilepsy accounts for a significant proportion of the world's disease burden, affecting more than 50 million people worldwide. The estimated proportion of the general population with active epilepsy (i.e. continuing seizures or with the need for treatment) at a given time is between 4 and 10 per 1000 people. However, some studies in low- and middle-income countries suggest that the proportion is higher, between 7 and 15 per 1000 people.