

9th European Conference on Epilepsy & Society
“Focusing on Change”
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My Experience of Epilepsy of Work

I would like to begin this talk with my experience at work. When I started on my first job I was very self-conscious of having seizures in front of other persons. I did not like the idea of other people knowing that I had epilepsy and this made my life at work difficult because I could not feel at ease among my fellow workmates. I wished to find another job but although I went through the adverts in the newspapers and enquired I could not pluck up the courage to apply.

After being employed with the same company for 18 years, this company closed down and I had to look for a new job. I found one as a clerk. During this time I had one seizure after which I was very tired and remained dizzy for a long time. When I came to, I noticed my employer standing besides me and when I was fully conscious he asked if I wished a lift home. Neither my employer nor I did discuss what had happened. The incident was never mentioned again. At that time I was still afraid to talk about my condition and I could not find the courage to talk about it to my employer. I used to think that I was the only person having epilepsy and thought that no one could understand me. After working with this employer for four years the business was sold and I had to look for another job.

My fear and self consciousness led to the fact that I remained a loner and afraid while those around me were still ignorant about epilepsy and its consequences.

After a few weeks I received a telephone call and the caller asked me if I was looking for a job, and if I was interested. He told me to go and discuss a vacancy. I was still unemployed so I had no choice but to talk to this person. During our meeting he told me that he knew everything about me as I was referred to him by my previous employer, who happened to be his cousin. The fact that he knew about my condition did not really bother me. On the contrary it made me feel more at ease and not afraid that he might find out later and so give him the excuse to discriminate against me. I have been in this job for the last ten years now.

At this present job I had several seizures. After the first one I was quite uneasy. However a few days later I was talking with my employer and he asked a question about driving hinting to my epilepsy. I realized that he wanted to know more about my condition and therefore this was the beginning of our dialogue about epilepsy. I explained what epilepsy is and that a seizure only lasts a few minutes and then everything is back to normal. With the questions asked I confirmed that he knew very little, if anything at all, about this condition. I realized that I needed to increase awareness about epilepsy with whom ever I met, so that this condition is better understood and people like me release themselves from fear of other people's reactions

My employer's wife, who happens to come everyday to our office, also approached me with personal questions and this gave me another opportunity to talk to her about my epilepsy. She asked several questions about epilepsy as she knew absolutely nothing about it. She asked whether it is contagious or hereditary. Again I explained what epilepsy is, what causes it and that it may effect anyone at any age

Once I had a seizure in front of her. I cannot say what happened until the time that everything was back to normal. When I was conscious I realized that she had gone and a workmate approached me and told me what had happened. He said that she seemed confused and anxious when she left. I felt the need to approach her and ask for her reaction towards what had happened. I had to be open with her and explain that I realized that even though a person knows about epilepsy it is normal that he or she would feel uneasy after seeing someone having a seizure especially for the first few times. This also gave me the opportunity to say how a person should treat someone having a seizure.

Talk more freely.

Today I realize that I did not talk about my epilepsy not because I was afraid of losing my job, but because I was ashamed to do so. I wanted no one to know I have epilepsy. Until recently I could not find the courage to talk about my condition, not even to friends. Today I find it is easy to talk freely about my epilepsy to anyone. This change mostly occurred in the last few years, when I joined the CMEA, and found out that there are many people who have epilepsy. Personally, knowing other persons who have epilepsy and facing the same problems as myself, has helped me to accept my disability.

Work & Self Esteem

Employment is one of the most important factors in our lives. Having a job, gives a person his / her self-esteem. One will also find financial independence, and enjoy social and recreational opportunities. Persons having epilepsy can work in almost every kind of job, unless there are other disabilities involved. It is a mistake to think that epilepsy by itself can limit a person's opportunity to live a productive and rewarding life, as what used to happen is the past. Frequent seizures can make it hard to keep a job, but most people with seizure disorders can and do work. With proper education to employers, people with epilepsy can be as successful as anyone else on the workplace.

Guiding the Employer:

The European Declaration on Epilepsy of 25 October 1998, held in support of the "Global Campaign Against Epilepsy", states that "The rate of unemployment is disproportionately high for people with epilepsy mainly due to the ignorance of employers" This is the main reason that employees hide their epilepsy from their employers, because they are afraid that they will be stigmatised. It is imperative that employers are sufficiently informed about epilepsy so that persons who have epilepsy can be more at liberty to talk about their condition without fear of being discriminated against.

During the European Year of Persons with Disability Closing Conference in Rome last December, it was stressed that organisations should work hand in hand with employers and guide them so that they may be able to create access at work for disabled people. This will create new jobs for these persons. So we need to increase advocacy with employers and create awareness of epilepsy at the places of work. It is something that we should strive for contentiously.

Informing the Employer:

A question that constantly arises is whether people having epilepsy should tell employers about their condition. Many authorities think it is wrong to conceal a disability or condition from a potential employer. Deliberately falsifying a job application can be grounds for dismissal. If this happens, the dishonest application gives the potential employer a valid reason for not hiring the applicant. This can keep a qualified person with epilepsy from getting a job even if the condition would not have interfered with the work.

People are not bound to tell their employer that they have epilepsy. However it would be better if they do so from the onset. Not disclosing that a person has epilepsy stems from the fact that few employers know what epilepsy is, so persons having epilepsy sometimes prefer to disclose this fact only after they have established a track record for being good and reliable workers.

Most employers are primarily concerned with the employee's ability to do the job. Their interest in the employee's epilepsy will be related to the safe performance of the job.

On the other hand, references can swing the balance in the applicant's favour. References come from people who know them, who can vouch for their skills and who can explain the way they cope with epilepsy. References can come from former employers, teachers, coaches, local business people, or a clergyman.

Conclusion:

The Global Campaign against epilepsy "out of the shadows" has been very instrumental in increasing awareness about epilepsy worldwide. However, we as individuals who have epilepsy need to focus on change for a better life and show people who we are and what our condition is. Who better than us who have epilepsy can explain how this condition affects our life. If we want that epilepsy is to be accepted by the general public it should first be openly discussed and we should not be afraid or ashamed to discuss it.

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