Social Aspects of Epilepsy

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THE MEANING OF EPILEPSY

The diagnosis of epilepsy is always a source of shock to the family and is frequently accompanied by anxiety concerning the cause. In extreme cases the diagnosis can even lead to suicide. Parents feel guilty and search for reasons why this has happened to one of their children. Is it attributable to some defect in their family, such as an alcoholic uncle or a mentally disturbed relative, or to their own misdeeds? The mother may blame herself for trying to avoid pregnancy, or for an attempted termination, or just not wanting the child. Arising from these deeply-felt feelings and anxieties the child may be rejected or overprotected.

The child who has epilepsy will have to grow up in an atmosphere of anxiety about his condition. Parents are concerned about their responsibility and how far they can allow the child to follow a normal existence. There may be disputes about this, and as to how far the child should be subject to the same discipline as the other children. The child may endure many restrictions (swimming, riding a bicycle, etc), limitations on activities or going out with other children. Drugs may have to be taken—a nuisance in itself—and he will suffer the effects of taking drugs even if these are minimal. There may be difficulty in keeping up with schooling, and in many ways he will feel different from other children. Later the inability to drive a car may be a social handicap.

Epilepsy, to the individual, means a great deal of uncertainty. Will a seizure interfere with taking an examination or an interview for a job, or plans for some social activity or a holiday? Epileptics may feel that the risk of causing a disturbance at a cinema or a dance by having a seizure is too embarrassing, and so they become more and more isolated.

All these factors play a significant role in the development of the individual and his personality. There is no clear evidence that epilepsy itself causes behavioural disturbance. Occasionally the underlying cause of the seizure may be responsible for disturbed behaviour in a child or some cases of temporal lobe epilepsy cause behavioural disorders. The extremes of epileptic personality are more often the sort of behaviour which follows long periods of institutional care and it is rare to find someone demonstrating the old textbook epileptic personality outside of an institution. Nevertheless, many people who suffer from epilepsy do have some degree of difficulty in making completely happy social adjustments, but this is more the consequence of their experiences in growing up than being directly due to epilepsy.

SOME MYTHS OF EPILEPSY

A great deal has been written about the bizarre ideas about epilepsy in Africa and other parts of the world. It should never be forgotten that some of these ideas were prevalent in Europe at one time. For example 60% of school teachers in Lagos may think that epilepsy is contagious and this has a very serious effect on children with epilepsy being allowed to attend normal schools. In the 15th and 16th centuries this idea was widely held in Europe, and there is on record the sermon of a good Christian bishop warning his hearers to keep away from one who was seized lest they should catch the infection from his contaminated breath.

It is widely held that epileptics are aggressive and violent. It is possible that someone has tried to restrain an epileptic during a major seizure or has heard of someone who received a severe blow in the process. We know that such blows are usually unpremeditated and that the patient is unaware of them, but still the idea persists that epilepsy and violence go hand in hand. Dr John Gunn made an intensive study of prisoners who suffer from epilepsy. He found that 15% of epileptic prisoners had committed crimes of violence, whereas 22% of the non-epileptic prisoners were guilty of such offences. More study is needed, but it seems from general observation that the idea that epileptics are usually violent is one of our present-day myths.

It is believed that epileptics cannot work with machinery for fear of accident. Social workers in the British Epilepsy Association are constantly on the look-out for information about industrial accidents in which epilepsy plays some part. The fact is they have no record of such cases. Dr Frank Rirch in Los Angeles established an EPI-HAB workshop to employ and rehabilitate veterans suffering from epilepsy. These people used many different types of light industrial equipment in the assembly of panels and parts for aircraft. Rirch found that the accident rate in his workshop was substantially less than in a nearby factory employing non-handicapped workers doing much the same sort of work, and that no serious accident over 3 or 4 years was caused by an epileptic seizure at work.

We have no statistics to prove that people with epilepsy at work are less likely to have seizures, but many physicians have reported cases of patients who seem to be fit-free when actively engaged in work. The industrial director of an epilepsy centre near Manchester in the UK reported that over a period of 3 months, 70% of his patients fell sideways and backwards. It would always be worth asking what happens during a seizure (or where or when it occurs)

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before deciding on the suitability of a particular employment. One other epilepsy centre provided another interesting piece of information. The weekly cinema show was usually designed to project quiet films not likely to disturb the patients too much. There were normally 10 - 12 seizures every afternoon among the 150 patients present. One day the films arrived and there was a great deal of gunfire and bombing in a war film during which no-one had a fit. The staff were much intrigued and proceeded to mix the programmes—one week quiet, the next week noisy—and they found that there were always fewer or no fits at the exciting film shows. It would seem that many patients, when absorbed in what they were doing, are less prone to seizures and to accident.

Another idea which is sometimes prevalent is that children with epilepsy need education in a special school. From our experience children who suffer from epilepsy and no other complication rarely need special schooling. It is estimated that there are 60 000 epileptics of school-going age in England and Wales. The special schools have place for 622 and these are rarely full. In fact, Lingfield Hospital School is at present seeking to widen its terms of reference to enable it to admit physically handicapped children who are not suffering from epilepsy.

Others have dealt with the myth that epilepsy and mental subnormality or mental disorder go hand in hand far more often than they actually do. Social workers are sometimes guilty of thinking and even saying that all epileptics have severely disturbed behaviour. This is frequently so because the cases we see are those who are handicapped in more ways than one. In social agencies we meet the truly difficult epileptic and we have to remember that we see only a small proportion of the total number.

The last myth I would like to discuss is the idea that once an epileptic always an epileptic. Scandinavian physicians have made careful studies of the risk of patients relapsing or having further epileptic seizures after a period of freedom from attacks. These studies are of particular importance in deciding whether someone with a previous history of epileptic attacks should be allowed to drive. One study has shown that 60% of patients remained seizure-free for 5 years after treatment and that the remainder responded well to renewed treatment. Some patients may have to continue treatment indefinitely if they are to remain seizure-free. In England there has been much debate about this in the past 20 years, but regulations which came into operation in June 1970 allow someone who has been free from seizures while awake, during the previous 3 years, to hold a driving licence. The regulations also allow someone who has only had attacks while asleep over a period of more than 3 years, to hold a licence. These regulations are based on the advice of a panel of senior neurologists and would suggest that a 3-year absence of attacks might be sufficient to allow people to undertake many occupations which have hitherto been barred to epileptics.

In fact, it is usual for someone to be allowed to teach after a 2-year period of freedom, and a number of hospitals would accept a nurse who has had a 2- or 3-year period of freedom from attacks.

Our difficulty is that no-one can guarantee that attacks will never recur. In certain types of epilepsy, however, such as petit mal, which is very uncommon after the age of 15 years, one may hope that the seizures are under control.

THE OUTLOOK FOR PEOPLE WITH EPILEPSY

We learn that epilepsy is a treatable condition and that all people in non-medical disciplines have a part to play in helping the epileptic patient to take his rightful place in the community. The more success the doctor has in controlling epileptic seizures, the more possibilities there are for social rehabilitation or adaptation. Epilepsy is becoming a more and more hopeful condition unless the seizures are an indication of some progressive brain disease, a brain tumour, or of the ageing process as in cerebral arteriosclerosis. We are justified in encouraging our patients to hope that things will improve, and that they can prepare for many different types of employment.

The more we can help the general public to realise that epilepsy is a treatable condition, the sooner some impact will be made on attitudes and prejudices which are based on long-held myths and misconceptions. In the UK there has been a remarkable change in the public attitude towards tuberculosis ever since people could see that colleagues, friends and relatives were able to recover fully by means of improved medical care and the medications available.

Lastly, a great deal can be done by our own attitude of mind. I believe it is not merely a question of semantics that many people now speak of 'people with epilepsy'. This was the title of a report by the British Department of Health 3 years ago. The handbook for employers issued by our Department of Employment is entitled *Employing Some-one with Epilepsy*. To label any person as an epileptic is to reduce his stature, and to forget that epileptics are people with hopes and aspirations like all of us. We know that all of us could be provoked into having an epileptic seizure by a number of various means. It is not scientifically accurate and it is not socially helpful to call someone an epileptic. I suggest that a small but important step is to think of and to speak of a child or a man with epilepsy.