

## The patient's viewpoint

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Throughout the past century the management of epilepsy has greatly improved, with a wider choice of treatments aimed at specific types of seizures. The social and psychological consequences of living with epilepsy have in the past been relatively neglected, both in the clinical setting and by society in general.

Until relatively recently there was a lack of awareness of how a diagnosis of epilepsy could affect the patient. Where seizures remain refractory to treatment they may have a disturbing effect on the patient's life, inducing an understandable feeling of insecurity, which may affect self-esteem and confidence. Attacks may be frequent or infrequent, they may also happen in public, during the daytime, or at night when the patient is alone. Each possibility brings its own attendant fears.

Uncertainty about when the next attack may occur presents a particular problem. The patient's dilemma is living with an ever-present threat, never knowing when the next attack will happen. To the unaffected however, the person with epilepsy is 'normal' between attacks. These two very different perceptions illustrate the patient's dilemma, and it is easy to see how some patients feel isolated and misunderstood, perhaps leading them to live a rather covert type of existence.

When attacks occur in public a common source of anguish is the response of the onlooker who may:

- Recoil in horror if ignorant about the condition
- Make fun of the patient, covering their own embarrassment at the situation
- Ignore the patient, turning a 'blind eye'
- Panic and call an ambulance
- Intervene inappropriately (holding the patient down or introducing a hard object into the mouth).

The reaction of family and friends is key and family support and encouragement is important for positive adjustment over time. Epilepsy may affect family equilibrium and may be a frustrating disorder for everyone. An accurate understanding of the diagnosis is vital in family adjustment, as is containment of anxiety, if the patient is to have a good chance of learning to cope. A partner or family may be feeling:

- Grief for the patient
- Fears for their safety
- Doubts about their own ability to cope with the situation
- Resentment – disruption to their own lives
- Guilt – is it their fault?
- Isolation.

Where the patient is overprotected at home there is a real danger that this may lead to illness behaviour and increased dependency. A young adult may manifest difficulties in education, social and personal relationships and in the workplace.

The main tasks of the patient are to:

- Overcome social slights and chance remarks
- Have confirmation of his/her self-worth
- Adjust positively to the condition and integrate it into their lives
- Over time pursue an active social and working life.

Public misconceptions about epilepsy include:

- The association of epilepsy with mental illness and learning disability
- The assumption that single seizures cause damage
- The idea that epilepsy is inherited irrespective of cause
- The assumption that epilepsy is always for life.

It is important that these issues are introduced and discussed by the patient's physician at an early stage. Without proper information patients and their families are left to cope with unnecessary 'taboo' concepts, which add to their anxiety. The relative risks of disclosure and concealment may arise with interpersonal relationships and especially when seeking employment, where fear of rejection is marked.

In some countries, even today, people with epilepsy are not allowed to marry and are considered to be uneducable, unemployable and a danger to the community. In the UK many people still feel that revealing their condition will deter their employers who may view them as unreliable and likely to cause accidents. Some therefore decide to remain silent and live in fear of an attack and losing their job. A well-adjusted person should be able to tell anyone with whom they come in regular contact about their condition. Explanations should be kept simple and practical and public ignorance should not be assumed to be rejection.

Drug treatment for epilepsy may bring side effects causing problems for some patients. These may include:

- Fatigue and lassitude
- Poor memory
- Concentration difficulties
- Unsteadiness
- Nausea
- Weight gain or weight loss
- Mood or psychological changes.

These symptoms may be difficult to tolerate in the long term and alternate drug and treatment choices may be appropriate.

Refractory epilepsy means the patient will have to reassess how much risk is acceptable in order to live an integrated life. Each individual must decide what precautions are sensible in order to strike a reasonable balance between risk and precaution. Once a balance has been found, a patient may then maximise their potential and develop their talents.

**Further reading**

CHADWICK, D. and USISKIN, S.C. (1997) *Living with Epilepsy – a Practical Guide to Coping, Causes and Treatments*. Vermilion, London.

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