Epilepsy clinic counselling

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The majority of patients seen at special epilepsy clinics have chronic refractory epilepsy. As such, they represent a worse than average epilepsy group, some of whom may have special psychological and social problems.

The need for skilled counselling within this group, in addition to ‘routine’ therapeutic intervention, has been recognised. At the National Hospital for Neurology and Neurosurgery epilepsy clinics a special counsellor is available to help address the problems commonly experienced by these patients and their families.

Refractory epilepsy may cause difficulty in a number of areas described in the previous chapter. Additional problems may arise in the patient’s ability to cope with daily activities, accepting the diagnosis, and concordance with drug therapy offered. There may also be special problems which affect women and also with sexual relations.

Referrals

Patients who in the opinion of the medical team might benefit on clinical grounds and who live in the community (i.e. non-residential) may be referred for counselling. Referrals may be made by neurologists, neuropsychiatrists, general physicians, epilepsy nurse specialists and GPs. Patients may be referred from other hospitals and medical practices. Typical reasons for referrals include:

- Anxiety
- Depression
- Non-concordance with treatment
- Need for emotional support
- Advice and information about specific areas of living with epilepsy, e.g. women’s issues, safety in the home, etc.

Common problems include:

- Perceived stigma
- Social isolation
- Low self-esteem
- Misconceptions about epilepsy
- Work/employment issues
- Anxiety and low mood.
The process

Patient motivation is key and must include an appreciation that success is dependent on equal effort by the counsellor and the patient. The counsellor must be consistent and not deny the patient’s reality.

Patients are given an initial interview of one hour and may be offered regular follow-up sessions. A detailed history of the problems presented is taken and various options may be considered, depending on the counsellor’s perception of the patient’s ability to benefit from them. The patient is also screened for depressive symptoms and social behaviour patterns are observed.

In the early stages it is common for a patient to hold negative beliefs which may block progress. These commonly include:

- I will never make it
- There is no point in trying
- Others will reject/dislike me
- I have no control over my life.

Time is important when addressing such issues as fear, anger, denial and confusion. Many fears arise out of public misconceptions about epilepsy which may be allayed with proper information, together with support and reassurance.

The counsellor’s actions are to:

- Identify problems
- Offer coping strategies
- Overcome blocks to change
- Set and review agreed tasks.

Coping strategies are important in epilepsy counselling. They enable the patient to deal with his or her problems in a particular way. Once it is understood that choices are available, the patient may explore these options with the counsellor. In time, a more balanced view of the potential intrusion of epilepsy into everyday life may be achieved and general anxiety levels lowered as the patient feels more in control.

Further reading