

## Employment

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People with epilepsy have been shown to be up to twice as likely as people without it to be at risk of unemployment<sup>1</sup>; and as being also subject to underemployment, relative to the level of their skills and qualifications<sup>2</sup>; with related impacts for their financial status and psychological well-being. Factors contributing to the likelihood of under- and unemployment in people with epilepsy are both internal and external. In the former category, a range of clinical factors have been demonstrated as predictive of employment status, including seizure frequency and type, age of onset of epilepsy and duration, and the adverse cognitive effects of antiepileptic drugs (AEDs); and the effects of these clinical factors may be further compounded by internal psychological factors, for example, reduced self-esteem and achievement expectations<sup>3</sup>. External mechanisms, in the form of stigma and discrimination<sup>4</sup>, which may be either formal or informal, overt or covert, intentional or unintentional, also contribute to the compromised employment position of people with epilepsy; and their effects may be felt particularly hard in areas or times of high unemployment. For many people with epilepsy, employment is the major quality of life issue facing them<sup>5,6</sup>.

The question of employment is crucial when considering the needs of people with epilepsy. Working, being an employee and earning a living, is an outward indication of integration and acceptance by others in society. The advent of seizures can have serious effects on work prospects and as a consequence can adversely influence psychosocial functioning of the person with epilepsy, and his or her family. In most surveys of people with epilepsy, employment problems are frequently highlighted<sup>7,8</sup>. From a societal viewpoint the economic cost of epilepsy in the workplace is also a concern. A recent study suggested that of the estimated 200,000 people with epilepsy of working age in the UK as many as half are experiencing moderate or severe problems with employment<sup>9</sup>. Employment was the third major concern cited by people with epilepsy after driving and medication in a survey conducted by Epilepsy Action, with a third of respondents describing the problem as serious.

### Employment problems

#### *Restrictions*

There are a number of ways in which epilepsy can have an impact on employment. In the first instance certain occupations are barred by law to the person with epilepsy because of the potential hazards to him or her or others if a seizure occurs in the workplace. These include working as an aircraft pilot, ambulance driver, merchant seaman, taxi driver, train driver, and in the armed services. Secondly, the stigma attached to epilepsy and the resulting prejudice on the part of the employers and co-workers limits employment opportunities for individuals with epilepsy. Thirdly, there are also some occupations in which difficulties may be experienced, although there are no statutory barriers concerning them, such as teaching posts involving physical education, science and technology in state schools, some nursing posts, work with young children and jobs in the prison service involving close contact with inmates. Certain positions also involve substantial risks if seizures are not fully controlled and therefore should not be recommended. These include working at heights and working alone near open water or around unguarded machinery or fires. To hold a Large Goods Vehicle

(LGV) or Passenger Carrying Vehicle (PCV) driving licence, an individual must have suffered no seizures or had no treatment for seizures for ten years (see Chapter 54). However, regulations can change so it is important to make sure information is up to date.

### *Unemployment*

Quoted unemployment rates vary widely. Figures cited for vocationally active people with epilepsy are at least twice that of the general population. Elwes and co-authors reported an unemployment rate of 46% for people with epilepsy, as opposed to 19% for a control group<sup>10</sup>. Significantly longer periods of unemployment and higher rates of early retirement are also reported. When epilepsy is well controlled, or seizures are nocturnal, it has much less impact on employment rates and history. Rates of underemployment are reported to be higher for people with epilepsy but these rates are more difficult to quantify. However, the majority of studies investigating employment and unemployment rates among people with epilepsy have been based on highly selected populations or small samples. In a 1995 study by Jacoby on a large cohort of people with relatively well controlled epilepsy, 71% of those of working age were in employment with 26% unemployed but for reasons other than epilepsy and only 3% citing epilepsy as the reason for not working<sup>11</sup>. A breakdown of employment rates by clinical and demographic factors is displayed in Table 1.

**Table 1.** Influence of demographic and clinical characteristics on current employment status.

	% Currently employed	Number of patients
<b>Sex</b>		
Male	79	213
Female	64	266
<b>Age at which first education completed</b>		
<16	67	340
17+	81	139
<b>Epilepsy was</b>		
Active	65	121
In remission	73	348
<b>Currently taking AEDs</b>		
Yes	67	355
No	70	139
<b>Self-assessed health status</b>		
Excellent/good	75	398
Fair/poor	49	79
<b>Neurological deficit</b>		
Yes	70	406
No	71	73
<b>Seizure type</b>		
Partial	53	32
Partial with secondary generalised	74	160
Generalised	70	286

Reproduced with permission from Jacoby 1995<sup>11</sup>

### *Work performance*

Assessing productivity is difficult as there is no agreed definition or means of testing it. To obtain data on the effects of epilepsy, comparisons should ideally be made with a person who does not have epilepsy performing the same task. The available evidence does not suggest any striking lack of efficiency at work in employees with epilepsy. One study of an electrical components firm recorded reduced working speed but this was reported to be associated with an increase in precision, which was considered a positive outcome.

Data on absenteeism do not indicate any markedly elevated rates in people with epilepsy and turnover rate has been reported as lower. This may be due to anticipated or real difficulties in obtaining another job.

#### *Seizures at work*

If a seizure does occur at work, three factors affect the level of disruption: the severity, the suddenness and the location. A severe seizure at work is likely to cause a good deal of disturbance and disruption, at least to those in the immediate vicinity. Milder attacks cause little disturbance and may even go unnoticed. Possibly the most disruptive seizures are those which occur without warning or in someone who was not known to have epilepsy.

#### *Stress*

Stress is recognised as a possible seizure precipitant. Reports in the literature suggest that the person with epilepsy may be particularly vulnerable during the first few weeks of a new job. At this time people who are keen to prove their worth and make a good impression may put themselves under the kind of stress that makes seizures likely to occur, particularly if they have not disclosed their epilepsy. It has also been reported from a US survey that as many as 80% of people with epilepsy regarded the fear of having a seizure at work as a reason for not seeking or maintaining open employment.

#### *Shift work*

It has been suggested that adapting to shift work will increase the chances of suffering a seizure in people with epilepsy who may be particularly susceptible to persistent fatigue, sleep disturbance and disruption of routine. If a patient has more seizures in the context of lack of sleep or occasional missed doses of medication then they might be vulnerable if they undertake shift work, as might individuals with well established nocturnal seizures.

#### *Working with computers*

For the majority of people with epilepsy, working in front of a computer monitor will not be a problem and will not trigger seizures. Individuals with photosensitive epilepsy are at risk, however this is a rare condition in adults with seizures. Most computers work at a frequency which does not tend to provoke seizures. Laptop computers are even less likely to trigger seizures than ordinary computers. Work involving computers has increased dramatically in recent years and this growth is of potential benefit to people with epilepsy. Working with computers is relatively safe and enables employment within the home, which can overcome the problems of transport.

#### *Accidents at work*

The few studies looking at the experience of people with epilepsy at work tend to show that they have no more accidents at work than anyone else. Of course, this may be because they are less exposed to potentially high-risk situations, such as working at heights or driving vehicles. It may also be that when accidents occur, particularly if they are relatively minor, they are less likely to be reported. In one study of a sheltered workshop employing people with epilepsy, the accident rate was considered so impressively low that the company was awarded insurance premium reductions. In most work situations it should be possible to minimise the risk of accidents.

#### *Employees accident liability*

The ineligibility of people with disabilities for employees' accident liability insurance has been used incorrectly as a reason for not employing someone with epilepsy. Employers are obliged to take out insurance to cover injury that might arise from work. The majority of insurance policies will treat anyone with a disability on the same terms as the rest of the workforce providing that the duties allocated take the disability into account. To ensure they

are covered employers may need to seek expert advice. In the UK this can be obtained from Health and Safety Executives and the Employment Medical Advisory Service.

#### *Pension schemes*

Many employers may believe that new recruits to their pension schemes should have high standards of health. This is not the case, however. If a person is suitable for employment then they are suitable for a pension scheme. Large company schemes are usually based on a group policy with no requirement for individual health criteria to be met.

#### *Disclosure*

Many people with epilepsy choose not to declare their epilepsy to their existing or prospective employers. Those who are more likely to have seizures during the working day are more likely to declare it than those whose epilepsy is in remission or occurs during sleep. The Health and Safety at Work Act (1974) requires that both employers and employees declare factors which might prejudice the safety of employees and epilepsy is regarded as a relevant factor. A failure to declare can result in instant dismissal which would not be considered unfair if brought before an industrial tribunal.

### **Overcoming employment disadvantages**

#### *Legislation*

Some protection from discrimination in employment is afforded by legislation which stipulates that people with disabilities are given equal rights to employment. In 1995, in line with several other European countries, the Disabilities Discrimination Act was introduced in the UK. It is too soon to judge what impact this will have on recruitment but similar legislation in the US has been successfully tested in the courts by people with epilepsy. Shortcomings of this legislation for people with epilepsy have recently been highlighted<sup>12</sup>.

#### *Adequate assessment*

When assessing employment prospects, many factors need to be considered. Too often, most focus is placed on seizure-related factors. While the timing, frequency and nature of attacks is important, these may actually not be the most relevant. A person's skills, qualifications and work experience will be crucial. In addition, some inquiry into a person's understanding and attitude toward his or her epilepsy may be helpful. A prospective employee's ability to present his or her own seizures in an appropriate and reassuring way can do much to allay the employer's concerns.

Difficulties obtaining relevant qualifications or maintaining employment may reflect an underlying cognitive difficulty. A thorough neuropsychological assessment may help to identify any problems that may be amenable to intervention, perhaps via a change in medication, which should be taken into account when advising on career options.

#### *Training, counselling and placement*

Unrealistic employment aspirations can be prevented by accurate guidance concerning career options. Counselling and training is vital to provide input on job presentation skills and the role of psychosocial factors. Most people with epilepsy do not have access to specialist epilepsy rehabilitation services and must rely on mainstream resources. Existing research indicates that employment training schemes aimed specifically at people with epilepsy generally achieve better results than more generic schemes. Components of these programmes include neuropsychological assessment, vocational training, interview techniques (including disclosure) and specialist placement and post-placement programmes.

**Table 2.** Principles for employing a person with epilepsy: good seizure control, work-related aptitudes and skills and a positive approach to epilepsy are key factors in determining a person's employability.

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### **Health care**

When assessing an employee or job applicant, the employer needs to understand some of the basic facts about epilepsy and its possible impact on work performance:

- Seizures can take many forms and many people have only one seizure in their lives – in such cases a diagnosis of epilepsy is not usually made
- When a seizure occurs for the first time there may be a detrimental effect on self-confidence and the person may require psychological support and education about epilepsy
- In most cases recurrent seizures can be controlled completely with drug treatment
- If prescribed properly, drugs for epilepsy should not produce side effects that have a noticeable effect on work performance
- In such cases, assessment by a physician expert in epilepsy will often improve seizure control and reduce side effects
- Employees with epilepsy should be provided with the same health and accident insurance cover as other employees

### **Job suitability**

The vast majority of jobs are suitable for people with epilepsy:

- When medical advice is sought about the suitability of particular jobs for people with epilepsy, the guidance given should take into account the known facts about epilepsy and seizures – blanket prohibitions should be avoided
- In those jobs known to carry a high physical risk to the individual worker or to others, the way the work practice is organised should be examined to reduce this risk to an acceptable level
- Only in those situations where this cannot be done are restrictions on the employment of people with epilepsy justified
- When a person with epilepsy possesses the right qualifications and experience, job suitability should be assumed

### **Recruitment and selection**

- When personal health information is required it should be processed separately from the job application form and evaluated by a suitably qualified person
- Interviews should focus on the capabilities of the individual and not on his or her real or assumed limitations
- Suitability for a particular job should be decided by the employer before any implications arising from the job applicant's epilepsy are considered
- If a medical opinion is sought, the guidance should be based on knowledge of the particular job and details of the individual's epilepsy

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(Continued)

**Table 2** (Continued)

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**Assistance at work**

When an employee has seizures for the first time, the employer should respond fairly by giving the employee adequate opportunity to receive proper medical treatment before making any decisions about job suitability:

- If seizures are likely to occur at work, the employer should help the employee with epilepsy to disclose the epilepsy to work colleagues
  - Some first-aid training or other information should be provided to those who might be involved should a seizure occur
  - If any special job restrictions are needed there should be clearly stated policies about how they are to be implemented, reviewed, or lifted, in terms of set time periods
  - If, despite proper medical attention, redeployment to another job is necessary, appropriate counselling and vocational guidance and if necessary rehabilitation services should be made available at an early stage
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*Educating employers*

Negative attitudes regarding the employment of people with epilepsy is often the result of ignorance. Much can be accomplished by educating employers. To this end the Employment Commission of the International Bureau for Epilepsy has drawn up a set of principles aimed at employers to improve awareness and hopefully employment practice. Attention is drawn to four key areas: health care, job suitability, recruitment, and selection and assistance at work. An adaptation of the Commission's Principles are presented in Table 2.

**Summary**

Employment serves a number of important functions, including providing a sense of self-worth, an identity and personal status. Being unemployed contributes to emotional and behavioural problems and is considered as a major source of stress and a contributory factor to increased psychopathology in people with epilepsy<sup>11</sup>. A number of studies have highlighted that rates of employment are lower in people with epilepsy than those without, however, more recent findings have suggested that rates will vary by clinical and demographic characteristics. For example, people with well controlled epilepsy and those in remission have employment rates similar to those of the general population without epilepsy<sup>6</sup>. Smeets and colleagues<sup>12</sup> have recently provided a conceptual overview of the employment barriers experienced by people with epilepsy. The authors conclude that there is a need for specific vocational rehabilitation that focuses on increasing self-efficacy and coping skills. However they also recognise the need for longitudinal research to demonstrate that employment opportunities can indeed be improved through specified vocational rehabilitation interventions.

Jacoby, Gorry and Baker<sup>13</sup> have recently argued that the need for continuing education of employers of people with epilepsy is self-evident. However, according to the authors 'education alone is not enough: the problem of bridging the gap between knowledge and attitudes and behaviour also needs to be addressed though exposure of persons without disabilities to those with them.'

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