



# Epilepsy and Quality of Life: Fact Sheet

Epilepsy is often misunderstood, leading to fear, stigmatisation and the risk of social discrimination.

In some patients, social stigma can pose a greater challenge than the epilepsy itself.<sup>5</sup>

People with epilepsy have an increased risk of poor self-esteem, depression, and suicide. Many people with epilepsy live in fear that they will have another seizure.<sup>12</sup>

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**Epilepsy can be associated with profound physical, psychological and social consequences,<sup>1</sup> and its impact on a person's quality of life can be greater than that of some other chronic conditions.<sup>2</sup>**

**A number of factors are thought to contribute to this, including the unpredictability of seizures as well as the stigma often associated with epilepsy.<sup>2</sup>**

Importantly, no two people with epilepsy are the same: seizure severity and frequency varies greatly from person to person. Research suggests that increased seizure severity can have a negative impact on a person's quality of life, contributing to anxiety and socially avoidant behaviour.<sup>3</sup>

### **An often misunderstood condition**

A World Health Organization (WHO) report estimated that 10% of the global burden of brain and mental disorders is caused by epilepsy, calculated in disability-adjusted life years.<sup>4</sup> This calculation includes premature deaths and loss of healthy life due to disability. The WHO noted that while significant, this figure does not include the stigma and social exclusion or the repercussions on the family of those with epilepsy. As a condition, epilepsy is misunderstood, leading to fear, secrecy, stigmatisation and the risk of social discrimination.<sup>1</sup> In some patients, the social stigma and impact on quality of life can pose a greater challenge than the clinical severity.<sup>5</sup>

Research assessing the quality of life associated with successful treatment of epilepsy is far behind that of other chronic conditions, such as cancer, diabetes and cardiovascular disease.<sup>2</sup> The International League Against Epilepsy believes however, that with

the appropriate treatment, more than three quarters of people living with epilepsy could lead normal lives free of seizures.<sup>1</sup>

### **Impact of epilepsy**

The impact of epilepsy on quality of life can be substantial with far-reaching and life-long consequences. There is now growing recognition that when assessing the impact of epilepsy, patients and physicians should look beyond counting seizures. Key areas of quality of life influenced by epilepsy include:

- **Education:** Often children living with epilepsy receive inadequate schooling.<sup>1</sup>
- **Employment:** Unemployment levels are disproportionately high for people with epilepsy; approximately two to three times greater than the general population and higher than is seen in people living with other disabilities.<sup>1</sup>
- **Independence:** Many people with epilepsy experience problems with physical disability, which may limit independence.<sup>1</sup> The fear of having a seizure, cognitive consequences of epilepsy and treatment, and ineffective treatments also hinder independence. An inability to obtain or retain a driver's licence due to uncontrolled or breakthrough seizures adds to limitations and restrictions experienced by people with epilepsy throughout their life.
- **Social isolation:** Many people with epilepsy hide their condition from others, which can result in social isolation and reduced self-esteem and can lead to a feeling of helplessness and depression.<sup>1</sup>

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### Education

A study carried out in the Isle of Wight in the UK demonstrated that children of average or above average intelligence, who were living with epilepsy had at least a two-year deficit in reading skills.<sup>6</sup> This significantly lower educational performance could be attributed to cognitive impairment caused by the aetiology of epilepsy itself, the frequency of seizure activity and the effects of AED (antiepileptic drug) therapy in people with epilepsy. Cognitive impairment can take various forms but the most common are memory impairments, mental slowing and attention deficits.<sup>7</sup>

### Employment

Research has shown that people with epilepsy are more likely to experience problems in identifying a job, than the general population. A study in the UK revealed an unemployment rate of 46% for people with epilepsy, in contrast to 19% for a control group.<sup>8</sup> In some European countries there are also legal barriers that restrict people with epilepsy in the workplace. This combination of institutional and social restrictions often results in people with epilepsy underperforming compared with the general population in the workplace.<sup>9</sup>

### Independence and driving

Driving is a key issue that can have a detrimental effect on the lives of people with epilepsy. Legal regulations vary from country to country, however, people with epilepsy are often prevented from holding a drivers' licence if they are not seizure free and this can impact a person's ability to take part in every-day life. Effective seizure control may enable people with epilepsy to drive, increase their level of independence and ultimately improve their quality of life.<sup>10</sup>

### Social isolation

Approximately a third of all people with epilepsy are currently living with uncontrolled seizures despite treatment with AEDs. Together with the social stigma that persists in some parts of society, people with epilepsy often feel a sense of social isolation and have an overall reduced quality of life. Social isolation and quality of life have also been shown to be significantly compromised in caregivers of people with epilepsy<sup>11</sup> and demonstrate the extent to which epilepsy can impact the quality of life of both those living with but also caring for the condition.

#### References

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