Getting the best out of life

As a nurse specialist in epilepsy, a huge part of my role is to ensure that a person’s quality of life is impacted as little as possible by their diagnosis and treatment. This means that they should be able to lead as full a life as possible in spite of their epilepsy.

Epilepsy is a very individual condition so quality of life will mean different things to different people. For some it may be defined by the ability to drive, for others the key issue may be employment and the ability to support a family. Many people with continuing seizures have concerns about socialising and making friends, worrying about how others will cope with or react to their epilepsy. The unpredictable nature of seizures can lead to lack of self esteem, even isolation. Epilepsy is different for everyone.

My role is to empower people to manage their epilepsy. Learning to adjust to a diagnosis, live with and manage your seizures is essential if you want to live as full a life as possible.

One of the greatest predictors of quality of life tends to be frequency and severity of seizures. We know that the more seizures you have, the more likely you are to experience associated health problems. Seizure-related incidents such as head injuries and burns tend to be more common as do hospital admissions. All these can increase the likelihood of being unemployed or underemployed and this in turn can affect quality of life both for you and your family.

‘You should be able to get on with your life with epilepsy being no more than a background consideration’

However, the impact of a single seizure can also be significant. Again, the loss of your driving licence may impact on ability to work, while fear about risk of further seizures and changes in lifestyle can cause anxiety and even trigger depression. When we are looking at quality of life we tend to assess the impact of epilepsy on four levels: physical, psychological, social and economic.

The physical effect focuses on the way your seizures affect your ability to carry out daily activities such as cooking, looking after your children, getting out and about. The psychological effect refers to how your epilepsy makes you feel. Many people can feel anxious and this can lead to loss of self confidence (see pages 15-17 for coping strategies). Socially, epilepsy can impact on personal relationships both with a partner, family, friends and the wider community. The economic impact refers to your ability to stay in or gain employment.

And of course there is the stigma of epilepsy. Many people with the condition say they are concerned about discussing their diagnosis with others for fear of feeling different or evoking a negative response.

So how can you improve your quality of life? There are often very basic things that anyone can do to improve their wellbeing, with very small changes to lifestyle. Fundamental to quality of life
is better seizure control and getting a balance between the effectiveness of a drug and its side effects. The aim is always to optimise seizure control while minimising side effects such as drowsiness, cognitive impairment and memory loss.

With the right medication, up to 70 per cent of people with epilepsy should be able to achieve seizure freedom, but in reality this figure tends to be more like 52 per cent. So, one of the most important areas to address in improving your quality of life is optimum seizure control.

Everyone is entitled to a structured review of their epilepsy at least once a year. This may be with your GP, nurse or specialist. This is a good opportunity for you to discuss how you are getting on with your medication and how your seizures affect you.

It could be that you are having issues around taking your medication and that this could be affecting your seizure frequency. You might like to discuss using a reminder service such as alarms or timed text messages.

Look at your lifestyle to see if there are any triggers you could avoid such as alcohol, stress or lack of sleep. Make sure you are eating a healthy, balanced diet with regular meals and exercise.

As well as having huge physical health benefits, exercise can also be good for your mental health. Taking a brisk walk every day can help to improve your mood and your wellbeing.

Poor memory can be a side effect of some medications or of the condition itself. If you are worried about your memory, ask your GP or specialist for a referral to a clinical psychologist who will be able to assess your memory function and suggest strategies to overcome any difficulties.

Are you feeling isolated? Social networking through facebook, twitter and online forums* offer the opportunity to talk to like-minded people. Knowing that there are other people out there who understand the way you feel can really help to get a perspective on your problems.

Sometimes having a routine or a structure in your life can help you to feel more in control. Employment can be beneficial for enhancing feelings of self-worth, but this is not always an option. Many people who are unable to work due to their seizures, do voluntary work instead or maybe take up a new skill or hobby.

The absolute goal is that you should be able to get on with your life with epilepsy being no more than a background consideration. Addressing the issues that concern you and seeking the right professional help are the first steps to enjoying as full a life as possible.

*http://forum.epilepsysociety.org.uk
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