recently heard a quote attributed to Dr. Heidi Hayes Jacobs, an author and internationally recognised education leader ‘As educators, we are only as effective as what we know’. I am sure this quote will resonate with many. For me, it made me reflect on my understanding and knowledge of epilepsy when I took on the role of Education and Training Manager for the Epilepsy Foundation in 2016.

The Epilepsy Foundation is a charity which undertakes research, develops best practice, educates and trains people so that they understand epilepsy and how best to support people living with epilepsy. When I started at the Epilepsy Foundation I thought that supporting the learning needs of a person living with epilepsy was all about knowing how to provide an emergency response when a learner has a seizure. While I am not alone in this thinking, I could not have been more wrong.

What is epilepsy?
Epilepsy is a neurological condition with a range of severities, widely differing seizure types and causes, and varying impacts on individuals’ dependant on the origin and location of the seizure in the brain and the level of seizure activity. An epilepsy diagnosis occurs when a person starts experiencing seizures on a recurring basis. A seizure is a physical sign that there has been a disruption to the normal functioning of the brain.

Epilepsy Reach
To put epilepsy into context 1% of people in Australia are currently living with epilepsy. Furthermore, 1 in 200 children live with epilepsy, and while there are a number of childhood epilepsies that children typically grow out of, just under 4% of Australians will be diagnosed with epilepsy at some time. Additionally, 25% of people with a disability are likely to live with epilepsy; this is significantly higher than the general population. Epilepsy occurs in both males and females and can occur at any age. Therefore, for educators it is highly likely that at some time in their career they will have a learner that is living with epilepsy.

Epilepsy and learning
The impact of epilepsy goes beyond the impact of the actual seizure event. Consider the well-known iceberg analogy, with the seizure being the iceberg you can see above the waterline and the impacts of the seizure as the 90% that sits below the waterline.

Most learners living with epilepsy progress well academically. However, the specific nature of an individual learners epilepsy may have a direct bearing on their learning journey and through that their academic or vocational outcome.

The impact of epilepsy on learning can be far reaching. Factors that need to be taken into consideration are the type of epilepsy, its cause and the brain regions affected. The left temporal and parietal lobe areas of the brain are critical for reading and language development.

Visual processing refers to how visual information is interpreted by the brain. This is different from problems involving sight or sharpness of vision. Reading and maths are two core areas where visual processing skills are very important. There are some specific factors which may cause visual processing difficulties for a learner with epilepsy.

Solid reasoning and thinking underpins numeracy and is demonstrated by manipulation of abstract symbols to gain a solution to a specific problem. Underlying the ability to manipulate abstract symbols are basic concepts and competencies. Some young learners with epilepsy may not have fully developed these required concepts and competencies.

Auditory processing refers to an individual’s ability to analyse or make sense of information taken in through the ears. This is different from problems involving hearing. An auditory processing deficit can interfere directly with speech and language, but can affect all areas of learning. It underlies a difficulty with attention and
The ability to make sense of new information is crucial to successful learning. Cognitive issues may be responsible for learning difficulties in learners with epilepsy and may impact negatively on their academic outcomes and behaviour.

Concentration. Seizure impacts may cause auditory processing difficulties for a student with epilepsy.

Cognitive skills enable a person to process information, reason, remember and relate. They involve mental activities such as thinking, understanding, learning and remembering. The ability to make sense of new information is crucial to successful learning. Cognitive issues may be responsible for learning difficulties in learners with epilepsy and may impact negatively on their academic outcomes and behaviour.

Memory is a complex process that occurs within our brain. It allows us to store, retain and recall information and experiences. Although not all people with epilepsy experience memory difficulties, it is one of the most common challenges faced by those living with epilepsy.

Epilepsy and behavioural issues can be related. Dealing effectively with a learner with epilepsy, who also exhibits distracting or challenging behaviours requires understanding and empathy. Depending on how an individual learners responds to a situation, a variety of behaviours may result. It is important to engage the learners both at a cognitive and emotional level.

The fundamentals of self-esteem are cultivated throughout childhood. This is also the time when many people develop epilepsy. For young people with epilepsy developing good self-esteem can be a struggle. They may have periods of increased feelings of anxiety and loss of control, due to the unpredictable nature of their epilepsy. These feelings may in turn negatively affect their self-image. Likewise an adult diagnosis can lead to loss of independence, stigma and work restrictions affecting self-esteem and self-image. All of which can influence a person’s perception of competence and capacity to effectively engage in learning.

The extent of the impact is very individual, some students are greatly affected while others may not be.

Inclusive learning and epilepsy
An inclusive learning environment which supports individual needs can go a long way towards supporting more favourable learning outcomes for the learners. An inclusive learning environment is one where students are given the opportunity to participate in all aspects of their education. Learners, no matter what the age, with epilepsy have a right to feel included, in the same way as student’s who don’t have epilepsy do.

There are three key steps that can be taken to enable inclusive learning for a student living with epilepsy.

Recognition of the individual learners’ needs and an understanding of the impact the learner’s seizure activity may have on their learning, including assessments. To do this you need a learning environment which actively seeks information from the learner about their learning needs and their learning support requirements underpinned by educator knowledge of the impacts of epilepsy on learning.

Complete a risk assessment so that the learners specific needs can be supported in a safe manner. This should not be seen as an onerous duty but rather an enabling process which ensures full participation and safe learning environments for all students.

From an epilepsy diagnosis perspective the risk assessments and management relates to potential seizure activity, the impact of that seizure and the resulting support needs.

Training staff to support the student living with epilepsy, this may include general Epilepsy Awareness training or specific training on the Administration of Emergency Medication training so that educators and other staff can provide an emergency response and administer emergency medication in the event of a seizure.

Further reading
Information on supporting a learner with epilepsy including training for educators can be found at epilepsysmartschools.org.au
Epilepsy Australia epilepsyausralia.net
Epilepsy New Zealand epilepsy.org.nz

References

Debra Parker is the Education and Training Manager for the Epilepsy Foundation with an education career spanning seventeen years working across a range of community and vocational education settings. Debra is an active proponent for inclusive learning practices supporting the work of the ACE Disability Network and holds a Masters in Professional Education and Training. Contact via LinkedIn.