Condition Insight Report (CIR)

Epilepsy

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Completed in collaboration with Epilepsy Action

Overview

What is the condition usually called / any abbreviations used?

Epilepsy

Brief overview of the condition

Electrical activity is happening in our brain all the time, as the cells in the brain send messages to each other. A seizure happens when there is a sudden burst of intense electrical activity in the brain. This causes a temporary disruption to the way the brain normally works, so the brain's messages become mixed up. The result is an epileptic seizure.
Various triggers can cause people to have a seizure. For example, lack of sleep, hunger, thirst, irregular sleep patterns and stress should be avoided because they can cause seizures in people with severe epilepsy.
Status epilepticus is when a seizure lasts longer than 5 minutes or when seizures occur close together and the person doesn't recover between them. There are two types: convulsive and non-convulsive. **Convulsive** poses a serious threat to life, it could require assistance from another person to administer rescue medication and could mean hospital admission. There is a risk of brain damage which can cause long term effects on memory and cognition. **Non-convulsive** describes a long or repeated absence or focal impaired awareness seizure. The individual may become confused and the situation can be harder to recognise. It can also be difficult to determine the seizure from the recovery period.

What is the generally preferred term for someone with this condition?

An individual living with epilepsy.

Presenting Symptoms

It is a hidden condition and there is a lack of understanding across society about the impact epilepsy has on people. This increases the discrimination and barriers people face in education, employment and other areas of life.

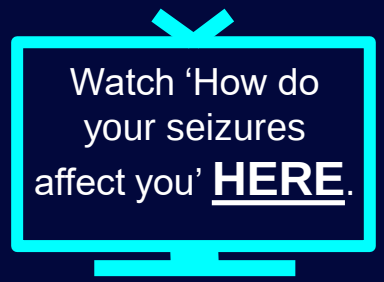
Frequency of seizures is not a complete assessment of the impact epilepsy has on an individual's life. It is important not to focus just on the seizure itself, but the time before, during and after too, this can impact on all areas of their life.

Epileptic seizures

- **Focal seizures** – when a seizure starts in one side of the brain, previously known as a partial seizure. This is where the individual is fully aware of what's happening, even if unable to move or respond.
- **Tonic-clonic seizures** – have two phases:
  Tonic phase: loss of consciousness and muscles go stiff, may cry out or bite down on toungue.
  Clonic phase: limbs jerk quickly and rhythmically, may have loss of bladder and/or bowel control, breathing may be affected causing blue tinge around mouth.
- **Absence seizures** – cause the individual to become unconscious for a few seconds. Will suddenly stop what they are doing but will not fall over. May appear to be daydreaming or 'switch off'.
- **Myoclonic seizures** – sudden, short-lasting jerks that can affect some or all of your body. They are usually too short to affect your consciousness. The jerking can be very mild, like a twitch, or it can be very forceful.
- **Tonic seizures** – experience just the tonic phase explained above.
- **Atonic seizures** – usually all your muscles go limp and you drop to the floor.

Other seizures

- **Febrile Seizures** – triggered by high temperature in children which can develop into epilepsy later.
- **Dissociative seizures** – other names include psychogenic and functional seizures.



Fluctuations

It is a hidden, fluctuating and complex condition, which affects people very differently. There is no control over when and where seizures will happen. There are a myriad of different types of seizures.

Think about exploring things like:

- How often does it occur?
- Do they have a warning aura *before*? If so, how long before a seizure does this occur?
  Are they able to recognise this themselves?
  Is their aura always reliable?
- Are there any triggers or patterns to when a seizure occurs?
  Is there a specific time of day they occur?
- What occurs *during* a seizure? Is there loss of consciousness, and if so how long does it last?
- What symptoms do they have, if any, *immediately following* a seizure?
- How long does the post ictal/recovery phase last?
- Have they sustained any injuries as a result of a seizure?
- Do they have safety strategies in place to avoid injury?
- When was the last seizure?
- Do they have any side effects of their medication?

REMEMBER: When there is evidence of risk secondary to seizures, this will supersede majority of days guidance.

Reliability

What specific areas should be covered to ensure a complete, reflective report?

SAFETY	TIMELY	ACCEPTABLE STANDARD	REPEATEDLY
Do they have any symptoms which could cause a safety consideration?	For any activities where restriction is reported how long does it take them to complete these activities? Has how long it takes them changed over time?	How have they adapted to completing tasks over time – is this different to what might be considered 'normal'?	Are they able to repeat a task as often as required? Is this the same every day?
For many the unpredictable nature of the condition means people are at risk and need supervision and support with various activities. You need to specifically explore extent of any previous incidents completing tasks, why this was and how it was managed in activities 1, 2, 3, 4, 5 and 11.	Whilst the individual may be able to complete daily tasks with no restrictions you need to consider how they may be impacted should they have seizures and how they manage this with tasks including recovery periods and the side effects of medication.	Consider that whilst someone might have an aura you need to consider if it is an acceptable amount of time to make themselves safe, and whether any precautions they take are deemed reasonable or whether this is beyond what is acceptable within PIP.	Recovery period including things like fatigue needs to be considered when thinking about how repeatable an activity is alongside frequency of seizures.

Status Epilepticus

Status epilepticus is a rare but **life-threatening** condition where **seizures last too long** or **occur back to back** without recovery.

A person's seizures usually last the same length of time each time they happen and stop by themselves. However, sometimes seizures do not stop or one seizure follows another without the person recovering in between. If this goes on for 5 minutes or more it is called status epilepticus or ‘status’.

What information can I gather to establish Status Epilepticus?

- ✓ Do you have multiple seizures in a day?
- ✓ Are they back to back?
- ✓ What happens during them?
- ✓ How long do they last?
- ✓ Do you require emergency rescue medication to be administered?
- ✓ Have you had injuries or hospital admissions secondary to your seizures?

Complete this short CPD module on what to do if someone has a seizure **HERE**.

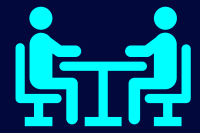
Sensitivities & Customer Care

What areas might they find difficult to mention or perhaps understate the impact of?

- Incontinence,
- Restrictions with memory and confusion
- Associated mental health problems

Some people with epilepsy may downplay the impact it has while they try to remain strong and defiant in the face of their condition. They may also not see themselves as disabled.

How is it best to ask about any sensitive topics and what are the common courtesies?



In general

- Keep an open mind. Listen to what they say
- Try not to jump to conclusions about how their epilepsy affects them
- Don’t ask questions in different ways, unless the person clearly doesn’t understand the first time
- Allow time for understanding of the questions and don’t move on unless you are sure the person has nothing else to say. They might need more time than usual, if the epilepsy or medicines cause cognition problems

During face to face interactions

- Explore what they would like you to do, if anything, should they have a seizure whilst with you
- Offer them a short break if they need it

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 1: Preparing food

There can be huge risk factors in the kitchen environment and many will have support from others. Many may avoid the use of sharp utensils if they have unpredictable seizures with no warning.

Remember in PIP…

It is imperative to establish risk in the kitchen. Have they had seizures whilst preparing a meal? Do they avoid this activity altogether due to risk? When they have seizures, do they have an aura? Is this long enough to get themselves to a place of safety? Have they had any incidents in the kitchen? Do they drop to the floor? Do they have grand mal or absent seizures? Do they lose awareness/consciousness?

If status epilepticus is present consider supervision would be likely to maintain safety.

Activity 2: Taking nutrition

There can be a risk of choking especially where there is status epilepticus and another is needed to monitor them for their own safety due to the high threat to life.

Remember in PIP…

Can they chew, swallow and bring food to their mouth? Are they at risk of choking? If so, when was the last incident? How do they mitigate this risk?

If status epilepticus is present consider supervision would be likely to maintain safety.

Activity 3: Managing therapy and monitoring a health condition

Cognitive impairment and memory issues are common in people with epilepsy. This has an impact on daily life. People may be unable to retain information or concentrate for long periods, they may have poor memory and need support for example, with medication, to travel or to carry out everyday tasks such as cooking.

Remember in PIP...

Can they manage their own medication? Do they remember when to take it? Do they require prompting or assistance to administer medication? Do they require assistance to administer emergency rescue medication?

If status epilepticus is present consider supervision/assistance would be likely to maintain safety.

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 4: Washing and bathing

Where there is unpredictable loss of consciousness and individuals can fall to the floor there is huge risk of drowning and/or other injuries in this wet and slippery environment. Many individuals are either supervised or have safety measures in place to support this risk.

Remember in PIP…

It is imperative to establish risk in the bath or shower. Have they had seizures whilst washing? Do they avoid this activity altogether due to risk? When they have seizures, do they have an aura? Is this long enough to get themselves to a place of safety? Have they had any incidents in the bathroom? Do they drop to the floor? Do they have grand mal or absent seizures? Do they lose awareness/consciousness?

Activity 5: Managing toileting needs and incontinence

Where there is unpredictable loss of consciousness and individuals can fall to the floor there is a risk of falls. Those who have status epilepticus may wear an alarm and have someone around at all times to support them should they have a prolonged seizure and rescue medication is required. Some can become incontinent during a seizure.

Remember in PIP…

If the claimant is incontinent, how frequent is it and is or bowel and bladder? Does it occur on the majority of days? Can this be managed with pads independently or do they need assistance to maintain hygiene?
How do they transfer on/off the toilet?

If status epilepticus is present consider supervision would be likely to maintain safety.

Activity 6: Dressing and undressing

For some there is cognitive impairment as a result of the epilepsy or side effects of medication. For those with severely uncontrolled epilepsy with long recovery periods support may be required.

Remember in PIP…

Safety is not outlined as a direct concern for this activity within PIP. Explore for any reported restriction or support required why this is and whether this would cover the majority of days.

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 7: Communicating Verbally

Some can have difficulty with communication due to slurring of words or slower processing post a seizure and may require support during this time.

Remember in PIP...

The scope of the activity is the ability to express and understand verbal information. They must be able to do both. Can they speak on the phone? Can they express what they want to say?

Remember that if a restriction is reported post seizure, to be considered it must occur the majority of the time.

Activity 8: Reading and understanding signs and symbols

Some can have restrictions with their comprehension or slower processing post a seizure and may require support during this time.

Remember in PIP…

What can they read? Could they read a household bill, appointment letter or text message?
Can they understand what they have read?

Remember within the scope of the activity, complex written information is more than one sentence.

Activity 9: Engaging with others face to face

Due to the restrictions many face with epilepsy it can cause social anxiety. Individuals can feel traumatised people get by having others known and unknown seeing them have a seizure, or even by the possibility that this may happen. Many individuals feel a level of discrimination day to day which can impact their how they form relationships with others.

Remember in PIP…

If someone reports their epilepsy has impacted their mental health, does that impact their ability to engage? Who are they engaging with regularly? How do they engage with unfamiliar people? Do they experience anxiety? If so, how do they overcome this? Do they require specific support?

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 10: Budgeting

For those that have cognitive impairment as a result of medication or the impact of their seizures they may need support to manage finances. Some also have associated mental health conditions which may also have an impact.

Remember in PIP…

Can they manage their own finances? Can they do online banking or shopping? Could they understand change in a shop? If they have associated mental health conditions, does this impact their motivation to budget?

Activity 11: Planning and following a journey

Transport is an issue for people with epilepsy. Many people are unable to drive and will have limited access to public transport. Depending on frequency and type of seizures, some people may be unable to travel without support and will have difficulty getting about independently on all journeys due to risks of being out in public/open spaces and having a seizure.

Seizures can be unpredictable and can happen anywhere, anytime. Some people will suffer from incontinence during a seizure.

Remember in PIP…

Safety will supersede majority of days. If they are having regular seizures, have they acquire injuries when out of the home? Do they lose consciousness or awareness which may make them vulnerable when following journeys?

REMEMBER: Even if someone has an aura prior to a seizure, it would appear clinically unlikely that this would be long enough for them to be able to get home from both a familiar or unfamiliar journey.

Activity 12: Moving around

Consider any comorbidities.

Remember in PIP...

Although seizures themselves would not be considered here, if they have acquired injuries secondary to their seizures, does this impact their mobility on the majority of days?
Lived examples are really beneficial to paint a picture of function. Where do they walk to? How long does this take? Do they require an aid? What pace do they walk at? Can they repeat this distance? How do they feel after? Does this exacerbate their symptoms?

Additional reading or other resources

EXTERNAL

- www.epilepsy.org.uk/info/employment
- www.epilepsy.org.uk/info/seizures-explained
- www.epilepsy.org.uk/info/memory/what-is-memory
- www.epilepsy.org.uk/info/stress
- www.epilepsy.org.uk/info/safety
- Driving and travel December 2016.indd (www.nhs.uk)
- For further information including medications see NHS Conditions and Treatments: https://www.nhs.uk/conditions/epilepsy/
- Status epilepticus | Epilepsy Society

INTERNAL

- Desktop Aid – Seizures, Activity 11

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