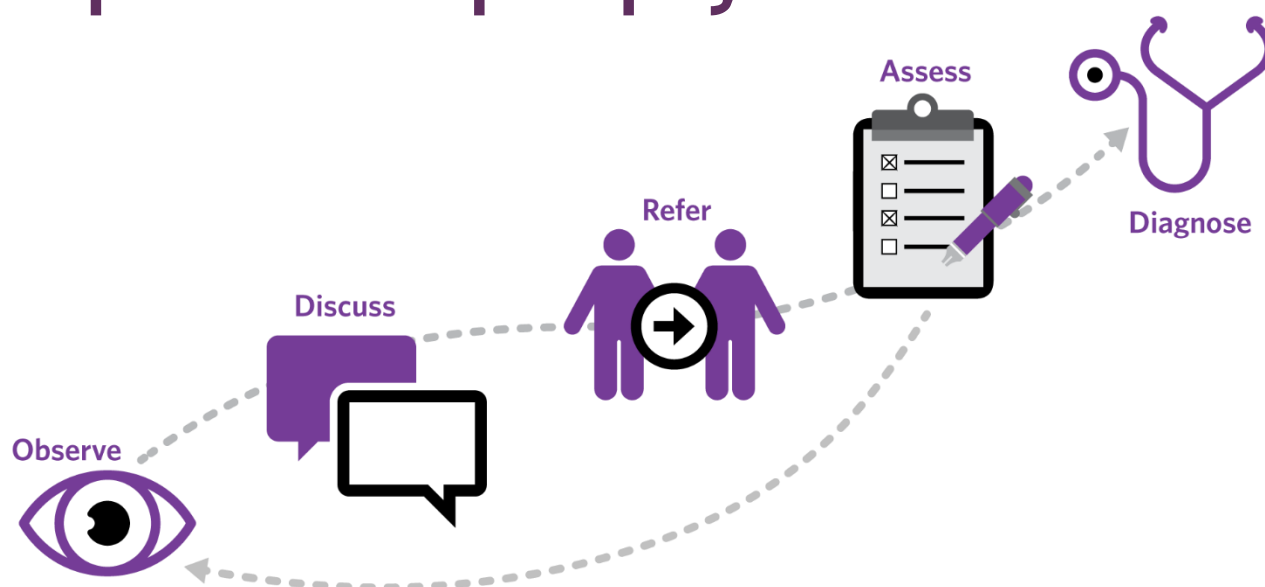


KNOW ME
SUPPORT ME

Referral pathways: further investigation of possible epilepsy



The reasons for making a referral for an epilepsy investigation can vary from person to person. Early involvement of an epilepsy specialist doctor means the right diagnosis can be made more easily.

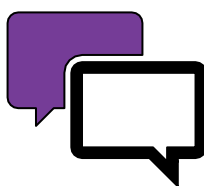


Observe

1. Disability support workers, carers, families and friends who notice changed behaviours*, should start taking notes, and talk about what they see with the person (at this point the referral process could progress to 5).
2. The person may start to recognise changed behaviours (e.g. confusion).
3. Symptoms may start affecting the person's life (e.g. lost time, falls, involuntary movements, sleep disturbances).

4. Disability support workers, carers, families and friends may see changed behaviours occur again. They should continue taking notes and at this point recommend medical assessment as behavioural changes are recognised as a pattern.

*Even if changed behaviours are only taking place once or twice, these observations should be referred to a doctor for investigation as they might be acute provoked seizures and require short-term treatment.



Discuss

5. The person can talk about and share concerns with family and friends.
6. The person accepts that changed behaviours are of concern or impacting on life and this should be discussed with a doctor. If living in a supported accommodation facility the person should discuss changes with disability support workers and/or doctor.



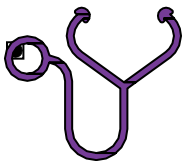
Refer

7. The doctor will review medical history and collect behavioural change information, consider the person's disability and any existing medical conditions which look like seizure signs or include similar symptoms.
8. The doctor may run some tests. Test results may come back conclusive or inconclusive.
9. The doctor may decide to wait and observe.



Assess

10. The doctor may suspect epilepsy and will refer to a specialist for accurate diagnosis (e.g. neurologist or epileptologist).
11. The specialist will review medical history and may request further tests. Discuss the type of tests to be conducted to reduce fears and concerns. Test results may come back conclusive or inconclusive.
12. The specialist may decide to wait and observe.



Diagnose

13. The specialist may make an accurate epilepsy diagnosis.

As diagnosing epilepsy can sometimes be a complex process a diagnosis may not be clear on first investigation. Further information supporting seizure activity and behavioural changes may be required before an accurate diagnosis can be made.

This is what others usually see
when a person has epilepsy

Seizures

Below are some of the other possible impacts of epilepsy that people may experience because of their seizures and which can often impact a person more than the seizure itself.

Memory

For some people with epilepsy, memory can be a significant challenge

Stigma

A person can experience stigma due to a lack of community awareness and understanding of epilepsy

Tiredness/fatigue

Due to seizure activity (including during sleep) people can be tired and find it difficult to concentrate

Medication

Side effects from medication may cause tiredness, difficulties with concentration or mood/behaviour changes

Self-esteem

The unpredictable nature of seizures can have a negative effect on a person's confidence and self-esteem

Depression and anxiety

Up to 50% of people living with epilepsy experience depression or other mental health illnesses

Disability support worker/carer observation

Person centred observation checklist for use by disability support workers or carers if you suspect that the person you support may be having seizures.



Person's name:

Date:

Is there already an epilepsy diagnosis? Yes No (please tick)

Have you observed any of the following behavioural changes?

	If Yes:			
	How long did the behaviour last?	Has the behaviour happened more than once?	Is the behaviour impacting the person's life?	Is there a potential trigger? If so, please list in further
	(please tick, if yes please provide further comments over page)			
Loss or disturbance of awareness ('absence', blackout spells), blank stare <input type="checkbox"/> Yes <input type="checkbox"/> No (please tick) hrs min	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Confusion <input type="checkbox"/> Yes <input type="checkbox"/> No (please tick) hrs min	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Falling events, with no memory of the fall by the person <input type="checkbox"/> Yes <input type="checkbox"/> No (please tick) hrs min	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Involuntary movement – twitching or abnormal sensory disturbance of a limb, limbs or face without a loss of consciousness <input type="checkbox"/> Yes <input type="checkbox"/> No (please tick) hrs min	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Automatisms – repetitive, automatic trance-like movements, e.g. fiddling with clothes or repeated swallowing <input type="checkbox"/> Yes <input type="checkbox"/> No (please tick) hrs min	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Sleep disturbances <input type="checkbox"/> Yes <input type="checkbox"/> No (please tick) hrs min	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
A reaction which would suggest the person is experiencing changes in: <input type="checkbox"/> Vision <input type="checkbox"/> Hearing <input type="checkbox"/> Smell <input type="checkbox"/> Taste <input type="checkbox"/> Touch (please tick) hrs min	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No

