Referral pathways: further investigation of possible epilepsy

UNDERSTAND ME SUPPORT ME

Assess

Refer

Diagnose

Discuss
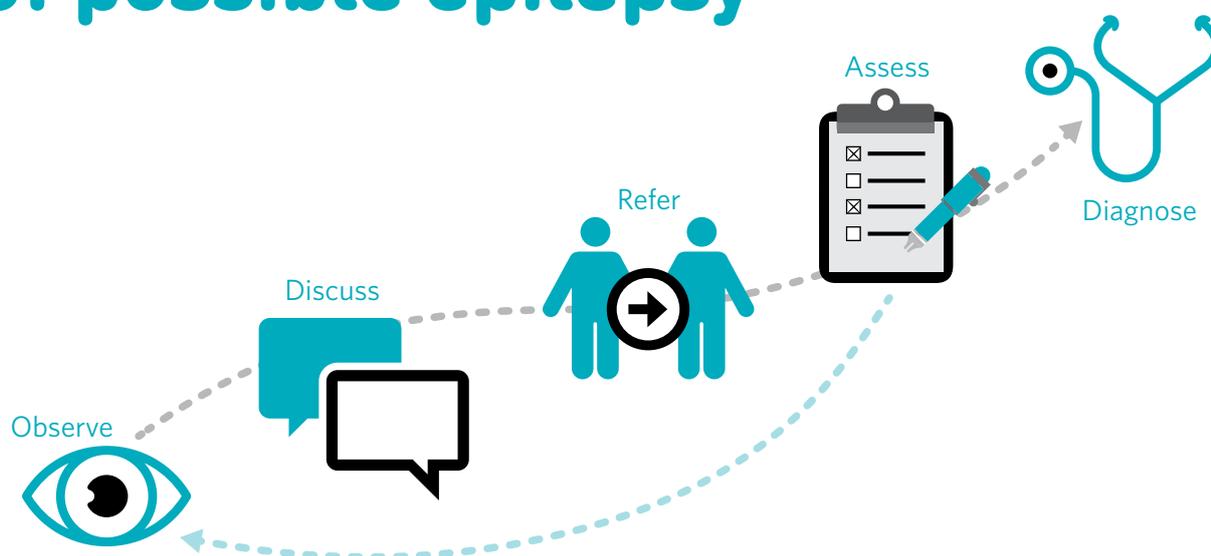
Observe

The reasons for initiating a referral for an epilepsy investigation can vary from person to person. Early engagement of a specialist epilepsy practitioner greatly improves diagnosis accuracy.

Observe

1. Aged care workers, carers, families and friends who notice changed behaviours*, should start taking notes, and discuss observations with individual (at this point the referral process could progress to 5).

2. Older person may start to recognise changed behaviours e.g. confusion.

3. Symptoms may start impacting the person's life e.g. lost time, falls, involuntary movements, sleep disturbances.

4. Aged care workers, carers, families and friends may notice recurrence of changed behaviours. 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. Older person can discuss and share concerns with family and friends.

6. Older person accepts that changed behaviours are of concern or impacting on life and should contact doctor. If living in an aged care facility the person should discuss changes with aged care workers and/or doctor.

epilepsy foundation

Refer

7. Doctor will review medical history and collect behavioural change information, consider existing medical conditions or other potential other ageing conditions which mimic seizure signs or include similar symptoms.

8. Doctor may conduct tests. Test results may come back conclusive or inconclusive.

9. Doctor may decide to wait and observe.

Assess

10. Doctor may suspect epilepsy and will refer to a specialist for accurate diagnosis e.g. neurologist or epileptologist.

11. Specialist will review medical history and may request further tests. Test results may come back conclusive or inconclusive.

12. Specialist may decide to wait and observe.

Diagnose

13. Specialist may make an accurate epilepsy diagnosis.

As diagnosing epilepsy is challenging in older people 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

Aged care worker/carer observation

Person centred observation checklist for use by aged care 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)

UNDERSTAND ME SUPPORT ME

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 comments.
	(please tick, if yes please provide further comments over page)			
Loss or disturbance of awareness ('absence', blackout spells), blank stare ☐ Yes ☐ No (please tick)	.... hrs .... min	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Confusion ☐ Yes ☐ No (please tick)	.... hrs .... min	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Falling events, with no memory of the fall by the person ☐ Yes ☐ No (please tick)	.... hrs .... min	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Involuntary movement – twitching or abnormal sensory disturbance of a limb, limbs or face without a loss of consciousness ☐ Yes ☐ No (please tick)	.... hrs .... min	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Automatisms – repetitive, automatic trance-like movements, e.g. fiddling with clothes or repeated swallowing ☐ Yes ☐ No (please tick)	.... hrs .... min	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Sleep disturbances ☐ Yes ☐ No (please tick)	.... hrs .... min	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
A reaction which would suggest the person is experiencing changes in: ☐ Vision ☐ Hearing ☐ Smell ☐ Taste ☐ Touch (please tick)	.... hrs .... min	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No

Epilepsy Information Line 1300 761 487

Further comments:

....
....
....
....
....
....
....
....
....
....
....
....
....
....
....
....
....
....

Aged care worker/carer name:

....
....

Epilepsy Information Line 1300 761 487

Referral pathways
© Epilepsy Foundation August 2017