Referral pathways: further investigation of possible epilepsy



IINDFRSTAND MF

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.

Discuss



Observe

Observe

- 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.



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

Refer

- 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.

© Copyright Epilepsy Foundation materials for use by licensed service delivery partners.



Refer

- 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



© Copyright Epilepsy Foundation materials for use by licensed service delivery partners.

Aged care worker/carer observation

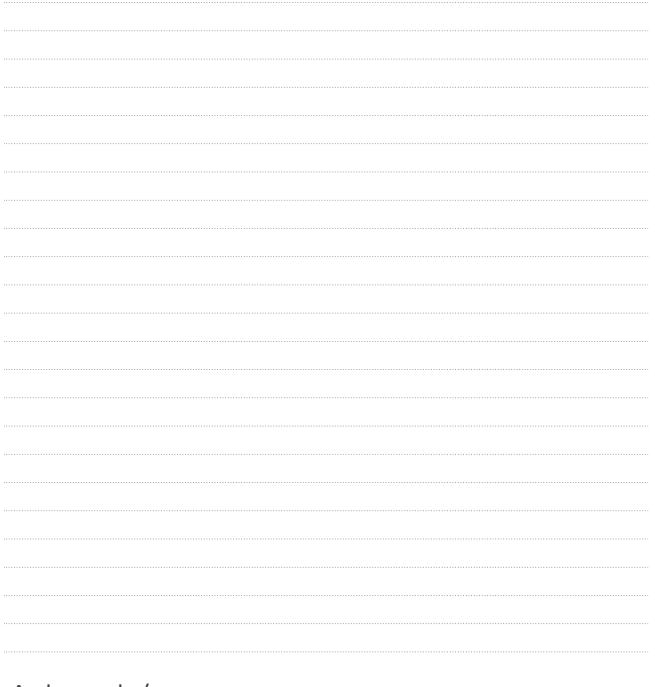
Person centred observation checklist for use by aged care workers or carers if you suspect that the person you support may be having seizures.

Person's name:				
Date:				
Is there already an epilepsy diagnosis? Yes No (please tick) 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	hrs min	Yes No	Yes No	Yes
Confusion	hrs	Yes	Yes	Yes
Yes No (please tick)	min	No	No	No
Falling events, with no memory of the fall by the person	hrs	Yes	Yes	Yes
Yes No (please tick)	min	No	No	No
Involuntary movement – twitching or abnormal sensory disturbance of a limb, limbs or face without a loss of consciousness	hrs	Yes	Yes	Yes
Yes No (please tick)	min	No	No	No
Automatisms – repetitive, automatic trance-like movements, e.g. fiddling with clothes or repeated swallowing	hrs	Yes	Yes	Yes
Yes No (please tick)	min			
Sleep disturbances Sleep disturbances Sleep disturbances Sleep disturbances	hrs	Yes No	Yes No	Yes
A reaction which would suggest the person is experiencing changes in: Vision Hearing Smell Taste Touch (please tick)	hrs min	Yes	Yes	Yes



© Copyright Epilepsy Foundation materials for use by licensed service delivery partners.

Further comments:



Aged care worker/carer name:



National Support Centre

Epilepsy House, 6 Vialou Street, Hamilton Central, Hamilton 3204 PO Box 1074, Hamilton 3240 Phone: 07 834 3556 Email: <u>national@epilepsy.org.nz</u>

This resource is part of a suite of resources targeted to aged care workers and carers of older people, to assist with caring for older people living with epilepsy. The information contained in this publication provides general information about epilepsy. It does not provide specific advice. Specific health and medical advice should always be obtained from an appropriately qualified health professional.