

How to contact the epilepsy team

The team secretary - Monday to Friday 9am - 5pm
Tel: 0115 849 3324

Epilepsy Specialist Nurse telephone advice line
Tel: 0115 970 9030 (this is **not** an emergency service)

The 24/7 answer phone message on the advice line will tell you when a nurse is next available to return your call. If no-one is available you may choose to contact your GP. In an emergency situation, please dial 999 for an ambulance.

Information about epilepsy

Epilepsy Action
Tel: 0800 800 5050
www.epilepsy.org.uk

The Epilepsy Society
Tel: 01494 601400
www.epilepsysociety.org.uk

Epilepsy Research UK
www.epilepsyresearch.org.uk

Feedback

We appreciate and encourage feedback. If you need advice or are concerned about any aspect of care or treatment please speak to a member of staff or contact the Patient Advice and Liaison Service (PALS):

Freephone: 0800 183 0204
From a mobile or abroad: 0115 924 9924 ext 65412 or 62301
E-mail: pals@nuh.nhs.uk
Letter: NUH NHS Trust, c/o PALS, Freepost NEA 14614,
Nottingham NG7 1BR
www.nuh.nhs.uk

If you require a full list of references for this leaflet please email patientinformation@nuh.nhs.uk or phone 0115 924 9924 ext. 67184.

The Trust endeavours to ensure that the information given here is accurate and impartial.

Keeping Epilepsy Records

Information for patients with learning disability

Epilepsy Service



This document can be provided in different languages and formats. For more information please contact:

Epilepsy Specialist Nurse telephone advice line
Tel: 0115 970 9030

Epilepsy & Learning Disability Nurses
Tel: 0115 854 2248

How you can help

Epilepsy is common in people with intellectual disabilities. Living with a diagnosis of epilepsy and having seizures can have a detrimental impact on a person's quality of life and that of family and carers.

People with intellectual disabilities often need the support of family or carers to ensure their health needs are recognised and appropriately met.

A seizure diary can provide valuable information about a person's epilepsy and associated health issues and help clinicians to tailor treatment to the specific needs of individual patients.

This booklet is a guide to help you complete and maintain a seizure diary. You may prefer to design your own record or use a diary provided by one of the voluntary epilepsy organisations such as those detailed on the back of this leaflet.

Epilepsy reviews

Everyone with epilepsy should have a health review at least once a year. This might be with an epilepsy specialist or GP. It is important the patient attends with someone who knows them well and is familiar with their epilepsy.

A review is an opportunity to discuss how epilepsy and its treatment are affecting health and lifestyle. It may be a time to make treatment changes or find out about new treatment options and learn more about the resources and support available to people with epilepsy.

What will I be asked to do?

Carers will be asked to keep a detailed record of the patient's seizures and bring this to health appointments. This booklet contains examples to help develop a seizure diary. Printed

Date & time	Activity at start of seizure	Describe the seizure & record duration	Describe recovery & duration	Rescue Medication	Comments	Name & Signature
03.04.11. 11.25 am	Sat at breakfast table. Suddenly stopped eating	Made a groaning sound, arms stiff, & raised above head. Face red & contorted. Legs extended. Eyes deviated upwards	Confused for 5 minutes, unable to recognise staff initially. Complained of headache after. Slept for 1 hour	No		Al Brigg A. BRIGG
07.04.11 09.45 am	Watching TV	Suddenly made a groan, arms & legs extended for about 30 secs, eyes deviated up. Arms & legs started jerking. Gradually slowed and stopped after 1 min.	Had wet herself. Confused, looked blank and pale. Unable to talk for 10 mins then slept for hour & half.	No	Had been off day centre previous 2 days with a cold. Poor appetite	Mel Foot M. FOAT
07.04.11 11.13 am	Sleeping. Was still recovering from last seizure	Sudden moaning noise, arms & legs stiff & extended for 20 secs. Face contorted, eyes open.. Started jerking, noticed jerking in facial muscles. Continued for 7 mins.	Had wet self. Slept for 4 hours. Complained of headache on wakening.	Given after 5 minutes.		Tracey Green T. GREEN
24.04.11 07.40 am	Eating breakfast	Repeated jerky movements in both arms. Was aware of them. Lasted 40 minutes	Made full recovery and went to day service	No	Had to wake Sue early for day trip	Al Brigg A. BRIGG

Name: Jan Smith		DOB: 12.04.58				NHS: 403 825 4365																		
Year 2018	Jan		Feb		Mar		Apr		May		June		Jul		Aug		Sep		Oct		Nov		Dec	
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Total	4	5	3	6	1	1	0	1	0	0	0	1	0	0	0	0	0	1	0	0	0	0	1	

Coding for different seizure types:
A= absence, T= tonic

Comments: Cluster Feb ear infection,
Epilim dose increased 24.02.12

seizure diaries are also available at Highbury Hospital, Kings Mill Hospital, the Queen's Medical Centre epilepsy clinics and from the epilepsy voluntary organisations detailed on the back page.

What are the records used for?

Different seizure types respond better to particular epilepsy treatments. Keeping detailed descriptions of seizures and how often they occur helps the epilepsy specialist to advise on the most appropriate treatment and management plan.

Detailed records can also help identify seizure patterns, triggers, and other health conditions often mistaken for epileptic seizures which can then be treated.

Diary recordings are of great value in measuring responses to recent changes in treatment. Information on how to write a detailed seizure description can be found on page 4.

Describing seizure events

The person with epilepsy is often unable to describe what happens during a seizure. An eyewitness account and video footage of seizures provides the epilepsy specialist with valuable information. Eye witnesses are usually family, carers, or friends, as they are most likely to see a seizure.

Describing seizures in detail

The list of pointers that follow are to help in the completion of detailed seizure records.

Before a seizure

- Are there signs the person is about to have a seizure e.g. complaint of feeling unwell, a change in mood or behaviour?

During the seizure

- What is the very first thing that alerts you the person is having a seizure?
- What was the person doing as the seizure started?
- Do they cry out or make a noise as the seizure starts?
- Do they fall, does this tend to be forwards or backwards, are they stiff or floppy?
- Is there a change in awareness, do they lose consciousness, and how can you tell?
- Is there a change in colour, are they flushed or pale, do they feel sweaty?
- What happens next?
- Which parts of the body move and in what order?
- Is there a change in facial expression, do the head or eyes turn to one side?
- Is there unusual eye movement, staring, dilated pupils, eye closure, or blinking, twitching?
- Are there facial movements; twitching in the cheeks, around the mouth, chewing, excessive swallowing, salivation?
- Is there a change in tone?
- Are the arms held in an odd position, do they fiddle with their hands, clothing or objects?
- Are there any twitchy or jerky movements in the limbs?
- Does their body go stiff and then jerk rhythmically or do the arms and legs flail about?
- Do the movements wax and wane?
- Do they suddenly or gradually stop?
- Does breathing alter during the seizure and what is it like towards the end of the seizure?
- Do they make any unusual sounds or say anything?
- How long does the seizure typically last?
- Do they bite their tongue, which part?

Seizure diary Sheet - example

Name: Alan Ashcroft	DOB: 24.01.61	NHS no: 427 146 8251
Date & Time	Seizure Refer to seizure description sheet for details	Comments
1st June 2010 8.30 am. Half an hour after getting out of bed	A	Lasted 5 minutes. Midazolam given and responsive after ten minutes. Slept for two hours
9th June 2010 3.45pm	C - cluster of 4 seizures	Each lasted about 30 seconds. Recovered after a further couple of minutes. Chest infection. Taking antibiotics
16th June 2010 10.05 am, 1pm, 6.15pm	Bx3	First two lasted about 45 seconds. Recovery 2 mins. Third lasted 90 secs. Recovered in couple of mins. Hadn't slept well last couple of nights
17th June 2010 11.00 am	BX1	Lasted 45 secs. 2 min recovery. Complained of headache afterwards. Given 2 paracetamol. No obvious trigger
20th June		Lamotrigine increased by 25mg

Seizure diary sheets

Record seizures on the diary sheets. The example opposite is to be used in conjunction with a completed description sheet (**page 7**). Use the name you have agreed as a team for each seizure type (e.g. Type A), or correct identification provided by the specialist. Don't forget to record how long individual seizures last and how the person recovers.

Other information to consider

The 'comments' section on the diary sheets is to record anything significant, such as missed medication doses, changes in mood or behaviour, illness, menstruation, altered drugs doses and when rescue medication is given. This provides useful information about how a patient is responding to changes in drug treatment and may help to identify other factors that impact on seizure frequency.

If the person you care for attends a day service or spends time with other service providers consider how you are going to ensure the seizure diary remains a reliable record of seizure activity and related information. Always bring the seizure diary and description sheets to health appointments.

Keeping seizure records

Further examples of seizure recording sheets can be seen on **pages 10 and 11**. It is often helpful to collate monthly record sheets on to a yearly calendar (**page 10**). Seizure frequency and seizure patterns can be more easily identified over the course of a year.

The epilepsy voluntary agencies produce helpful fact sheets and seizure diaries (**see back page**) which you may prefer to use. Additional information is also available from the epilepsy team.

- Is there incontinence?
- Is rescue medication ever needed and how do they usually respond to this?

After the seizure

- Is the person confused, agitated, aggressive, restless, tearful?
- Is speech or communication affected?
- Do they complain of headache or muscle ache, do they feel weak or tired?
- Do they sleep and for how long?
- How long is it before they start to respond and return to their usual self?
- Are they aware they have had a seizure. If so what can they tell you about it?

Additional questions to consider

- Are seizures more likely to occur at particular times or in particular situations and environments?
- Is there a reliable monitoring system in place if the person has night time seizures to ensure someone can attend and give first aid?
- Do carers know how to check the airway, monitor breathing and put someone in to the recovery position?
- Is there a history of tonic clonic seizures lasting more than 5 minutes and if so is rescue medication prescribed and readily available?
- Do all carers know how to give this?
- Is pain relief required?
- Have carers had epilepsy awareness training?
- Are there any factors likely to provoke a seizure e.g. high temperature, constipation, menstruation, recent medication changes or missed doses and can these be avoided or minimised?

- Have potential risks been assessed e.g. bathing?
- Does the person have a regular epilepsy and drug review?
- Does the person take their medication reliably or would it be better tolerated in a different formulation e.g. liquid, sprinkle, dispersible?
- Is the person experiencing treatment side effects and has this been discussed with the GP or specialist?

Completing a seizure description sheet

The following pages show examples of seizure charts. When there is more than one carer involved it is important to get together to agree what happens during a seizure. You may choose to record this information on a seizure description sheet (see examples on page 7 and 9).

If there is more than one type of seizure start with the one that is most frequent or troublesome. When trying to recall what happens imagine the person is about to have a seizure and think what usually alerts you to this.

Carers should try to describe the order of events. Think about every part of the body and the changes you notice. Remember to describe how the seizure ends and the person recovers, and how long this usually takes (see page 4 and 5).

Remember to identify each different type of seizure with either the name you normally use for it, a letter of the alphabet, or the correct name provided by the epilepsy specialist if you know it. All carers should be clear about the agreed terms.

It is important to record how long each seizure typically lasts. This will help identify when rescue medication is needed.

Seizure description sheet - example

Name: Alan Ashcroft **D.O.B:** 24.01.61 **NHS:** 427 146 8251

Type A Classification (if known): Tonic clonic seizure

Mr A suddenly goes stiff. His eyes open widely and he grimaces. He falls to the floor and his whole body jerks for about one minute.

He is then still and unresponsive for about two minutes.

He is usually able to respond fully after ten minutes.

He usually sleeps for 1 to 2 hours after these. He complains of a headache on waking.

Type B Classification (if known): Complex partial

Mr A complains of a funny feeling in his tummy. He stops what he is doing and stares vacantly. If standing, he will fall. His left arm is rather stiff. It is raised and held away from his body. He picks at his clothes with his right hand. He smacks his lips and salivates. He is unresponsive. This lasts about 45 seconds. He is confused and unable to respond for a further 3 minutes before making a full recovery.

Type C Classification (if known): Not sure. To ask Doctor

Mr A will suddenly make a groaning sound and goes very stiff. His face and neck are red. His face looks contorted and his mouth is open. His arms and legs straighten. His arms rise above his head. This lasts 30 seconds. He relaxes and is rather confused for a minute before making a full recovery. He will often have a cluster of these seizures.

Possible triggers:

Lack of sleep at night or two nights before.