

- Do not try to focus on a colour change as this cannot always be seen when watching a video
- If you are capturing a blank episode then call the child/young person and if they do not respond lightly stroke their face so that their reaction can be seen
- Videos can bring you good news that the episodes are not epileptic in nature

But my child has already has a diagnosis so why have I been asked to video?

Children's and young people's brains are constantly developing. If children/young people present with a different type of seizure then the team will want to identify if this is due to epilepsy or other reasons as detailed earlier

If the child/young person was diagnosed a long time ago then the team may need to look into the episodes to decide if they are epileptic or not in order to adjust medication if required.

Remember if something is not broken we won't try to fix it. Similarly with epilepsy if it's not epileptic then we shouldn't start a child/young person on treatment.

I have a video, so what now?

During your clinic appointment your team should have told you what to do once you have your video:

- Email it to a certain email account
- Burn the video to disc and send to your Consultant or Epilepsy Specialist Nurse
- Upload to a certain place - Patients Know Best (Peterborough)

FIRST AID

Convulsive Seizures

- Note the time and start to obtain video
- Turn onto side as soon as possible without restricting movements – but please note that this is unlikely to be possible whilst a convulsive seizure is ongoing.
- 999 if concerned about breathing
- 999 if convulsive seizure lasts 5 minutes or more
- 999 if seizures are clustering and consciousness is impaired between

Non-Convulsive Seizures

- note the time
- guide away from danger
- talk reassuringly to them
- stay with them until fully recovered

Where possible please try to capture the seizure/episode on video



Eastern Paediatric Epilepsy
Network



Why have I been asked to video?

This leaflet explains why you have been asked to video a child/young person, the importance of obtaining a video and how a video can be used to support a diagnosis

Why are videos the most helpful tool in diagnosis?

Why would I need to video a child having a seizure or strange episode?

We understand that it seems disrespectful, scary and not a natural thing to do but it is really important for the following reasons:

- Children/young people rarely have a seizure when they attend a hospital appointment so the doctors and nurses do not get to witness them
- If we asked 10 people to watch a video of a seizure or episode, each person would give a different description of what they have seen
- For every description of an epileptic seizure, there is a non-epileptic mimic. Most of these are good news so it is important for us to be able to discriminate between them.
- 20 years ago, epilepsy was often misdiagnosed. With the use of video footage, misdiagnosis is now rare.
- There is no reliable test for epilepsy between episodes; a brain wave test can't give us the answer!

Not all changes in behavior are caused by Epilepsy so we want to get the diagnosis right

Both the doctors and nurses that you meet in the Children's and Young Person's epilepsy clinic have completed Paediatric Epilepsy Training. During this training they have learnt how to interpret videos

The team can tell if a child/young person is having a seizure

The team can identify the type of seizure

The team can try and identify the type of epilepsy the child/young person has

We think it is possible to get video footage if seizures last for more than 20 seconds, or occur frequently, or at predictable times.

Seizures that are both very brief and very infrequent are rarely epileptic

We really value video footage from **schools and nurseries** if the episodes are only occurring there. We know that most educational environments have policies in place which prevent the teachers from videoing their pupils, but we have found that 'Chair's action' by the Chair of the Governors, on a named pupil basis, for the purpose of diagnosis, is usually adequate permission.

But how can I video during a seizure or strange episode?

We understand that your priority is the safety of your child. However, it is very rare for a seizure to be dangerous within the first five minutes, and 98% of seizures finish within 5 minutes. There is very little that anyone needs to actively do within that time apart from get video!

What do you need me to video?

We do not expect you to follow the child/young person with a camera ready in case they have a seizure but the following tips may be helpful

- If the seizures or episodes happen at a certain time of day then ensure you have a video capturing device such a camera, smart phone, tablet etc. available and fully charged with memory available
- Once you know your child is safe then start to record the seizure/episode - it is great if you can catch the very start of the seizure, but any video is better than no video
- Try to video the parts of the body involved and talk through what you are seeing working from head to toe, are they floppy or stiff?