Reducing or stopping antiepileptic medications for video telemetry

Consent to investigation

Information for patients
Sheffield Teaching Hospitals

What is video telemetry?

Your neurologist has requested that you have an inpatient EEG video telemetry recording. You may have already had a standard EEG (electroencephalogram or brain wave recording) or a previous EEG video telemetry.

Video telemetry involves a prolonged, usually 3-5 day, EEG with simultaneous video recording.

Why have I been given this leaflet?

Your neurologist has advised reducing or stopping your antiepileptic medication for video telemetry.

This leaflet provides more details about why this is necessary and the risks and benefits involved.

Why do I need to reduce or stop my antiepileptic medication?

In order to gather the information that is needed from this investigation, it is important to record seizures.

The reduction of antiepileptic medications increases the chance of recording a seizure. By recording these episodes it gives us the best chance to make an accurate diagnosis of your seizure disorder or to find out which area of the brain seizures are coming from.

What changes will be made to my medication?

One or more of your medications may be stopped or the dose reduced. How your medications are reduced or stopped is decided by your neurology doctor. The doctor will take into account how severe your seizures are and how often they occur, as well as any injuries or other complications of seizures you have had in the past.

Usually these changes will be made by the medical staff after your admission to hospital. Rarely, your neurologist may ask you to reduce your medications before you come in to hospital, but **you should not do this unless you have been given instructions to do so**.

What are the risks of reducing or stopping antiepileptic medication?

It is important to be aware of the potential risks of reducing your medication before giving your consent to video telemetry.

Serious or frequently occurring risks include:

- **Increase in the number of seizures you have**
  We are trying to make seizures more likely but sometimes reducing or stopping medications can cause frequent seizures or clusters of seizures which could need additional rescue medications to be given to stop the seizures.
- **Longer or more serious seizures**
  As well as increasing the number of seizures you have, reduced medication can cause seizure activity to spread further in the brain. If the activity spreads to both sides of the brain then it causes a bilateral tonic-clonic seizure (sometimes called a 'convulsion' or 'grand mal seizure').There is also a risk of the seizures lasting longer and rarely of seizures that do not stop without emergency treatment (this is called status epilepticus).The risk of this happening is about 15 in every 1,000 patients admitted to a video telemetry unit.

Having epileptic seizures particularly bilateral tonic-clonic seizures have some associated risks which are increased if medications are reduced/stopped because seizures are more likely to happen. The most important risks are:

- **A change in behaviour after the seizure** which may include hallucinations and delusions which feel real but are not, this is called a psychosis. The risk of this happening is 18 in every 1,000 patients.
- **Injuries (such as bone fracture)** may occur because of the seizure or a fall, this risk is about 5 in 1,000 patients.
- **SUDEP (sudden unexpected death in epilepsy)** is estimated to occur in 1 in every 10,000 patients having video-telemetry.

In order to reduce the risk of the serious consequences which could occur in the video-telemetry unit, you will have 24-hour supervision during the admission. Any increase in the number or severity of seizures will be managed by the medical staff on the ward.

Consent

As with any procedure or treatment, we must ask for your consent beforehand. Staff will explain all the risks, benefits and alternatives before they ask for your consent. If you are unsure about any aspect of the procedure or treatment proposed, please do not hesitate to ask for more information.

Who should I contact if I have any questions or concerns?

If you have any questions after reading this leaflet please speak to your Consultant or call the Clinical Neurophysiology Department:

- **0114 271 3237** (Monday - Friday, 8.30am - 4.30pm)

Consent Form 1

Patient agreement to: Reducing or stopping antiepileptic medications for video telemetry

Name:
DoB:
(Affix Patient Label here)
Hosp. no.
NHS no.

Responsible healthcare professional:

Name: ……

……

Job title: ……

Contact details: ……

Does this patient have any special requirements? (e.g. other language / other communication method)

Yes ☐ No ☐

If Yes, details to be provided here: ……...

Does this patient have an advanced decision to refuse treatment? (e.g. Jehovah's Witness form)

Yes ☐ No ☐

If Yes, has the advanced decision been included within the consent discussions? Yes ☐ No ☐

Statement of healthcare professional (to be filled in by healthcare professional with appropriate knowledge of proposed procedure, as specified in consent policy)

In particular, I have explained to the patient the;

1. Name of the proposed treatment or procedure (or course of treatment or procedures - include brief explanation if medical term is not clear):

Your neurologist has advised reducing or stopping your antiepileptic medication for video telemetry.

2. The intended benefits, for this patient, being to:

The reduction of antiepileptic medications increases the chance of recording a seizure. By recording these episodes it gives us the best chance to make an accurate diagnosis of your seizure disorder or to find out which area of the brain seizures are coming from.

3. I have also discussed:

- ☐ what the procedure is likely to involve
- ☐ the benefits and risks of any available alternative treatments
- ☐ the benefits and risks of no treatment

Name:

DoB:

(Affix Patient Label here)

Hosp. no.

NHS no.

In particular, I have explained to and discussed with the patient the;

4. Recognised risks and/or complications for this particular procedure or treatment:

4.1 What are the known risks for this treatment or procedure? In particular the recognised significant, serious, frequently occurring or other risks this patient should be made aware of:

Serious or frequently occurring risks include:

- **Increase in the number of seizures you have**
  We are trying to make seizures more likely but sometimes reducing or stopping medications can cause frequent seizures or clusters of seizures which could need additional rescue medications to be given to stop the seizures.
- **Longer or more serious seizures**
  As well as increasing the number of seizures you have, reduced medication can cause seizure activity to spread further in the brain. If the activity spreads to both sides of the brain then it causes a bilateral tonic-clonic seizure (sometimes called a 'convulsion' or 'grand mal seizure').There is also a risk of the seizures lasting longer and rarely of seizures that do not stop without emergency treatment (this is called status epilepticus).The risk of this happening is about 15 in every 1,000 patients admitted to a video telemetry unit.

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- **A change in behaviour after the seizure** which may include hallucinations and delusions which feel real but are not, this is called a psychosis. The risk of this happening is 18 in every 1,000 patients.
- **Injuries (such as bone fracture)** may occur because of the seizure or a fall, this risk is about 5 in 1,000 patients.
- **SUDEP (sudden unexpected death in epilepsy)** is estimated to occur in 1 in every 10,000 patients having video-telemetry.

In order to reduce the risk of the serious consequences which could occur in the video-telemetry unit, you will have 24-hour supervision during the admission. Any increase in the number or severity of seizures will be managed by the medical staff on the ward.

4.2 Do any of the risks discussed carry a greater significance for this patient? For example, existing co-morbidities, patient's concern, patient's work, hobbies, driving or other.

Yes ☐ No ☐

If Yes, details to be provided here;

……

……

……

Name:

DoB:

(Affix Patient Label here)

Hosp. no.

NHS no.

5. Are there any extra procedures which may become necessary during the treatment or procedure?

□ blood transfusion
□ other procedure/s (please specify)

……

6. The following leaflet(s) has been provided: PIL4470, Issue Date: November 2019 / PIL……..…, Issue Date:…… / PIL……..…, Issue Date:……

Accompanying leaflet accepted by patient: Yes ☐ No ☐

I have fully informed this patient about this procedure or treatment to the best of my ability and in a way in which I believe they can understand.

Patient refused information ☐

(NB: If this patient has refused information ensure this is documented in the patients' medical records. Notify the GP of this and send the patient information leaflet to the GP with the letter in case the GP gets the opportunity to discuss this with the patient at a later date.)

Signed (Healthcare professional) …… **Date** ……..……

Name (PRINT) …….. **Job title** …….

GMC/NMC Number ……

Statement of interpreter

Does this patient require an Interpreter? Yes ☐ No ☐

I have interpreted the information above to the patient to the best of my ability and in a way in which I believe they can understand.

Signed (Interpreter) …… **Date** ……..

Name (PRINT) ……..

Name:

DoB:

(Affix Patient Label here)

Hosp. no.

NHS no.

Statement of patient (to be signed, printed and dated by the patient)

Please read this form and the accompanying leaflet carefully. The leaflet describes the benefits and risks of the proposed treatment or procedure and possible alternatives. If your treatment or procedure has been planned in advance, you should already have your own copy of the leaflet. If not, you will be offered a copy now. If you have any further questions, do ask – we are here to help you. You have the right to change your mind at any time, including after you have signed this form.

I agree to the procedure or course of treatment described on this form.

I understand that you cannot give me a guarantee that a particular person will perform the procedure. The person will, however, have appropriate experience.

I understand that any procedure in addition to those described on this form will only be carried out if it is necessary to save my life or to prevent serious harm to my health.

I have been told about additional procedures which may become necessary during my treatment. I have listed below any procedures **which I do not wish to be carried out** without further discussion.

……

Signed (Patient) ……. **Date** ……..……

A witness should provide their signature if the patient is unable to sign but has indicated his or her consent.

Name (PRINT) ……..

Name:

DoB:

(Affix Patient Label here)

Hosp. no.

NHS no.

Confirmation of consent (to be completed by a health professional when the patient is admitted for the procedure, if the patient has signed the form in advance)

On behalf of the team treating the patient, I have confirmed with the patient that they have no further questions or concerns and consent for the procedure to go ahead.

Signed (Healthcare professional) ……. **Date** ……..

Name (PRINT) …….. **Job title** …….

GMC/NMC Number ……

Withdrawing of consent to proceed with treatment or procedure (to be completed at any stage the patient withdraws consent to proceed with the treatment or procedure).

I, the patient, confirm that I have withdrawn consent and do not want to proceed with the treatment or procedure.

Signed (Patient) ……. **Date** ……..……

A witness should provide their signature if the patient is unable to sign but has indicated his or her withdrawal of consent.

Name (PRINT) ……. ……..

On behalf of the team treating the patient, I have confirmed with the patient that they have withdrawn consent and do not want to proceed with the treatment or procedure.

Signed (Healthcare professional) ……. **Date** ……..

Name (PRINT) …….. **Job title** …….

GMC/NMC Number ……

Consent to treatment or procedure - Guidance to health professionals (to be read in conjunction with *Sheffield Teaching Hospital's Consent to Examination or Treatment* policy, 2017)

What a consent form is for

This form documents the patient's agreement to go ahead with the treatment or procedure you have proposed. It is not a legal waiver – if patients, for example, do not receive enough information on which to base their decision, then the consent may not be valid, even though the form has been signed. Patients are also entitled to change their mind after signing the form, if they retain capacity to do so. The form should act as an aide-memoire to health professionals and patients, by providing a check-list of the kind of information patients should be offered, and by enabling the patient to have a written record of the main points discussed. In no way, however, should the written information provided for the patient be regarded as a substitute for face-to-face discussions with the patient.

The law on consent

See the Department of Health's, *Reference guide to consent for examination or treatment*, for a comprehensive summary of the law on consent. Also available at https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/138296/dh_103653__1_.pdf

Who can give consent

Everyone aged 16 or more is presumed to be competent to give consent for themselves, unless the opposite is demonstrated, and therefore may sign this form **(Consent form 1)**. If a child under the age of 16 has "sufficient understanding and intelligence to enable them to understand fully what is proposed", then they will be competent to give consent for themselves. Young people aged 16 and 17, and legally 'competent' younger children, may therefore sign this form for themselves, but may like a parent to countersign as well. If the child is not able to give consent for themselves, someone with parental responsibility may do so on their behalf and a **separate form (Consent form 2)** is available for this purpose. Even where a child is able to give consent for themselves, you should always involve those with parental responsibility in the child's care, unless the child specifically asks you not to do so. If a patient is mentally competent to give consent but is physically unable to sign a form, you should complete this form as usual, and ask an independent witness to confirm that the patient has given consent orally or non-verbally.

Where an adult patient (18 or over) lacks capacity to give or withhold consent to treatment then **Consent form 4** should be completed.

When NOT to use this form

If the patient is 18 or over and is not legally competent to give consent, you should use **Consent form 4** (form for adults who are unable to consent to investigation or treatment) instead of this form. A patient will not be legally competent to give consent if:

- they are unable to comprehend and retain information material to the decision; and/or
- they are unable to weigh and use this information in coming to a decision.

You should always take all reasonable steps (for example involving more specialist colleagues) to support a patient in making their own decision, before concluding that they are unable to do so. Relatives cannot be asked to sign this form on behalf of an adult who is not legally competent to consent for himself or herself.

Information

Information about what the procedure or treatment will involve, its benefits and risks (including side-effects and complications) and the alternatives to the particular procedure or treatment proposed, is crucial for patients when making up their minds. The courts have stated that patients should be told about 'significant risks which would affect the judgement of a reasonable patient'. 'Significant' has not been legally defined, but the GMC requires doctors to tell patients about 'serious or frequently occurring' risks. In addition if patients make clear they have particular concerns about certain kinds of risk, you should make sure they are informed about these risks, even if they are very small or rare. You should always answer questions honestly.

Sometimes, patients may make it clear that they do not want to have any information about the options, but want you to decide on their behalf. In such circumstances, you should do your best to ensure that the patient receives at least very basic information about what is proposed. Where information is refused, you should document this on the form or in the patient's notes.