

# Long-term EEG monitoring (telemetry): information for families

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**Telemetry is a test that looks at the function of the brain. The brain works by a series of nerve impulses, which cause electrical signals. These signals (also called brainwaves) can be recorded through the scalp. This information sheet from Great Ormond Street Hospital (GOSH) explains the procedure for a telemetry test and what to expect when your child has one.**

Telemetry is similar to an electroencephalogram (EEG) test, but it records over a much longer period of time, sometimes taking up to five days to get the information needed. A digital video recording will also be made during the test. More information about how we use video recordings is available in the accompanying information sheet.

## How is telemetry used?

Telemetry can be carried out on patients of all ages and abilities, making it a good way to get an overall view of the function of the brain. It is helpful as part of general investigations and more specific problems, such as blackouts and seizures.

Recording for a longer period of time will allow us to capture your child's brainwaves in different states such as wakefulness, drowsiness and sleep. Most importantly, we will hopefully capture some events and provide more information about these to your doctor. Telemetry can also be used to obtain a complete night's sleep recording, to record seizures or tell the difference between seizures and other types of events. It can also be used to pinpoint if one or more particular areas of the brain are causing the seizures.

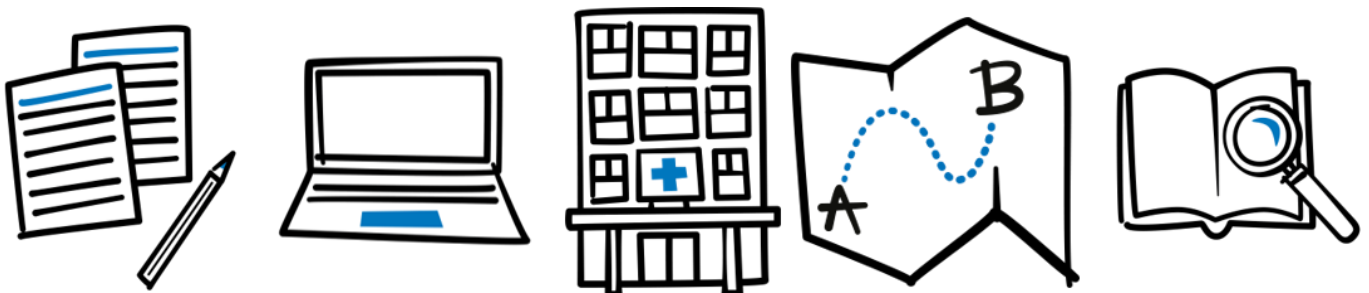
## When you receive your appointment letter

If you are unable to keep this appointment, please inform the ward as soon as possible beforehand. Sometimes, we can offer the appointment to another child on the waiting list.

As so many children and young people need to use our services, we have had to introduce a policy where if a child cancels or does not attend two appointments in a row, we will inform their GOSH consultant and close their referral.

The person bringing your child to the Telemetry Unit should have 'Parental Responsibility' for them. Parental Responsibility refers to the individual who has legal rights, responsibilities, duties, power and authority to make decisions for a child. If the person bringing your child does not have Parental Responsibility, we may have to cancel the test.

Your child will need an adult present for the duration of this admission to hospital. Nursing staff are available to look after your child when you need a break. If you are unable to stay with your



child, please telephone the epilepsy service coordinator.

## Getting ready for the test

It is helpful if you make sure that your child's hair is clean before the test, with no mousse, gel, oil or hairspray. If your child is taking medicines, you should continue to give them as normal.

Your child will be able to change clothes during the test, however, it will be easier if you bring in a zip or button front top for your child to wear.

## The day of the test

Your child will be admitted to Koala Ward to have telemetry which is on Level 5, Morgan Stanley Clinical Building.

Once you are in Koala Ward, check in with reception and you will be taken to your room. These rooms are larger than usual hospital rooms, so your child will be able to move about during the test. The Play Specialist will be able to provide things for your child to do during the day, but you can also bring in any favourite games, toys or DVDs.

One of the doctors on the ward and the Clinical Physiologist (CP) will explain the test in more detail, discuss any worries you may have and ask you to give permission for both the telemetry and video recording by signing a consent form. For this test, both are needed to analyse the results. They may also discuss reducing or stopping the medication your child is taking.

They will also ask your permission activation procedures (flashing lights and over-breathing). If you want a copy of any of these forms, please ask us.

## Students and trainees

As we are a teaching hospital, on occasion you might be asked if you would agree to a trainee to perform the test under direct or indirect supervision. Sometimes other healthcare

professionals or students might ask to observe the test as well. Refusing this will not affect your child's treatment.

## What does the test involve?

The CP will attach a number of small silver discs (electrodes) to certain points on your child's head using a soft paste. They will measure the head beforehand and mark the points with a soft pencil before attaching the electrodes. Extra electrodes will also be applied on the shoulders to record your child's heart rate and muscle activity. Sometimes, additional electrodes may be applied to other areas in order to get more information.

As each electrode is attached, the CP will clean the area of the scalp with a cotton bud and some cream. This does not hurt but some children do not like it. This should take around 30 to 45 minutes. In some cases (such as very active children or those who might try and remove the electrodes), the CP might need to use a special glue to attach the electrodes – this will not hurt, but it does have a strong smell.

After all the electrodes are applied, the CP will bandage your child's head and use a net to cover the head and the electrodes.

The electrodes are attached by wires to a 'headbox' and then to the recording machine. The 'headbox' will be placed into a bag which your child will need to keep close to them. While all the electrodes are being applied, your child can sit on a chair, the bed or your lap, and can play with toys – we have many toys on the ward but feel free to bring your child's own favourite book, toy or comforter. We can also ask a Play Specialist to help during electrode application.

The CP will record your child's brainwaves on the computer and monitor them on a screen – they look like wiggly lines. Your child will not feel anything while the telemetry is being recorded. At the same time, a digital video recording of your child will be made – this is helpful for the doctor to observe any symptoms, changes in behaviour or



movements that could be associated with seizure activity on the recording. Your child can move around the room as long as they stay in range of the camera. Parents are often best placed to identify a typical event or seizure should they occur.

Your child will be able to eat and drink as normal during the test. We will provide food and drink for your child but parents need to bring in food or buy it from one of the eating places in the hospital. There is a kitchen with a kettle and microwave you can use to make drinks and heat up food. No showers or baths are allowed for your child, while the electrodes are in place.

At some point during the admission, the CP may ask your child to do some tasks (if they are old enough), such as close their eyes for short periods of time, take deep breaths by blowing on a windmill (over-breathing) or look at flashing lights (intermittent photic stimulation). Your child will be continuously monitored throughout the exercises and the tasks can be stopped if necessary.

### **How long does the telemetry last?**

Depending on the information needed and based on the first few hours of recording, the test may continue for five days. In some cases, an overnight stay is long enough to get the results needed.

The doctors may need to ask you to sleep deprive your child or reduce/stop their anti-epilepsy medicines for the test, but this will be discussed with you in more detail before the test starts and also during the admission.

### **Are there any risks?**

If the doctors decide to reduce or stop your child's anti-epilepsy medicines for the test, this can cause your child to have a longer or more intense seizure than usual. However, the doctors and nurses will monitor your child closely to stop this happening.

If your child's medication is continued as usual, there are not additional risk for increased seizures. The test is painless and there are no after effects.

### **What happens if my child has a seizure during the test?**

If your child has a seizure during the test, their safety will be our first priority and we will take care of them – there are doctors on the ward and there is always a nurse outside the room looking after your child. In addition, there will be an emergency alarm you can use to alert staff – this will be shown to you upon admission.

In addition, if a seizure occurs we will ask you to push an 'Event Button' which marks the recording, and also to describe out loud to the camera what is happening. This will allow us to pinpoint where the event happened and to have a good description from you in case the video is not ideal.

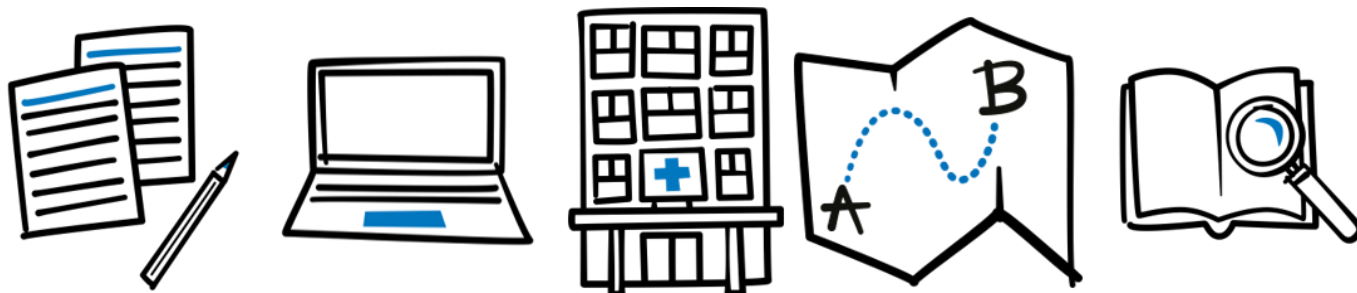
### **After the test**

The CP or nurse will remove the electrodes from your child's head. This will not hurt as the paste stays soft and is easy to remove. They will also clean your child's hair but it may feel a bit sticky to the touch until you wash it. If glue is used, this will be removed with a special solution, again with a strong smell.

If your child's anti-epilepsy medicines have been reduced or stopped for the test, they will be started again at the normal dose 24 hours before discharge. You will be able to take your child home once they have had two doses of anti-epilepsy medicines and the frequency of their seizures is back to normal.

### **Getting the results**

We may be able to let you know some brief information about what the telemetry is showing during the test. The team will analyse the results and write a detailed report of the test results. We



will send this to your child's consultant in time for their next appointment.

## Further information and support

If you require more information about the test or have any questions, please contact the Epilepsy Service Coordinator on 020 7405 9200 (extension 5789), Monday to Friday between 9am and 5pm.

Out of hours, you can ring Koala Ward on 020 7829 8827.






**CBeebies** "Get Well Soon Hospital" series has an episode about having an EEG – Series 2, Episode 5 at [www.bbc.co.uk/iplayer/episode/b09204fx/get-well-soon-hospital-series-2-5-eeeg](http://www.bbc.co.uk/iplayer/episode/b09204fx/get-well-soon-hospital-series-2-5-eeeg)

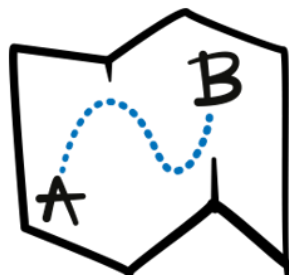
## How to find us

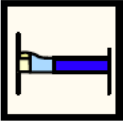





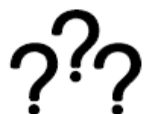
Koala Ward is located on Level 5 Morgan Stanley Clinical Building. Come in through the Main Entrance and walk through Main Reception. At the glass doors, turn right and you will find the lifts. Take the lift to Level 5 and follow the signs to Koala Ward.

For more information about Traveling to GOSH, please visit our website on [www.gosh.nhs.uk/your-hospital-visit/travelling-gosh](http://www.gosh.nhs.uk/your-hospital-visit/travelling-gosh)

## Having telemetry

	You are coming to hospital for telemetry. This is the same as an EEG but you will stay in hospital for a few days. An EEG records your brain waves.
	We will measure your head and will clean small areas with a cotton bud. This will not hurt.
	We will put some silver discs with stickers and paste where we have cleaned on your head. This will not hurt.
	We will join the stickers to the EEG machine with wires. This will not hurt.
	We will also make a video of you. This will show us if you move around in the room or bed.



	You will need to stay in your room while you are having the test. There is a toilet in the room you can use.
	You will have all your meals in the room too. You can choose what to eat from the menu.
	When it is bedtime you will go to sleep as usual. You will still be having the EEG test.
	The Play Worker will bring you lots of things to do. You can bring your favourites from home too.
	The doctor will say when the test stops. We will take off the stickers and wipe your head again.
	You may have to stay for a few more hours to make sure you are getting better.
	Please ask us if you have any questions.

