

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

Telemetry is a test that looks at the function of the brain. The brain works by a series of 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.

In most cases, we prefer the person bringing your child to their appointment to 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. This is because the person may need to give consent for your child to have the test. If you are unable to attend with your child but we still need you to give consent, we might need to contact you by phone during the test.

Telemetry is like an electroencephalogram (EEG) test, but it records for much longer. It can take up to five days.

Your child will need an adult present while they are in 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 call the epilepsy service coordinator to discuss this.

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 seizures and blackouts.

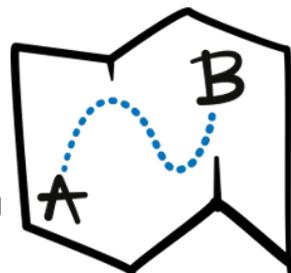
Recording for a longer period of time will allow us to capture your child's brainwaves in different

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 see 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.

Please note that there is great demand for our services. Due to this demand we have a policy



where if a child cancels or does not attend **two** appointments in a row, we will inform their referring consultant and close the referral.

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, but it will be easier if you bring in a zip or button front top for them to wear.

The day of the test

Your child will be come to Koala Ward to have telemetry. This is on Level 5 of the 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 normal 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. You can also bring in any favourite games, toys, DVDs, or a tablet.

One of the doctors on the ward and the clinical physiologist will explain the test in more detail and discuss any worries you may have. They will ask you to give permission for both the telemetry and video recording by signing a consent form. You need to give permission for both of these for the test to go ahead. They may also discuss reducing or stopping any anti-seizure medicine your child is taking.

They might also ask you to give permission for any extra procedures that the doctor has asked for. This could include looking at flashing lights or hyperventilating ('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 supervision. Sometimes other healthcare professionals or students might ask to observe the test as well. Saying no to this will not affect your child's treatment.

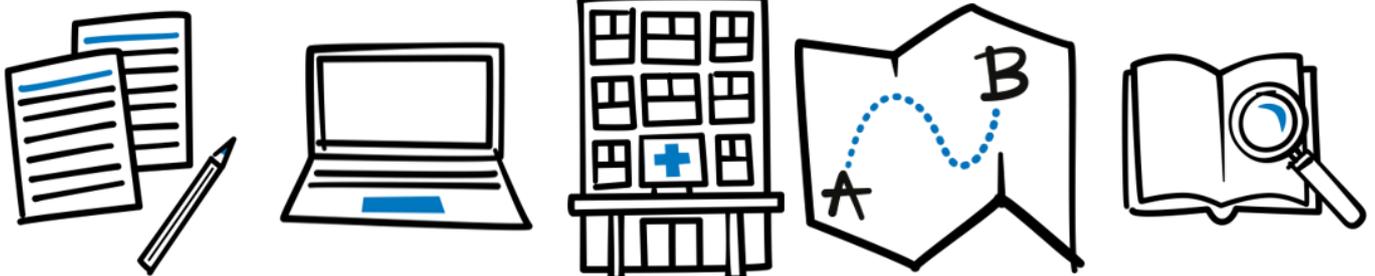
What does the test involve?

The physiologist will attach a number of small silver discs (electrodes) to certain points on your child's head using a soft paste. They will measure their head 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 physiologist 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 with very energetic children or those who might try and remove the electrodes), the physiologist 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 physiologist 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 lots of 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 distract them during this part of the test. The physiologist will record your child's brainwaves on a computer – they look like wiggly lines. Your child will not feel anything while the telemetry is being recorded. At the same time, a video recording of



your child will be made – this is helpful for the doctor to see any changes in behaviour or movements that could be linked to 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 the best people to say what is a ‘normal’ event for their child and what is not.

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 cafes in the hospital. There is a kitchen with a kettle and microwave you can use to make drinks and heat up food. Your child will not be able to bathe or shower while the electrodes are in place. It is not waterproof.

At some point during your stay, the physiologist 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 (hyperventilation or ‘over-breathing’) or look at flashing lights (‘intermittent photic stimulation’). Your child will be continuously monitored throughout these tasks, and they will be stopped if necessary.

How long does the telemetry last?

Depending on the information needed, the test may continue for up to five days. In some cases, an overnight stay is long enough to get the results needed.

The doctors may need to ask you stop your child from sleeping or reduce or stop their anti-seizure medicines for the test. This will be discussed with you in more detail before the test starts.

Are there any risks?

If the doctors decide to reduce or stop your child’s anti-seizure 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. Your child’s safety is our first priority.

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

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. There will be an emergency alarm you can use to alert staff. You will be shown this when you arrive.

If a seizure occurs, we will ask you to push an ‘event button’ which marks the time on the recording. We will also ask you to describe out loud to the camera what is happening. This will allow us to know when the event happened and to have a good description from you in case your child is out of view of the camera.

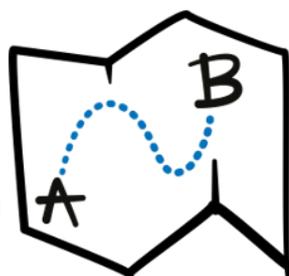
After the test

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

Getting the results

We might be able to let you know a little bit about what the telemetry is showing during the test. The team will look at the results and write a detailed



report. This will be sent 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 Department of Clinical Neurophysiology on 020 7813 8471, Monday to Friday between 9am and 5pm.

How to find us

Come in through the main entrance and walk through the main reception. At the glass doors, turn right and walk through the corridor until you find the second set of lifts. Go up to Level 5 and follow the signs to Koala Ward.

For more information about travelling to GOSH, please visit our website on www.gosh.nhs.uk/your-hospital-visit/travelling-gosh

Your feedback

We take all feedback very seriously and want to hear about your experiences. Your feedback helps us to understand what we are doing well but importantly how we can improve. We will give you a feedback card during your stay on the ward but if you haven't received one, please ask a member of staff. You can also provide feedback using this QR code or via our website:



<https://www.gosh.nhs.uk/your-opinion-matters/>

Any concerns?

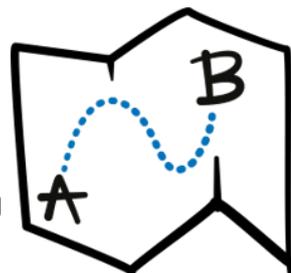
We know we do not always get things right. Please do raise any queries or issues with the

ward/ clinic staff in the first instance. We want to help and often we are able to resolve things quickly.

Another way of raising a concern is to contact our **Patient Advice and Liaison Service 'Pals'** – they are based in the main reception area and open from Monday to Friday from 10am to 5pm. You can also call them on 020 7829 7862 or email pals@gosh.nhs.uk. The Pals team can offer independent advice and support, working with you to sort out a problem along with members of staff.

The **Complaints** team are also available if you want to make a complaint – you can call them on 020 7813 8402 or email complaints@gosh.nhs.uk

Having telemetry





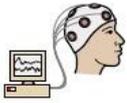
You are coming to hospital for telemetry. This is the same as an EEG, but you will stay in hospital for a few days. An EEG records your brain waves.



We will measure your head and will clean small areas with a cotton bud. This will not hurt.



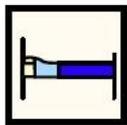
We will put some silver discs with stickers and paste where we have cleaned on your head. This will not hurt.



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.

