



Intravenous infusion of dihydroergotamine for headaches and migraines

This information from Great Ormond Street Hospital (GOSH) explains about your admission for a course of infusions of a medicine called dihydroergotamine (or DHE for short) given into a vein. You might have already tried various other medicines to improve your headaches and migraines. This is the next step in treatment. As well as explaining what will happen during the admission, this information sheet tells you about the medicine itself and any side effects that may happen.

What is dihydroergotamine (DHE)?

DHE is a medicine that attaches itself to the pain receptors in your brain and nerves, altering how messages pass backwards and forwards. This alters the pain signal perception in the brain. DHE does not 'cure' your headache but it should improve how often you get them and how bad they feel. This should improve your quality of life and make it easier to go to school and do your everyday activities.

How is it given?

DHE works best when it is delivered (infused) into your bloodstream through a vein. To make this easier, you will usually have a Peripherally Inserted Central Catheter (PICC) placed in to a vein in your arm before the infusions can begin. This will involve a short procedure in our Interventional Radiology department.

We expect you to have three DHE infusions each day of your stay, except for the first day, when there may only be time for two infusions. The plan will be to gradually increase the dose of medicine until you are at the best level – one that is strong enough to work but not so strong that it causes side effects. You will usually stay in hospital for five days – usually from Monday to Friday.

Before you come into hospital

Please download a copy of our headache diary from our website at www.gosh.nhs.uk/headache_clinic and fill it in for the two weeks before your admission. We will ask you to carry on filling in the diary during your admission as well. It is really important to do this as this will help us work out if DHE is helpful in improving your headaches and migraines.

Pack enough clothes for your stay – you will need day and night clothes as between infusions you will be free to go out and about within the hospital and the local area. It is also possible to attend the Hospital School – please contact the school directly on 020 7813 8269 to organise this. You can also bring your tablet or laptop computer, portable DVD player, or anything else to occupy you during the stay. We have free WiFi on the wards – the ward administrator or housekeeper will give you further information about signing up for a password. All your meals will be provided but you can also bring along any treats and snacks you like. One parent can stay with you if you want and other friends and family can visit the ward before 8pm.

When you arrive on the ward

Your admission letter will tell you what time to arrive on the ward, this will be a few hours before the PICC insertion so we can do some checks and measurements, and make sure you understand what will happen during the infusions.

If you are a girl, we will ask you about your periods and any chance that you could be pregnant. We will ask you to give us a urine sample so that we can do a pregnancy test. Some procedures – including PICC insertion – carry a risk to unborn babies because they involve x-rays. Some medicines can have unwanted effects on unborn babies too. We are legally required to ask you and carry out a pregnancy test if needed.

You will meet the Interventional Radiology doctor before the procedure. They will explain the procedure again, answer any questions you may have and ask you (and/or your parents) to confirm the details of the consent form that you (and/or your parents) signed giving permission for the PICC procedure to go ahead.

Getting ready for the infusions - having a PICC inserted

You will not need a general anaesthetic and so you will stay awake. More information about the PICC is available on our website at www.gosh.nhs.uk/teenagers/your-condition/tests-and-treatments/picc

As you will be having the PICC inserted under local anaesthetic, you will usually not need to 'fast' or stop eating and drinking before the procedure. However, it may be better to avoid a heavy breakfast on the day so you don't feel sick when you're lying down. Please let us know if not eating much might make your headaches worse.

You will have a local anaesthetic (numbing) injection into your arm, so that you do not feel the PICC being inserted. The injection will sting a bit but will soon become numb. The nurse will put some numbing cream on both your arms so you won't feel the local anaesthetic injection so much. We will take you to the Interventional Radiology Suite and make sure that you are as comfortable

as possible. As you will be awake during the procedure, you can choose some music to listen to or a film to watch or just chat to the Interventional Radiology team.

When they have inserted the PICC, you will come back to the ward. Your arm may feel a little bit sore when the local anaesthetic wears off, but we can give you some pain relief medicines to help with this. The next task will be to set up an electrocardiogram (ECG). This involves having some sticky patches on your chest, which are connected to the ECG machine. This shows us a picture of how your heart usually beats.

Day 1

The first infusion will usually start soon after the ECG has been completed and reviewed by your doctor. About 30 minutes before the first medicine infusion, your nurse will give you a dose of anti-sickness medicine, usually in the form of a liquid or tablets. We know that DHE can make people feel a bit sick and so the anti-sickness medicine can often help. Your nurse will first connect your PICC to a fluid infusion to keep you hydrated during the medicine infusion. Finally, your nurse will connect the infusion bag to your PICC as well.

The infusion is controlled by a pump, so that the medicine drips into your veins at a set rate. Your nurse will see how you are feeling by checking your temperature, pulse, breathing and blood pressure at various points during the infusion, which will last for about an hour. You can keep yourself busy during the infusion by reading, watching films or playing computer games. When the infusion has finished, the nurse will disconnect the infusion bag and pump from your PICC. The nurse will make sure you understand what to do if your PICC is damaged or breaks – after this, you will be free to leave the ward, until the next infusion is due in around eight hours or so.

The next two infusions will follow a similar pattern, but the amount of medicine in the medicine infusion will be increased. You may find that as the dosage increases, you start to feel some side effects. If you carry on feeling sick, we can give you some more anti-sickness medicine and there are other ways we can help you to deal with the side effects too. If you find them difficult





to manage, then tell your nurse, as they can slow down the infusion (give it over a longer period) which might help. The nurses will be checking that you carry on filling in the headache diary.

If your arms and legs feel very cold or you have any chest pains, heart flutters or dizziness, tell the nurses immediately so that we can stop the infusion and ask the doctor to check you over.

Day 2 to 5

You will carry on having infusions for the next three to four days – each about eight hours apart and lasting an hour, depending on the rate. Again, if you start to feel any side effects, please tell your nurses so that they can help. In between infusions, you can leave the ward if you like but please tell the nurses where you are going and when you expect to be back. You could visit our Pals Office in main reception to pick up a copy of our What's on guide for some suggestions of things to do. You must continue to fill the headache diary every day on an hourly basis, whether you are in the hospital or out and about.

Removing the PICC

On Day 5, you should have received the maximum total dose of DHE prescribed so you will not need to have any more. The nurses will remove the PICC on the ward by gently releasing the stitches holding it in place – this may be a bit uncomfortable but only for a few minutes. They will then pull the PICC from your arm and press down on the exit site for five minutes before applying a dressing. This dressing should stay in place until the following day.

Going home

Once the doctors and nurses are happy that you are recovering well, you will be able to go home. It can take some time for the medicine to work its way around your body so do not worry if you carry on having headaches for several more days.

The nurses will telephone you two or three weeks after you have gone home to see how you are doing. We will need you to carry on filling in your headache diary until your clinic appointment so that we know how often you are having headaches and how bad they feel. We will post you details of the clinic appointment after the telephone call.

Useful numbers

Clinical Nurse Specialists for Neurology – 020 7405 9200 extension 1333 or 1051

Compiled by staff from the Headache Clinic in collaboration with the Child and Family Information Group
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