

Therapeutic Apheresis Services

Patient Information Leaflet – Extra Corporeal Photopheresis (ECP)

Introduction

This leaflet has been written to give patients information about extra corporeal (outside the body) photopheresis (sometimes called ECP or just photopheresis). If you would like any more information or have any questions, please ask the doctors and nurses involved in your treatment at the NHS Blood and Transplant (NHSBT) Therapeutic Apheresis Services Unit.

When you have considered the information given in this leaflet, and after we have discussed the procedure and its possible risks with you, we will ask you to sign a consent form to indicate that you are happy for the procedure to go ahead. Before any further procedures we will again check that you are happy to proceed.

What is photopheresis?

Blood is made up of red cells, white cells and platelets which are carried around the body in a fluid called plasma. The white cells can be separated from the rest of your blood, this process is called apheresis. Photopheresis is a treatment which involves removing the white blood cells and exposing them to ultraviolet light (UV light). This is done after adding a drug which makes the white cells sensitive to the UV light. These treated white cells are then given back to you to help improve the skin or other condition being treated.

How do we perform photopheresis?

Photopheresis is performed using a machine called a cell separator, which can separate blood into its various parts. The machine separates and removes some of the white cells in your blood into a bag and once we have enough white cells we add a drug called 8 – methoxsalen (also known as Psoralen) which makes the cells sensitive to UV light. The white cells are then exposed to UV before they are given back to you. The remaining parts of your blood, including red cells and white cells, are returned to you during the treatment. The treatment is made up of two procedures on two days, one after the other, and these two days make up a single treatment. A treatment usually takes place every 2-4 weeks, but can be more or less frequent depending on your individual needs.



In order for us to carry out photopheresis, a needle will be put into a large vein in each arm. If you wish, you may receive a small injection of local anaesthetic to numb the skin before we insert the needles.

The machine will then take blood from one arm and return it through the needle in your other arm. Your white cells are removed and stored for return to you later after exposure to UV light. Only a small amount of your blood passes through the machine at one time (about the same amount as is in a mug of coffee) and the blood is removed and replaced at the same time. It is essential that there is a steady flow of blood through the machine, and to help achieve this we need to use healthy, good sized veins.

If the veins in your arms are not suitable, you may need to have a special tube inserted into a larger vein in your neck or groin under a local or general anaesthetic. We can then remove and return blood through this line. If this is necessary you will be given more information about the type of tube to be used, why it is needed and how it would be inserted.

What is it like being on the machine?

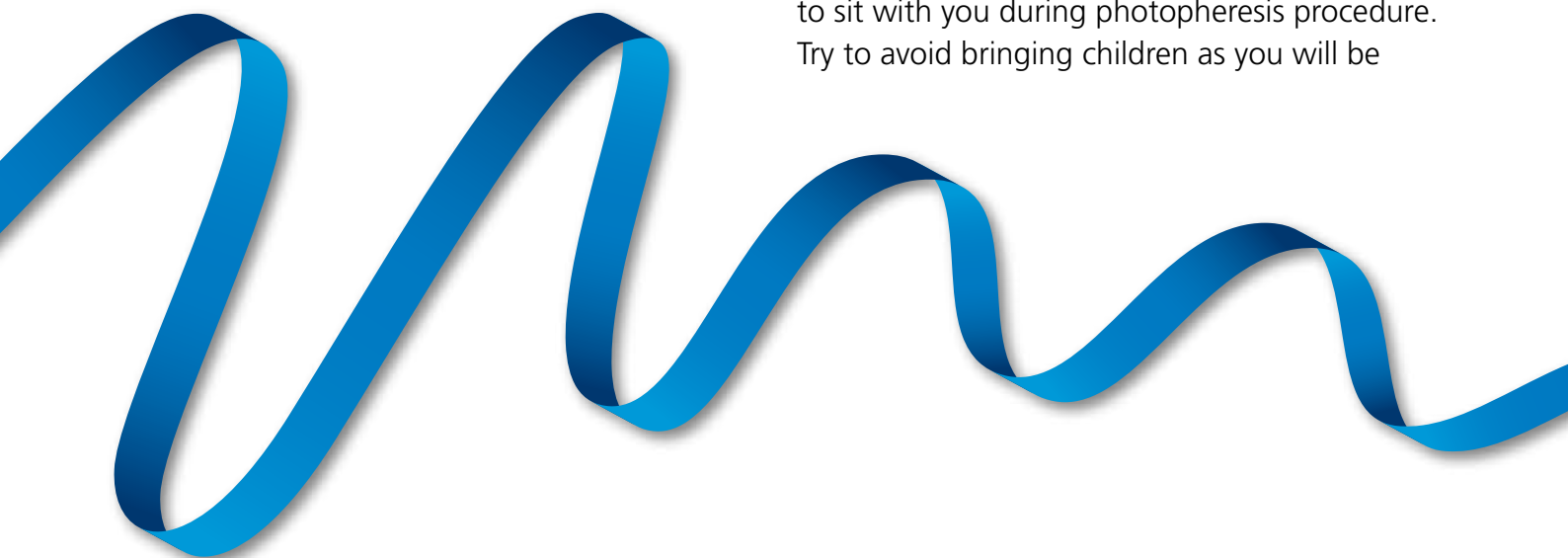
Your safety and comfort are of the utmost importance to us and a trained nurse will look after you throughout the procedure. The treatment takes place while you rest on



a reclining chair or bed. We will try to make you as comfortable as possible. You should not hesitate to ask for anything that you need during the exchange. For your comfort it is best to wear loose-fitting clothing.

Photopheresis is carried out where possible on an outpatient basis and you will attend the Therapeutic Apheresis Services Unit if you are well enough. Occasionally you may need to be admitted to hospital or you may already be an in-patient, in which case you may still attend the unit as an outpatient but be transported to the unit from the hospital ward. However if you are not well enough we will come and treat you on the ward at your bedside.

You are welcome to bring a friend or relative to sit with you during photopheresis procedure. Try to avoid bringing children as you will be



attached to a machine and therefore will be unable to attend fully to their needs. If you do have to bring children with you it is preferable that another adult accompanies you to take care of them.

As your blood enters the cell separator, an anticoagulant (blood thinner) solution is added to it to stop it clotting in the machine. The anticoagulant used is called Heparin and it slows the blood clotting process so your blood will take longer to clot. This effect does not last long but if you notice any signs of bleeding, such as unusual bruising, contact your doctor or nurse for urgent advice.

Some patients experience light headedness, dizziness or nausea while being treated. These symptoms will stop once the procedure is finished. If you experience any symptoms that cause you concern or distress let the nurse know immediately so that we can deal with them, as they are normal and simple to treat. After



treatment some patients experience skin redness or increased itchiness. Some patients also experience a slight fever, which may occur 6-8 hours after treatment. These effects are temporary and should wear off. They are nothing to worry about, and can be relieved by taking paracetamol for the fever, moisturisers and/or antihistamines for the itching. There is no need to take any action for these symptoms unless you find them troublesome. If these symptoms persist please contact your doctor or nurse, especially if you have a high temperature for more than 24 hours following treatment or if your skin develops open sores or becomes weepy.

How should I prepare for the photopheresis?

Take any prescribed medicines as normal unless advised otherwise. The drug (Psoralen) added to make the white cells sensitive to UV light, will also make you sensitive to UV light for 24 hours. It is important that you:

- Protect your eyes with UV sunglasses for 24 hours after treatment (except when sleeping).
- Protect your skin by wearing clothing which covers as much of your body as possible, including a hat.
- Apply sun block cream on all exposed skin.

You will need to do this even if the sun is not shining and also when you are indoors, because UV light is also present in some artificial lighting. AVOID eating fatty foods for at least six hours before your treatment as this may affect how well the treatment works.

It is important to have something to eat and drink before the procedure and you can eat and drink normally during and after photopheresis.

Please bring some food with you as the day can be very long. Food such as sandwiches and rolls are easiest to eat when attached to the machine.

We can offer a limited range of hot and cold drinks and savoury and sweet snacks such as crisps or biscuits. We have no facilities for preparing hot food, however there are catering outlets in the hospitals near most of our units which you may like to visit before or after the procedure.

Once you are connected to the machine you will be unable to visit the toilet so please go immediately before your treatment starts. Assistance will be provided if you do need to use the toilet once you are attached to the machine. Commodes, urinals and bed pans are available for use.

If you are having regular photopheresis as an outpatient and you become unwell, for example if you have flu or a chest infection, your procedure may need to be delayed. If you are feeling unwell or have any concerns, do not hesitate to contact the Therapeutic Apheresis Services Unit.

How will I feel after the photopheresis?

Some people feel tired after the procedure, so it is advisable that a friend or relative takes you home afterwards. If this is a problem it may be possible for transport to be arranged. Please inform your nurse or doctor in advance so that they can help with arrangements if needed.

We do not recommend driving yourself home. You should not do any hard physical exercise for the rest of the day.

Occasionally we cannot return the blood that is in the machine back to you which means you lose some red cells as a result. The machine only holds a relatively small amount of blood and this loss should not cause you any problems. We will however routinely check your blood levels to ensure they remain at a safe level.

How long does it take?

The photopheresis takes about an hour and a half to two hours. We calculate how much blood you have in your body from a blood sample together with your height and weight and this determines how long your treatment takes.

How many photopheresis procedures are required?

It may take between 6-12 months of treatment before you notice an improvement in your condition. Photopheresis is not effective in all cases and your consultant will monitor your response.

You are welcome to visit the unit before your procedure if this is an option for you. You will be able to meet the staff and become familiar with the unit where your procedure will take place.

Please Note: It is important to arrive on time for your treatment appointment as another patient may be booked for treatment after you.

Please do not hesitate to ring if you have any questions or queries. We are here to help you.

NHS Blood and Transplant

NHS Blood and Transplant (NHSBT) saves and improves lives by providing a safe, reliable and efficient supply of blood and associated services to the NHS in England and North Wales. We are the organ donor organisation for the UK and are responsible for matching and allocating donated organs. We rely on thousands of members of the public who voluntarily donate their blood, organs, tissues and stem cells.

For more information

Visit nhsbt.nhs.uk

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Call **0300 123 23 23**