

Department of Photopheresis

Patient Information

Your Consultant has referred you to Rotherham for Extracorporeal Photoimmune Therapy, often referred to as Photopheresis.

Where are we located?

The Photopheresis Unit is located on Ward A7. This is A Level Junction 3 and a lift is available.

Our contact details are:

Photopheresis Department, Ward A7, Rotherham NHS Foundation Trust

01709 427003

The Rotherham Photopheresis Unit operates from 08.00-16.00hrs Monday – Friday. Sometimes your treatment may be delivered on a Saturday Morning.

Where possible you should inform the Unit if you wish to cancel your treatment or you are unable to attend for treatment; where possible you should also cancel your taxi.

The Team

The service is led by Clinical Director, supported by a Consultant Haematologist, and Research team

The Nursing team is led by the Unit Manager

Details of the team can be found on the Photopheresis web site.

What is Photopheresis?

This document will hopefully explain what Photopheresis is. We also have a very informative website that explains about Photopheresis, see www.photopheresis.co.uk

Photopheresis is a safe therapy with very few side effects used to treat skin and other conditions where the white blood cells are thought to be the cause of your condition. The particular white cell we target is the T-Cell. It is used to treat conditions such as Graft versus Host Disease and certain types of skin conditions.

Extracorporeal Photoimmune Therapy may sound complicated but broken down it means:

- “Extra corporeal “means outside the body
- “Photo” means light.

So Photopheresis is a light activated treatment of your white cells which takes place outside the body.

Photopheresis treatment primarily involves you being attached to a machine either by your central line if one is in place or by inserting a needle into a vein in your arm (numbing cream is offered if the latter is used)

Once attached to the machine blood is drawn from you, and it is spun in a special bowl to separate your blood cells in order for us to collect the white cells needed for treatment. Any cells not required will be returned to you.

Once all the cells are collected for treatment are collected a drug called Uvadex (Methoxsalen), (which is a Psoralen – a group of Chemical compounds found naturally in Bishop Weed) is added to them to make your T Cells sensitive to UVA light

Only a small portion of blood will be removed from you about 250-300mls which will be returned to you at end of treatment.

Each treatment takes between 1-3 hours.

Medication

On the day of your treatment please do not take any:-

- Antihypertensive medication (tablets to lower your Blood Pressure)
- Diuretics (water Tablets)

You can bring these tablets with you and take them after the collection of your cells.

It is **important** that you contact the unit on 01709 427003 and inform us of any of the following: -

- if you have been started on any blood thinning agents such as Warfarin or Low Molecular Weight Heparin (e.g Tinzaparin, Fragmin , Dalteparin etc)
- if you have been diagnosed as having a blood clot

If you take Warfarin, your INR levels must be checked at least 48 hours prior to the Photopheresis treatment. This can be done at your local hospital however once you have had your INR levels checked please contact the Photopheresis department

with a contact number for your local hospital so that we can obtain permission for your result to be faxed to us.

If you are on heparin injections or any other form of blood thinning treatment please contact the Photopheresis Unit at least 48 hours prior to attending for treatment to discuss your treatment plan (this may require stopping your treatments or altering the timing or dose of your injection).

Any other medication will be safe to take as usual. Please bring all medication you need with you.

Diet

Two days before treatment you should drink 2 -3 litres (approx 8-10 glasses) of fluid a day to maintain hydration (unless you are on restricted fluids for any other medical condition). You **must** inform the unit if you have been advised to take restricted fluids.

Eat a low fat diet to prevent your plasma becoming lipaemic (Fatty)

Whilst receiving treatment certain foods may increase skin sensitivity .Foods such as Limes, Figs, Parsnips, Mustard, Carrots and Celery should be avoided if possible whilst having treatment (This is because these foods naturally contain Psoralen)

Transport

We can provide transport to the hospital however; we can only offer transport home on the same day if you live within a 30 mile radius of the hospital.

A local taxi firm is used and they operate a No Smoking Policy, and do not tolerate abusive or aggressive behaviour. They also ask the following:

- Food should not be consumed in the taxi without permission of the driver.
- The taxi should be left clean and tidy when you leave the vehicle

If you need to cancel your taxi **you** should contact A1 Taxis on 01709 555555 and inform them as soon as possible. Please ensure that the Photopheresis Nurses have a current contact number so that A1 Taxis contact you if they are delayed.

The Taxi will drop you off at the Maternity Entrance of the Hospital for your treatment and take you back to your home address or the Photopheresis nominated hotel.

A1 Taxis and the Photopheresis team strive to deliver an efficient and courteous service at all times however, if you are not happy with your transport arrangements or any driver and wish to raise concerns please report them to the Nursing team in the first instance.

If you have any suggestions on how A1 can improve their service please telephone 01709 555555 or email Tony@a1taxi.com

Accommodation

If you live out of the 30 mile radius we can offer overnight accommodation at a local Photopheresis nominated hotel.

One room is provided free of charge for you and a companion (a family room is available if a child is the patient)

The Hotel operates a No Smoking Policy, and does not tolerate abusive or aggressive behaviour.

There are no telephones in the rooms, so please ensure that you have access to a mobile telephone.

There is no restaurant within the Hotel, but the meals are available in the adjoining Public House.

If you are using the provided taxi service please could you ensure that you are ready for a prompt pick up by the driver.

Meals

Please note drinks and biscuits will be offered while you are being treated, all other meals must be provided by you. There is a restaurant within the Hospital and a Coffee Shop, and other local outlets where snacks can be purchased however, you may prefer to bring a packed lunch.

Please Note: the restaurant does not open at the weekends.

After Care.

Once all your cells have been returned to you your skin and eyes will be very sensitive to sunlight or UVA light for 48 hours.

We recommend that you use a **Total Sun Block** and **UVA treated Sun glasses** (wrap around if possible)

Do not carry any thing heavy with the arm we have used for treatment (to prevent bleeding from the site). Keep the pressure bandage in situ for 4-6 hours

Side Effects

Photopheresis is a relative safe treatment with very few side effects however there

are a few side effects that you may experience. They are:

Approved PCG Meeting 14/02/14

- Increase in redness of your skin
- Increase in itchiness
- You may feel like you are starting with a fever (shivering, hot aching)

This is because we have disturbed your Immune System, this feeling should only last for a few hours. However, if you continue to feel unwell or are worried at all and you have gone home you should contact your usual hospital for advice.

If you are staying at the hotel you should contact:

Ward A7: 01709 424231

Children's Ward: 01709 424049

Deferral of Treatment

Sometimes your treatment may need to be deferred. This may happen with any of the following circumstances / conditions.

- Low Haemoglobin below 10
- Haematocrit below 0.27
- Temperature 38° or above
- Low platelets below 20
- Vomiting or Diarrhoea until a stool sample is obtained an infection is ruled out
- Recent Blood clots (will not be able to treat for 6 weeks)
- Recent Heart Attack (will not be able to treat for 6 weeks)
- Shingles or chicken pox (can not treat until all the lesions are dry)

Once your symptoms have resolved you will recommence your treatment however, if the deferral of treatment becomes prolonged you may need to be reassessed for treatment.

Approved PCG Meeting 14/02/14

Version 2014