



NATL 116 01
(Relates to NATS CLIN APH 020)



PHOTOPHERESIS INFORMATION LEAFLET

Introduction

This information leaflet has been written to be read alongside the booklet 'Understanding THERAKOS® Extracorporeal Photopheresis (ECP)'

Before you commence treatment you will be assessed in the Glasgow Apheresis Unit.

Due to photopheresis being a specialised treatment it is currently only offered in either Glasgow or Edinburgh. This means we may have to ask you to travel to a unit which is not necessarily the closest to your home address. This is so we can avoid any delay in starting your treatment.

Please note it is important to arrive on time for your appointment as another patient may be booked in for treatment after you.

If you are having regular treatments but have a cold/flu, chest infection and/or a temperature please contact your apheresis centre prior to your appointment day as your treatment may need to be delayed.

You may bring a friend or relative with you and as you may feel tired after the procedure it is advisable not to drive yourself home.

Procedure

In order to draw blood in to the photopheresis machine a needle will be inserted in to a large vein in each arm. Local anaesthetic can be given to numb the area before needle insertion and once the needle is in place the arms will need to remain fairly straight.

If, at assessment, your veins are found to be unsuitable you may need a permanent line inserted for example a Hickman line or port. This will be explained in more detail should a line be your best option. The line needs to remain in for the full course of treatment and will be removed on completion.

The amount of blood out of your body at any one time is around 600ml (approximately one pint). To prevent the blood from clotting while out of your body a small amount of anti-coagulant is mixed with the blood as it flows in to the machine. The anti-coagulant is short acting and should be out of your system approximately 30 minutes after the end of the procedure.

A procedure could last between one and a half and two and a half hours you will be able to eat and drink whilst the treatment is in progress.

At the end of your procedure we will remove your needle(s).

If you have a Hickman line or port this will be flushed post procedure.



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Side effects

- If a needle has been inserted in to your vein there is a possibility you may experience some bruising around this area.
- During your procedure some of your blood is removed for short periods and although the amount is monitored closely you may feel light-headed and/or dizzy during the procedure, although this is not common. This is easily corrected by giving you some intravenous fluids but to reduce the possibility of this happening it is important that you have something to eat and drink prior to attending for your photopheresis treatment.
- The drug (Uvadex) used to treat your cells will make you sensitive to sun light (even through a window) and more prone to burning. **It is important that you wear a high factor sun lotion (50) and UVA sunglasses for 24 hours post treatment.**
- Previous patients have often felt quite tired after the procedure and some have mentioned that their skin feels warm “like a hot flush”, for six to eight hours after.
- If you experience any of these side effects or any other problems which are causing you concerns please discuss them with the nurse looking after you.
- Some patients in the USA have experienced thrombosis (blood clot) while receiving ECP treatment. It is not completely clear whether or not this is a side effect of the ECP. There is more information about this below.

Possible risk of thrombosis (blood clot)

A small number of patients receiving ECP treatment in the USA have experienced a complication called venous thrombo-embolism (VTE). VTE means that a patient develops an abnormal blood clot in one of the large veins deep inside the body, most commonly the large vein at the top of the leg. This is called Deep Vein Thrombosis or DVT. Sometimes, part of the clot may break off and travel through the bloodstream to the patient’s lungs, causing breathlessness and/or coughing up blood. This is called Pulmonary Embolism or PE.

It is not clear at present whether the ECP treatment actually caused some patients in the USA to develop VTE. It is also possible that the VTE may have been caused by the patient’s underlying condition. In other words, the disease for which they were receiving the ECP treatment may actually have been the cause of the clot, rather than the ECP treatment itself. It is also important to say that the total number of patients involved (seven altogether) was really quite small, compared to the large number of patients treated with ECP in the USA each year who presumably did *not* develop VTE.



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However, as a precaution, we wish to make you aware of this. If you experience any of the symptoms listed below, please get in touch immediately with the hospital medical team which normally looks after you. If you are not able to do this right away, then please call NHS 24 but please also tell them about this letter.

The symptoms to look out for are:

- Unusual swelling in your legs, especially if it is only on one side
- Sudden onset of breathlessness
- Pain in your chest that is worse when you breathe in
- Coughing up blood

Hopefully it is quite unlikely that you will experience VTE yourself.

HOW MANY TREATMENTS WILL I NEED?

A 'treatment' consists of two procedures, usually one day after the other. The number of total treatments required will depend on the disease being treated. This will be discussed with you at your assessment visit and you will receive an individual treatment plan. You will also have a regular three monthly review in Glasgow.

If you require any further information please don't hesitate to contact either of the centres below.

CONTACT DETAILS

Glasgow Clinical Apheresis Unit

Consultant: Dr Kenny Douglas
Senior Charge Nurse: Joy Sinclair
Clinical Apheresis Unit
Level 1
The Beatson
West of Scotland Cancer Centre
1053 Great Western Road
Glasgow
G12 0YHN

Tel: 0141 301 7013/14

Edinburgh Clinical Apheresis Unit

Consultant: Dr Lynn Manson
Senior Charge Nurse: Moira Anderson
Clinical Apheresis Unit
Out Patient Department 1
Royal Infirmary of Edinburgh
51 Little France Drive
Edinburgh
EH16 4SA

Tel: 0131 242 3609