



Extracorporeal photopheresis (ECP) treatment

Information for patients

Therapeutic Apheresis Services





Introduction

This leaflet gives information about extracorporeal photopheresis (ECP) treatment. If you have any questions or want more information, please ask the specialist nurses who give this treatment.

After you've read this leaflet and we've talked about the procedure and possible risks, we'll ask you to sign a form to show you agree to go ahead with the treatment.

Extracorporeal

- means *outside the body*

Photo

- means *light*

Apheresis

- means *separation*

What is extracorporeal photopheresis (ECP)?

ECP is a treatment where your blood is taken out and goes into a special machine. The machine separates your white blood cells from the rest of your blood (plasma, red blood cells, platelets). A special drug is added to the white blood cells, which only works when exposed to UV (ultraviolet) light. The white blood cells are then treated with UV light and put back into your body.

ECP is used when other medicines like steroids don't work well. It helps your immune system work better, which can help control your symptoms and protect you from infections.





How do we perform photopheresis?

The treatment is done usually on two days in a row. These two days count as one treatment cycle. A treatment cycle usually happens every 1-4 weeks, but how often you get it may differ based on your treatment plan. We will explain your plan before you start treatment.

To do ECP, we use a machine called a blood cell separator.

We'll put a needle or tube (cannula) in a large vein in each of your arms (if you want, we can use a numbing medicine before we put the needles in). The machine has sterile tubing loaded into it which your blood is drawn into during the treatment. The machine takes blood from one arm, separates the white blood cells, and then returns the rest of your blood through the other arm. The blood needs to flow smoothly through the machine, so we need veins that are healthy and big enough. If your veins are too small, we'll talk with you and your doctor about other options. If you already have a central line in place, we may be able to use it for the treatment instead of placing needles but would depend on the type of line it is and how well it is working.

Only about 600ml (about a pint) of blood is in the machine during treatment. If you weigh less than 40 kilograms, we might need to use a unit of blood to make sure your blood levels stay safe and balanced. Some adults may need this, too, if their red blood cell level is low.

The white blood cells are put in a treatment bag, and the nurse adds a drug to make the white cells sensitive to UV light. Then the white cells are treated with UV light before being put back in your body.





What is it like being on the machine?

Your comfort and safety are important. A nurse will look after you while you're being treated. You will sit in a reclining chair or on a bed. It's best to wear loose clothes, and feel free to ask for anything you need during the treatment.

Due to limited space in some of our units, it is not always possible for a friend or family member to sit with you during the procedure. Children should not be brought to your appointment as you will be attached to a machine and likely unable to take care of them during the treatment. If there is no other alternative for your child, then another adult must attend to take care of them. Please contact your apheresis team to discuss prior to attending for your appointment.

Your blood will be mixed with a special solution to prevent it from clotting in the machine. This solution is called Citrate, and it slows down the blood clotting process.

It doesn't last long, but can cause some mild effects, like:

- Tingling in your lips, nose, or fingers
- A strange taste in your mouth
- Feeling a little shaky or nauseous
- Muscle spasm

These side effects happen because the solution lowers your calcium levels for a short time, and we will treat it with a calcium infusion during your treatment.

If you can't have Citrate, we use a medicine called Heparin.

It also slows the clotting process but lasts longer in your body so if you notice unusual bruising or bleeding, let your doctor know right away.





How should I prepare for the photopheresis?

Take your usual medicines unless your doctor tells you otherwise. It is important to let us know if you are taking blood thinners or blood pressure medicines prior to attending.

Some medicines, creams, lotions, shampoo and dyes can make the risk of a reaction to the UV light treatment higher. If you're not sure about what to use, contact the treatment team before your appointment.

You can eat and drink as usual before and during the treatment. Avoid fatty foods for at least 6 hours before your appointment, as it helps the machine work better. But make sure to eat and drink before your treatment.

The drug we use to make your white cells sensitive to UV light also makes you sensitive to UV light for 24 hours after treatment.

During this time, you need to:

- Wear UV wraparound sunglasses to protect your eyes
- Wear clothes that cover most of your body, including a hat
- Apply sunscreen (SPF 15 or higher) on any exposed skin
- Not attend eye doctor/optician appointments as the bright lights used can damage your eyes
- Avoid dentist appointments if heparin is used as risk of bleeding is higher

This is important even if it's cloudy or if you're indoors since UV light is everywhere.





The drug (methoxsalen) should not be used if you are pregnant or planning to become pregnant. If you are sexually active and can have children, both men and women must use reliable birth control during and after ECP treatment to prevent pregnancy. This is because the drug could harm a baby if you get pregnant while using it.

Breastfeeding is not recommended as there is a risk the baby will receive the drug via this route.

Before your treatment starts, make sure to use the bathroom, since you won't be able to leave the machine once you're connected. If you need help, we can bring you a commode, bedpan, or urinal.

If you feel sick or have new symptoms before your appointment, call the treatment team for advice.

If your blood counts are low, your medical team may need to give you a blood or platelet transfusion before treatment can be started.

How will I feel after the photopheresis?

Some people feel tired after the treatment, so it's a good idea to have someone drive you home. If that's a problem, contact the team who asked for you to have ECP and they can help arrange transport. We don't recommend you drive yourself. You should also avoid any heavy physical exercise for the rest of the day.

Sometimes, the machine can't return all your blood, and you may lose some red blood cells. This shouldn't cause problems, but we'll check your blood to make sure everything is okay.

Some people may feel dizzy, light-headed, or nauseous during treatment, but these feelings usually go away after the treatment is done. If you have any concerns, tell the nurse right away so we can help you.

Your skin may get red and itchy a few hours after treatment. Some people get a fever 6-8 hours after the treatment. If you develop a fever, you should contact the team that referred you for ECP for advice on what to do, particularly if you have a central line inserted. You should also contact your doctor if your fever lasts more than 24 hours or if your skin gets open sores.



How long does it take?

ECP treatment usually takes about 90 minutes to 2 hours for adults, and up to 3 hours for babies and children.

How long it takes depends on how much blood you have in your body and your height and weight.

Sometimes, it might take longer if there are problems with how blood flows in or out of the machine.

How many photopheresis procedures are required?

Response times to ECP treatment can be different for each person. Some patients start to see results within a few months but may take longer. Patient responses will vary depending on severity of disease and the condition of your immune system. Improvement is usually a gradual process. Not everyone responds to photopheresis, so your doctor will keep checking how well it's working.

It's important to get to your appointment on time because we follow a set schedule. If you are late, there might not be enough time to finish your treatment on the day.

Please contact us if you have any questions. We're here to help.





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