



Immunoglobulin (Ig) Therapy

A guide for patients

Your doctor has referred you for immunoglobulin therapy. This leaflet explains:

- what immunoglobulin therapy is
- why you have been referred for this therapy
- how it is given, and
- what the possible risks are.

If after reading this leaflet you have any questions or concerns, please speak to your specialist nurse or the contact given to you by your specialist.

Patients may need immunoglobulin therapy for many reasons. Your doctor will have discussed your particular situation with you.

What is immunoglobulin and what are antibodies?

- **Immunoglobulin** (shortened to 'Ig') is a protein in your blood that helps to fight infections. Ig is a collection of many different **antibodies**.
- These **antibodies** kill particular germs (such as bacteria and viruses). A healthy immune system makes antibodies when it meets a new infection or after vaccination.

Who needs treatment with Ig?

Ig therapy is often used for people who cannot make their own antibodies. This causes them to have infections due to a weakened immune system. This is called Ig replacement therapy. It can be a short-term or long-term treatment, depending on the reason you are having the therapy. How long you need to have Ig therapy will be discussed with your doctor.

Ig therapy is also used to treat conditions where the immune system is overactive. The mixture of antibodies in the Ig preparation calms down the person's immune system. This treatment is usually given in hospital after a thorough medical assessment.

If you are not sure why you need Ig treatment, or have any questions, please speak to your doctor.

What is the treatment?

- Ig is manufactured from blood given by healthy blood donors.
- Over 1000 blood donations go into each batch of Ig. This means it provides antibodies which protect against a wide range of infections.
- After a donor gives blood, the Ig is separated out by a series of manufacturing steps. The end result is highly purified Ig, that also contains small amounts of other normal blood proteins.

How is the treatment given?

Ig treatment comes as a liquid and is injected either:

- into a vein (**intravenous**) or
- under the skin (**subcutaneous**).

Intravenous is commonly used in hospital. Whereas, for long-term conditions, subcutaneous can be used.

- **Intravenous therapy**

This usually takes 2 to 4 hours. It is started very slowly and the drip rate is then increased. For regulation of the immune system, it may take longer and infusion given to you over several days to achieve the dose.

For long-term use of Ig as a replacement for Ig's that the patients lack, most people need treatment every 3 weeks.

To start with you will be given Ig in hospital. However, you may be able to be trained by one of the healthcare staff to administer the treatment yourself at home. Please ask a member of staff for more information.

- **Subcutaneous therapy**

This therapy takes about an hour and is usually given weekly. It is usually given only if you are being trained to treat yourself at home (home therapy).

The way you are given Ig therapy depends partly on the condition it is being used for. We also take your wishes and circumstances into account. So, if you change your mind about using subcutaneous therapy, please let your doctor know and you can switch back to intravenous.

Can I give this treatment myself at home?

For long-term conditions, many patients can be trained to give their own Ig treatment at home. However, not everyone is suitable for home therapy.

If you would like to discuss home therapy, please speak to your nurse or doctor.

Could there be any problems with Ig therapy?

As with all medicines, there are some potential risks associated with treatment, but serious problems are rare. We outline some of the potential risks of Ig therapy below.

1. Infusion reactions

You may feel unwell during or soon after your infusion. Most of these reactions are mild but they might be unpleasant for a while. If you do experience any side effects of treatment, let a member of the team know immediately.

- **Mild reactions** include headache, flushing, fever or shivering, rash, back pain. About 1 in 10 patients may have these. They are usually easy to control and not harmful.
- **Moderate reactions include** chest pain, vomiting, dizziness, severe headache.
- **Severe reactions include** acute severe wheezing, swelling of face, neck or tongue, difficulty swallowing or breathing, faintness or unconsciousness.

Moderate and severe reactions are very rare, but you still need to know what to look out for. Tell your specialist nurse or the contact given to you by your specialist, if you have any symptoms or concerns. They can then reassure or treat you as necessary.

2. Transmission of blood-borne infections

Ig is made from donated blood, so there is a risk that an infection can transfer from a donor to the person receiving Ig. There are many steps in the manufacturing process that minimise this risk.

- Blood donors are screened on their personal and medical history, and through blood tests.
- A donated blood unit is only used after the donor has attended again for another donation, and is still well.
- Often, manufacturers only take blood from donors they have known for a long time. Who they know have normal tests over an extended period.
- Many of the steps in the manufacturing process kill viruses.
- Doctors review the available Ig preparations. They then decide which ones to recommend and use. This includes reviewing their safety record, and details of their manufacturing processes.

These safety steps help to minimise the risk of transmitting:

- infections we know about (like hepatitis), and
- infections we may discover in the future.

1. Other rare side effects (affects between 1 in 10,000 and 1 in 1,000 people)

- **Kidney failure.** Ig treatment can affect your kidneys. This would be found when you have blood tests after your treatment. It does not usually cause any symptoms.
- **Haemolytic anaemia.** The Ig product reacts with and damages the patient's red blood cells. This might cause a mild infusion reaction, and show up as anaemia on a blood test.

- Thrombosis. Patients on Ig therapy have a slightly increased risk of suffering blood clots. This could include a heart attack, stroke or blood clots in the lung or legs. Whilst potentially serious, the risk of these is very low.

It is important to drink plenty of water before your infusion, to reduce your risk of developing a blood clot. Keeping active before and after treatment will also help.

For more information, please ask a member of staff for the Trust's Preventing a blood clot whilst you are in hospital leaflet. (/preventing-a-blood-clot-whilst-you-are-in-hospital)

- Immunoglobulin therapy can very rarely cause severe allergic reactions.

If you experience any of the risks listed above, please speak to your specialist nurse or the contact given to you by your specialist. In an emergency, call 999.

Other questions

- **Can I take any other medicines whilst on immunoglobulin therapy?**

Immunoglobulin does not normally interfere with other medicines. However, it is important that you tell your doctor what other medicines you are taking. This includes over-the-counter medicines that are not prescribed.

- **Can I drink alcohol?**

Yes. You can drink alcohol in moderation. However, you should avoid drinking too much. For more information, please read the NHS Alcohol Advice (<https://www.nhs.uk/live-well/alcohol-advice/>).

Where can I get more information?

If you have any questions or concerns, please speak to your specialist nurse or the contact given to you by your specialist. Please feel free to ask us any questions you have.

The following web sites have useful information about immune deficiency and immunoglobulin therapy.

- Immunodeficiency UK (<https://www.immunodeficiencyuk.org>)
- UKPIPS (<https://www.ukpips.org.uk>)
- British Society for Immunology (<https://www.immunology.org>)
- International Patient Organisation for Primary Immunodeficiencies (IPOP) (<http://www.ipopi.org/>)
- Immune Deficiency Foundation (<http://primaryimmune.org/>) (US information)
- NHS immunoglobulin (<https://igd.mdsas.com/patient-info/>) website- CIDP, MMN
- Plasma Protein Therapeutics Association (<https://www.pptaglobal.org>) (Ig manufacturers)

This leaflet has been produced with and for patients.

Please let us know:

- If you have any accessibility needs; this includes needing a hearing loop or wanting someone to come with you to your appointment.
- If you need an interpreter.
- If you need this information in another format (such as Braille, audio, large print or Easy Read).

You can let us know this by:

- Visiting the Trust web site (<https://www.ekhuft.nhs.uk/ais>).
- Calling the number at the top of your appointment letter.
- Adding this information to the Patient Portal (<https://pp.ekhuft.nhs.uk/login>).
- Telling a member of staff at your next appointment.

Any complaints, comments, concerns or compliments, please speak to a member of your healthcare team. Or contact the Patient Advice and Liaison Service on 01227 783145 or email (ekh-tr.pals@nhs.net).

Patients should not bring large sums of money or valuables into hospital. Please note that East Kent Hospitals accepts no responsibility for the loss or damage to personal property, unless the property has been handed into Trust staff for safe-keeping.

Further patient information leaflets are available via the East Kent Hospitals' web site (<https://www.ekhuft.nhs.uk/patient-information>).

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