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A patient guide to immunoglobulin replacement therapy

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This piece of information has been written to answer some of the common questions asked by patients and relatives about immunoglobulin and it's safe use.

Treatments for primary and secondary immunodeficiencies vary according to individuals needs and the following information sheet is for general reading. If you have specific questions please ask your doctor.

Why have I been prescribed immunoglobulin?

Antibodies are natural chemicals in the body that help fight infection. Tests have shown that if you have a low or absent antibody count, this means you are more susceptible (prone to) infections.

Recurrent infections (infections that continuously come back), can make you feel unwell and can cause scarring. For example, a recurrent chest infection can cause scarring in your lungs. This scar tissue provides an environment for infections to begin making you more prone to infection.

Immunoglobulin replacement therapy is used to increase the amount of antibodies in your immune system to help fight infections. Immunoglobulin is made from purified (free from contamination) human antibodies donated by blood donors.

Immunoglobulin treatment has been shown to reduce infection rates in people with a low antibody count.

How is immunoglobulin given to me and how often?

Immunoglobulin can be given through a vein (intravenous or IVIg) or under the skin either as an injection or an infusion using a pump (sub–cutaneous or SCIg).

- **IVIg** is given as an infusion (drip) using a butterfly needle which is inserted into a vein in the arm or hand. It is usually given every three to four weeks depending on the individuals needs.

- **SCIg** can be given as an infusion through a butterfly needle which is inserted just under the skin. It can either be given once a week through a **pump** or 3–4 times a week as a single injection known as **'rapid push'**.

- **Pump driven SCIg (immunoglobulin administered through a pump)** usually requires two or three needles to be inserted into different sites around your stomach or thighs. The more sites used, the less time will be spent infusing. The volume of immunoglobulin which can be infused into one site varies from person to person; it usually ranges between 10 and 40 millilitres. The pump distributes the immunoglobulin from a single syringe through to the separate sites around your thighs and stomach. This process takes about an hour.

- **Rapid push SCIG (immunoglobulin administered by an injection)** splits your weekly infusion into single injections. These injections are spread throughout the week allowing a steady amount of immunoglobulin into the blood stream. Instead of using an infusion pump, 10–15 millilitres of immunoglobulin is drawn up into a syringe and then injected into a single site through a butterfly needle. Each injection takes five minutes.

Where can I have my immunoglobulin treatment?

It is possible for you to have your infusions or injections at home or as a day case (when you are admitted and released from

hospital on the same day). You and your doctor will decide together the best place for you to have treatment.

If you are treated in hospital

Your hospital visits will be arranged by experienced nurses and you will know the dates in advance. You will visit the hospital every three to four weeks for your immunoglobulin treatment; the treatment will take between two to three hours.

If you are treated at home

Administering immunoglobulin through a vein (IVIg) is more complex than under the skin (subcutaneous SCIg). Most patients choose a subcutaneous method, however both options are available.

You will be trained by an immunology specialist nurse or doctor on the following;

- How to prepare for your injection or infusion
- How to site your needle(s)
- How to give your immunoglobulin in a safe and sterile way

Your training will be begin in hospital, but you will also be visited at home to make sure you are confident and the infusions or injections are being given correctly, before you administer them alone.

You will be given contact details to ensure that you know who to call if you experience problems whilst treating yourself at home.

It is recommended that you have an 'infusion or injection buddy'. This is someone that can support you during your infusion or injection and can call for help if necessary. If you live alone this may be a friend who can visit regularly.

A medical delivery company will regularly deliver all of the

equipment you will need for your infusion or injection including the immunoglobulin product.

Immunoglobulin comes from blood – is it safe?

Blood borne infections (infections passed on via direct blood contact) can be passed from the immunoglobulin, however this risk is low.

Companies that produce immunoglobulin have strict procedures in place to prevent the transfer of infection through immunoglobulin. There have been no known infections caused by immunoglobulin treatment since the 1980s.

All blood donors are carefully screened and their blood donations are tested for a range of known viruses. Strict blood purification (cleaning the blood of toxins) steps are then undertaken and the immunoglobulin product is tested again for any evidence of infection.

Like all medical procedures, there are some unknown medical risks which have not presented themselves. To ensure these risks are minimised and monitored, your blood samples will be stored and screened every year. All the immunoglobulin products you receive will also be recorded by batch number.

What side effects may I experience?

Immunoglobulin has been used as a treatment for patients with a low antibody count since the 1980s and is received well by most.

Around a third of patients may experience mild side effects during their infusion or injection, or a few days after. Symptoms include; headaches, aches and pains, flu like symptoms, or a rash around the infusion/injection site. These symptoms are more common in the first few infusions or injections and usually settle down with time. This varies from patient to patient.

If you are experiencing any of the symptoms listed above, please tell your doctor. They can prescribe some simple, effective medication, such as paracetamol or anti–histamine's (medication to treat allergic reactions).

Severe side effects or reactions are rare. They are most likely to happen during your first few infusions or injections, whilst your body is getting used to the immunoglobulin. All first infusions or injections are given in hospital, to ensure that any allergic reactions can be acted upon promptly.

Severe side effects are more common in patients who have other illnesses. For example, immunoglobulin treatment has been associated with worsening kidney function in patients who already have kidney problems. Similarly the immunology team would take precautions when treating patients who have had blood clots or are at risk of a blood clot. Severe headaches have also been experienced by patients.

Side effects are more common if the speed of the immunoglobulin is given is too high. It is important that your immunoglobulin is given safely, therefore you should not rush the treatment. If you do experience symptoms, you should slow your infusion or injection rate.

Side effects seem to be more common if an infection is active (produces symptoms). You should always seek medical advice before infusing or injecting if you feel unwell.

If you do feel unwell, you should delay your infusion or injection by one to two days until you feel better. Your next infusion or injection should be commenced at a slower rate.

How much immunoglobulin should I have?

Doses of immunoglobulin vary between patients. Your first dose will be based on your height and weight. The dose and frequency will then be adjusted according to your infection rate (the speed an injection progresses). It is very important to

monitor any infections that you may have had, which part of the body is affected and how long you took antibiotics to treat the infection for.

The level of immunoglobulin in the blood is measured by taking a blood sample just before an infusion or injection; this level is called the trough level. The trough immunoglobulin level, your weight, and the number of infections you may have had, are all taken into account by the doctor when prescribing your dose.

A usual dose of immunoglobulin ranges between 200mg and 400mg per kilogram of the your weight per month.

Which immunoglobulin product should I have?

There are several immunoglobulin products which are available to you in the UK. These are all made from large plasma pools (a collection of blood donations) from healthy donors.

Your immunoglobulin product will be chosen by a specialist who is familiar with each immunoglobulin product.

Once a suitable product has been chosen for you, it will not be changed unless for clinical reasons such as; recurrent mild side effects, or if the product is unavailable.

I am afraid of needles – what are my options?

If you are uncomfortable using needles a local anaesthetic (numbing) cream called 'Emla' can be used on the skin before using needles. Please ask your doctor for more information.

What if I have a question?

If you have a question please speak to your doctor or nurse at your next appointment. If your question is urgent please contact your consultant.

The Trust provides free monthly health talks on a variety of medical conditions and treatments. For more information visit www.uhb.nhs.uk/health-talks.htm or call 0121 371 4323.

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