Immunoglobulin infusions

Patient information
Immunoglobulin Treatment

This booklet provides information about immunoglobulin infusions. It is aimed to help you understand why you or your child has been prescribed this treatment. If you have any questions please discuss these with your doctor or treating nurse.

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What are immunoglobulins?

Immunoglobulins, or antibodies, are normally made by the body as a part of the body’s defense against infection and disease. The body makes different antibodies to fight different diseases. For example, the antibody needed to fight off the common cold is different to the antibody needed to fight off measles.

Immunoglobulin products are made from the plasma of donated human blood. Plasma is the straw coloured fluid that is left when the red blood cells have been removed. The immunoglobulins are collected from the plasma and then prepared into a solution that is stored in bottles for later use.

There are many brands of immunoglobulin products that are produced across the world. The Therapeutic Goods Administration (TGA) approves the products that can be used in Australia.

Australia produces two immunoglobulin products (Intragam 10 and Evogam 16%). Other products are imported to make sure there is enough supply.

What is an immunoglobulin infusion?

An immunoglobulin infusion is a treatment where immunoglobulins are dripped into a vein. This is called an ‘intravenous’ or ‘IV’ infusion. They can also be given as an injection into the subcutaneous tissue (just under the skin). This is called a ‘subcutaneous’ or ‘subcut’ infusion or injection.

The immunoglobulin preparation you are prescribed by your doctor will depend on the reason for your treatment (diagnosis), the length of time it is expected that you will be having treatment and also on which brand is available at the time.

Your doctor or nurse will discuss the option that will best suit you (or your child / family member).
What are the risks of infection from immunoglobulin infusions?

The plasma used to produce immunoglobulin products is tested for blood borne diseases such as Hepatitis and Human Immunodeficiency Virus (HIV/AIDS). The production process also involves steps designed to inactivate viruses that may have not been detected on screening tests.

The risk of infection is very low, lower even than the risk of being struck by lightning.

Why have I (or my child / family member) been prescribed this treatment?

There are 2 major types of treatment that immunoglobulin infusions are used for:

1. Replacement therapy

Immunoglobulin infusions are given to people who are unable to make enough of their own immunoglobulins to fight infection and to have a healthy immune system. This can occur because of immune deficiencies present at birth or because of certain diseases or treatments.

Low immunoglobulin levels can occur with some cancers, before or during treatment of the cancer (examples include Non-Hodgkin’s Lymphoma and Multiple Myeloma). These people need immunoglobulin infusions to help protect them from infections.

2. Immunomodulating Treatment

Sometimes things can go wrong with the body’s immune system where it makes antibodies against itself. This causes the body to treat healthy organs and tissues like foreign invaders to fight against. This is called an auto-immune disorder.
Some examples of auto-immune disorders that can be treated with immunoglobulin infusions include:

> Chronic inflammatory demyelinating polyneuropathy (CIDP)
> Guillain-Barré Syndrome
> Inflammatory myopathies
> Auto-immune disorders of the blood

The length of treatment and the dose of immunoglobulin therapy vary for each disorder. Your doctor will inform you of what is right for you.

What are the side effects?

Reactions to immunoglobulin treatment are uncommon and are more likely to occur during your first few infusions. Your doctor or nurse will explain these side effects to you. Reactions are more common with intravenous infusions than with subcutaneous infusions.

Some of the more frequently reported side effects include:

> Headache
> Nausea (feeling sick)
> Abdominal and back pain

If these symptoms occur, please tell your (or your child’s) nurse. Reducing the rate of infusion or stopping the infusion for a short time can reduce these symptoms. Simple measures such as being well hydrated (drinking enough water) before your infusion, taking paracetamol or an anti-nausea tablet can help, but please speak to your doctor or nurse before taking any medication. Do not take (or let your child take) any medication that your (or your child’s) doctor does not know about.
**Rarely,** intravenous immunoglobulin infusions can cause a more serious allergic reaction. Symptoms can include;

> Shortness of breath, wheezing
> Chest tightness
> Skin rash,
> Low blood pressure

*If you experience any of the above reactions,* report this to the nurse or doctor immediately.

Very rarely, and usually in people with other circulation problems, intravenous immunoglobulin can increase the risk of clots forming in the blood, which can result in heart attack, stroke or other vascular problems. Intravenous immunoglobulin may also worsen kidney function in people with pre-existing kidney conditions. It is **extremely important to let your doctor or nurse know if you have any significant change in your health as you get closer to your infusion time.** Even simple dehydration or an infection can be very important.

For subcutaneous infusions the most common side effect is some swelling around the needle site. This will go down as the body slowly absorbs the fluid, usually within 24 - 48 hours. Some redness / irritation may also occur to the skin at the needle site. Your doctor and/or nurse will explain this to you in more detail if this type of infusion is recommended for you.
When do I need to call the doctor or treatment centre?

Before the infusion
Notify your doctor or nurse of any change in your health or medication. This includes temporary or simple conditions (such as minor infections, dehydration or conditions that could cause dehydration such as loss of appetite, vomiting or diarrhoea).

After the infusion
Sometimes after the infusion and for the next day or two you (or your child) might experience flu-like symptoms such as fever, chills, aching joints and muscles. These usually disappear within 24 - 48 hours and can be treated with simple measures such as paracetamol. Occasionally some people have reported a severe headache with their eyes being oversensitive to light after an infusion. If this happens please call your doctor or the nurse in your treatment centre.

Are there alternative treatments?
There may be alternative treatments for your (or your child’s) condition. It is important to discuss these with your doctor. Do not stop immunoglobulin treatment without first talking with your doctor as this can be dangerous.
How can I help myself (my child) with this treatment?

> Once you have (or your child has) started having regular immunoglobulin infusions it is important that you regularly see your doctor to discuss:
> - how the treatment is affecting your (or your child’s) health;
> - any side effects you (or your child) may be experiencing; and
> - any adjustments that may need to be made to the treatment.

> It is important that you understand the risks and benefits of the treatment and the alternatives. You will be asked to sign an informed consent form (‘Next of Kin Consent’ for your child) for this treatment every 12 months.

> It is a requirement that you (or your child) be reviewed by your medical team at least every 12 months (or more frequently if your doctor requests) to ensure you maintain approval to access this treatment.

> If you are giving yourself your immunoglobulin treatment subcutaneously (or helping your child with this) at home, you must ensure that you have enough supplies to do this. Supplies include the immunoglobulin product, syringes, infusion tubing, butterfly needles and anything else your health team provides. Your pump (if you use one) should be well maintained and serviced annually (your doctor or nurse will be able to advise you on this).

How do I fill in the symptom diary?

To help you remember how you (or your child) felt after each dose of immunoglobulin it might be useful to fill in a symptom diary. A sample is included in this pamphlet and your doctor or nurse will give a copy for you to complete. You do not have to complete it, but it may help you remember issues / side effects that you may wish to discuss with your doctor or nurse at your next visit.
Immunoglobulin dosage/symptom record

Please bring this record with you when you visit a health care professional

Contact details

Hospital___________________________________________________________________________________ Phone ______________________

Doctor_____________________________________________________________________________________ Phone ______________________

Nurse/Department___________________________________________________________________________ Phone ______________________

Allergies – Detail all allergies including reactions to medication

Patient Label
Surname_________________________ URN___________
Given Names _______________ D.O.B.___________
Address__________________________________________
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For more information

Contact the SA (IVIg) Transfusion Nurse
C/- Australian Red Cross Blood Service
Telephone (08) 8112 1341

This booklet has been endorsed by the SA Immunoglobulin Therapy Advisory Group.

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