NHS
University Hospitals Sussex
NHS Foundation Trust

Intravenous Immunoglobulin (IVIg) therapy

Haematology

Patient information

What is this information about?

This information is about intravenous immunoglobulin (IVIg) therapy. It explains:

- What IVIg therapy is and how it is given.
- Why you might need IVIg.
- Some of the conditions that IVIg is used to treat.
- Why your treatment may need to be slowed down or stopped.
- How safe IVIg therapy is and some of its side effects.
- What you should do if you are pregnant or breast feeding.
- How IVIg therapy might affect other medicines you are taking and blood test results.

Why have I been given this information?

You have been given this information because your doctors have found that your immune system (or your child's immune system) is not making antibodies. They have recommended that you have IVIg therapy. This can help to treat your or your child's condition by giving you the antibodies you need to fight infections.

Reading this information will:

- Help you to know what to expect from your treatment.
- Help to make sure that your treatment is as safe and effective as possible.

What is intravenous immunoglobulin (IVIg) replacement therapy?

IVIg replacement therapy is a treatment which uses immunoglobulins which are taken from human blood to treat your condition. Immunoglobulins are a type of protein that contain antibodies. Antibodies help your body to fight infections.

We may give you IVIg:

- Through a needle that goes into a vein (intravenously).
- Subcutaneously (injected under the skin).

Why do I need IVIg?

You need IVIg therapy to increase the immunoglobulin levels in your blood because they are too low.

Low immunoglobulin levels can happen in people who:

- Cannot make enough immunoglobulin in their body. This is called primary immunodeficiency (PID).
- Have blood cancer (chronic lymphocytic leukaemia) and so have low immunoglobulin levels in their blood. This means that they keep getting infections that cannot be treated with antibiotics.
- Have bone marrow cancer. This causes low immunoglobulin levels. They may still get some infections even if they have been vaccinated against them.
- Have low immunoglobulin levels in their blood after a stem cell transplant.
- Have AIDS (acquired immunodeficiency syndrome) and keep getting infections.

IVIg is used:

- In people who have an immune deficiency to replace the antibodies that they should make.
- In therapy to make changes to a person's immune system so it works better (immunomodulation therapy) and in therapy to reduce symptoms of inflammation such as swelling, high temperature and redness (anti-inflammatory therapy). This includes:
  - Immunomodulation therapy of blood and organ autoimmune conditions. An autoimmune condition is one where the immune system is overactive, causing it to attack and damage your body's own tissues.
  - As an anti-inflammatory in:
    - Rheumatic inflammatory conditions such as arthritis.
    - Infections.
    - Disorders of the nervous system and brain (neurological conditions).
- To provide protection, that works straight away but is usually short-term, against specific infections. This is called hyperimmune therapy.

Are there people who should not have IVIg therapy?

Yes. **Do not** take IVIg if:

- You are allergic to human immunoglobulins or to proline.
- You have antibodies against IgA immunoglobulins in your blood.
- You have hyperprolinaemia type I or II. This is a very rare disorder.

Please tell your doctor or nurse if you know that you have any of these conditions.

How will you give me my IVIg?

We will give you a fluid containing IVIg from a drip. It will go into a vein through a tube with a small hollow needle at the end. This is called having an infusion.

A nurse will check how you are while you have your IVIg and for 20 minutes afterwards.

If you are having an infusion:

- That flows quickly (at a high infusion rate).
- For the first time.
- After a long break in treatment.

Someone will watch you closely for the whole time that you are having the treatment and for at least an hour afterwards to make sure that you are ok.

How will you know what dose of IVIg I need?

A nurse will work out the dose of IVIg that is right for you. This depends on your weight, your general health and how well you respond to the treatment.

To start with we will give you IVIg at a slow infusion rate. If you respond well to this the infusion rate will be increased slowly.

The dose for children and young people is worked out in the same way as the dose for adults.

Will the infusion need to be slowed or stopped?

The infusion will be slowed or stopped if:

- You have an allergic reaction to IVIg. You may be allergic to immunoglobulins without knowing it. You could have an allergic reaction even if you have had human immunoglobulins before and tolerated them well. Allergic reactions to IVIg are rare.
- If you have transfusion-related acute lung injury (TRALI). This can happen after you have had immunoglobulins including IVIg. Symptoms of TRALI include finding it difficult to breathe and fever. They typically appear one to six hours after receiving treatment.

It is very rare for people to get TRALI.

IVIg is made from human blood plasma. How safe am I from getting an infection from the IVIg infusion?

IVIg is made from blood plasma (the liquid part of the blood). When medicines are made from human blood or plasma, certain measures are taken to prevent infections being passed on from the blood donors. These include:

- Careful selection of blood and plasma donors to make sure those at risk of carrying infections do not provide blood to make medicines.
- Testing of each donation and batches of plasma for signs of virus or infection.
- Doing things that remove viruses from the blood or plasma or stop them from being able to give you an infection.

Even with these safety measures it is possible, but unlikely, that infections could be passed on.

The steps that are taken to make blood and plasma safe are considered enough to make sure that these viruses are not passed on:

- HIV.
- Hepatitis B.

- Hepatitis C.
- Non-enveloped Hepatitis A.
- Parvovirus B19.

Every time you are given a dose of IVIg, the name and batch number of the product are recorded so there is a record of the batches used.

What are the possible side effects of IVIg?

Like all medicines, IVIg can cause side effects although not everybody gets them. Side effects may be reduced or avoided by infusing at a slow rate.

Main side effects (which may happen to more than 1 in 10 patients) can include:

- Headache.
- Upset stomach.
- Pain including pain in the:
  - Back.
  - Legs, arms hands, or feet (the extremities).
  - Joints and bones.
  - Neck and face.
- Fever.
- Flu-like illness.
- Sore throat, blisters in mouth and throat, throat tightness.

Very rarely, side effects can include:

- Severe hypersensitive reactions like a fall in blood pressure or anaphylactic shock. If you have a severe hypersensitive reaction, you may:
  - Feel light-headed, dizzy, or faint when you stand up.
  - Feel cold in the hands and feet.
  - Have an abnormal heartbeat or chest pain.
  - Have blurred vision.

- Blood clots.
- Chest pain and painful breathing.
- Temporary non-infectious meningitis. This could give you a stiff neck, fever, nausea (feeling sick), headache and sensitivity to light.

Do tell your doctor or nurse straight away if you have any of the above symptoms.

What if I am pregnant or breast-feeding?

Tell your doctor or nurse if you:

- Are pregnant.
- Plan to become pregnant.
- Are breast-feeding.

Your doctor will decide whether you can have IVIg while you are pregnant or breast feeding.

Medicines with antibodies in them have been used to treat pregnant people and people who are breast feeding for many years. They have not been shown to have caused harm to the pregnancy or newborn babies.

If you have IVIg while you are breastfeeding the antibodies will be in your breast milk. This means your baby will also benefit from the protection they give.

Can I drive and use machines?

Some people get side effects such as feeling dizzy or sick when they have IVIg therapy. If this happens to you it could mean that you cannot drive or use machines safely.

Do not drive or use machines until these side effects have stopped.

How does IVIg affect other medicines and blood tests?

IVIg may:

- Change the results of some blood tests. This can happen for some time after your treatment has finished.

Do tell your doctor if you have had IVIg before you have any blood tests.

- Stop some vaccinations from working. This includes vaccinations against measles, mumps, rubella, and varicella.

Do wait for at least three months after your IVIg treatment before having these vaccinations.

Who can I contact if I would like further information or support after I have read this information?

Please contact your local ward or unit:

Royal Sussex County Hospital, Brighton.
Haematology Day Unit, Sussex Kidney Unit. **01273 696 955 Ext. 67413**
Monday to Friday 8:00 am to 7:00 pm

St. Richard's Hospital, Chichester.
Fernhurst Unit. 01243 788 122 Ext. 35154
Monday to Friday 8:00 am to 6:30 pm

Worthing Hospital
Amberley Unit 01903 205 111 Ext. 85710
Staffed Monday to Friday 8:00 am to 6:30 am

Balcombe Ward 01903 202 111 Ext. 86550
Staffed 24 hours a day, 7 days a week.

If you need help outside of staffed hours, please use the **NHS 111** online service **111.nhs.uk.**

This information is intended for patients receiving care in Brighton & Hove and Chichester St.Richard's hospital.

Ref. number: 2457 Publication date: 12/2024 Review date: 12/2027

CPIG
carer and patient information group approved