

Patient information factsheet

Intravenous immunoglobulin (IVIg) for neurological autoimmune conditions

We have given you this factsheet because your neurologist (a doctor who specialises in diagnosing and treating conditions of the brain and nervous system) has referred you for intravenous immunoglobulin (IVIg) to treat your neurological autoimmune condition.

This factsheet explains what IVIg is and how it is given so that you know what to expect. It aims to support the discussions you will have with your neurologist. If you have any questions or concerns, please contact us using the details at the end of this factsheet.

What are immunoglobulins?

Immunoglobulins, also called antibodies, are proteins naturally made from the liquid part of the blood (plasma). They form part of your body's immune system, helping you to fight infection and control inflammation.

What is IVIg?

IVIg is a blood product that is made up of concentrated immunoglobulins taken from plasma from a large number of blood donations.

IVIg can be used to treat conditions that cause the body to produce too many antibodies and attack itself (known as autoimmune diseases). The overproduction of antibodies, caused by a fault in the body's immune system, can lead to nerve and muscle damage. IVIg treats autoimmune diseases by dampening down and/or changing the body's harmful immune system response.

IVIg is given as an intravenous infusion. This means the treatment will be given to you via a cannula (a small plastic tube) that is placed in a vein in your arm.

Why do I need IVIg?

IVIg is used to treat a number of neurological autoimmune conditions, including:

Conditions affecting the nerves

- Guillain-Barré syndrome (GBS)
- Chronic inflammatory demyelinating polyradiculoneuropathy (CIDP)
- Multifocal motor neuropathy (MMN)

Conditions affecting the muscles

- Myositis

Conditions affecting the neuromuscular junction (connection between your nerves and your muscles)

- Lambert-Eaton myasthenic syndrome (LEMS)
- Myasthenia gravis

Conditions affecting the brain and spine

- Encephalitis
- Stiff person syndrome (SPS)

Your neurologist has reviewed your condition and believes IVIg to be the best treatment option for you.

How do I prepare for the treatment?

We will send you a letter containing important information about your upcoming IVIg appointment (such as the date, time and location). Please make sure you read this carefully.

Before you have IVIg, your physiotherapist or medical team may wish to see you in clinic to assess how your condition impacts your day-to-day function. If this is the case, they will contact you to arrange this.

Please note that not everyone will need to see a physiotherapist. This decision will be made by your neurologist and will depend on your diagnosis.

Eating and drinking

You will be able to eat and drink as normal before, during and after your treatment. It is important that you drink more fluids than usual on the day of your treatment so that you stay well hydrated.

Medication

You can continue to take your usual medications while you are having IVIg treatment. However, you must tell your neurologist of any medications you are taking (including over-the-counter medications).

Clothing

You will be able to wear your own clothes for this treatment.

Where will I receive the treatment and who will perform it?

You will receive IVIg on the neurology day case unit which is located on E level in the Wessex Neurological Centre. It will be performed by a specially trained IVIg nurse.

What will happen before the treatment?

Before your treatment, we will explain what IVIg involves, including the benefits and risks. This is a good opportunity for you to ask any questions that you may have. If you are happy to proceed with the treatment, we will then ask you to sign a consent form.

What will happen during the treatment?

We will take your blood pressure, temperature, and pulse. We will then carefully insert a cannula into a vein in your arm. If you have previously had a minor allergic reaction when receiving IVIg, we may give you an antihistamine (a medication that helps to relieve symptoms of allergies). We will then connect the bottle containing the IVIg to your cannula.

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The infusion will be given to you slowly over a period of several hours. We will monitor you closely for any side effects during this time and will provide treatment if necessary.

You will need to stay seated while you are receiving the infusion. However, if you need to move around (for example, go to the toilet), you will be able to do this.

After you have received the full dose of IVIg, we will remove the cannula from your arm.

What will happen after the treatment?

You will be able to return to your usual activities immediately after your treatment is complete as long as you are feeling well.

Most people will receive their treatment over the course of one day. However, if your neurologist has arranged for you to have treatment over several consecutive days, we will leave the cannula in your arm and cover it with a protective sheet. It is important that you keep the area around your cannula clean and dry to reduce your risk of infection.

How long will I be in hospital?

We will usually ask you to come to the day case unit first thing in the morning on the day of your treatment (please see your appointment letter for more details). Your first IVIg treatment session will usually take around eight hours in total. Following treatment sessions may be quicker depending on how your body tolerates the treatment.

How many treatment sessions will I need?

The precise dose of IVIg and the total number of treatment sessions you will need will vary depending on your weight and particular illness. Your neurologist will discuss this with you.

Are there any risks or complications?

IVIg is generally a safe treatment, but as with any medical treatment there are possible risks.

Common side effects

Common side effects that occur during the infusion include:

- headaches
- increase in blood pressure
- rash or mild fever

It is important to note that not everyone who has IVIg will experience side effects. However, if you develop any of the above symptoms during or after the infusion, let us know immediately.

Occasionally, people can develop an infection in the skin or vein where the cannula was inserted. If this is the case for you, please contact us as you may need to take antibiotics for a few days.

Serious complications

Serious complications from IVIg are rare but can include:

- a severe allergic reaction
- kidney problems
- blood clots

If you experience any of the above side effects or complications after you leave hospital, call our neuromuscular co-ordinator and specialist physiotherapist on **07824 124626** (Monday to Friday, 9am to 5pm). Outside of these hours, call NHS **111** for advice.

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Transmissible agents

IVIg products are screened for all known transmissible agents (viruses and bacteria that can be passed from person to person via a blood transfusion). For example, human immunodeficiency virus (HIV) and hepatitis A, B and C. We only use IVIg products that pass all these screening tests. However, despite taking multiple steps to avoid passing on infection, there could be other transmissible agents that we have not yet discovered. This means that infection from the IVIg products is still a very small potential risk.

Are there any alternatives?

Alternative treatment options for conditions caused by an overactive immune system attacking the body include:

- steroid medication
- non-steroid medication
- a medical procedure called plasma exchange

Please note that these alternative treatment options may not be appropriate for everyone. If IVIg is not a suitable treatment option for you or you do not wish to have IVIg, your neurologist will discuss these alternative treatment options with you in more detail, including the benefits and risks of each.

Will I receive any follow-up care?

Your neurologist will arrange for you to have a follow-up appointment with them three to six months after completing your treatment.

If you were assessed by a physiotherapist before having your IVIg treatment, your physiotherapist will arrange for you to have a follow-up appointment with them within one month of completing your treatment. At this appointment, the physiotherapist will perform tests to see how much the treatment has improved your condition.

Contact us

If you have any further questions or concerns, please contact us using the relevant details below.

For IVIg queries

Neuromuscular co-ordinator and specialist physiotherapist

Mobile: **07824 124626** (Monday to Friday, 9am to 5pm)

Email: neuroivig@uhs.nhs.uk

For appointment queries

Neurology care co-ordinator

Telephone: **023 8120 2303** or **023 8120 6784** (Monday to Friday, 9am to 5pm)

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