

Intravenous Immunoglobulin (IVIg) for Neurological Conditions

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This leaflet aims to answer your questions about Intravenous Immunoglobulin (IVIg) to treat your autoimmune condition, in which your immune system attacks your own body. If you have any questions or concerns, please speak to a doctor or nurse caring for you.

What is Intravenous Immunoglobulin (IVIg)?

Immunoglobulins, also called antibodies, are proteins naturally made by the body's immune system to help us fight infections. Intravenous Immunoglobulin (IVIg) is a medical product made up of many concentrated immunoglobulins. IVIg is made from the separated clear fluid part of blood (called plasma), pooled from many different blood donations.

How does IVIg work and what is it used for?

Your neurologist has recommended IVIg because you have an "autoimmune" illness, which is when your overactive immune system attacks your own body. IVIg works by helping to dampen down and change this harmful autoimmune response. In certain situations, IVIg can help treat:

- Autoimmune illnesses attacking the **nerves** in your arms and legs, such as *Guillain-Barré Syndrome (GBS)*, *Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)* or *Multifocal Motor Neuropathy (MMN)*.
- Autoimmune illnesses attacking the **muscles**, such as *Myositis*.

- Autoimmune illnesses attacking the **neuromuscular junction** (connection between the nerves and muscles), *such as Myasthenia Gravis*.
- Autoimmune illnesses attacking the **brain or spinal cord**, *such as Autoimmune Encephalitis, Stiff Person Syndrome (SPS) or Neuromyelitis Optica Spectrum Disorders (NMOSD)*.

How is IVIg given?

IVIg is given into a vein ('intravenous infusion') in your arm through a small plastic tube ('cannula'). Each infusion takes place in hospital and is given slowly over several hours. During the infusion, nurses will routinely check your pulse, blood pressure and temperature.

You might require only one course of IVIg, with infusions given on two to five successive days or you may need further courses of IVIg every few weeks, with infusions given on one day or on two successive days. The precise dose of IVIg, and total number of IVIg infusions, varies depending on your weight and particular illness. Your neurologist will discuss what is appropriate for you.

Will I benefit from IVIg treatment?

Medical research studies have shown that many, but not all, patients with the above listed neurological conditions can benefit from IVIg. The degree of benefit varies from person to person and generally IVIg does not "cure" the underlying disease but instead dampens the harmful inflammatory effects of it. This has the potential to lead to more rapid recovery and to minimise further damage from continuing harmful inflammation.

Dependant on your underlying illness, there may be a need to temporarily pause your regular IVIg treatment every one to two years, to find out whether your disease is still active (meaning you will need to

continue IVIg) or inactive, also known as “in remission” (meaning you will not need to continue IVIg).

What are the possible side effects of IVIg treatment?

As with all treatments, there is a risk of side effects from IVIg. Everyone is different and may react differently and it is important to note that not everybody gets side effects. Most IVIg side effects when they do happen are minor and more serious side effects are rare.

Common (5 - 20%)

- During the infusion: mild flu-like symptoms including headache, chills, fever, feeling hot or cold, flushing and mild ache in the back or joints. These are usually related to how quickly you are receiving the infusion and get better on slowing down the infusion rate or with paracetamol. Please let the nurse know if you experience problems during the infusion.
- Headache, especially if you already get migraines.

Uncommon (under 5%)

- Itchy skin rash, similar to eczema, which can last for a few weeks.
- Infection in the skin or vein in your arm where the cannula needle was inserted, which may require antibiotics for a few days.

Rare but more serious problems (less than 1%) - all treatable

- Inflammation of the brain’s protective linings leading to a severe headache, called aseptic meningitis.
- Stroke, heart attack or blood clot in lung or leg. The risk of these complications is higher if you have already had one of these or if you have other risk factors like diabetes, heart problems or uncontrolled high blood pressure.
- Kidney problems. The risk of this is higher in people who already have kidney problems.

- A very rare, less than 0.01%, risk of severe allergic reaction (anaphylaxis) which leads to swelling of the face and throat, difficulty breathing, low blood pressure (feeling very faint) and widespread itchy skin rash.

IVIg is a blood product. Is there a risk of infection?

All blood donors are carefully screened and their blood donations are tested for a range of known viruses. The manufacturing process of IVIg also includes virus inactivation steps against common viruses including HIV, Hepatitis B and Hepatitis C and the pooled IVIg product itself is then again tested for any evidence of infection. Since the improvement of sterilisation procedures, no case of infection caused by IVIg has been reported in the last 30 years.

Despite the current strict sterilisation measures, the extremely rare possibility of transferring an infection through infusion of IVIg cannot be totally excluded, including unknown or emerging viruses or other types of infections such as variant Creutzfeldt Jakob Disease (vCJD), which cannot be tested for in blood products. This is also why you cannot donate blood for the rest of your life after receiving IVIg.

These extremely rare risks remain theoretical and to date there is no evidence of vCJD ever being transmitted by IVIg, despite the many years of worldwide IVIg infusions.

Which IVIg product will I receive?

IVIg is made by different manufacturers, so there are different brand names such as Intratect, Privigen, Octagam, Flebogamma, Kiovig etc. These all contain the same active ingredient (immunoglobulins) but they have slightly different other ingredients which can affect the risk of side effects for some people. If you have continuing side effects with one brand of IVIg, your treating team might discuss trying another brand.

Apart from IVIg, are there other options to treat my overactive immune system?

Some autoimmune illnesses, caused by an overactive immune system attacking the body, may also be treated with other options including steroid medication, non-steroid tablets or a medical procedure called plasma exchange which involves removing the liquid part of your blood (plasma) with a replacement fluid that does not contain harmful immune substances.

These other treatments might not be appropriate for all patients and like IVIg they all have potential benefits and potential risks. Your neurologist will discuss these options with you and what might be most suitable in your individual case.

Useful sources of information

Guillain-Barré & Associated Inflammatory Neuropathies (GAIN) Charity

<https://gaincharity.org.uk>

Myositis UK

<https://www.myositis.org.uk>

Myasthenia Gravis (Myaware) Charity

<https://www.myaware.org/>

NHS NMOSD Specialised Services website

<http://www.nmouk.nhs.uk/what-is-nmo>

Encephalitis Society Charity

<https://www.encephalitis.info/>

Contact us

If you have any questions or concerns about IVIg, please speak to a member of the ward team if you are an inpatient (in hospital) or contact your consultant's secretary if you are an outpatient (at home).

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit

www.stgeorges.nhs.uk

Additional services

Patient Advice and Liaison Service (PALS)

PALS can offer you on-the-spot advice and information when you have comments or concerns about our services or the care you have received. You can visit the PALS office between 9am and 5pm, Monday to Friday in the main corridor between Grosvenor and Lanesborough Wing (near the lift foyer).

Tel: 020 8725 2453 **Email:** pals@stgeorges.nhs.uk

NHS Choices

NHS Choices provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health.

Web: www.nhs.uk

NHS 111

You can call 111 when you need medical help fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones.

AccessAble

You can download accessibility guides for all our services by searching 'St George's Hospital' on the AccessAble website (www.accessable.co.uk). The guides are designed to ensure everyone – including those with accessibility needs – can access our hospital and community sites with confidence.

