NHS
Lancashire Teaching
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Information for patients and carers

Home therapy with intravenous immunoglobulin (IVIG)

Please read this leaflet as well as the others listed at the end. If you have any questions please ask the neuromuscular nurse, your consultant, or a member of the day treatment centre staff.

What is IVIG?

Intravenous immunoglobulin (IVIG) is a blood product made from pooled plasma from many different people. Intravenous immunoglobulin preparation contains antibody molecules dissolved in a sterile solution. Most products contain sugar which is added to help keep the antibody molecules stable during storage.

What is IVIG used for?

IVIG is licensed to treat numerous inflammatory neurological conditions. It is used both in the acute emergency settings and as long-term treatment for chronic neurological disorders. It is sometimes used in conditions without a license but where IVIG is commonly prescribed by neurologists in the UK.

How does IVIG work?

The way that IVIG works in these conditions is not fully understood. It probably blocks harmful antibodies and other immunological factors produced by the patient’s own immune system, which attack nerve fibres.

How is IVIG given?

IVIG is given through a drip at a rate, dose and time which is individualised for each person based on height and weight for the initial doses. The first treatment is usually given over 3-5 days as an inpatient. This may be all that is required, but it may need to be repeated in some cases. Subsequent IVIG treatments can normally be given as a day case in the hospital. It is usually given every 3 to 4 weeks depending on the individual’s needs. Once the patient is stable alternative arrangements can be made to have the IVIG at home with the support of a Home Care Provider (HCP) (this is termed home therapy (HT)).

What are the possible side effects?

As with all treatments, side effects can occur with IVIG. These are usually mild and do not require the treatment to be stopped. Common transient side effects are hives, flushing, fever, shivering, muscle aches, high blood pressure, sickness, and headaches. These usually respond to slowing the infusion. Occasionally, people may develop a rash, or low blood pressure.

Rarely there may be more serious side effects, which can include allergic reactions, kidney failure, blood clots in the legs or lung (deep vein thrombosis or pulmonary embolism), heart attacks and strokes, as well as clotting problems or severe headaches. Another rare side effect is an abnormal break down of red blood cells (haemolysis), this causes severe anaemia and the urine to become very dark.
As IVIG does thicken the blood slightly, particular caution is taken with people with a past history of heart or kidney diseases, poorly controlled blood pressure, strokes or blood clots.

Any of these side effects can happen immediately or several days after treatment and if you are unwell after treatment, you should seek urgent medical advice. Either contact the neuromuscular team urgently for advice or out of hours call the Neurology ward at Royal Preston Hospital). Contact numbers are below.

Side effects are more common if the immunoglobulin is given too quickly. It is important that your immunoglobulin is given safely; the HCP nurse will supervise the infusion rate. If you are unwell the nurse will slow your infusion rate. As with IVIG treatment in the hospital we recommend that you ensure good fluid intake before, during, and after treatment as this may help reduce the risk of side effects.

Side effects are more common if you are suffering from an active infection. You should always seek medical advice before infusing if you feel unwell. If you feel unwell your infusion will be delayed by the HCP nurse for one or two days until you feel better. If you are uncertain what to do, contact the neuromuscular nurse for advice.

Please see our document ‘IVIG at home – what to do if you have an adverse reaction’ for advice on what to do if you experience any side effects.'

Are there any other risks with IVIG?

As IVIG is a blood product, the blood from which it is made is checked for all known transmissible agents that can be screened (e.g. hepatitis B and C and HIV). Although stringent steps are taken to avoid passing on an infection, there remains a remote theoretical risk of it occurring. Variant Creutzfeldt Jakob Disease (vCJD) is a very rare potentially transmissible disease but there is so far no evidence that it can be transmitted by IVIG. At present there is no test to see if vCJD is present in IVIG.

Which immunoglobulin product should I have?

There are several immunoglobulin products which are available in the UK. These are all made from pooled plasma from many different 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 usually be changed except for clinical reasons such as recurrent side effects, or if the product is unavailable.

What will happen prior to starting your treatment at home?

Your consultant will assess your suitability for home therapy (HT) with the neuromuscular nurse. They will then discuss HT with you prior to starting the treatment at home and provide you with relevant written information. You will need to sign a consent form agreeing to accept the requirements of the HT programme (for example, attending the HT clinic at Royal Preston Hospital for a review every three to six months).

The HCP delivers the immunoglobulin and consumables to your home, you will need to find adequate space to store the immunoglobulin safely (this may require storage in a fridge which will be provided). The HCP arranges for an infusion nurse to visit you and provide treatment. The neuromuscular nurse will be present at the first visit. You will be expected to maintain an infusion diary, recording batch numbers and contact the specialist nurse following your IVIG with these details.

All batch numbers from your immunoglobulin are recorded on the national immunoglobulin database by the specialist nurse so you must send the batch numbers to the nurse via phone or email on the same day of your infusion.

Who will deliver all the equipment?

The HCP will deliver all the medication and consumables you need for the first 3 months, and you will receive regular re-supply from the company every 1 to 3 months. The IVIG comes in a variety of bottle sizes, usually 5gm (50ml), 10gm (100ml), 20gm (200ml). A home visit will be carried out by the neuromuscular nurse to identify any further problems or issues with administering the treatment at home.

Before the infusion

Please ensure you are well hydrated. Ensure you have good fluid intake whilst you are receiving IVIG (2 to 3 litres on the day of infusion, and on the day before and the day after). Let the HCP or neuromuscular nurse know if you are pregnant, or if you have diabetes, kidney problems or a previous allergic reaction to IVIG or other drugs.

Vaccination and IVIG

If you require any vaccines, you must check your health care provider whether or not it is a live vaccine. For more information see the information leaflet ‘Information sheet about intravenous immunoglobulin (IVIG) in the treatment of acute and chronic neurological diseases’

Holiday

To reduce the risk of thrombosis, you are advised not to fly for 1 week following your IVIG treatment. Please take this into account when booking your holidays, and let the neuromuscular nurse know of any potential difficulties as soon as possible. We may be able to change your treatment dates, but it is important to continue a regular treatment cycle.

What if I have a question?

If you have any non-urgent questions, please speak to your consultant or specialist nurse at your next appointment. If your question is urgent, please contact your specialist nurse or the Brock Infusion suite.

Contact numbers for help or advice:

Neuromuscular specialist nurse	**01772 523412**
Brock Infusion suite	**01772 523248**
Neurology ward at Royal Preston Hospital (out of hours urgent advice)	**01772 524312**

Other relevant leaflets

- Information sheet about intravenous immunoglobulin (IVIG) in the treatment. of acute and chronic neurological diseases.
- Intravenous immunoglobulin (IVIG) at home - what to do if you have an adverse reaction.

Sources of further information

www.lancsteachinghospitals.nhs.uk
www.nhs.uk
www.accessable.co.uk
www.patient.co.uk

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If you want to stop smoking, you can also contact Smokefree Lancashire on Freephone **08081962638**

Please ask a member of staff if you would like help in understanding this information.
This information can be made available in large print, audio, Braille and in other languages.

Department: Neurology
Division: Medicine
Production date: October 2023
Review date: October 2026
JR 1031 v1