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Information for patients and carers

Intravenous Immunoglobulin (IVIG) in the treatment of acute and chronic neurological diseases

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 additives to help keep the antibody molecules stable during storage.

What is IVIG used for?

IVIG is a licensed treatment for numerous inflammatory conditions and is commonly used for neurological diseases. It can be used in the acute emergency setting or as a long-term treatment for chronic conditions. Sometimes IVIG is used for conditions where it is not licensed but is routinely used by neurologists in the UK and elsewhere.

How does IVIG work?

The way that IVIG works in these conditions is not fully understood. It is thought that it blocks harmful antibodies and other Immunological factors produced by the patients 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 weight. The first treatment is usually given over 3-5 days in hospital as an inpatient. This may be all that is required.
In some patients, treatment may need to be repeated and subsequent treatments can normally be given as a day case. IVIG is initially given in hospital, but for some people arrangements can be made to have the treatment at home. If you are offered home treatment you will be given further information leaflets to explain this in more detail.

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 short lasting side effects are flushing, fever, shivering, muscle aches, sickness and headaches. These sort of side effects usually respond to slowing the infusion. Occasionally, people may develop a rash, or low blood pressure. Some individuals may feel unusually tired for a day or two after treatment. Some patients may develop a more severe headache, similar to a migraine. This is sometimes termed 'aseptic meningitis' (inflammation of the tissue covering brain and spinal cord). It is important to know that this is a benign condition which recovers fully over a few days and is NOT linked to other more serious forms of meningitis (infection of the protective membranes and spinal cord).

Rarely there may be more serious side effects, which include allergic reactions (including very rarely severe reactions termed anaphylaxis), 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 headache. Another rare side effect is abnormal break down of red blood cells (haemolysis), this causes severe anaemia and the urine to become very dark. Any of these side effects can happen immediately or several days after treatment. If you experience any severe symptoms, please seek medical advice urgently – either contact the neuromuscular team for advice, or out of hours call the Neurology ward at Royal Preston Hospital. In an emergency, dial 999. Contact numbers are below.

Because IVIG does thicken the blood slightly, particular caution is taken with people with a history of heart or kidney disease, poorly controlled blood pressure, strokes or blood clots.

Therefore, various blood tests are required before you start IVIG treatment, and the nursing staff will monitor you carefully during and after the infusions.

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 A, B and C and HIV). Although extensive 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 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.

Before the infusion

You will be required to consent to the IVIG treatment, and the doctor will discuss this with you prior to your first treatment. This involves you signing a consent form.

Please ensure you are not dehydrated. We recommend a minimum fluid intake of 2 to 3 litres per day (on the day of the infusion, and also the day before and the day after). Your fluid intake will be recorded whilst you are receiving IVIG. Let the nurses know if you are pregnant, or if you have had diabetes, kidney problems or a previous allergic reaction to IVIG or other drugs.

After the infusion - delayed reactions

Some reactions to IVIG can be delayed, occurring up to a few days after treatment. These include blood clots in the lung and haemolysis. Symptoms may include a rash, itchiness of the skin, headaches, tightness or wheeze in the chest, breathlessness, pain or swelling in the legs, drowsiness, marked dizziness, collapse or fainting, or passing very dark urine. If you get any symptoms as described above after an infusion you should get medical advice urgently – either contact the neuromuscular team for advice, or out of hours call the Neurology ward

at Royal Preston Hospital. In an emergency, dial 999. Contact numbers are below.

Holidays

It is advised that you should not fly for 1 week following your IVIG treatment. Please be aware of this at the time of your booking. We may be able to change your treatment dates, but it is important to continue a regular cycle of IVIG.

Vaccination

Immunoglobulin may interfere with the immune response to live virus vaccines which should therefore only be given at least 3 weeks before or 3 months after an injection of normal immunoglobulin. These vaccines include measles, rubella, mumps, TB and varicella. This does not apply to yellow fever vaccine since normal immunoglobulin does not contain antibody to this virus.

In the case of measles, this impairment of response may persist for up to 1 year. Therefore, patients receiving measles vaccine should have their antibody status checked subsequently.

Contact details

Neuromuscular specialist nurse	**01772 523412**
Brock Infusion suite contact number	**01772 523248**
Neurology ward at Royal Preston Hospital	**01772 524312**

Sources of further information

www.lancsteachinghospitals.nhs.uk
www.nhs.uk

www.accessable.co.uk
www.patient.co.uk

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