

Information for patients and carers

Intravenous immunoglobulin (IVIG) at home

What to do if you have an adverse reaction

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.

Immunoglobulin can be safely given at home. There are some simple measures you can take to reduce the likelihood of reactions and to treat any reactions that occur. If you are not sure, always seek medical advice from your neurology team. Please read this and the other leaflets listed at the end carefully. It is quite common for patients to feel tired for a day or two after the treatment. 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).

How to avoid adverse reactions

Remember you must not infuse if you have signs of an untreated infection. These can be feeling generally unwell, feeling hot or cold, having a temperature or specific symptoms like a persistent cough or symptoms of a urine infection (lower stomach pains, pain on passing urine, passing urine more frequently).

If you are unsure, delay your infusion and phone the neuromuscular nurse for advice. If tests show that you have an infection, then you should only have your next IVIG infusion when you have started taking antibiotics and you are feeling well.

You must have antihistamine (e.g. Piriton (chlorpheniramine) 4mg or cetirizine 10mg) and paracetamol at home - remember to check the expiry dates periodically.

Mild reactions (common)

Mild symptoms of headache, rash, mild itching, feeling sick, aches all over the body, anxiety, dizziness, irritability or other mild symptoms.

To treat these symptoms, you should do the following:

Alert the Home Care Nurse (HCN), who will stop the infusion

- Take an antihistamine (such as Piriton (chlorphenamine) 4mg or cetirizine10mg) and take paracetamol 1gm
- The HCN will restart the infusion when the symptoms subside
- If your symptoms do not subside, then the infusion will not be restarted – see the next section on moderate reactions.

Moderate reactions

If you experience any of the following symptoms:

Headache, dizziness, severe itching, flu like symptoms such as going from very hot to very cold, skin rash or any of the mild reaction symptoms described above getting worse:

To treat these symptoms, you should do the following:

- At the earliest opportunity alert the HCN who will stop the infusion and let the neuromuscular nurse or Brock Infusion suite team, or your GP know that you are feeling unwell
- Take an antihistamine (such as Piriton (chlorphenamine) 4mg or cetirizine10mg) and take paracetamol 1gm, if taken earlier do not repeat the dose of antihistamine and paracetamol
- Do not do any more infusions until advised to do so

Severe reactions (rare)

Patients may experience a severe reaction; however, this is exceptionally rare.

Symptoms are rash, itchiness in areas away from the injection site, headaches, tightness in the chest, wheeze in the chest, breathlessness, drowsiness, marked dizziness, collapse or faint, passing very dark urine, or any of the moderate symptoms described above getting rapidly worse:

If you experience these severe symptoms, you should:

- Alert the HCN who will stop the infusion
- · Lie down on your side in the recovery position
- The HCN will dial 999 for an ambulance
- Keep all the bottles of the immunoglobulin do NOT throw them away
- Report to the neurology team (contact details below). If you have any sort of reaction, you must inform the neuromuscular nurse specialist as soon as possible. For safety reasons your next infusion may need to take place in clinic

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. Please see the other information leaflets at the end of this document for more details. 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 (ward 17, Royal Preston Hospital). Contact numbers are below.

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.
- Patient information home therapy with intravenous immunoglobulin (IVIG).

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

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