

Information for patients and carers

Subcutaneous immunoglobulin (SCIG) 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 below 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 inject if you have symptoms 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 water (urine) infection (lower stomach pains, pain on passing urine, passing urine more frequently).

If you are unsure, delay your injection and telephone the neuromuscular nurse for advice. Only inject when you have started taking antibiotics to treat the infection and you are feeling well.

Do not inject when you are in a rush – mistakes are more likely to happen. You must have antihistamine (e.g. Piriton (chlorphenamine) 4mg or cetirizine 10mg) and paracetamol at home and 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:

- Take an antihistamine such as Piriton (chlorphenamine) 4mg or cetirizine10mg and take paracetamol 1gm; if the symptoms go away then continue with the injection as normal; if the symptoms persist go to 'Moderate reactions' (See below)
- If there is abnormal swelling or pain at the injection site, the needle will need to be re-sited. Throw away the original needle using a sharps container and re insert using a new needle

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:

- Stop the injection
- 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
- Let your injection partner know and the neuromuscular nurse or Brock infusion suite team or your GP at the earliest opportunity for advice
- Do not do any further injections until advised to do so

Severe reactions (rare)

Patients may experience a severe reaction however this is exceptionally rare. Symptoms are rash, itchiness in area away from the injection, headache, tightness in the chest, wheeze in the chest, breathlessness,

drowsiness, marked dizziness, collapse or faint, dark discolouration of your urine, or any of the moderate symptoms getting rapidly worse:

If you experience these severe symptoms, you / your partner should:

- Stop the injection
- Lie the person down on their side in the recovery position
- 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

Is it safe to have the injection?

The injection contains a small amount of radioactivity that emits gamma rays (these are similar to X-rays). We use the smallest dose possible, in line with national regulations to provide as much information as we can about your condition. The results of your scan will give your doctor useful information about your condition and will help to plan your treatment.

Delayed reactions

Some reactions to SCIG 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 information. If you have any symptoms as described above after an infusion you should get medical advice urgently – either contact the neuromuscular team urgently for advice or out of hours call the Neurology ward (Royal Preston Hospital). All contact numbers are below.

Contact for help or advice

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

Other relevant leaflets:

- 1. Information sheet about intravenous immunoglobulin (IVIG) in the treatment of acute and chronic neurological diseases.
- 2. Patient information home therapy with intravenous immunoglobulin (SCIG).

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.

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