

University College London Hospitals 
NHS Foundation Trust

National Hospital of Neurology and Neurosurgery

Queen Square Centre for Neuromuscular Diseases

Patient information leaflet: **Intravenous Immunoglobulin (IVIg)**

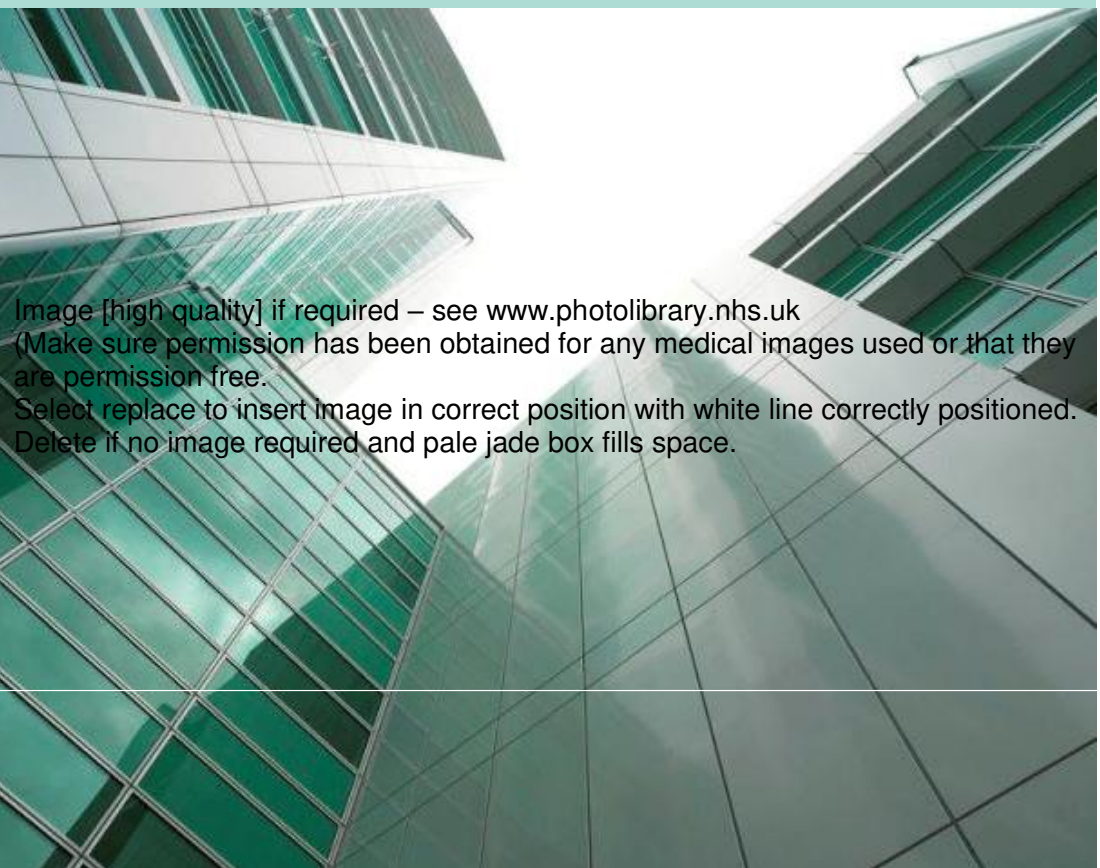


Image [high quality] if required – see www.photolibrary.nhs.uk
(Make sure permission has been obtained for any medical images used or that they are permission free.
Select replace to insert image in correct position with white line correctly positioned.
Delete if no image required and pale jade box fills space.

uclh

Contents

1. Introduction	3
2. What is intravenous immunoglobulin?	3
3. Why is it used?	3
4. What are the possible side effects?	3
5. Is there an alternative?	5
6. What happens if I choose not to take it?	5
7. How do I take it?	5
8. Is IVIg safe in pregnancy and breast-feeding?	6
9. Where can I get more information?	7
10. References	7
11. Contact details	7
12. How to find us	8

Introduction

This booklet discusses the use of intravenous immunoglobulin (IVIg) in inflammatory neuromuscular diseases: what is it, why is it used, how is it taken, the aims and possible side effects related to its use.

The Queen Square Centre for Neuromuscular diseases have produced this leaflet as part of a guideline for patients and healthcare staff on the safe and appropriate use of medication which suppresses the immune system in inflammatory neuromuscular diseases. Content is reviewed and updated every 2 years by Dr Aisling Carr, consultant neurologist.

What is intravenous immunoglobulin?

Immunoglobulins are proteins produced by the immune system (the body's own defence system) that help to fight infection. Intravenous immunoglobulin, or IVIg, can dampen down some inflammatory diseases that involve the immune system.

IVIg is a blood product that combines immunoglobulins from several donors. The donors will have been screened to make sure that they have no serious diseases that can be passed on, for example hepatitis B, hepatitis C and HIV.

Why is it used?

IVIg is used in the treatment of several inflammatory neuromuscular conditions including:

- Chronic inflammatory demyelinating polyradiculoneuropathy (CIDP)
- Multi-focal Motor Neuropathy with conduction block (MMN)
- Severe exacerbations of myasthenia gravis
- Guillan Barre syndrome (GBS)
- Polymyositis and dermatomyositis.

What are the possible side effects?

People having IVIg may occasionally experience a reaction during or after the infusion. The symptoms of this include:

- chill,

- headache,
- stomach pain,
- fever,
- nausea or vomiting,
- joint pain (particularly low back pain)
- or tiredness.

If these symptoms occur during the infusion it will be slowed down or stopped as necessary and the symptoms usually settle quickly. If possible, you'll be given the same brand of IVIg (e.g. Flebogamma or Octagam) each time. However, sometimes difficulties with supply of IVIg mean that another brand has to be used.

In rare cases, people having IVIg may experience:

- a rash
- severe headache (aseptic meningitis)
- a type of anaemia called haemolytic anaemia, which will improve over time.

All these rare side-effects can be treated.

Very rarely, people may experience a severe allergic reaction. The symptoms can include chest tightness, breathing difficulties, a rash, swelling of the face or tongue, and a drop in blood pressure. If this happens, urgent medical attention is needed. If the reaction is severe, then your treatment can't be continued.

Very occasionally it can cause increased clotting of the blood leading to an increased risk of problems such as heart attack, stroke, and blood clots in the lung (pulmonary embolism) or legs (deep vein thrombosis, or DVT).

A nurse will monitor you during the infusion but you should report any new symptoms during or after the infusion. These reactions occur only in a minority of patients.

What are the risks?

All donors of the blood from which IVIg is made are carefully screened for serious diseases that could be passed on to you. However, it's impossible to completely eliminate the risk of passing on infection, for example with an unknown virus.

Is there any reason I won't be prescribed IVIg?

You may not be prescribed IVIg if you've had a severe previous reaction to immunoglobulin. If one particular type of immunoglobulin (called IgA) is absent, then you may not be given IVIg.

If you have an active infection, even something mild like a cold or a flu, your IVIg will be postponed until you are well again.

If you are at high risk of blood clots (stroke, heart attacks, DVT or PE) your consultant will carefully consider the pros and cons of IVIg in you before deciding whether the treatment is suitable.

Is there an alternative?

In some conditions (CIDP, MG, dermatomyositis and polymyositis) oral or intravenous steroids can be given instead of IVIg. The indications and side effects of steroids are documented in another of our patient information leaflets. However, steroids can worsen other conditions such as MMN and GBS. Another alternative is plasma exchange (PLEX). You may be offered the chance to participate in a clinical trial. You will be approached by your consultant if this is an option for you.

The medical team will explain the alternatives and the typical outcome in people with your condition if treated or left untreated. If they are happy that you fully understand the implications of your decision your choice will be respected.

How do I take it?

IVIg is given by intravenous infusion (a drip into a vein). The starting dose is calculated according to your body weight and will be given in hospital, usually in our Day Care Unit (DCU). Some patients have the treatment as an inpatient on the ward. Bloods are taken before your first ever treatment, but we do not need to check your bloods every time.

The infusion will take several hours as the drug has to be given slowly at first. The rate of the infusion can be gradually increased if you have no problems. You'll be observed closely and have your blood pressure, pulse and temperature checked regularly.

If there is a clear response to the treatment and you have one of the conditions that requires regular ongoing IVIg (CIDP, MMN, myositis) you may require repeat courses every few weeks. The exact dose, how often you need it and how quickly it can be infused (usually over between 1 and 5 days) will be worked out between you and your neurology team.

How long does IVIg take to work?

IVIg doesn't work straight away. It may take 2–12 weeks to take effect. At this point treatment response is measured by a set of examinations performed by your doctor. This information is used to work out if you need regular infusions, what dose and how frequently you will require it.

This information must be entered onto a national IVIg database to ensure appropriate use of this limited medical product.

Not all people who respond well to IVIg initially will need it forever. It is very important to constantly reassess your need for IVIg. These assessments are performed by your neurology team.

Can I take other medications with IVIg?

IVIg doesn't usually interfere with other medications. However, you must tell your doctor which medicines you're currently taking, including over-the-counter preparations and herbal remedies.

Can I drink alcohol while taking IVIg?

There's no particular reason to avoid alcohol before or after IVIg treatment.

Should I get regular vaccinations?

Pneumococcal vaccine (which gives protection against the commonest cause of pneumonia) and yearly flu vaccines are recommended. But IVIg may interfere with the immune response following any vaccine and this can make the vaccine less effective. Therefore it's best to avoid vaccines for at least six weeks (sometimes longer, depending on the exact vaccine) after having IVIg.

Is IVIg safe in pregnancy and breastfeeding?

IVIg is safe in pregnancy and breast feeding.

References

IVIg Guideline Development Group of the IVIg expert Working Group. Department of Health Second edition **Clinical guidelines for Immunoglobulin Use**. May 2008.

Association of British Neurologists. **Guidelines for the use of intravenous immunoglobulin in neurological diseases**. Revised July 2015.
<http://www.theabn.org/media/docs/ABN%20publications/IVIg-guidelines-final-July05.pdf>

Contact details

Laura Compton

Neuromuscular Immunology Nurse Specialist

Email: Laura.Compton@nhs.net

Direct tel: +44 (0)20 3448 8026

Extension: 88026

Address: Queen Square Centre for Neuromuscular Diseases, 8-11, Queen Square, London, WC1X 1BD

Website: <http://www.cnmd.ac.uk/>

Where can I get more information?

www.wikipedia.org/wiki/intravenous_immunoglobulin

www.arthritisresearchuk.org

For further detail please also see the relevant Summaries of Product Characteristics (SPC) document at www.medicines.org.uk

Guillain-Barré & Associated Inflammatory Neuropathies Charity

Tel: 01529469910

<http://www.gaincharity.org.uk/>

British Rheumatological society: Patient information

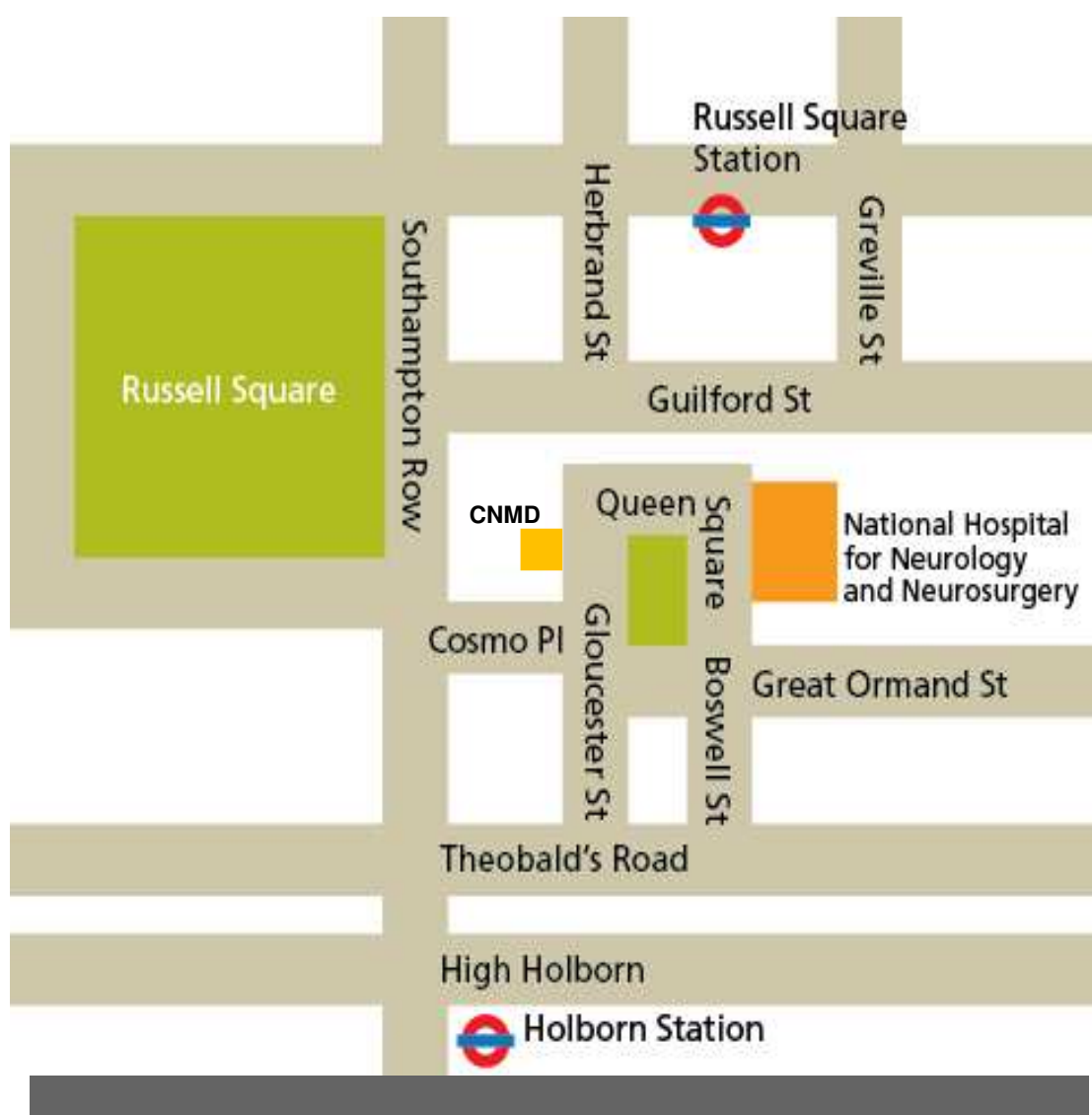
Tel: +44 (0) 20 7842 0900

<http://www.rheumatology.org.uk>

UCLH cannot accept responsibility for information provided by external organisations.

How to find us

Neuromuscular outpatient clinics run across the hospital outpatient departments, please see your appointment letter for further information. The Centre for neuromuscular diseases (CNMD) is based on the ground floor of 8-11 Queen Square, directly across from the main hospital entrance.



Space for notes and questions

First published: December 2016 Date last reviewed: April 2020
Date next review due: April 2022
Leaflet code: [CONTACT THE PATIENT INFORMATION CO-ORDINATOR]
© University College London Hospitals NHS Foundation Trust



We are committed to
delivering top-quality patient
care, excellent education
and world class research

Safety
Kindness
Teamwork
Improving