

IMMUNOGLOBULIN PRODUCTS FOR CIDP

Chronic inflammatory demyelinating polyradiculoneuropathy (also known as chronic inflammatory demyelinating polyneuropathy, CIDP) is a rare autoimmune disease that affects the nerves in the arms and legs. The disease can be treated, and symptoms may even be reversed if diagnosed early enough. There is no cure for CIDP.

This fact sheet explains how immunoglobulin (Ig) products can be used to treat CIDP, to help you make informed decisions about the care that is right for you.

What is CIDP?

C	Chronic The disease occurs gradually over a long period of time.
I	Inflammatory Inflammation is the main cause of damage to the nerves.
D	Demyelinating The damage affects the myelin (protective protein coating) around nerves.
P	Polyradiculoneuropathy (also known as polyneuropathy) The disease affects multiple nerves in the arms and legs.

In people with CIDP, the immune system attacks the protective nerve covering called myelin. CIDP can affect people of all ages but is more common in males and those over the age of 50.

The most common symptoms of CIDP are weakness, numbness and tingling in the arms and legs. It can make walking difficult and impair balance.

Treatment options for CIDP

The main evidence-based treatments for CIDP are immune modulation therapy (IMT) with immunoglobulin products, corticosteroids and plasma exchange. These treatments help reduce the immune-mediated nerve damage.

The goals of CIDP treatment are to:

- ▶ improve physical function
- ▶ reduce symptoms that stop you from undertaking daily activities, and
- ▶ reach and maintain long-term remission (recovery without the need for ongoing treatment) if possible.

Most people respond to one or more of these treatments. Your doctor will discuss your history and needs, so you can agree on the treatment that is right for you.

How can immunoglobulin products help my condition?

Immunoglobulins, also known as antibodies, are proteins in the blood that help the immune system fight infections and diseases. IMT uses immunoglobulin products that have been purified from plasma collected from thousands of healthy blood donors. These products are carefully tested, screened, filtered and treated to make sure they are safe to use.

The healthy antibodies in immunoglobulins block the processes that attack and destroy myelin. This helps protect nerves and their myelin covering, allowing them to gradually regrow. IMT can help reduce the effects of CIDP, but it is not a cure for CIDP.

How is immunoglobulin given?

Immunoglobulin products can be injected into a vein (intravenous immunoglobulin, IVIg) or injected just below the skin (subcutaneous infusion of immunoglobulin, SCIg). Both methods are effective and safe.

- ▶ **Initial (first) treatment:** IVIg is given over 2 or more days while you are monitored in hospital. Many people with CIDP show some response after this initial treatment.
- ▶ **Maintenance (ongoing) treatment:** You may continue treatment with IVIg (normally every 3–4 weeks) in hospital or SCIg (1–3 times per week) at home. The best method for you will depend on factors such as your medical history and preferences. SCIg is accessed through hospitals approved to offer SCIg programs.

Your dose and the number of infusions will be determined by your doctor. The dose may change depending on your response to treatment. This will help make sure you receive the best amount of immunoglobulin for you.

What are the side effects of immunoglobulin products?

Side effects differ according to the method used and your condition.

- ▶ Most people tolerate IVIg well, but side effects from **IVIg** can include headache, fever, chills, nausea, fatigue, or flu-like illness ('systemic' effects) and are usually mild and short lived. They often occur just after your infusion and usually can be reduced by a slower infusion rate or by taking paracetamol, antihistamines, or other medications before and/or after the infusion. Serious adverse events are rare but include severe allergic reactions (anaphylaxis), aseptic meningitis, reduced kidney function and blood clots.
- ▶ Systemic side effects from **SCIg** are much less common than from IVIg. Local injection-site reactions (eg, redness, itching and swelling) are common but improve with time.
- ▶ The risk of receiving a blood-borne infection from a plasma-derived blood product is close to zero due to various testing and screening stages and safety measures.

As with any treatment, you should discuss individual risks and benefits with your healthcare team.

How long will I need treatment for?

Most people who respond to immunoglobulin products show some improvement in symptoms within the first 6 weeks, often after the initial induction treatment. If no improvement is seen within the first 4 months, your doctor will stop your immunoglobulin treatment and discuss other treatment options.

Depending on your response to immunoglobulin products, your healthcare team may discuss changing dosage, treatment intervals, or trialling new formulations to make sure your treatment is tailored to you. The goal is to find the lowest effective dose needed to keep your condition stable.

Your doctor may suggest trying a short break from treatment if you have been stable and are well.

CIDP can go into remission, which means the disease is inactive and does not require treatment. Your doctor may test whether you are in remission by stopping or decreasing your immunoglobulin treatment if you are well and your symptoms have been stable.

Monitoring and follow-up

As immunoglobulin is derived from blood (plasma) and reserved for people with confirmed abnormalities in antibody production, access to immunoglobulin products is highly regulated. Your doctor must register you and comply with specific criteria and policies to ensure that product is provided equitably and goes to those that need it the most. Regular contact with your healthcare team is an important part of care for anyone receiving treatment with immunoglobulins. Regardless of your specific condition or the type of immunoglobulin you are receiving, your healthcare team will need to see you to monitor:

- ▶ your response to therapy: this is measured by specific tests of muscle strength and how much CIDP affects your daily activities
- ▶ side effects from treatment
- ▶ other health concerns.

If you are self-administering SCIG at home, your healthcare team will want to assess your technique.

Recording your symptoms and side effects in a treatment management plan (such as the [Immunoglobulin treatment and wellbeing management plan](#)) can help you and your healthcare team monitor how you feel after each dose.

Important points to remember

- ▶ CIDP is a treatable condition. Most people respond to one or more of the main therapies that are given repeatedly.
- ▶ Not all patients with CIDP will get better with immunoglobulin therapy. If there is no improvement on specific measures, immunoglobulin treatment will be stopped and another treatment started.
- ▶ Immunoglobulin products are carefully tested and purified so the risk of getting an infection or virus from them is close to zero.
- ▶ IVIg and SCIG are two equally effective approaches to administering immunoglobulins. The best method is the one that works for your circumstances and preferences, and this may change over time.
- ▶ Most people who respond to immunoglobulin products show some improvement in symptoms within the first 6 weeks.
- ▶ Some patients with CIDP go into remission. For patients who are clinically stable, a trial of Ig weaning towards cessation should be performed at least annually to identify patients who no longer require ongoing treatment.
- ▶ Keep a record of any symptoms and signs, good or bad, that you experience. A treatment management plan can be used to record your treatment history and help your specialist develop a more effective treatment plan.

? Want to know more?

- ▶ The Guillain-Barré Syndrome Association of NSW supports people impacted by Guillain-Barré Syndrome (GBS)/CIDP and related disorders: <https://www.gbs-cidp-nsw.org.au/>
- ▶ The Inflammatory Neuropathy Support Group of Victoria supports patients impacted by GBS/CIDP and other inflammatory neuropathies: <http://www.ingroup.org.au/>
- ▶ The Criteria for the clinical use of immunoglobulin in Australia outlines the conditions for access to government-funded immunoglobulin products: <https://www.criteria.blood.gov.au/>
- ▶ Find out more about access to subcutaneous immunoglobulin (SCIG): <https://www.blood.gov.au/SCIG>
- ▶ Find out more about access to intravenous immunoglobulin (IVIg): <https://www.blood.gov.au/Intravenous-Ig>
- ▶ For information on access and consent: https://www.nps.org.au/assets/NPS/pdf/NPS2342_IG_Products_GovernanceConsent_FactSheetC.PDF
- ▶ For more information on the NPS MedicineWise Value in Prescribing Immunoglobulin program: <https://www.nps.org.au/immunoglobulins>

VALUE IN PRESCRIBING PROGRAM – IMMUNOGLOBULIN PRODUCTS

Increasing the awareness and understanding amongst health professionals of access to immunoglobulin products in Australia, and improving health outcomes for patients through access to better health information to manage their health conditions. Funded by the Australian Government Department of Health through the Value in Prescribing Program: Immunoglobulins Products Grant.

