IMMUNOGLOBULIN PRODUCTS: WHEN TO REDUCE OR STOP TREATMENT

Immunoglobulin (Ig) treatment can be a lifesaving treatment for some people with various immune system disorders and conditions. However, for some people Ig treatment is not effective and not everyone will require long-term treatment. Here's what you need to know if your healthcare team suggests reducing or stopping your treatment.

Monitoring treatment

When you start Ig treatment, your healthcare team will set up regular appointments to review your response to treatment and how your condition is progressing. There must be evidence of clinical benefit from the treatment for you to continue.

Modifying or stopping treatment

Depending on your response to Ig therapy, your doctor may recommend changing your dose, treatment schedule or formulation. Ig products are not always needed long term, and for some conditions, a trial of reducing or stopping Ig products may be an option. Requirements for each condition are set out in the Criteria for the Clinical Use of Immunoglobulins in Australia.

Optimising your treatment

In some cases, it may be beneficial to reduce or stop your Ig treatment.

You can discuss your options with your healthcare team during your regular appointments.

Never make any changes to your treatment without first talking to your doctor.

If you have an immune deficiency disorder

Most people with a primary immune deficiency disorder need ongoing treatment, known as immunoglobulin replacement therapy (IRT), to replace their missing Ig.

There are some instances where Ig may not be needed at all or a trial of stopping can be considered. These include certain cases of common variable immunodeficiency (CVID) and secondary ('acquired') immune deficiencies.

If your doctor thinks you are at low risk of developing an infection after stopping Ig products, they may suggest trialling a short break from treatment. This is usually done in the warmer months when there is less chance of catching the common cold or flu.

Your doctor will do some tests to determine if it is safe to reduce your Ig dose. These may include measuring your Ig levels to make sure your immune system is able to work properly.

If you have an inflammatory or autoimmune disorder

Immune modulation therapy (IMT) supports patients by modulating their immune system to prevent it attacking its own body. The length of treatment with IMT is different for each condition and each person.

Autoimmune or inflammatory conditions can improve over time, and in some cases may become inactive or go into remission.

The only way to know if your condition has become inactive is to do a trial where Ig treatment is gradually reduced over time or even stopped. In some cases, symptoms may not return at all.

If medical tests, your history and examination show that your condition has been stable for some time, your doctor may consider trying this approach.

Your doctor will monitor how your condition is progressing by measuring symptoms specific to your condition, such as tingling or weakness in your hands, or how well you can walk up stairs.





What are the risks from reducing or stopping my Ig treatment?

Many people can safely reduce or stop their Ig therapy (under a doctor's guidance). However, there is a chance that your symptoms will return. Your doctor will discuss your treatment changes with you, explain what symptoms you need to look out for and work with you to find a treatment plan that best manages your symptoms.

If you have been receiving **IRT**, the main risk to be aware of when reducing or stopping treatment is an increased risk of infection. If you have been receiving **IMT**, you may notice that your symptoms initially disappear but worsen again several months later – this is called relapse. The chance of this happening is very different for each condition and will vary from person to person.

Will I be able to resume Ig treatment after stopping?

Your doctor may want to trial alternative treatments first (eg, antibiotics), but yes - your doctor can restart your Ig treatment if they think it is the best treatment for you.

If you have an immune deficiency disorder and frequent or severe infections return after stopping Ig products, your treatment will be restarted as soon as possible.

If you have an inflammatory or autoimmune disorder and your symptoms return after stopping Ig products, your doctor will consider your previous response to Ig and will recommend next steps based on your history.

What you can do

Track your symptoms
Use a symptom diary (such as the Immunoglobulin management and wellbeing plan) to keep track of any signs or symptoms, good or bad, that you experience when your treatment regime is changed. Symptoms to note might include: numbness or tingling; fatigue; changes in your ability to complete every-day tasks or activities. Include details of how long symptoms lasted.

It is also useful to include other key personal information, such as any recent changes or stressful events in your life. This information can help your doctors develop a more effective treatment plan.

Bring support

If is normal to feel overwhelmed by the amount of information discussed at an appointment with your specialist. Bringing a close friend or family member can help you keep track of important questions and information.

Ask questions

If you are still feeling uncertain at the end of your appointment, make sure to tell your doctor.

List any other questions or concerns about your treatment, condition, or symptoms:

More information

NPS MedicineWise:

- ▶ Ig access and consent: www.nps.org.au/immunoglobulins#consumers
- ▶ Factsheets Ig products and how to access them: www.nps.org.au/immunoglobulins/factsheets
- ▶ Keep track of medicines and access important health information: www.nps.org.au/medicinewiseapp

National Blood Authority:

- ► Immunoglobulin: www.blood.gov.au/lg
- ▶ Criteria for the Clinical Use of Immunoglobulin in Australia: www.criteria.blood.gov.au/
- ▶ Patient resources: <u>www.blood.gov.au/lg-resource</u>

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.



