

Frequently asked questions about stopping immunoglobulin infusions

Why are my infusions being stopped?

Immunoglobulin (Ig) is purified from donated blood and is called a blood product. We are always very cautious about using blood products as there is a theoretical risk of infection, although we believe that all viruses and other infectious agents are removed. All Ig has to be imported to the UK at the moment to avoid any possibility of infectious agents called prions being passed via Ig. For these reasons Ig is a scarce and precious product. As you know Ig has to be given by infusion, which may be inconvenient and may cause some side effects. We therefore always review patients regularly to make sure they still need it.

We will stop your Ig if we believe there is an alternative option that would be better for you, such as a regular antibiotic. Sometimes we are not certain if Ig will improve your symptoms and the only way is to give a trial of Ig and then stop it and compare your symptoms when you are on the infusions and afterwards. Finally, sometimes your immune system may recover, and the only way to find out is to stop the infusions and retest your immune system.

How long does it take for the Ig infusions to wear off?

It takes about 3 months for your body to clear the Ig from the infusions.

I am worried about taking a regular antibiotic. What if I get a serious infection and the antibiotics don't work?

In most cases you will be asked to take a regular antibiotic, such as doxycycline or azithromycin. This is called a prophylactic antibiotic. You must take these antibiotics continuously. Most people are aware of government advice to avoid taking antibiotics unless necessary. This is good advice to prevent build-up of resistance to antibiotics in the population. However, because your immune system is not working normally, you are at risk of bacterial infections and need antibiotics. Taking a regular antibiotic will prevent many infections and we will give you an alternative type of antibiotic to keep as a standby and this will prevent any problems of antibiotic resistance.

What should I do if I get an infection?

If you develop symptoms of infection such as a cough, shortness of breath and fever:

1. STOP your regular or prophylactic antibiotic
2. START taking your standby antibiotics
3. Make an appointment to see your GP to be assessed and replace your standby course

4. If possible send a sample of sputum to the hospital. This will help us to understand more about the cause of your symptoms and whether the Ig is helpful or not.
5. RESTART your regular or prophylactic antibiotic when you have completed the standby antibiotic course
6. Record details on your Home Infection Record

For home therapy patients -As usual, do not infuse immunoglobulin when you are unwell, even if you have some at home still. It can cause more severe side effects and will not help you get better any more quickly.

I still have some Ig at home, shall I return it? (Home therapy patients)

Unfortunately we cannot use any of your immunoglobulin for other patients. If you have some boxes of immunoglobulin left at home, then keep these safe and if you need to restart infusions they can be used.

I am worried that I will get severe or frequent infections despite the prophylactic antibiotic?

Some people will need to restart their Ig infusions. We will book you frequent clinic appointments so that we can check how you are. However please contact the immunology nurse on **01782672504**:

- if you have a severe infection that does not get better with your standby course of antibiotics
- if you have to go to hospital
- If you need to take more than two courses of standby antibiotics before your appointment

My regular prophylactic antibiotic is (mark as appropriate):

Doxycycline 100mg daily
Azithromycin 250mg three times a week
Amoxicillin 250mg twice daily

My standby antibiotic course is (mark as appropriate):

Doxycycline 200mg daily for 10 days or 14 days
Amoxicillin 500mg three times daily for 10 days or 14 days
Co-amoxiclav 625mg three times daily for 10 days Or 14 days

