



Manchester Royal Infirmary

Antibody Deficiency

Information For Patients



What is Immunodeficiency?

Immunodeficiency is the name given to the condition of having a faulty immune system which reduces your body's ability to fight infections. There are two types of Immunodeficiency: Primary Immunodeficiency and Secondary Immunodeficiency.

What is Primary/Secondary Immunodeficiency?

- Primary Immunodeficiency is a broad term for the group of disorders affecting the cells and function of the immune system. It is so called because no infection or medicine has caused the immunodeficiency. If you have a primary immunodeficiency you may experience recurrent infections which may be persistent, severe or unusual. Once you have been referred to an immunologist and primary immunodeficiency has been identified, the treatment you will be offered will depend on the nature of the disease.
- Secondary Immunodeficiency can result from many causes including treatment for certain cancers particularly those of the blood cells and bone marrow (leukaemia, lymphoma or myeloma). Long term treatment with medication used to treat other conditions may also affect the immune system and cause antibody deficiency. Secondary immunodeficiency can also arise from increased loss of protein in your urine or stool.

Both conditions mean that you are likely to develop more infections than is normal and they tend to keep coming back or be difficult to get rid of. This may be because you have too few immune cells or because the cells don't function as effectively as they should. The infections tend to occur in the sinuses (sinusitis), respiratory tract (chest infections like pneumonia) or gut (infectious diarrhoea). Quite often vaccinations are given to either help diagnose or treat your immune problem. If you have any concerns about any vaccinations please ask your doctor or

nurse. Once all your investigations are complete your immunologist will provide you with a treatment plan if your tests suggest that you have immunodeficiency.

- **Antibiotics** – Your immunologist may consider prescribing you long term antibiotics or give you a course of antibiotics to keep at home which you can take should you develop symptoms of infection. If antibiotics are required it is usual in immune deficient patients to have an increased dose for a longer period of time (10-14 days).
- **Immunoglobulin Replacement Therapy** - There are two types of treatment available – Intravenous Immunoglobulin (IVIG) and Subcutaneous Immunoglobulin (SCIG). Immunoglobulin is a blood product made from human plasma and it contains antibodies to help you fight infections. This treatment can be short or long term depending on the cause of your immunodeficiency and some patients will require it for the rest of their life. Some patients however may have a trial of immunoglobulin to see if it improves symptoms. If you require Immunoglobulin replacement, you will be offered a choice of one of the following options:

Intravenous Immunoglobulin (IVIG)

This treatment is given into a vein usually every 3 weeks. It takes a couple of hours to infuse and with appropriate training and support from an infusion partner (spouse, partner or friend) most patients can learn to infuse it themselves at home. We do have the option of nursing staff attending to undertake infusions for those who are unable to infuse at home or do not have an infusion partner to assist them.

Subcutaneous Immunoglobulin (SCIG)

This treatment is given as an infusion into the fatty tissue just under the skin in the tummy and thighs. This makes it easier to infuse yourself at home and you don't need an infusion partner to assist you. It is usually given every week, although can be given by a daily injection. As with IVIG, there is an option for nursing staff to attend your home and assist if you are unable to undertake this independently.

The intended benefits of Immunoglobulin Replacement Therapy

- Reduction in frequency and severity of infections.
- Reduced likelihood of long term lung damage caused by recurrent chest infections.

Frequently occurring side effects of immunoglobulin

- Local site reactions (subcutaneous immunoglobulin replacement).
- Rash, fever, headache may occur.

Less frequently occurring side effects of immunoglobulin

- Reduced kidney function.
- Blood clot disease.
- Theoretical risk of other as yet unknown factors.

Safety of Immunoglobulin

Immunoglobulin is a blood product, which means that it has been made from donated blood, specifically from the straw-coloured watery part of blood which is called plasma. Each bottle of immunoglobulin comes from a batch of several thousand blood donations, called a plasma pool. Any product manufactured from blood has the theoretical risk of spreading infection from person to person. However, in the case of immunoglobulin there is no evidence this has happened in the

last 20 years. The plasma is obtained from carefully selected donors and each donation is screened for known viruses including hepatitis B and C, and HIV. The plasma is purified using a fractionation or filtering process and further steps are used in the manufacturing process to reduce the risk of virus transmission even further. There is a theoretical risk of variant CJD transmission and other infections may enter the blood supply chain in the future. We take steps to make sure that if there was an infection outbreak in the immunoglobulin supply we could tell you very quickly whether you had been affected. Patients receiving immunoglobulin are carefully monitored for side effects of treatment.

Consent

Prior to commencing treatment you will be asked to give consent. A copy of this will be given to you and a copy filed within your notes. We will discuss the risks and benefits of treatment with you at this time. As part of this process you will be asked to consent to the storage of a sample of your blood in our laboratory. This is only used if we need to look back at your blood in the future. We will ask you to reaffirm your consent to treatment every year at your review appointment.

Home therapy

Infusion of immunoglobulin at home provides greater convenience and independence. The immunology department at Manchester Royal Infirmary offer home therapy to all patients and the patients/partners are taught in all aspects of self infusion with intravenous/subcutaneous immunoglobulin. Nursing staff are able to attend the homes of those who do not wish to undertake their infusions independently at home. If you are infusing immunoglobulin at home we will ask you to record your treatment and bring your record sheets to your appointments. Please bring your infection diaries to your appointments.

Monitoring

You will be monitored at regular intervals by your clinical immunologist or immunology specialist nurse to ensure that the treatment is working for you and you are not having any side effects. This will include 3-6 monthly blood monitoring and an annual technique review if you are doing your own infusions at home. You will have your weight checked regularly and your dose of immunoglobulin checked and recorded.

Every year we undertake an annual review to discuss your diagnosis and treatment. Sometimes we will make changes to your treatment, including stopping your immunoglobulin but we will always discuss this with you first.

Care of the Family

A diagnosis of an immunodeficiency and the prospect of having life-long treatment can have an impact on both you and your family. We aim to give appropriate support as an integral part of our care.

Other Health Care Professionals

Your GP and other specialists involved in your care will be notified of your treatment and changes in health. It will be necessary for you to inform us of specialist care you receive at other hospitals or clinics to ensure a holistic approach to care is given.

Patient support groups

P.I.D. UK <http://www.piduk.org>

UK PIPS <http://www.ukpips.org.uk>

Proof

No Smoking Policy

Please protect our patients, visitors and staff by adhering to our no smoking policy. Smoking is not permitted in any of our hospital buildings or grounds, except in the dedicated smoking shelters in the grounds of our Central Manchester site.

For advice and support on how to give up smoking, go to <http://www.nhs.uk/smokefree>.

Translation and Interpretation Service

It is our policy that family, relatives or friends cannot interpret for patients. Should you require an interpreter ask a member of staff to arrange it for you.

تنص سیاستنا علی عدم السماح لأفراد عائلة المرضى أو أقاربهم أو اصدقائهم بالترجمة لهم. اذا احتجت الى مترجم فيرجى ان تطلب ذلك من احد العاملين ليرتب لك ذلك.

ہماری یہ پالیسی ہے کہ خاندان ، رشتہ دار اور دوست مریضوں کے لئے ترجمہ نہیں کر سکتے۔ اگر آپ کو مترجم کی ضرورت ہے تو عملے کے کسی رکن سے کہیں کہ وہ آپ کے لئے اس کا بندوبست کر دے۔

ইহা আমাদের নীতি যে, একজন রোগীর জন্য তার পরিবারের সদস্য, আত্মীয় বা কোন বন্ধু অনুবাদক হতে পারবেন না। আপনার একজন অনুবাদকের প্রয়োজন হলে তা একজন কর্মচারীকে জানান অনুবাদকের ব্যবস্থা করার জন্য।

Nasze zasady nie pozwalają na korzystanie z pomocy członków rodzin pacjentów, ich przyjaciół lub ich krewnych jako tłumaczy. Jeśli potrzebują Państwo tłumacza, prosimy o kontakt z członkiem personelu, który zorganizuje go dla Państwa.

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我们的方针是，家属，亲戚和朋友不能为病人做口译。如果您需要口译员，请叫员工给您安排。



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