Antibiotics

Use of antibiotics in the treatment of immunodeficiency

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IMMUNO DEFICIENCY UK

Supporting families affected by primary and secondary immunodeficiency

About this booklet

Antibiotics are important medicines for managing and treating infections caused by bacteria. This booklet for patients with a primary immunodeficiency (PID) or a secondary immunodeficiency (SID) and their carers aims to promote the safe and effective use of antibiotics. It has been produced by the Immunodeficiency UK Medical Advisory Panel and Patient Representative Panel to help answer the questions patients and their families may have about the use of antibiotics in the treatment of immunodeficiency but should not replace advice from your medical team.

Contents

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What are antibiotics?

Antibiotics are medicines used to treat infections caused by bacteria. They work either by killing or slowing the growth of bacteria. Antibiotics are used in immunodeficiency:

- To treat bacterial infections, such as chest, sinus or ear infections
- As prophylaxis, which is prolonged treatment with the aim of preventing bacterial infection, or reducing its frequency or severity.

What types of antibiotics are available?

There are many different types of antibiotics that are used to treat different kinds of bacterial infections. Antibiotics are often categorised by their 'spectrum' of activity.

A 'broad-spectrum' antibiotic is one that acts against a wide variety of bacteria. Examples of broad-spectrum antibiotic tablets often used in immunodeficiency are co-amoxiclav, doxycycline and azithromycin.

Other antibiotics work against certain types of bacteria and are used only in very specific circumstances, such as when laboratory tests identify the presence of a specific bacteria.

Which antibiotic should you take?

Your doctor will decide which antibiotic is appropriate for you based on your clinical history, examination and laboratory results (e.g. which bacteria grow from a sputum sample). In addition, each hospital will have local guidance on antibiotic use to support your doctor in the decision-making process.

Please remember to always give a sputum sample, where possible, before taking antibiotics for a chest infection. This might help your doctor make decisions on antibiotic treatment now and in the future.

How to take antibiotics

Antibiotic treatment is usually taken by mouth in tablet form (or suspensions for children). Antibiotics can also be administered into a vein (intravenous) or for certain infections applied directly to the affected part of the body (topical; e.g. antibiotic eye drops). Occasionally and for very specific lung infections, inhaled (nebulised) antibiotics may be used.

The do's and don'ts

If your doctor has decided that antibiotics are necessary, it is very important to take them in a responsible manner.

- Follow the instructions on the label or patient information sheet. Some antibiotic tablets are best taken on an empty stomach (an hour before or two hours after meals), whilst others should not be taken with certain foods.

- Take the antibiotics at the correct time and complete the course. Not completing the course might contribute to bacteria becoming 'antibiotic resistant' and the antibiotic being less effective in the future. This is particularly important in immunodeficiency because antibiotics can sometimes be used regularly.

- Tell your doctor if your symptoms continue to get worse, you are unable to take the prescribed antibiotics, or you experience unwanted side effects.

Sometimes your doctor may decide that intravenous antibiotics are needed. Intravenous antibiotics are often used for the most severe infections. However, certain antibiotics do not work very well (or at all) when given orally. In these situations intravenous antibiotics are necessary. Hospital admission for intravenous antibiotics is often required, but longer-term administration can sometimes be facilitated at home.

Remember

You should always complete the course of antibiotics, even if you start to feel better.

What are the possible complications of taking antibiotics?

Antibiotics are safe and highly effective medications, but as with all therapies, there are sometimes unwanted effects (side effects).

Nausea, vomiting and diarrhoea are the most common side effects. Experiencing one or more of these side effects may mean that the particular antibiotic you have been prescribed is not suitable for you at this time. You should contact the prescribing team for further advice on what to do next.

Occasionally antibiotics lead to a fungal infection, or 'thrush' of the mouth, digestive tract or vagina. This is rarely serious and is readily treated with antifungal drops and creams where necessary.

Allergy to antibiotics is rare. Antibiotics can lead to rashes, swelling of the skin or tongue and difficulty breathing. If you have had a reaction to an antibiotic in the past, it is important to remind your doctor, nurse or pharmacist of this because your reaction may infuence the types of antibiotics you are given in the future.

Important

Inform your doctor immediately if you get a reaction while on an antibiotic.
If you are unable to contact your doctor, stop the antibiotic and continue to try and contact your medical team.

Interactions with other medications

Some antibiotics can affect how other medications work. For example, some antibiotics make the oral contraceptive pill less effective, in which case you may need to use a different form of contraception. Some may affect the activity of blood-thinning medication, such as warfarin, or tablets used to control epilepsy. Your doctor, nurse or pharmacist will be happy to help you with any concerns.

How is the use of antibiotics in immunodeficiency different?

The use of antibiotics in immunodeficiency may differ from general use in a number of ways. Occasionally it may be necessary to remind a healthcare professional of these differences. This may be particularly important when dealing with new or temporary staff, as they may not have your full medical details to hand. The main differences are:

Longer courses and stronger courses
Patients with immunodeficiency are often prescribed longer and stronger courses of antibiotics than usual. This might mean courses of 14 days, or sometimes longer. The reason for this is to prevent relapse or recurrence of infection. As always, you must complete the course, even if you are feeling better.

Standby antibiotics at home
Under certain circumstances a 'reserve' course of antibiotics to be kept at home may be recommended. Your doctor will give you very specific advice regarding when these antibiotics are to be used. It can be helpful to collect a sputum sample (in the case of a chest infection) before these emergency antibiotics are started. This can be dropped into your family practice. You should keep a record of when you use these standby antibiotics, and obtain a replacement supply after they have been used.

Long-term (prophylactic) antibiotics (see page 7)
Antibiotics are often prescribed for much longer periods of time with the aim of reducing the number and severity of infections. As with all antibiotics, it is particularly important to take prophylactic antibiotics exactly as prescribed and not to skip or miss doses.

Four golden rules of taking antibiotics in immunodeficiency

- Always take your antibiotics exactly as directed.
- Always complete the course.
- Inform your doctor, nurse or pharmacist if you experience side effects.
- Seek advice from your medical team if you do not feel better or you think things are getting worse.

About prophylactic antibiotics

Long-term antibiotics are often used in immunodeficiency to reduce the number and severity of infections. They can be used as a standalone treatment or be added to other therapies, such as immunoglobulin replacement. While much of what we know about antibiotic prophylaxis is taken from studies of conditions such as cystic fibrosis and bronchiectasis, this treatment approach has been found to be very effective by doctors specialising in immunodeficiency and is common practice.

The choice and dose of prophylactic antibiotic depends on the type of immunodeficiency; the presence of complications such as lung, sinus or ear disease; information from previous laboratory tests; and local guidelines on antibiotic use. Patient-specific concerns, such as dosing intervals and previous side effects, are also taken into account when making a selection.

Your doctor will carefully weigh up the risks and benefits of using antibiotic prophylaxis before offering this treatment. How well this treatment strategy works will be an important part of your regular immunodeficiency follow-up. If you and your doctor find no discernible benefit from long-term antibiotics, then the antibiotics may be changed to an alternative or discontinued entirely. Prophylactic antibiotics will never be prescribed without good reason.

Prophylactic antibiotics are well tolerated and problems with their use are not common. Concerns have been raised about the impact of certain antibiotic families on the heart when they are used for long periods. This may be particularly relevant for older patients and those with known heart problems. If your doctor is considering the use of such medications, then he or she may wish to obtain an ECG (heart trace) and discuss the risks with you before starting this approach.

Antibiotic resistance is a concern for doctors and patients alike. Studies in other diseases do suggest that long-term use of certain antibiotic drugs can contribute to a level of resistance, but this has not been well studied in immunodeficiency. Some specialists will change a patient's antibiotics every few months in an attempt to avoid resistance, but the benefit of this approach is uncertain.

At present, the best advice to minimise resistance is to take the antibiotic regime exactly as prescribed by your team, never skip doses, and raise any concerns you have with your specialist directly.

Glossary of terms

allergy – an exaggerated sensitivity resulting from a heightened or altered reactivity of the immune system to an external substance.

antifungal – a medicine used to treat infections caused by fungi.

bronchiectasis – a widening of the tubes (bronchi) that lead to the air sacs of the lung; this can happen because of repeated bouts of infections.

clinical history – the patient's 'story' of their medical information.

clinical immunologist – a doctor that specialises in looking after patients who have problems with their immune system.

ECG – electrocardiogram. A way of detecting abnormal heart rhythms and investigating the cause of chest pains.

epilepsy – any disorder that results in seizures.

intravenous – inside or into a vein; e.g. antibiotics may be given directly into a vein.

prophylactic/prophylaxis – something that works to defend or protect against disease.

sinuses – air-filled space within the bones of the face and around the nose. Infection of the sinuses is called sinusitis.

sputum – mucus that is coughed up from your airways.

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About Immunodeficiency UK

Immunodeficiency UK is a national organisation supporting individuals and families affected by primary and secondary immunodeficiency.

We are the UK national member of IPOPI, an association of national patient organisations dedicated to improving awareness, access to early diagnosis and optimal treatments for PID patients worldwide.

Our website has useful information on a range of conditions and topics, and explains the work we do to ensure the voice of patients with primary and secondary immunodeficiency is heard. If we can be of any help, please email us or call on the number above, where you can leave a message.

Support us by becoming a member of Immunodeficiency UK. It's free and easy to do via our website. Members get monthly bulletins.

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