Primary immunodeficiencies

Moving from child to adult care

IPOPI
INTERNATIONAL
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Introduction

This booklet explains the issues that young people with primary immunodeficiencies (PIDs) face in managing their condition during adolescence, the period of moving from childhood to adulthood.

PIDs are a large group of different disorders caused when some components of the immune system (mainly cells and proteins) do not work properly. People with PIDs are more prone than other people to infections. PIDs can also cause the body to attack itself – this is called ‘auto-immunity’. This can cause pain and swelling in the joints (‘arthritis’), skin rashes, a loss of red blood cells (anaemia) and various other problems.

If you are a young person with a PID, you may be cared for by a doctor who specialises in the immune system (an immunologist) or a specialist in treating children (a paediatrician), together with nurses and other healthcare staff. The types of treatments you are given depend on exactly which PID you have, what treatments are available where you live, and other factors. Some treatments have to be given in a hospital or clinic, while others can sometimes be given at home.

Modern treatments can help most people with PIDs to live as normal a life as possible. Patients and the people around them, especially their families, also play a very important role in this. Children are, of course, looked after by their parents or other carers. This begins to change during adolescence, the period when the child grows towards adulthood.

Adolescence is an important period in any person’s life. During this time the body changes and there can be emotional and hormonal problems. There may also be disruptions caused, for example, by changing schools, going to college or starting work. Young people become more independent during this time, and at some point may leave home. They start to take control of many aspects of their lives, including their health.

If you are a young person with a PID you will need to take a greater responsibility for understanding your condition, looking after yourself and managing your treatment. You will take over some of these roles from your parents, or whoever else has been looking after you. This can be a difficult time for everyone, and this booklet is designed to help you.

Moving from child to adult care

The way that people with PIDs are cared for differs across the world. In some countries there are few immunologists and those that exist treat both children and adults. Where no immunologist is available, the family doctor (also known as a ‘general practitioner’) will have a greater role.

In other countries there are separate children and adult immunology services and, in some cases, there are special arrangements to help young people move from one to the other. This process is sometimes known as ‘transition care’. In other countries patients and their families may have to find an adult immunologist by themselves, or with help from their children’s immunologist. If this is the case where you live, your national PID patient organisation may be able to help (visit www.ipopi.org).

If you live somewhere where the transition between child and adult care is well organised, it may be planned early (when you are 14 to 16 years old) to give you and your family time to prepare. However, this timing depends on individual circumstances, such as the availability of an immunologist who treats adults, your general health, your understanding of your PID, your independence, and your family or support situation. Transition may be delayed if you are ill or your personal circumstances are not so settled. If you have a brother or sister with a PID, transition for whoever is oldest might be delayed so that you can move into adult care together.

You might be nervous about the idea of moving to an adult clinic or hospital and taking responsibility for making appointments, attending them on time, and overseeing other aspects of your healthcare. To help you through this, staff from the adult centre may attend your last appointment at the children’s clinic so that you can meet them. Staff from the children’s clinic may attend your first adult clinic visit. A particular nurse may be named as your first point of contact at the adult centre. If this is not possible, arrangements must be made to have your records transferred and to ensure that your paediatric and adult specialists communicate.

Whichever hospital or clinic you attend, ideally you and the staff will identify your needs and make plans to address these. As you grow older you will have a greater role in these decisions. To do this you will need to understand about your PID and its treatment.

Managing your PID therapy

Immunoglobulin replacement

Immunoglobulin replacement therapy is the main treatment for most people with PIDs. Immunoglobulin replacement helps to protect against infections and reduces some autoimmune symptoms. Because it only has a temporary effect it must be given regularly. In most cases, immunoglublin replacement needs to be life-long.

It is crucial that you do not miss any doses of immunoglobulin, because if you do you will no longer have sufficient protection from infections. As you grow older you will need to take greater responsibility for making sure you receive all your doses. As you grow and gain weight, the amount of immunoglobulin you need will increase. If you receive immunoglobulin at a clinic, you will eventually need to make your own appointments — and of course keep them! It may be possible for you to receive your immunoglobulin doses at home, and perhaps even to give yourself the doses. To do this you will need to learn new skills and keep accurate records. If all this sounds difficult, do not worry — any changes in your treatment should take place at your own pace and only if you are willing and able to do what is needed.

You and your family should ensure that you get all the information you need from the hospital or clinic, or from PID patient organisations. Don’t be afraid to ask questions!

Other treatments

You may also receive other treatments for your PID, some of which may need to be given in the hospital or clinic. You may also need medicines to treat or prevent infections caused by bacteria (antibiotics), fungi (antifungals, for example against thrush) and viruses (antivirals, for example against chickenpox). You should learn exactly what medications you need, and make sure you take these according to the instructions. You may be asked to keep records of what medicines you take and when. These records can help you and the healthcare staff to monitor your health. They are also useful if you have to change between different healthcare services, or if you move to another area.

You should find out whether your PID centre offers special help for young people. For example, some centres run out-of-hours clinics to help you fit appointments around school, college or work. They may also offer special clinics for young people, self-care clinics and ‘parent-free’ consultations.

Health insurance

In many countries people pay for healthcare through health insurance plans. If this is true where you live, you and your family may need to check your plan in case there are any issues relating to your change from child to adult health services. It is very important that you never let your health insurance coverage lapse.

Staying healthy

As you grow older you will be expected to do more and more things for yourself. This includes taking precautions to keep yourself healthy. This can be hard sometimes, especially with the distractions of being a teenager, but it is important.

Hygiene

Personal hygiene is especially important for people with PIDs, in order to help reduce the risk of infections. For example, it will be up to you to regularly wash your hands (especially after using the toilet, playing with pets or doing things outdoors) and to brush your teeth. If you get a cut or scrape, you will need to clean and dress this or get some help if necessary.

It is also vital that you learn to spot the signs of infections, as these will need to be treated quickly. You should also learn whom to contact if you think you have an infection and in case of an emergency.

If you have a PID it is very important that you do not smoke, as this can cause infections and lead to lung disease. If possible, try to ask people around you not to smoke.

Sports and activities

Most young people with PIDs can enjoy sports, just like everyone else. Of course, these are a good way to let off energy and stress, to keep the body healthy and to build friendships. However, people with certain types of PID need to avoid some activities, so you should ask your hospital or clinic if there are any activities you should avoid.

Diet and sleep

Other ways you can help yourself to stay healthy including making sure you eat well (for example, by making sure not to miss any meals) and getting enough sleep. Food and rest are both important in helping you to stay as healthy as possible.

Sexual health

PIDs are not related to AIDS (‘acquired immunodeficiency syndrome’), which is caused by a viral infection (human immunodeficiency virus, or ‘HIV’). PIDs cannot be spread from one person to another through sex or any other type of contact. However, if you have sex it is very important that you practise safe sex to reduce the risk of sexually transmitted infections.

Emotional support

Many teenagers face emotional difficulties related to things like relationships, home life and pressures of education or work. PIDs can place particular demands on patients and their families during the years of adolescence. Some patients have feelings of fear, depression or even anger because of their condition. They may also feel isolated and alone as a result of feeling ‘different’.

If you have a PID, it is important that you do not feel abandoned. You should try to take advantage of all sources of help and support, such as family members, friends and school teachers. Your clinic may be able to arrange for you to see a psychologist or counsellor who can also help you cope with your problems and fears. It may also be possible for you to request to be with patients of similar age and gender during your appointment. Talking with other people with PIDs can also help, and this can often be done by contacting PID patient organisations in your country.

Remember that your PID also affects your family and anyone else who looks after you. They are likely to worry about your health and to find it difficult to hand over to you the responsibility for your own care. This may cause stress and conflict. You may also feel that you want more privacy as you grow older. Again, it is important to discuss these matters openly, if necessary with someone who can help solve any problems.

Education and work

Having a PID need not necessarily prevent you from getting a full education or doing the sort of job you would like to do. It is important that you and your family find out about your opportunities and the available support to help ensure that your PID has as little effect as possible on your school or college studies, or your applications for work. You may be able to get advice from an occupational therapist (someone who helps people to do various activities, including work and study) or a social worker, if these are available locally. Staff from your school or college may also be able to help, for example if there is a careers advisor.

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Further information and support

This booklet has been produced by the International Patient Organisation for Primary Immunodeficiencies (IPOPI). Other booklets are available in this series. For further information, and details of PID patient organisations in 43 countries worldwide, please visit **www.ipopi.org**.

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UK

Supporting families
affected by primary
and secondary
immunodeficiency

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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