

Avoid swimming in polluted sea, lakes or rivers as doing so can cause dysentery and respiratory infections, as well as ear, nose and throat infections. Enquire how clean the sea and lakes are before you take the plunge. The water in swimming pools and hot tubs may also pose a health risk, so ask how often it is monitored for bugs and cleaned.

## Hobbies

Gardening can increase exposure to moulds and fungi. In particular, leaf mulch and other dead plant material may be an issue with some types of PID. If you enjoy gardening, talk to your immunology team about ways to prevent infection.

## Pets

Some people with a PID may need to take extra precautions when in contact with pets and other animals. Ask your immunology team about this.

## Sleep and rest

Getting enough quality sleep can make the world of difference to your health. If you cough a lot you may have a disturbed sleeping pattern. Listen to your body when you are feeling tired and 'under the weather' and take it easy for a few days.

## Surgery and dental procedures

If you are due to have an operation or a dental procedure, such as a root filling or an extraction, it's important that your surgeon or dentist knows you have a PID. This is because additional steps may need to be taken to help prevent infections related to the surgery, e.g. a short course of preventative antibiotics. If you encounter any reluctance from your surgeon or dentist, get in touch with your immunology team to confirm what is required for you.

## Going on holiday and travel

Having a PID doesn't mean you can't travel and go on holiday, but you do need to plan ahead. Take a look at our leaflet 'Going on holiday'.

## About Primary Immunodeficiency UK

Primary Immunodeficiency UK (PID UK) is a national organisation supporting individuals and families affected by primary immunodeficiencies (PIDs).

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

Our website at [www.piduk.org](http://www.piduk.org) provides useful information on a range of conditions and topics, and explains the work we do to ensure the voice of PID patients is heard.

If we can be of any help, please contact us at [hello@piduk.org](mailto:hello@piduk.org) or on **0800 987 8986**, where you can leave a message. Visit [www.piduk.org](http://www.piduk.org) for further information.

Support us by becoming a member of PID UK. It's free and easy to do via our website at [www.piduk.org/register](http://www.piduk.org/register) or just get in touch with us. Members get monthly bulletins.

PID UK is reliant on voluntary donations. To make a donation, please go to [www.piduk.org/donate](http://www.piduk.org/donate)



Keeping well  
and healthy when  
you have a PID

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This leaflet suggests practical ways to stay healthy if you have a primary immunodeficiency (PID).

Trying to reduce the number of infections you have when you have a primary immunodeficiency (PID) helps to keep you out of hospital and to go about your daily life, doing what you want to do. Some infections, such as colds and other viruses, are inevitable. However, it's still important to try and reduce the frequency of infections.

If you or a member of your family is living with a PID there are lots of things that you can do yourself to keep well. This leaflet includes ways to stay fit and healthy. These are suggestions for your consideration rather than a set of instructions to follow: there is a balance to be struck between ensuring that life is safe but also fun. Not all suggestions apply to all patients, and if in doubt, consult your clinical team.

## Recognise the signs of an infection and seek prompt medical help

### The general signs of infection include:

- fevers, night sweats and chills
- an unexplained feeling of tiredness, and aches and pains
- loss of appetite
- weight loss.

### Specific signs of infection in parts of the body prone to infections in PID

Body part affected	Symptoms of infection
Airways (bronchi)	Difficulty breathing; coughing up phlegm
Lungs	Persistent cough or chest pain
Eyes	Itching, redness, discharge or pain
Ears	Earache or discharge
Sinuses	Facial pain; persistent cough
Skin	Sores with pus or persistent rashes
Intestines	Tummy ache; persistent diarrhoea
Urinary tract	Pain or difficulty passing urine; blood in the urine
Joints	Pain, stiffness and swelling

It's important that you contact your doctor when you think you have an infection. This helps ensure you get treatment quickly, to prevent any infection taking hold.

## Take the full course of any medication given by your doctor

It's important that you complete any course of antibiotics (used to treat bacterial infections), antifungals (used to treat fungi) or antiviral medicines (used to treat viral infections) that your doctor or nurse may prescribe to treat your infection, even if you are feeling better. This helps ensure that the infection causing your health problems has been fully treated. You may need a higher dose or a longer course than those with a functioning immune system. Supplying a sputum sample for your GP will help confirm if the correct antibiotics have been prescribed.

Some patients may be advised to have a supply of standby antibiotics stored at home so that these can be started promptly in the event of an infection.

## Preventing infections

Good hygiene is really important. Here are our top tips for practising good hygiene:

- Wash your hands regularly and thoroughly, especially before meals and after using the toilet, engaging in outdoor activities and playing with pets. If you can't wash your hands properly, then use antibacterial alcohol hand gels, available from chemists and other shops. Encourage family and friends to do the same so they don't spread infections to you.
- Wash all cuts and scrapes thoroughly with soap and water, and follow with antiseptic.
- Don't smoke or let anyone smoke around you or your child as smoking can cause further chest problems. In general, avoid smoky and crowded places.

- Keep immunisations up to date as recommended by your immunology team. Encourage members of your household to have the flu jab.
- If you are a parent of a child with severe PID, ask the school to inform you of any infection outbreaks, and then ask for advice from your immunology team.
- Good personal hygiene is very important. Brush your teeth carefully and make regular visits to the dentist.
- Practise good food hygiene to help avoid food poisoning.
- Keep your house clean and avoid high humidity levels to prevent lung problems.
- Wash all children's toys regularly.

## Skin care

Some people with a PID may need to pay extra attention to skin care, so consult your immunology team.

## Diet and food hygiene

Eating a good diet, full of fruit and vegetables, is beneficial for everyone's health, and most people with a PID don't need to take extra supplements such as vitamins. Consult your immunology team before taking any supplements. Generally, if you have a PID you should avoid raw or undercooked food, e.g. meat, eggs and cheese. Also avoid drinking water of unknown origin, or water that has remained too long in the same container. If travelling outside the UK, take a look at our leaflet 'Going on holiday'.

## Keep as fit as you can

People with a PID can enjoy sports and exercise just like everyone else. Certain PID conditions can interfere with blood clotting, and patients with these conditions need to discuss what sports are suitable with their immunology team. Follow your health team's recommendations on specific exercises to help with breathing.