

Living Well with PID

Health and Wellness tips for individuals living with primary immunodeficiency disease (PID)



Learning that you have PID can be a little daunting at first, but it doesn't have to be.

The information and tips in this guide will help you to:

- Identify ways to reduce the chances of infection
- Maintain general health and wellness
- Take care of your body



Tips and Suggestions

Connect with peers who understand. Consider joining a:

- Peer support group or peer support program
- Patient education event

Maintaining good hygiene is a key measure to help prevent infections

- Wash your hands frequently and learn proper washing techniques
- Encourage your friends and family to also follow good hygiene practices
- Carry hand sanitizer if hand washing is not possible

Avoid exposure to people who have colds, flus or signs of infection

- Avoid crowded areas and places where smoking occurs
- Consider wearing a mask in public places (e.g. doctor's office or anywhere exposure is higher)
- Stay informed about disease outbreaks in schools and workplaces

Good nutrition is important. Maintain a healthy, balanced diet

- Follow guidelines for recommended fruits, vegetables, fibre and protein intake
- Avoid raw or uncooked foods to prevent infection
- Consult Canada's Food Guide (www.canada.ca)

Exercise regularly and stay fit

- People with PID can enjoy sports and exercise just like everyone else.
- Discuss with your healthcare team what sports/activities may be suitable for you
- Take extra precautions when using public swimming pools, showers or gym equipment

Get adequate sleep and rest on a daily basis

- Maintaining consistent sleep/rest habits is also important

Manage your stress levels

- Incorporate 'stress reducers' in your daily routine; from regular physical exercise to massage or other relaxing activities

Recognize general signs of an illness or infection and get prompt treatment

- It is important to manage your health through any illness you may have
- Pay attention to symptoms and warning signs
- Always take your medication as prescribed and talk to your doctor

Living well and healthy with PID – an introduction

If you or a family member is living with a PID there are many things that you can do for 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. Not all suggestions apply to all patients, and if in doubt, consult your clinical team.

Reducing the risk of infection and trying to reduce the number of infections will help 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.

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

Peer Support – Connect and speak with someone who understands

Consider joining a peer support group or program. Feelings of isolation often accompany the everyday effects of living with chronic or long-term conditions. Sometimes you simply need to talk freely about how you're feeling, to someone who understands what you are going through. Many Canadians living with PID or other immunodeficiencies have joined peer support groups to share and exchange their experiences and to support one another.



Peer Support – Connect and speak with someone who understands

1. Patient/Peer Support Organizations – Two of the primary patient organizations in Canada are:

- Canadian Immunodeficient Patients Organization – www.cipo.ca
- Association des patients immunodéficients du Québec – www.cipo-apiq.ca

CIPO provides advocacy, support and education to all immunodeficient patients diagnosed and not yet diagnosed across Canada, as well as patient support groups and events.

APIQ is a French language, Québec-based organization for patients with immunodeficiencies; offering comparable programs and services as CIPO. Similar to CIPO, its three main goals are to provide disease information, patient care/services and to advocate the rights of those individuals living with PI. APIQ also conducts patient events across the province of Québec.

2. Support Groups

CIPO offers local support groups through its provincial chapters; currently in Vancouver, Vernon, Ottawa, Toronto and Winnipeg with groups planned in Edmonton and Halifax. Visit the CIPO or APIQ websites if you're interested in joining a group or would like to see a group or event in your area.

3. Peer Support Program

Peer Support Programs give those affected by PID the opportunity to connect with a trained volunteer who shares a similar personal experience. Contact CIPO or APIQ if you or a family member would like to take part in this.

4. Patient Education Events

Visit the CIPO or APIQ web sites for details/dates for upcoming Patient Education Events – ‘live’ events where those whose lives are affected by PID can learn and share in an open environment. These are also venues where you can meet others who share similar experiences.

5. PI Social Media Community on CIPO

The CIPO PI Community was created to connect with others whose lives are affected by PI. It's a closed group to patients and family members only. Visit the CIPO Facebook page to join the group.

The importance of hygiene and measures to prevent infections



General principles of good hygiene are essential for patients with PID and their families, especially routine handwashing. Many infections can be prevented just by using some of the suggestions below:

- Frequent hand washing is critical to prevent the spread of infections. Wash your hands before, during, and after preparing food. Encourage family and friends to do the same so they don't spread infections to you.
- Other times to wash your hands include the following:

- Before meals and after using the toilet
 - Prior to, and after self-administered treatments (such as subcutaneous IV medications)
 - Engaging in outdoor activities and touching an animal or animal waste
 - After handling money
 - After changing diapers
 - Before and after caring for someone who is sick
 - After blowing your nose, coughing, or sneezing
 - After touching garbage
 - Before and after treating a cut or wound. Wash all cuts and scrapes thoroughly with soap and water, and follow with antiseptic.
 - **Also** - Wash down surfaces that are handled by sick individuals (e.g., phones, countertops, toys).
- Practice good handwashing techniques:
 1. Wet your hands and apply liquid or clean bar soap. Place the bar of soap on a rack and allow it to drain.
 2. Rub your hands vigorously together and scrub all hand surfaces.
 3. Continue for at least 20 seconds. It is the soap combined with the scrubbing action that helps dislodge and remove germs.
 4. Rinse well and dry your hands.
 - Carry a hand sanitizer with you, for situations where hand washing with soap and water is not possible. Use a hand sanitizer that contains at least 60% alcohol, or antibacterial hand gels.

- Good dental hygiene is very important. Brush and floss your teeth carefully and schedule regular visits to the dentist. Change your toothbrush after having cold symptoms.
- Practice good food hygiene to help avoid food poisoning.
- Avoid drinking non-purified water. It may contain parasites and bacteria that can cause illness. Do not share water bottles with friends.

Other measures to help prevent infections - Individuals with PID should avoid exposure to people who have signs of an obvious infection, such as coughing, fever or vomiting and/or diarrhea. During periods of influenza outbreaks, avoid crowded areas such as shopping centres and movie theatres. When in doubt, ask your immunologist or primary healthcare provider for advice.

- Consider wearing a mask in public places (e.g. subways) where risk of exposure is higher.
- Keep your house clean and avoid high humidity levels to prevent lung problems.
- Don't smoke or let anyone smoke around you or your family as smoking can cause further chest problems. In general, avoid smoky and crowded places.
- Keep immunizations up to date as recommended by your immunology team. Encourage members of your household to get flu vaccines. Talk to your doctor prior to receiving a live vaccine.

- If your child has severe PID, ask the school to inform you of any infection outbreaks. Review all notices from school regarding infectious disease exposure, and contact your doctor to discuss any necessary next steps.
- If you or other family members have been exposed to chickenpox, be sure to contact your doctor immediately.
- Treat cold symptoms aggressively with medications at home and seek medical attention if symptoms do not resolve in 3-5 days.

Nutrition and PID - Maintaining a balanced, healthy diet is important

A balanced, healthy diet that includes daily recommended amounts of fruits, vegetables, fibre, protein and calcium should be maintained. Generally, you should avoid raw or undercooked food, such as meat, eggs and cheese. Also, avoid drinking water of unknown origin, or water that has remained too long in the same container. For more information on dietary guidelines and healthy eating recommendations, consult Canada's Food Guide (www.canada.ca).

Most people with PID don't need to take extra supplements such as vitamins, if a balanced diet is followed. There is no scientific evidence that these will strengthen the immune system. Extreme caution should be used when considering such supplements, as some

can be harmful or interact adversely with prescription medicines you may be already taking. Consult your immunology team before taking any of these products. Sometimes the healthcare provider will recommend vitamins, electrolyte supplementation or probiotics for certain patients - but remember that supplements are no substitute for a healthy, balanced diet.



Exercise and PID - Be as fit as you can

People with 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.

Swim with caution, as water in swimming pools and hot tubs may pose a health risk if the water/pool is not cleaned often enough. 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. Ask experts about how clean the sea and lakes are before you take the plunge.

If you are using fitness clubs or other public venues, watch out for fungal infections like athlete's foot:

- Wash feet carefully and keep feet dry as possible
- Do not share shoes or socks with friends
- Nails should be clipped short and kept clean
- Avoid walking barefoot in locker rooms or public showers (wear sandals)

Adequate sleep and rest - Essential requirements for good health

- Getting enough quality sleep can make the world of difference to your health. Experts recommend consistency in the amount of sleep per night, with regular bed times and waking times. While "sleeping in" may seem like a special treat, it may not be the best thing to do to ensure good health.
- Erratic sleep patterns have been shown to have negative effects on the immune system. If you cough a lot you may have a disturbed sleeping pattern. Talk to your doctor if you suspect that you suffer from sleep apnea.
- Listen to your body when you are feeling tired and 'under the weather' and take it easy for a few days.

Stress management is also important



- The notion that people get sick more often when they are under increased stress is supported by scientific data. Chronic illness, itself, is known to be a major life stressor. Some studies suggest that stress negatively affects the functioning of the immune system. There are also scientific studies that suggest reducing stress can improve immune function.
- Many stress reducers are easy to incorporate into one's daily life. These include massage therapy, biofeedback, meditation and hobbies. The importance of physical activity and adequate sleep in helping to reduce stress has already been discussed.

- If you find that you are unable to deal with the stresses in your life, you should absolutely discuss these concerns with your doctor or nurse. They can assist or refer you to someone who can help you in minimizing and effectively dealing with stress.

Managing your health during illnesses

Due to the nature of PID, patients are likely to experience illness more often. When you, or the family member with PID is ill:

- Rest
- Drink fluids
- Do NOT self-medicate
- Use a saline nasal rinse to help clear sinuses
- Follow doctor's orders (stay home, in bed, etc.)
- Keep stress levels low

Recognize the general signs of an infection and seek prompt medical help:

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

Take the full course of any medication given by your doctor to treat an illness

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 has prescribed, even if you are feeling better. This helps ensure that the infection causing your health problems has been fully treated.

A few more topics and questions raised by persons living with PID

- Can I go on holidays or travel abroad? - You can travel and go on holiday, but need to plan ahead. Take a look at our leaflet '**Planning a Trip? A useful travel guide for individuals living with primary immunodeficiency disease (PID)**'.
- Can I keep 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.
- Are there any special precautions for surgery and dental procedures? - Prior to an operation or a dental procedure (such as fillings or extractions), it's important that your surgeon or dentist knows you have PID. This is because additional steps may be required to help prevent infections related to the surgery, e.g. a short course of preventative antibiotics.



Where to find more resources

We hope that the information in this guide has been useful in helping you and your healthcare team in addressing and dealing with many health/wellness topics. If you have additional information needs, please consult the following web sites:

- CIPO (Canadian Immunodeficient Patients Organization)
www.cipo.ca
- Association des patients immunodéficients du Québec
www.cipo-apiq.ca
- Immune Disease Foundation
www.primaryimmune.org
- UK PID disease/patient association
www.PIDuk.org



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