

Dear PID UK member,

We are writing to give you the following advice concerning the Coronavirus (COVID-19). The situation is changing all the time and we advise you to monitor for the latest government advice at: <https://www.nhs.uk/conditions/coronavirus-covid-19/>

What is COVID-19?

Coronaviruses are a family of viruses that can cause anything from a common cold to severe acute respiratory syndrome (SARS) and Middle East respiratory syndrome (MERS). COVID-19 is probably, overall, more at the cold and flu-like end of the spectrum of these infections. To date about 80% (80 in 100) of patients recover completely with no treatment. About 1 in 6 people get difficulty in breathing severe enough to need to attend hospital and about 2% (2 in 100) of people; particularly those with cancer, existing lung or heart problems might die from this infection (<https://www.who.int/news-room/q-a-detail/q-a-coronaviruses>).

Is it worse than influenza?

Every year the WHO estimates about 3-5 million severe cases of influenza worldwide with 250,000 – 650,000 deaths. This would suggest that the risk from coronavirus is similar to that of season flu for most people. The main difference is that we have vaccines that limit the spread and infection with influenza, but at present there is no vaccine and no community immunity to COVID-19 to halt spread.

How is COVID-19 spread?

The disease can spread from person to person through small droplets from the nose or mouth, which are spread when a person with COVID-19 coughs or exhales. These droplets land on objects and surfaces around the person. Other people then catch COVID-19 by touching these objects or surfaces, then touching their eyes, nose or mouth. People can also catch COVID-19 if they breathe in droplets from a person with COVID-19 who coughs out or exhales droplets.

Reducing the chance of infection and transmission

Since droplets spread the virus, good hand hygiene is the top priority in preventing transmission of COVID-19, like most respiratory viruses. When out and about, alcohol-based hand-gel can be used to sanitise your hands. Washing your hands, thoroughly and frequently, with soap and water throughout the day will also help reduce the chance of infection.

Should I wear a mask?

Masks are generally not effective, most people do not have appropriate training for a good fit, they need replacing regularly and there is probably greater risk of contaminating your face from your hands adjusting a mask than the benefit from wearing one. The exception is a healthcare setting when you are given a mask, shown how to wear it and it is disposed of appropriately.

Am I specifically at risk of catching COVID-19 with my immune deficiency?

Having many immune problems does not specifically predispose you to increased risk of acquiring this type of viral infection; the risk comes from being exposed to it.

Are PID adults or children at greater risk of becoming very sick?

The main risk factors for more severe disease are older age and lung or heart disease including those individuals with a primary immunodeficiency (PID) and lung or heart disease.

From the limited information that we have from other countries around the world we believe children in general are less severely affected. There has not been a reported excess of patients with PID developing severe complications from COVID-19.

What should at risk groups do?

Children with severe combined immunodeficiency (SCID), adults and children with combined immunodeficiency (CID) or undergoing bone marrow transplant (BMT) are a group at risk from all infection, no specific guidance is needed for this group because they will already be aware of the need to avoid infection and what to do in the event they become unwell or a contact of any infectious disease.

Should I self-isolate until this is over – who is “vulnerable”?

Isolation to prevent exposure is already recommended if you are in the SCID/CID or BMT group and already advised to take precaution to prevent all infection.

In light of the Prime Minister’s statement on 16th March 2020 highlighting the latest recommendation of the SAGE (Scientific Advisory Group for Emergencies) we have changed our advice for primary immunodeficiency patients. We now recommend social distancing for PID patients, even if they remain symptom free. PID patients who require regular treatment or are eligible for annual influenza vaccination should follow Public Health England social distancing advice for vulnerable adults.

<https://www.gov.uk/government/publications/covid-19-guidance-on-social-distancing-and-for-vulnerable-people/guidance-on-social-distancing-for-everyone-in-the-uk-and-protecting-older-people-and-vulnerable-adults>

Should I keep my child home from school?

If your child has a PID that requires them to take a regular medicine to prevent infection you should now make plans to keep them at home.

If you are a parent living with a PID then to reduce your likelihood of COVID-19 you should consider keeping your child at home. This step will not be helpful if your child is still going to meet up with lots of other children, in those instances you and they will be better off if they remain at school.

It is likely that schools will close very soon. Make sure you look for resources on the government websites to keep your child up to date with their education, they may be at home for some weeks to come.

Should my partner or I stop going to work?

The plans for isolation and social distancing are to reduce the probability that members of the household will be exposed to COVID-19. The government advice is that everyone should now reduce unnecessary travel, group gatherings and work from home where possible. This is to reduce exposure to the virus.

If you fall into the vulnerable category above that the government is advising to stay at home for your own health reasons, discuss with your employer how to make this work. Advice on employment issues is still available via the Citizens Advice Bureau or via PID UK.

I think I have COVID-19, what do I do?

Stay calm; the majority of people do not have severe disease. Maintain household hygiene measures to protect those around you, but isolate yourself as much as possible.

Check your symptoms on [111.NHS.UK/Covid-19](https://111.nhs.uk/covid-19) or [NHS24 service](https://nhs.uk/services/111), if in Scotland, for the latest advice.

For most patients who are following basic measures of rehydration and medicine to lower temperature who are improving no further action will be necessary. If you are not getting better check again with NHS111/24 and then contact your PID centre to see if they need to provide more specific advice.

I have a PID and think a household member has COVID-19, what do I do?

Stay calm; the majority of people do not have severe disease. Maintain household hygiene measures to protect the person with a PID. The current advice is to manage the person at risk somewhere else if possible (e.g. they go to a family member). Where this is not possible e.g. a child with PID looked after by a parent with COVID-19, then minimising contact as much as possible, ensuring hand and household hygiene are key.

Check [111.NHS.UK/Covid-19](https://111.nhs.uk/covid-19) or [NHS24](https://nhs.uk/services/111) for the latest advice.

If your family member is not getting better contact NHS111/NHS24 and follow their advice.

I think I have COVID-19 can I go to my Immunologist for review?

Access online 111.NHS.UK or NHS24 and follow their advice. Contact your immunology centre by phone to update them if you are not getting better. Hospitals now have specific arrangements for receiving patients with suspected COVID-19 and these are outlined on NHS 111/24. You should not be attending your immunology centre with suspected COVID-19.

The advice is to avoid unnecessary travel, should I go to my regular outpatient appointments?

To reduce the risk to patients of acquiring COVID-19, most hospitals are now reviewing patients wherever possible by telephone. Some patients will need to attend in person and hospitals are doing all they can to protect those patients and staff from COVID-19. Specific arrangements for blood tests taken outside of booked clinics are being made in some centres. Centres may send you a message to actively confirm altered arrangements. If you have an upcoming appointment and are unsure, contact the clinic booking number for your centre.

What will happen to my immunoglobulin (Ig) infusions?

At present there are no supply issues with IVIG or SCIG. We are aware that plasma donations will fall at this time, but at present companies believe they have adequate stocks to maintain supply. Longer prescriptions for patients on home therapy may be needed to ensure you don't run out, your centre will be able to advise. For patients having infusions at a hospital facility, it may be possible for some patients to be trained to self-infuse Ig subcutaneously or intravenously at home, depending on the capacity and resources at your Immunology centre.

Some patients will still need to attend the hospital, in which case discuss your transport needs with your centre. Appropriate arrangements to deliver treatment safely will be made by individual centres.

Keep up to date

As the number of cases of COVID-19 rises in the UK then this advice may change and you should follow the general advice given by the Government.

<https://www.nhs.uk/conditions/coronavirus-covid-19/>

This advice has been approved by [PID UK Medical Advisory Panel](#) 18th March 2020