

## CGD Society FAQs

### **Q. I am hearing now about SARS-CoV-2 virus. What is this and is it the same as COVID-19?**

**A.** Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) is the virus strain that causes coronavirus disease (COVID-19). It is the same thing, but researchers and scientists have given it a more precise name.

### **Q. In the event of a non-COVID medical emergency what should I do?**

**A.** The risk of developing other serious or life-threatening conditions remains unchanged during the COVID-19 pandemic and you should be fully confident that you can, and should, seek medical assistance if you are worried about yourself, your child or other relative. Such circumstances may include having the symptoms of a heart attack, a stroke, signs of sepsis and meningitis. These are situations when the sooner medical attention is given the better the outcome will be. So, the key message is do not delay in seeking help because you are concerned about putting pressure on NHS services or frightened because of COVID-19. You should ring 999 emergency services as per normal.

### **Q. I'm confused about what I should do if I have other health problems that are not COVID-19 related. What do you advise?**

**A.** If you need a GP appointment about something other than coronavirus then contact your practice, either online, by an app or by phone. You will be assessed and as far as possible you will receive advice or care online or over the phone. If a face-to-face appointment is necessary, you will be advised on what to do. Everyone is being told NOT go to your GP unless you have been advised to. This will ensure the surgery can continue to provide essential care safely.

### **Q. I'm in the highly vulnerable group and having to shield. What should I do if I run out of the medicines I need?**

**A.** Contact your GP either online, by an app or by phone telling them your situation. To get the medicines to you ask friends or family to help. In some areas volunteers are helping deliver medicines. You can also ask your pharmacy and ask them to deliver. People who deliver things to you must not come into your home and you must not leave your home to meet them.

### **Q. I am taking an immunosuppressant medicine. Should I stop taking or reduce my dosage because I've heard immunosuppressants might make me more vulnerable to COVID-19?**

**A.** You should continue your immunosuppressive medication or you risk the disorder it is controlling re-activating. You should check the advice re: Shielding – if your immunosuppressive therapy is in the list you should be minimising contact to prevent infection. If you have read [our resources](#) and still aren't sure, discuss with your health team.

### **Q. Should I take Ibuprofen if I get a COVID-19 infection?**

**A.** The current advice is that patients who have been prescribed non-steroidal anti-inflammatory drugs (NSAIDs) as a treatment for a long-term condition, such as arthritis, should keep taking these medicines as normal. Adult patients who take low-dose 75 mg aspirin regularly for prevention of heart attacks or for vascular disease should continue to do so. The full guidance is at: <https://www.gov.uk/government/news/commission-on-human-medicines-advice-on-ibuprofen-and-coronavirus-COVID-19>

**Q. I have had the pneumonia vaccine. Does that give me any protection against COVID-19?**

A. This vaccine specifically protects against infection with a bacterium called pneumococcus, which can cause a secondary bacterial chest infection in someone who has a viral pneumonia, but the vaccine does not protect against coronavirus itself.

**Q. How do you best look after someone with COVID-19 symptoms?**

A. This is a really good video guide to what measures you should take if someone in your household gets the virus:

<https://www.bbc.co.uk/news/av/health-52161088/coronavirus-how-do-you-care-for-someone-at-home>

**Q. How are immunology centres maintaining good patient contact during the pandemic?**

A. The NHS have recommended that immunology centres services consider having individual discussion with patients, particularly those at the highest risk of COVID-19 about the risks and benefits of attending hospital. Many centres have done this. Another recommendation is that centres should set up a generic email for patient queries with access to clinical staff to provide responses to patients.

**Q. Should I attend my outpatient appointment?**

A. Wherever possible patients will be offered telephone consultations. If your appointment is considered essential, then you are advised to attend (see below).

**Q. How do I get to my hospital safely if I'm in the highly vulnerable group?**

A. If your appointment is non-essential you should re-schedule. If you are attending for essential treatment or tests, confirm with your unit that arrangements are unchanged. Where possible people are encouraged to use private transportation or taxis with the least exposure to others. If travelling on public transport, maintain strict social distancing and travel at quieter times (avoid early morning in particular).

**Q. I have an appointment at the hospital. What precautions are the hospitals taking to ensure I am safe from coronavirus infection?**

A. All hospitals and staff are risk assessing their clinical areas and who enters them on an ongoing basis. Already all non-essential hospital outpatients, infusions etc have been stopped so that traffic into and out of clinical areas is minimised. Visitors are only allowed in to the hospital to see children (one visitor per child) or those who are at the very end of life, so hospitals are now very quiet places compared to normal. Within the hospitals clinical areas are setup in a way to minimise risk of cross infection.

**Q. The Government says I'm extremely vulnerable and must shield myself at home. This seems to contradict making a trip to hospital. I'm confused.**

A. The government advice is quite clear on this:

**"What should you do if you have hospital and GP appointments during this period?**

We advise everyone to access medical assistance remotely, wherever possible. However, if you have a scheduled hospital or other medical appointment during this period, talk to your GP or specialist to ensure you continue to receive the care you need and determine which of these appointments are absolutely essential.

It is possible that your hospital may need to cancel or postpone some clinics and appointments. You should contact your hospital or clinic to confirm appointments."

There are many people needing treatments who are vulnerable e.g. dialysis and so hospitals are assessing the need, asking if treatment can be done another way e.g. having infusions at home, can the treatment be stopped? If this is not possible people should come to hospital in a way that minimises contact outside, but with strict social distancing that is much easier now and there are now limited flows of people in the hospital.

**Q. How do I weigh up the benefit over risk of attending a hospital appointment? Is it safer for me to self-isolate as long as possible 12 weeks plus, or do I go into a scheduled hospital for treatment soon, ultimately putting myself at possible risk?**

**A.** This is a clinical and personal judgment. Both options have risk and without all the information this cannot be balanced. Talk this through with your health team or if not available your GP who will have more information and who may be able to call the consultant directly if needed. As you will appreciate the CGD Society cannot provide you with an individual risk assessment.

**Q. Are companies developing an anti-COVID-19 plasma product?**

**A.** The companies Biotest, BPL, LFB, and Octapharma have joined an alliance formed by CSL Behring and Takeda Pharmaceutical Company Limited to develop a potential plasma-derived therapy for treating COVID-19. The alliance will begin immediately with the investigational development of one, unbranded anti-SARS-CoV-2 polyclonal hyperimmune immunoglobulin medicine with the potential to treat individuals with serious complications from COVID-19.

## **Testing for COVID-19**

**Q. What is the test for COVID-19 and who in the NHS are being tested?**

**A.** There are two main types of COVID-19 tests:

**Polymerase chain reaction (PCR)** testing looks for the presence of the virus' genetic material (RNA) on a nasal or throat swab. These tests can tell whether someone has an active infection.

The other type is **serological testing**. This type of blood test looks for the presence of antibodies produced by the immune system against COVID-19. If anti-COVID-19 antibodies are present in the serological test then that means that a person has had the infection in the past. People with weakened immune systems, though, may not make these antibodies properly.

In the NHS the main use of the test is for the presence of virus in a symptomatic individual. No symptomatic staff should be in contact with patients. In asymptomatic staff some hospitals have tested some people who have had high-level exposure from family members or work. The majority of asymptomatic staff who have been exposed are negative on the PCR test. As the epidemic progresses and NHS are exposed more and more to COVID-19 positive patients, it would not be practical or possible to test staff every day. So at present asymptomatic staff are not being tested.

NHS staff who have had symptoms and self-isolated for a week may be tested to make sure they no longer have active virus in their nose/throat before going back to work and seeing patients unless they are completely asymptomatic at that point.

**Q. How can I get tested for coronavirus? Can I be tested at home?**

**A.** At present the only place you can be tested is at a hospital. You need to be showing two symptoms of coronavirus to be tested. We do not advise anyone to buy home testing kits.

**Q. Would someone who has had a COVID-19 infection and recovered be immune to the virus in future?**

**A.** They are likely to be immune to the current version (strain) of the virus. However, the current knowledge of the COVID-19 virus is limited as yet so questions remain as to how long the immunity will last, will the virus mutate to overcome the immunity, or if people who had mild or no symptoms gain the same protection. Research will help give answers to these questions.

**COVID-19 research**

**Q. What research studies are being done on the impact of COVID-19 on the PID community?**

**A.** PID UK is leading on this project, in collaboration with the UKPIN and the CGD Society and are encouraging people with PID to register for this APP [https://twinsuk.ac.uk/our-research/ COVID-19/](https://twinsuk.ac.uk/our-research/COVID-19/). We are asking that everybody who registers to use the App to provide details of their name and postcode to their immunology teams or PID UK, so that the relevant information can be pulled together at the later date. **So please do take part and get in touch with PID UK to tell them you are registered [hello@piduk.org](mailto:hello@piduk.org).**

Further information about the app can be found on following this link: <https://twinsuk.ac.uk/our-research/COVID-19/COVID-19-symptom-tracker-app-faqs/>

**Q. Why is this research important?**

**A.** Information is key in understanding of the spread of infection and its impact on the PID community. Please do get involved as this will help inform us on the impact of COVID and how better strategies for dealing with the pandemic might be developed.

**Q. I have signed up for the COVID- 19 PID APP tracker study but it doesn't ask questions specifically relating to PID. Why is that and does it matter?**

**A.** The APP we are encouraging the community to get involved with is generic and not PID specific. Making the APP PID specific would have taken time and resources and time is pressing to collect the data. We are asking those that take part to inform their treatment centre or PID UK about their involvement by sending us details of their name, email address and postal code. This will enable cross-correlation of data submitted with the data held in the UK PIN registry so that PID relevant data can be analysed.

**Q. Is the COVID-APP tracker only for people who live in England?**

**A.** No people in all four nations can take part.

**Q. How will the findings of COVID-19 research in the PID community be compared to that of the general population who are following strict social distancing?**

**A.** The general population data will act as a control group. The PID community data will show how effective social distancing is at preventing transmission in this group and will allow follow-up on the outcome of infection.

**Q. How is the NHS building a picture of how the COVID-19 outbreak is affecting people and how it is spreading?**

**A.** The government has launched a coronavirus status checker that will help the NHS coordinate its response and build up additional data on the COVID-19 outbreak.

[NHS asks people to share their coronavirus symptoms to help others.](#) Please encourage friends and family to take part.

**Q. What is being done to develop treatments and a vaccine against COVID-19 and how long is this going to take?**

**A.** Research is happening at breakneck speed with collaborative efforts being forged between companies, laboratories and researchers around the world.

There is an “adaptive” protocol national trial called ‘RECOVER’, which changes as new treatments emerge. There are trials of anti-virals and trials of potential vaccines are already place. Several companies are developing or testing currently available anti-virals against the COVID-19 virus, this includes testing those that were found to be effective against the SARS virus and EBOLA. Another research avenue is synthetically engineering antibodies that could be able to block the virus infecting human cells. As with all research this will take time, for example it is not expected that manufacturers will be able to produce a mass-produced vaccine until the second half of 2021.

**Q. How long will it take for herd immunity to COVID-19 to develop within the UK population?**

**A.** Herd immunity usually requires 60-70% of the population to have had the infection or be vaccinated, so in the UK that is approximately 40 million people. The rate at which the population acquires infection is dependent on exposure. At present the infection rate has fallen to less than 1, which means that every infected person is now infecting less than one other person. If that continues we may end up with small outbreaks that can be contained by the use of technology e.g. contact tracing apps on phones.

**Q. Should I wear a mask?**

**A.** At present the WHO does not recommend that the general public wear masks.

<https://www.who.int/emergencies/diseases/novel-coronavirus-2019/advice-for-public/when-and-how-to-use-masks>

**Q. If enough people recover from COVID-19 could their antibodies be used to help people with serious COVID-19 infections?**

**A.** Biotest, BPL, LFB, and Octapharma have joined an alliance formed by CSL Behring and Takeda Pharmaceutical Company Limited to develop a potential plasma-derived therapy for treating COVID-19. The alliance has already started with the investigational development of one, unbranded anti-SARS-CoV-2 polyclonal hyperimmune immunoglobulin medicine with the potential to treat individuals with serious complications from COVID-19. In the press release they say ‘Developing a hyperimmune will require plasma donation from many individuals who have fully recovered from COVID-19, and whose blood contains antibodies that can fight the novel coronavirus. Once collected, the “convalescent” plasma would then be transported to manufacturing facilities where it undergoes proprietary processing, including effective virus inactivation and removal processes, and then is purified into the product.’

We will keep you updated on progress when we have more concrete news.

## Mental well-being

### **Q. I am finding it hard to cope with self-isolating. What advice can you give?**

**A.** Our top tips are to stay connected with friends and family through apps such as Facetime, Zoom, Houseparty etc; sticking to some sort of routine gives you a sense of control so develop a routine and plan for your day; maintain a healthy lifestyle that involves some type of exercise, exercising will help you sleep better; limit your exposure to the news and social media etc. For more helpful information visit <https://cgdsociety.org/covid-emotional-well-being/>

### **Q. How can I explain what is happening with COVID to my children?**

**A.** As we read from the charity Childline statistics children are being seriously impacted emotionally by the pandemic. Our advice is to make time to talk; find out what your children know, explain COVID in a way your child understands and tune in to your child's feelings. There are lots of great resources out there to help you to do this. Some can be found here:

[https://emergingminds.org.uk/wp-content/uploads/2020/03/COVID19\\_advice-for-parentsand-carers\\_20.3\\_.pdf](https://emergingminds.org.uk/wp-content/uploads/2020/03/COVID19_advice-for-parentsand-carers_20.3_.pdf)

[https://www.who.int/docs/default-source/coronaviruse/helping-children-cope-with-stress-print.pdf?sfvrsn=f3a063ff\\_2](https://www.who.int/docs/default-source/coronaviruse/helping-children-cope-with-stress-print.pdf?sfvrsn=f3a063ff_2)

[Guidance for parents and carers on supporting children and young people's mental health and wellbeing during the coronavirus \(COVID-19\) outbreak](#)

You can access a full list of resources at this webpage: <https://cgdsociety.org/covid-emotional-well-being/>

### **Q. I am worried that my partner is not coping well mentally with the current situation and is showing signs of depression. What should I do?**

**A.** It is natural to feel a range of emotions, such as stress, worry, anxiety, boredom, or low mood. Many people feel distressed by the constant news and overwhelming amount of information at this time. However, if you feel he needs professional help encourage him to talk to his GP, contact the charity SANE <http://www.sane.org.uk/>, the charity MIND <https://www.mind.org.uk/information-support/helplines/>; the Samaritans (free phone number 116 113) or, [in an emergency](#), attend your local accident and emergency department.

### **Q. Someone in my family is on the 'frontline' and the situation is clearly impacting badly on their mood and mental health. What can I do to support them?**

**A.** Listening to them and acknowledging the strain they are under and saying that how they feel is perfectly normal and understandable are good starting points. You should ask them to contact and discuss how they are affected with their occupational health at work team as soon as possible. This support helpline has been set up specifically for NHS staff <https://www.frontline19.com/>. You should also encourage them to contact their GP for support.

Please find information on support services for mental health and wellbeing on this webpage: <https://cgdsociety.org/covid-emotional-well-being/>

## Benefits

**Q. I am on statutory sickness pay (SSP; £95.85/week) and just cannot get by on this. What other benefits can I claim?**

**A.** This website gives details of the benefits you may be entitled to whilst claiming SSP <https://www.citizensadvice.org.uk/work/rights-at-work/sick-pay/getting-money-when-youre-off-work-sick/> These include Personal Independence Payment (PIP) and Employment Support Allowance (ESA). The CGD Society can send you guides as to how to fill out the PIP and ESA forms. Just get in touch with us at [hello@cgdsociety.org](mailto:hello@cgdsociety.org)

**Q. I must go to hospital for my treatment. Is there any scheme whereby I can claim back the cost of travel?**

**A.** The Healthcare Travel Costs Scheme (HTCS) scheme may help you. Details can be found at <https://www.nhs.uk/using-the-nhs/help-with-health-costs/healthcare-travel-costs-scheme-htcs/>. However, you do need to meet the exact criteria to qualify but if you are already on some sort of benefit then this is worth applying for.

**Q. How do I get help with health costs for prescriptions etc?**

**A.** Prescription charges only apply in England. If you are on any type of benefit you may qualify for help. Find out more at <http://www.piduk.org/livingwithpids/affectedadultswithpids/prescriptionchargesandpids>

**Q. I have been furloughed from my work. What does this mean and what are my rights?**

**A.** To furlough means to “lay off or suspend temporarily”, usually without pay. It is not a recognised term in UK employment law, although it is commonly used in the USA. [Government guidance](#) says someone is furloughed if they remain employed but are not undertaking work.

The CGD Society is not a legal expert on the furlough scheme but this link provides useful information on various scenarios <https://www.wired.co.uk/article/uk-furlough-scheme-job-protection>. See also this website which looks at this issue from the employer perspective <https://www.cipd.co.uk/news-views/coronavirus/faqs>.

## I need practical help!

**Q. I'm shielding and finding it really difficult to get a home delivery slot for food deliveries. What should I do?**

**A.** Yes, the demand for supermarket delivery slots is huge and seems to be outstripping what can be provided even if you are in a high priority group. Friends, family, neighbours may be able to help and if this is not possible you could try and find local support groups through these websites <https://COVIDmutualaid.org/local-groups/> and at <https://nextdoor.co.uk/>.

Other options include trying online shopping using local shops. There are now lots of small businesses now doing home delivery services in order to keep their businesses afloat and many do not charge a delivery fee if a minimum order is placed. Remember people who deliver things to you must not come into your home and you must not leave your home to meet them.

If you self register on the government website, you are more likely to become eligible for home delivery and support: <https://www.gov.uk/coronavirus-extremely-vulnerable>