

## COVID-19 Frequently Asked Questions: Information for Patients on Home Parenteral Nutrition

**Please note:** Information within this document and hyperlinks were checked as correct at time of document issue: **24 April 2020**

The COVID-19 pandemic has particular relevance to patients on home parenteral nutrition (HPN) as you are in a high risk group if you were to become infected with the coronavirus. This information also applies to patients on home parenteral electrolytes or fluids but the term HPN is used to include all of these groups.

We have identified the most useful links that we also use as a resource for ourselves. The situation is changing regularly, so please do be prepared to be flexible: we follow NHS guidance, but have tried to make information that we share with you as relevant as possible. We are very aware that conflicting advice and guidance from multiple other sources is being communicated to our patients via text messages, websites and social media, however the Oxford Nutrition team is following the approach outlined here.

**Prevention has to be the key. Reducing the number of people that you are in contact with reduces the risk of catching the virus**

As of March 2020, there are three levels of action considered appropriate for all people, including children, who are at higher risk of severe illness from coronavirus (COVID-19) because of an underlying health condition, and for their family, friends and carers. This can be accessed at:

<https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19>

The three levels of action are:

1. **Shielding** [this includes patients on HPN– please see the letter from the NHS (available on our website) and our own letter we sent to you in April 2020]
2. **Stringent social distancing** [for ‘moderate risk’ groups]
3. **Social** (physical) **distancing** [for everyone]

Shielding is a measure to protect extremely vulnerable people by minimising interaction between those who are extremely vulnerable and others. This means that those who are extremely vulnerable should not leave their homes, and within their homes should minimise all non-essential contact with other members of their household.

As from the date of issue of the Government advice on 22 March 2020 which has recommended shielding, this means that you **must self-isolate for 12 weeks**, and take protective steps where possible, including:

- staying at home
- avoiding situations where you come into contact with other people, such as in a supermarket queue or on public transport.
- asking others if they can shop for basic essentials, collecting prescriptions, or do anything that can help you to avoid going out.

We have also identified some frequently asked questions and hope that the information below will help answer your questions and address your concerns. We understand that this is a particularly anxious time for patients and their families.

## Frequently Asked Questions

### What do I do if I think I might have COVID-19?

The key symptoms to look out for are a high temperature or a new continuous (persistent) cough. Of course, for patients on HPN a high temperature may also be caused by other issues including line infections.

If you have only developed a fever of 37.8C or higher (but have no other symptoms suggestive of COVID-19) then please phone us on 01865 740378 (during office hours). If it is out of hours, then please phone the John Radcliffe Switchboard on 01865 741166 and ask for the Gastroenterology Ward. During any phone call assessments, we would then seek to determine whether this could be COVID-19 related or alternatively if symptoms are more suspicious for a central venous catheter infection.

If you have any other symptoms suggestive of COVID-19 then you should follow the advice on the NHS 111 website for coronavirus (<https://111.nhs.uk/covid-19>).

### Do I need to stop my medication?

Do not stop your medication; the risks associated with stopping medication can be greater than the risk of contracting serious complications of COVID-19. If you have been diagnosed with COVID-19 please continue to self-isolate. Contact us for specific recommendations regarding your treatment.

**Is my medication an immunosuppressant? (immunosuppressants suppress or reduce the strength of body's immune system)**

- a. Colesevelam, colestyramine, codeine, loperamide, mesalazine/ 5-ASA, and proton pump inhibitors (PPIs such as omeprazole, lansoprazole, pantoprazole) **DO NOT** suppress or reduce the immune system
- b. Steroids (prednisolone) **DO** suppress or reduce the immune system. However, budesonide is not felt to affect the immune system.
- c. Azathioprine/mercaptopurine/methotrexate/mycophenolate/tacrolimus/ciclosporin **DO** suppress or reduce the immune system
- d. Advanced therapies (such as adalimumab, golimumab, infliximab, tofacitinib, ustekinumab) **DO** suppress or reduce the immune system
- e. Vedolizumab (also a biologic) works by suppressing the gut immune system, so this should avoid systemic immunosuppression

**What happens if I am on medication to suppress my immune system due to my underlying conditions?**

This applies to medications such as adalimumab, azathioprine, ciclosporin, golimumab, infliximab, mercaptopurine, methotrexate, prednisolone, tacrolimus, tofacitinib, ustekinumab, vedolizumab, or clinical trial medication.

If you have been told to take these medications to manage your condition, it is not recommended that you stop taking them. The best course of action is to continue your normal treatment and follow the further recommendations below.

**What if I am pregnant?**

Any person on HPN who is pregnant should follow the government guidelines for 'shielding'.

**How do I reduce the risk of contracting the virus?**

- Handwashing, more handwashing and yes, more handwashing
- Avoid touching your face (difficult!)
- Social distancing: no shaking hands, no kiss-greeting, aim for a physical space of 2 metres around you (3 paces)
- Avoid meeting people
- Travel only if essential for hospital appointments or essential blood tests – you should avoid using public transport...and wash your hands, again

### **Am I at an increased risk of severe COVID-19?**

If you are unfortunate enough to get COVID-19, most infections are mild. However, some patients develop severe disease. The main risk of severe consequences appears to be in those with other conditions – especially affecting the lungs or heart, diabetes. This also includes older patients. It may help to know that there is some evidence that suppressing the immune system reduces the chance of a damaging immune response to the virus. This is quite the opposite of what might be suspected – but the truth is that nobody yet knows. The decision about a person's treatment should they get COVID-19, has to be made on an individual basis: that will involve discussion between infectious diseases and intestinal rehabilitation specialists.

### **Do I need to social distance / self-isolate?**

Patients on HPN should be shielding (self-isolating) as described above. Part of this includes social distancing which is something all of us should be practising.

Social distancing will reduce the number of people you come into contact with and therefore reduce your chance of coming into contact with COVID-19. In simple terms 50% less contact with others = 50% less chance of coming into contact with the virus, etc. Visit:

<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>

### **My job involves interacting with the general public or meeting others, do I need to change my duties?**

As you should be shielding, you should arrange with your workplace to work from home and avoid physical interactions with the general public. You should try and reduce non-essential contact with others in your household.

### **Should I restrict travel?**

Yes as you should only travel for hospital appointments or essential blood tests where really necessary. Please follow the government guidance on travelling. You should avoid using public transport, always ensure good hand hygiene and avoid touching your face with unwashed hands.

### **Should I attend my appointments?**

**Infusions:** The day case units are contacting patients prior to their infusions to screen for risk of COVID-19 in order to ensure general safety. Where possible, infusions are being arranged in locations outside the main John Radcliffe hospital. Local, national and international advice at this stage is to continue medication and infusions.

**Clinic appointments:** Clinic appointments booked as from Monday 16th March 2020 for routine Gastroenterology appointments have cancelled; patients are being contacted with regard to telephone or video-conference based appointments instead. Nutrition clinic appointments are being managed in this same way. Those individuals who are unwell and need to be seen will be discussed on a case-by-case basis with the relevant health professionals and patient involved.

The Nutrition Team are trying to get video clinic facilities up and running using software called NHS Attend Anywhere. In order for you to be able to access the software when it becomes available, you need to have a certain set up on your computer. It would be really helpful whilst you are waiting for us to do this at this end, that you ensure you are able to update your operating system or obtain a suitable browser to be able to do this. If you cannot, that is completely fine, and we will continue with a telephone call.

You will need the following minimum requirements for your computer, tablet or smartphone to make a video call:

- **Windows PC** with an i5 processor and 3GB of RAM (Windows 7 or later)
- **Apple Mac** with an i5 processor and 3GB of RAM:
  - (Using Chrome) MacOS version 10.11 or later
  - (Using Safari) MacOS version 10.12 (Sierra) or later
- **Android-based smartphone or tablet** (Android 5.1 or later)
- **iPhone** (iOS 11.4 or later)
- **iPad** (iOS 11.4 or later; iPadOS 13 or later)

You need to have one of the following web browsers:

- (Windows, Android, MacOS) **Google Chrome** version 74 or later
- (MacOS, iOS, iPadOS) **Apple Safari** version 11.4 or later
- To find out which browser version you are using type in [www.whatismybrowser.com](http://www.whatismybrowser.com)

**Endoscopy appointments** – routine endoscopy appointments are being cancelled, but patients are being contacted individually, so please stay flexible and we will do our best.

## Top 10 tips for everyone on HPN

1. We will do everything we can to keep you safe and well during the COVID-19 pandemic. (Note that hospitals are undergoing massive re-organisation to prepare to care for those with serious infection)
2. Don't stop your medication; preventing disease flares is a priority (We want to keep you out of hospital if possible, but if you are unwell, we will be there for you)
3. Ensure you have a good supply of medication should you need to self-isolate or shield yourself (Do not take steroids (prednisolone) from your GP without checking with us or your IBD team)
4. If you have IBD (usually managed by the Oxford team) and are experiencing a flare, please contact the IBD team via the IBD Advice Line: [ibd.advice@nhs.net](mailto:ibd.advice@nhs.net)
5. Wash your hands frequently and avoid touching your face; this goes for everyone
6. Work from home, avoid non-essential travel & contact with people who are currently unwell
7. Quit smoking as this increases the risk and severity of COVID-19 infection
8. Government guidelines on self-isolation and social distancing are changing rapidly so please visit [gov.uk](http://gov.uk) and [www.nhs.uk](http://www.nhs.uk) to keep up to date.
9. If you develop a fever of 37.8C or higher but have no other symptoms of COVID-19 please contact us for advice. If you have any other symptoms suggestive of COVID-19 please use the NHS 111 online coronavirus service.
10. Take care of yourself but also be kind and considerate to others in these difficult times.

## Helpful Links:

British Association of Parenteral and Enteral Nutrition (BAPEN) – a number of different healthcare related resources:

<https://www.bapen.org.uk/resources-and-education/education-and-guidance/covid-19>

Crohn's and Colitis UK – routine advice with regards to immunosuppression therapies and risks associated with these:

<https://www.crohnsandcolitis.org.uk/news/coronavirus-covid-19-advice>

NHS England – precautions to take:

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

Government and other approved guidance:

<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>

<https://www.gov.uk/government/publications/covid-19-stay-at-home-guidance/stay-at-home-guidance-for-households-with-possible-coronavirus-covid-19-infection>

<https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19>

<https://www.bsg.org.uk/covid-19-advice/>