

# FAQ For Rheumatology Patients on Immunosuppressive Medications April 2020

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Many patients share similar overlapping queries surrounding the effects of immunosuppressive medications in these pandemic times. We will continue to update these answers to those frequently asked questions on a weekly basis as new information emerges.

## STAY SAFE & STAY WELL

### I'm on immunosuppressive medication (IS), are they bad for my immune system, do they suppress my immune system? I'm worried because now we are in the middle of a pandemic?

(Examples of **IS medications** include methotrexate, azathioprine, mycophenolate, rituximab, tocilizumab and adalimumab)

#### iOWNA gem

*The term 'immunosuppressive medication' is confusing as it implies that these drugs suppress the immune system and are bad for it. In actuality they help regulate an immune system that has gone a bit wrong.*

*You may be on these drugs for a disease that affects your eye and they aim to keep the immune system under better control.*

Let's use the analogy of working overtime: the more we work the more tired we become, and there comes a point at which we become inefficient and may even burn out. The same happens with your immune system. Let's say you have a condition such as uveitis or rheumatoid arthritis causing scleritis or vasculitis (inflammation of blood vessels) that requires you to be on an immunosuppressive drug, this is because your immune system has been overworked trying to fight that condition. It has become tired and inefficient.

These **IS medications** help your immune system to recover. They give a boost to certain aspects of your immune system, similar to when you are overworked and burnout from work, you take a break, boost yourself with a relaxing treat and nourish your mind and body to recover. The immune system is the same, it also gets tired and burnt out and these drugs help you get over that.

## – Do my immunosuppressive medications increase my chance of developing severe COVID-19 infection?

### iOWNA gem

*The government has identified groups of patients at high risk of more severe illness some patients on immunosuppressive agents will be in this high risk category but not all*

Some immunosuppressive medications may put you at higher risk of more severe infection which is why we want to identify patients who are at the highest risk so they can shield and stay safe. However we also know that when a person becomes infected with the COVID-19 virus the body's immune system may become very overactive and start producing many proteins known as cytokines in response to the virus - some good, some bad. This process is called a cytokine storm. The **IS medications** you are on may prevent this cytokine storm happening in the first place, thus helping you fight the infection. We will come back to how you can self identify as high risk towards the end of this document using the British Society of Rheumatology guidelines for patients on **IS medications** which we are adopting for eye patients on **IS medications** also.

## – Can my immunosuppressive medication protect me?

There have been some reports that various **IS medications** are being used to rescue very sick patients in ICU in Italy for instance. One such drug is called tocilizumab. There are also reports about a drug called hydroxychloroquine which is being said to 'prevent or cure the virus'. We will try and explain what these drugs are and how they might help but also dispel some of the unclear information circulating on Twitter and other forums about their role in combating COVID-19.

## – What is hydroxychloroquine and how might it protect me?

Hydroxychloroquine is an anti malarial drug, you may be on it for mild Rheumatoid Arthritis or indeed if you live in/ have visited an area where malaria is very common. It appears to make the cells in your body more acidic, the virus doesn't like this acidic state and consequently does not wish to enter the body. For this reason it may be protective. We cannot go so far as to say it is protective for all patients and it's certainly not a cure.

## – What is Tocilizumab and how might that help me?

Tocilizumab is a drug that reduces one of the cytokines (proteins) that may play a big role in the cytokine storm we mentioned. It blocks a cytokine called interleukin 6 (IL-6) which is responsible for a lot of inflammation in response to an infection or background inflammation condition such as Juvenile idiopathic arthritis or Ankylosing spondylitis, both of which are associated with uveitis. It is already used as treatment of patients with uveitis.

### iOWNA gem

*There is currently no evidence that you should go on these drugs if you are not already on them, unless your doctor recommends them for your condition.*

*If you are on these drugs you should not stop them as they might help you, unless of course your doctors tell you to stop.*

## – What can I do to reduce my risk of catching COVID-19?

The best thing you can do to reduce your risk of catching COVID-19 is to follow the advice of the government: Stay at home, Stay safe, Wash hands.

## – Should I stop my immunosuppressive medication?

No, we do not advise that you stop your IS medication. If you are taking anti-inflammatory drugs or steroids this may be a different matter and your doctor will advise you to use these with caution at this time.

Only use anti-inflammatories (i.e. ibuprofen, froben, naproxen) if absolutely necessary. If you get viral symptoms use paracetamol instead. We also want to avoid having to increase your steroid dose at this time. If you come off your **IS medications** that might destabilize your underlying condition and make it necessary for your doctor to start you steroids or increase your current dose of steroids.

Steroids may make it harder for your body to fight COVID-19. Steroids are often used to treat a flare up in your disease. This is why we would like you to stay on your **IS medication, to avoid a flare up**, unless we specifically tell you to come off it for other reasons. Reasons you may need to stop your **IS medications** or reduce the dose include: if they are not working for your underlying condition, if you develop a side effect from them, or infection whilst on them or your blood tests are known to be abnormal and we would routinely advise you to reduce or stop your medications. We don't however recommend you stop your steroids abruptly if on them as prescribed by your doctor.

### iOWNA gem

*The best way to avoid a flare up of your condition is to stay on your IS medication. Stopping your **IS medications** may destabilize your underlying condition and lead you to taking more anti inflammatories or steroids which may be less safe overall if you get COVID-19.*

## – Will I still be able to attend my clinic appointment?

Clinic appointments are currently being reviewed to decide who needs to come in on a case by case basis. Where at all possible your appointment will be postponed to avoid you taking unnecessary risk. If you need to be seen the possibility of this being done remotely will be investigated. Remote consultations won't work for everyone and if you do need to attend hospital you will be given instructions upon entrance on what to do and how to stay safe. Your safety at this time is our biggest concern.

## – Are drug monitoring blood tests still required?

At the moment we need to balance the risk of you attending for a blood test and risk contracting COVID-19 with the risk of not doing a blood test and possibly missing an abnormal result. We will try to review this on a case by case basis. But in general we offer the following guidance:

- If you have been on your **IS medications** for 6 months or more at a stable dose and your bloods are stable then we would suggest you do not attend for the moment for routine blood tests whilst you are social distancing

- If you already have abnormal bloods that we need to follow up, or if a blood test is necessary to start you on a treatment to save your condition from deteriorating, then we will advise you to attend for a blood test.

The government is reviewing their advice about lock down at three weekly intervals and as we get more information on national policy we will let you know.

– **How do I know if I am high risk?**

You will have received a letter from us recently explaining how to work out if you are high risk, moderate risk or low risk because you are on an immunosuppressant drug. It's important to know if you are high risk so you can protect yourself to reduce your risk of getting COVID-19, as those that get it may become sicker. This applies to those of you on **IS medications** and/ or steroids only.

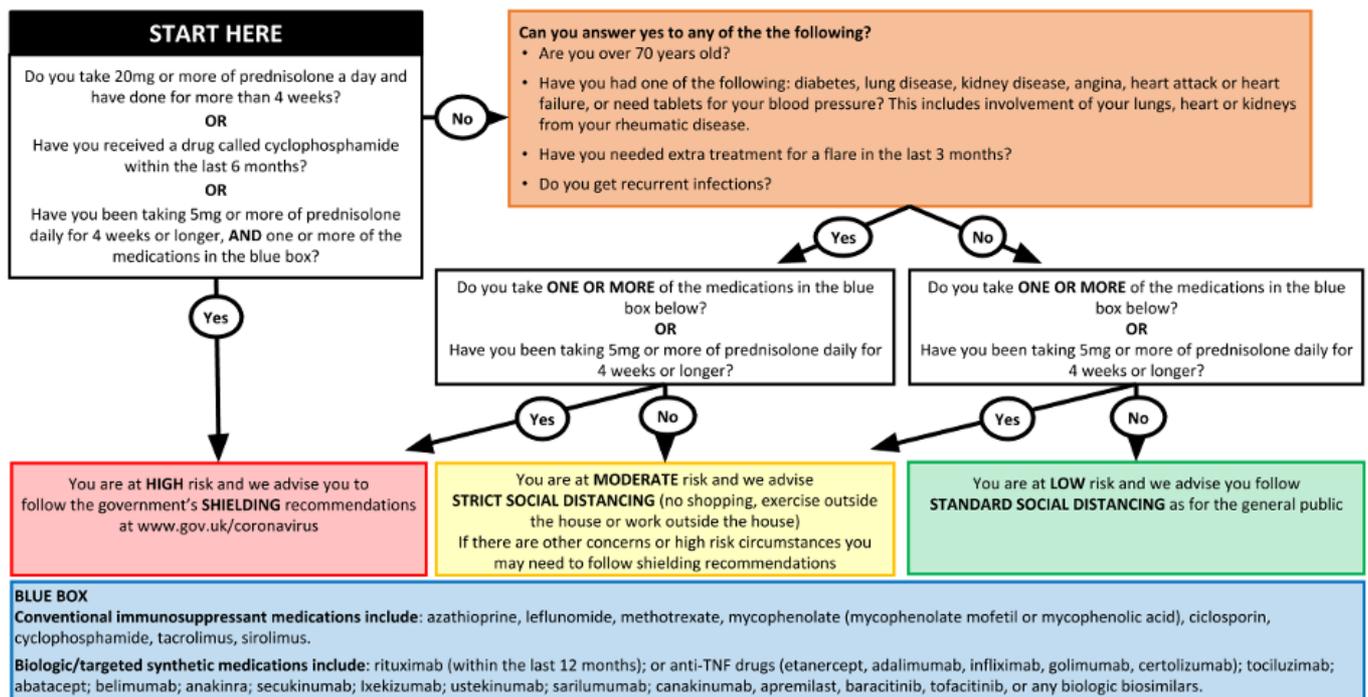
The official Government letter sent with this explains what to do with regards to social distancing depending on which category you fall into.

We realise this document has a lot of technical words in it and you may have found it hard to understand, and indeed many of you with low vision may have found it hard to read it as a result.

If you are still unsure, you might find it easier to look at the diagram below to work out which category you may fall into. Start in black box, entitled 'start here' and answer all those questions. If 'yes', move to the pink box, if 'no', move to the orange box and follow the arrows until you finish the exercise. At the end you will know if you are high risk, moderate risk or low risk. Please follow the guidance for these categories exactly as written to stay safe.

If you have trouble reading because of low vision, please ask a family member or friend to help you. We are working on a system to be able to send this by an audio link to your phone.

1 April 2020 **Guide to social distancing for Rheumatology and Ophthalmology patients on immunosuppressive medications**  
*Based on guidelines from British Society for Rheumatology and related medical associations and agreed by consultant rheumatologists at Leeds*



Adapted from Leeds teaching hospital guidance for rheumatology patient based on The British Society of Rheumatology, this flow sheet will help you identify which risk category you are in and what you should do depending on the risk category

### – How will I obtain prescriptions for my medications?

For any drugs that you routinely get from your GP we advise you liaise with your GP or community pharmacist practice to obtain them as normal.

For drugs that I have been prescribing relating to your arthritis condition only, or for any that I start you on where your GP does not have a shared care arrangement in place with me to prescribe, I will continue to prescribe them.

Please email requests to my PA [✉ drstone@thephysiciansclinic.co.uk](mailto:drstone@thephysiciansclinic.co.uk)

Please put 'prescription query' in the subject line.

### – What should I do if I develop symptoms of COVID-19 and I cannot contact my specialist immediately?

You should dial 111 and follow the advice given.

### – What can I do to stay well?

Everyone should try and stay healthy with the following strategies to help both their overall health and their immunity:

- Regular exercise – in self isolation consider a workout programme from an online instructor, focussing on aerobic exercise.
- Jogging on the spot for 10 minutes each day is a gentle workout which can be performed in self isolation either inside or outside.
- Healthy diet with fruit and vegetables.
- Avoid excessive alcohol consumption.
- Take your regular medication as prescribed by your doctor.

## Useful links

Useful links:

[✉ https://www.guysandstthomas.nhs.uk/](https://www.guysandstthomas.nhs.uk/)

[✉ https://www.nhs.uk/conditions/coronavirus-covid-19/](https://www.nhs.uk/conditions/coronavirus-covid-19/)

[✉ https://www.gov.uk/coronavirus](https://www.gov.uk/coronavirus)

[✉ https://www.rheumatology.org.uk/covid-19/](https://www.rheumatology.org.uk/covid-19/)

<https://www.ageuk.org.uk/information-advice/coronavirus/staying-safe-and-well-at-home/>

<https://www.england.nhs.uk/coronavirus/>

<https://www.versusarthritis.org/news/2020/march/coronavirus-covid-19-what-is-it-and-where-to-go-for-information/>

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