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Coronavirus FAQs for TED patients

Dear Members,

During the coronavirus outbreak, there may be some concerns and precautions that apply especially to people with thyroid eye disease. We have drawn up this FAQ list to try to answer some of the most common queries.

Best wishes & keep safe!

Rebecca

Rebecca Ford & the TEDct committee

Am I at increased risk from coronavirus COVID-19?

It does not appear that people with thyroid problems or TED are more likely to catch coronavirus than anyone else. Thyroid problems also do not seem to confer a greater risk of severe disease if you do catch COVID-19.

Am I immunosuppressed / immunocompromised?

Graves disease and TED are autoimmune diseases. However, this does not mean that you are immunosuppressed and most people with TED can fight off infections as well as anyone else.

People with TED may however be immunosuppressed if they are on certain medications. Immunosuppressive drugs in use for TED include:

- Prednisolone / methylprednisolone
- Ciclosporin
- Azathioprine
- Mycophenolate
- Methotrexate
- Rituximab

If you are on any of these, you should consider yourself to be immunosuppressed and take appropriate precautions (see below).

Should I attend my upcoming outpatient appointments?

Most routine outpatient appointments will be cancelled during the COVID-19 outbreak. This is to protect all of us, and especially the most vulnerable, from spread of the virus. If your condition is stable, it is unlikely that you should attend your appointment. Medical staff will be reviewing all appointments on a week-by-week basis, and it is likely that you will get a phone call advising you what to do.

If you are over 70 or on one of the immunosuppressing treatments above, you should avoid attending hospital unless you have a medical emergency or need urgent treatment.

It is likely that you will need to attend only if your thyroid eye disease is active and getting worse, i.e. symptoms of:

- Worsening vision
- Worsening double vision
- Severe eye pain
- Corneal exposure (eyes becoming severely red and painful due to inability to close eyes)

Please await contact from your ophthalmology team, but also be sensible and avoid attending hospital if your eyes are stable.

Should I continue my medication?

Please continue your medication as usual unless discussed and agreed with your doctors. In particular, anti-thyroid drugs such as carbimazole / methimazole / propylthiouracil and thyroid hormone replacement such as levothyroxine do not pose any additional risk if you do catch coronavirus and should be continued.

If you are on immunosuppressive drugs, in most cases you are also better to continue. Many such drugs take several months to wear off from your system, so stopping now may not make any difference to your risk from the virus. However, many doctors are taking the practical stance that we might lower our threshold for reducing immunosuppression. It is likely that you will get a phone call from your prescriber who can advise you whether cutting down might be right for you.

Please note that ***steroids should not be reduced without medical supervision***. In particular, drugs like prednisolone should not be stopped abruptly as this can have very dangerous consequences.

Please also remember that if you are on immunosuppressive drugs, your blood monitoring will need to continue as usual.

I am currently on a course of intravenous methylprednisolone (eg 'EUGOGO protocol'). What should I do?

In this case, you and your doctors will need to make an informed individual choice about whether to continue. This will depend on the severity of your TED and whether it is

threatening your sight, as well as any other health risks you may have and the prevalence of COVID19 in your area.

I am scheduled for surgery. Will this be cancelled?

All elective surgery has now been postponed in England, with the rest of the UK likely to follow suit imminently. Therefore TED surgery is unlikely to go ahead until after the outbreak, unless it is sight-preserving surgery such as decompression for optic nerve compression.

The cancellation of surgery is obviously very disappointing, but is necessary for several reasons:

- Avoiding exposure of staff and patients to the virus.
- Keeping anaesthetists free to provide urgent care for COVID19 patients.
- Keeping medical equipment free to care for emergency cases.

It is likely that hospitals will rebook all elective surgery for after the outbreak in order of waiting time.

Should I be self-isolating?

If you are not immunosuppressed, you should follow advice as for the general public. At the time of writing, this includes 'social distancing'. If you are immunosuppressed or over 70 years old, you fall into the higher risk group who should be self-isolating or shielding.

For up-to-date advice, please refer to the NHS 111 website:

<https://111.nhs.uk/covid-19>

Advice for those in vulnerable groups is available here:

<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>

Should I order extra supplies of my medication?

At present there is no reason to believe that COVID-19 will affect the supply chain for drugs related to Graves or TED. Please request repeat prescriptions at your usual times and do not 'stockpile' medication as this may lead to a shortage of supplies for others with the same conditions in your community.

Are there any other precautions I should be taking?

It is important to maintain your general health, now as ever. Smoking is bad for thyroid eye disease and places you at higher risk if you do catch COVID-19 so now would be a great time to stop if you are a smoker!

Where else can I find advice?

Our sister charity the British Thyroid Foundation have gathered useful information for all thyroid patients during the coronavirus epidemic; it can be found on their website at:

<https://www.btf-thyroid.org/news/thyroid-disease-and-coronavirus-covid-19>

We hope that this advice answers some of your questions and we are available via the TEDct email and phone advice lines if you have queries that are not covered by these FAQs. If in doubt about your individual circumstances please contact your doctor, but be patient in waiting for a reply as medical staff are extremely busy right now.

Please stay safe and look out for family, friends and neighbours!