

FREQUENTLY ASKED QUESTIONS FOR FAMILIES OF CHILDREN AND YOUNG PEOPLE WITH INFLAMMATORY EYE CONDITIONS concerning the current coronavirus (COVID-19) pandemic

This advice is based on expert opinion from UK paediatric rheumatologists and ophthalmologists. It is based on the currently available information. It may change as more information becomes available. It is reassuring that so far COVID-19 is not causing severe infections in children and young people with rheumatic disease. The guidance has been adapted for children with inflammatory eye conditions (for example uveitis, scleritis or orbital inflammation) who are looked after by ophthalmologists and rheumatologists, and the original version for children with rheumatic diseases can be found here:

<https://www.ccaa.org.uk/wp-content/uploads/2020/04/Paed-Rheum-Child-COVID-FAQ-v6-07-04-20.pdf>

1. What do you know about COVID-19 in children and young people with rheumatic disease?

A lot is already known about COVID-19 in children and young people. This information comes from China, Italy, Spain and USA. All the papers on COVID are free and openly available on line <https://www.ncbi.nlm.nih.gov/research/coronavirus/>. We know that younger age is a very strong protection. Children and young people in general do very well, and usually recover quickly without going to hospital. Many children/young people and their families do not even know they have the virus (in one study an estimated 40% of children and young people who tested positive for COVID did not know they had it). Less is known in Paediatric Rheumatology patients. However we are in touch with doctors in China and Italy, looking after children/young people on immune suppression medicines. Their experience and early reports suggest there are very few who show any serious signs. Children and Young people rarely seem to get the pneumonia, that can happen in older people when they are very sick with COVID-19.

MEDICATION

2. Should I stop my/my child's medication if they are on an immune suppressant?

- No. If you stop medication the child/young person may be more at risk of disease flaring. If this happens they may need a longer course of steroids. This might make them more at risk from the virus. It might also move them into the so called 'shielding group'. See <https://www.ccaa.org.uk/wp-content/uploads/2020/04/Paed-RheumOphth-Risk-Stratification4Families-FINAL-02042020.pdf>. If your child is on steroids you may have been advised to take special care. Ask your team if you are unsure. Do not stop your child's steroids or change the dose that was advised before talking to your team.

3. Is taking NSAIDS such as Ibuprofen/Naproxen safe for the child/young person now? And what about if they contract COVID-19?

- There is a suggestion that using ibuprofen and other non-steroidal anti-inflammatories (NSAIDS) might be a problem during a fever with COVID 19. Most of the evidence however suggests it is quite safe. If your child develops a fever and you are concerned that they have a coronavirus infection, paracetamol can be used instead. However, if the child/young person takes a NSAID medicine for their disease they should not stop taking it. This is because having a flare will not be helpful at this time.

TREATMENT

- 4. I am frightened about taking my child/young person into hospital for an appointment - will it be safe?**
 - If your child/young person is unwell and needs to be seen in hospital it is important to attend the hospital visit. Patients with COVID infections are kept in a separate area. There are very few patients in childrens' wards who are unwell with this infection.
 - Most outpatient appointments have been changed to telephone appointments to avoid coming to hospital. The team who look after you will decide if it is necessary for you to come to hospital or not.
 - Please do not bring your child/young person to the hospital for an appointment if they, or anyone in the family are unwell or isolating due to contact with coronavirus. Please contact your team in advance of the appointment to decide what should be done. It is likely the appointment will be postponed. If you do attend an appointment, only one parent and no siblings should come with the patient.
 - If your child/young person needs to attend for an infusion, your team will review this. Some patients may be able to get the same treatment a different way. This might be an injection instead of an infusion. Others still need to come to hospital for their infusion.
- 5. What should I do if my child/young person has a disease flare?**
 - Contact your team for advice. Although we will have less team members available we will still be here to support you.
- 6. I am concerned about eye checks - how can I be sure my child/young person's disease is well controlled? What if they need regular monitoring?**
 - Children/young people who have well controlled eye disease will be monitored using video or telephone eye health checks.
 - Children/young people will be asked to keep coming into eye clinic for a face-to-face appointment if they have unstable disease.
 - If you have any concerns that the disease is active, contact your ophthalmology or rheumatology team.
- 7. I have been told I can wait longer before my child/young person needs bloods taking again. Is this safe? How long is too long between blood tests?**
 - If blood tests have previously been normal then these can be done less frequently. Once blood tests are stable it is usually safe to do them every 3 months.

- If there have been problems with your blood test previously and your team are monitoring them closely, then ask your team what is needed.
- If your GP prescribes the methotrexate and does the blood tests, your team can advise your GP on how frequently bloods can be done during the COVID pandemic.

8. I have been told I need to give my child/ young person their medication via injection now when they normally have an infusion. Is there any help available with this?

- Yes. Your team will know what support is available. This might be in their hospital or locally. Many families manage to give the injections themselves once they have been shown how to do this. If you are struggling then contact your team for help.

9. Is it safe to still let community nurses or Healthcare at Home nurses into my house to give my child/ young person their injection?

- Yes. They will take precautions to protect your child and themselves against possible transmission of infection.

10. What do I do if my child/young person gets ill with COVID 19?

1. Check current guidance <https://www.gov.uk/government/collections/coronavirus-covid-19-list-of-guidance>
2. Let your team know your child/young person is unwell so they can help with what to do with medicines. These will be managed in the same way they would be if they became unwell at any other time. If your child/ young person has a fever, you are likely to be asked to stop their medicines (except steroids) until they have recovered. Do not do this without informing your Paediatric Rheumatology and Ophthalmology teams.
3. If you are concerned about your child/ young person call for emergency help as you would do normally.

SHIELDING AND ISOLATING

11. My child/young person has received a shielding letter - does that really mean they cannot even go in the garden?

- No it does not mean that. There is information on the Public Health England website about shielding:

<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>

And from NHS Scotland:

<https://www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19/coronavirus-covid-19-shielding>

- It is difficult to know exactly how to apply all of this guidance to children/young people and we are waiting for more guidance on this for children/young people specifically. **Simple good hygiene is important for example, everyone washing their hands well. As more information comes out for children and young people with rheumatic diseases the guidance may be updated.**

12. What do I do if my child/young person's risk status has been lowered from high to moderate?

- This just means it is safe to practice sensible precautions we are all using. This means washing hands well, staying at home for much of the time and social distancing (keeping 2 m distance from people who are not in the same household). More detailed guidelines are now being developed for children and young people, as we understand this disease affects them much less severely than older adults. This includes children/ young people with rheumatic diseases like arthritis. If you are unsure about your child's risk status, your team will advise you which category your child falls into, and therefore what precautions are recommended.

13. What can I do to protect my child/young person if other siblings/parents become unwell?

- Follow the advice that is being issued for the general public including good hand hygiene. The unwell person would need to be shielded from the rest of the family as much as is possible. Information is in the Public Health England Shielding advice:

<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>

WORKING OUTSIDE THE HOME

14. I/we (carers/parents/guardians) are key workers - should we also be self-isolating to keep our child/young person safe? My child/ young person is of 'moderate risk' but do I have to go to work still?

- If your child/ young person is in the moderate or low risk group, you should continue to work. You should take all the usual and necessary precautions when you return home.
- Situations for those in the 'shielding group' will need individual consideration depending on the level of risk. This will take into account the child's condition, the parent's job and how likely they are to be exposed to the virus. In general, if good social distancing and hand hygiene is applied, parents are currently being advised to continue to work and be very careful with the usual precautions.

15. If we continue to go to work (whether as key workers now, or anyone when the current lockdown is over) what precautions should we take on coming home to care for our child/young person?

- Hand washing thoroughly, changing and cleaning clothes, taking off work shoes when you get home and leaving them by the front door is important. Leave any ID badge or lanyard in a bag and don't take it out at home. Mobile phone case can be wiped with anti-bacterial wipes / hand sanitiser after being at work.
- 16. My employer is not sympathetic to the fact that I need to stay at home to help isolate my child/young person - what should I do?**
- If your child/young person is in the very vulnerable/high risk/shielding group and your work involves a risk of being in contact with people with coronavirus, your team may be able to provide a letter to support working from home to protect your child/young person. Talk to your consultant or team about this.

If you still have concerns, please talk to your rheumatology and ophthalmology team. We are almost certainly going to be working with less staff than usual. This is because our team members are needed to work on the wards. We cannot guarantee a quick response, but we will all do our best to support you and your families through this time.