Steroid management advice for patients already taking steroids during COVID-19 outbreak

Many patients with muscular dystrophies, particularly Duchene Muscular Dystrophy, take steroids to protect their muscles. Steroids are also the body's natural response to fighting infection and stressful situations. With the current concerns about the COVID-19 virus some patients may be worried about taking steroids and if their dose needs to be changed. Stopping, or reducing, steroid dose suddenly is dangerous and will not protect anyone from infection with the virus.

1. Anyone who takes a steroid medicine daily for their muscles should continue to take them throughout the outbreak.

When a person becomes unwell with any infection, the body can need more steroids in order to fight the infection. Some patients have a plan of what to do with their steroids if they become unwell and will have injectable hydrocortisone at home.

2. If you have home hydrocortisone and a management plan for illness then you should continue with your personalised plan if you become unwell

Some patients do not have hydrocortisone or an emergency dose plan at home. For these patients we recommend doubling the usual dose of oral steroids if the person who usually takes steroids becomes unwell.

- 3. If you do not already have a steroid plan AND regularly take steroid medicines AND become unwell with moderate illness (flu-like symptoms, worse than common cold) then: increase your dose so that you take your usual morning dose in the morning and the evening. This means you are doubling your usual dose for the day.
 - For example if you usually take 20mg once a day in the morning then you should take 20mg in the morning and 20mg in the evening.
 Continue at this higher dose for 3 days and then progressively go back to your normal dose over 5 days.
 - For example, after 3 days continue to take 20mg in the morning and take 15mg in the evening for 2 days (day 1 and 2), 10mg in the evening for 1 day (day 3), 5mg in the evening for 2 days (day 4 and 5) and then stop taking the evening dose.
 - If you are on the "10 days on 10 days off" regime of steroids, we recommend that you undertake doubling the dose, as mentioned above, even when you're on the "10 days off" part of the steroid treatment.
- 4. If you are unwell and/or symptoms do not improve within 2-3days (or sooner if symptoms rapidly worsen), please ask for medical opinion either through your existing FastTrack arrangement with the local hospital, neuromuscular specialist, GP or calling 111

Because of self-isolation and protecting patients from social contact, it is possible that you will find it difficult to get repeat prescriptions for oral steroid doses completed urgently. Please try to plan ahead and ensure that you do not run out or run very low on your steroids, in case you need to increase the dose at short notice. If you run out then you MUST urgently contact your GP for further doses the same day.

If a person cannot take their usual or increased dose of steroids for some reason (for example because they are vomiting) it is very important to get steroids into the body another way. As well as a sign of infections, vomiting can also be a sign that the body does not have enough steroid.

5. If you vomit back your steroids try to repeat the dose after one hour. If you still cannot keep your steroids down or cannot take your steroids and do not have home hydrocortisone then you <u>MUST</u> contact your GP or emergency department as you may need emergency treatment with an injection of hydrocortisone.

If you have concerns about changing your own or your child's steroid dose then please contact your neuromuscular team to discuss this.