Questions and answers

As situation around COVID-19 continues to develop we, together with other PAGs, are asking clinicians questions and here are some answers we think may be useful. These come from three different clinicians (children and adult services) and we hope that they will add some clarity. If you have further questions please contact us on treatsma@treatsma.uk and we will pass these on the clinical panel.

There are still many people who have not received NHS letters emails or texts stating they are in the 'extremely vulnerable' group and can access extra support.

We know of occasions where GPs are telling people that they can't send the letters and that the neuromuscular team should be doing this. Unsurprisingly some neuromuscular services do not have the capacity to respond to these requests.

Inevitably, lots of people and their families are very concerned about this as they are shielding and are then unable to access the services that are available and be given flexible working or time off work.

Q1. Could you share what you are doing at your centres and also what you think is being done elsewhere in the neuromuscular clinical community?

A 1.1 Here in Newcastle we are sending out an advice letter to all our patients.

A 1.2 GOSH WILL START 8th of April.

A 1.3 We have created a list of 2500 extremely vulnerable patients attending our service, no names but NHS numbers, which our Trust has forwarded to NHS England, I have done the same for our Scottish patients and sent CHI number to NHS Scotland. These patients should get a text, we have also written to these patients directly advising them to shield. If they have not yet received our letter by email, they should check their junk folder.

(NOTE FROM TREATSMA - We have discovered that whilst your neuromuscular team may write a letter, you still should contact GP and make sure that GP adds your number to the extremely vulnerable NHS list. GPs may not be aware that they must do this because they may not have been told. Please call them and explain that they should do it ASAP. Neuromuscular teams do not actually have a way to do this. You may get a letter from neuromuscular team, but it does not mean you are registered on the vulnerable list. Check with your GP!)

Q2. What is the protocol for using NIV if dealing with the coronavirus? Should you increase pressure or rate or other settings?

A 2.1 This need to be addressed by the respiratory team.

A 2.2 You need to ask your respiratory expert for more detailed advice. However, you should not alter your NIV settings but it is safe to use your NIV more frequently for example during the day time rather than night time alone

Q3. Are people on NIV more likely to get a severe case than a mild one?

A 3.1 There is currently no data to support this but it is likely because of already impaired respiratory function.

A 3.2 We do not know why some people get this virus more severely than others. We have no data for people on NIV, probably NIV per se does not increase the risk of the severe cytokine reaction but someone on NIV may struggle with their breathing more if they develop a cough or pneumonia.

Q4. If admitted to hospital, would people on NIV be given oxygen treatment, or would that only be provided if they are admitted to critical care?

A 4.1 Oxygen can be provided even outside critical care.

A 4.2 People do not need to be in ITU to receive oxygen treatment.

Q5. As we know admittance to critical care will depend on prognosis, what are the influencing factors on prognosis?

A 5.1 Influencing factors on prognosis will be life expectancy, impaired cardiac and/or respiratory function, nutritional status, degree of disability in addition to covid-19 specific morbidity and level of organ involvement

A 5.2 The virus causes a pneumonia and intense inflammatory reaction. It is the extent of this secondary inflammatory reaction that causes severe disease. Inflammatory markers such as CPR, ESR, IL6, Ferritin and markers for thrombosis are raised. The blood count is also abnormal with low white cells. Prognosis depends on the level of these markers in the blood, the degree of lung involvement on XRAY. Another poor prognostic feature is the presence of acute inflammation in the heart. The inflammatory reaction leads to multi-organ failure which is a poor prognostic sign

Q6. Is there any evidence that people on NIV will be less likely to benefit quickly from critical care treatment?

A 6.1 It is likely that people with respiratory muscle weakness and on NIV may require longer period of time to recover from critical care treatment and also deteriorate in their global function following a prolonged admission.

A 6.2 I WOULD SAY THAT AT THE MOMENT WE ARE GATHERING EVIDENCE ON HOW PATIENTS WITH NEUROMUSCULAR DISEASES ALREADY ON VENTILATED ARE RESPONDING TO COVID-19, SO AT THE MKMENT THERE IS NO EVIDENCE, BUT CLEARLY THE PROGNOSIS WILL BE MORE GUARDED IN PATIENTS WITH SEVERE RESPIRATOIRY INVOLVEMENT FOR COVID 19 AND ANY OTHER RESPIRATORY INFECTION

A 6.3 It is important to be aware that when people with Covid-19 are admitted to ITU their condition is extremely critical. Only 50% of people will survive ITU and those that do will have longstanding respiratory problems. People who are intubated are likely to be paralysed and ventilated for 2-3 weeks.

Q7. "If I have symptoms, and am finding it harder to breath, at what point should I go to hospital? Should I try altering my use of NIV first?"

A 7.1 If you develop symptoms you should call 111.

A 7.2 Call 111 for advice

Q8. I know that some people with mild CMT have been told they don't need to shield. If I have cmt1a and get sleep apnoea, does this put me in the highest risk group in your consensus clinical advice and should I be shielding and encouraging my household to shield as well?

A 8.1 There is no increased risk from OSA but it will also depend on other risk factors and co-morbidities. Your doctor is best placed to assess the individual risk. additional information is available here https://www.brit-thoracic.org.uk/media/455098/osa-alliance-cpap-covid-19-advice-20-3-20-v10.pdf

A 8.2 THE MAIN DETEINANT FACTOR IS THE RESPIRATORY FUNCTION. IF RESPIRATORY FUNCTION IS NORMAL, THE USUAL PRECAUTIONS ARE RECOMMENDED; IF NOT NORMAL OR YOU ARE NOT SURE, SELF ISOLATION WILL BE SAFER. DISCUSS WITH YOUR DR.

A 8.3 The British Thoracic Society have issued a statement that obstructive sleep apnoea requiring CPAP without any other co-morbidities such as obesity, heart disease or diabetes, is not a risk factor.