COVID-19: Guidelines on Charcot Marie Tooth disease from the Neuromuscular Service, National Hospital for Neurology and Neurosurgery (NHNN), Queen Square, London.

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The following are general guidelines and are adapted from NHS website and Public Health UK.

Charcot Marie Tooth disease (CMT) is a condition that affects sensory and/or motor nerves. For most patients with CMT, your risk is the same as the general public. HOWEVER- there are patients with CMT who have additional problems due to their CMT (e.g. some patients, including some with kyphoscoliosis, neuromuscular chest problems, diaphragm weakness or vocal cord paralysis may require help with their breathing such as with NIV or CPAP at night). If you are on CPAP or NIV please contact your Respiratory Centre for information. Patients with CMT may also have other unrelated medical problems that put them at risk.

If you fall frequently or have balance problems please be MINDFUL. We need to bear in mind that A&E and GP services will be under much more pressure than usual. This will mean delays in all usual hospital services.

If you are on regular medications contact your local GP services on how to get your repeat prescriptions and their contingency plan in the event of decreased services.

Please visit the Centre for Neuromuscular Diseases (https://www.ucl.ac.uk/centre-for-neuromuscular-diseases/) and the Association of British Neurologists (ABN) websites for more information: The ABN website has a patient section and is updated regularly. https://www.theabn.org/page/covid-19_patients

General Health Advice (https://www.gov.uk/coronavirus)

The risk of Coronavirus has been raised to high. <u>Advice from Public Health England is</u> updated daily here

- The government published its coronavirus action plan on 3rd March. The Prime Minister has issued strong and clear guidance on 23rd March 2020 to <u>STAY AT</u> <u>HOME</u>
- 2. The Health Protection (Coronavirus) Regulations 2020 have been put in place to reduce the risk of further human-to-human transmission in this country by keeping individuals in isolation where public health professionals believe there is a reasonable risk an individual may have the virus.
- 3. <u>STAY AT HOME</u> (https://www.gov.uk/government/publications/full-guidance-on-staying-at-home-and-away-from-others/full-guidance-on-staying-at-home-and-away-from-others)
 - Only go outside for food, health reasons or work (but only if you cannot work from home)
 - If you go out, stay 2 metres (6ft) away from other people at all times
 - Wash your hands as soon as you get home
 - Cover the mouth and nose when coughing or sneezing with a tissue or a sleeve

- 4. Do not travel. All non-essential travel has been strongly discouraged both within and outside the UK, if at all possible. Risks of not being able to return are very high. People who are returning to the UK and have symptoms of coronavirus have been advised to self-isolate for 14 days.
- 5. If you or any members of your family have symptoms suggestive of coronavirus please do not come to the hospital unless it is absolutely essential
- 6. Patients with symptoms suggesting Coronavirus should self-isolate for 7 days and contact 111 (https://www.gov.uk/government/publications/covid-19-stay-at-home-guidance-for-households-with-possible-coronavirus-covid-19-infection). If a member of your family or somebody that you live with has symptoms then your household will need to self-isolate for 14 days. Ask someone else to do your shopping for essential groceries.
- 7. People who are at increased risk* of severe illness from coronavirus (COVID-19) are advised to be particularly stringent in following social distancing measures.
- 8. Patients at even higher risk ("extremely vulnerable)** are advised to <u>self isolate</u> ("shielding") for 12 weeks and register at https://www.gov.uk/coronavirus-extremely-vulnerable
- Useful advice about covid 19 for patients with neurological conditions which is updated regularly can be found on the Association of British Neurologists (ABN) website here

*People with increased risk of severe illness from coronavirus (COVID-19)

https://www.gov.uk/government/publications/covid-19-guidance-on-social-distancing-and-for-vulnerable-people/guidance-on-social-distancing-for-everyone-in-the-uk-and-protecting-older-people-and-vulnerable-adults)

This group includes those who are:

- aged 70 or older (regardless of medical conditions)
- Anyone with the neurological conditions listed in the ABN document here
- In addition to the neurological conditions, anyone under 70 with an underlying health condition listed below (ie anyone instructed to get a flu jab as an adult each year on medical grounds):
 - chronic (long-term) respiratory diseases, such as <u>asthma</u>, <u>chronic obstructive</u> <u>pulmonary disease (COPD)</u>, emphysema or <u>bronchitis</u>
 - o chronic heart disease, such as heart failure
 - o chronic kidney disease
 - o chronic liver disease, such as hepatitis
 - o <u>diabetes</u>
 - problems with your spleen for example, <u>sickle cell</u> disease or if you have had your spleen removed
 - a weakened immune system as the result of conditions such as <u>HIV and AIDS</u>, or medicines such as <u>steroid tablets</u> or <u>chemotherapy</u>
 - o being seriously overweight (a BMI of 40 or above)
 - those who are pregnant

**People with even higher risk ("extremely vulnerable).

(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)

This group includes those who are:

- 1. Solid organ transplant recipients.
- 2. People with specific cancers:
- 3. People with severe respiratory conditions including all cystic fibrosis, severe asthma and severe chronic obstructive pulmonary (COPD).
- 4. People with rare diseases and inborn errors of metabolism that significantly increase the risk of infections (such as Severe combined immunodeficiency (SCID), homozygous sickle cell).
- 5. People on immunosuppression therapies sufficient to significantly increase risk of infection
- 6. Women who are pregnant with significant heart disease, congenital or acquired.