



## **Coronavirus Information for Myotonic Dystrophy Patients and their Carers**

The general information found in this document has been adapted and modified from that already published by the [World Health Organisation \(WHO\)](#), [Centres for Disease Control and Prevention \(CDC\)](#), [National Health Service \(NHS\)](#) and [Public Health England](#) websites.

***The Coronavirus (COVID-19) information is rapidly changing, therefore, please use the links above to get updated information and guidance.***

### **What is coronavirus and what is the coronavirus COVID-19?**

A coronavirus is a type of virus. As a group, coronaviruses are common across the world. **Novel coronavirus (COVID-19)** is a new strain of coronavirus first identified in Wuhan City, China. It is a respiratory illness that can spread from person to person.

### **What's the risk of coronavirus (COVID-19) in the UK?**

The UK Chief Medical Officers have raised the risk to the public from low to moderate.

### **Are all the people affected in the same way?**

Generally, coronavirus (COVID-19) can cause more severe symptoms in people with weakened immune systems, older people, and those with chronic conditions.

### **What's the risk of coronavirus (COVID-19) for patients with Myotonic Dystrophy?**

There is no evidence that adults or children with Myotonic Dystrophy are more likely to be infected with coronavirus (COVID-19) than the general population.

However, the coronavirus (COVID-19) can cause severe symptoms in patients with chronic conditions. Therefore, it would be reasonable to assume that DM patients, especially those with other pre-existing medical conditions, could be at increased risk of developing more severe symptoms. People with Myotonic Dystrophy can be more susceptible to chest infections and may take longer to recover from them, so it is important that you follow recommended advice for yourself or those you care for.

### **How does coronavirus (COVID-19) spread?**

Although it is not yet very clear, some evidence has shown that the virus can spread between people that are in close contact with one another (within about 6 feet) through respiratory droplets produced when an infected person coughs or sneezes.

It also may be possible that a person can get COVID-19 by touching a surface or object that has the virus on it and then touching their own mouth, nose, or possibly their eyes, but this is not thought to be the main way the virus spreads.

### **When should I be worried that I might have coronavirus (COVID-19)?**

If in the last 14 days you have been in contact with someone with coronavirus, or have returned from an [affected area](#) identified by the Chief Medical Officer as high risk, *and* you are feeling unwell with a cough, difficulty breathing or fever, *stay at home and use the [NHS 111 online coronavirus service](#) or call NHS 111.*

### **What are the symptoms of Coronavirus (COVID-19)?**

The symptoms of COVID-19 are similar to other illnesses that are much more common, such as cold and flu. These symptoms include cough, fever, and shortness of breath.

### **What are severe complications from this virus?**

A small number of people infected with COVID-19 become very unwell, with severe chest infections. A small percentage of patients do not survive, the majority of these patients have been over 65 years of age, and those with underlying medical conditions.

### **How to avoid catching or spreading coronavirus (COVID-19) according to NHS?**

- wash your hands with soap and water often – do this for at least 20 seconds. (The physical action of washing with soap that breaks the protective oily outer shell of the virus, damaging it and allowing it to be washed away).
- always wash your hands when you get home or into work
- use hand sanitiser gel if soap and water are not available
- cover your mouth and nose with a tissue or your sleeve (not your hands) when you cough or sneeze
- put used tissues in the bin straight away and wash your hands afterwards
- try to avoid close contact with people who are unwell
- do not touch your eyes, nose or mouth if your hands are not clean

### **Is there a treatment?**

There is no specific antiviral treatment for COVID-19. Antibiotics do not help as they do not work against viruses. Medical care helps to relieve symptoms and prevent secondary health problems, especially to patients with coexisting medical issues. Patients with COVID-19 are usually put in isolation, away from any other people, until they recover from the virus.

### **Is there a vaccine?**

There is currently no vaccine to protect against COVID-19. The flu jab does not provide any protection against COVID-19.

### **What should I do if I have travelled recently?**

If you have returned from an [affected area](#) in the last 14 days, stay indoors and avoid contact with other people even if you **do not** have symptoms. Call 111 to inform them and take advice.

If you become unwell:

- please call NHS 111 immediately in order for you to be assessed by an appropriate specialist in hospital as quickly as possible

Please check the [Public Health England](#) website for an up to date list of the high risk (category 1) areas.

### **Additional measures for Myotonic Dystrophy patients and their carers:**

What to do in the meantime while you do not have any symptoms or risk factors of COVID-19?

#### **General recommendations:**

- If you do not already have a patient alert card for DM please contact the neuromuscular team that is responsible for your care. Make sure that your carer has a copy as well. You can get these alert cards direct from MDUK here: <https://www.musculardystrophyuk.org/about-muscle-wasting-conditions/information-factsheets/conditions/alert-cards-and-care-plans/alert-cards>  
Cure DM have MDUK alert cards and care plans that can be collected from our shop base or posted out. Please contact us.
- Make sure that you have a contact number or email of the neuromuscular team that is responsible for your Myotonic Dystrophy care.
- Make sure that you and your carer have a printed version of the anaesthetic guidelines for DM patients in case this will be required in the future. You can find the guidelines at: <https://www.myotonic.org/mdf-releases-updated-anesthesia-guidelines>
- Make sure that you and your carer have a printed version of the clinical care recommendations for patients with DM. You can find the guidelines at: <https://www.myotonic.org/toolkits-publications>
- If you do not have access to the internet or a printer please contact Cure DM and we will be happy to send you a printed version.

#### **Health-related recommendations:**

- If you have not had an ECG in the past 12 months, please contact your local GP to get one. (This will give an up to date cardiac baseline that can be referred to in case of illness)

- If you have been asked by your medical team to use ventilatory support such as CPAP, BiPAP or Cough Assist, make sure that you are using your device as per the recommendations of your respiratory team. If, for any reason, you have difficulties using your respiratory support devices, please contact your respiratory team to arrange a phone call or appointment.

### **What to do if you think that you need medical help for coronavirus COVID-19?**

*If you think that you have coronavirus DO NOT go to a GP surgery, pharmacy or hospital. Call [111](tel:111) if you need to speak to someone.*

**NHS 111** has an online coronavirus service that can tell you if you need medical help and can advise you what to do.

Use this service if:

- you think you might have coronavirus
- in the last 14 days you've been to a country or area with a high risk of coronavirus – see the official advice: [coronavirus advice for travellers](#)
- you've been in close contact with someone with coronavirus

### **Getting help in Scotland, Wales or Northern Ireland**

- Scotland: call your GP surgery or call [111](tel:111) if your surgery is not open
- Wales: call [111](tel:111)
- Northern Ireland: call [111](tel:111)

### **What to do if you have been diagnosed with coronavirus COVID-19?**

- Patients with DM are at higher risk of respiratory and other complications, therefore, it is advised that you mention your condition to a health professional as the measures that will be implemented will greatly depend upon this information.
- Please ask your carer to provide a print-out of the DM alert card, anaesthetic and clinical care recommendations to the hospital staff who will be taking care of you.
- Provide the contact details of your neuromuscular team to the hospital staff so that they can contact a consultant with a specialist knowledge in DM if the need arises.

If you are not attached to a neuromuscular specialist, please contact us for details of possible specialists in your area.

This information is correct to the best of our knowledge at the time of publishing (10.03.2020).

This information will be updated as we learn more about risks of COVID-19 in our population. Please continue to check the [Public Health England Website](#) for up to date information.

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