COVID-19 Emergency Preparedness Planning for the CMD Community

While we hope that you will not need to implement a personal COVID-19 emergency preparedness plan, Cure CMD would like to encourage you to begin discussions about the what-ifs about this and any similar health-related emergency. Here is a list of topics to consider with your family, caregivers, physicians, and other community members. It is imperative to develop a plan of action before you find yourself in the midst of a health crisis.

**What are the possible symptoms and how/when should we seek medical care?**
COVID-19 is a respiratory virus which spreads primarily through droplets generated when an infected person coughs or sneezes, or through droplets of saliva or discharge from the nose.

Recognizing symptoms of COVID-19 can be difficult. A number of recent publications indicate evidence that there are a significant number of infected individuals who are asymptomatic (show no signs of having the virus). So the first thing to understand is that your social distancing and isolation procedures should not be relaxed because a friend or loved one doesn’t “seem” sick.

According to the CDC, the following is a list of potential COVID-19 symptoms:

<table>
<thead>
<tr>
<th>Fever</th>
<th>Chills</th>
<th>Headache</th>
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<tr>
<td>Cough</td>
<td>Repeated shaking with chills</td>
<td>Sore throat</td>
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<td>Shortness of breath or difficulty breathing</td>
<td>Muscle pain</td>
<td>New loss of taste or smell</td>
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If someone in your home is experiencing any of these symptoms, call your physician to report the symptoms, reminding them that you have a CMD-affected individual with respiratory weakness residing in your home. Your physician can then advise you on next steps, including where to go for testing.

Note: One CMD community member has reported that the COVID-19 test offered to their affected child involved spitting into a collection tube. As many people with CMD cannot perform this maneuver, it may be useful to check with your physician on the type of testing utilized by your center to ensure it is not an effort-based maneuver your affected loved one cannot perform.

**Will our hospital allow us to use our own ventilatory equipment?**
Often, hospitals do not allow personal equipment to be used for an inpatient stay due to potential liability concerns about the equipment not working properly. It may be a good idea to check with your care center to find out what their regular policy is, and whether the policy has been modified during the pandemic.

**The ER "go bag" - what do we need to bring with us if headed to the emergency room/hospital?**
This list will be very personal to you and your family, so take a few minutes to identify the things you will want or need for a hospital stay, and make sure you know where these items are in your home and that they are in working order. It’s also helpful to make a checklist that you can refer to when you need to move quickly. There may be additional procedures related to isolation that will limit what you can bring and when, so prepare accordingly.

**What’s the plan if an affected individual’s caregiver(s) become infected?**
It is highly likely that COVID-19 exposure will first come into a family through caregivers or other unaffected family members. And, because individuals may be infected without symptoms, it can quickly spread. Discuss this scenario with your family and outline a plan should all caregivers become infected. If there are no caregiving alternatives, risk of passing on the virus to your affected loved one can be mitigated by limiting contact as much as possible, always washing hands before handling items or touching the affected individual, and both the affected individual and caregiver wearing masks.

**When quarantine orders are lifted, will we continue self-imposed isolation?**
Will you elect to self-isolate until a vaccine is available? Will you self-isolate for X number of weeks after the quarantine has been lifted? Will you choose to homeschool your children next year? All of these questions are important to think through and discuss with your physician. The CDC will likely publish guidance on this issue, but for now, there is no “right” answer.