

Q&A: Cystic fibrosis and COVID-19

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DEAR MAYO CLINIC: My cousin has cystic fibrosis. After graduating from college last December, she moved across the country to take a new job. Now she lives with me. I have always been worried about her, but I am more concerned now that COVID-19 cases are rising in our area.

Although I know coughing is common with her condition, every time I hear her cough, I worry it's COVID-19. Complicating the situation, since moving she has not found a health care provider who is comfortable treating cystic fibrosis. How can I help her remain well?

ANSWER: Cystic [fibrosis](#) is a genetic disease that causes abnormalities of mucus, sweat and digestive juices. Common signs include wheezing, recurrent lung or sinus infections, and difficulty gaining weight. It can lead to damage to the lungs, digestive system and other organs in the body.

It is estimated that 30,000 people are living with cystic fibrosis in the U.S. But, like your cousin, most of these people are usually able to attend school and work.

Although your cousin may be accustomed to her disease, it could be frightening for you, especially since cough and shortness of breath are signs of COVID-19 infection. She is lucky to have a family member who is concerned for her safety.

Encourage your cousin to identify an accredited cystic fibrosis center to establish care. Since cystic fibrosis is a disease that affects many organ systems, having access to a multidisciplinary group of health care providers who are well-versed in the disease can ensure she will have access to the latest therapies and [best practices](#) in treatment. This includes being evaluated for a liver or lung transplant, should her disease ever progress to that point.

Over the past few years, new medications have been developed that can dramatically improve lung function and overall well-being for most patients with cystic fibrosis. Also, these cumulative medical advances, coupled with attentive multidisciplinary care, have helped increase the [life expectancy](#) for patients with cystic fibrosis to an all-time high. This

trend is anticipated to continue, and with consistent and appropriate care, your cousin can have a long, healthy life ahead of her.

Also, a cystic fibrosis center can help your cousin address any concerns, especially as the COVID-19 pandemic continues.

Although the effects of COVID-19 are not fully understood, patients with cystic fibrosis and people with underlying health conditions, including lung disease, may experience more severe issues from COVID-19 if they become infected. However when patients with cystic fibrosis have contracted COVID-19, outcomes have been encouraging. To date, most cystic fibrosis patients who developed COVID-19 have recovered without hospitalization.

Encourage your cousin to continue practicing the safety measures recommended to slow the spread of COVID-19. Most of these practices are customary for people with cystic fibrosis. For example, it is common practice for patients with cystic fibrosis to wear a mask in many settings, maintain social distancing and practice excellent personal hygiene. Chat with your cousin and ask her advice, as people with cystic fibrosis are skilled and experienced in optimizing virtual interactions and knowing how to live a full and vibrant life while still maintaining safe practices. Everyone can learn from their experience and expertise.

It is critical that everyone remains attentive to the guidelines for infection control. Wear a mask when out in public, and practice good hand hygiene and social distancing. Also, limit inviting guests to your home.

Recognizing that cystic fibrosis is a complex disease and affects each person living with it differently, continue to encourage your cousin to establish care at an accredited cystic fibrosis center. An active partnership with a cystic fibrosis care team is the best way for her to

maintain optimal long-term health and well-being. Visit the Cystic Fibrosis Foundation website for more information about accredited [cystic fibrosis](#) centers.

—Dr. Margaret Johnson, Pulmonary and Critical Care Medicine, Mayo Clinic, Jacksonville, Florida

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