

Fabry Focus on Health

Discussions with experts on health issues that affect the Fabry Community

Sponsored by Chiesi Global Rare Diseases

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Focusing on Our Emotional Health



Dr. Kendra J. Bjoraker is a pediatric neuropsychologist with specialized training and expertise in rare genetic and neurodegenerative diseases.

She has two consulting businesses – 3:1 Neuropsychology Consultants, PLLC, in Minneapolis, Minnesota, and Doulots, LLC.

Q: *How can a chronic condition affect patients emotionally?*

People living with a chronic condition in general are at higher risk of depression and anxiety. These feelings can be especially acute in the period right after a diagnosis, and in general the patient's emotional health is often a reflection of how well they adapt to the circumstances of their health. I like to refer to it as a need to "build a shelf" in your mind to place a new diagnosis. As a process, you fill that shelf with the resources you need to move forward – information, a time to grieve, and the coping mechanisms that can help. Without filling that shelf, patients might feel like they don't have a plan or a way to manage their disease. You plan by setting short, manageable goals towards adaptive strategies.

Q: *What about Fabry disease specifically?*

Studies have shown that about 50% of people living with Fabry experience depressive symptoms after a diagnosis, but that these symptoms can improve if patients take time to grieve and work to identify coping strategies that can help. Patients with Fabry disease can also be at higher risk of stress, which can be a trigger for some symptoms of Fabry including fatigue and pain. Conversely, pain and fatigue may contribute to stress, depression and anxiety.

Q: *How can the emotional impact of Fabry be affected by COVID-19?*

We know that the risk of anxiety is associated with three things: uncertainty, lack of control and perceptions of danger. Unfortunately, COVID-19 causes all these things, and so for all of us the risk of anxiety is very high during this pandemic. As a result, for people living with Fabry or other chronic diseases who are already at higher risk of anxiety, COVID-19 can be especially challenging. It can be helpful to better understand the impact if we look at COVID-19 from the perspective of loss. In this pandemic, we

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are losing the opportunity for social interaction and in-person enjoyment. We have lost the structure and routine of our daily lives. In some cases, people have lost jobs or are no longer at school. And we have lost the levels of safety and security we had previously. A key element in assessing the impact of COVID-19 in the Fabry community is to understand how these losses affect us physically and emotionally.

Q: *What can patients do to try to address the impact of COVID-19 on their well-being and emotional health?*

The very best way to address the lack of control and the loss we all feel in this pandemic is to set a routine. By structuring our day and our time we can have a higher feeling of control and predictability. This will also help us regulate our bodies with established patterns for eating, sleeping, and time for exercise, activities we enjoy, etc. An important part of maintaining control for people with Fabry is to manage your care as best you can. Coordinate your care with your physician and make sure to get some exercise, eat well and limit use of alcohol or other substances. You might also consider wellness options including breathing exercises, keeping a gratitude journal, stretching and meditation. We should also make time for activities that bring us joy – like gardening, reading, playing with pets, listening to music, having virtual visits with friends and family members.

Q: *What about the issue of isolation and loneliness?*

It is very important to take steps to remain connected and if possible have someone regularly monitor how a patient is doing both physically and emotionally. There are many online and smart phone options to help people living with Fabry disease stay connected with others. It can be especially helpful to connect with other Fabry patients who may be facing similar challenges. One important consideration is that you should try to connect with others who have a positive attitude and who are actively finding the best ways to cope and thrive during this pandemic. And you should do your best to have a positive and helpful attitude when you connect with others. Helping others is a great way to retain your sense of control and your own positive outlook!

Chiesi Global Rare Disease is committed to connecting patients with information from experts and healthcare professionals. This information is intended for patient education and should not replace or modify the information provided by your treating physician.