PNHsource

MENTAL HEALTH MATTERS

When diagnosed with and living with a rare disease like paroxysmal nocturnal hemoglobinuria, or PNH, individuals may experience a range of emotions, including confusion, uncertainty, or profound sadness. Although the journey can feel isolating and overwhelming, many patients and families share similar experiences and there are resources to support you in managing your mental health.

Dr Al Freedman, a psychologist who has spent the past 25 years supporting people living with rare disease along with their families, provides his thoughts on his most frequently asked questions (FAQs).

Select a topic below to view FAQs.

RECEIVING A DIAGNOSIS

NAVIGATING RELATIONSHIPS AND SOCIAL DYNAMICS

MANAGING EMOTIONS WHILE LIVING WITH A RARE DISEASE

SUPPORTING A LOVED ONE

Albert Freedman, PhD, has a unique voice as a mental health expert and as the father of an adult son who lived to the age of 26 years with a rare disease. As a practicing psychologist in independent practice, Dr Freedman has provided counseling services to children, adolescents, adults, and families for over 25 years. He specializes in working with patients and families affected by rare disease, disability, and complex medical conditions.

Dr Freedman provides consultation to rare disease advocacy organizations, biopharmaceutical companies, healthcare organizations and schools. He speaks at conferences nationally and globally on challenges facing families affected by special healthcare needs and has written widely on the topic.

RECEIVING A DIAGNOSIS

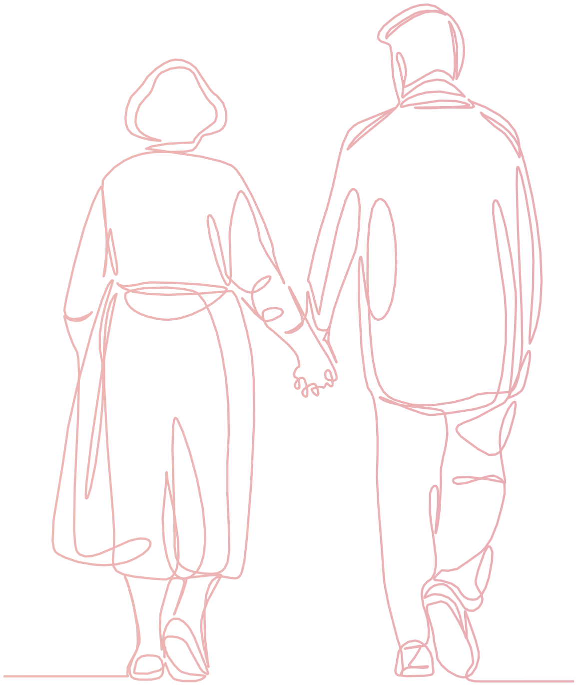
Select a question to view the answer.

1. I've just been diagnosed with a disease I have never heard of before and I'm feeling overwhelmed. How can I manage this stress along with everything else?
2. How do I communicate with my family and friends about what I'm feeling about this diagnosis?
3. How do you recommend I explain my condition to my children without upsetting them?
4. How do I lessen my anxiety about what the future may hold for me now that I am living with a rare disease?
5. In a strange way I was relieved to finally have a diagnosis, but now I'm obsessing over researching it. How can I balance learning about my condition with wanting to feel like myself again?
6. How can I approach a discussion with my employer about my diagnosis? I'm worried about the repercussions but know that I may need more time away from work for medical appointments. Any advice?
7. What coping mechanisms are most effective when your loved one's fears related to the rare disease diagnosis begin to affect your own mental health?

MANAGING EMOTIONS WHILE LIVING WITH A RARE DISEASE

Select a question to view the answer.

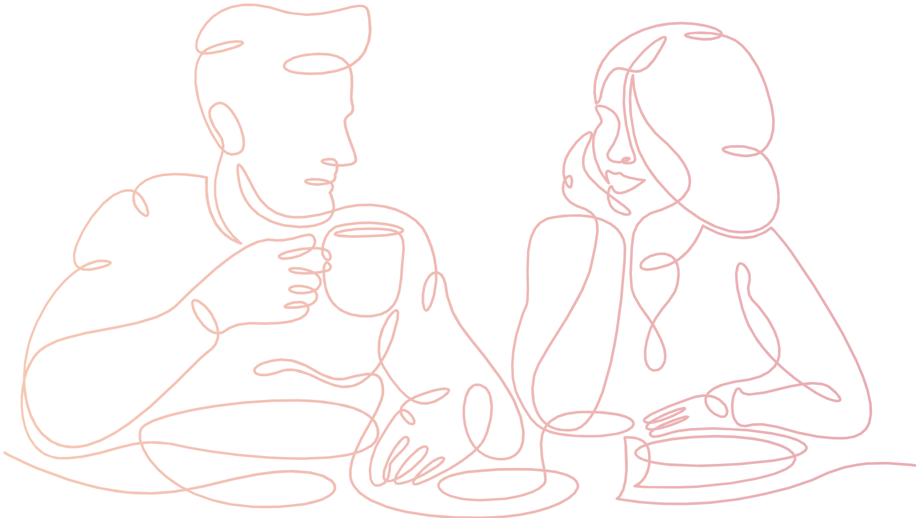
1. I've been living with a rare disease for some time and have a solid routine in place. I feel like my condition is well-managed, but I still feel waves of sadness and grief for the life I used to live without my condition. What can I do to feel better?
2. What are some methods for calming my mind when I get worked up about my rare disease?
3. I get frustrated when I feel like no one understands what I'm going through, and I feel totally alone.
4. Sometimes I experience periods of anger and feelings of "Why me?" as I chronically live with this condition—what should I do about it?



NAVIGATING RELATIONSHIPS & SOCIAL DYNAMICS

Select a question to view the answer.

1. Sometimes when my rare disease is especially challenging, I don’t have the energy or mental capacity to be there for my loved ones and I feel guilty. How do I balance taking care of my mental health while still showing up for my family and friends?
2. Since my diagnosis, our family dynamic has shifted, and there’s a lot of focus on me. People often don’t know what to say or do, and I just want to be treated like everyone else. How can I handle this?
3. Now that I have been living with this rare disease for a while, my family and friends are always giving me advice on how to better manage my symptoms. I am tired of getting these suggestions, and they are stressing me out. I know they care about me, but how should I tell them to stop without hurting their feelings?
4. I’ve decided not to tell people about my rare disease. I struggle with whether to be honest or keep it secret. I don’t want my disease to define me. Is this normal?
5. Many people don’t realize that those with rare diseases face all the usual stresses of life, like divorce, sick children, menopause, aging parents, and money problems. These stresses are even harder to handle because of my disease. Any advice?
6. How can I cope with feelings of isolation if my loved ones are unable to truly understand what I’m going through?



SUPPORTING A LOVED ONE

Select a question to view the answer.

1. I see the emotional toll living with a rare disease takes on my loved one and I feel helpless. How can I best support them?
2. My loved one lives with a rare disease, yet sometimes I am the one who feels overwhelmed. I hate that I feel this way. Any advice?
3. How can I manage my own feelings when my emotions take over, without losing focus on the needs of my loved one?
4. What are some ways I can support my loved one when I see they are shutting down or becoming frustrated? What do I say?