

Mental Health and Pompe Disease

It is normal to have a wide range of emotions after getting a diagnosis of Pompe disease or as challenges happen living with Pompe. Finding and coordinating medical care and supportive therapy can be difficult. There are also financial worries. Unexpected things may happen that complicate disease management. All of this can be overwhelming.

Some people with Pompe experience mental health conditions such as anxiety, stress, or depression. A key to psychological well-being is realizing mental health conditions exist and finding ways to cope. Managing your mental health is an essential and on-going part of the treatment process.

Wherever you are on your journey with Pompe disease, it is important to remember that you are not alone. The AMDA's goal is that no person with Pompe or their family and caregivers will ever be alone when questions and needs arise. We have resources and programs to support patients and families.

AMDA's Mentor Program puts patients and families in touch with other people who have been through similar experiences. AMDA volunteer mentors from the Pompe community are available to help in dealing with a new diagnosis or with disease management. They can share experiences, feelings, and resources related to Pompe disease. Details about the program can be found at AMDA-Mentoring <https://amda-pompe.org/mentoring-2/> or contact Morgan.Burroughs@amda-pompe.org

You may want to reach out to AMDA's Patient Advocate, Marsha Zimmerman, who is a registered nurse. She has been working as a Pompe Patient Advocate since 2001. She has experience assisting families with everything from access to therapy to disease education and tips for communicating with medical professionals. She also provides emotional support. Whatever questions or issues you may have, Marsha Zimmerman can help. Her email address is: marsha.zimmerman@amda-pompe.org

We also suggest that you talk with your care team about your mental health concerns. You may want to join a support group, see a therapist, or need to take medication.

Mental Health Resources

Global Genes: Allies in Rare Disease
<https://globalgenes.org/blog/mental-health-in-rare-disease-taking-care-of-your-mind-is-taking-care-of-your-body>
Discusses common mental health conditions experienced by people with rare diseases. Provides links to RARE Patient Advocacy Summit videos such as: *Beyond the "Impossible Thing" – Breaking Barriers and Redefining Strength*

IPA/Pompe Connection -
<https://worldpompe.org/resources/patient-focused-publications/>
The Emotional Impact of Pompe Disease
Provides guidance for patients and caregivers. Explains that every patient's situation is different. "Pompe disease is progressive, and symptoms evolve over time. It is important to maintain a positive attitude, to be creative at problem-solving, and have a strong support system that will help you navigate these new challenges."

NIH Genetic and Rare Diseases Information Center – Living with the Disease
<https://rarediseases.info.nih.gov/diseases/5714/glycogen-storage-disease-due-to-acid-maltase-deficiency/living>

- Has a testimonial video, *Keep on Fighting*, about living with a rare disease. Provides links to patient resources for coping with a rare disease, including Pompe.
- Suggests that for a step-by-step guide to find a mental health professional, call 800-950-6264 or text "HelpLine" to 62640.



**Acid Maltase Deficiency
Association**

PO Box 700248
San Antonio, Tx 78270
www.amda-pompe.org

National Alliance on Mental Illness
<https://www.nami.org/About-Mental-Illness>
Discusses warning signs, conditions, common mental illness, treatment, research. Links to finding a mental health professional, support groups, podcasts, webinars, and more.

Rare Disease Legislative Advocates –
Webinar on Mental Health and Rare Diseases
<https://www.youtube.com/watch?v=dp6dXCJEKac>

If You are in Crisis

If you, or someone you know is in crisis, seek help immediately.

The National Institutes of Health/Genetic and Rare Diseases Information Center
<https://rarediseases.info.nih.gov/diseases/5714/glycogen-storage-disease-due-to-acid-maltase-deficiency/living> - Patient Resources/Coping with Disease tab lists these resources:

The 988 Suicide & Crisis Lifeline.
Call 9-8-8. You can also text 988.
The 988 Lifeline (formerly known as the National Suicide Prevention Lifeline) provides free and confidential emotional support to people in suicidal crisis or emotional distress 24 hours a day, 7 days a week, across the U.S.A. The 988 Lifeline is a national network of over 200 local crisis centers staffed with trained crisis counselors. For details, see <https://988lifeline.org/>

Crisis Text Line. Text HOME to 741741
The Crisis Text Line is available for any crisis. A live, trained crisis counselor receives the text and responds from a secure online platform. Visit <https://www.crisistextline.org/about-us/>

For Family and Caregivers

Your caregiving situation may have happened suddenly or maybe it has been gradual. Whatever the case, there is little to prepare you for the emotional rollercoaster that comes with being a caregiver. It can be overwhelming. Some caregivers experience anger, depression, guilt, and other emotions. Others may find being a caregiver deeply rewarding.

Whatever you are feeling as a caregiver is normal. And you are not alone. There are millions of caregivers helping people live with rare diseases, including Pompe disease.

Some resources for caregivers include:

Family and Caregiver Resources

ARCH National Respite Network and Resource Center
<https://archrespitene.org/caregiver-resources/respitelocator/>
Helps caregivers and professionals find respite services in their communities.

Caregiver Action Network (CAN)
<https://www.rarecaregivers.org/>
Sections cover topics on complex emotions, selfcare with guidance such as “Lifting Your Loved One Safely,” family matters, and more.

CAN Caregiver Help Desk – 855-227-3640
Offers free support to family caregivers across the country. Have confidential conversations with caregiving experts about your caregiving questions.

Family Caregiver Alliance
<https://www.caregiver.org/connecting-caregivers/services-by-state/>
Their Services by State tool helps caregivers locate public, nonprofit, and private programs and services. These include government health and disability programs, legal resources, disease-specific organizations, and more.

Global Genes: Allies in Rare Disease
<https://globalgenes.org/blog/mental-health-in-rare-disease-taking-care-of-your-mind-is-taking-care-of-your-body>
Links to rare disease-specific resources for caretakers such as
Mental Health: Shifting Our Mindset
<https://www.youtube.com/watch?v=eTDPDyLEHOY&t=372s>

National Organization of Rare Diseases (NORD) CareGiver Aid Program -
<https://rarediseases.org/patient-assistance-programs/caregiver-respite/>
Offers grants of up to \$250 annually, for those who qualify, to give caregivers a break to attend a conference, event or have an afternoon or evening away from caregiving.

Rare Caregivers Support – Give an Hour®
<https://www.giveanhour.org>
One-on-one group support, counseling and navigating services, training, and tools.

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