RARE DISEASES POSE NUMEROUS CHALLENGES TO PATIENTS AND CAREGIVERS.

ATLANTIS HEALTHCARE
Understand.Connect.Change.

As with all long-term conditions, rates of non-adherence to treatment recommendations are often sub-optimal among people living with rare and ultra-rare diseases.

In addition to the reasons for non-adherence that are observed in chronic disease, it is important to be mindful of the unique characteristics of rare disease that may also impact equal access to care, disease self-management and amplify social isolation.

58-65%
NON-ADHERENCE IN RARE DISEASE[1]

The 'diagnostic odyssey'

Countless referrals and inconclusive investigations are typical of the experience for many patients with rare disease as they struggle to find a diagnosis and access to care.

This arduous and frustrating process may lead patients to harbor a distrust in the medical profession, impede treatment adherence, and worsen the psychosocial burden rare disease patients already experience. This frustration may lead to the rejection of treatment, even if patients have already been through successive or unsuccessful treatments previously.

Patient advocacy

Medical expertise is rare, knowledge is scarce and access to either is inequitable.

Unfortunately, for some patients this lack of medical knowledge and expertise can also translate to a lack of support from healthcare services, with patients receiving care that they perceive to be inadequate to cope with the day-to-day challenges they face in living with a rare disease. Patients therefore play a vital role as experts in their disease and should be encouraged to share their experiences with their treating healthcare team. Indeed, when it comes to how to manage the disease on a day-to-day basis, patients often have a better grasp than the medical professionals involved in their care.

Family involvement

Over 70% of rare diseases have a genetic component[2], and with many patients being diagnosed in early childhood, rare diseases are inescapably family diseases.

Families therefore need to be involved in any agreed treatment plan to support ongoing adherence. As well, supporting the index patient and extended family through the important but sometimes difficult process of family tree mapping and familial testing can help shorten the path to diagnosis and treatment, improving long-term health outcomes, but also reduce overall costs of medication and care.

Feelings of isolation

The very nature of rare disease means people may feel especially isolated, which can lead to psychological distress. It's not uncommon for patients and caregivers to experience anxiety and depression.

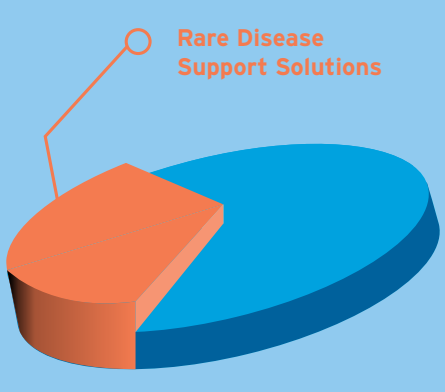
In a recent study of 300 patients with one of 79 different rare diseases, 42% reported moderate or severe depression, and 23% reported anxiety[3].

Close family relationships, advocacy, and community support to cope with illness is critically important—even more so during a global pandemic when feelings of isolation are compounded. Patient advocacy organizations, online support groups and social media platforms have increased in importance as interventions of connectedness. Individuals across the globe with similar diseases are increasingly reliant on these connections to learn and share information and experiences, thereby reducing the psychological burden of coping with a rare disease.

Clinical trial experience

As these patients are often difficult to reach, engage and retain in studies to test potential treatments, working directly with them to design the trial experience for optimal engagement is vital.

Focused, personalized support can help to build motivation and commitment to engage within the trial setting over the long-term, especially if patients will need to stop current therapies to participate.



More than one third of our personalized support solutions focus on supporting people living with rare disease including, where genetic, help in identifying other patients within the family.

All our programs address the range of barriers that may impact treatment adherence, including those challenges unique to people living with a rare disease. Our programs are grounded in behavioral science, leveraging close to 100 evidence-based behavior change techniques.

Our personalized programs help people living with rare disease to:

- Make sense of the condition and treatment
- Learn skills to self-advocate and self-manage
- Connect and share experiences with others
- Find meaning and motivation to ensure success

We're here to help

Contact us to learn how we can help you to provide personalized support to people living with rare disease, including case examples and research insights from a range of solutions we have implemented globally.

www.atlantishealthcare.com/en-us/contact-us

20+ Years
20+ Countries
200+ Health Programs
100+ Disease States

Offices in United Kingdom, Germany, United States, Australia and New Zealand

www.atlantishealthcare.com

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[1] V Cooper, J Clatworthy. Unique patient challenges and support solutions in rare disease. Atlantis Healthcare, 2014.

[2] European Organisation for Rare Diseases, 2021. https://www.rarediseaseday.org/article/what-is-a-rare-disease

[3] Uhlenbusch N, Löwe B, Härter M, Schramm C, Weiler-Normann C, Depping MK. Depression and anxiety in patients with different rare chronic diseases: A cross-sectional study. PLoS One. 2019 Feb 20;14(2):e0211343. doi: 10.1371/journal.pone.0211343. PMID: 30785907; PMCID: PMC6382125.