



AtlantisHealth

# Evidence for Change: Rare Disease in Focus

“As someone who has developed support programs for people with a wide range of rare diseases, I have become very aware of their unique challenges and needs. All of this highlights the importance of providing the right sort of personalized support for individuals and their families.”



**Professor John Weinman**

Professor of Psychology as applied to Medicines  
School of Cancer & Pharmaceutical Sciences  
King's College London & Atlantis Health -  
North Hemisphere Head of Behavioral Science



**1 in 10 people**

are affected by a  
rare disease, and just

**1 in 20**

of those have a treatment<sup>1</sup>.

## Looking beyond the patient, exploring unmet needs

Altantis Health conducted a global research project to explore the experiences of 117 people (72 patients and 45 caregivers) living with rare disease. We included exploratory questions and psychometrically validated questionnaires to uncover the unmet needs and perspectives of people living with rare disease. These were our key findings:

## Physical symptoms

*“My biggest challenge is constant pain that is not relieved.”*

*– Erica B, person living with complex regional pain syndrome, Australia*

**Physical symptoms like fatigue, pain, hair loss, and incontinence are typical for respondents living with a rare disease.**

These may also lead to other challenges, like limited mobility as well as work and social opportunities. Unfortunately, respondents said they do not always know how they will feel, and whether their symptoms can be managed. This disrupts their daily plans and results in unpredictability.



## • INSIGHTS •

Ultimately, respondents hoped to manage their symptoms and the side effects of their treatment, to help live with their rare disease. Many stated that reducing their pain and fatigue would help them gain independence.

At Atlantis Health we support people across a range of rare diseases to better identify and manage symptoms. For example: in sickle cell disease (SCD), we developed digital diaries to facilitate the tracking of pain crises. This initiative supported patients to discuss the frequency and impact of pain crises more readily, thereby enabling easier access to the necessary treatments and supports.

## Feelings of isolation

*“It has also turned me into a person who is somewhat anti-social as many activities I am unable to participate in with my friends”*

*- Celine C, person living with lupus SLE, Australia*



The nature of living with a rare disease and invisible symptoms such as pain and fatigue means respondents can feel isolated and misunderstood.

Other people tend to lack an awareness of rare diseases, and even close friends and family do not truly understand what it is like to live with a rare disease. As a result, many respondents felt misunderstood and unseen.



## • INSIGHTS •

Helping to increase public awareness and understanding of rare diseases can reduce feelings of judgement and stigma. Improving knowledge of healthcare professionals about rare diseases and available treatments can support better patient care.

The majority of our rare disease programs support patients in learning the skills of self-advocacy, thereby enabling people living with rare disease to feel more confident to talk about their condition. The development of self-advocacy skills can lead to more collaborative and therapeutic patient-healthcare professional relationships and open the door to more supportive relationships with family, friends, and colleagues.

## Adjusting life

*“ It’s unpredictable. I’m a planner by nature and it feels cruel to have a disease that is so unpredictable. It’s hard to lead a normal life and run my own business with this disease. ”*

*- Rebecca R, person living with multiple sclerosis, USA*

**For those with rare diseases, it can be a struggle to engage in activities they enjoyed doing before their diagnosis, like spending time with their children, socializing and working.**

Some respondents’ lifestyles had entirely changed since their diagnosis, making it difficult to adjust their lives. Respondents explained that reducing stress and adhering to a new diet, exercise schedule or treatment plan can be challenging.



## • INSIGHTS •

To help with life adjustments, respondents were looking for support to increase motivation, to reduce stress and to support the adoption of positive lifestyle changes.

Atlantis Health develops patient support programs to help navigate people through the adjustment process. For example: in narcolepsy, we run an ongoing digital newsletter series of patient stories. The power of the patient voice and lived experience is key to engaging and motivating patients to support more positive adjustment.

## Poor mental wellbeing

*“Mindfulness, finding joys in simpler things, slow down, try not to focus on what has been lost.”*

*– Jodi C, person living with mixed connective tissue disorder, USA*



**Maintaining mental wellbeing when living with a rare disease can be challenging.**

Physical symptoms, the unpredictability of the condition and isolation can all lead to poorer mental wellbeing. As a result, respondents felt emotional, insecure, and struggled to have a positive outlook on life. Some experienced body image issues as their conditions progressed. This need was often unmet, with respondents struggling to find support to help them maintain their mental health.



## • INSIGHTS •

Respondents explained that more support and connection are needed, with many simply wanting someone to listen to them. Others wished for more practical or financial support and flexibility for remote working. Healthcare providers could also share information and research, help to explain the illness to others and establish peer support groups.

Atlantis Health patient support programs are designed by Health Psychologists, many of whom have worked clinically alongside patients experiencing mental health difficulties. Our programs take a holistic view of the patient, and this includes addressing a person's emotional needs. For example, one of our programs for people living with multiple sclerosis includes several psycho-educational modules that are designed to support people to learn a range of skills to better cope with negative emotions. Modules within this program include adapting unhelpful thinking patterns, supporting daily activity scheduling, and value-based goal setting. Each of these modules draws on evidence-based psychological theory to support people to change their perspective and engage meaningfully in their lives.

## Treatment

*“There’s very little if anything that my healthcare team could do to address this. We have tried motility medications and other types of treatments and unfortunately I will be feeding tube dependent for the rest of my life”*

*- Alisa L, person living with gastroparesis, complex regional pain syndrome, and superior mesenteric artery syndrome, USA.*



**For some respondents, there isn't a cure or effective treatment for their rare disease. In contrast, others are challenged in choosing the safest treatment, with minimal side effects.**

They hoped for surgeries, medications, and other procedures to effectively treat their conditions. Respondents wanted to be healthy again, to live their lives as fully as possible, without restrictions.



## • INSIGHTS •

Helping support the decision-making and treatment initiation stage with open discussion about pros and cons can build confidence and trust. Ultimately, this can lead to greater satisfaction and persistence with treatment.

Atlantis Health has developed a digital app designed to support patients through diagnosis acceptance and treatment initiation. The app systematically works the person through a series of skills-based activities to set treatment expectations and facilitate motivation to continue with medication over the long term.

# 20+ programs



in rare disease

We see the person beyond the patient,  
and we empower

**Change for Good.**

Globally, we have implemented 20+ programs with a common focus of addressing the unmet needs of people living with rare disease.

Our personalized behavior change solutions are designed to help people:

- Understand their condition and treatment options
- Develop skills for self-advocacy
- Learn strategies for managing symptoms, including pain and fatigue
- Connect with and learn from others
- Feel empowered and motivated to manage long-term treatments and disease impacts

Contact us to learn more about the full findings of this research and our experience in designing and delivering personalized, multichannel support to people living with rare diseases.

[www.atlantishealth.com/contact](http://www.atlantishealth.com/contact)

**Contact Us**



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