



AtlantisHealth

Evidence for Change: Rare Disease in Focus

“As someone who has conducted research and developed support programs for people with a range of rare diseases, I have become very aware of the vital roles which caregivers play and the many challenges they face. In providing constant daily care, often alongside their other roles, research has shown just how much all this can take its toll on their mental and physical well-being. As a hidden part of the healthcare system, their own support needs can be overlooked by healthcare professionals and family members. Providing proper recognition and support for caregivers is crucial to ensure that they can continue to function effectively.”



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 treatment¹.



Evidence for Change: Rare Disease in Focus

Release 2

Understanding and Supporting the Caregiver Experience

According to the 2021 report on the Global State of Caring, up to 1 in 5 people provide care and support to others, including those living with a rare disease.¹

Caregivers often are unpaid family members who juggle their caring work with other responsibilities. As informal carers, their work is not always recognized or understood.

Atlantis Health conducted a global research project to explore the experiences of 45 people caring for a person living with a rare disease. More than half of the respondents were caring for someone who had been diagnosed more than 3 years earlier. Through a series of exploratory questions, the research uncovered 5 key themes central to the experience of caring for a person living with a rare disease. Each of these themes is outlined below.

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1. International Alliance of Carer Organizations. Global State of Caring 2021 report. Available from: <https://internationalcarers.org/wp-content/uploads/2021/07/IACO-Global-State-of-Caring-July-13.pdf>

Providing constant care

*“The stress and fatigue from it.
Never getting away from it.”*

– Lori L, caregiver for a person living with Lennox-Gastaut syndrome (LGS) and panhypopituitarism, United States

Caregivers dedicate their personal time, finances, and energy to caring for their loved ones.

Respondents stated that they are needed and available 24/7 to assist with hygiene, toileting, and monitoring. Many juggle caregiving with other responsibilities, like family and full-time work. Even when some respondents take a break, they worry about what happens in their absence. This ongoing worry is stressful and tiring and means that they are constantly engaged in care.



• INSIGHTS •

To support caregivers with the provision of constant care, respondents wanted better healthcare services, including more punctual medical transportation and removal of unnecessary bureaucracy. More coordination and innovation are desired, such as timetables or a platform for monitoring, logging information, and reminders about medication or healthcare appointments. Others want cameras that can be accessed remotely.

Dealing with the unknowns

“The unknown and not being taken seriously is challenging. Medical staff refuse to take us seriously because they won’t educate themselves. Teachers have no idea, and expect him to fit into their box, which he doesn’t.”

– Caregiver for a person living with Marfan syndrome, Australia

There are many unknowns of rare diseases, from little research and understanding from the healthcare system to not knowing how patients feel.

Respondents felt like medical professionals, teachers, and the public do not know about their loved one’s rare disease. This often leads to frustrations, such as not being taken seriously or being misunderstood. For some, uncertainties are related to understanding their loved one’s pain and experience and how they could most appropriately provide support.



• INSIGHTS •

Respondents want healthcare workers to be more caring, understanding, proactive, and informed about rare diseases. They expect them to do additional research to find answers and to be willing to have conversations. Some caregivers want more in-person visits from healthcare workers and access to mental health programs. These suggestions highlight the importance of emotional support when dealing with the uncertainties of caring for a person living with a rare disease.

Managing mental wellbeing

“Main challenges are a lack of exercise – no shopping, social events, etc—lack of social interactivity and general depression surrounding COVID.”

– Keith A, caregiver for a person living with a rare type of dementia, United Kingdom



Caregiving can take an emotional toll on carers.

Respondents explained that they are often challenged to remain calm and patient, and constantly worry that something might go wrong. Managing a patient’s mental wellbeing can also be difficult, as they are sometimes irrational and other times feel low. Managing fluctuating emotions requires an empathetic and balanced response. Other challenges include maintaining their loved one’s positive mood, as well as maintaining their motivation to engage in exercise and to continue to take their medication.



• INSIGHTS •

Respondents wish for more support and practical assistance. They want family and friends to help motivate the patient, and seek out advice on how to make the patient feel better as well as more in-person physical support. Healthcare teams could also reach out to caregivers to support them emotionally and alleviate their workload by helping with paperwork and making respite care more accessible.

Coping with limited treatment and symptom management

“If I had a magic wand, I would take his pain away.”

– Dianne D, caregiver for a person living with trigeminal neuralgia, United States



For many rare diseases, no effective treatments, cures, or specialists are available, making it difficult for caregivers to manage the impact of the condition.

Respondents explained that managing chronic symptoms like pain and fatigue is challenging. Others stated they worried about the effectiveness of medications in managing symptoms; for some, this was compounded by treatment fatigue.



• INSIGHTS •

Respondents hope for better treatments—from effective medications and access to specialist surgeons to custom joint braces and assistive technologies, such as robotic limbs. They also express a desire for more support, including accessing clinical trials and training to help cope with symptoms.

Combatting feelings of helplessness

“It’s absolutely heart-breaking to watch someone who you love so much go through these agonizing and painful episodes.”

– Austin F, caregiver for a person living with Dup15q syndrome, United States



Caregivers may experience feelings of helplessness when they cannot give relief to the person they are caring for.

Respondents explained that it is heart-breaking to see loved ones suffering from various symptoms and to be unable to alleviate their discomfort and pain. Knowing that there may never be a cure and that they are not able to help relieve symptoms can cause caregivers to feel helpless and upset.



• INSIGHTS •

As a result, respondents hope that the people they care for could be cured or at least have their symptoms alleviated. They wish that people with rare disease do not have to endure a lifetime of challenges, discomfort, and pain.



Research Highlights

Overall, this research highlights the myriad challenges that come with caregiving for a person living with a rare disease. Sadly, the practical, physical, and emotional needs of caregivers are too often neglected by traditional healthcare services. Caregiver voices are often not even considered in the care process, leaving caregivers feeling powerless. Atlantis Health hears these voices—and responds. Across rare disease, our patient support programs also include a caregiver component, helping caregivers to care for their loved one and for themselves—practically, physically, and emotionally.



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 living with, or caring for someone with, a rare disease. Our solutions allow people affected by rare diseases to

- 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



AtlantisHealth
GLOBAL EXPERTS IN BEHAVIOR CHANGE

