DARE TO CARE
WHERE DATA MEETS VOICES OF THE AUTOIMMUNE COMMUNITY

EPISODE 2:
RECLAIMING QUALITY OF LIFE WITH NEURO-AUTOIMMUNE DISEASES

REPORT

Living with rare neuro-autoimmune diseases like **Myasthenia Gravis (MG), Chronic Inflammatory Demyelinating Polyradiculoneuropathy (CIDP) or Multifocal Motor Neuropathy (MMN)** affects more than just physical health: it **impacts families, relationships and daily routines.** In the second episode of the Dare to Care webinar series, patients, experts and advocates come together to explore the realities **of reclaiming overall quality of life while navigating the unpredictable challenges** of MG and CIDP. The personal testimonies of Gabi Faust (CIDP patient and President of the German Association for CIDP, Guillain-Barré-Syndrome and variants) and Alisa Matei (MG Patient and Member of the Patients Group of the Romanian Association for MG), among others, underscore the **mental and physical adjustments** required **to cope**—accepting help, adapting environments, and emotionally navigating **the loss of former abilities while striving to maintain dignity and autonomy.**

This report highlights key insights from the discussion, focusing on the invisibility of these conditions, the impact on daily life and the crucial role of caregivers and peers, **highlighting what it really takes to balance energy, emotions, and relationships while living with a rare disease. The strain on hobbies, holidays and leisure time in general plays a major role as well in search of reclaiming quality of life.**

From left to right: Gabi Faust (CIDP Patient and President of the German Association for CIDP, Guillain-Barré-Syndrome and variants), Alisa Matei (MG Patient and Member of the Patients Group of the Romanian Association for MG), Caroline Collard (Patient Care Consultant), Sarah Dewilde (Doctor in Public Health) and Rogier Elshout (Moderator)

1. BALANCING (IN)DEPENDENCE: A DAILY DILEMMA

Living with chronic neuro-autoimmune conditions like MG and CIDP profoundly **impacts daily routines and independence.** What many consider ordinary—getting out of bed, commuting, or going out spontaneously—can become exhausting or inaccessible. Patients describe the disease as unpredictable and physically oppressive, with symptoms varying widely between individuals. As the disease progresses, tasks like driving, shopping, or grooming may require assistance or become impossible without aid. **MG and CIDP patients experience decreased autonomy, dependence on caregivers, and difficulties with basic selfcare and mobility.**

RESHAPING EVERYDAY LIFE

This shift towards being less self-reliant requires emotional labour, time, and a willingness to be vulnerable, but it is crucial in maintaining mental resilience. Still, logistical challenges remain — **patients often have to structure their lives around rigid healthcare systems.** And as Caroline Collard, Patient Care Consultant, underlined: **"It's a dual responsibility. The healthcare practitioner has to see the person behind the patient, but the patient has to see itself behind the disease as well."** Many patients are **forced to make significant life adjustments.** However, beyond physical symptoms, there's also the **risk of one's identity becoming consumed by the illness.** Alisa describes this very well: "Every aspect of my life was not only influenced by MG, but it was all about MG". For her, and many others, **therapeutic support helped to reclaim a sense of self beyond the disease.**

Communication is another key challenge. Patients often find it difficult to clearly explain complex or vague symptoms like fatigue. As Gabi mentioned: "You have to **accept that** sometimes **it's hard to find the right words,** especially when you get tired". This disconnect can delay proper treatment and understanding. With the help of skilled healthcare providers and personal effort, patients gradually learn how to describe their experiences more accurately and differentiate between symptoms of their disease and side effects of treatment. **A collaborative, empathetic approach between healthcare professionals and patients helps bridge these gaps, creating better outcomes for patients navigating their new reality.**

> *"A few weeks ago, I couldn't even go shopping for clothes because I wasn't able to just move the clothes away."*
> **Alisa, MG Patient.**

> *"I had to learn to accept the help of others. Now I need help in all activities of daily life and in selfcare."*
> **Gabi, CIDP Patient.**

> *"MG feels like concrete being poured over you, wrapping around you, and pressing you down, as if gravity is way stronger than what we all usually feel."*
> **Marta, MG Patient.**

DATA INSIGHTS

IMPACT ON DAILY LIFE

90%
of people with CIDP experience limitations in daily life[1]

59%
of people with MG report losing personal independence[2]

SELFCARE

52%
of people with CIDP[3] have difficulty with grooming and selfcare

36%
of people with MG have difficulty with grooming and selfcare[4]

2. WHEN ENERGY AND LEISURE TIME BECOME LUXURIES IN LIFE

Leisure time and social activities are some parts in life that become more and more luxuries after the diagnosis of a rare neuro-autoimmune disease. Simple pleasures like running, visiting the zoo, or going on vacation often become challenging due to pain, low energy, overstimulation, or emotional strain. **Many patients report a drastic reduction in physical[5] and social activities[6]**, requiring careful planning and structured routines just to engage in basic fun or social interactions.

PERSONAL SACRIFICES TO BATTLE FATIGUE

Alisa shares a personal struggle to combat fatigue, in her case linked to the strain on her voice caused by MG: **"Sometimes I don't talk the entire week, just so I can have a few hours to talk to my friends in the weekend"**, highlighting the **personal sacrifices** in order to retain a social life along with a rare and fluctuating disease.

Fatigue is a central issue, most patients experience severe tiredness that affects hobbies, travel, family life, and even eating. **This results in many needing to plan their days or weeks meticulously to conserve energy for meaningful activities.** Gabi for example: "I look at the whole week and **plan rest periods around the most important things I want to do,** like meeting my friends at the theatre".

"When I'm doing an activity, even though it's not in the way I planned, I'm still doing it. Like that, it still feels like I'm living a normal life. So, I'm fighting the fatigue, I'm not letting it control my life."
Alisa, MG Patient.

"I used to be very active in sports, going running and going to the gym, but that's only possible to a limited extent."
Alexa, CIDP Patient.

"We have to cope with our energy. Before you are in the fatigue, you have to say: "Now I have to rest." I have to leave a little bit more energy for the next day."
Gabi, CIDP Patient.

"I can go on holiday, I can go for afternoon with my friends to go shopping. But it's all structured and from time to time we need to rest, if we are happy with it or not."
Lutgarde, MG Patient.

DATA INSIGHTS

LEISURE/HOBBIES

92%
of people with CIDP[5] experience limitations in physical and fun activities

TRAVEL/ HOLIDAYS

88%
of people with CIDP struggle with traveling or going on holidays[7]

80%
of people with MG experience limitations in physical and fun activities[6]

84%
of people with MG have to make plans around their condition[8]

Alisa and Gabi, MG & CIDP Patients.

3. THE EMOTIONAL JOURNEY: FROM DIAGNOSIS TO DAILY RESILIENCE

The emotional toll of living with chronic neuromuscular conditions like MG and CIDP **is profound and often underestimated.** Patients commonly experience fluctuations in mood and motivation, with fatigue not only diminishing physical energy but also deeply affecting emotions—leading to cycles of joy, hopelessness, and self-doubt. For many, **diagnosis brings mixed emotions: relief at having an explanation, but also grief over a life changed.** Some feel validated, while others experience anxiety or denial. **Mental health struggles are common** and translate into feelings of frustration and being overwhelmed, **highlighting the need for emotional support as part of holistic care.**

YOU'LL NEVER WALK ALONE ON THE MENTAL HEALTH PATH

For patients facing rare diseases like MG and CIDP, **peer support becomes a vital source of strength.** Gabi highlights how sharing experiences helps build a resilient and understanding patient community: **"It's important to get in contact with other people to talk about CIDP, so more and more people know about the condition".** Listening to others' journeys fosters connection, empathy, and a sense of belonging—all key ingredients in managing the emotional toll of chronic illness. Alisa shares her own story of confronting mental health struggles early on: "In the beginning, there was a lot of **shame** involved in my disease and diagnosis. That made me spent a lot of time being **isolated** and reading a lot. **I went to my therapist and step by step, I put myself out into the world again".** Through therapy, coping exercises, and self-study, she learned to **manage panic attacks and embrace acceptance as part of her healing process.** Acceptance often comes with time and reflection, as individuals learn to balance loss with gratitude for what remains possible. Gabi: **"Focus on the most important things you enjoyed in life and take your energy to spend time with these important things".**

Social misconceptions and stigma still pose challenges, especially for women who are initially dismissed or misdiagnosed. Yet many patients cultivate resilience, sometimes shaped by personal history, family support, or deliberate mental training. **Through peer support and mental health care, these patients find ways to adapt, persevere, and regain balance in their lives.**

"Even after 7 years I sometimes feel like I'm still on day one, emotionally speaking. Even with everything I learned, I can still get mixed up in this storm of feelings and still feel anxious and frustrated."
Alisa, MG Patient.

"The moment of the diagnosis was good to have a clear picture. But the fear is coming very soon in that moment too."
Gabi, CIDP Patient.

"Society reminds us daily that we are a bunch of useless people, although in reality we are much less mentally useless than the majority."
Alejandra, CIDP Patient.

DATA INSIGHTS

MENTAL HEALTH

29%
of people living with CIDP rate their mental health as poor or fair[9]

54%
of people living with MG feel depressed or overwhelmed and 75% feel frustrated[10]

4. CHALLENGES EXTENDING THE BODY INTO RELATIONSHIPS

Living with conditions such as MG and CIDP can deeply **affect emotional well-being and significantly alter the dynamics within families and social circles.** Patients often face overwhelming fatigue, limited energy, and physical restrictions, which can lead to decreased availability and participation in daily life. **These challenges create emotional strain, disrupt roles within the household, and force many to rely on loved ones as caregivers.** Gabi confirms: "The roles changed, and my husband became my caregiver."

As roles shift, partners may become full-time carers, and children or parents may take on unexpected responsibilities, creating emotional complexity and, at times, feelings of guilt or loss of identity among patients.

However, communication and mutual understanding within relationships emerge as essential tools for resilience. Gabi emphasizes the importance of honest dialogue: **"You need to have good conversations,** you have to talk about all the struggles". For Alisa, boundaries and maintaining some level of independence to preserve relational equality is equally important: "It was **important to regain my independence** because in the beginning my mom helped me with literally everything and **I never wanted to feel like a burden**". Despite the hardships, **relationships—when nurtured—remain central to coping and quality of life, with social engagement often identified as a key treatment goal.**

"When my MG was bad, I lost a lot of my friends. I felt all alone in the world. Nobody really understood me."
Sasa, MG Patient.

"When it comes to dating for example, you never know when to drop the bomb: hey, I live with this rare condition."
Alisa, MG Patient

"The roles changed, my husband became my caregiver."
Gabi, CIDP Patient.

"It never occurred to me to end the relationship or to leave her for someone else because of the disease. That has never been a topic and will never be a topic either."
Christian, husband of a CIDP Patient

DATA INSIGHTS

SOCIAL LIFE

82%
of people with CIDP[11] see their social life affected by the condition

70%
of people with MG limited their social activities[13]

63%
of people with CIDP have to limit their social activities due to fatigue[12]

FAMILY NEEDS

60%
of people with MG have trouble meeting the needs of their family[14]

5. IN A NUTSHELL: KEY TAKEAWAYS

FOR THE PATIENT

- **Life changes, but joy remains possible:** Everyday tasks can become major hurdles. But through adaptation, pacing, and accepting help, many patients regain a sense of independence and joy.
- **Emotional resilience is a journey:** The emotional rollercoaster of misdiagnosis, diagnosis and daily limitations is real. Therapy, mindfulness, and peer (e.g. patient organisations) support are powerful tools in building mental strength.
- **Plan for energy, not just time:** Fatigue and pain are constant companions. Careful planning, rest breaks, and prioritising helps protecting enough energy for life's joys.

FOR THE CAREGIVER

- **Your support is vital but complex:** Loved ones often step into caregiving roles, balancing practical help with emotional support. This will change family dynamics and relationships but honest conversations and shared boundaries help maintain respect and connection.
- **Listen and learn:** The impact of MG and CIDP isn't always visible. Take the time to listen to how your loved one feels physically and emotionally and understand that plans may change due to unpredictable symptoms.
- **Help patients keep their identity:** Encourage your loved one to pursue hobbies, relationships, and moments that remind them they are more than their illness. But don't forget to take some time for yourself, your wellbeing matters equally as much.

FOR THE HEALTHCARE PROFESSIONAL

Beyond the diagnosis: Redefining the HCP's role in chronic illness

- **See the whole person, not just the patient:** Treatment plans should go beyond managing symptoms—help patients set life goals, maintain dignity, and find meaning in daily life.
- **Communication is key:** Help patients describe their vague or invisible symptoms clearly, and work with them to distinguish between disease symptoms and medication side effects.
- **Multidisciplinary care matters:** Occupational therapy, mental health support, aid tools and social services are not optional extras—they are essential parts of managing rare, chronic diseases like MG and CIDP.

TO CONCLUDE

Living with MG or CIDP means navigating a constantly shifting landscape of physical limits, emotional highs and lows, and social challenges. But through teamwork—between patients, families, and healthcare providers—and with empathy and open communication, people facing these rare diseases can reclaim parts of their lives and identities. Life with chronic illness will look different, but it can still be rich, joyful, and full of meaningful connections.

- Balance Independence
- Prioritising Energy
- Peer Support
- Open Communication

INTERESTED IN LEARNING MORE?

Watch our webinar series ‘Dare to Care’ by argenx - to hear expert insights, patient stories, and strategies for reclaiming quality of life.

https://argenx.com/events/dare-to-care

1. Roberts A., Williamson N., Griffiths N. et al. (2023), Qualitative Exploration of the Patient Experience of Chronic Inflammatory Demyelinating Polyradiculoneuropathy (CIDP) (Study sample: 15 adults with CIDP from the US were interviewed with a mean age of 57 years (range: 38-82) and a range of demographic and clinical characteristics). Data explanation: Impacts on physical functioning, activities of daily living, and work were reported for at least 90% of people living with CIDP, reported by HCPs. DOI: https://www.ispor.org/docs/default-source/euro2023/sa8936h---ispor-cidp-ce-poster-v30131892-pdf.pdf?sfvrsn=aa2d3842_0

2. Dewilde S., Philips G., Paci S. et al. (2023), The Burden Patients with Myasthenia Gravis Experience in Terms of Breathing, Fatigue, Sleep, Mental Health, Discomfort and Usual Activities in Comparison to the General Population Adv Ther 41, 271–291 (2024). (MyRealWorld-MG Study sample: 2,074 adults with myasthenia gravis in 9 countries). Data explanation: 35.7% of people with MG report having ‘somewhat’ lost their personal independence and 23.9% reports having lost it ‘very much’ (those two put together makes 59.8%). DOI: https://doi.org/10.1007/s12325-023-02704-w

3. Paci S., Arvin-Berod C., Van de Veire L. et al. (2025), CIDP patients’ health-related quality of life, daily activities and fatigue: results from a multinational real-world survey (Study sample: 199, European data from Adelphi’s CIDP Disease Specific Programme™, a real-world, multinational, cross-sectional survey of CIDP patients and their neurologists in France, Germany, Italy, Spain and the UK (September 2022-April 2023). Data explanation: 48% of people living with CIDP report having no problems with selfcare, resulting in 52% that do experience minor to severe problems. PMID: 29787189

4. Dewilde S., Philips G., Paci S. et al. (2022), Patient-reported burden of myasthenia gravis: baseline results of the international prospective, observational, longitudinal real-world digital study MyRealWorld-MG (Study sample: Baseline results of 841 adult patients with MG from seven countries: USA, Japan, Germany, UK, Italy, Spain and Canada) Data explanation: 66.4% of people with MG report having ‘no problems’ with performing their personal grooming needs and selfcare, this leaves about 36% of people living with MG that report having ‘mild’ to ‘extreme’ problems. DOI: https://doi.org/10.1136/bmjopen-2022-066445

5 & 7. Adelphi CIDP DSP (2022-23) PRF, Section J, Q6 (sample: 83 neurologists provided data for 542 patients with CIDP, of whom 199 provided self-reported data. The study was conducted in France, Germany, Italy, Spain, and the UK.). Data explanation: With regard to traveling or going on holidays, physicians report that 12% of people with CIDP see their ability to travel or go on vacation not at all affected by their condition, resulting in 88% that are slightly to extremely affected in their ability to travel or go on vacation. In the eyes of physicians, 7% of people with CIDP experience no limitations in their physical activities, while 93% see their physical activities slightly to extremely limited by the disease.

6 & 8. Dewilde S., Philips G., Paci S. et al. (2023), The Burden Patients with Myasthenia Gravis Experience in Terms of Breathing, Fatigue, Sleep, Mental Health, Discomfort and Usual Activities in Comparison to the General Population Adv Ther 41, 271–291 (2024). (MyRealWorld-MG Study sample: 2,074 adults with myasthenia gravis in 9 countries). Data explanation: 46.4% of people with MG report being ‘somewhat’ limited in their ability to enjoy hobbies and fun activities and 33.7% report it to be ‘very much’ (those two put together makes 80.1%); 44.3% of people with MG report to ‘somewhat’ have to plan around their condition and 40% reports ‘very much’ (those two put together makes 84.3%). DOI: https://doi.org/10.1007/s12325-023-02704-w

9. Paci S., Arvin-Berod C., Van de Veire L. et al. (2025), CIDP patients’ health-related quality of life, daily activities and fatigue: results from a multinational real-world survey (Study sample: 199, European data from Adelphi’s CIDP Disease Specific Programme™, a real-world, multinational, cross-sectional survey of CIDP patients and their neurologists in France, Germany, Italy, Spain and the UK (September 2022-April 2023)) Data explanation: Physicians report that 25% of people with CIDP rate their mental health as ‘fair’ and 4% as being ‘poor’.. PMID: 29787189

10. Dewilde S., Philips G., Paci S. et al. (2023), The Burden Patients with Myasthenia Gravis Experience in Terms of Breathing, Fatigue, Sleep, Mental Health, Discomfort and Usual Activities in Comparison to the General Population Adv Ther 41, 271–291 (2024). (MyRealWorld-MG Study sample: 2,074 adults with myasthenia gravis in 9 countries). Data explanation: 52.3% of people with MG report feeling ‘somewhat’ frustrated and 24.2% reports ‘very much’ (those two put together makes 76.5%), 45% of people with MG report feeling ‘somewhat’ depressed and 11.3% reports ‘very much’ (those two put together makes 56.3%), 42.3% of people with MG report feeling ‘somewhat’ overwhelmed and 13.3% reports ‘very much’ (those two put together makes 55.6%). DOI: https://doi.org/10.1007/s12325-023-02704-w

11. Adelphi CIDP DSP (2022-23) PRF, Section J, Q6 (sample: 83 neurologists provided data for 542 patients with CIDP, of whom 199 provided self-reported data. The study was conducted in France, Germany, Italy, Spain, and the UK.). Data explanation: In the eyes of physicians, 18% of people with CIDP see their social life not being impacted at all by their condition, while 82% see their social life slightly to extremely impacted by the disease.

12. Paci S., Arvin-Berod C., Van de Veire L. et al. (2025), CIDP patients’ health-related quality of life, daily activities and fatigue: results from a multinational real-world survey (Study sample: 199, European data from Adelphi’s CIDP Disease Specific Programme™, a real-world, multinational, cross-sectional survey of CIDP patients and their neurologists in France, Germany, Italy, Spain and the UK (September 2022-April 2023)) Data explanation: 63% of people with CIDP have to limit their social activities due to fatigue. 37% reported not having to limit social activities at all. PMID: 29787189

13 & 14. Dewilde S., Philips G., Paci S. et al. (2023), The Burden Patients with Myasthenia Gravis Experience in Terms of Breathing, Fatigue, Sleep, Mental Health, Discomfort and Usual Activities in Comparison to the General Population Adv Ther 41, 271–291 (2024). (MyRealWorld-MG Study sample: 2,074 adults with myasthenia gravis in 9 countries). Data explanation: 41.6% of people with MG report to ‘somewhat’ have to limit their social activity and 28.3% reports ‘very much’ (those two put together makes 69.9%); 39.5% of people with MG report to ‘somewhat’ struggle to meet their family needs and 20.6% reports ‘very much’ (those two put together makes 60.1%). DOI: https://doi.org/10.1007/s12325-023-02704-w