Living with CIDP:
Adapting strength, independence & daily life

How patients rethink mobility, energy, emotions and relationships

Living with Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) means facing challenges that affect movement, independence and emotional well-being. From needing support in daily activities to coping with fatigue and uncertainty, CIDP reshapes how patients engage with leisure activities, relationships and society. This infographic combines scientific insights with patient experiences to show how individuals adapt, reclaim their independence, and build a fulfilling life with CIDP.

BALANCING (IN)DEPENDENCE: A DAILY DILEMMA

90%

of people with CIDP experience limitations in daily life due to their condition[1].

52%

of people with CIDP have mild to extreme difficulty with selfcare[2].

79%

of people with CIDP feel slightly to extremely tired[2].

> ***"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.

THE EMOTIONAL JOURNEY: RESILIENCE OVER TIME

Diagnosis brings relief but also grief. Emotional ups and downs are common. Therapy, peer support and acceptance are key.

29%

of people with CIDP were rated by their neurologists as having "poor" or "fair" mental health[2].

58%

of people with CIDP feel frustrated of being too tired to do the things they want to do[2].

> ***"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.

WANT TO DIVE DEEPER?

Watch the second episode of the Dare to Care webinar series to hear patients stories and expert insights on living fully with autoimmune diseases.

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

WHEN LEISURE BECOMES LUXURY

Fatigue, pain and emotional overload make hobbies, travel and fun activities rare. Planning rest becomes essential.

76%

of people with CIDP experience difficulty running or cannot run and 62% of people with CIDP experience difficulty walking outdoors or cannot do it[2].

88%

of people with CIDP see their ability to travel or go on vacation affected by the condition, as reported by their physicians[3].

> ***"I look at the whole day, week or weekend and plan rest periods around the things I want to do. I make a list of the important things and around those I organise my life."*** Gabi, CIDP Patient.

WHEN SUPPORT SYSTEMS SHIFT

Living with CIDP often means depending on family and partners, which reshapes household roles and daily relationships. This shift in support also extends to social life, where fatigue and emotional strain create additional barriers.

82%

of people with CIDP see their social life affected by the condition, as reported by their physicians[3].

63%

of people with CIDP have to limit their social activities due to fatigue[2].

KEY TAKEAWAYS

FOR THE PATIENT: Plan energy, not just time to adapt without losing your identity & seek peer and emotional support.

FOR CAREGIVERS: Talk openly, set shared boundaries, be supportive without overstepping & take care of yourself, too.

FOR HCPS: Help patients describe invisible struggles & promote holistic, multidisciplinary care.

EU-UNB-25-00075 - Date of preparation: August 2025

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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. 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. 79% of people with CIDP feel tired, 21% reported not being tired at all. With regards to running and walking outdoors, 34% of people with CIDP have some difficulty running and 42% cannot do it, and 41% have difficulty walking outdoors and 21% cannot do it. Physicians report that 25% of people with CIDP rate their mental health as 'fair' and 4% as being 'poor'. 42% of people living with CIDP report not being frustrated for feeling too tired to do things they want to do, resulting in 58% that do experience a little bit to 'very much' frustrations. 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

3. 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, 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.