EURORDIS
RARE DISEASES EUROPE

Rare Barometer

IMPROVE OUR MENTAL HEALTH!

Key findings from a Rare Barometer survey on the mental health of people with rare diseases

June 2026

11 Sept. – 14 Dec. 2025

9897 participants in Europe

1657 rare diseases represented

45 European countries

Around **30 million people** live with a rare disease in Europe. **Alongside their families**, they face physical and practical challenges but also a significant psychological burden. Uncertainty around diagnosis and prognosis, limited treatment options, and the impact of symptoms on daily life all affect emotional well-being.

Yet mental health remains insufficiently recognised in rare disease care and policy, despite being a fundamental human right and a key factor in treatment adherence and participation in daily life.

This Rare Barometer survey explores the mental health of people living with a rare disease and their family members, using validated tools to assess self-reported symptoms of depression, anxiety, loneliness and suicidal ideation. Results highlight the high levels of emotional distress experienced by the rare disease community.

The findings underline the urgent need to better integrate mental health into rare disease care and policy, and to recognise this community as a vulnerable population in mental health strategies.

1 MOST PEOPLE LIVING WITH A RARE DISEASE AND THEIR FAMILY MEMBERS REPORT POOR MENTAL HEALTH

Mental health was estimated based on four self-reported indicators: depressive symptoms with the Patient Health Questionnaire (PHQ-8), anxiety symptoms with the Generalised Anxiety Disorder questionnaire (GAD-2), loneliness with the UCLA questionnaire and a question on suicidal thoughts over the past 6 months.

7/10 people living with rare diseases and their families report poor mental health

68% of participants reported at least one mental health difficulty among moderate to severe ***depressive symptoms*** *(PHQ-8 score ≥ 10), clinically significant* ***anxiety symptoms*** *(GAD-2 score ≥ 3),* ***loneliness*** *(UCLA loneliness scale score ≥ 9) or* ***suicidal thoughts*** *in the past six months. All participants (n=9897).*

2 THE RARE DISEASE COMMUNITY ENCOUNTERS SEVERAL MENTAL HEALTH DIFFICULTIES

Levels of psychological distress are comparable to those observed in **exceptional contexts** such as the COVID-19 pandemic[1], or among **highly vulnerable populations**, including people living with HIV in Uganda[2], individuals treated in psychiatric hospital settings[3] or those living with severe mental disorders[4].

People living with a rare disease and their family members encounter different types of mental health difficulties:

44%

report moderate to severe **depressive symptoms**

7 times more than in the EU population (6.1%)[5]

45%

feel **lonely**

4-20 times more than in the EU population (2-10%)[7]

42%

report clinically significant **anxiety symptoms**

7 times more than in the EU population (5.4%)[6]

31%

report **suicidal thoughts** in the past six months

5-10 times more than in the EU population (3-6%)[8]

Many encounter several mental health difficulties:

47%

report at least **2 difficulties**

28%

report at least **3 difficulties**

12%

report all **4 difficulties**

> “My symptoms (severe insomnia, feeling of suffocation...) prevent me from leading a normal life: working, socialising, and even studying are difficult. They greatly affect my daily life and, altogether, cause anxiety and depression.”
>
> Person living with a rare disease, Italy

> “There are many situations I do not know how to handle. Caring for my daughter every day, I often feel extremely tired and exhausted, and I have lost friends and social contacts.”
>
> Parent of a person living with a rare disease, Czech Republic

***Depressive symptoms (PHQ-8)**: percentage of participants with a score of 10 or more to ‘Over the last two weeks, how often have you been bothered with the following problems?’ (i) little interest or pleasure in doing things, (ii) feeling down, (iii) sleep troubles, (iv) energy level, (v) appetite, (vi) feeling bad about oneself, (vii) concentrating, (viii) moving or speaking. 0=not at all; 3=nearly everyday. All participants (n=9897). **EU population**: PHQ-8 ≥ 10[5].*

***Anxiety symptoms (GAD-2)**: percentage of participants with a score of 3 or more to ‘Over the last two weeks, how often have you been bothered with the following problems? (i) Feeling nervous, anxious or on edge; (ii) Not being able to stop or control worrying’. 0=not at all; 3=nearly everyday. All participants (n=9897). **EU population**: IHME estimation for WHO[6].*

***Loneliness (UCLA loneliness)**: percentage of participants with a score of 9 or more to ‘Over the past six months, how often have you [felt] (i) that [you] lacked companionship, (ii) left out, (iii) isolated from others’. 1=never; 5=very often. All participants except non-responses (n=9277). **EU population**: systematic literature review[7].*

***Suicidal thoughts**: percentage of participants who report suicidal thoughts over the past six months. All participants except non-responses (n=8676). **EU population**: systematic literature reviews[8].*

If you have suicidal thoughts, you can contact someone anonymously by phone or chat in your country: blog.opencounseling.com/suicide-hotlines or befrienders.org

3 PEOPLE LIVING WITH A RARE DISEASE ENCOUNTER SPECIFIC MENTAL HEALTH DIFFICULTIES

Among people living with a rare disease, **two thirds report mental health difficulties**, highlighting the significant psychological impact of living with a rare condition. Alarmingly, one third also report having experienced suicidal thoughts in the past six months, underlining the **urgent need for accessible and adapted mental health support**.

67% **of people living with a rare disease report poor mental health:**

45% report moderate to severe **depression symptoms**

43% feel **lonely**

38% report clinically significant **anxiety symptoms**

35% report **suicidal thoughts** in the past 6 months

Percentage of participants reporting poor mental health, depressive symptoms (PHQ-8 ≥ 10), anxiety symptoms (GAD-2 ≥ 3), loneliness (UCLA ≥ 9) or suicidal thoughts in the past 6 months among those living with a rare disease (n=6627).

Most people living with a rare disease experience disabilities, pain, severe symptoms, and discrimination, all of which negatively affect mental health[9]. The impact is especially strong for those who are young or developed symptoms during childhood. **These individuals should be considered at higher risk of poor mental health and receive appropriate support.**

More people living with a rare disease report poor mental health when they experience:

93% bad or very bad **quality of life**

85% **severe disabilities**

84% **many severe symptoms**

86% bad or very bad **health**

85% **pain** everyday

78% **discrimination** related to their condition or disability

Percentage of people living with a rare disease who reported poor mental health among those who reported 'bad' or 'very bad' quality of life (n=1807); 'bad' or 'very bad' health in general (n=2480); Having been severly limited because of a health problem in activities people usually do for at least the past 6 months (n=2157); Experiencing pain everyday in the past six months (n=1947); Experiencing many severe symptoms from their condition (n=1655); Experiencing dscrimination related to their their rare condition or to a disability (n=4540). All p-values <0.01.

More people living with a rare disease report poor mental health when they:

78% **are under 30** years old

71% **were minors** at first symptoms

70% of rare diseases have a paediatric onset[10]

Percentage of participants who reported poor mental health among those who were 30 years old or less (n=452), and among those who were under 18 years old when first symptoms appeared (n=2568). All p-values <0.01.

If you have suicidal thoughts, you can contact someone anonymously by phone or chat in your country: blog.opencounseling.com/suicide-hotlines or befrienders.org

4 MOST PARENTS OF PEOPLE LIVING WITH A RARE DISEASE REPORT POOR MENTAL HEALTH

More than two thirds of parents of people living with a rare disease report poor mental health, and **more than half of them** report anxiety symptoms and feeling lonely, highlighting the need for adapted support.

71% **of parents of people living with a rare disease report poor mental health:**

42% report moderate to severe **depression symptoms**

52% feel **lonely**

52% report clinically significant **anxiety symptoms**

25% report **suicidal thoughts** in the past 6 months

Percentage of participants reporting poor mental health, depressive symptoms (PHQ-8 ≥ 10), anxiety symptoms (GAD-2 ≥ 3), loneliness (UCLA ≥ 9) or suicidal thoughts in the past 6 months among parents of people living with a rare disease (n=3270).

Parents of people living with rare diseases often manage numerous medical appointments, cope with concerns about their child's health and face high medical costs. They also balance caregiving responsibilities, disrupted professional lives and greater social vulnerability, including unemployment, separation, divorce or single parenthood, while reporting poorer health than the general population. Together, these challenges can significantly affect their mental health and should be considered for adapted support.

More parents of people living with a rare disease report poor mental health when:

89% they report difficulties managing the **numerous medical appointments**

88% **their child's health** is poor or very poor

86% the medical costs represent **a heavy financial burden**

80% they often have to **explain the condition to healthcare professionals**

80% they are **unemployed or homemakers**

80% they are **single, separated or divorced**

Percentage of parents of people living with a rare disease who reported poor mental health among those who 'had difficulty managing the numerous medical appointments' (n=731), who reported that their child's health was 'poor' or 'very poor' (n=510), that 'overall, the costs associated with the rare or undiagnosed condition' represent 'a heavy financial burden' (n=839), that they 'often' or 'very often' had to explain the condition to healthcare professionals (n=1562), that they are 'unemployed' or a 'homemaker' (n=469), that they are single, separated or divorced (n=318). All p-values<0.01.

Only half the parents of people living with a rare disease report good or very good health:

53% report **good or very good health**

69% of the EU population report good or very good health[11]

Percentage of parents of people living with a rare disease who answered 'good' or 'very good' to 'In general, would you say that your health is...' (n=2749). **EU population:** *Eurostat SILC 2024 (same question)[11].*

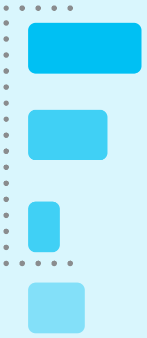
If you have suicidal thoughts, you can contact someone anonymously by phone or chat in your country: blog.opencounseling.com/suicide-hotlines or befrienders.org

5 HALF THE RARE DISEASE COMMUNITY RECEIVED NO SUPPORT DURING DIAGNOSIS SEARCH OR DELIVERY

Emotional and psychological support is essential for people living with a rare disease and their families during the diagnostic journey and at diagnosis delivery. **It helps them cope with uncertainty, distress and isolation**, while strengthening trust in healthcare professionals and engagement with care. **Such support may also enable faster diagnosis** – improving access to appropriate care – and facilitate acceptance when no treatment is available.

During their diagnosis journey, they received emotional or psychological support from:

Those who received support experienced faster diagnosis:



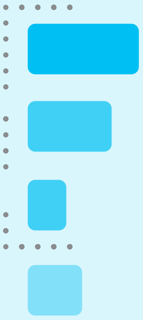
75% **no professional psychological support**

- **50%** **No psychological or emotional support** → **4.9** years to diagnosis
- **35%** **Family, friends, neighbours** → **3.6** years to diagnosis
- **14%** **The rare disease community** (organisations or individuals) **or a charity** (e.g. helpline) → **3.8** years to diagnosis
- **25%** **Mental health professionals or healthcare professionals** → **3.8** years to diagnosis

> “We started physiotherapy for my son after his birth, but we saw no improvement after three years. So I began searching for a diagnosis on the internet. When I found an obvious answer, it was so devastating that I could not accept it. I was in complete denial and because I had no support from anyone, I stopped searching for answers.
>
> Only a year and a half later, when my son developed new symptoms that I could no longer deny, I resumed my search for a diagnosis. It then took another two years to confirm it. In total, we spent seven years visiting doctors every couple of months and wasting public and family resources, instead of focusing on appropriate treatments and making sure he could find his place in society.”
>
> Parent of a person living with a rare disease, Romania

***Left:** 'Since the first symptoms were noticed (when undiagnosed) or while you were still searching for a diagnosis for the rare condition (when diagnosed), did YOU receive emotional or psychological support from...' Several answers possible. All participants except non-response and option 'other' (n=9631).*
***Right**: average time between first symptoms and confirmed diagnosis for each type of support received during diagnosis search. All participants except undiagnosed and non-responses (n=8362), p-value < 0.01.*

At diagnosis delivery, they received emotional or psychological support from:



76% **no professional psychological support**

- **49%** **No psychological or emotional support**
- **37%** **Family, friends, neighbours**
- **17%** **The rare disease community** (organisations or individuals) **or a charity** (e.g. helpline)
- **24%** **Mental health professionals or healthcare professionals**

> “In reality, I did not receive any emotional support. I was never properly informed about my condition or what could be done to improve the situation. What affected me most, and was hardest to accept, was being told that my condition is chronic with no real cure, only stabilisation. As a teenager, I also struggled to accept the impact of the condition on my appearance and the way I dressed.”
>
> Person living with a rare disease, France

'When the diagnosis was announced, did YOU receive emotional or psychological support from...'. Several answers possible. Diagnosed participants except answers 'other' (n=9010).

6 THE SOCIAL ENVIRONMENT CAN IMPACT MENTAL HEALTH

A positive social environment can support and protect mental health, with family and friends providing essential and regular emotional support, but more complex needs may require professional care. However, discrimination and stigma within one's social environment can harm mental well-being.

Two thirds are emotionally supported by their social environment, but it is still insufficient for a large proportion of them:

65% **received emotional support** from family, friends or neighbours in the past six months.

38% of them report that it was **not enough to cover their needs**

People living with a rare disease who report discrimination from their social environment have poorer mental health:

33% of people living with a rare disease **report discrimination from family, friends or neighbours**

85% of them report **poor mental health**

Left: *percentage of participants who answered 'Yes' to 'Over the past 6 months, did you receive emotional or psychological support from your family, friends, neighbours?', among all participants except non-responses (n=9265). Percentage of participants who answered 'Not enough to cover my needs' among those who answered 'Yes' to the same question (n=9045).* ***Right***: *percentage of people living with a rare disease who answered 'In the social environment (family/relatives, friends, neighbours...)' to 'Have you ever experienced discrimination related to your rare or undiagnosed condition, or to a disability?' (n=6423), and proportion of those who reported poor mental health among them (n=2135). p-value < 0.01.*

7 THE RARE DISEASE COMMUNITY HAS VERY HIGH UNMET NEEDS FOR PROFESSIONAL SUPPORT...

Beyond the diagnostic period, living with a rare disease can significantly impact daily life. People living with a rare disease and their families often have ongoing psychological support needs that remain largely unmet.

Most of those who needed professional support over the past six months did not receive any from:

1. **74%** **Centres of Expertise** (multidisciplinary care teams specialised in the rare or undiagnosed condition)
2. **70%** **reimbursed mental health professionals** (psychologist, psychotherapist or psychiatrist with consultations being partially or totally reimbursed)
3. **64%** **non-reimbursed mental health professionals** (psychologist, psychotherapist or psychiatrist paid by themselves or their family)
4. **55%** **general practitioners or nurses**

Percentage of participants who answered 'No but it was needed' to 'Over the past 6 months, did you receive emotional or psychological support from...', among participants who reported that they needed each type of professional psychological support (i.e. who answered 'Yes and enough to cover my needs', 'Yes but not enough to cover my needs' or 'No but it was needed'): Centres of Expertise n=5188, Reimbursed mental health professional n=5226, Non-reimbursed mental health professional n=4505, general practitioner or nurse n=5135.

8 …WHILE IT HELPS THEM BETTER MANAGE EVERYDAY LIFE AND TREATMENTS

49% **accessed professional psychological support** in the last six months, and most of them report that it helped them to:

- **72%** **better manage daily life,** including stress or anxiety
- **65%** **develop more skills** to face challenging situations
- **62%** **live better with the symptoms** of the condition
- **56%** better deal with **constraints related to the treatment**, or with the **lack of treatment** for the condition
- **49%** improve their ability to **focus on work or studies**

> “I am part of a support group with other people living with the same condition, led by a psychologist at the Neuromuscular Centre. It is very supportive, like a second family, and we share helpful tips and tricks.”
>
> Person living with a rare disease, Belgium

> “The private psychological support I have received for the past five years helps me focus on the positive aspects of my family life and find the strength and energy to face new projects and challenges. It gives me confidence in the future and helps me keep pessimism and negativity at bay.”
>
> Person living with a rare disease, Italy

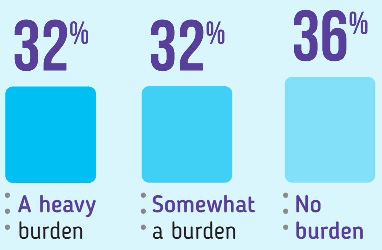
> “My personal resilience has been strengthened through psychotherapy and exchanges within self-help organisations.”
>
> Parent or a person living with a rare disease, Germany

Top: *percentage of participants who received psychological support from a mental health professional, a Centre of Expertise or a healthcare professional in the past six months. All participants except non-responses (n=9265).*
Bottom: *percentage of participants who answered 'To a great extent' or 'Somewhat' to the question 'Did the support you received over the past 6 months help you to…' among participants who said that they received professional psychological support over the past six months (n=4501).*

9 PSYCHOLOGICAL SUPPORT ADDS TO MEDICAL COSTS

For those who accessed professional psychological support, the associated costs add to the financial burden of medicines and medical care, which is already higher in the rare disease community than in the EU population.

Professional psychological support represents a financial burden for 64% of those who accessed it:



The financial burden related to medicines and to medical care is high in the rare disease community:

23% **prescribed and non-prescribed medicines** are a heavy financial burden — **2 times** more than in the EU population (12%)[12]

20% **medical examinations or interventions** are a heavy financial burden — **1.5 times** more than in the EU population (13%)[12]

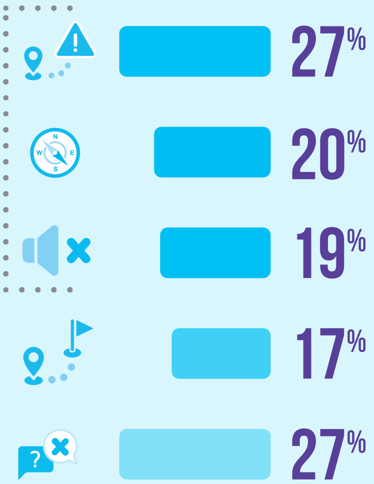
'To what extent were the following costs a financial burden to your household in the past 12 months?'. ***Left***: *answers to 'Professional psychological support' among participants who accessed professional psychological support (n=3203).* ***Right***: *answers 'a heavy burden' among all participants except non-responses (n=9590).* ***EU population***: *Eurostat SILC 2022 (same question)[12].*

10 MOST REPORT BARRIERS TO ACCESS PROFESSIONAL PSYCHOLOGICAL SUPPORT

Most people living with rare diseases and their families report barriers to accessing professional psychological support, regardless of whether they accessed it.

Logistical and informational obstacles are the most frequently cited, while many of those who report not needing professional psychological support also report poor mental health:

55% report barriers to access professional psychological support



27% **Could not access it** because of logistical barriers (they could not afford it, it was too far, the waiting was list too long, the professional was not available...)

20% **Did not know how to access it** (who to turn to, that such support was available...)

19% **Did not feel ready** (feared it could be too difficult, thought they could manage by themselves, did not trust the person...)

17% **Report no obstacles**

27% **Say they do not need it**

4/10 of those who say they do not need professional psychological support **report poor mental health**

'Have any of the following things ever stopped you from getting professional psychological help?' Several answers possible. All participants except non-responses (n=8979).
4/10*: proportion of participants who reported poor mental health (depressive symptoms (PHQ-8 ≥ 10) or anxiety symptoms (GAD-2 ≥ 3) or loneliness (UCLA ≥ 9) or suicidal thoughts in the past 6 months) among those who answered 'I did not need professional psychological support' (n=2463).*

More information: eurordis.org/voices or rare.barometer@eurordis.org
Full report in English: https://doi.org/10.70790/MHRE2026

THANK YOU to all the people with rare diseases and family members who participated in the survey, and to Rare Barometer partners!

---

1. Delpino et al. 2022: 35% anxiety symptoms - GAD and other scales. doi.org/10.1016/j.jad.2022.09.003; **2.** Kaggwa et al. 2022: 8-67% depression symptoms - PHQ-9 ≥ 10. doi.org/10.3389/fpsyt.2022.781095; **3.** Plummer et al. 2022: 30-50% anxiety symptoms - GAD-2 and GAD-7. doi.org/10.1016/j.genhosppsych.2015.11.005; **4.** Bai et al. 2021: 30% point prevalence of suicidal ideation. doi.org/10.1038/s41398-021-01671-6; **5.** Eurostat EHIS 2019: 6.1% depression symptoms - PHQ-8 ≥ 10. ec.europa.eu/eurostat/databrowser/product/page/hlth_ehis_mh2e$defaultview; **6.** IHME estimates in WHO 2018, 5.4% anxiety symptoms. doi.org/10.1787/health_glance_eur-2018-en; **7.** Surkalim et al. 2022: 2-10% loneliness depending on country and age, doi.org/10.1136/bmj-2021-067068; **8.** Castillejos et al. 2020, Liu et al. 2020: 3-6% 12-months prevalence of suicidal ideation, doi.org/10.1017/S003329171900391X, doi.org/10.1080/13811118.2020.1765928; **9.** Faye et al. 2025, doi.org/10.70790/PDIR1346, Dubief et al. 2026, doi.org/10.70790/MHRE2026; **10.** Nguengang et al. 2020: https://doi.org/10.1038/s41431-019-0508-0; **11.** Eurostat SILC 2024: 69% good or very good health, ec.europa.eu/eurostat/databrowser/product/page/sdg_03_20; **12.** Eurostat SILC 2022: 13% (medical care) and 12% (medicines), https://ec.europa.eu/eurostat/databrowser/view/ilc_hch01__custom_21139489/default/table

Rare Barometer
A EURORDIS INITIATIVE

Rare Barometer is a not-for-profit survey initiative run independently by EURORDIS-Rare Diseases Europe. It conducts regular studies to identify the perspectives and needs of the rare disease community and be their voice within European and international initiatives and policy developments. Rare Barometer brings together a panel of more than 25,000 people living with a rare disease or family members to make the voice of the rare disease community stronger. Samples are self-selected and representativeness cannot be assessed as the characteristics of the rare disease population are largely unknown.