

Mental Health Toolkit

Supporting Mental Wellbeing
in the Bleeding Disorders Community

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Foreword

This toolkit has been developed by the [European Haemophilia Consortium \(EHC\)](#) to support mental health awareness and action across the bleeding disorders community. It draws on findings from the EHC Mental Health Survey, conducted in 2025 across EHC's 49 [member organisations](#), which returned responses from 27 countries and 325 respondents, including patients, carriers, and caregivers.

The toolkit is organised into four self-contained sections, each written for a specific audience. You do not need to read it in full. Find the section that applies to you and start there.

Section 1: For Patients and Carriers covers how to recognise mental health challenges, what you may be experiencing, and how to seek support.

Section 2: For Caregivers addresses the specific pressures of caring for someone with a bleeding disorder, including burnout and how to access help.

Section 3: For Healthcare Professionals provides practical guidance on recognising mental health needs in patients and caregivers, initiating conversations, and supporting access to care.

Section 4: For National Member Organisation (NMO) Staff and Advocates outlines how NMOs can strengthen mental health communication, peer support, and advocacy at the country level.

If you are an NMO integrating this toolkit into local programmes, the content in each section can be adapted, translated, and combined with country-specific resources as needed. To do so, contact EHC at office@ehc.eu for guidance and support.

Important Notice

This toolkit is intended for informational and educational purposes only. It does not constitute medical or psychological advice, and it is not a substitute for professional mental health assessment, diagnosis, or treatment.

If you are a patient, carrier, or caregiver, please speak with a qualified healthcare professional about any mental health concerns. The information in this toolkit is designed to help you recognise experiences and navigate support, not to replace clinical care.

If you or someone you know is in crisis or immediate distress, please contact a [crisis service](#) or [emergency services](#) in your country.

The EHC has taken care to ensure the accuracy of the information in this toolkit at the time of publication. However, support services, referral pathways, and clinical guidance vary by country and may change over time. NMOs are encouraged to verify and update local references before distribution.

This toolkit was developed based on [findings from the 2025 EHC Mental Health Survey](#) and published evidence in the bleeding disorders field. It has been reviewed by the [EHC Mental Health Working Group](#) and the [EHC Steering Committee](#). It does not represent the official clinical guidance of any national health authority.

Disclaimer

The name “European Haemophilia Consortium (EHC)” and the EHC logo are the exclusive property of the European Haemophilia Consortium. Any use of the name or logo must receive prior approval from the EHC Steering Committee. This rule entails all forms of publication, including print and digital formats. Reprinting, redistribution, or translation of any EHC publication is subject to the permission request. Requests for review and approval should be submitted to the EHC Communications Team at communications@ehc.eu in a timely manner.

Section 1: FOR PATIENTS AND CARRIERS

Understanding Your Mental Health

Living with a bleeding disorder affects more than your body. Managing treatments, navigating healthcare systems, planning around unpredictable symptoms, and carrying the uncertainty of a long-term condition all take a psychological toll that is real, valid, and worth taking seriously.

The [survey](#) conducted in 2025 by the EHC and its Mental Health Working Group found that 44% of respondents in the bleeding disorders community scored below the threshold for good mental wellbeing on the [WHO-5 Well-Being Index](#). You are not alone in finding this difficult.

Recognising What You May Be Feeling

Mental health challenges do not always look the way we expect. Below are three common experiences in the bleeding disorders community, with signs to help you recognise them in yourself.

Anxiety

Anxiety was the most commonly reported condition in the survey, affecting 28% of respondents.

You may be experiencing anxiety if you notice:

- Persistent worry about your health, treatments, or the future
- Difficulty relaxing or switching off, even when things are stable
- Physical symptoms such as a racing heart, tension, or difficulty sleeping
- Avoidance of situations that feel unpredictable or hard to manage

Burnout

62,9% of survey respondents reported high or very high levels of personal burnout. Burnout in the context of a chronic condition is a state of cumulative depletion — physical, emotional, and cognitive — arising from the unrelenting demands of living with an illness that offers no resolution.

You may be in burnout if:

- Rest doesn't restore you
- You're managing your illness on autopilot — or you've stopped managing it at all
- You've become patient first, person second
- Small things that used to be nothing now break you
- You feel flat rather than sad; not overwhelmed, just empty
- You can't imagine feeling different than you do right now

Depression

13% of respondents reported depressive symptoms. Depression is not simply feeling sad; it is a persistent low state that can affect your energy, concentration, relationships, and daily functioning.

You may be experiencing depression if you notice:

- Low mood lasting more than two weeks
- Loss of interest in things you previously enjoyed
- Feeling hopeless, worthless, or disconnected
- Changes in sleep, appetite, or ability to concentrate

What You Can Do

Talk to someone at your [haemophilia treatment centre \(HTC\)](#). You have the right to raise mental health concerns at your appointments. If your centre has a psychosocial professional, ask to be referred. If not, ask your care team who they would recommend.

Contact your [National Member Organisation \(NMO\)](#). Your NMO may offer mental health resources, peer support programmes, or referral guidance. Reach out to ask what is available in your country.



Know that access barriers are recognised. 54% of survey respondents reported difficulty accessing psychosocial support through their haemophilia centre. This is a systemic issue the EHC is actively working to address. Difficulty getting support does not mean support does not exist; it means you may need to ask more than once, or ask in more than one place.

Consider peer connection. Speaking with others who share your experience can reduce isolation and provide practical perspective. Ask your NMO whether a peer support network exists in your country.

A Note on Help-Seeking

Many people in chronic illness communities delay seeking mental health support because they feel their psychological struggles are less important than their physical ones, or because they worry about being seen as unable to cope. Neither of those things is true. Your mental health is part of your health, and addressing it is a legitimate and important part of your care.

SECTION 2: FOR CAREGIVERS

Your Wellbeing Matters Too

Caring for someone with a bleeding disorder is demanding. You carry practical responsibilities, emotional weight, and often a level of vigilance that does not switch off. This section is written for you, because 57,6% of the [EHC Mental Health Survey 2025](#) respondents reported work-related burnout, and caregivers are among those most at risk.

Recognising What You May Be Experiencing

Caregiver Burnout

Burnout in caregivers develops gradually. It is the result of sustained effort without adequate rest, recognition, or support. It is **not** a sign of failure. It is what happens when care has no edges.

You may be experiencing caregiver burnout if you notice:

- Rest doesn't restore you
- You feel things about the person you love that you can't say out loud
- The life you had outside caregiving has quietly shrunk
- You've stopped tending to yourself: your health, your body, your relationships
- You don't know who you are when you're not caring for someone else



Anxiety

Caregivers often experience anxiety related to the unpredictability of their loved one's condition, concern about future deterioration, and fear of making mistakes in care. Signs are similar to those listed in the patient section: persistent worry, physical tension, difficulty sleeping, and avoidance.

Secondary Traumatic Stress

Witnessing someone you love in pain or distress over time can produce a form of stress that resembles trauma. This may include intrusive thoughts, hypervigilance, or emotional shutdown. If this resonates, it is worth discussing with a mental health professional.

What You Can Do

Name your role at the [haemophilia treatment centre](#) (HTC). When your family member attends their haemophilia treatment centre, you are part of the picture. Ask the care team directly whether support is available for caregivers, not only for patients.

Contact your [National Member Organisation](#) (NMO). 49% of survey respondents were unaware whether their NMO promotes mental health initiatives. It is worth asking directly, since support may exist but not be widely communicated.

Set boundaries with yourself. Burnout is partly managed by recognising that sustained caregiving without recovery time is not sustainable. This is not a moral failing; it is a physiological and psychological reality.

Seek peer connection. Other caregivers in the bleeding disorders community understand your specific experience in ways that general support groups may not. Ask your NMO whether caregiver peer networks exist.

Prioritise your own healthcare appointments. Caregivers often deprioritise their own health. Your wellbeing directly affects your capacity to care for others.

SECTION 3: FOR HEALTHCARE PROFESSIONALS

Integrating Mental Health into Bleeding Disorder Care

The [EHC Mental Health Survey 2025](#) found that 44% of respondents in the bleeding disorders community scored below the [WHO-5 threshold](#) for good mental wellbeing, and 54% reported difficulty accessing psychosocial support through their haemophilia treatment centre. These findings indicate a significant and largely unmet need within the populations you serve.

This section provides practical guidance for recognising mental health needs, initiating conversations, and supporting patients and caregivers in accessing appropriate care.

Why This Matters in Your Setting

People with bleeding disorders face elevated mental health risks compared with the general population. In haemophilia, for instance, a systematic review and meta-analysis found an odds ratio of 2.45 for depressive symptoms and 1.74 for anxiety disorders ([Al-Huniti et al., Haemophilia, 2020](#)). Despite this, psychosocial care remains inconsistently integrated within comprehensive care pathways across Europe.

Burnout is also prevalent: 62,9% of EHC Mental Health Survey respondents reported high or very high personal burnout. This is not incidental to the condition; it is a predictable consequence of long-term disease management, treatment burden, and systemic access challenges.

Recognising Mental Health Needs in Your Patients and Their Caregivers

Not all patients will raise mental health concerns unprompted. Watch for:

- Declining engagement with treatment plans or appointments
- Reports of persistent fatigue that cannot be explained by the physical condition alone
- Changes in affect, withdrawal, or irritability across visits
- Expressions of hopelessness about the condition or future quality of life
- Caregivers appearing exhausted, distressed, or disengaged

Starting the Conversation

A brief, non-judgmental check-in can open the door. Consider language such as:

“Managing a condition like this long-term can be hard in ways that go beyond the physical. How have you been feeling in yourself lately?”

Or for caregivers:

“We focus a lot on [patient name]’s needs in these appointments. I also want to ask how you are doing.”

You do not need to be a mental health specialist to ask. Your role is to create an opening, not to provide therapy.



Screening

The [WHO-5 Well-Being Index](#), which was used in the EHC survey, is a validated, brief, and freely available tool that can be incorporated into routine appointments. A score below 50 suggests poor wellbeing and warrants follow-up. Routine use of a validated screening tool normalises mental health as part of comprehensive care.

Referral and Support Pathways

- If your centre has a psychosocial professional, ensure patients and caregivers know how to access them and that referral is offered proactively, not only in crisis.
- If your centre does not have an embedded psychosocial professional, establish a referral pathway to external services and communicate it clearly to patients.
- Provide patients with their [National Member Organisation’s](#) (NMO’s) contact details and encourage them to ask about mental health resources.
- Document mental health concerns in patient records so they are visible across the care team.

Advocating for Systemic Change

Individual clinical action matters, but so does structural integration. Consider advocating within your institution for routine mental health screening, inclusion of psychosocial professionals in multidisciplinary teams, and staff training on chronic illness psychology. The EHC survey findings provide an evidence base to support that case.

SECTION 4: FOR NMO STAFF AND ADVOCATES

Your Role in Mental Health Support

National Member Organisations (NMOs) are often the closest point of contact between the bleeding disorders community and the support it needs. Yet 49% of [EHC Mental Health Survey 2025](#) respondents were unaware whether their NMO promotes mental health initiatives. This gap between what organisations may offer and what members actually know is itself an area for action.

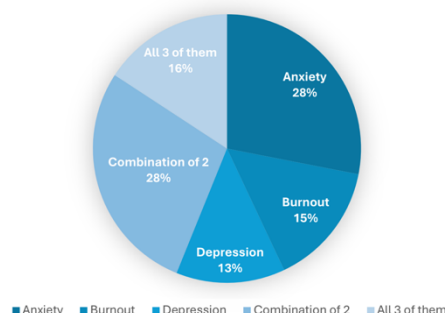
Understanding the Landscape of Need

The EHC survey found:

- 44% of respondents scored below the [WHO-5 threshold](#) for good mental wellbeing
- 62,9% reported high or very high personal burnout
- 57,6% reported work-related burnout
- 54% reported difficulty accessing psychosocial support through their haemophilia centre
- Anxiety was the most prevalent self-reported condition (28%), followed by burnout (15%) and depression (13%)

These findings offer a clearer picture of what many people across our community are living with. They can be a useful starting point for reflecting on where mental health support fits within your organisation's work, and how it is communicated to members.

Have you ever been diagnosed with any of the following by a healthcare professional ?



Practical Actions for NMOs

Communicate What You Offer

If your NMO has mental health resources, peer support programmes, or referral pathways, make them visible. Website pages, newsletters, event communications, and social media should all reference mental health support clearly and regularly. Do not assume members will find this information on their own.

Build or Strengthen Peer Support

Peer support is one of the most accessible forms of psychosocial support for chronic illness communities. If your NMO does not yet have a peer support programme, consider piloting one, even informally, through facilitated online groups or trained peer volunteers.

Reduce Stigma Through Normalisation

Include mental health as a standing agenda item in member communications, not only during awareness campaigns. When mental health is treated as an ordinary part of health, members are more likely to seek support without shame.



Engage Under-Represented Groups

People with ultra-rare bleeding disorders, members in less-connected regions, and those who are not active in community networks may face compounded isolation and reduced access to support. Targeted outreach to these groups, through partnerships with [haemophilia treatment centres](#) (HTCs), rare disease networks, or translated materials, is an important equity consideration.

Use the EHC Survey Findings in Advocacy

The data provides a documented evidence base. Use it in conversations with health ministries, payers, and healthcare institutions to advocate for integrated psychosocial care, routine screening at HTCs, and funded support pathways. You are encouraged to reach out to the [EHC](#) for support with your advocacy efforts.

Localise This Toolkit

This toolkit is designed to be adapted. Translate it, adjust references to local support systems, and add country-specific resources so it is actionable for your members rather than generic.

Measuring Impact

If you implement any of the above, track it. Record how many members access peer support, how many enquiries your NMO receives about mental health resources, and how communications about mental health affect engagement. This data will strengthen future advocacy and help the broader EHC network learn what works.