

Mental Health in Bleeding Disorders: What the Data Tells Us

A cross-community survey of patients, carers, carriers, partners, and families, revealing the psychological burden, unmet support needs, and pathways towards better care.

325
RESPONDENTS

44%
LOW WELLBEING
(WHO-5 INDEX)

54%
NO EASY ACCESS
TO PSYCH SUPPORT

158
LIVING WITH
CHRONIC PAIN

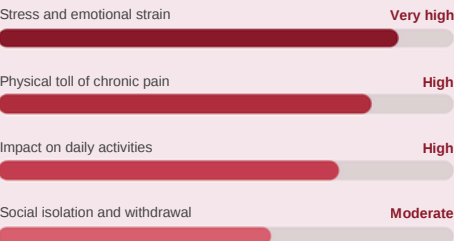
EMOTIONAL BURDEN

People with bleeding disorders and their families carry a substantial psychological load, often invisible to healthcare providers and underrepresented in clinical consultations.

Anxiety Stress Isolation Uncertainty
Emotional Pressure

44% scored in the low wellbeing range on the WHO-5 Index

Chronic pain reported by 158 respondents, compounds this toll, creating a reinforcing cycle of physical and psychological distress.



FAMILIES AND CONVERSATIONS

The impact extends far beyond the individual. Families bear significant worry, responsibility and fatigue, yet their psychological needs often go unrecognised.

Responsibility Worry Uncertainty Fatigue

Many respondents were unsure whether their National Member Organisation (NMO) actively promotes mental wellbeing, highlighting a critical gap in communication and outreach.

Open conversations about mental health remain a significant barrier. Psychological concerns are rarely addressed in routine clinical consultations.

Key opportunities:

- NMOs to actively promote mental health literacy and signposting
- Routine mental health screening in all bleeding disorder clinics
- Family-inclusive support programmes and carer burden recognition
- Training clinicians to initiate mental health conversations

SUPPORT AND COMMUNITY

Respondents identified clear priorities for support. Psychological care leads, but peer community connection is equally vital for sustained wellbeing.

Top support needs (respondents):



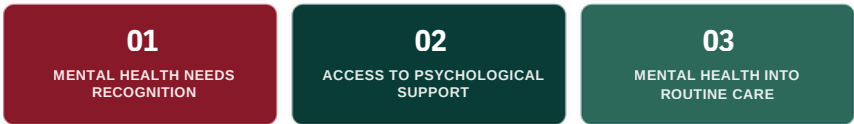
54% have no easy access to psychological support

Access to peer networks and shared lived experience measurably reduces isolation and improves long-term mental health outcomes.

Towards Integrated Mental Health Care in Bleeding Disorders

Embedding psychological support at every stage of the care pathway

A COMPREHENSIVE CARE FRAMEWORK



Comprehensive care means addressing the whole person — physical, psychological, and social. These three pillars provide a framework for NMOs, clinicians, and policymakers to close the gap between current practice and community needs.



More than half of respondents lack access to psychological support, a gap that must be urgently addressed by healthcare systems and patient organisations.

THE CASE FOR CHANGE

Mental health is not a secondary concern in bleeding disorders, it is central to quality of life, treatment adherence, and long-term outcomes for patients and their families.

This survey sends a clear message: the psychological dimension of bleeding disorders is **systematically underserved** across Europe.

NMOs, clinicians, and policymakers have a shared responsibility to make psychological support as routine as physiotherapy or prophylaxis.

- Integrate mental health screening into haemophilia treatment centres
- Fund peer support and community-based programmes
- Make psychological care a core pillar of every care plan