The physical impact of haemophilia greatly influences quality of life

Many people with haemophilia are in constant pain

HERO (Haemophilia Experiences, Results and Opportunities) is an international, multifaceted, multidisciplinary initiative that aims to deepen understanding of life with haemophilia.
Frequent or chronic pain has an impact on quality of life for many people with haemophilia (PWH).

**Most PWH experience pain that affects daily life**
According to the HERO study results, most PWH experience pain that interferes to some extent with their daily lives. Only one in 10 PWH said they had not experienced any pain in the past four weeks that had impacted on their daily lives.\(^1\)

**Chronic pain places a significant burden on many PWH**
Half of PWH affected by pain are in constant pain (regardless of whether it was linked to their haemophilia).\(^1\) Over a third of PWH in the HERO study experienced chronic pain related to their haemophilia.\(^2\)

Find out more at [herostudy.org](http://herostudy.org)

---

Haemophilia can place a physical and psychological burden on people with haemophilia and their parents

Few receive treatment for psychological or psychiatric conditions

HERO (Haemophilia Experiences, Results and Opportunities) is an international, multifaceted, multidisciplinary initiative that aims to deepen understanding of life with haemophilia.
Haemophilia is often associated with co-morbidities, including both physical and psychological conditions.

**Haemophilia has a physical impact**

The HERO study utilised a standardised questionnaire to assess the health status of people with haemophilia (PWH). Nearly two thirds of PWH reported having **limited mobility**, and almost half experienced **limitations with usual activities**.

**Haemophilia has a psychological impact**

The HERO study showed that many PWH and parents experience **psychological/psychiatric conditions**, due to the impact of haemophilia, yet few receive treatment.

Find out more at herostudy.org

---


---

**THERE IS A NEED FOR GREATER PSYCHOLOGICAL SUPPORT FOR PWH AND PARENTS**

- **47%** PWH have reported having psychological/psychiatric conditions
- **22%** PWH have received treatment for their psychological/psychiatric conditions
- **24%** Parents have received psychotherapy or counselling to help cope with their son’s haemophilia
- **33%** Parents would have liked to (but did not) receive psychological support

---

Changing Haemophilia™ is a registered trademark owned by Novo Nordisk Health Care AG and the Apis bull logo is a registered trademark of Novo Nordisk A/S. - HQMMA/CH4/015/0120(1) – Preparation date: November 2015
People with haemophilia may face challenges in forming relationships

Haemophilia influences the quality of sexual intimacy

HERO (Haemophilia Experiences, Results and Opportunities) is an international, multifaceted, multidisciplinary initiative that aims to deepen understanding of life with haemophilia.
Relationships are affected by haemophilia in various ways, particularly in terms of disease burden, age and social life.

Haemophilia impacts the formation of close relationships

Over one third of adults with haemophilia and parents of children with haemophilia felt that haemophilia impacted their ability to develop close relationships. The main reasons for this were worry about the impact haemophilia in future years and the ability to support a family.1

Supportive relationships

According to the results of the HERO study, most people with haemophilia (PWH) and parents were married or in long-term relationships and were satisfied with support from partners and family.1 PWH may, however, face challenges in developing relationships with prospective partners. PWH also report that haemophilia affects the quality of their sex lives.2

Find out more at herostudy.org

People with haemophilia and parents are educated and working but haemophilia challenges job options

HERO (Haemophilia Experiences, Results and Opportunities) is an international, multifaceted, multidisciplinary initiative that aims to deepen understanding of life with haemophilia.
People with haemophilia (PWH) and parents experience employment challenges.

**Employment decisions take haemophilia into account**

The HERO study showed that most PWH and parents had received formal education and the majority were employed.¹ Many PWH and parents select their jobs taking into account their/their son’s haemophilia needs, yet many felt that current treatments enabled them to work in most situations.²

**Haemophilia can negatively affect employment**

More than half of PWH and parents reported a negative impact of haemophilia on working life and some believe they have lost a job because of haemophilia.¹

Find out more at herostudy.org

---

Most parents feel supported by their social contacts

Lack of knowledge is a common source of dissatisfaction

HERO (Haemophilia Experiences, Results and Opportunities) is an international, multifaceted, multidisciplinary initiative that aims to deepen understanding of life with haemophilia.
People with haemophilia (PWH) and parents generally feel well supported, although many have experienced negative reactions following disclosure.

**Parents feel well supported**
According to the results of the HERO study, three quarters of parents felt they had the support of other children/classmates, with even greater levels of support from teachers and other adults with regular contact. PWH and parents disclose haemophilia to most social contacts, with friends and teachers being most confided in.

**Dissatisfaction often linked to a lack of knowledge**
The most common reason among parents for dissatisfaction with support was a lack of knowledge. Nearly a third of PWH and slightly more parents reported a negative experience or reaction following disclosure.

Find out more at herostudy.org
There is considerable country variation with regards to access to care and treatment at home.

HERO (Haemophilia Experiences, Results and Opportunities) is an international, multifaceted, multidisciplinary initiative that aims to deepen understanding of life with haemophilia.
Access to haemophilia care varies worldwide.

**Access to replacement factor varies globally**
According to the HERO study, nearly half of people with haemophilia (PWH) and one third of parents worldwide reported difficulties in obtaining replacement factor within the last five years. The most common reasons for this difficulty were lack of supply, issues with health insurance and personal finance problems.

**Access to haemophilia treatment centres varies globally**
Based on results of the HERO study, over half of all PWH and parents found accessing the haemophilia treatment centre easy. Although most PWH worldwide are treated at home, almost one quarter rely on the haemophilia clinic/hospital for treatment.

Find out more at herostudy.org