Haemophilia Society
of Singapore

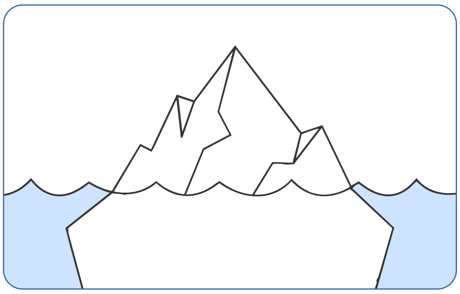
Living with Haemophilia in Singapore

Care, Lived Experiences & Outcomes

An inaugural study exploring the lived experiences of people with haemophilia (PwH) and their caregivers

Singapore has made significant progress in haemophilia management, driven by policy advancements, clinical expertise, and therapeutic innovation. What was once a life-threatening diagnosis is now a treatable chronic condition.

Today, the community's aspirations reach further – towards a definition of care that includes the **holistic needs** of PwH and their families in Singapore.



The Resilience Burden Iceberg

80% of PwH maintain high adherence to their prescribed treatment plan. Beneath this visible dedication lies a constant, often unseen effort: managing breakthrough bleeds, joint complications, and the daily demands of a lifelong condition. For caregivers, this extends to ongoing treatment support, monitoring, and constant vigilance.

The Physical Toll

50%

of PwH are uncomfortable self-infusing; **20% do not adhere to their preventive treatment.**

85% report bleeding episodes in the past year; nearly half requiring hospital care.

Average of **6 breakthrough bleeds per year**, despite consistent preventive treatment.

70% live with joint-related symptoms affecting mobility and independence.

The Psychosocial Weight

1 in 3

PwH report significant impact on their mental wellbeing, daily lives and work.

Of these, **nearly half (45%) struggle with mood and self-worth**.

And **33% have missed work days** or stopped working entirely due to their condition.

30% of all respondents **fear long-term dependence on subsidies**.

The Shared Burden

1 in 2

caregivers struggle with mental, social, and career burdens.

31% report chronic anxiety from worrying about their loved one.

25% reduce working hours to care for their loved one.

S$7,004: The average annual cost of care per PwH **excluding the cost of medication.***

**Please refer to the full report for a breakdown of these costs. At the time of the study, the ongoing cost of haemophilia medication was S$6,000 per annum. As enhancements to MediShield Life and MediSave coverage have since come into effect, this number may no longer be representative and is thus excluded from the report.*

Interplay of Gratitude and Aspiration

Nearly 90% of PwH consider their current treatment effective. Yet nearly one in three respondents still express a desire to switch. For PwH, the ideal treatment offers greater flexibility, more stable protection, and peace of mind.

Top Reasons for Switching
(among Type A PwH on treatment)

1. Breakthrough bleeds despite regular preventative treatment
2. Inconvenient injection frequency

Ideal Treatment

- Reduces long-term complications and provides peace of mind
- Easy and non-invasive to administer
- Fits daily life with minimal disruption to school and work

Living with Confidence and Thriving

Our aspiration is simple: that PwH and their families may one day achieve a **"haemophilia-free mind"** and move to a life where they can participate fully and contribute meaningfully to Singaporean society.

Less Mental Load

Shifting the focus from managing bleeds to living fully so that fear no longer limits daily choices.

Stronger Support Systems

Embedding counselling and peer support directly into haemophilia care pathways.

Confident, Active Living

Enabling PwH and their families to participate fully and contribute their potential to Singaporean society.

Read the full report:

This study was led by HSS, conducted by Blackbox Research and supported by Roche.