Women & Bleeding Disorders Committee

EHC

10 Facts about Women with Bleeding Disorders

Ready-to-use evidence-based advocacy toolkit

1. Menstruation is a recurring bleeding challenge
Women experience around **450 menstrual cycles during their lifetime**, each presenting haemostatic challenges of ovulation and menstruation. | *van Galen et al., Haemophilia, 2021*

2. Diagnosis is often delayed for years
Women and girls with bleeding disorders experience a median diagnostic delay of **8–16 years**.
van Galen et al., Haemophilia, 2021

3. Heavy menstrual bleeding (HMB) can be a sign of an underlying bleeding disorder
Around **1 in 5 women presenting to a gynaecologist with HMB have an underlying bleeding disorder**.
van Galen et al., Haemophilia, 2021

4. Most girls with heavy menstrual bleeding are not tested for bleeding disorders
In a large US study, only **16% of girls with severe HMB were screened for von Willebrand Disease**.
Jacobson et al., Obstet Gynecol, 2018

5. Haemophilia carriers can have significant bleeding symptoms
Being a carrier does not mean being unaffected. **Heavy menstrual bleeding occurs in around 64% of haemophilia carriers.** | *Weyand et al., Haemophilia, 2022*

6. Heavy menstrual bleeding can lead to iron deficiency
HMB in women and girls with haemophilia can lead to **iron deficiency with or without anaemia**.
Weyand et al., Haemophilia, 2022

7. Women with bleeding disorders are at risk of postpartum haemorrhage
Pregnancy, delivery and the postpartum period are critical times for women with bleeding disorders and require appropriate planning and specialist care. | *van Galen et al., Haemophilia, 2021*

8. Women are underrepresented in haemophilia research
80% of studies analysed offered recruitment only to males or children. Of 22 studies open to females, only three reported recruiting women over 12 years of age. | *O'Donnell et al., Haemophilia, 2025*

9. Bleeding disorders affect quality of life
HMB is associated with **poor quality of life, work and school absence, reduced sports participation, and impacts on sexual and reproductive functioning**. | *van Galen et al., Haemophilia, 2021*

10. Access to multidisciplinary care remains limited
A survey of 59 European haemophilia treatment centres found that **58% did not offer combined gynaecology/haematology clinics**. | *van Galen et al., Haemophilia, 2020*

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