# Managing teenagers and adolescents with haemophilia

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# Disclaimer

- The **Factor Think Tank** is an educational activity funded by Sobi™
- This document is intended as a resource supporting communication to engage discussion on the **need for a specific approach to managing teenagers and adolescents with haemophilia**
- Information presented herein is based on an article in *Journal of Clinical Medicine*,[1] and has been prepared by the authors, who are also **experts** in the **Factor Think Tank**, and supported by Sobi™
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1. Königs C, et al. J Clin Med. 2024;13:5121.

# Teenagers and adolescents with hemophilia – need for a specific approach

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# Managing haemophilia in adolescents

Adolescents (10–24 years) with haemophilia pose **unique management challenges** and are at high risk of complications due to **low adherence, psychological impact** of the disease and a **desire to fit in** with their peers

## Suggested solutions to management challenges in adolescents with haemophilia

### Prevention and management of bleeds

- Individualisation and personalisation of prophylaxis
- Educate on bleed recognition and the consequence of bleeds
- Promote self-advocacy and self-care management

### Treatment adherence

- Aid the transition of shared decision making to adolescents from the parent/caregiver
- Educate on how treatment choice can aid lifestyle during early adolescence
- Provide support on barriers related to treatment adherence

### Physical activity and health-related issues

- Provide guidance and promote participation in physical activities
- Provide psychosocial support on self-esteem and/or sexual activity concerns
- Provide multidisciplinary care

### Comprehensive care and communication

- Support in the transition to adult healthcare centres
- Utilise digital technology to communicate with patients
- Encourage face-to-face meetings and consider ways to promote these

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# Challenges in managing adolescents

- Adolescent years (covering ages 10–24) are a challenging period of transition, especially for those with haemophilia[1–4]
- As well as changes to body composition and rapid growth, other changes, including lifestyle, can affect treatment expectations and therapeutic decisions[1]
- Adolescent patients can be at high risk of haemophilia-related complications due to:

**Low adherence[5,6]**

**Psychosocial impact of the disease[6]**

**Desire to fit in with peers[1]**

**Perceived idea that treatment is no longer needed[5,6]**

- HCPs must approach the management of adolescents with **specific considerations** and highlight the benefits of **continuing effective treatment** received during childhood, as appropriate[1]
- To best inform **shared decision making**, HCPs must appreciate the requirements of all adolescents affected by haemophilia, including individuals with **non-severe disease** and **girls/women**[1]

HCP, healthcare professional

1. Königs C, et al. J Clin Med. 2024;13:5121; 2. Brand B, et al. J Haematol. 2015;95(Suppl. 81):30–35; 3. Quon D, et al. Am J Hematol. 2015;90(Suppl. 2):S17–S22; 4. Young G. Haemophilia. 2012;18(Suppl. 5):27–32; 5. Hoefnagels JW, et al. Patient Prefer Adherence. 2020;14:163–71; 6. Lee Mortensen G, et al. Haemophilia. 2018;24:862–72.



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# Prevention and management of bleeds

**Changes in body composition due to rapid growth, and changes in lifestyle may impact treatment choice**[1]

**Personalised prophylactic regimen**, considering personal goals and lifestyle[1,2]

**Due to treatment effectiveness, bleed symptoms may be unfamiliar for many adolescents**[1,3,4,5]

**Regular education on bleed recognition and early treatment**, with awareness on **changes during adolescence** and impact on bleed management[1,4]

**Adolescents start to self manage their condition and rely less on parent/caregiver support**[6,7]

**Educate and train adolescents** on **self-care management** and encourage their **increased involvement** in haemophilia over time[1,2]

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1. Königs C, et al. J Clin Med. 2024;13:5121; 2. Srivastava A, et al. Haemophilia. 2020;26:1–158; 3. Quon, D et al. Am J Hematol. 2015;90(Suppl. 2), S17–S22; 4. Young G, et al. Haemophilia. 2012;18:27–32; 5. Lee Mortensen G, et al. Haemophilia. 2018;24:862–72; 6. Schrijvers LH, et al. Haemophilia. 2016;22:499–506; 7. Hoefnagels JW, et al. Patient Prefer Adherence. 2020;14:163–71.

# Treatment adherence

**Low adherence due to self-management concerns increases the risk of bleeding, joint damage and pain**[1–4]

**Lack of experience of treatment benefits can lead to questioning the necessity of prophylaxis**[3,5]

**Desire to fit in with peers can result in neglecting long-term health goals**[6]

**Discussion on personal goals** and benefits of treatment **beyond bleed protection**[7]

**Education** on prophylactic treatments **before puberty** and **adapting treatment** to their evolving lifestyle[7,8]

Transition to **shared decision making** with adolescents rather than parents/caregivers[7]

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1. Richter D, et al. In: Proceedings of the Annual Meeting of the Society of Thrombosis and Hemostasis (GTH), Basel, Switzerland, 16 February 2017; 2. Srivastava A, et al. Haemophilia. 2020;26:1–158; 3. Hoefnagels JW, et al. Patient Prefer Adherence. 2020;14:163–71; 4. McLaughlin JM, et al. Haemophilia. 2014;20:506–12; 5. Young G. Haemophilia. 2012;18(Suppl. 5):27–32; 6. Russo K. J Health Serv Psychol. 2022;48:6978; 7. Königs C, et al. J Clin Med. 2024;13:5121; 8. Pertrini P, et al. Haemophilia. 2009;15:15–9.

# Joint health and physical activity

**Even few joint bleeds can lead to synovitis and arthropathy, which may require lifelong treatment**[1,2]

**Regular exercise contributes to healthier joints, better QoL and reduces the risk of bleeds**[6–9]

**Due to parental or other restrictions, participation is often limited to non-contact sports**[1,7,10,11]

**Musculoskeletal ultrasound** can detect joint damage and **early changes** reinforcing the value of **early prophylaxis**[1,3–5]

Highlight benefits of physical activity and promote **participation**[1]

**Physiotherapists** can provide guidance on **physical activity-related queries** and the **preparation** required to **avoid injuries**[1]

QoL, quality of life.

1. Königs C, et al. J Clin Med. 2024;13:5121; 2. Rodriguez-Merchan EC, et al. Haemophilia. 2011;17:1–23; 3. Manco-Johnson MJ, et al. Blood. 2018;129:2368–74; 4. Oldenburg J, et al. Haemophilia. 2015;21:171–9; 5. Mancuso ME, et al. Haemophilia. 2023;29:619–28; 6. Fromme A, et al. Haemophilia. 2007;13:323–27; 7. Srivastava A, et al. Haemophilia. 2020;26:1–158; 8. Tiktinsky R, et al. Haemophilia 2002;8:22–7; 9. Harris S, Boggio LN. Haemophilia 2006;12:237–40; 10. Moretti L, et al. Current Trends Children. 2021;8:1064; 11. Schoenmakers MA, et al. Haemophilia 2001;7:293–8.



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# Other health-related issues

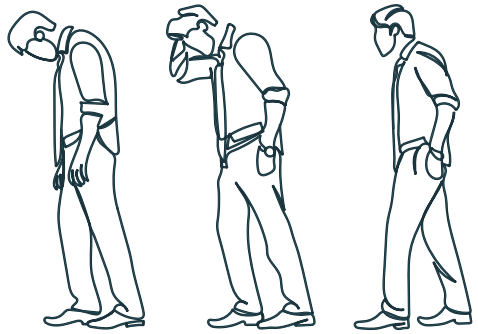
**Bleeding episodes can impact school attendance and social situations**[1]

Support adolescents to **overcome barriers to treatment adherence**, engage with treatment and learn to manage their condition **independently**[1,2]

**Concerns about sexual desirability and performance; some noted muscle and joint bleeding due to physical exertion**[3–5]

**Open conversations** about strategies to overcome **musculoskeletal complications** and **address psychosocial concerns**[1,3–5]

**Some report lower self-esteem than healthy individuals**[1,6]



**Psychosocial support**, via psychologists/social workers, **peer support** and **empowerment to self-manage**[1,2,6,7]

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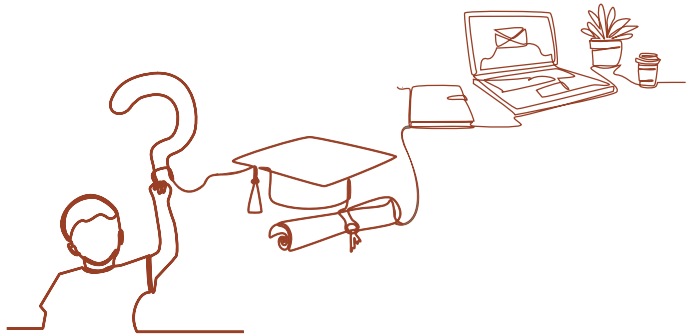
1. Königs C, et al. J Clin Med. 2024;13:5121; 2. Srivastava A, et al. Haemophilia. 2020;26:1–158; 3. Parish KL. Haemophilia. 2002;8:353–59; 4. Blamey G, et al. Patient Relat Outcome Meas. 2019;10:243–55; 5. Banchez A, et al. Acta Biomed. 2023;94:e2023003; 6. Aydin Koker S, et al. J Pediatr Hematol Oncol. 2020;42:e159–e163; 7. van Os S, et al. Health Psychol. Behavi Med. 2020;8:55–72.

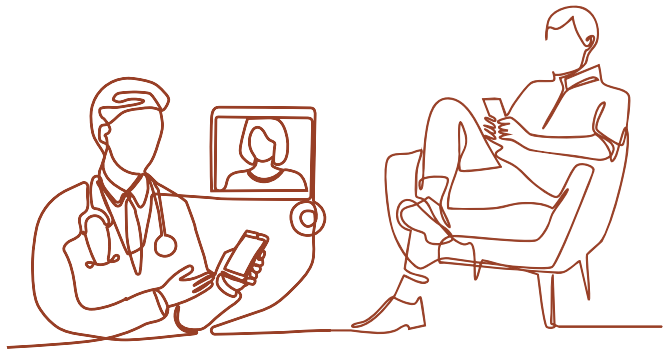
# Comprehensive care and communication

**Some may feel uncertain around the transition to adult healthcare and feel lost in the switch**[1–4]

**Concerns about future life and career due to perceived and imposed barriers**[2]



**Many may prefer information via a website or app than in-person communication alone**[1,6]



**Close cooperation** between **paediatric and adult healthcare centres** can ensure a smooth transition[5]

**Social law counselling, interview training** and **online resources** can help patients prepare for the future[1,2]

HCPs can leverage **online resources** and **use the** latest technologies **(florio HAEMO, WAPPS-Hemo)** to complement **face-to-face meetings**[1,7,8]

HCP, healthcare professional; WAPPS, Web-Accessible Population Pharmacokinetic Service-Hemophilia.

1. Königs C, et al. J Clin Med. 2024;13:5121; 2. Bidlingmaier, C et al. Haemostaseologie. 2020;40:97–104; 3. Gray WN, et al. J Pediatr Psychol. 2018;43:488–502; 4. Brand B, et al. Eur J Haematol. 2015;95:30–35; 5. Quon D, et al. Am J Hematol. 2015;90:S17–S22; 6. Low JK, et al. JMIR Mhealth Uhealth. 2019;7:e12042; 7. Zapotocka E, et al. Res Pract Thromb Haemost. 2022;6:e12685; 8. Iorio A, et al. JMIR Res Protoc. 2016;5:e239.



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