

1. Advice for young people moving away from home

- 2. Register with a local GP:** When you arrive at your new location, find and register with a local General Practitioner (GP). This ensures you have access to routine and emergency care. Share your medical history, including details about your bleeding disorder and treatment plan, with your new GP.
 - Emergency Care:** Familiarise yourself with the nearest hospital and its emergency services. Always carry information about your condition and treatment in case of an emergency.
 - Stay Connected:** Maintain contact with the NCC, let us know your new address and details of your new GP so we can ensure your GP has all necessary documentation about your bleeding disorder.
 - Moving abroad:** If you plan to move abroad to work or study, please let us know so we can link you in with a comprehensive care centre in that country who can manage your bleeding disorder while you are living away from Ireland.
- transition. Remember, your health care team is here to support you every step of the way.

Conclusion

- Transitioning to adult care is a crucial step in managing your bleeding disorder. By preparing early, building your knowledge, and staying organised, you can ensure a smooth and successful transition. Remember, your health care team is here to support you every step of the way.

Contact Information

Emergency Contact Details : in relation to an active bleed or possible bleed or an urgent unplanned procedure , Mon to Fri 0800-1700- please call: 014103129 or 01-4103000 and ask for bleep 721

Out of Hours' service : After 17:00 hours on week-days, at weekends and on bank holidays please contact the H&H inpatient Ward on 014103132 .

A nurse will carry out a telephone triage, and assess if you need to attend the H&H assessment unit, your local emergency department or SJH Emergency Department.

The nurse will inform the Haematology SHO 'on-call' of your attendance. A review will be done as soon as possible upon arrival to SJH.

Please always carry your Bleeding Disorder ID Card in case of emergency.

Transitioning from paediatric to adult health care for adolescents and young adults with bleeding disorders

Patient Information Leaflet



National Coagulation Centre St James's Hospital

Welcome

Transitioning from paediatric to adult health care is an important step in managing your bleeding disorder. This guide will help you prepare for a smooth transition and introduce you to the services available in the National Coagulation Centre (NCC) in St James's Hospital.

Why Transition to Adult Care?

As you grow older, your medical needs change. In the NCC we are specialists in treating adults with bleeding disorders and can provide you with the most appropriate care. Transitioning to adult care ensures you continue receiving the best possible treatment and support.

Making transition to adult care easier

Understand Your Condition: Learn about your type of bleeding disorder, how it affects you, and the treatments you need.

Know Your Medications: Know the names, dose, and schedules of your medications. Understand how to administer them yourself if necessary.

Recognise Symptoms: Be aware of signs of bleeding and know when to seek medical help.

Schedule Appointments: Start managing your own health appointments.

Maintain Records: Keep track of your medical history, treatment records, and emergency contact information.

Communicate Openly: Share any concerns or changes in your condition with your care team. Contact us if you are due to have a procedure.

Participate Actively: Be proactive in your care by following the advice and treatment plans provided by your multidisciplinary team.

The Transition Process

1. Transfer Records: Your medical records are transferred to the National Coagulation Centre by your paediatric team. The paediatric and adult teams meet to discuss your transfer of care before your first appointment.

2. Ongoing Communication: Maintain regular communication with your new care team. Update them on any changes in your condition.

Meet the team in the NCC

Clinical Nurse Specialists provide education on management of your bleeding disorder, assist with treatment plans, and administer treatments. They are available for questions and guidance on daily management of your condition.

Doctors oversee your treatment plan, monitor your condition, and prescribe treatment as needed. They conduct

Dentists manage oral health which is important for preventing bleeding complications during dental procedures. They provide specialized care for some people with bleeding disorders and advice to your local dentist if needed.

Physiotherapist will review you, as appropriate, depending on your bleeding disorder. They can offer physical therapy sessions and guidance on safe physical activities.

Social Workers can provide resources for coping with social and financial aspects of living with a bleeding disorder if required.

Psychologists are available to offer counselling and mental health support to help manage the emotional challenges of living with a bleeding disorder if needed.

Additional Services

Orthopaedic clinics are run in conjunction with the NCC to offer surgical review as required in the management of joint problems associated with some bleeding disorders.

- **Pain management clinic** is available to access specialists who can help manage chronic pain associated with some bleeding disorders.

- **Gynaecology** referrals are also available. They can assist with managing menstrual bleeding especially important for women with bleeding disorders.