Scottish Inherited Bleeding Disorders Network (SIBDN)

Guidance for Transitional Care of Children and Young People with Bleeding Disorders

NOTE
This guidance is not intended to be construed or to serve as a standard of care. Standards of care are determined based on all clinical data available for an individual case and are subject to change as scientific knowledge and technology advance and patterns of care evolve. Adherence to guidance recommendations will not ensure a successful outcome in every case, nor should they be construed as including all proper methods of care or excluding other acceptable methods of care aimed at the same results. The ultimate judgement must be made by the appropriate healthcare professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan. This judgement should only be arrived at following discussion of the options with the patient, covering the diagnostic and treatment choices available. It is advised, however, that significant departures from the national guidance or any local guidance derived from it should be fully documented in the patient's case notes at the time the relevant decision is taken.

This document has been prepared by NHS Public Services Delivery Scotland (NSDS) on behalf of the Scottish Inherited Bleeding Disorders network (SIBDN). Accountable to Scottish Government, NSDS works at the heart of the health service providing national strategic services to the rest of NHS Scotland and other public sector organisations to help them deliver their services more efficiently and effectively. SIBDN is a collaboration of stakeholders involved in the care of patients with inherited bleeding disorders, who are supported by a Programme Team to drive improvement across the care pathway.

©PSD Scotland 2026. You can copy or reproduce the information in this resource for use within NHS Scotland and for non-commercial educational purposes under creative commons CC BY-NC 4.0 Deed | Attribution-Non Commercial 4.0 International | Creative Commons. Use of this document for commercial purposes is permitted only with the written permission of PSD Scotland.
Approved: October 2025
Review: October 2028
NSD610-030.01 V1
Unless this guidance is being accessed from nn.nhs.scot/sibdn/, it may not be the current version.

Authors	SIBDN Steering Group members (adapted from NHS Lothian transition document with their permission).
Stakeholders involved	• Haematology Oncology Risk Management Group • Haemophilia Treatment Centre • Consultant Paediatric Haematologists • Consultant Haematologists • Paediatric/ Adult Haematology Nurse Specialists • Physiotherapists • Psychology
Methodology used	• Literature search • Review of evidence • Engagement with key stakeholders • Guidelines drafted with review date • Submitted to Steering Group (see appendix 1) for comment then approval
Rationale	The network was established to support and develop bleeding disorders services throughout Scotland in improving standards of clinical care for patients. The network supports the delivery of evidence based, patient centred care through the development and implementation of clinical guidance, care pathways and information resources utilising a once for Scotland approach.
Scope	To be used by all trained staff (nursing, medical, physiotherapy and psychology) for the management of children and young people who have inherited bleeding disorders transitioning to adult services.
Approval process	The guideline was approved by the SIBDN Steering Group on 29 October 2025. See appendix 1 for list of Steering Group members.

Authors	SIBDN Steering Group members (adapted from NHS Lothian transition document with their permission).
Stakeholders involved	• Haematology Oncology Risk Management Group • Haemophilia Treatment Centre • Consultant Paediatric Haematologists • Consultant Haematologists • Paediatric/ Adult Haematology Nurse Specialists • Physiotherapists • Psychology
Methodology used	• Literature search • Review of evidence • Engagement with key stakeholders • Guidelines drafted with review date • Submitted to Steering Group (see appendix 1) for comment then approval
Rationale	The network was established to support and develop bleeding disorder services throughout Scotland in improving standards of clinical care for patients. The network supports the delivery of evidence based, patient centred care through the development and implementation of clinical guidance, care pathways and information resources utilising a once for Scotland approach.
Scope	To be used by all trained staff (nursing, medical, physiotherapy and psychology) for the management of children and young people who have inherited bleeding disorders transitioning to adult services.
Approval process	The guideline was approved by the SIBDN Steering Group on 29 October 2025. See appendix 1 for list of Steering Group members.

		Page
1.0	Purpose	5
2.0	Scope	5
3.0	Definitions	5
4.0	Main content	5
	Introduction	5
	What is transition?	5
	Time points in transition	6
	Ready, Steady, Go	7
	Feedback and Audit	8
5.0	Associated Materials	8
6.0	Evidence base	9
	Appendix	11

1.0 Purpose

To provide guidance for transitional care of children and young people with bleeding disorders.

2.0 Scope

To be used by all trained staff (nursing, medical, physiotherapy and psychology) for the treatment of children and young people who have inherited bleeding disorders.

3.0 Definitions

Transition: "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult oriented health care systems"

4.0 Introduction

What is 'transition'?

Transition is the concept of describing the process of preparing, planning, and moving from services for children to services for adults.

Transition is a gradual process that gives everyone involved in the care of patients with bleeding disorders time to discuss how healthcare needs will be met as an adult and to prepare for the move to adult services.

Transition is about making plans with patient and not about the patient.

The key principles of successful transition are:

- That it is a systematic and formal process
- There is early preparation
    - Transition begins at diagnosis. At very early ages this will be parent centred and involves gradual introduction. Often this will not be a major aspect of consultation to start
    - There will be key time points during the patient journey
        - Diagnosis to age 8: Introduction to transition
        - Age 8 to 9: Pre-transition planning
        - Age 12 to 13
        - Age 14 to 15
        - Age 15 to 18

    Ready, Steady, Go programme

        - It is crucial that this is person and family centred
- A transition lead/coordinator is identified

- The haematology nurse specialist is fundamental in facilitating this process
- The haemophilia physiotherapist is fundamental to in facilitating this process
- Early involvement of the clinical psychologist for inherited bleeding disorders if appropriate is fundamental to underpinning the success of the transition process
- That there is good communication
- Transition plans are individualised
- It empowers patients to self-manage
- At all times the patient is at the centre of care

Key elements include:

- A written transition policy between paediatric and adult services
- Flexible timing of transfer
- An education programme for patient and parent which addresses all aspects of care
- A written individualised plan for transition for each patient

In order to achieve these goals, the 'Ready, Steady, Go' model is followed.

Time points in the transition process

Diagnosis to age 8

This part of the transition process is gentle and may involve brief discussion in clinic. There are often many other more important issues to both the patient and family, and we should be sensitive to this. At each visit the opportunity to discussion transition and answer any questions should be taken. This should be documented in the clinic letter.

Age 8 to 9

Pre-transition phase: This should recognise the involvement of the patient. It needs to be flexible and sensitive to the patient and family. Key points to discuss are:

- Ensure patient knows the name of his illness
- Encourage child to interact independently with team
- Teaching patient to express symptoms of bleed to parent/caregiver
- Provide developmentally appropriate patient literature
- If patient has CVAD, discuss transition to peripheral access
- Discuss developmental tasks of school age (deciding to tell)
- Discuss transfer of knowledge to their child
- Encourage the child to interact independently with you
- Recap haemophilia general education and discuss

Ready, Steady, Go

This is a nationally recognised model that is recommended by NICE

This should be undertaken as part of each clinic visit from age 12 although there is recognition of flexibility in the timepoints to cater to the person and family's individual needs and understanding.

This process is supported by relevant documents to aid in the process.

The relevant documents in relation to the timepoints are:

- **Age 12: Ready phase.** The following documents should be provided, discussed and addressed at each clinic visit (and if necessary, outside of clinic times) until the start of the steady phase.
    - Ready Steady Go Easy Read Booklet: For all the family to read
    - Ready Steady Go Parent Plan: for the parent/carer to read and complete
    - Patient's Ready Questionnaire: For the patient to read and complete
    - Parent's Ready Questionnaire: For the parent/carer to read and complete
    - NHS Youth Rights in Health Care: For the family to discuss to support advocacy (both self-advocacy and for the family to advocate as well)

- **Age 14: Steady Phase**. The following documents should be provided, discussed and addressed at each clinic visit (and if necessary, outside of clinic times) until the start of the steady phase.
    - Ready Steady Go Parent Plan: refer back to the parent plan given in the ready phase and address any questions.
    - Patient's Steady Questionnaire: For the patient to read and complete
    - Parent's Steady Questionnaire: For the parent/carer to read and complete
    - It is important in this phase to prepare the patient and family that the go phase is conducted in a formal transition clinic setting.

- **Age 16: Go phase**. The following documents should be provided, discussed and addressed at each clinic visit (and if necessary, outside of clinic times). These should be done in formal transition clinics where the members of the adult haemophilia team are present.
    - Ready Steady Go Parent Plan: refer back to the parent plan given in the ready phase and address any questions.
    - Patient's Go Questionnaire: For the patient to read and complete
    - Parent's Go Questionnaire: For the parent/carer to read and complete
    - This will be done over a number of transition clinics. The exact number should be determined by the patient and may differ dependent on differing needs between patients.

The key points to be discussed during transition are:

- Ensuring the patient can interact independently with team
- Ensuring the patient can identify their illness, treatment and products used
- Ensuring the patient is independent in record keeping for factor use and bleeds
- Discussing transition to the adult haemophilia treatment centre
- Discussing patient responsibility to maintain good health i.e. appropriate treatments
- Discussing any issues with peers
- Ensuring the patient interacts independently with the team; allow mostly 1:1 time – (from 16 years)
- Recap haemophilia general education with the patient
- Discussing alcohol, tobacco, drug use and consequences of impaired judgement
- Offering assistance to parents in discussing sexual health with their child/young person
- Discussing the consequences of serious joint or muscle bleed
- Discussing sexual health and puberty with the patient

Feedback and audit

In order to review and improve the transition process feedback with audit is crucial. After transition the adult haemophilia team will provide the transitional care questionnaire to seek views. This will be audited on an annual basis.

5.0 Associated materials

NHS Youth Rights in Health Care, Parent's Go Questionnaire, Parent's Ready Questionnaire

Parent's Steady Questionnaire, Patient's Go Questionnaire, Patient's Ready Questionnaire

Patient's Steady Questionnaire, Ready Steady Go Parent Plan, Ready Steady Go Easy Read Booklet

6.0 Evidence base

Bolton-Maggs P. H. (2007). Transition of care from paediatric to adult services in haematology. *Archives of disease in childhood*, *92*(9), 797–801.

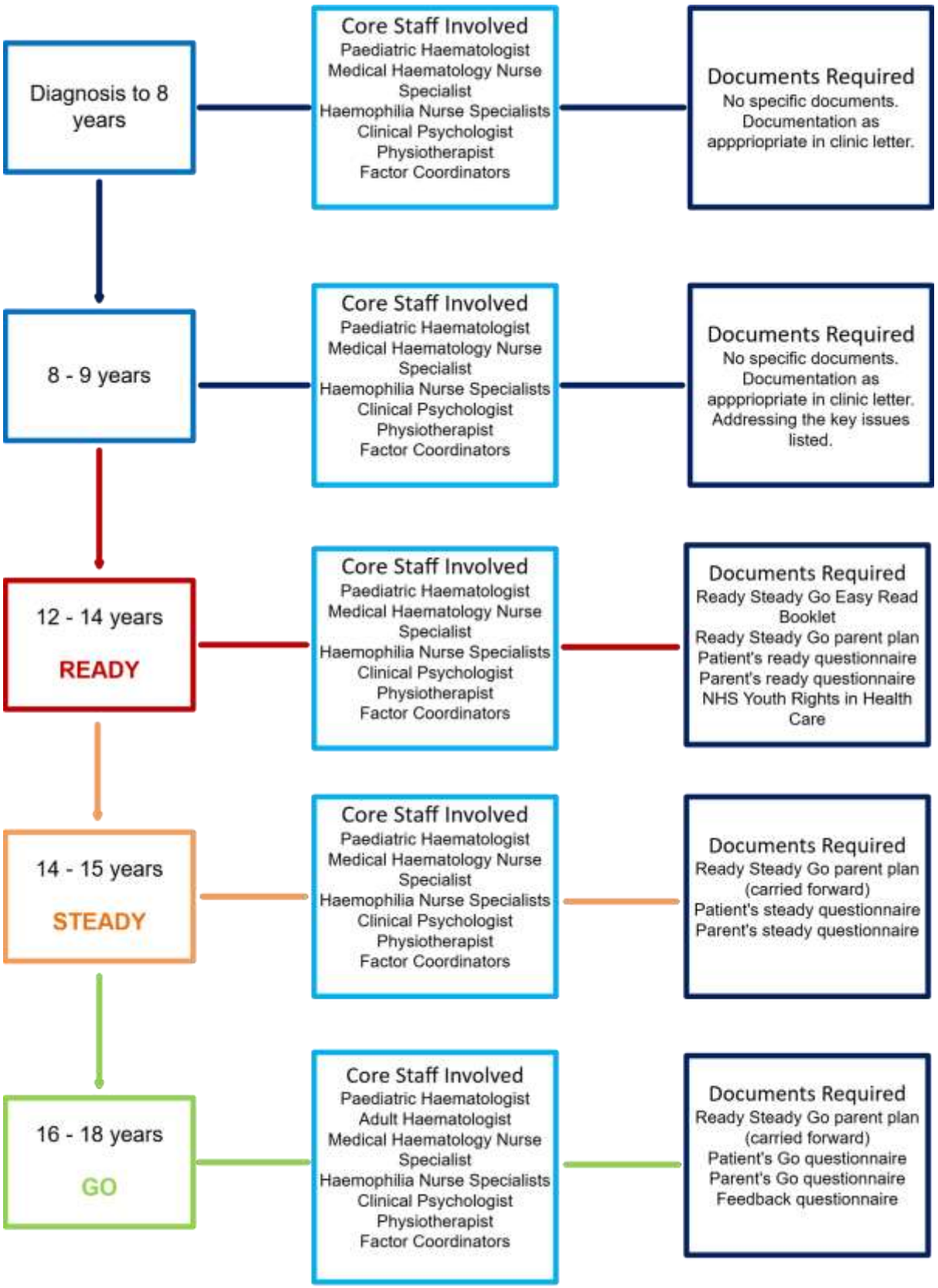
Brand, B., Dunn, S. and Kulkarni, R. (2015), Challenges in the management of haemophilia on transition from adolescence to adulthood. Eur J Haematol, 95: 30-35.

Breakey, V.R., Blanchette, V.S. and Bolton-Maggs, P.H.B. (2010), Towards comprehensive care in transition for young people with haemophilia. Haemophilia, 16: 848-857.

Department of Health Transition: getting it right for young people. 2006. Available from www.dh.gov.uk

Royal College of Paediatrics and Child Health Bridging the gaps. Health care for adolescents. 2003. Available from www.rcpch.ac.uk

van Staa, A.L., Jedeloo, S., van Meeteren, J. and Latour, J.M. (2011), Crossing the transition chasm: experiences and recommendations for improving transitional care of young adults, parents and providers. Child: Care, Health and Development, 37: 821-832.



Approved: October 2025
Review: October 2028
NSD610-030.01 V1
Unless this guidance is being accessed from nn.nhs.scot/sibdn/, it may not be the current version.

Appendix 1 – Steering Group membership

Name	Designation	Area representing
Alan Martin	Director	Haemophilia Scotland
Andrew Page	Consultant Haematologist	NHS Lothian
Cameron Wright	Commodity Manager	NHS National Services Scotland
David McLaughlin	Consultant Haematologist	NHS Tayside
Gayle Cargill	Highly Specialist Physiotherapist	NHS Greater Glasgow & Clyde
Gordon Taylor	Consultant Haematologist	NHS Grampian
Matthew Howard-Jones	Consultant Paediatric Haematologist	NHS Lothian
James How	Blood, Tissue & Organ Donation Team Leader	Scottish Government
Karyn Robertson	Senior Programme Manager	NHS National Services Scotland
Kirsty Young	Programme Support Officer	NHS National Services Scotland
Mhairi Gallacher	Programme Manager	NHS National Services Scotland
Michelle Kivlin	Blood Policy Officer	Scottish Government
Grainne O'Brien	Clinical Psychologist	NHS Lothian
Mairi Gibson	Commodity Manager	NHS National Services Scotland
Pamela Wick	Specialist Haematology Nurse	NHS Greater Glasgow & Clyde
Ryan Rodgers	Consultant Haematologist/ SIBDN Lead Clinician	NHS Greater Glasgow & Clyde