

Clinical Guideline

# South Wales and South West Congenital Heart Disease (SWSW CHD) Network-wide Transition Guidelines

<b>SETTING</b>	Level 1, 2, and 3 centres across the South Wales and South West Congenital Heart Disease Network
<b>GUIDELINE FOR</b>	For paediatric cardiology and ACHD clinical teams working with children and young people across the Network
<b>PATIENT GROUP</b>	Children and young people with congenital heart disease aged 12-20, including those with simple, moderate and complex lesions

## GUIDANCE

### Introduction

In line with the NHS England Congenital Heart Disease (CHD) Standards and Service Specifications, transition from paediatric to adult congenital heart disease (ACHD) services is defined as a planned, structured and developmentally appropriate process, distinct from the point of transfer. Transition should begin in early adolescence and continue until the young person is established within adult services.

The South Wales and South West (SWSW) CHD Network is committed to providing seamless, equitable and high-quality transition across all Level 1, 2 and 3 centres. These guidelines set out a network-wide approach to transition and transfer for children and young people (CYP) with CHD, supporting consistent practice, effective communication between paediatric and adult services, and minimising loss to follow-up.

**These guidelines are intended to support and complement local policies and standard operating procedures, not replace them.**

### Aims

- Ensure consistent, equitable high-quality transition across the Network
- Improve readiness, confidence and engagement of CYP
- Ensure safe, efficient and accurate communication between paediatric and adult services regarding transfer of care
- Reduce loss to follow-up following transfer to adult services
- Support CYP, families and carers through the gradual change in roles and responsibilities

### Definitions

**Transition:** A planned, purposeful process addressing the medical, psychosocial, educational, and vocational needs of young people as they move from child to adult-centred healthcare. Well

planned transition improves clinical, educational, and social outcomes for young people.

**Transfer:** The formal point of handover at which responsibility for care moves from paediatric cardiology to adult congenital heart disease (ACHD) services.

## Principles of Transition

- **Early Start**

Ideally, transition should begin **between ages 12–13** with introductory discussions.

- **Developmentally Appropriate**

Progress through transition and the transition support provided to CYP should reflect the CYP's cognitive, emotional and psychosocial development, and should be delivered in line with the Department of Health You're Welcome framework to ensure care is accessible, respectful, developmentally appropriate and responsive to the needs of 12–25-year-olds.

- **Active Involvement**

Young people are empowered to understand their condition, treatment, contraception/pregnancy risks where appropriate, lifestyle needs, and emergency actions and develop skills in decision making, self-care, self-management and communication.

- **Family Involvement**

Parents/carers are supported to gradually shift responsibility to the CYP over time.

- **Named point of contact**

Each CYP should have a named have a named point of contact to coordinate transition across paediatric and adult services.

- **Multidisciplinary Approach**

Transition should be delivered collaboratively by paediatric and adult CHD clinicians, with involvement of specialist nurses and the wider MDT.

- **Continuity & Safety**

Transfer to ACHD services should occur when the CYP is clinically and developmentally ready, rather than at a fixed age, though the process is usually completed by 18 years. Transfer should take place at a time of relative stability for the young person.

- **Equity Across the Network**

All centres should, where possible, use the same framework, tools, documentation, and readiness criteria to promote consistency and equity.

## Transition Process

It is recognised that local staffing and nursing resources vary across the network and may limit

the ability to provide dedicated transition clinics.

However, where a separate transition clinic is not feasible, a recommended minimum standard is to group transition-aged CYP within the same clinic, using a structured approach. More time may need to be allocated for each patient in these clinics.

The following five stages describe a structured transition pathway informed by international consensus guidance, NICE recommendations, and established UK transition frameworks (including Ready Steady Go Hello). While no single mandated staged model exists for congenital heart disease, a phased approach to transition is widely recognised as best practice.

### **Stage 1: Introduction to Transition (12–13 years)**

- Introduce the concept of transition during paediatric clinic appointments.
- Provide a transition information leaflet, such as *Transition: moving into adult care*, Ready steady go transition programme.
- Document start of transition in patient records.
- Introduce role of ACHD services.
- Begin encouraging the young person to speak for themselves during consultations.

### **Stage 2: Early Transitional Education (13–15 years)**

- Provide education on:
  - understanding their heart condition;
  - the importance of lifelong care; and
  - lifestyle guidance
- Use an established transition assessment tool, such as the Ready Steady Go, Hello transition programme, moving through the progressive stages as appropriate. Documentation should be scanned and added to patient notes.
- Assess early self-management skills, including medication awareness and appointment attendance
- Encourage CYP to have part of consultation alone where appropriate
- Begin copying CYP into correspondence about their healthcare. This may need to manually be added by the clinician.
- Provide a named point of contact for the CYP; this person can be individually determined, according to team members involved in transition care locally.

### **Stage 3: Preparation for Transfer (15–17 years)**

- Assess readiness for transition using an agreed tool (e.g. Ready, Steady, Go– Go ).
- Where possible, particularly for patients with complex conditions, offer joint or young adult clinics with ACHD clinicians/nurse specialists.
- Discuss:
  - sexual health, contraception, pregnancy risks.
  - exercise and physical activity.
  - mental health and emotional wellbeing; and
  - education, employment, and career planning.
  - Mental Capacity Act (2005) and changes to consent process
- Support parents to step back during appointments.
- Encourage part of the consultation with the CYP alone, where appropriate.

- Begin preparing the **Transfer Summary / Transfer of care document**.

#### **Stage 4: Transfer (16–18 years depending on readiness)**

The timing of transfer should consider:

- Medical complexity
- Emotional and cognitive maturity (a capacity assessment will be required over the age of 16, if there is doubt about their ability to consent for any medical intervention/surgery)
- Safeguarding or social circumstances
- Stability of cardiac condition
- Educational or life transitions (e.g., exams)

Paediatric services will hold clinical responsibility for the CYP until the point of transfer.

#### **Extended or adapted transition**

Transfer is usually completed by 18 years, but age alone should not determine the age of transfer. Some CYP may require an extended or adapted transition pathway, including those with:

- Learning disability / neurodiversity
- Mental health vulnerabilities
- Experience of care or safeguarding concerns

#### **Minimum requirements before transfer:**

- Readiness assessed and documented
- Final paediatric appointment completed
- Completed Transfer Summary Transfer of care document (when available), copied to local ACHD team, patient and GP
- Confirmed appointment with ACHD service
- Ensure CYP are aware of the ACHD service they are being transferred to and have the appropriate contact details
- If the CYP is currently being prescribed medication, ensure responsibility for prescriptions are confirmed.

#### **Stage 5: Early Adult Support (Up to 24–25 years)**

ACHD teams should provide:

- Early post-transfer review (ideally 6–12 months), this could be nurse led, or phone appointment, if no clinical requirement for medical review
- Ongoing reinforcement of self-management skills
- Continued support for psychosocial needs and referral to psychology if indicated
- Active tracking and follow-up of missed appointments
- Youth worker support

Where possible, the first adult appointment should be in a dedicated Young Person's Clinic.

## Support and training for Staff

- Support and/or visits to set up clinics from Network Lead Nurse/core team
- Network guidelines – e.g. *Specific Discharge guidance at Transition for Minor Lesions, Guidance for Pregnancy and Contraception in patients with CHD for Paediatric Cardiologists and Paediatricians with Expertise in Cardiology (PECS)*
- Professionals delivering transition care should ideally attend the Network delivered Transition Study sessions (two half days per year)

## Appendix 1

**Table A**

<b>REFERENCES</b>	<p>Department of Health (2011) <i>You're welcome: quality criteria for young people friendly health services</i>. 2nd edn. London: Department of Health</p> <p>NHS England (2016) <i>Supporting young people to transition from children's to adult health services</i>. London: NHS England. Available at NHS England.</p> <p>University Hospital Southampton NHS Foundation Trust (n.d.) <i>Ready Steady Go transition programme</i>. Available at: <a href="#">Ready Steady Go Programme</a></p>
<b>RELATED DOCUMENTS AND PAGES</b>	Ready Steady Go resources
<b>AUTHORISING BODY</b>	
<b>SAFETY</b>	
<b>QUERIES AND CONTACT</b>	<p>CHD Network Lead Nurse</p> <p>Bristol and Cardiff CHD Clinical Nurse Specialist teams</p>
<b>AUDIT REQUIREMENTS</b>	

Plan Elements	Plan Details
<b>The Dissemination Lead is:</b>	
<b>Is this document: A – replacing the same titled, expired SOP, B – replacing an alternative SOP, C – a new SOP:</b>	A
<b>If answer above is B: Alternative documentation this SOP will replace (if applicable):</b>	
<b>This document is to be disseminated to:</b>	South West and South Wales Congenital Heart Network
<b>Method of dissemination:</b>	Email
<b>Is Training required:</b>	

Document Change Control				
Date of Version	Version Number	Lead for Revisions	Type of Revision	Description of Revision
June 2026	1.1	Lead Nurse	Minor	