

# Neonatal Checklist for Babies with Down's Syndrome

## 1. Introduction and Who Guideline applies to

This guideline is aimed at all Health care professionals involved in the care of infants within the Neonatal Service.

### Key Points

- Both the checklist and referral form need to be completed for all children with confirmed or suspected Down's syndrome before discharge from the neonatal unit or postnatal ward.
- Neonatal management of Down syndrome includes clinical assessment, referral to specialist services (community child services and cardiology) and providing parents with appropriate information.

### **Related documents:**

[Leicester, Leicestershire and Rutland, Hospital and Community Services Care Pathway for Children and Adults with Down's syndrome Postnatal Ward Handbook UHL Neonatal Guideline.pdf](#) Trust ref: C12/2021

### Aim


Pages 5 and 6 (based on Appendix 3 and Appendix 5 of the Down Syndrome Care Pathway) provide a printable version of the checklist and referral forms that need to be completed for **all** children with confirmed or suspected Down's syndrome before discharge from the neonatal unit or postnatal ward.


## UHL Discharge Checklist


Neonatal Checklist for Babies with confirmed or suspected Down's Syndrome


**ALL FIELDS MUST BE COMPLETED PRIOR TO DISCHARGE.**

Tick Box when complete

 Clinical Assessment	<input checked="" type="checkbox"/>
1. Oxygen saturations measured and documented (pre- and post-ductal).	
2. Ensure baby has opened his / her bowels.	
3. Ensure feeding is established.	

 Investigations	<input checked="" type="checkbox"/>
1. FISH and chromosome microarray (LiHep and EDTA)	
2. FBC and film (need to indicate Down syndrome on the request form)	
3. ECG performed (ECG assessment form to be completed)	

 Referrals	<input checked="" type="checkbox"/>
1. Has referral to Paediatric Cardiology been made? <i>Please follow the Cardiology referral pathway overleaf and document the agreed assessment plan</i>	
2. Has a referral been made to the Community Paediatric services? <i>(FYPC -Families, Young People and Children's Services referral)</i>	
3. Has a Neonatal Follow-up Clinic (neonatal consultant) been arranged?	
4. If referral to infant feeding coordinator is required, has this been done?	

 Information	<input checked="" type="checkbox"/>
1. Ensure parents have been given adequate information regarding Down's Syndrome.	
2. Offer parents the Down's Syndrome Association guide for new parents: 'Congratulations on the birth of your baby'	
3. Ensure the Down's Syndrome specific growth charts are in the Child Health Record	

**PLEASE FILE CHECKLIST IN HOSPITAL MEDICAL RECORDS.**

## **CARDIOLOGY ASSESSMENT PATHWAY** (for infants with Down Syndrome)

- Paediatric cardiology assessments will normally take place at Leicester Royal Infirmary.
- For all infants, the initial referral will be made by contacting the duty cardiology middle-grade (tier 2) doctor. Team escalation may be required if there are logistical difficulties with arranging a timely assessment.
- The assessment plan will need to take into consideration information from fetal scanning, the postnatal condition of the infant and location of birth.
- Please document the agreed assessment plan in the notes.
- For a well and asymptomatic baby with no clinical / ECG signs who has a postnatal diagnosis of Down's syndrome, a cardiology assessment and echocardiogram can be performed routinely (within seven days acceptable, although usually within 2-3 working days) with escalation should symptoms or signs develop.

### **A: For infants born at LEICESTER ROYAL INFIRMARY** (co-located with the Paediatric Cardiology Service)

#### **1. ANTENATAL DIAGNOSIS OF DOWN SYNDROME**

##### **1A. Patients with an antenatal diagnosis and *NORMAL* fetal cardiac assessment:**

- Follow any instructions regarding follow up from the fetal cardiology clinic letter
- ECG to screen for superior axis and physical examination: for inpatient review if superior axis present or any cardiac signs on examination (contact on-call cardiology middle-grade on call)
- Otherwise for "Soon" outpatient review (this should be within 6 weeks) with safety netting advice to be seen if there are any symptoms of heart failure (respiratory distress, sweatiness on feeding, failure to thrive)

##### **1B. Patients with antenatal diagnosis and *ABNORMAL* fetal cardiac assessment:**

- Follow any instructions on the fetal cardiology clinic letter
- Inform paediatric cardiology team (most likely for review as an inpatient and for the paediatric cardiology team to arrange appropriate follow up) - contact the on-call cardiology middle-grade

#### **2. POSTNATAL DIAGNOSIS OF DOWN SYNDROME born at LRI**

- Postnatally diagnosed Down syndrome - SYMPTOMATIC
- A symptomatic baby or baby with a murmur- inpatient review by paediatric cardiology team (contact the on-call cardiology middle-grade on the same day)
- Postnatally diagnosed Down syndrome- NOT SYMPTOMATIC

- Review by paediatric cardiology within two or three working days (contact on-call cardiology middle-grade)

**B: For infants born at LEICESTER GENERAL HOSPITAL**  
(Not co-located with Paediatric Cardiology Service)

**Postnatally diagnosed Down syndrome at LGH**

- For all infants- ECG to screen for superior axis and physical examination:
  - for early cardiology review if superior axis present or any cardiac signs on examination (contact on-call cardiology middle-grade on the same day)
  - A symptomatic baby or a baby with a murmur will require evaluation and echocardiogram sooner (to be discussed on the same day with the middle-grade cardiologist at LRI – see possible options below)
  - No symptoms- aim for a cardiology echocardiogram at LRI in the first week of life (see possible options below)
- Safety netting advice: to be seen sooner if there are any symptoms of heart failure (respiratory distress, sweatiness on feeding, failure to thrive)

Options for babies born at LGH include (to be agreed with the duty cardiology team):

- Transfer to LRI using CenTre (this will require transfer via the LGH and LRI neonatal units in the first instance, even if the baby is on the postnatal ward at LGH)
- A 'drive-through' echocardiogram with parents taking a well asymptomatic baby to the LRI on the day of discharge. Please ensure that parents have their own transport before making this arrangement.
- An acute outpatient review within the first week ('hot clinic' slot or echocardiography appointment if available)

**FAMILIES, YOUNG PEOPLE & CHILDREN'S SERVICE REFERRAL FORM**

Forename of child		Surname of child		Referrer Name	
Parent's names				Designation	
Address				Address	
Postcode					
School/Nursery					
How long have the family lived in the UK?				Telephone Number	
Contact Numbers	Gender			Fax Number	
	Male <input type="checkbox"/> Female <input type="checkbox"/>				
NHS Number	Date of Birth				
Languages Spoken		Languages Read		Is interpreter needed	
				Yes <input type="checkbox"/> No <input type="checkbox"/>	

**Referral information**

Which services\pathway do you consider are needed
State if mental health needs requiring assessment by CAMHS
Principle reason for referral
Nature of concern

**FAMILIES, YOUNG PEOPLE & CHILDREN'S SERVICE REFERRAL FORM**

**Any additional information that you feel is relevant?**

*(Please attach relevant documentation & reports)*

**Other professional's \ services currently involved with the family?**

*(Please provide details of relevant previous input as well if available)*

**Any Safeguarding concerns?**

Yes

No

Not known

*(If yes please specify with details of Social Worker if Known)*

**Any Special Education Needs**

Yes

No

Not known

*(If yes please specify)*

**Please record if the patient has given consent to access information recorded via the SystemOne Electronic Record System.**

*(please note referrals cannot be processed without consent obtained)*

Consent given  Dissent given  Consent obtained on patient's behalf

**Views of child/parent or carer: *(optional)***

**Signature**

**Date**

**Once completed please return form to us by:**

**Email:** [fypc.referrals@nhs.net](mailto:fypc.referrals@nhs.net)

**Fax:** 0116 2958302

**Post:** FYPC Referrals. Families, Young People and Children's Services,  
Leicester Partnership NHS Trust, Bridge Park Plaza, Bridge Park Road, Thurmaston,  
Leicester, LE4 8PQ.

*Where possible please complete the form electronically, if completing by hand please use additional sheets if needed. For more information view [www.leicspart.nhs.uk/fypcreferrals](http://www.leicspart.nhs.uk/fypcreferrals).*

### **3. Education and Training**

None

### **4. Monitoring Compliance**

<b>What will be measured to monitor compliance</b>	<b>How will compliance be monitored</b>	<b>Monitoring Lead</b>	<b>Frequency</b>	<b>Reporting arrangements</b>
A paediatric cardiology appointment must be made with a review arranged for within a week post-delivery (100%)	Audit	Consultant lead		
A referral to the community services must be made for all infants with confirmed or suspected Down's syndrome (100%)	Audit	Consultant lead		

### **5. Supporting References**

Leicester, Leicestershire and Rutland, Hospital and Community Services Care Pathway for Children and Adults with Down's syndrome

### **6. Key Words**

Cardiac, Cardiology, ECG, Paediatric

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**The Trust recognises the diversity of the local community it serves. Our aim therefore is to provide a safe environment free from discrimination and treat all individuals fairly with dignity and appropriately according to their needs. As part of its development, this policy and its impact on equality have been reviewed and no detriment was identified.**

<b>CONTACT AND REVIEW DETAILS</b>			
<b>Guideline Lead (Name and Title)</b> Authors: Robin Miralles Guideline lead : Robin Miralles NNU Clinical guidelines lead: Sumit Mittal		<b>Executive Lead</b>	
<b>Details of Changes made during review:</b>			
<b>Date</b>	<b>Issue Number</b>	<b>Reviewed By</b>	<b>Description Of Changes (If Any)</b>
<b>March 2012</b>			Care Pathway for Children with Down's Syndrome: Birth to 19 <sup>th</sup> Birthday LLR Hospital & Community Services overarching policy 2012 Reviewed on behalf of the neonatal service by A. Currie
<b>June 2016</b>	<b>1</b>		Printable version of UHL neonatal Down syndrome checklist and FYPC community services referral form compiled
<b>June 2024</b>	<b>2</b>	Robin Miralles Neonatal guidelines group Neonatal Governance group	Additional information regarding investigations and referrals