

National Neonatal Network Guideline

The Scottish Standard Care Pathway for Babies Born with Down's Syndrome

Document Control Sheet

Title	The Scottish Standard Care Pathway for Babies Born with Down's Syndrome
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Date Published/ Issued	18.12.2024
Date Effective From	18.12.2024
Version/Issue Number	1.0
Document Type	Guideline
Document Status	Final
Owner	National Neonatal Network (NNN)
Approver	NNN Guideline Oversight Group
Approval Date	17.12.2024
Contact	nss.perinatalnetwork@nhs.scot
File Location	K:\09 PCF\NSD\Strategic Networks\Perinatal\Workstreams\Neo GdIns_Drg

Revision History

Version	Date	Summary of Changes	Name	Changes Marked
1.0	18.12.2024	None - original version		

Aim

This Pathway is intended to guide the initial care for a newborn infant with a diagnosis of Down's Syndrome. It is intended for use by all health professionals involved in the care of these infants across Scotland.

Background

Down's Syndrome (DS) is one of the most common chromosomal conditions and the commonest cause of identifiable learning disability. The current UK incidence is 1-1.1/ 1,000 babies and a Scottish prevalence of 15.9/10,000 total births or 77 babies born with Down's Syndrome each year in Scotland (Congenital Conditions Scotland 2023).

The genetic syndrome is caused by an extra copy of chromosome 21. In the majority of cases (94%) there is a complete trisomy, where every cell of the individual contains 3 copies of chromosome 21. 4% of cases are translocations, in which cells contain a partial extra copy of chromosome 21, this may reflect an abnormal chromosomal arrangement in the parents, therefore determining parental karyotype is recommended. In the remaining 2% of cases there is a mosaicism, where the individual has both 'normal' cells and cells with trisomy 21. (A guide for Healthcare Professionals 2019).

Antenatal Screening and Diagnosis

Screening for Down's Syndrome is an optional test that women and their partners can choose to have as part the prenatal testing during the antenatal period. The National Screening Committee recommends the use of first trimester combined screening for Down's Syndrome, this screening is performed between 11+2 - 14+1 week's gestation.

Some families learn that their baby will have Down's syndrome through antenatal screening and prenatal diagnosis (amniocentesis or chorionic villi sampling). In other cases, a diagnosis of Down's syndrome is made after birth, following normal routine antenatal scans or "low chance" antenatal test results (less than 1 in 150 chance). In all cases, joint counselling with a Multi-Disciplinary Team (MDT) is recommended, with specialist involvement dictated by any associated anomalies.

- **Antenatal diagnosis with no major structural anomalies identified on detailed scan**
 - Joint counselling by the local Obstetric and Neonatal team.
 - Provide parents with the 'Hello Baby' information pack from Down's Syndrome Scotland and direct them to the Down's Syndrome Scotland website.
 - Offer a referral to the Down's Syndrome Family Support Team (use the referral postcard in the DSS baby pack). Following parental consent, the support team will contact and visit the family.

- **Antenatal diagnosis and suspected cardiac anomaly on detailed scan**
 - Joint counselling by the local Obstetric and Neonatal team.
 - Provide parents with the 'Hello Baby' information pack from Down's Syndrome Scotland.
 - Referral to Foetal Medicine at the QEUH Glasgow for a detailed assessment and joint counselling by the Foetal Medicine and Cardiac team. Discussions will typically include deciding on the appropriate centre for delivery and any postnatal management plans.

- **Antenatal diagnosis and suspected duodenal atresia**
 - Joint counselling by the local Obstetrics/Foetal medicine and Neonatal Team.
 - Parents to be given 'Hello Baby' Information pack from Down's Syndrome Scotland.
 - Referral to foetal medicine centre for detailed assessment and joint counselling including discussions with the paediatric surgical team about delivery and postnatal management.

Disclaimer

The recommendations in this guideline represent the view of the National Neonatal Network Guideline Development Group, arrived at after careful consideration of the evidence available. When exercising their clinical judgement, healthcare professionals are expected to take this guidance fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to follow the guideline recommendations and it remains the responsibility of the healthcare professional to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

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1. Recognising Down's Syndrome

Though the phenotype is variable, there are typically several common features that enable an experienced clinician to suspect the diagnosis. Additionally, there is a wide range of health conditions associated with Down's Syndrome, including a higher frequency of congenital and acquired medical conditions such as congenital heart defects, hearing and visual impairments, gastrointestinal issues, haematological conditions, and thyroid problems. Staff need to have a heightened awareness of these associated conditions and ensure essential screenings are conducted.

General Features

- Hypotonia
- Poor feeding
- Protruding Tongue
- Flat nasal bridge & low set small ears
- Short appearing neck & redundant

Eye Features

- Prominent epicanthic folds
- Congenital cataract
- Upward Slant of Eyes
- Glaucoma
- Brushfield Spots

Limb Features

- Short incurved little fingers (clinodactyly)
- Sandal gap (between 1st & 2nd toes)
- Short broad hands and feet
- Single transverse palmar crease

Heart

Congenital heart disease occurs in about 40% of individuals and include:

- Atrioventricular canal
- Atrial and ventricular septal defects

Associated Conditions

- Mild pancytopenia
- Neutropenia
- Transient Abnormal Myelopoiesis (TAM, 10%)
- Polycythaemia
- Congenital leukaemia (most commonly acute Megakaryoblastic Leukaemia)
- Hirschsprung's Disease
- Intrahepatic biliary hypoplasia
- Duodenal atresia / stenosis
- Hip problems
- Dislocation of the knee
- Renal anomalies (2-4 times more common)

Associated Conditions and Rare Problems

In addition to some conditions present more commonly in patients with Down's Syndrome, 50-60% of babies born with Down's Syndrome have at least one congenital anomaly. These include:

1. **Cardiovascular** - The most commonly occurring congenital anomaly in patients born with Down's Syndrome occurring in 44-46% is congenital cardiac disease. AVSD (1 in 6), VSD (1 in 10), PDA (1 in 50) and TOF (1 in 100).
2. **Gastrointestinal** - 5% of patients have GI manifestation including Gastro-Oesophageal Reflux Disease, Duodenal Atresia, Oesophageal atresia, and Hirschprung's disease.
3. **Endocrine** - Congenital Hypothyroidism (1%) at birth or developed later.
4. **Visual** - Congenital and acquired cataracts. Glaucoma, nystagmus and strabismus may present later.
5. **Hearing** - Up to three quarters of children with Down syndrome have some hearing loss, related to structural problems within the ear. Congenital hearing loss screening forms an essential part of early postnatal screening.
6. **Haematological** - Polycythaemia, Transient Abnormal Myelopoiesis (TAM, 10%), Congenital leukaemia (most commonly Acute Megakaryoblastic Leukaemia, pancytopenia, mild neutropenia etc).
7. **Growth:** Around a third of babies are born Small for Gestational Age or born late preterm because of Foetal Growth Restriction (25%) secondary to Doppler abnormalities (68%). Serial antenatal growth scans may be required in this instance.

2. Postnatal Suspicion and Diagnosis

Clinical suspicion of a baby having Down's Syndrome in a baby who has not received an antenatal diagnosis is commonly raised soon after birth or during the Newborn and Infant Physical Examination (NIPE). When such a suspicion arises, the attending doctor should notify the most senior clinician (Consultant grade or middle grade staff) to ensure timely communication of the clinical suspicion, clinical evaluation, and review.

If non-consultant grade staff are directly approached or questioned by parents, they should provide a basic description of the clinical suspicion while emphasizing the need for escalation to senior staff for a comprehensive review. It is important to clearly explain the reason for the senior review to the family. The choice of language and wording regarding the reasons for the suspicion should be considered carefully and communicated respectfully to the parents. (See appendix 1, p16 for "Sharing the news that baby has Down's Syndrome information DSS leaflet")

Sharing the diagnosis

When sharing the news with parents, it is important to explain what Down's Syndrome is. However, it is not recommended to provide detailed explanations about features or anticipated medical conditions beyond those identified in the individual child. If the parents were aware that their baby had Down's Syndrome before birth, they might have additional questions or seek further information. Additionally, they should receive support from familiar maternity staff, ideally those involved in their care during the labour and delivery period. The discussion should always be led by the parents.

If immediately clinically evident that the baby has Down's Syndrome, discussions on the diagnosis should not be delayed until blood tests results are available. The genetics team do not need to be involved in making the diagnosis except to confirm the karyotype. If there are only subtle features or any clinical uncertainty, explain to the family that a blood test will be required to confirm or exclude the diagnosis. QF PCR test results would usually be available within 2 to 3 working days.

Guiding Principles

- **Anticipate Parental Awareness:** Determine in advance if the parents knew antenatally that the baby has Down's Syndrome or had a high-chance antenatal screen result as this is useful in guiding your conversation.
- **Timing:** Determining the right time to relay the news in the immediate post-partum period can be challenging, particularly when it is obvious that the baby has Down's Syndrome following the initial clinical examination. It is recommended to allow initial mother and family bonding, including skin-to-skin contact and memory making, before discussing the diagnosis.
- **Consider the Environment:** Ensure the setting is private, not too clinical or gloomy, providing a comfortable space for the discussion.
- **Include Both Parents and the Baby:** Ensure both parents are present, along with their baby if possible. Use the baby's name if they have been named.
- **Begin with Congratulations:** Start by congratulating the parents and allowing them to have precious quality time welcoming their baby.
- **Careful Communication:** Think carefully about wording, tone, and body language. Use plain language, avoiding medical jargon and ambiguous terms. Provide information that is immediately relevant to their baby and avoid information overload. Avoid conversations shrouded in secrecy and mystery. Reports from parent group indicate direct and honest report of any suspicion are helpful in decreasing anxiety.
- **Clarify and Follow Up:** Ensure parents understand the information shared. Allow sufficient time for them to process the news and ask questions. Revisit them to address any follow-up questions or concerns. (See appendix 1, p16 for "Sharing the news that baby has Down's Syndrome information DSS leaflet")

3. Postnatal Care of Mother and Baby

The baby should remain on the postnatal ward close to his/her mum. Separation of mother and baby should be discouraged except on clinical grounds. A physical examination and review must be carried out and documented with increased vigilance for signs and symptoms of conditions associated with Down's Syndrome including:

1. Bile stained vomiting – Intestinal obstruction including Duodenal atresia.
2. Delayed passage of meconium- Hirschsprung's.
3. Cyanosis and differential Pre-Post ductal saturations - Cardiac problems including PPHN, congenital cardiac anomalies.
4. Haematological abnormalities and abnormal blood film.
5. Hypotonia and feeding difficulties.

Feeding

Babies with Down's Syndrome may have a weak and uncoordinated suck, resulting in slow feeding and delayed establishment of suck feeds.

- A daily clinical review, close monitoring and careful documentation of feeding is recommended.
- Ensure successful establishment of feeding and adequate weight gain.
- Provide support in initiating and establishing breast feeding.
- Feeding assessment should be carried out on all babies with Down's syndrome and if clinically indicated a referral made to the Infant feeding team at the earliest opportunity.
- Agree a plan for monitoring and supporting feeding after discharge.
 - A referral to the speech and language therapist should be made for babies with suckling or swallowing problems.

(See appendix for useful breastfeeding resources for parents)

Cardiovascular

Between 40 - 60% of babies with Down's Syndrome have congenital heart defects. 30 - 40% are complete Atrio-Ventricular Septal Defects (AVSD). With early diagnosis most AVSD can be successfully managed by early referral to for specialist cardiac assessment. These babies are also at a higher risk of persistent pulmonary hypertension of the newborn (PPHN), this can be picked up early using bed side Pulse Oximetry Saturation (POS) Pre and Post ductal recording.

- All babies born with Down's Syndrome should have an echocardiogram as a

first line investigation. When this is not readily available a careful clinical examination including measurement of pre-post pulse oximetry saturation recording should be done. An out-patient echocardiogram should be arranged for within 2-4 weeks post discharge. The echocardiogram can be undertaken by the local team, scanned and reviewed by a Paediatrician with Expertise in Cardiology (PEC). If normal, a paediatric cardiology referral is not required. If abnormal, discuss with the on-call cardiology team via the standard referral pathway.

- For those neonates in whom an associated cardiac anomaly has been detected antenatally, the agreed prenatal management plan should be followed. The postnatal clinical assessment of the patient can supersede a prenatal plan. Early contact should be made with cardiology team in those instances. However, all symptomatic babies should be referred for urgent cardiac assessment.

Haematological

Haematological problems are common in babies with Down's Syndrome.

Thrombocytopenia (<100) occurs in up to 28% of infants, this is usually mild and transient (lasting 2-3 weeks). Polycythaemia is common (18-60%) and may require active management.

Transient Leukaemia of Down's Syndrome (TL-DS) - also known as Transient Abnormal Myelopoiesis (TAM) - can be found in between 5-10% of babies with Down's Syndrome. This most commonly presents as a high white cell count and abnormal film, but may also present with hepato-splenomegaly, pleural/pericardial effusions and a skin rash. Discussion with paediatric haematology should be undertaken to guide further investigation (e.g. GATA1 gene, immunophenotyping) to guide both acute management and ongoing follow up. TL-DS usually regress spontaneously within the first 3 months of life. A small number of these patients may require active management with chemotherapy if they present with life threatening symptoms. FBC and blood film should be done and any abnormal results discussed with the paediatric haematologist to guide further investigation (e.g. GATA1 gene, repeat film) and management. Parents of baby's with TMD should be counselled regarding the risk of leukaemia and made aware of the signs to look out for.

Thyroid

Approximately 1% of infants with Down's Syndrome will have congenital hypothyroidism and 15% of Down's Syndrome individuals will develop hypothyroidism. The UK Newborn Blood Spot screening test (Day 5-7) is designed to detect only primary CHT. If the infant has clinical signs suspicious of hypothyroidism

for example prolonged jaundice, a T4 and TSH should be done. Congenital hypothyroidism can be missed if only T4 concentration is measured. Children with abnormal thyroid function should be discussed with the paediatric endocrinologist urgently.

Audiology

In addition to routine newborn hearing screening, all babies born with Down's Syndrome should be referred for extended audiology testing and follow up.

3.1 Investigations Prior to Discharge

1. **Genetic Investigations** – send an EDTA and Lithium Heparin sample to genetics laboratory, stating the clinical suspicion of Down's syndrome. The laboratory will first perform QF-PCR with results generally available with 2-3 working days.
 - a. If this is positive for trisomy 21, the laboratory will proceed to karyotype to exclude translocation.
 - b. If QF-PCR is normal, it may be appropriate to proceed to microarray to exclude other chromosomal diagnoses. State on the referral form if you wish chromosome microarray to be completed if QF-PCR is negative.
2. **Pulse Oximetry Saturation** measurement (Pre and post ductal)
3. **Echocardiogram** – to be done as inpatient if specialist available and ideally should not delay discharge. If clinically well and POS and ECG normal, this can be arranged as outpatient echocardiogram in 2- 4 weeks.
4. **Thyroid function tests** – newborn Blood Spot Screening card is sufficient if there are no other clinical suspicions. [\[06\]](#)
5. **Eyes** – rule out cataracts, onward referral to ophthalmologist if any concerns.
6. **Examination of the Newborn** – review antenatal scans, hip exam, red reflex etc. Further investigations and referrals as an inpatient to be guided by results of anomalies found on general examination
7. **Full Blood Count and Blood Film** – in all neonates with known, or a high suspicion of Down's Syndrome a Full Blood Count and blood film should be requested in the first 3 days of life and a formal assessment of the peripheral blood blast cell percentage performed by a haematologist with experience in reviewing neonatal blood films.

Babies whose full blood count, blood film and/or clinical examination is suggestive of TL-DS should have further investigations undertaken including liver function tests (including conjugated bilirubin if the baby is jaundiced), chest X-ray, echocardiogram, and abdominal ultrasound (Grade 1B). Any neonate with a

blast percentage >10% and/or clinical features suggestive of TL-DS should be discussed urgently with the regional Paediatric Oncology Principal Treatment Centre to discuss further investigation and management. Further testing may include sending a peripheral blood sample sent for GATA1 mutation analysis (Grade 1A).

In addition, consider discussion with paediatric haematology for any child who did not have a peripheral blood blast cell percentage performed in the first 3 days of life or in whom there was significant intra-uterine growth retardation (as blast counts may be suppressed) as these patients may still be at risk of TL-DS in the first 4-8 weeks of life and should be monitored accordingly. GATA1 mutation analysis may be considered (Grade 1B) following discussion with haematology for these patients and they will have follow up organised with haematology as appropriate.

All patients with TL-DS should be referred to haematology and will receive ongoing surveillance of their full blood count until the age of 4.

3.2 Screening and Surveillance

Screening forms a vital part of ensuring positive health and wellbeing for individuals with Down's Syndrome. In the neonatal period, hearing screening and the Newborn Blood spot screening (on Day 5-7) are particularly important for these babies and must not be missed. Anticipatory planning for longer term screening and clinical reviews should be put in place as planning. Refer <https://www.healthforallchildren.com/wp-content/uploads/2020/02/A5-Downs-charts.pdf>

4. Information for Parents/Carers

Giving appropriate information to the parents and carers is essential, ideally as part of the initial discussion to ensure they have a clear understanding about what Down's Syndrome is. Parents should be provided with the opportunity to ask questions or discuss any concerns they may have. The information shared must be accurate and unbiased verbal and written information about the condition including:

- Explanation of the condition
- Genetics of the condition
- Local resources – Down's syndrome passport

- Contact details of Down’s Syndrome Scotland and links to website
Medical conditions associated with Down’s syndrome, particularly those immediately relevant to their baby (See appendix 1, p16 for useful parental resources)

5. Discharge Planning

The timing of discharge will vary; however, discharge planning should begin as soon as possible to ensure a patient centred package of care is put in place. The following is a list of considerations that should be made, many teams find the use of a discharge planning check list useful.

1. The baby must be feeding satisfactorily and feeding support put in place if necessary. In some instances, home NGT feeding may be required, a post discharge management plan should be in place.
2. A record of weight and Head Circumference should be on the appropriate growth chart for babies born with Down’s Syndrome before discharge. * Note electronic growth charts (iGrow) are available on Clinical Portal.

CHI.....
First name.....
Surname.....
Address.....
.....

<p>BABIES BORN WITH DOWN’S SYNDROME</p> <p>NEONATAL PRE-DISCHARGE CHECKLIST</p>

3. Notification to the GP and Public health nurse of the baby having Down’s syndrome.
4. In some cases, the chromosome results after discharge, it is important to decide with the parents on how the results will be shared and a named consultant identified. Best practice would usually be a face-to-face consultation; however parental wishes should be followed to ensure this is delivered in line with family centred care principles. The process for each relevant health board should be communicated to the parents to ensure they are aware of approximate timelines within which the results will be communicated.

5. Neonatal/community paediatrics outpatient follow-up clinic appointment.
6. An updated and completed Investigation list and results is recommended as a useful tool to document any pending results, who to action and timelines.
7. Parental information packs and useful links – Down’s Syndrome Scotland website, consider using the “My Going Home Passport” and 0-3 AHP packs
(See appendix 1, p16 Scottish AHP Pathway 0-3 link)
8. Referrals: ensure all necessary referrals have been made prior to discharge and ideally should always include referral to Community Child Health.
Community Child Health – refer as soon as diagnosis made, but shared care with the local neonatal team may be required for a period until acute medical issues have resolved.
9. List of useful contacts within the board - Community midwife or community nurse and support organisations- Family Support Service from Down’s Syndrome Scotland.
10. National useful contacts and family support services- All Down’s Syndrome Scotland documents.

Task	Other details	Completed	Date of completion	Name & Signature
Newborn Examination				
Growth measurements	OFC: Weight: Length:			
Genetics screen				
Multisystem review <ul style="list-style-type: none"> • Newborn Hearing 				
Blood Investigations: <ul style="list-style-type: none"> • FBC and film (Day 1-3) • Newborn Blood spot • Others (Specify) 				
Referrals: if required <ul style="list-style-type: none"> • Community team • SALT (if indicated) • Dietetics (if indicated) • Down’s Syndrome Family Support – Complete slip in New Baby Pack • Others (Specify) 				
Outpatient Follow up / Notifications <ul style="list-style-type: none"> • Neonatal clinic 				

<ul style="list-style-type: none"> • Community Paediatrics • HV notification • GP notification 				
Baby's Going Home Passport				
Resource for parents <ul style="list-style-type: none"> • Information leaflets • Support group info • Other (Specify) 				

Appendix 1: Information Resources

- **Information for parents**
 - a. <https://www.Down's Syndromescotland.org.uk/>
 - b. <https://www.Down's Syndromescotland.org.uk/about-downs-syndrome/information-for-expectant-parents/>
 - c. <https://www.Down's Syndromescotland.org.uk/our-services/new-parents/>
- **Feeding resources**
 - a. Down's Heart Group <https://dhg.org.uk/information/feeding-problems/>
 - b. La Leche League International <https://www.lli.org/breastfeeding-info/special-needDown's Syndrome/>
 - c. Blog by a mum <https://theseamazingdays.blogspot.com/2021/01/breastfeeding-my-baby-with-downs.html?m=1>
 - d. Breastfeeding Leaflet https://perinatalnetwork.scot/wp-content/uploads/2024/12/DSS_Breastfeeding-Leaflet.pdf
- **Scottish Allied Health Professional Pathway for Children with Down's Syndrome**
<https://www.dsscotland.org.uk/our-services/new-parents/health-checks-and-additional-support/scottish-allied-health-professional-ahp-pathway-for-children-with-downs-syndrome-aged-0-3-years/>
- **Personal Health Care Record (PHRC)**
<https://www.healthforallchildren.com/wp-content/uploads/2020/02/A5-Downs-charts.pdf>
- **Communication resources**
 - a. Sharing News that the Baby has Down's Syndrome https://perinatalnetwork.scot/wp-content/uploads/2024/12/DSS_Sharing-News-the-Baby-has-Downs-Symdrome.pdf
 - b. Parent reflections on the impact of good practice in sharing the diagnosis:

Mum A "The consultant who gave me the official diagnosis said to me that 'yes she has t21, yes she may need extra hospital appointments, but your job as her mummy is to take her home and love her exactly the way you had intended because that's all that matters."

Mum B "In my shock I did keep saying to our Dr "but he can't have Down's Syndrome, he looks so much like his big brother" To which her reply was always - "of course they both look alike, they are brothers they are going to share many features and traits as well as having lots of unique traits, his Down syndrome is his unique trait."

Mum C "The doctors and paediatrician were amazing, when the results came back he came in just said "we have the results and they have confirmed P has Down's syndrome, talked us through all the support she'd need in terms of cardiologist/physio etc., there was 1 doctor who said to me 'she'll do amazing things as she grows up so don't worry about what the future holds, just enjoy every day as it comes like you did with your first'

Mum D "We had a postnatal diagnosis & having heard other people's stories I'm very happy with our experience whilst in hospital. We were never told "I'm sorry" the consultant said they wanted to run some genetic tests including for Down's Syndrome, my niece has a chromosome deletion, so my 1st thought was something along those lines till Down's Syndrome was mentioned then I knew. The midwife was fab, making sure I was ok (I wasn't), she asked me how I wanted to feed (I wanted to breastfeed) and got me to focus on that, telling me there was absolutely no reason why J wouldn't be able to. The next day the consultant came to see me again & pointed out the markers they had seen but reassured me there was no reason to be sad & that J would more than likely be able to do anything her sister did, although it might take slightly longer.

Appendix 2: Guideline Development Group Membership

Chair, Dr Augusta Anenih, Consultant Neonatologist, NHS Lanarkshire

Dr David Quine, Consultant Neonatologist, NHS Lothian

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