

Down Syndrome Pathway

Version 1.0



Contents

- 3 Introduction
- 5 Antenatal Screening Pathway
- 11 Paediatrician Review and Checklists
 - 3 months to 2 Years
 - 3 years to school leavers
- 18 Transitions
- 19 Audiology
- 20 Ophthalmology
- 21 Speech and Language Therapy
- 22 Sleep Related Airway Obstruction
- 23 Occupational Therapy
- 24 Physiotherapy
- 25 Dietetics
- 26 0-19 Team Hartlepool
- 27 0-19 Team Stockton
- 28 Signposting/Contacts

Pathway Development

This pathway was created in partnership with parents, carers, and health professionals and will be reviewed annually unless errors or changes are highlighted sooner. Further information can be found at

[https://nenc-teesvalley.icb.nhs.uk/our-work/
down-syndrome-pathway/](https://nenc-teesvalley.icb.nhs.uk/our-work/down-syndrome-pathway/)

Any errors or changes please email
nencicbtv.enquiries@nhs.net

FAO Children and Young People Portfolio.

We would like to thank our local parents who are members of the Stockton and Hartlepool Parent Carer Forums for sharing their lived experiences to help inform the production of this pathway.

We would also like to acknowledge Hull and Oxfordshire CCG's and Bristol NHS Trust for the work done on their pathways on which the design and content of our pathway was inspired by.

Introduction

Any person who has Down Syndrome is a person first. As with any other child or adult, they will have their own unique personality and attributes. It is important to remember that despite someone having Down Syndrome, this alone does not define them. Down Syndrome is the commonest autosomal anomaly, present in 1 in 600-700 live births. In the majority of cases (95%) there is an extra chromosome, 47 chromosomes rather than 46. The extra chromosome being number 21. In 2.5% there is mosaicism where only some of the cells have the extra Chromosome.

The patient experience and feedback from families in Stockton and Hartlepool has identified the need for a clinical care pathway for children with Down Syndrome. Input has been sought from parent/carers and the services closely involved with the care of these children. It is effectively putting all the health information that may be pertinent for people with Down Syndrome in one place. Multidisciplinary representatives from Community Services, North Tees and Hartlepool NHS Foundation Trust, Education, James Cook University Hospital, Harrogate and District Foundation Trust, Positive About Down Syndrome and Down Syndrome North East Charities, all working with Parent/Carers with lived experience. The Down Syndrome Pathway Improvement Steering Group was created to produce a clinical pathway emphasising the need for information and engagement with families.

This pathway does not replace those services that all children and adults have access to e.g. GP services, midwifery, health visiting, school nursing (now the 0-19 service in Stockton on Tees), therapy services, community health services and hospital services. It seeks to clarify additional services that may need to be involved in the care of a person with Down Syndrome because of some common health difficulties experienced. These guidelines are largely based on work done by Down Syndrome Medical Interest Group (DSMIG, UK and Ireland) who have produced guidelines for basic medical surveillance in children with a diagnosis of Down Syndrome. These guidelines and a wide range of other health information can be found at www.dsmitg.org.uk.

We would also like to acknowledge the work done by Hull CCG, Nottingham Down Syndrome Children's Services and Oxford Health NHS Foundation Trust and County Council as we have also utilised their guidelines for this pathway. The pathway and guideline has been co-produced with parents/carers/ service users and professionals to ensure the information is accurate, and is driven by those who will benefit the most from using it. Consent from parents and carers should be obtained prior to referral and notification of needs within the pathway as per local policy. Clarification regarding consent arrangements for each service should be sought.

Access to the following resources has been implemented as part of this project. Please see below for details of how to replenish this stock of resources :-

Charitable Gift Boxes

These are provided by the local Charity, Down Syndrome North East (DSNE). They are available from the Antenatal Screening Team and from the Postnatal and Neonatal Wards. When more stock is required please email support@dsne.org.uk

New Parent Packs

These are provided by North Tees and Hartlepool Trust. The contents can be downloaded and printed from the following website <https://nenc-teesvalley.icb.nhs.uk/our-work/down-syndrome-pathway/>

The folders can be re-ordered by contacting nth-tr-healthy-lives-admin-support@nhs.net.

Inserts	Comments	Inserts	Comments
Covering introduction letter from local parents with input/comments from the Trust	(see link above)	Together 21 Leaflet (local area signposting)	Available from support@dsne.org.uk
"Meet your professionals" leaflet	(see link above)	Down Syndrome Association – Congratulations new baby leaflet	Available from support@dsne.org.uk
Reminder to file Down Syndrome Red Book Insert	(see link above)	Parent/Carer Forum details for Stockton and Hartlepool	Available from support@dsne.org.uk
Copy of the Hospital Passport	(see link above)	Details of facebook groups and Neonatal Playgroup	(see link above)
Positive About Down Syndrome information card (national signposting)	Available from support@dsne.org.uk	Leaflet with email address of Down Syndrome North East Parent Champion Service	(see link above)
Down Syndrome North East Leaflet (local area signposting)	Available from support@dsne.org.uk		(see link above)

Antenatal Screening and Postnatal/Neonatal Pathway

Antenatal Screening and Care Pathway

- A minimum of 10 visits over the whole of the pregnancy (nulliparous)
- All women offered screening and supported in their choices by the Antenatal Screening Co-ordinators and Community Midwives
- Initial test – Combined screening unless cannot get nuchal measurement or more than 14 weeks and one day then second trimester screening optimally at 16 weeks.
- If increased chance, offer non-invasive pre-natal testing (NIPT) (Evaluation programme due for review for next year) or pre-natal diagnosis (amniocentesis or CVS). Information to be given around both tests and parents supported with choice. Offer of Maternity Services Counselling if required (referral accepted from any professional). Signposting information given regarding local support groups as soon as diagnosis received, PADS, DSNE, ARC.
- Leaflets and booklets also available from screening team
- Ensure careful use of language. Training now available to all health professional regarding this.
- Posters and information giving general screening information available in clinical areas.
- General support throughout pregnancy from the ANNB screening team, direct contact number given with open access at testing.
- Meeting arranged (with consent) between parents and Paediatrician antenatally to include place of birth discussions.
- Neonatal alert put onto hospital systems to ensure all health professionals involved in care are aware of needs. Birth plan formulated by Paediatricians at antenatal discussions including individualised plan of care also uploaded. Any needs led referrals made i.e. Infant Feeding Specialist Midwife, RVI (Regional Fetal Medicine Unit).
- Fetal Echocardiogram at 6 to 23 weeks, if abnormalities detected, refer to RVI.
- 28 to 32 weeks recheck cardiac views if indicated
- US Scan every 3 to 4 weeks to check growth from 28 weeks
- All women have open access via Maternity Day unit if they have any concerns
- Appointment with named consultant to discuss the option of elective delivery at 39 weeks if indicated.

At Birth

- Chromosomes from baby taken by appropriate healthcare professional (if down syndrome suspected and not previously diagnosed). Results returned to requesting Healthcare Professional for action. Appointment made for parents to return to see Paediatrician in Outpatients to discuss results.
- Discharge appointments/care plan given to parents for future outpatient appointments as required i.e. Paediatrics, Community Paediatrics, Speech and Language Therapist (SALT)
- Continuous assessment of baby's needs up to 6 weeks from Maternity services (Community Midwife)
- Ensure comprehensive hand over to primary health care, including HV and GP, Post-natal/Neo natal wards communicate with wider services, discharge letter copied to all services.
- Full clinical examination by Paediatrician – Refer to NTHFT SOP PAE16V2 (Down Syndrome Early Care Pathway- Management by Neonatal/ Postnatal staff including checklist)
- Full assessment of feeding and attachment, (see SALT Checklist in SOP PAE16V2), if difficulties with sucking and swallowing are identified, please refer to the SALT service.
- Observations as necessary
- Ensure Baby Pack given, ie signposting, meet your professionals etc, reiterate local support, next steps etc

Management by Neonatal/Postnatal Staff including checklist

- The timing of diagnosis disclosure and its handling are central to the parents' initial reaction and adjustments to their baby, as well as their subsequent working relationship with health care professionals
- If there is a clinical suspicion of Down syndrome the Consultant Paediatrician on call should be asked to review the baby as soon as possible. Confirmation by chromosomal analysis is usually available within 48-72 hours.
- Diagnosis should be given by a Senior Paediatrician where possible (usually consultant) in the presence of both parents in a suitable environment.
- Ensure that parent has been provided with a North Tees and Hartlepool New Parent Pack. (Contains relevant signposting and support).
- Ensure that the Down Syndrome insert is put in the baby's personal Child Health Record (the 'red book') and that their growth is plotted both in this book and on a specific Down Syndrome Growth Chart in their hospital notes. The red book insert is available on the Post/Neonatal wards and from the Antenatal Screening Co-ordinators. Write Health Visitor and Community Paediatrician's contact details in Red Book
- Parents are to be given a DSNE Gift Box along with the North Tees and Hartlepool New Parent Pack at birth (stock available on neonatal ward, see Ward Clerk or contact support@dsne.org.uk to replenish). Check if parent has linked in with a DS Champion, if not signpost to DSNE Gift Box information.
- Complete checklist at the end of this document to ensure all investigations are performed or requested, parent information has been provided and onward referrals completed.
- If the baby demonstrates difficulties with sucking and swallowing, please refer to the SALT service for assessment prior to discharge.

Babies who have Down Syndrome are at increased likelihood of experiencing dysphagia (swallowing difficulty). Difficulties can arise in the mouth and/or throat and signs of difficulty can include:

- Absent suck or weak suck on a bottle teat
- Difficulty latching effectively to the breast to feed
- Lengthy feeds and/or fatigue whilst feeding resulting in incomplete feeds and inability to meet nutrition and hydration requirements
- Requiring NG feeds – This is a prompt for a referral
- Anterior spillage of milk from the lips during feeding
- Inability to coordinate sucking, swallowing, and breathing whilst feeding
- Difficulty protecting the airway whilst swallowing resulting in aspiration, symptoms of which can include

- Chest infection and pneumonia
- Oxygen desaturation during or immediately after feeding
- Facial colour change during or immediately after feeding
- Wet and gurgling breath sounds during or immediately after feeding
- Wet and gurgling voice quality during or immediately after feeding
- Coughing during or immediately after feeding
- Choking during or immediately after feeding
- Watery eyes during or immediately after feeding
- Distress behaviours during feeding such as back arching, pulling away from the bottle/breast, head bobbing, finger splaying, limb extension, crying

When these signs are observed then a referral should be made directly to the speech and language therapy service.

The following investigations need to be arranged and their details noted in both the hospital record using the checklist below and the red book prior to discharge:

Newborn Discharge Checklist:

Detailed Checks	Yes	No
Cardiac defects, including pre and post ductal saturations, if cardiac defect may be eligible for Palivizumab immunisation	<input type="checkbox"/>	<input type="checkbox"/>
Cataracts	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty with sucking and swallowing refer to the SALT service	<input type="checkbox"/>	<input type="checkbox"/>
Delayed passage of meconium (>24 hours)	<input type="checkbox"/>	<input type="checkbox"/>
Bowel atresia/functional obstruction	<input type="checkbox"/>	<input type="checkbox"/>
Birth weight and head circumference plotted on down syndrome specific growth chart	<input type="checkbox"/>	<input type="checkbox"/>
Investigations Prior to Discharge		
Babies with a murmur should be evaluated by a Neonatal consultant urgently as an inpatient, before discharge, if symptomatic (given the logistics, this may not always be possible in which case escalated to Freeman Paeds Cardio) or if asymptomatic can have ECHO within 8 weeks	<input type="checkbox"/>	<input type="checkbox"/>
ECG should be done at the Cardio appointment if the Paediatric Consultant with Cardiology expertise doing the ECHO feels it appropriate/ necessary	<input type="checkbox"/>	<input type="checkbox"/>
Karyotype	<input type="checkbox"/>	<input type="checkbox"/>
FBC and blood film	<input type="checkbox"/>	<input type="checkbox"/>
Routine newborn blood spot including thyroid function taken on day 5 after birth	<input type="checkbox"/>	<input type="checkbox"/>
Routine neonatal hearing screen	<input type="checkbox"/>	<input type="checkbox"/>

Information for Parents

Provision of North Tees and Hartlepool "New Parents Pack"	<input type="checkbox"/>	<input type="checkbox"/>
Provision of DS Charitable Gift Box	<input type="checkbox"/>	<input type="checkbox"/>
Check if parent has been linked with DS Champion, if not signpost to information in gift box	<input type="checkbox"/>	<input type="checkbox"/>
Ensure DS insert filed in Personal Child Health Record and completed (Available from supply on post/neonatal wards (see ward clerk) and Antenatal Screening Co-ordinators)	<input type="checkbox"/>	<input type="checkbox"/>

Referrals/Follow up/ANNB

Parents spoken to by Consultant (where possible) ensure received Gift Box and New Parent Pack and informed of pre discharge meeting with professionals	<input type="checkbox"/>	<input type="checkbox"/>
GP Informed	<input type="checkbox"/>	<input type="checkbox"/>
HV Informed and invited to pre discharge meeting with parents and clinical staff (via MS Teams or F2F)	<input type="checkbox"/>	<input type="checkbox"/>
Community Midwife informed	<input type="checkbox"/>	<input type="checkbox"/>
Community Paediatrician informed for Stockton or Hartlepool via letter (Send a formal referral letter to named Community Paediatrician giving ALL details of the above tests and referrals with results or dates of appointments as known. Include a copy of the checklist and send with letter - Infant's name and DOB, Address, GP details, Referring Consultant Paediatrician name, Location of baby (PNW / Home) now and over next few days	<input type="checkbox"/>	<input type="checkbox"/>
ECG Done/Arranged if indicated	<input type="checkbox"/>	<input type="checkbox"/>
Cardiology	<input type="checkbox"/>	<input type="checkbox"/>
Refer to Speech and Language Therapy for any baby with sucking or swallowing difficulties (acute or outpatient, see advice above)	<input type="checkbox"/>	<input type="checkbox"/>
Arrange paediatrician follow up where required, triaged appropriately dependant on need/urgency	<input type="checkbox"/>	<input type="checkbox"/>
Audiology is done via Universal Screening but results need to be noted in Red Book.	<input type="checkbox"/>	<input type="checkbox"/>
If indicated, consider referrals to any other services such as Physio, Dietetics, OT	<input type="checkbox"/>	<input type="checkbox"/>

3 Month Review

Unless complex, child already under Health Visiting Service (with open access to advice from Neurodisability service if needed)

Discussion

Feeding

GOR symptoms

Check whether there are any bowel problems

Sucking and swallowing – consider onward referral to SALT service for an assessment if there are concerns and if the baby is not already known to the service'

Examination

ECHO hearing and vision

Any unusual or recurrent infections

Discuss immunisation – encourage routine primary immunisation to be done in primary care setting unless immunity issue identified

Discuss family adjustment to the diagnosis

Plot growth/development on the Down Syndrome chart in records and in the Red Book

Referrals

(Check on referrals already made, and consider any new needs identified)

Verbal notification to the Physiotherapist and recommend initial assessment to parents

Discuss Disability Living Allowance (DLA) (note that this is often more successful when applied for at 6 months but it is good to start the process, 3 months before application can be made)

Genetic counselling if parents wish

Refer to the SALT service if there are concerns regarding the baby's emerging early communication skills'

6 Month Review

Unless complex, child already under Health Visiting Service (with open access to advice from Neurodisability service if needed)

Discussion

(As for 3 months) Discuss immunisation ,encourage routine primary immunisation plus advise annual influenza vaccine within primary care if applicable

Reinforce support network i.e. PADS, DSNE, PCF

Examination

(As for 3 months)

Referrals

Check that the newborn hearing screen results are known and follow-up organised.

Refer to SALT service if there are concerns regarding the child's early communication skill development, or concerns regarding eating, drinking and swallowing

Inform Pre-school education team/ Inclusive Education team and Educational Psychologist for the child's area (i.e. Small Steps Hartlepool, Early Years Stockton, initial notification to add to any waiting lists for when service is needed)

Ensure physiotherapy input if any particular concerns about motor development including extreme hypotonia

1 Year Review

Refer to SALT service if there are concerns regarding the child's speech, language and communication development, or there are concerns regarding eating, drinking and swallowing, where there is concern that these difficulties are having a negative impact on the child/young person's function, quality of life, achievement, or safety

Discussion

Parental concerns developmental progress, general health, including full history of any respiratory, cardiac, or bowel symptoms (have a low threshold for investigation of coeliac disease)

Any unusual or recurrent infections

Sleep-related upper airway obstruction. If clinical symptoms are present discuss need for overnight saturations with ENT/refer. Arrange for those who are asymptomatic to have oximetry /sleep study at 2 years of age.

Consider need for behaviour therapy and educational input - Early Support Nursery/Small Steps

DLA and other benefits - signposting for help

Cervical spine and atlanto-axial instability and give information leaflet (please see DSMIG guidelines)

Discuss immunisation – encourage routine primary immunisation plus annual influenza vaccine Consider need for booster jabs if required Reinforce support network i.e. PADS, DSNE, PCF

Examination

Full clinical examination with particular attention to the following: Cardiovascular Neurological - Look for any signs of cervical spine instability or cord compression, ENT - Signs of middle ear disease or upper airway obstruction), eyes - squint, cataract, nystagmus or blepharitis

Nasolacrimal duct obstruction sometimes needs referral

Check hips/knees/foot position

Growth - Plot on the Down Syndrome charts and also the child's Red book

Referrals

Audiological assessment should be carried out at least once a year but more often as needed

Thyroid function tests (T4, TSH and thyroid autoantibodies). If a finger-prick/ spot test is done for TSH only this must be repeated yearly

Annual oximetry/sleep study (as indicated)

Check immune function (including lymphocyte subsets) - if 4 or more infections over a 6-month period/ admission for sepsis (check at least 4 weeks after completion of primary immunisation course)

2 Year Review

Refer to SALT service if there are concerns regarding the child's speech, language and communication development, or there are concerns regarding eating, drinking and swallowing, where there is concern that these difficulties are having a negative impact on the child/young person's function, quality of life, achievement, or safety

Discussion

Parental concerns developmental progress, general health, including full history of any respiratory, cardiac, or bowel symptoms (have a low threshold for investigation of coeliac disease)

Any unusual or recurrent infections

Sleep-related upper airway obstruction. If clinical symptoms are present refer to ENT and/or repeat sleep study/behaviour- emerging co-morbidities
Therapy and educational input DLA and other benefits - Signpost for support if needed

Cervical spine and atlanto-axial instability

Discuss immunisation – advise re: annual influenza vaccine and Pneumovax II if child in “ at risk group” for pneumococcal infection

Examination

Full clinical examination with particular attention to the following: Growth - Plot on the Down Syndrome charts and also the child's Red book
Cardiovascular Neurological - Look for any signs of cervical spine instability or cord compression

ENT - Signs of middle ear disease or upper airway obstruction eyes – squint, cataract, nystagmus or blepharitis

Nasolacrimal duct obstruction sometimes needs referral

Investigations

Audiological assessment should be carried out at least once a year but more often as needed

Thyroid function tests (T4, TSH and thyroid autoantibodies). If a finger- prick/ spot test is done for TSH only this must be repeated yearly

Low threshold for screening for coeliac disease

Annual oximetry where indicated

Ensure child known to Early Years Team/Educational psychologist

Referral to Paediatric ophthalmology where indicated

Hip screening – for any child not yet weight bearing request hip x-ray and ensure physiotherapy input

3 Year Review

Refer to SALT service if there are concerns regarding the child's speech, language and communication development, or there are concerns regarding eating, drinking and swallowing, where there is concern that these difficulties are having a negative impact on the child/young person's function, quality of life, achievement, or safety

Discussion

Parental concerns developmental progress, general health, including full history of any respiratory, cardiac, or bowel symptoms (have a low threshold for investigation of coeliac disease)

Any unusual or recurrent infections

Sleep-related upper airway obstruction. If clinical symptoms are present repeat sleep study and/or refer/discuss with ENT otherwise refer to Tees Valley Sleep Service <https://teesvalleysleepservice.co.uk/>

Behaviour therapy and educational input DLA and other benefits signposting for support if needed cervical spine and atlanto-axial instability

Discuss immunisation – advise re: annual influenza vaccine and Pneumovax II if child in “ at risk group” for pneumococcal infection

Examination

Full clinical examination with particular attention to the following: Growth - Plot on the Down Syndrome charts and also the child's Red book

Cardiovascular Neurological

Look for any signs of cervical spine instability or cord compression ENT - Signs of middle ear disease or upper airway obstruction Eyes - Squint, cataract, nystagmus or blepharitis.

Nasolacrimal duct obstruction sometimes needs referral

Investigations

Audiological assessment should be carried out at least once a year but more often as needed

Thyroid function tests (T4, TSH and thyroid autoantibodies). If a finger- prick/ spot test is done for TSH only this must be repeated yearly

Annual oximetry low threshold for investigating for coeliac disease multi-agency MDT review meeting (including Education) for children with complex needs, arranged around the third birthday to include all agencies

4 Year Review (As for Three Year Review)

Refer to SALT service if there are concerns regarding the child's speech, language and communication development, or there are concerns regarding eating, drinking and swallowing, where there is concern that these difficulties are having a negative impact on the child/young person's function, quality of life, achievement, or safety

Consider <https://teesvalleysleepservice.co.uk/> for any sleep issues

Sleep-related upper airway obstruction

Annual oximetry/refer for sleep study

Thyroid surveillance low threshold for coeliac screening

5 year review Year Review + subsequent annual reviews

(As for other reviews) Refer to SALT service if there are concerns regarding the child's speech, language and communication development, or there are concerns regarding eating, drinking and swallowing, where there is concern that these difficulties are having a negative impact on the child/young person's function, quality of life, achievement, or safety

Full Clinical Examination

Ensure DSMIG checks are continuing as per schedule. (Investigations, thyroid, coeliac etc)

Unusual or recurrent infections and sleep related upper airway obstruction, if no clinical symptoms refer to <https://teesvalleysleepservice.co.uk/>

Refer to ENT if symptoms present

Discuss therapy and educational input and consider referrals to specialist dentist and orthotics for boots

Are the family aware they can apply for Disability Living Allowance, if not already in receipt of this? if unaware signpost for support

Discuss immunisation and influenza annual vaccine discussion about puberty, sex and relationship education when the time is appropriate at annual review

Discuss behaviour

School Age Reviews (annual reviews)

Refer to SALT service if there are concerns regarding the child's speech, language and communication development, or there are concerns regarding eating, drinking and swallowing, where there is concern that these difficulties are having a negative impact on the child/young person's function, quality of life, achievement, or safety

Discussion

Parental concerns developmental progress, general health focusing on symptoms of disease known to be more common in Down Syndrome, in particular coeliac disease which may present atypically

Any unusual or recurrent infections

Behaviour

Dental care

Menarche and menstrual management, therapy and educational input

Advice regarding cervical spine instability (a useful resource for screening prior to participation in competitive sport can be found at www.british-gymnastics.org/technical-information/discipline-updates/disabilities/11985-atlanto-axial-instability-information-pack-2021/file

Check benefits e.g. mobility bus pass

Check access to other services e.g. sport, clubs

Discuss immunisation – advise re: annual influenza vaccine and Pneumovax II if child in "at risk group" for pneumococcal infection

Examination

Growth - Plot on Down Syndrome chart and Red Book (according to guidelines plot on BMI charts if child is on or above the 75th centile for weight)

Neurology - look for any signs of cervical spine instability or cord compression

ENT - Middle ear disease and obstructive sleep apnoea

Eyes - squint, cataract, blepharitis and keratoconus

Cardiac status

Orthopaedic problems e.g. foot posture or scoliosis

Investigations

Audiology to be carried out yearly which should be automatic, unless the family repeatedly DNA. If so, keep referring but discuss reasons for DNA.

Yearly Ophthalmological assessment. If the Child has not had any visual problems annual vision check by school nurse or optician is sufficient

Thyroid function tests (T4, TSH and thyroid autoantibodies) every two years, more frequently if any suspicion of thyroid disease. If a finger prick/spot test is done for TSH only this must be repeated yearly

Community Paediatrics – Down Syndrome Pathway

School Leaver Review/Transitions (around 13 to 14 years)

(As for Annual Review)

Use Ready, Steady, Go model to plan for transitions

Refer to Trust Transitions Co-ordinator where possible

Discussion

Review of health to date

Requirements for ongoing care

Further education and adult placement

Preparation of medical report for GP, carers and the young person testicular examination – discuss if self-examination is appropriate or alternative arrangement as testicular tumours are more common in Down Syndrome

Fertility and need for contraception

Referrals

Transition co-ordination Social Care Team if mental health issues present Adult Learning Disability Team, where necessary GP for ongoing surveillance

Investigations

Audiology, vision, thyroid function, echocardiogram (A repeat is now recommended in early adult life, because of the high incidence of mitral valve prolapse and aortic regurgitation in adults with Down Syndrome who are asymptomatic

Discuss therapy and educational input and consider referrals to specialist dentist and orthotics for boots.

Are the family aware they can apply for Disability Living Allowance, if not already in receipt of this? if unaware signpost for support

Discuss immunisation and influenza annual vaccine

Discussion about puberty, sex and relationship education when the time is appropriate at annual review.

Discuss behaviour

Appendix 1 – Audiology for Children’s Services – NTHFT

Before Birth

Not known to audiology

3. Birth to three years

- If hearing screening is not satisfactory babies are referred into audiology according to national protocols. Referral can be to audiology at Hartlepool or James Cook hospital
- Children identified with Down Syndrome are added to routine follow up to begin at 7-9 months
- Prior to first contact with the Hartlepool service a telephone appointment will be arranged to discuss readiness for testing and any preferences or needs to assist with the appointment
- Prior to appointments at JCUH an easy read leaflet will be shared with the family to help prepare for the appointment
- Testing for children with satisfactory hearing is around 6 monthly until 2 years old but annually at a minimum i.e. needs led, tests taken during optimum time for testing and when most likely to be successful for the individual child but not longer than 12 months
- Children with identified hearing loss will be reviewed more often but annually at a minimum
- Any children who have not been seen by 12 months old will have a risk assessment and be chased more actively to encourage engagement with the service

5. Five to Eleven Years

- We offer annual hearing assessment
- Children with identified losses will be reviewed more frequently
- Children who we feel benefit from more frequent appointments in order to provide a more consistent approach are offered this

2. At Birth

- Neonatal hearing screening is completed and referral into audiology will be made if screening is unsatisfactory for immediate follow up
- If Down Syndrome has been confirmed at the time of hearing screening the hearing screeners will alert this for routine follow up to be arranged

4. Three to Five

- We continue to offer annual hearing assessment
- Children with identified losses will be reviewed more frequently
- Children who we feel benefit from more frequent appointments in order to provide a more consistent approach are offered this
- Individual needs assessed and referred to JCUH as and when appropriate. Referrals to include any individual preferences or needs to be considered prior to the appointment

6. Secondary School Age (11 – 18 Years)

- We offer annual hearing assessment
- Children with identified losses will be reviewed more frequently
- Children who we feel benefit from more frequent appointments in order to provide a more consistent approach are offered this
- Transition into Adult Services when appropriate and reviewed more frequently, minimum biannually

NB: Hearing aids batteries for all ages can be collected from Hartlepool Hospital or if specialist can be posted by James Cook Hospital

Ophthalmology

Birth to 6 weeks

- Check visual behaviour
- Check red reflex for congenital cataract and other congenital abnormality such as coloboma of the iris
- Refer urgently to Ophthalmology if problem identified/suspected at this stage

3 Month Review

- Check visual behaviour and red reflex as previously
- Refer to Ophthalmology if any concerns are raised

6 Month Review

- Check visual behaviour and red reflex as above
- Look for presence of nystagmus, either on fixation of target or when following
- Look for presence of squint
- Ask about any parental concerns regarding visual behaviour
- Refer to Ophthalmology if any concerns

1 Year Review

- Check as above
- Problems with nasolacrimal duct may be a problem so consider referral for this if parents are concerned
- At age 18/12 an alert on SystmOne to alert Health Visitor of need to refer to Orthoptic Screening for routine review. Attendance at a local screening clinic will be followed by a referral to an Ophthalmologist regardless of outcome

2 Year Review

- Check that referral to Orthoptic/Ophthalmic Screening has taken place. If not it is recommended that at this stage all children should be reviewed by an Ophthalmologist for a fundus and refraction check. The assessment will also include an orthoptic assessment to check vision levels and presence of squint
- Paediatricians and GPs can refer directly Ophthalmology
- Health visitors can refer to orthoptic screening following which the child will be referred on to Ophthalmology

6. 3 and 4 Year Review

- Checks as above including squint
- Check that referral and attendance at the eye clinic has taken place
- If unclear then refer to Ophthalmology

6. Ongoing

- Annual review by Optometrist (in the community) or Ophthalmology if not suitable to be seen in the community

Speech and Language Therapy

Before Birth

- Speech and Language Therapy (SALT) Service not involved at this stage

3. Birth to three years

- SALT open referral service
- Sucking and swallowing
- Chewing and cup drinking skills
- Parent-child interaction, language comprehension, Makaton sign, verbal memory, sound awareness, modelling speech articulation, vocabulary development
- Assessment and intervention at home, clinic, early education setting
- Skilling up primary partners
- Provision of written information/report
- Liaison with MDT
- Signposting services including information and support services
- Provision of EHCP assessment report

NB:

- SALT available across the 0-19 range
- Onward referral to post-19 SALT service
- Intervention provided based on clinical need
- CYP may move in and out of SALT service at different stages
- Education and training provision on a needs basis

6. Secondary School Age (11 – 18 Years)

- As per box 3, 4 and 5 with the addition of
 - Provision of SALT service up to 19 years old
 - Assessment and intervention at secondary school (mainstream and SEN provision), college of FE, residential setting etc)

2. At Birth

- SALT open referral service
- Disorder of sucking and swallowing impacting on oral feeding
- Concern about aspiration of fluids
- Assessment and intervention on the hospital ward
- Skilling up primary partners
- Provision of written information/report
- Liaison with MDT
- Signposting services including information and support services

4. Three to Five

- SALT open referral service
- As per box 3 with the addition of:
 - Targeted assessment and intervention for speech sound production
 - Phrase and sentence building
- Assessment and intervention as per box 3 with the addition of:
 - School-based assessment and intervention (mainstream and SEN school provision)

5. Five to Eleven

- SALT open referral service
- As per box 3 with the addition of:
 - Targeted assessment and intervention for speech sound production
 - Phrase and sentence building
- Assessment and intervention as per box 3 with the addition of:
 - School-based assessment and intervention (mainstream and SEN school provision)

Episode of Care Model

- Intervention delivered when it is clinically indicated
- Intervention is delivered by the right person, with the right skills, at the right time, and in the right place
- Children/young people will flow in and out of the service based on changing clinical need over time. Each new reason for contact will require a new referral that will be triaged appropriately and generate a new episode of care
- Primary Partners, e.g. parents, carers, teachers will become the 'therapist' delivering intervention

Occupational Therapy

Before Birth

- Occupational Therapy are not involved at this time



2. At Birth

- Occupational Therapy are not involved at this time



3. Birth to three years

- Occupational therapy assessment of child's development/functional skills e.g. fine motor skills, feeding
- Education and advice to parents/carers/nursery on how to promote the development of the child's functional independence skills
- Implement Occupational Therapy programme in liaison with parents/ carers and all professionals involved with the child
- Specialised equipment assessment/provision including – not including equipment needed for home/home adaptations this is Social Services OT
- Environmental assessments and removing barriers to function e.g. toileting
- Liaison with MDT
- Provision of report/ EHCP.



4. Three to Five

- As per box 3 with the addition of
- Support for sensory needs with ASD diagnosis.
- Sunflower service for age 4 to 11



5. Five to Eleven Years

- As per box 3 and 4



6. Secondary School Age (11 – 18 Years)

- As per box 3 and 4
- Sunflower service until age 11

Physiotherapy

Before Birth

- Paediatric Physiotherapy (PT) not involved at that stage

2. At Birth

- PT is a needs led service with open referral
- Allocation of a named Therapist
- Discussion with parents/carers on general presentation ie low tone and its influences on global development
- Advice on handling and positioning – considering tonal changes
- Advice on postural aids
- Liaison with MDT
- Signposting to other services including consideration of local offer and groups such as waterbabies, kalma baby
- Ward assessment/intervention if indicated/referred
- Respiratory care if indicated/referred
- Sensory Integration (babies) trained Therapist – involved if sensory issues are identified – this will be needs led

3. Birth to three years

- As 2
- Continued neurodevelopmental assessment – including gross and fine motor and patterns of movement
- Identification of need for specialised equipment including referrals to other services – Orthotics
- Provision of specialised equipment – linking in with company representations for assessment
- Continued management of respiratory needs
- Involvement in EHCP process
- Lycra provision service

4. Three to Five

- As 2&3
- Assess and treat within school/nursery setting – including specialised equipment provision
- Specialised equipment assessment with company Reps
- Continued assessment of 24 postural management
- Referral to MDT – other paediatric therapy services – Occupational Therapy (OT)
- Pain management
- Continued involvement in EHCP process

5. Five to Eleven Years

- As 2,3,4
- Identification of change in needs across different environments
- Recognition of physical growth

6. Secondary School Age (11 – 18 Years)

- As 2,3,4,5
- Continued liaison with MDT and Paediatric Therapy Services (OT)

Dietetics

Before Birth

Challenge: Neural tube Defects (NTD)

- Although not specific to those with a pregnancy of a baby with suspected Down Syndrome, a Dietitian can ensure that a woman meets recommended levels of:
- 400µg/daily Folic Acid prior to pregnancy and until 12 weeks of pregnancy, achieved via diet and through supplementation
- This may be increased if there is a suspected higher chance of pregnancy being affected by Neural Tube Defects

2. At Birth

Challenge: Poor suck reflex which can lead to feeding difficulties

- If the sucking reflex is delayed:
- Provide information and advice on nipple shields and/or appropriate bottle teats to support bottle feeding rates
- Provide information on the benefits of expressing breast milk (e.g., antibody content, nutritional specificity to baby)
- Provide information surrounding the nutritional needs at birth, this can include:
If exclusively breastfeeding: Vitamin D Supplementation for Mum, Vitamin D supplementation for baby

3. Birth to three years

Challenge: Weaning

- Explore and provide dietary advice and information on more appropriate weaning foods for babies with Down Syndrome, as poorer tongue coordination and low muscle tone can make weaning more challenging in those with Down Syndrome
- If faltering growth is present, offering advice and guidance on how to increase nutritional intake to meet growth needs

5. Five to Eleven Years

Challenge: Constipation in those with Down's Syndrome

- Assess current fluid and fibre intake, comparing this against recommend levels of:
 - Fluid 6-8 glasses/daily of fluid3
 - Fibre 15-20g/daily (subject to age)2
- Offer practical tailored dietary advice to increase fluid and fibre intake to help alleviate feelings of constipation in this population

4. Three to Five

Challenge: Assessing growth appropriately

- Although not specific to this age-range, a Dietitian can appropriately assess a child with Down Syndrome growth against growth charts suitable for this population. These are published by The Royal College of Paediatrics and The Down's Syndrome Medical Interest Group

Challenge: Allergies, intolerances, deficiency, or food-related disease

- Although not exclusive to those with Down's Syndrome or this age range, a Dietitian can help to support surrounding:
 - Cow's Milk Protein Allergy
 - Coeliac Disease
 - Food-specific allergies
 - Iron-deficiency anaemia

0 to 19 Team - Hartlepool

Before Birth

- Pregnant mothers are all offered antenatal screening
- Antenatal Home visit from named health visitor - Health Needs Assessment
- Pregnancy Birth and Beyond Group
- Breastfeeding workshop
- HV to signpost to Down Syndrome Association/DSNE for parents to contact and obtain a new parents pack , you and your baby
- Midwifery face to face liaison – with named midwife

3. Birth to three years

- HV completes New Birth Visit at 10-14 days – Health Needs Assessment, needs led approach
- Promote Children Centre groups – baby massage, all about feeding , baby resus, weaning support , Children Centre play groups – sing and sign, Ready to Grow and Learn Groups
- Offer partnership plus pathway
- Offer mandated development reviews
- Signposted to Down Syndrome Association/DSNE/PADS
- Consider referral to Small Steps – Educational Psychologist team
- Referral to Sunflower Sensory Service – Children's Occupational Therapy
- Consider Early Help
- Referral to SEND services – plan Educational Health Care Plan preparation and assessment to be made
- Liaise with education in readiness for 2 yr nursery provision
- HV to liaise / refer to specialist services dependant on individual need, eg physio, SALT, audio, vision screening , ENT, Consultant Paediatrician etc
- Promote Hartlepool One heart One Mind, One future

5. Five to Eleven Years

- School Nurse overview of continued support from Specialist services in school setting and access to curriculum
- Continue to offer health reviews with Consultant and specialist services
- Continue to offer support from Down Syndrome Association

2. At Birth

- NIPE examination within 72 hours
- New Born Hearing Test
- Birth Notification to HV Team
- Named Health Visitor to be invited to pre discharge meeting (MDT) (Dependent on length of stay)
- Down Syndrome Growth Chart to be inserted in PHR
- Partnership working with named Midwife
- Check referrals completed prior to discharge home have been received
- Discuss ongoing health needs on an individual basis
- Reinforce signposting to local charities and groups
- Signpost to West View Advice Resource Centre / Citizens Advice regarding financial support – Disability Living Allowance application

4. Three to Five

- To continue to support family as partnership plus
- Liaise with education setting
- Referral into school nursing team (Named School Nurse Assigned)

6. Secondary School Age (11 – 18 Years)

- School Nurse overview of continued support in education setting
- School nurse overview of continued ongoing support to the young person by specialist services, eg physio, OT, Consultant Paediatrician
- Plan transient into Adult services

0 to 19 Team - Stockton**Before Birth**

- Antenatal visit will be arranged by named health visitor
- Antenatal diagnosis from screening team to be shared by midwife to named HV
- Tailored ante natal visit dependent on need (i.e. Enhanced Visiting Pathway)
- Antenatal breastfeeding advice and education sessions can be provided from GWGH infant feeding team before baby is born
- Option for unborn and family to be on the specialist 0-19 practitioner case load
- Family health needs assessment commenced to identify need and look at what services are needed

3. Birth to three years

- Early Support as a possible referral depending on needs
- Referral into GWGH infant feeding to provide breast feeding support at home
- Proactive breastfeeding support can be offered and tailored to meet the needs of mum and baby
- Starting solids and progressing with solid food support
- Deliver mandated contacts and targeted visits as needed
- Consider for Enhanced Visiting Pathway if wider family vulnerability identified
- Make any appropriate referrals that have not been previously done especially to early support service
- Linking child and family in to appropriate SEND services and support in Stockton
- Signposting to Family Hubs
- Support and signpost with DLA
- Consider early help and key working
- Support with appropriate nursery placement
- Consider if request to assess for EHCP is needed
- Support transition into nursery / school setting

5. Five to Eleven Years

- Access to 0-19 service if required
- Support transition if required
- Deliver any ongoing or new targeted interventions
- We provide support around any and all continence issues at the tier one level to children and young people in the Stockton 5-19 area
- We accept referrals around daytime wetting, night time wetting, poo issues – including soiling, smearing, stool withholding and we also provide support around toilet training
- We offer positive encouragement and support to help children and families achieve increased continence and in turn improve their overall well-being
- If there is no improvement after the tier one advice has been implemented and it is agreed that further support is needed we will refer on to the Specialist Children's continence service

2. At Birth

- New birth visit by named health visitor between 10 -14 days. If baby is in hospital then a more suitable time will be arranged with parent
- Notified by midwifery services baby born with Down Syndrome
- Re visiting and building upon Health Needs assessment and new assessment of baby
- Consider for Enhanced Visiting Pathway programme if wider family vulnerability identified
- New birth visit between 10-14 days if baby is neonates or hospital will link in with acute setting and family and attend “pre discharge” meeting on ward dependent on LOS
- Will undertake enhanced visiting dependent on need and what support family require which will be over and above the mandated contacts

4. Three to Five

- Deliver mandated contacts and targeted visits as needed (including 3-4 year review)
- Consider for Enhanced Visiting Pathway programme if wider family vulnerability identified
- Make any appropriate referrals that have not been previously done especially to early support service
- Linking child and family into appropriate SEND services and support in Stockton
- Signposting to Family Hubs and HENRY Programme
- Support and signpost with DLA
- Consider early help and key working
- Support with appropriate nursery placement
- Consider if request to assess for EHCP is needed
- Support transition into nursery / school setting

6. Secondary School Age (11 – 18 Years)

- Access to 0-19 service if required
- Support transition if required
- Deliver any ongoing or new targeted interventions
- Continence support as at 5 to 11 years
- Bespoke intervention through the Growing Well Growing Healthy Team.
- GWGH - one to one intervention in the home
- Group GWGH intervention in the community
- GWGH Digital intervention online (which supports all other intervention pathways)
- GWGH 12 months support including up to 12 weeks intervention shaped on the needs of the family and child, follow up events with Tees Active, in the community or at home



Positive about Down syndrome provides information and support to new and expectant parents of a little one with Down syndrome.

We have amazing online support for our families, we know how important it is for them to have access to our book #NobodyToldMe the truth about Down syndrome to families and literature to maternity units.

We have recently introduced online early development groups for our preschoolers baby makaton signing courses for new parents and makaton training for members nurseries/childminders

We believe every parent should receive the best possible care and support.

We believe the arrival of every baby with Down syndrome should be celebrated.



Down syndrome NE is the leading organisation for the help and support of all people with Down syndrome and their families and friends we cover Northumberland Tyneside wearside Durham and Teesside



www.pcp.uk.net/together-21

References and Acknowledgements

Stockton Parent Carer Forum (and associated parent carers)

HDDFT Stockton

North Tees and Hartlepool NHS Trust

With thanks to

Physiotherapy

Occupational Therapy

Speech and Language Therapy

Dietetics

Neonates

Midwifery/Antenatal Screening Team

Communications

Audiology

Paediatrics

Growing Well Growing Healthy Team – Stockton Local Authority

PADS (Positive About Down Syndrome)

Down Syndrome North East

Hartlepool Parent Carer Forum (and associated parent members)

Hartlepool Health Visiting and School Nursing Team

South Tees Hospitals Foundation Trust

With thanks to

Ear Nose and Throat

Audiology

Ophthalmology

Sleep Team

Hartlepool Local Authority

Stockton Local Authority



North Tees and Hartlepool
NHS Foundation Trust



STOCKTON
PARENT CARER FORUM



North East and
North Cumbria