COMBINED CARE PATHWAY FOR CHILDREN AND YOUNG PEOPLE WITH DOWN SYNDROME

BARNET HOSPITAL AND COMMUNITY SERVICES

ROYAL FREE LONDON NHS FOUNDATION TRUST

Review date: 9th December 2021

"You have absolutely no idea the difference having a team invested in your child makes. This pathway brings expertise in Down syndrome along with an entire network of people working together. Seriously, it's amazing! This is a huge amount of work and we know a lot of it was in people's own time - it is an incredible achievement in such a short space of time. Do not underestimate how important this piece of work is and most importantly the difference it will make to so many children and their families". – Anna Petsas, parent of a child with Down Syndrome.

This Pathway was developed in partnership with parents, carers, education, social care and health professionals and those living with Down Syndrome (Spring 18 to Winter 2020). This pathway will be reviewed annually and updated accordingly, through the Barnet Leading Edge Group (LEG) for Children and Young People with Down Syndrome. The document is strategically managed via the SEND Development Group and Partnership Boards. If there are any errors or changes that should be made please email corrections to Dr E. Rachamim: erachamim@nhs.net

The most up-to-date version of this pathway can be found on Barnet Local Offer page: https://www.barnetlocaloffer.org.uk

Introduction

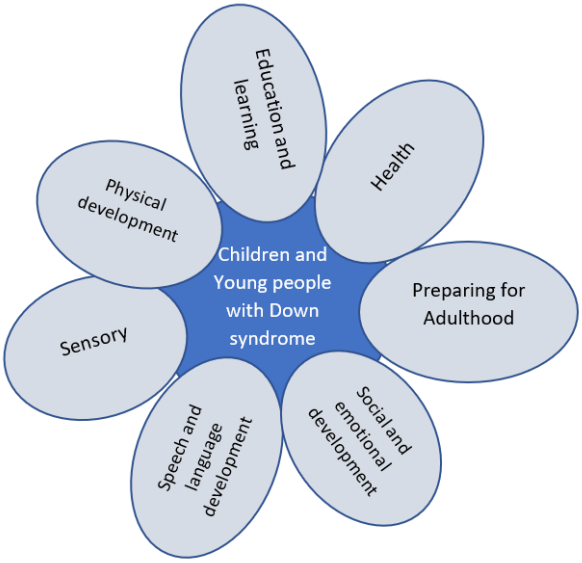
Any person who has Down Syndrome (DS) is a person first. As with any child or adult, they will have their own unique personality and attributes. It is important to remember that having Down Syndrome does not define them.

Down Syndrome is the commonest autosomal anomaly, present in 1 in 600-700 live births. About 95 percent of people with Down Syndrome have trisomy 21, where there is an extra number 21 chromosome in every cell of their body. Three to 4 percent of people with Down Syndrome have translocation Down Syndrome, where all or part of the extra number 21 chromosome is attached to another chromosome. The remaining 1 to 2 percent of individuals with Down Syndrome are mosaic, where there are at least two types of cells, some with the usual number of chromosomes (46 total), and others with an extra number 21 chromosome (47 total).

In Barnet there are approximately 6 live births per year of babies who are diagnosed with Down Syndrome. Some families know that their child is going to be born with Down Syndrome due to screening processes, while other families have no indication that their child will have Down Syndrome until they receive a diagnosis after birth.

Even though everyone who has Down Syndrome is different, there are some clinical features present at birth, and some health conditions they may be more prone to. (More information for parents can be found here: https://www.healthforallchildren.com/wp-content/uploads/2013/04/A5-Downs-Instrucs-chartsfull-copy.pdf and for professionals here: https://www.downs-syndrome.org.uk/download-package/top-tips-for-triaging-treating-children-with-downs-syndrome/)

Scope of the Combined Care Pathway



There are many factors that impinge on the life opportunities of children and young people with Down syndrome. The combined care pathway aims to deliver:

• The right people • In the right order • In the right place • Doing the right thing • In the right time • With the right outcomes • All with attention to the patient experience

Feedback from families has identified the need for a clarity and consistency in the care of children with Down Syndrome. We have collaborated closely with families, and multidisciplinary representatives from Community Services, Barnet Hospital, Education, Therapy Services, Community Paediatricians, Royal Free Hospital Trust to devise a combined care pathway that is based on national guidelines and applicable to our local services and community. We recognise that transition to adult services can be a worrying time for many families and have incorporated this within the pathway to allow transparency and reassurance that appropriate care and support continues into adulthood.

This pathway will enable people to navigate their way through the relevant health, and integrated services to ensure no one who has Down Syndrome gets 'left behind'. It is effectively putting all the health and therapies information pertinent for people with Down Syndrome in one place emphasising the need for combined care. The pathway does

not replace those services that all children and adults have access to; e.g., GP services, Midwifery, Health Visiting, School Nursing, 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 by some people who have Down Syndrome. The pathway also signposts education and social care services.

Appendix 1 details which services are covered dependent on GP and home address

Authors

Dr Ella Rachamim, Community Paediatrician, Barnet CDT, Child health HQ, Edgware General Hospital, Burnt Oak Broadway, London HA8 0AD

Mrs. Sandra Redman, Pre-school Support Teacher and Lead for the Barnet Integrated Group for Down Syndrome.

Dr Christine Jenkins, MB BS, BSc, FRCPCH, FRCP, DCH, DRCOG, MRCGP. Consultant Paediatrician, Community Child Health. Barnet Community Paediatric Team. Royal Free London NHS Foundation Trust

Dr Anisha Soor, ST6 Paediatric Trainee, Royal Free NHS Trust.

Dr Anna Petsas, parent representative for Barnet Leading Edge Group for DS.

Acknowledgements

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 and in association with the Down Syndrome Association (**see Appendix 2)**

We would also like to acknowledge the work done by Nottingham Down Syndrome Children's Services, Leicestershire Partnership NHS Trust and Hull in developing and sharing their team pathways.

Thank you

Thank you to Sue Bills for starting this all off with the ever-expanding Multi-Disciplinary Team (MDT) and mostly thank you to all of you that came on that day – we did it! We have tried to mention you in your specific sections.

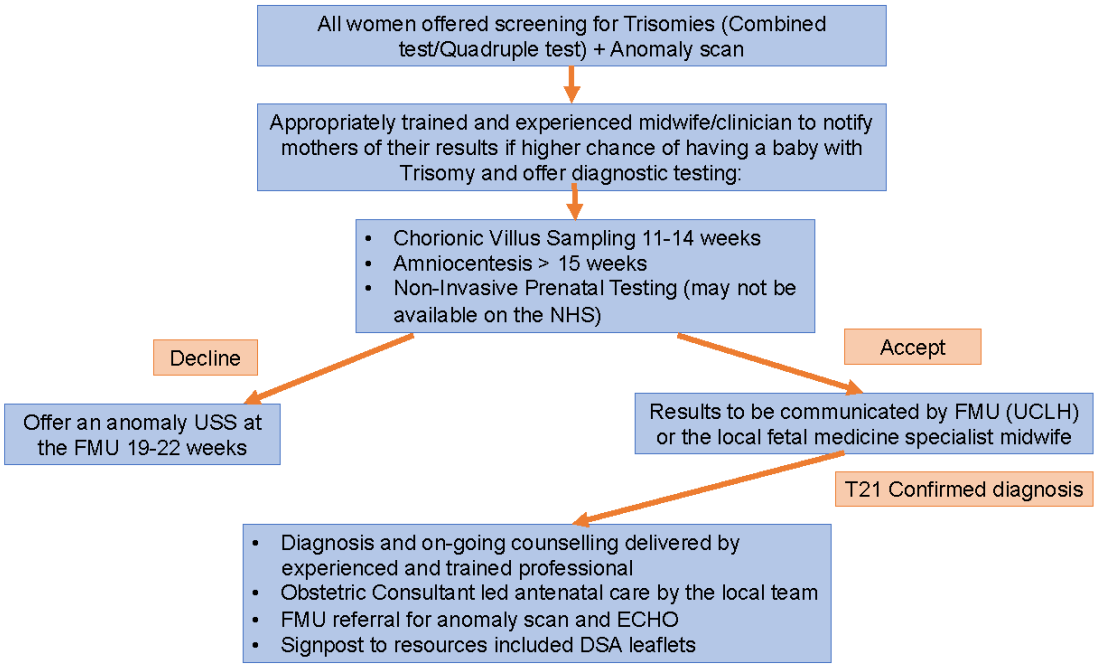
Thank you specifically to Dr Shpilberg for her contribution to the neonatal pathway, to Dr Nagendran for her hard work and dedication, to ALL the parents and children we have had the pleasure to meet, to Sarah Geiger for her patience and effective time-management, to Richard Gurney for his support, to parents Aviva for striving for inclusivity, Marilia for her honesty and Lucy for her editing, to Dr Gita Croft for giving Ella a first glimpse of what good care for children and young people with Down Syndrome (DS) could look like, to the Child Development Team for their strength and support, to the hospital based paediatricians, neonatologists and obstetric teams for setting such high standards of care and to the tertiary specialists Dr Tan, Dr Rosenthal, Dr Abel and Dr Colin Wallis who ~~a~~nswered our constant queries, well into the night. Last but not least to our colleagues from the Down Syndrome Medical Interest Group (DSMIG) for their inspiration and dedication.

Contents

Please note: During the Covid-19 pandemic, some services in this document are only being offered virtually, so please do check.

Antenatal pathway

Screening for Trisomy's in Pregnancy



Antenatal diagnosis of Trisomy 21

- At Barnet Hospital, Chorionic villous sampling (CVS)/Amniocentesis is offered to pregnant women with a screen positive result on their combined or quadruple screening test. Women are given an appointment at the University College London Hospital (UCLH) Fetal Medicine Unit (FMU).
- NIPT (non-invasive prenatal testing) is not offered to women as one of their options for the management of a screen positive result at Barnet/Royal Free hospital Trust (2020). However, the women who are seen at UCLH, are often offered NIPT as part of the care package there.
- Questions can be directed to Laura Bouma, Fetal Medicine Specialist Midwife, Royal Free London NHS Foundation Trust, Monday – Friday, 8am to 4pm, Telephone: 0208 216 5140, Internal extension: 65140.

1. The results from diagnostic testing should be communicated directly to the family and to the local fetal medicine specialist midwife by the Fetal Medicine Unit (FMU).
2. The local midwifery team should offer a face-to-face appointment (within hospital policy access arrangements) to the woman and family to discuss the diagnostic test results with the local fetal medicine specialist midwife.
3. Test results confirming a diagnosis of Trisomy 21 and subsequent counselling should be given by a trained and experienced professional, in an open, honest and non-judgmental manner. For staff training and guidance in communicating diagnoses of T21 please see:

   "Tell it Right" Training, organised by the DSA. **(Appendix 2)**
4. Pregnancies should be managed in an obstetric led unit.
5. The contact details for the local Child Development Team (CDT) should be available to the fetal medicine midwife and obstetric team in the event the family or medical team would like to discuss any specific queries with the CDT in the antenatal period (See **Appendix 1** for referral form and contact details). The CDT can also offer opportunities to meet with other families.
6. Women and families should be given the chance to ask questions and be sign-posted to further resources:

- Antenatal Results and Choices (ARC) website and helpline.
- Down's Syndrome Association (DSA) website
- Written information that can be downloaded e.g. "Looking forward to your baby" leaflet
- If anomalies have been diagnosed in pregnancy, families may benefit from the input of relevant specialist paediatric teams for post birth planning.

Management of Pregnancy

Issues relating to the pregnancy:

- There is an increased risk of the following in pregnancies with Down Syndrome:
- Prematurity – the average length of gestation is 38 weeks.
- CTG anomalies in labour – continuous monitoring may be required if identified risks have been ascertained e.g. growth restriction.
- Fetal loss – there is an increased risk of miscarriage, intrauterine fetal death, still birth and neonatal death

Issues relating to the fetus:

- Growth: babies with DS have a lower mean birth weight. Regular growth scans are recommended at 28, 34 and 38 weeks.
- Fetal movements: Fetuses with DS do not have reduced fetal movements, and any pregnancies with reduced fetal movements must be investigated.
- Hydrops: fetal anaemia can be assessed using middle cerebral artery Doppler velocities on ultrasound scan. Hydrops can be idiopathic, secondary to Transient Abnormal Myelopoiesis (TAM) or secondary to cardiac abnormality. Delayed cord clamping should be avoided in labour due to the increased risk of polycythaemia in DS.
- Transient Abnormal Myelopoiesis (TAM) is a pre-leukemic condition affecting up to 10% of neonates with DS and requires prompt referral to a fetal medicine specialist. It can present with hepatosplenomegaly and hydrops.
- Structural anomalies:
    - Congenital Heart Disease (CHD) is present in approximately 40-60% of babies with Down Syndrome. All fetuses should undergo a fetal ECHO.
    - Bowel Atresia may be identified by ultrasound in the third trimester or by the presence of polyhydramnios. If suspected, referral to the neonatal team/paediatric surgeons is required.
    - Brain: mild ventriculomegaly is common and does not require further investigation if identified in isolation.
    - Renal anomalies: Renal pelvis dilatation is more common in Down Syndrome and requires referral to paediatricians/nephrologists.

Neonatal Pathway

The first 24-48 hours

Confirming the Diagnosis

- Chromosomal analysis: Lithium Heparin sample (1-2mls) for rapid Fluorescence in situ hybridization (FISH) and karyotyping to Great Ormond Street Hospital before 12pm. If collected overnight or after 12pm the sample can be refrigerated and sent the following day. All antenatal (and postnatal) diagnoses requires repeat genetic testing after birth.
- An EDTA bottle for a microarray should also be considered if the diagnosis is unclear but there is a suspicion of an underlying genetic condition.
- FBC and blood film to be tested for in the first 2-3 days of life due to risk of polycythaemia, thrombocytopaenia and TAM. Request for the blood film to be reported by a Haematologist experienced at reviewing neonatal blood films.
- TSH as part of Guthrie card - Do not perform routine TFTs unless there is a clinical suspicion of thyroid disease. There is a surge of TSH after birth resulting in a higher concentration of T4 for the 1st week of life.

Communication:

- Deliver diagnosis of DS early if there is a high suspicion or confirmed postnatal diagnosis of DS.
- Diagnosis should be delivered early by an experienced professional.
- Give out appropriate leaflets and signpost to the Down Syndrome Association (DSA) website. Leaflets from the DSA include, 'Congratulations on the birth of your baby' and 'Down Syndrome: A leaflet for family and friends'.

The Neonatal Infant Physical Examination (NIPE) to be completed within 72 hours of birth.

- Performed by the neonatal team if there is a suspicion or confirmed diagnosis of DS.
- Aimed at diagnosing any associated complications
- Findings should prompt appropriate referrals and should be documented on the NIPE SMART system and discharge summary.

Documentation should include the following:

- Passage of meconium within 24 hours of life and presence of an anal opening (Hirschsprung's Disease and bowel atresias).
- Presence or absence of cataracts.
- Description of feeding including the type, frequency, volume, timing and quality of the suck. Clearly note the absence of coughing/ spluttering/ choking/ gurgling and cyanosis during feeding.
- Presence or absence of a heart murmur including pre and post ductal saturations, a 4-limb BP and ECG (or preferentially echocardiogram if available before discharge).

Period of observation:

All babies with a suspected or confirmed diagnosis should be monitored for jaundice, poor feeding and other associated complications for a minimum of 48 hours after birth. Individualised Care Rooms on the neonatal unit should be made available to all babies with DS and their mothers or fathers, enabling them to stay together whilst enabling full assessment/observation by the neonatal nurses. Barnet hospital is unique in having this kind of facility and the use of these rooms for neonates with DS has been agreed by the neonatal team. These rooms are available for mother and baby, once the mother is well enough to be discharged by the midwifery team. Community neonatal nurses to see all babies with DS, whether they are admitted or not.

Indications for admission to the neonatal unit include:

- Poor feeding requiring observation or nasogastric supplementation
- Oxygen requirement associated with underlying Congenital Heart Disease (CHD), Pulmonary Vascular disease (PVD) or respiratory pathology.
- Concerns regarding an underlying surgical pathology (bowel atresia, Hirschsprung's disease) e.g. bilious vomiting or failure to pass meconium.
- Polycythaemia requiring a dilutional exchange transfusion.

Prior to discharge - Further considerations, examinations, investigations and referrals:

Cardiovascular

The incidence of CHD in babies with DS is 40-60%. In 30-40% of cases there is a complete Atrioventricular Septal Defect (AVSD). Other common causes of CHD include Atrial Septal Defect (ASD), Ventricular Septal Defect (VSD) and Patent Ductus Arteriosus (PDA). Early diagnosis and referral for corrective surgery is important to reduce the risk of irreversible pulmonary vascular disease (PVD).

All babies with confirmed or suspected DS require:

- clinical examination and auscultation for heart murmurs.
- 4-limb BP
- pre and post ductal saturations
- Electrocardiogram (ECG) if the echo cannot be performed prior to discharge.
- An echocardiogram (Echo) should be performed in all babies with Down Syndrome including those who had a fetal echo, but the suggested time frame is dependent upon the clinical findings.

  If there are abnormal clinical findings or an abnormal ECG, particularly a superior QRS axis indicative of an underlying AVSD, aim to perform an echo as soon as possible and definitely within 2 weeks of birth. If they have been discharged home, arrange an urgent outpatient echo with Dr Wickham or Dr Laila Hamidi-Manesh.

  If there are no clinical or ECG abnormalities arrange an inpatient echocardiogram or outpatient follow-up with consultant paediatrician (those specialised in cardiac echo) as soon as possible and within 6 weeks of birth.

  .

Growth and feeding

Description of feeding including the type, frequency, volume, timing and quality of the suck should be documented. Clearly note the absence of coughing/ spluttering/ choking/ gurgling and cyanosis during feeding.

Factors which can impact on oral feeding include CHD, gastro-oesophageal reflux, hypotonia and respiratory problems. Parents and staff should be advised not to feed in the side-lie position but instead feed with the head above the level of the rest of the body given the risk of gastro-oesophageal reflux and Eustachian tube blockage.

A standard 23 week-term growth chart should be used if born prematurely. Once they have reached term switch to the Down Syndrome Growth charts kept on the neonatal unit. If the PCHR (red book) insert is available ensure all measurements are plotted on the relevant growth chart.

Weight loss may be more than 10% and it can take longer than 2 weeks to reach birth weight. The majority of babies with DS will be close to the same centile as their birth weight by 4 weeks of age. In cases where there is early weight loss of >10% with a slow recovery or failure to regain birth weight after 4 weeks of age, a thorough clinical review is required to exclude an underlying pathology.

Breastfeeding should be encouraged and supported for all mothers who wish to do so. Please provide additional midwifery support where required.

Refer all babies for a detailed feeding assessment performed ideally by the Infant Feeding Team who are contactable on 02082165141 or **rf.bhfeeding@nhs.net** at Barnet Hospital. This will be performed as an outpatient unless any of the following are present: an inadequate duration or volume of feed, choking, wheezing, spluttering, weak suck or coughing. In these cases, babies must be referred to the hospital based SLT dysphagia team +/- the infant feeding team. Have a low threshold for admission to the neonatal unit for naso-gastric feed supplementation if there are any feeding concerns. (**See Appendix 3 - Paediatric complex needs and dysphagia speech and language therapy (SLT) service).**

Gastrointestinal

There is an increased incidence of gastrointestinal abnormalities in DS which present in the neonatal period or first few months of life. Around 3% have an imperforate anus and this should always be examined for in the NIPE. The incidence of Hirschsprungs disease is around 2-15%, and may present with failure to pass meconium, constipation, abdominal distension and vomiting. Duodenal obstruction may be present in up to 5% of babies with DS and presents with features of small bowel obstruction. Tracheo-oesophageal fistulas are rare (1%) but requires prompt identification and management.

Hearing

50% of individuals with Down Syndrome have significant hearing impairment, either conductive and or sensorineural. Persistent Otitis Media with Effusion (OME) is the most common cause of conductive hearing loss.

All babies will have a Newborn Hearing Screen (NHS) performed prior to discharge. If the NHS is normal, the Community Paediatrician will complete an audiology referral for an assessment at 6 to10 months of age. If the Newborn Hearing Screen is abnormal, please refer to Audiology.

Vision

There is a 10-fold increased risk of cataracts in babies with DS. In addition, there is an increased risk of infantile glaucoma and nystagmus (present in 10% of the population with DS).

As part of the NIPE, be sure to exclude an absent red reflex and nystagmus and clearly document findings on the NIPE proforma and discharge summary. Refer to ophthalmology only if there are any abnormalities detected but there is no requirement for a routine referral.

Haematology

Neonates with DS have recognised differences in their blood cell morphology and counts, which are usually mild and benign and resolve spontaneously by approximately 3 weeks.

Polycythaemia – Approximately 20% of individuals with DS will develop Polycythaemia (Haematocrit> 0.65) as a result of increased intrauterine erythropoiesis. In cases where there is an antenatal diagnosis of DS, avoid delayed cord clamping. For management refer to the local guidelines for 'Polycythaemia'.

Thrombocytopenia – 50% of babies with DS tend to have a platelet count <150 x 109/L but it is important to consider other causes of thrombocytopenia e.g. Sepsis and IUGR. This tends to be asymptomatic and other than regular monitoring does not require further intervention.

Transient Abnormal Myelopoiesis (TAM) – this condition is unique to Down Syndrome and affects around 10% of babies. All babies with DS require a FBC and peripheral blood film on day 2-3 of life, with a request for a Haematologist experienced at reviewing neonatal blood films to report the film. It is usually asymptomatic and spontaneously resolves by 3 months of age although some can develop severe disease including hydrops fetalis, liver fibrosis, renal disease and cardiopulmonary failure. Clinical features include hepatosplenomegaly, rash and pleural/ pericardial effusions. Later development of Acute Myeloid Leukaemia (AML) occurs in some. 10-20% of asymptomatic cases go on to develop Myeloid Leukaemia of Down Syndrome (ML-DS) in the first 4 years of life and continued follow up is required. (See **Appendix 4** – Haematology guidance).

Renal

Babies with Down Syndrome are at increased risk of severe renal and urological abnormalities including, benign renal hypoplasia, obstructive uropathy (Posterior urethral valves), hypospadias and undescended testis (higher incidence of testicular cancers). Ensure the antenatal scans were normal and that baby is passing urine normally; if unsure request a renal ultrasound.

Discharge and follow up

Referrals that must be made:

- Complete the Discharge Checklist.
- Complete the Badgernet or EPR discharge summary if remained on the postnatal ward. Ensure there is sufficient information about feeding and the outcome of the feeding assessment by the Infant Feeding Team or SALT. A copy should be sent to the GP and Health Visitor.
- Local neonatal follow-up within 12 weeks (sooner if clinically indicated, often seen by 6-8 weeks in practice) – this appointment must not be cancelled unless discussion has taken place with the community paediatrician and plan agreed.
- Referral to neonatal community nurses – the community neonatal nurses see babies within a few days of discharge and as frequently as required, with regular weights etc. They work closely with the hospital-based consultant neonatologists/paediatricians highlighting any concerns, providing a close link to families and safety-netting**.** This is done verbally by speaking to the neonatal community nurses directly on the neonatal unit.
- Referral to Community Paediatrics using CDT referral form (see **Appendix 1** with all CDT contact details) – Community Paediatrician aims to review within 12 weeks from point of acceptance at intake meeting (sooner if clinically indicated). In addition please email a copy of the CDT referral form and the Discharge Checklist to the Intake Co-ordinator at Barnet CDT at **rf-tr.childdevreferrals@nhs.net** (Tel: 020 7794 0500 ext. 26457). Remember that a CONSENT form is required (CDT referral) by the parent in order to share information with the whole CDT team (GDPR) or referral will be sent back. The CDT referral form encompasses the following services:
    - Paediatric Community Dysphagia team (SLT),
    - Pre-school Teaching Team (PsTT) – (Pre-school Teaching Team Down Syndrome advisor)
    - Paediatric physiotherapy

  This is all on the one CDT referral form; however please do specify these teams as well. At the intake meeting, every new baby with DS will get accepted by community paediatrics, paediatric physiotherapy, PsTT and paediatric dysphagia team for assessments.

Referrals that may be required:

- If genetic results are awaited, a meeting with a Neonatal Consultant should be organised as an outpatient to discuss the results and ensure all the necessary investigations and referrals have been made.
- Consider Ophthalmology / Audiology referral if any abnormalities.
- Paediatric dietician for children discharged on naso-gastric tube feeding. Email: clcht.paediatricnutrition@nhs.net **(Appendix 6**)
- Local cardiology follow-up unless there is a normal neonatal echo and clinical examination.
- Consider MASH referral if there are any social concerns. https://www.barnet.gov.uk/children-and-families/keeping-children-safe/worried-about-safety-child
- Inform the community paediatrician of any A and E attendances or hospital admissions. (**See Appendix 7** for infographic on top tips for triaging and children with Down Syndrome).
- Provide parents with the resources listed below.

Resources for parents, advice and support.

- A red book with the Down Syndrome PCHR insert (red book insert). The red books are kept in the office on labour ward, DS growth charts can also be found in the neonatal unit, children's outpatients and postnatal wards. If no inserts, parents can get a copy from DSA or their health visitor, although best practice is to give these DS inserts before discharge. If the PCHR inserts are unavailable they can be downloaded at http://www.healthforallchildren.com/wp-content/uploads/2013/04/A5-Downs-Instrucs-chartsfull-copy.pdf. In addition to the DS specific growth charts as well as advice for parents regarding feeding, immunisations, development, associated health problems and useful resources. Red Books are going digital (https://www.eredbook.org.uk/) and the DS inserts needs to be incorporated into this e-version. There is an *e*red Book app that parents can download (on Google Play and App Store).

- DSA (Down Syndrome Association) Parent Pack – Copies to be kept on the neonatal unit and handed to parents at discharge. Inform parents that they can become a member of the DSA and receive a hard copy of the parent pack free of charge. (**Appendix 8)**
- Pre-school Teaching Team Down Syndrome Advisor's Parents letter containing her contact details should parents have any questions. Upon receipt of the Community Paediatric referral form she is informed of the patient at the Child Development Clinic (CDC) intake meeting and will make contact with the family within 3 weeks of discharge. She will aim to visit the baby and parents or have a telephone consultation whilst they are an inpatient. If they wish to speak to a parent of a child with DS she can advise further. **(Appendix 9)**
- Down Syndrome Heart Group where relevant (**Appendix 2).**
- Copy of the pathway – available online through the Barnet Local Offer page or can be emailed or printed out.

Additional resources available and depending on need:

- Infant feeding and breastfeeding support information Contact: Infant Feeding lead (Barnet), Barnet Breastfeeding Project Coordinator, 07815717055. CLCHT.breastfeedingsupport@nhs.net , http://www.facebook.com/breastfeedingsupportinbarnet/ (**Appendix 10** for referral form)
- Direct mothers to feeding support groups such as La Leche League and the National Childbirth Trust which contain some specific advice for feeding babies with Down Syndrome.
- Contact A Family information pack "About diagnosis: for families and disabled children" including the information sheets e.g. "Support for fathers, siblings and grandparents." These documents are available online. www.cafamily.org.uk/HealthSupportPack.pdf (www.cafamily.org.uk)
- Positive about Down Syndrome contact details (**Appendix 2)** https://positiveaboutdownsyndrome.co.uk/
- Barnet Local Offer https://www.barnetlocaloffer.org.uk
- A letter from a parent (**Appendix 11).**
- And several other Barnet based support groups and organisations **(Appendix 2)**

Trisomy 21 Discharge Checklist – all fields must be completed prior to discharge for all babies with suspected or confirmed Trisomy 21.

Communication with Parents	**Date Completed**
Consultant Review with parents to explain diagnosis and answer questions	
Down Syndrome Association parent pack to be given to parents *If copies unavailable parents advised to become a DSA member to receive a free copy (**see Appendix 2)***	
PHCR (red book) with the Down Syndrome insert given to parents. Growth parameters to be plotted on the Down Syndrome specific growth chart **(For Inserts – see Appendix 8)**	
Safety Netting Advice *Focusing on feeding, cardiac complications and importance of seeking help early if there are signs of infection **(see Appendix 7 – infographic on infection which can be given to parents and see Appendix 3 on feeding)***	
Pre-school Teaching Team postcard given to parents **(Appendix 9)**	
Provide a copy of the pathway – either via a link to the Barnet local offer, via email or a printed copy ***(www.barnetlocaloffer.org.uk)***	
Examination	
Examination by a Registrar/Consultant confirming features of Trisomy 21	
NIPE	
Passed meconium	
Pre/post ductal saturations, 4 limb BPs	
Feeding Assessment by Infant Feeding Team (IFT) +/- SLT	
Newborn Hearing Screen	
Blood Tests/Imaging	
Confirmatory genetics - FISH and Full Karyotype	
Full Blood Count with blood film	
TSH as part of the Guthrie card	
ECG if an echo has not been performed before discharge	
ECHO – within 2 weeks if abnormal clinical finding or ECG, otherwise within 6 weeks	
Day 5 Blood Spot	
Referrals	
Community Paediatrics referral -Email the referral in addition to this discharge checklist and parental consent form to **rf-tr.childdevreferrals@nhs.net**	
Infant Feeding team/ Speech and Language Therapist (dysphagia) referral	
Health Visitor and GP informed via Discharge SEND or discharge summary	
Referral to neonatal community nursing team for **ALL** babies with DS	
Referral to paediatric dietician if going home on NG feeding	
Local cardiology follow-up if echo not completed, or an abnormality found.	
Local neonatal follow-up within 3 months (sooner if clinically indicated)	
Ophthalmology follow up required if problem with red reflexes/ nystagmus/ other eye abnormality- ***MUST DOCUMENT YOUR FINDINGS IN NOTES AND DISCHARGE PAPERWORK – low threshold for referral - senior paediatrician to decide if referral needed at this stage.***	
MASH referral if there are any social concerns https://www.barnet.gov.uk/children-and-families/keeping-children-safe/worried-about-safety-child	

Transitioning to Community Based child development services – what to expect in the first few weeks.

On hospital discharge, a referral to the child development made will be made by the discharging team (in-take form in **Appendix 1**). For older children who have moved into the area, the same referral form should be used with as much retrospective information as possible.

All cases discussed in the following Tuesday's multi-agency intake meeting where a plan will be made for who within the team will be see the family and when.

For urgent medical concerns Telephone 020 7794 0500 ext. 26457 to discuss with one of the Paediatricians (for professionals only).

EVERY new baby will be referred to and seen by:

- Community paediatrician (for families who have a Barnet GP). First appointment by 3 months of age. Appointments usually held at Edgware Community Hospital (EGH), Burnt Oak Broadway, Edgware HA8 OAD in children's outpatients or occasionally in an alternative centre, like Underhill children's centre.
    - Under 5's/preschool – Dr Ella Rachamim
    - Over 5's/school age – Dr Christine Jenkins
- Community paediatric physiotherapists usually see families at Oak Lane clinic in East Finchley within 3 months from leaving hospital.
- Pre-school Teaching Team (PsTT) Down Syndrome advisor contacts the family within a week during term-time and arranges a visit within 1-2 weeks. There may be a delay in school holidays but there will always be a point of contact given to families. Pre-school Teaching Team Down Syndrome advisor can be contacted by the hospital team when a baby is born if they identify that very early support would be beneficial. This is only for families who live in the Borough of Barnet, otherwise a referral to PsTT will need to be made to that borough. See further information below.
- Paediatric dysphagia team (part of the Speech and language therapy (SALT) service) - all children with DS will receive a feeding assessment by a specialist SALT early on, in community setting or in hospital if concerns arise prior to discharge. Sometimes a referral to a tertiary centre for this assessment may also be recommended. We know these babies can have significant feeding difficulties, with risks of aspiration which can go undetected, so this needs to be evaluated at every point of contact with families. **(See Appendix 3 - Red Flags for feeding)**
- In Barnet, there are also community neonatal nurses who see all babies with DS within a few days of discharge and as frequently as required, with regular weights etc. They are based in the neonatal unit and will liaise with the neonatal consultants to troubleshoot any issues.

SOME BABIES WILL ALSO be referred to and see:

- Paediatric dietician - Children at risk of aspiration or who are unable to meet their nutritional requirements orally may need a period of enteral tube feeding which will be managed by the community home enteral tube feeding dietitian. Any health professional can refer but referrals usually come from discharging hospital dietitian or nurse. Referrals to Specialist Paediatric Dietitian, Home Enteral Tube Feeding team (**Appendix 6)**.
- Homecare nurses (paediatric) – a referral form for homecare will also be done by the hospital if the baby is going home with an NGT or on oxygen and needs ongoing support at home to manage these, working closely with the paediatrician.

Health Visitors

Every child has a community health visitor. Health visiting teams work with mothers and fathers, their families, and community groups to promote the health and wellbeing of children and reduce inequalities from the antenatal period until your child starts school.

Health visitors are nurses or midwives who have undertaken additional training in community public health nursing. They help parents learn and develop the skills required to bring up their children. Health visitors deliver the **Healthy Child Programme,** supporting families to give their children the best possible start in life and reach their

full potential. As part of this universal offer, health visitors carry out mandated health and child development reviews at key stages:

Antenatal, new birth (9 - 14 days), 6 – 8 weeks, 9 – 12m and 2 – 2 ½ years.

These mostly take place in children's centres around the borough.

https://clch.nhs.uk/services/health-visiting

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/167998/Health_Child_Programme.pdf

Referral information: Barnet 0-19 Single Point of Access (SPA)

- **Phone (Option 1):** 0208 200 2500
- **Email**: **CLCHT.ChildHealthInformationHub@nhs.net**
- **Opening hours**: 7 days a week, 9am to 5pm

Breastfeeding support service (also accessed via health visiting)

Infant feeding support is offered by all members of the health visiting team at the new birth visit and any follow up contacts at home or in the child health clinic. There is also a Breastfeeding Support Service which provides mothers with information on breastfeeding, delivered by qualified breastfeeding support workers. Health visitors do support parents who are formula feeding their babies by providing information on choosing milks and making up feeds and helping them to feed safely and responsively.

- **Phone: 07815 717055**
- **Email: CLCHT.Breastfeedingsupport@nhs.net**
- **Opening hours:** 9am to 5pm

Facebook: Breastfeeding support in Barnet

https://www.facebook.com/breastfeedingsupportinbarnet

https://clch.nhs.uk/services/new-baby-and-parent-resources/infant-feeding-services/breast-feeding-barnet

Community Children's Services – Managing On-Going Health and Development Needs

Preschool support teaching team (PsTT).

Initial contact is made by Pre-school Teaching Team (PsTT) Down Syndrome advisor for all preschool age children who live in Barnet within 1-2 weeks from referral within school term time, may be longer in holiday periods.

The Pre-school Teaching Team (PsTT) Down Syndrome advisor provides regular contact for families and visits regularly in the early weeks-months. She is a point of contact for ongoing support and helps you liaise also with other professionals. She gives families her contact details and is incredibly passionate and knowledgeable about supporting families with children with Down Syndrome. Sometimes in the early weeks it can be very overwhelming and there are numerous medical appointments, so these needs to be prioritised, but slowly as the appointments lessen and things settle, and the community team will continue to support you and encourage you to meet other families, particularly through our local Down Syndrome hub at Underhill children's centre.

What to expect during a PsTT visit?

- A comprehensive assessment of need
- Discussion and information on local services
- Offer of counselling services – GP, clinical psychology, post-diagnosis counselling hospital support (where available), local charities.
- Support and review at key transition stages if required
- Liaison and referral to other services as needed:
    a. family health visitor
    b. GP
    c. Community paediatricians
    d. Health Visiting and School Nursing (for child transitioning to school)
    e. Speech and Language Therapy
    f. Physiotherapy and Occupational Therapy
    g. Community Paediatrics
    h. Nutrition & Dietetics
- Provide families with the parent pack from Down's Syndrome Association: https://www.downs-syndrome.org.uk/
- Ensure families have this Down Syndrome combined care pathway and have received the Down Syndrome insert for the red book.
- Information and invitation to the **DS Hub (the BIG-DS Barnet Integrated Group for Down Syndrome).** The DS hub gives families opportunities to meet up, supports their child's developmental needs with early intervention, and also see a variety of health professionals too who work closely with the PsTT at the hub e.g. paediatricians, speech therapists and feeding specialists, dentists, physiotherapists and more. The Pre-school Teaching Team (PsTT) Down Syndrome advisor and her team will give families information about this and together work out when best to access these groups. These groups are held every Wednesday (term time) at Underhill Children's centre (Mays Lane, London EN5 2LZ. 0208 349 2423).
- Signposting to additional support services as required e.g.:
    a. Down's Heart Group, https://dhg.org.uk/ and support/e-learning for children facing congenital heart surgery https://dhg.org.uk/information/
    b. Early Support Information for parents/families https://www.downs-syndrome.org.uk/
    c. National Down's Syndrome Association: https://www.downs-syndrome.org.uk/
    d. Local health services information: **https://www.barnetlocaloffer.org.uk**
    e. Early Years Education Services: **https://www.barnetlocaloffer.org.uk**
- Benefits advice / signposting including support with Disability Living Allowance and Carer's Allowance.

PsTT will continue to work with families until the child has successfully transitioned in to school.

If an older child is referred in, i.e. school-aged and moved from abroad or moved into Barnet, they will not see PsTT but will have input from community paediatricians and the school nurses and school-based teachers and therapists.

Contact information:

Pre-school Support Teaching team (PsTT):
Early Years Centre
Oakleigh Road North
LONDON
N20 0DH

Telephone: 020 8261 2456 ext. 1

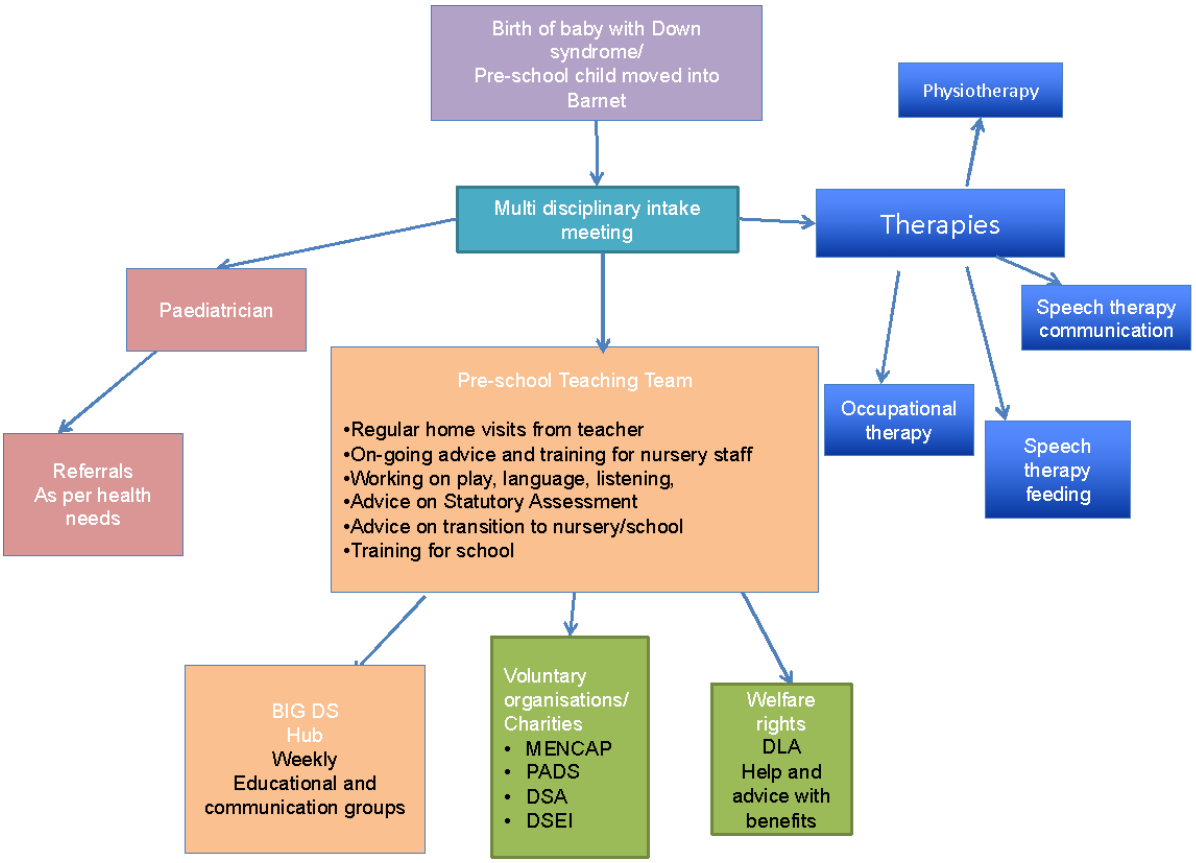
Children's integrated therapy (CIT) services:

Physiotherapy, Occupational therapy, Speech and Language therapy and Paediatric Dysphagia teams are all based together and contact information here:

Barnet Children's Integrated Therapies (CIT)
3rd Floor, Westgate House
Edgware Community Hospital
Burnt Oak Broadway
HA8 0AD
Email: nem-tr.barnetcit@nhs.net

Tel: 03003001821
https://www.clch.nhs.uk/about-us/publications/referral-forms

All the therapies (physiotherapy, SLT, OT and the dysphagia team) form the Barnet Children's Integrated Therapies.



Community Paediatrics

Community paediatricians routinely review children at the following time intervals:

- 3 months
- 6 months
- 12 months
- Yearly after this until transition to adult services which takes place once a child has left full-time education

Additionally, from 14 years, they also have annual enhanced reviews with their GP.

The hospital paediatrician will also review as planned within 3 months at Barnet hospital children's outpatients.

Routine reviews can be more frequent if needed.

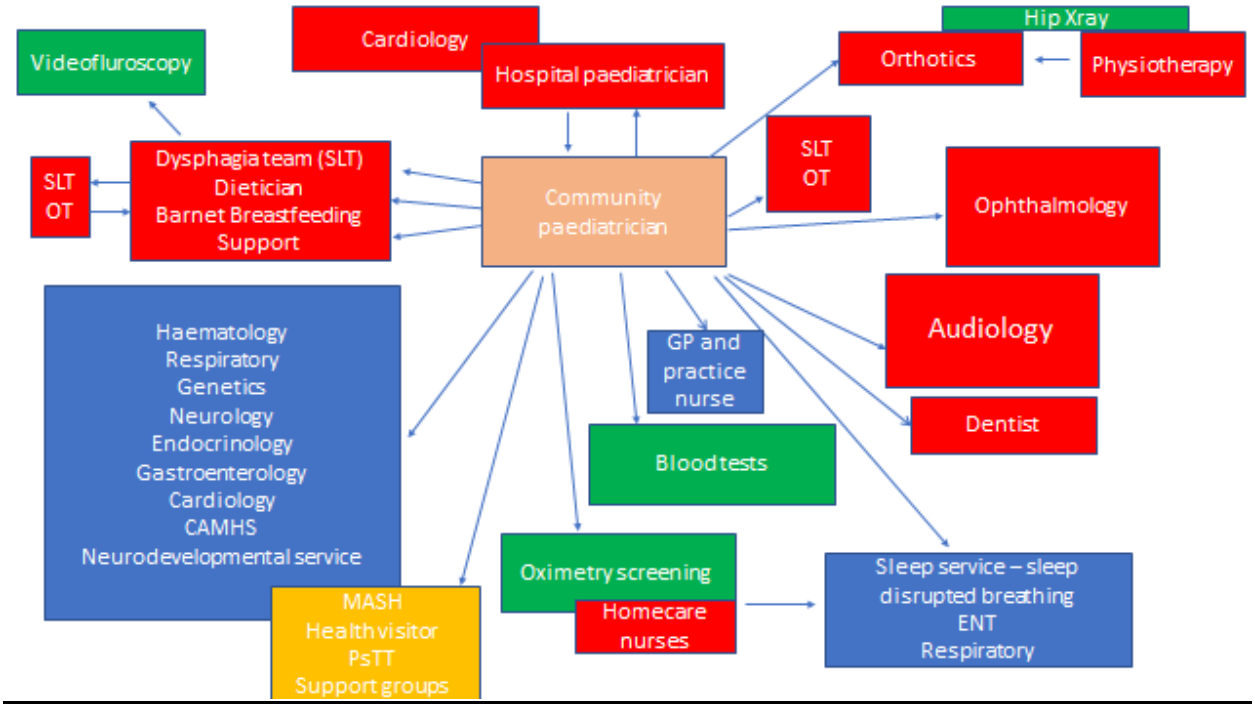
Contact details:

Child Health HQ, Edgware Community Hospital (EGH), Burnt Oak Broadway, Edgware HA8 OAD Telephone:

020 7794 0500 followed by extension:

Deputy office manager and medical secretary: x26457 or x26382
Audiology secretary and appointments: x82398 (DD: 020 3758 2398)
Clinic coordinator: x82420 (DD: 020 3758 2420)
Office manager: x26217
Medical and SEN secretary: x26272

Medical reviews by community paediatrician- The preschool years



PLEASE ENCOURAGE PARENTS TO BRING THE PCHR (personal child health record) TO EVERY APPOINTMENT

PLEASE ENCOURAGE PROFESSIONAL TO DOCUMENT THEIR FINDINGS IN THE PCHR (red book)

Note:

All the therapies (physiotherapy, SLT, OT and the dysphagia team) form the Barnet Children's Integrated Therapies.

Missed appointments

Parents/carers need to be aware that all services have a policy to discharge following 1 or 2 non-attendances. As children with Down Syndrome have complex needs (health and developmental) it is vital families engage with all services provided. If there is a situation where the child's needs are not being met because parents are not engaging with professionals, this will need discussion with the family and team around the child, and strategies put into place to support the family. Sometimes we may need to involve outside agencies to also support this engagement, like social care, to benefit the child.

Appointments take place at Edgware Community Hospital, or at Underhill children's centre (BIG-DS). Initial appointments are 90 minutes and follow ups are 45 minutes.

For each appointment, ensure that the following takes place:

Notes review:

Review of the hospital notes and any discharge summaries.

Look for any interim admissions to hospital – enquire specifically about infections. **(Appendix 12)**

Any concerns regarding hearing and vision as identified by the neonatal team, parents or educational setting (**Appendices 6 and 7)**

Collate information from tertiary centres / GOSH.

History and discussion:

Enquire specifically regarding medical problems known to be associated with Down Syndrome and take every opportunity to remind families and carers of "red flag" symptoms.

- Perform a full feeding history and assess for risk of aspiration, GORD - and treat according to NICE or local policy guidelines. Ask specifically for coughing after feeds, choking or wheezing episodes (**see Appendix 3 for Red Flags**)

  - Developmental progress

  - Check sleep patterns including any signs of sleep disordered breathing (**see Appendix 13**). Any red flags for sleep apnoea such as snoring, sweating, gasping, excessive restlessness, mouth-breathing, daytime somnolence. A video of them sleeping and the noise/sounds associated is very useful which can be at naptime or nighttime.

- Signs of constipation or other bowel problems. See **Appendix 14** to evaluate further – history, examination, triggers, management and treatment, use Bristol Stool Chart to help). http://dsagsl.org/wp-content/uploads/2012/11/gastrointestinal_problems.pdf

  - Ask about family and social history, and support network.

  - Take time to listen to any parental concerns and watch any videos they have recorded on personal devices that have been concerning them including sleep concerns or unusual movements.

  - Encourage families to attend our DS hub in Underhill children's centre. There are weekly early intervention groups lead by the PsTT, multidisciplinary input from other allied health care professionals (physiotherapy, Occupational therapy (OT), dentists etc.) and the opportunity to meet other families.

  - At each clinic attendance ensure parents are aware of the 'red flags' for cervical spine instability, and that they should seek immediate medical help if they are present (DSMIG guidelines, **Appendix 21)**

- Remind families and GP's of the importance of aggressively treating sepsis. Where sepsis is suspected, they need to be seen immediately, and treated with appropriate antibiotics. Doses may need to be increased or prolonged, discussion with the hospital based paediatricians on call is recommended. If recurring infections occur, consider antibiotic prophylaxis in discussion with a respiratory paediatrician and seek to find an underlying cause. (**See Appendix 12)**

- Promote the flu vaccine and immunisation schedule (**See Appendix 12)**
    - Annual influenza vaccine via GP/practice nurse (from 6 months to 2 years this is the inactivated injected form, after 2 years it is the nasal flu vaccine)
    - Pneumococcal vaccines – an additional pneumococcal immunisation is now universally agreed (from Autumn 2019 onwards) for ***every*** child with Down Syndrome and not only those at "high-risk:" Via GP/practice nurse.
    - Age 2-5 yrs: single dose of Pneumovax II (at least 2 months after final dose pcv – usually given at 2, 3, 4 and 13 months as routine in the UK)
    - Age > 5 years: single dose of Pneumovax II (although should not be repeated within 5 years).

Examination

- Plot growth & OFC on Down Syndrome Growth Chart in notes and in Red Book (PHCR). **(See Appendix 8 on growth charts)** Rapid weight gain (from 1 year) should prompt check of Thyroid function

- Developmental Assessment/milestones - Griffiths developmental check or SOGS (Schedule of Growing Skills) – highlights can be found in the PCHR (Personal Child Health Record, also known as the Red Book with the extra green insert for DS).

- Social communication skills.

- Cardiovascular examination. Rarely, echocardiography, particularly in the first few days after birth, may fail to diagnose AVSD and other major shunt lesions. Hence there should be a low threshold for repeating this investigation if symptoms or signs of cardiac disease are detected at any age even in the presence of 'normal' early echocardiogram.

- Respiratory examination. Aspiration, viral induced wheeze.

- Skin (looking in particular for signs of thrombocytopenia).

- Neurological - Look for any signs of cervical spine instability or cord compression.

- Lower limb alignment and foot position when weightbearing e.g. standing, walking.

- ENT - Signs of middle ear disease or upper airway obstruction

- Eyes - Squint, cataract, nystagmus or blepharitis. Nasolacrimal duct obstruction sometimes needs referral.

- Dentition

Investigations

Thyroid Function:

- Venepuncture at age 6months, 1 year and annually thereafter throughout life - To check T4, TSH and thyroid antibodies. **(See Appendix 20)**

Where the T4 is normal and the child is asymptomatic but there is a mildly raised TSH (less than or equal to 10mu/l) or thyroid antibodies are present re-check after 6months. A specialist opinion may be warranted.

Have a low threshold for testing thyroid function at other times if clinically indicated e.g. lethargy and/or changes in affect, cognition, growth, or weight. Testing should be continued throughout lifetime.

If the child is already under the endocrinology team on Thyroxine supplements, please leave monitoring of TFT's with the endocrine team.

Cardiology:

- Seen locally by paediatricians with a specialist interest in cardiology in Barnet unless there were any abnormalities prompting expedited tertiary referral. Every baby needs a minimum of one echocardiogram by the paediatric cardiologist in the hospital

Feeding/Aspiration:

Liaise/communicate with paediatric dysphagia team (SALT) if any RED FLAGS or concerns; much of aspiration in DS is silent and thus difficult to detect on history alone. Specifically, aspiration must be actively excluded in any child with respiratory issues above what would be expected for any normally developing child with the use of videofluoroscopy. Help with prescribing special feeds or thickeners if needed and liaise with GP for ongoing prescribing if any issues.

Respiratory:

- Overnight oximetry is required for asymptomatic children with the paediatric homecare nurses at 6 months of age, then 12 months of age and annually thereafter until 3-5 years of age. (**Appendix 13 and 5**). Nurses email community paediatrician the reports/trace – we need a minimum of 4 hours to have value. Discuss with respiratory lead at local hospital or with respiratory consultant at GOSH if concerns or help in interpreting. Refer onto tertiary centre for a formal sleep study if screening oximetry shows signs of SDB (both the baseline saturations overnight and desaturations). Please note the oximetry is a screening test and is being used in ASYMPTOMATIC children with Down Syndrome as we know even in this group there is a significant risk of missing SDB which can have health and cognitive effects. The SYMPTOMATIC group would have been referred to tertiary ENT or sleep services without this oximetry screening. (**See Appendix 13** for research, current thinking and discussions Dr Ella Rachamim has had with key professionals in this area). In Barnet we have a Nelcor oximetry machine and software.

Gastrointestinal:

- Consider coeliac screening

Test for coeliac with the antibody test (TTG with a TOTAL IgA (a blood test)). The child needs to be on an adequate amount of gluten (should be on a gluten-containing diet >6g/day) to validate this test. Discuss with paediatric gastroenterologists at RFH if you are unsure). The alternative option is to carry out HLA testing (a blood test), which does not require the child to be on sufficient amounts of gluten. This will give us an indication if the child is in a group that may go on to develop coeliac disease or is in a group that will not, in which case we only need to watch the first group and have a low threshold for repeat testing using TTG as they grow. This HLA test can be organised through the Anthony Nolan laboratories and is something being considered by the Royal Free for our population of children with Down Syndrome in Barnet and Camden. Guidance on this is being discussed and will be updated.

Immunology:

- Consider immunological investigations – can discuss with local consultant immunologist, Tel 020 7830 2141 (Ext 34519**). (See Appendix 12)**

Check the above immunology tests at:

Any review if - with ≥ 4 infections in 6 months requiring GP visits/ill-health **>** 5 days OR admission for sepsis

OR any review with unusual infection.

Timing of immunology blood tests: at least 1 month after completion of the 12month routine Hib/MenC/PCV booster immunisations.

Note: Immunoglobulins, Functional Antibodies, Prevnar Antibodies, Lymphocyte subsets are checked routinely in some boroughs so have a low threshold to consider doing these or to discuss.

Haematology:

- Consider check of Ferritin and iron studies and vitamin D if nutritional concerns (or restless sleep reported which could be iron deficiency and need ferritin above 50, ideally, and vitamin D above 75).
- TAM requires ongoing surveillance until age four with FBC and blood film.

Referrals

Paediatric Alert: Ensure an alert is added to the patient's electronic medical record. If not, inform officer manager/secretaries at CDT. The alert ensures the child is seen by the paediatric team if presenting to the Emergency Department.

Growth/Feeding:

- Consider dietician referral for faltering growth and need for nutritional supplements.
- Discuss infant feeding/breastfeeding support at local children's centres (Barnet Breastfeeding Project Coordinator, **Appendix 10**)
- Dysphagia service at GOSH for assessment of feeding including a videofluoroscopy (via SLT). There are also options for paediatric VFF at the Royal Free hospital.

Upper Airways Obstruction or Sleep disordered breathing:

- Refer to ENT at GOSH
- Consider referrals to the Sleep Service at GOSH if worries about Sleep disordered breathing (SDB). Alternatively, The Evelina children's hospital for sleep services

Respiratory:

- Consider referrals to Respiratory team at GOSH if worries about recurrent respiratory infections or persistent oxygen requirements or local Barnet/Royal Free paediatrician with a respiratory interest
- Refer to hospital consultant or neonatal outreach nurses for RSV prophylaxis, in season, for those with a significant cardiac left to right shunt, according to local criteria (**See Appendix 16)**
- Homecare nursing team for an overnight oximetry investigation **(referral form in Appendix 5).**

Many of these services overlap, in particular sleep can be affected by respiratory, ENT and feeding issues, and it can be hard to work out which referral is best. In the local setting we have access to home based overnight oximetry (but not any more detailed sleep studies) which can be helpful for screening for SDB. We also have access to infant feeding assessments +/- VFFs but these can be difficult to obtain locally sometimes. Therefore, with this in mind, consider discussion with local and tertiary teams about the best way forwards e.g. GOSH sleep service works closely with respiratory and ENT so they can be a good starting point.

Audiology:

- Follow-up is required for 8-10 months. Hearing (at 8-10 months) test should Include a full audiological assessment including thresholds, impedance and otoscopy. Referral by letter to Audiology at EGH.
- Refer for further check at 15-18 months and yearly follow up thereafter (usually as the child will already be in the audiology DS pathway, by letter to paediatric audiology team at Edgware General Hospital). **(Appendix 23)** To discuss with the team, speak to Consultant in Audiovestibular medicine.

Ophthalmology:

- Any concerns over visual development, refer to Consultant paediatric ophthalmology at Barnet.
- Refer for full ophthalmology assessment by 18 months (and repeated routinely at 4 years unless otherwise indicated **Appendix 24**) – by letter to Consultant Ophthalmologist, Ophthalmology department at Barnet hospital. For nasolacrimal duct obstruction also refer.

Dental:

- The best time so see a patient is as soon as teeth come through. The British Society of Paediatric Dentistry recommendation is at age 1. (See referral information **in Appendix 22**).

Endocrine:

- Local endocrinology referral for any children requiring thyroxine.

Gastroenterology:

- Any child with coeliacs or other gastrointestinal related problems - RFH or Barnet paediatrician or GOSH

Immunology:

- Recurrent infections - Please refer to 'Immunology guidance for children with Down Syndrome' for reference and investigations- **Appendix 12.**

Orthotics:

- If any concerns regarding feet rolling inwards (valgus ankle), refer to orthotic department for suitable ankle/foot support. (See **Appendix 25** for referral form, can also discuss with their physiotherapist first).

Orthopaedics:

- If lower limb alignment is excessively abnormal e.g. severe valgus knees or feet refer to orthopaedic consultants for monitoring.

Social Care:

- Referral to Social Care/ 0-25 Disabled Children's Team might be of benefit too (Referral form – **Appendix 17)** for early support/universal services assessment.

Children's Social Care commissions the following services which are open to those with Down Syndrome, or parent-carers of those with Down Syndrome:

- Advisory services for parents of children with disabilities, provided by Barnet Mencap. This includes advice, signposting and support in applications for things like blue badges, disability related housing issues and disability living allowance.
- Parenting Programmes for parents of children with disabilities, also provided by Barnet Mencap

Both services can be accessed by going direct to Barnet Mencap. https://www.barnetmencap.org.uk/what-we-offer/children-and-family/0-25-advice-support/#

London Borough of Barnet also commission services for adult and young carers too, provided by the Barnet Carers Centre. Barnet Young Carers - http://barnetyoungcarers.org.uk/ Barnet Carers Centre - https://barnetcarers.org/

Therapy Services:

- Ongoing Barnet Pre-school Teaching team
- Ensure physiotherapy input ongoing, especially if any particular concerns about motor development including extreme hypotonia.
- Ensure ongoing dysphagia team involvement as needed and get updated.
- Referral to appropriate therapy if indicated (contact the relevant therapy department for referral criteria if required) e.g. Occupational therapy. **The form is the same as in Appendix 1 and also has the contact details for advice.**

Letters to the GP:

In addition to your full report, include:

Vaccination recommendations: recommended extra vaccinations **(See Appendix 12)** – annual flu vaccine and the extra pneumococcal vaccine and remind GPs that chickenpox can be more problematic in this group of children (presents differently and can cause more serious complications so need more careful monitoring). There will also be routine letters being distributed around Autumn to GPs to remind the about these vaccinations due for ALL children with Down Syndrome. Ideally too, ensure that these children are given the first batches of flu vaccine that is made available for the GPs. If there is a history/investigation showing immunocompromise, then the chickenpox (VZV) vaccine is recommended.

Reminders to check for symptoms of atlanto-axial instability and complete and update the screening form or document in your report.
https://www.british-gymnastics.org/technical-information/discipline-updates/disabilities/9316-atlanto-axial-information-pack-1/file **(See Appendix 21)**

Additional considerations at 3-month review

Notes review:

- Cardiology – initial echo findings and ensuring appropriate follow up in place.
- Collate information from physiotherapist and dysphagia team initial assessment reports and from PsTT.
- Ensure all required professionals are involved including physiotherapist, PsTT, SLT, Health visitors, hospital paediatrician.
- Ensure there are no missed or outstanding appointments from hospital discharge.
- Hospital paediatrician: Discuss with the hospital-based team - do they still need to see the family, or can they cancel their appointment with all future medical care coordinated by community paediatrician?

History and Discussion:

- Are there any unusual movements or spasms? (consider Reflux and consider infantile spasms/West syndrome and refer for an EEG **(Appendix 15)** +/- referral to consultant paediatrician with a neurology interest at Barnet Hospital)
  - Discuss infant feeding and recommend upright feeding to reduce ear inflammation/otitis media and gastro-oesophageal reflux disease (GORD). Explore thoughts around weaning.
  - Careful counselling with explanation of the condition, including genetics of the condition and associated medical conditions.
  - Enquire as to how the family have adjusted to the diagnosis and offer support as required.
  - Make sure a red book insert has been given to parents.
  - Signpost again to local resources and contact details of Down's Syndrome Association, if not already known.
  - Discuss Disability Living Allowance (DLA and Carer's allowance. This is often more successful when applied for at 6 months of age, but it is good to start the process as it is rather lengthy. Pre-school Teaching Team Down Syndrome advisor, MENCAP and Barnet Carers are all able to help with this (see **Appendix 2)**
  - Social support services – Consider referral to Social Care/ 0-25 Disability Service Social Work team (Referral form – **Appendix 17)** for early support/universal services assessment. The Multi-agency safeguarding hub (MASH) looks at referrals and can decide which services are most useful for the family. This may be for support for families, therapeutic work around bonding and relationships, support for siblings, a family support worker, help with benefits, housing, social concerns, later on for clubs and activities, short breaks, respite and so on.
  - Encourage parents to take videos of any behaviour or concerns they have.

Examination:

General physical examination

- Eyes: Check for cataracts – check red reflexes and document, fixing and following and visual behaviour, check for squint and for nystagmus

Investigations:

- Check results of chromosomal testing.
- Check results of TSH on Guthrie card.
- FBC and blood film - Has this all been checked and managed accordingly by the hospital paediatric team. Does it need discussing with the haematologist? (See **Appendix 4** – haematology guidance).
- Check that Neonatal Hearing test has taken place and act upon any results that require follow up.
- Ensure cardiology assessment is completed – every baby needs a minimum of one echocardiogram by the paediatric cardiologist in the hospital

Additional considerations at 6-month review

History and discussion:

- Discussion around weaning onto solids in liaison with the paediatrician/feeding team/SLT +/- dietician. Usually guided by these professionals as to when to start and how to progress with textures. It may be delayed if concerns around aspiration and food may need thickening. If the baby was born prematurely, ensure professionals are aware so they can advise accordingly.
- Report back thyroid results (**See Appendix 20** for advice).

Investigations:

- *Repeat FBC and blood film* at this stage if the baby *was born prematurely.* (DSMIG - **Appendix 18)**

Additional considerations at 1 and 2 year reviews

History and discussion:

- Have a low threshold for investigation of coeliac disease – **see Appendix 14**. Any constipation? Pain? Fluctuating bowel habit? Concerns around weight?
- Triggers for constipation - consider: pain (e.g. a fissure), fever/dehydration, dietary intake (in terms of fibre content), other medicines, other conditions and family history of constipation. Psychological issues and expression of distress? Toilet training/aversion? (See **Appendix 14** for treatment)
- Behaviour and social communication
- DLA and other benefits
- Dental hygiene and tooth brushing
- Therapy and educational input – e.g. Makaton signing through The Pre-school Teaching Team (PsTT) Down syndrome advisor or local signing groups
- Pre-school Teaching Team Down Syndrome advisor leads on discussions and timings of nursery provision, EHCP planning and also about special educational needs inclusion funding (SENIF).
- Discuss sleep hygiene and routine, daytime naps, night-time wakenings and sleep onset difficulties? For ongoing sleep issues and sleep onset or overnight wakenings – consider if this could be medically related e.g. GORD, aspiration, OSA, SDB +/- behavioural component.

Ensure you have checked the following:

- The child is not having excessive sleep in the day (catching up on poor night-time sleep quality) or not enough naps or naps that are too late in the day interfering with bedtime.
- There are no clear environmental causes for night wakenings (like loud noise or light).
- There are no behavioural cause/sleep associations affecting the child from learning to self-soothe (such as rocking the child to sleep or allowing the child to fall asleep on the breast or bottle). E.g. The child learns to expect the rocking in order to get to sleep, so wakes up and cries as they do not know how to self-soothe and rely on the rocking to get back to sleep.

Some sleep problems can be improved with good sleep habits (sometimes called sleep hygiene). These are some general strategies that may improve the person's chances of a good night's sleep:

- A nightly consistent routine at bedtime
- A bedroom that is free of distractions (e.g. cut out any unwanted light or noise).
- Regular sleeping hours
- Regular exercise and activities
- Avoidance of caffeine and other stimulants in the evening
- Some people have been helped to sleep by a soundtrack of calming sounds.
- Sleep diary can be helpful too

For children specifically:

- Watch for daytime naps – is this age appropriate? Timings? Are they interfering with nighttime sleep? Remember too car journeys or nursery/school transport – is the child nodding off?
- Look up how much sleep is needed (it is a range) for the child's age and how long it is recommended for the child to stay awake for before going down for a nap (if still having naps). Use this knowledge to plan the daytime routine into chunks of time.
- Use this knowledge to help learn and look for sleep cues
- Encourage the child to fall asleep on their own when DROWSY but not actually asleep, so they learn to self-soothe themselves.

Further support and resources:

- Discuss with the health visitor who has an important role here and expertise.
- Consider referral to sleep service at GOSH or Evelina hospital (**Appendix 13**), or trial of *melatonin* if it is predominantly sleep-onset difficulties. (**See also Appendix 13** for melatonin information).

https://www.thechildrenssleepcharity.org.uk/
https://www.downs-syndrome.org.uk/for-families-and-carers/supporting-behaviour-positively/

Referrals

- Refer to Speech and language therapy ***at age 2 years*** if not already known to them (sometimes they will have been known by the paediatric dysphagia team which is run by speech and language therapists with a feeding specialism but they also need to be referred to the other part of their team, the Speech and Language service). **Use form from Appendix 1.**
- Makaton signing through The Pre-school Teaching Team (PsTT) Down Syndrome advisor Underhill groups or local signing groups.

- Ensure Child known to Inclusive Education team/Educational psychologist (refer by letter to SEN and EP teams, separately, North London Business Park).

- Referral to CAMHS for psychological support if required (referral form, **see Appendix 27)**

- Behaviour **-** https://www.downs-syndrome.org.uk/for-families-and-carers/supporting-behaviour-positively/ is an excellent guide for parents.

- Consider Occupational therapy referral for ongoing sensory needs or fine motor skill difficulties impacting on their activities of daily living (See OT criteria for acceptance, **Appendix 28).**

- Dental referral if not done before - the best time so see a patient is as soon as teeth come through. The British Society of Paediatric Dentistry recommendation is at age 1. (Referral information -**Appendix 22**).

- If concerns about social communication (a small number of children with DS can have a dual diagnosis with ASD), discuss with other professionals and family about referral to TASC forum (Team Assessing Social Communication) and usually the child's community paediatrician takes the lead here (referral via TASC form or through child development team referral, can also discuss with the lead paediatric community consultant for the ASD pathway at Barnet child health HQ/CDT, **see Appendix 1** for contact details and forms).

- Referral to Social Care/ 0-25 Disability Service Social Work team might be of benefit too (**Appendix 17** for referral form**)** for early support/universal services assessment.

Additional considerations at 3 and 4 year review

History and discussion:

- Enquire about school choices and liaise with PsTT.

- Discuss future follow-up with parents and refer to designated community paediatrician, for ongoing medical reviews on an annual basis (School based Down Syndrome clinic at Edgware General hospital, Chase Farm Hospital and special schools). The 5th and subsequent annual reviews continue to be carried out by community paediatricians. If the child is going into a special school, then this will be with Dr Ella Rachamim and if the child is going into a mainstream school this would be with Dr Christine Jenkins. There are some children who are shared, or under other community consultants or who do not fit this model of care exactly, but from 2019 onwards this is the plan in Barnet. This is discussed with the parent/carer.

- Children will be discharged from individual services when appropriate with agreement with parents/ carers for example often physiotherapy services will discharge the child before they start school, if walking and reaching developmental appropriate milestones. However, it is important to check the child's development at each review by the paediatrician and other professionals involved and refer back to the appropriate team if concerns e.g. if gait issues develop, investigate and refer back to physiotherapy if needed.

Referrals:

- Hip screening – for any child not yet weight bearing (3+) request hip x-ray and ensure physiotherapy input.

- Referral to Specialist feeding team/SALT if on fluid thickeners and previously discharged as feeding was stable – consider an assessment of feeding prior to school and to help with transition e.g. if child is on thickeners for food and/or fluids, this needs to be put into a mealtime individualised guideline and school staff need training in how to make up and use the thickeners. SALT team to liaise with dietician and SENCO and school nursing team to ensure these needs are properly documented. (See **Appendix 30** – guidelines on thickeners).

- Referral to Occupational therapy to assess school-based needs e.g. seating and positioning in class or in lunch hall, any additional equipment needed to support feeding or writing or learning. Social care OT may also be needed within this assessment.

- Consider referral to CAMHS if needed - a good contact to discuss the child with the child psychologists or psychiatrists based at SCAN (Service for Children and Adolescents with neurodevelopmental needs - a subservice of CAMHS) on 02087024500 or email.

- If concerns about social communication, discuss with other professionals and family about referral to TASC forum (their community paediatrician to take the lead here).

- Family Services have a Short Break offer available to children and young people, with Down Syndrome, up to their 19th birthday. Further information, including how to apply, can be found on the Short Breaks page on the Local Offer website as follows: https://www.barnet.gov.uk/children-and-families/children-and-young-people-disabilities/disabled-childrens-activities-short The current offer for families in Barnet is 15 days/90 hours (using the Barnet approved provider list) or £1200 Funding via a pre-paid card to allow families choice and flexibility of services. (Subject to a 0-25 service funding policy and Short Breaks written agreement).

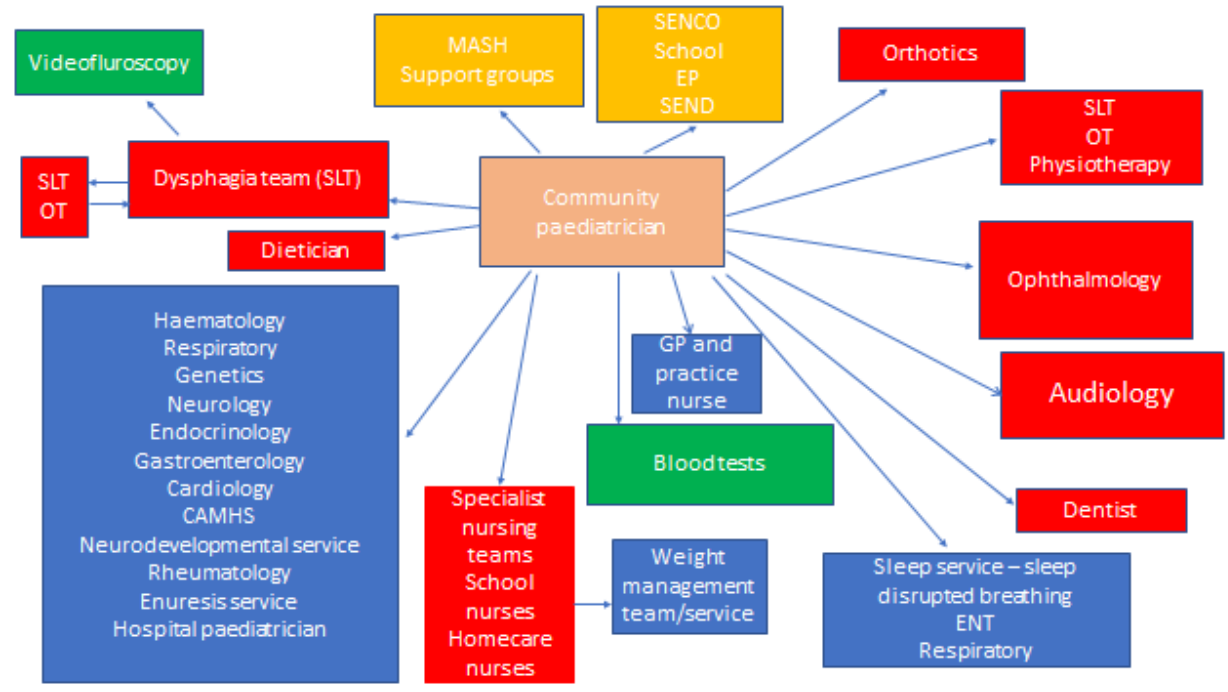
- Some children and young people with Down Syndrome may meet the criteria for the 0-25 Disability Service Social Work team. The team offers a service to children and young people who have a diagnosed severe/profound disability or diagnosed chronic health condition resulting in severe and profound disability. Your child needs to meet the eligibility Criteria to access a service offered by the 0-25 Disabilities Service.

For the eligibility criteria please click on the document link that can be found on the Local Offer webpage: https://www.barnet.gov.uk/children-and-families/children-and-young-people-disabilities/0-25-disability-service

- Referral to specialist school nurse/school nursing team for children starting school (**see Appendix 29)** with additional health needs in mainstream schools e.g. if gastrostomy or needs continence support.

Medical reviews by community paediatrician -The School Age Years

Age Five year and Subsequent Annual Reviews by community paediatrician:



Note:

All the therapies (physiotherapy, SLT, OT and the dysphagia team) form the Barnet Children's Integrated Therapies.

How does it work?

Community paediatricians are involved until the young person leaves full-time education; this is age 18 yrs usually in mainstream school but could be 19 years in a special school. Transition plans are made with the GP, who is asked to do their own annual reviews with the family and young person from age 14yrs. (See below).

Barnet Community Paediatric Service sees children who are registered with a Barnet GP, regardless of the borough of their school or borough of residence. Children who have a GP in another borough will need to be seen by the community paediatric service that covers that specific borough.

The review at age 5 years, and subsequent annual reviews, are carried out by the community paediatrician. Children attending mainstream schools will be seen either in Edgware community hospital or Chase Farm Hospital, usually in a specialist Down Syndrome Clinic. There are dedicated clinics, term-time only, at Special schools (Oakleigh, Northway, Mapledown and Oak Lodge) along with the school nurse. This model of care was set up in 2019 for children with Down Syndrome (DS) to ensure continuity and joined-up care. Dr Christine Jenkins is lead for children in mainstream school, from reception to school leaving age, and Dr Ella Rachamim is lead for children in special schools with Down Syndrome and preschool children. If care is being transferred, it will be discussed with the family/carer and child, ensuring a smooth transition of care. The team work closely together, with the local Barnet Multidisciplinary and Interagency teams, to ensure holistic joined-up care for each child.

Transition to School and EHCPs (Education Health Care Plans)

Transition to School and EHCPs will be planned and adapted according to each child's needs. Planning will involve the family, school SENCO (Special Educational Needs Coordinator), school teachers, Pre-school Teaching Team Down syndrome advisor, medical and therapy reports. The community paediatrician will be asked to contribute to the EHCP medical report. Pre-school Teaching Team Down Syndrome advisor will remain involved during the settling in period, supported by the EHCP plan. The Pre-school Teaching Team Down Syndrome advisor works very closely with the family during this time, visiting different schools and liaising with SENCOs. Pre-school Teaching Team Down Syndrome advisor also writes a thorough report for the EHCP and for the school, e.g. it might cover how to create the best visual environment for children with DS, with bold lines on paper and large pens for writing and much more (Think Big, Think Bold Campaign by DSA) (**See Appendix 31** for further education advice and information on the Barnet DS Awareness days, run by a Senior Educational Psychologist and Pre-school Teaching Team Down Syndrome advisor.

Discussion at Every Medical Appointment:

Parental concerns

Professionals involved and appointments since last review and coming up.

For ALL Including:

- Audiology all children
- Ophthalmology. Optician all children
- Ophthalmology Eye Clinic if appropriate
- Dental care for all. Family dentist +/- Barnet Community Dentist or Specialist Dental service.
- Speech and Language Therapy (SLT)

If appropriate consider for children on an individual basis:

- Cardiology

- Endocrinology
- ENT
- Other specialist medical appointments if appropriate
- Physiotherapy
- Speech and Language therapy for communication
- Occupational Therapy (OT)
- School Nurses
- Weight Management Service (school nurse team)
- Dietician
- Advisory Teacher for Hearing/ Vision impairment
- CAMHS if appropriate
- Before Puberty, consider sexual health and menstrual problems

- **From year 9 (age 14) discuss transition planning for health**
- **From year 9 (age 14) inform GP that the young person is now eligible for a Directed Enhanced Service, DES by their GP** – this is an enhanced annual review by GPs for all young people with learning disabilities in their practice - see below for detailed information on this. The community paediatrician will notify the GP via letter, at their 13/14 year review, using a specific letter created by our team **(See Appendix 32).** The ***Community paediatrician will continue to do annual reviews IN ADDITION to this annual DES by the GP, until the young adult is formally discharged from paediatric care to adult care (varies between 17-19 years), whereby the GP will continue their annual DES/review throughout adulthood.***

  If the GP does not offer the Directed Enhanced Service (DES), then the community paediatrician will discuss different options with the family and the GP.

Development:

- Developmental progress – Activity? Classroom learning?
- Communication. Language development. Makaton, signing
- Self-care skills – toileting, feeding, dressing, life skills in older child
- Fine Motor skills
- Gross Motor Skills
- Therapy and Educational input
- Behaviour – including friendships, peer interaction, social communication, any unusual or repetitive behaviours? Any challenging behaviours – and current strategies and plans? If there are any concerns about a dual diagnosis (of Down Syndrome and Autism Spectrum Disorder) discuss with family and school (**See Appendix 33).**

Health:

- General health focusing on symptoms of disease known to be more common in DS including:
- Congenital heart disease
- Sleep and disturbed sleeping pattern (see **Appendix 13**)

- Possible Obstructive Sleep Apnoea (OSA) sleep related upper airways obstruction; symptoms include snoring, gasping, restlessness, sweating at night, unusual sleeping posture or persistent mouth-breathing.
- Changes in Bowel habit, constipation, awareness of possible Coeliac disease (which can present atypically).
- Thyroid hormone deficiency: should be picked up with routine annual blood tests prior to physical signs developing (such as lethargy, dry hair and skin, changes in affect e.g. depression, cognition, growth or weight)
- If Thyroid problems, awareness of other associated autoimmune problems e.g. diabetes, alopecia.
- Nutritional inadequacy due to feeding problems. This will also be part of their growth assessment.
- Diet
- Growth change
- Exercise

Medical Update

Any recurrent infections or unusual or prolonged infections?

Any admissions to hospital – check history and treatment needed e.g. antibiotics? Oxygen? Get an antibiotic and chest history from parent/carer and/or GP if concerns over recurring infections. Do they need prophylactic antibiotics if they have had frequent infections, which can be used throughout the year or just September to April? Doctor can discuss with hospital paediatrics or refer to paediatrician with respiratory interest to consider. **(Appendix 12)**

- Feeding (**Appendix 3)** – aspiration red flags? Is advice being followed e.g. if on thickeners still for clear fluids? Has this been followed at school and staff trained in its use? Could this be a cause for any respiratory infections as above? Do they still need the thickeners – has this been assessed in last year by the dysphagia team and does it need reassessing?
- Gastro-oesophageal reflux disease (GORD) and medication? Is further investigation needed if reflux is still symptomatic and continuing? E.g. pH manometry. Or is it improving, so can we trial a period off medication? Can we wean the medication?

  Often reflux and aspiration go hand in hand. Aspiration is well-managed by the dysphagia SLTs and in conjunction with the paediatrician and parents, GORD is always considered and the paediatrician or GP can prescribe a trial of medication, e.g. with a PPI, to see if symptoms improve. Questions to ask/consider - is there pain after meals? A distaste in the mouth with after food? Dislike of lying flat? Abnormal sleep postures, which could indicate reflux? Remember to ask but it can be hard to elicit a history of discomfort, so have a low suspicion.

- Dental care – review by dentist every 6 months ideally. Can be referred to specialist dentist (**See Appendix 22)** if not seen one before or carry on with their local high street dentist. In special schools they will have dentists visiting school annually to see all the children. Advise on good dental care, supervised tooth brushing, avoiding sugar and between meals snacks etc.
- Advice regarding cervical spine instability/ atlanto-axial instability (AAI) (**See Appendix 21**):
  At each clinic attendance ensure parents are aware of the 'red flags' for cervical spine Instability and that they should seek immediate medical help if they are present.
- Musculoskeletal Problems

  Pes Planus (flat feet); can consider physio, orthoses and footwear

  Hypotonia and Joint laxity common

  Problems with Foot, Spine and Hip

  Scoliosis

  Inflammatory Arthritis

Involve school nurse (and/or GP/practice nurse) with growth checks, weight management, immunisation catch up. Copy reports to the school nurse, via the school.

Medication

- Review and document medication
- Antibiotics for cardiac conditions are not usually recommended any longer. It is important for those children who have a cardiac condition or previous surgery, to document if prophylactic antibiotics are recommended by the child's cardiologist for non-cardiac surgery and dental procedures. (Community paediatrician to verify with consultant cardiologist if needed).

Allergies

Review and Document any allergies.

Immunisations (see Appendix 12):

Immunisation history (School nurse to aid with this review) – advise:

- Annual flu vaccine for child and household members to be offered,
- Maximise immunity by ensuring appropriate vaccines have been given according to childhood schedule and any additional vaccines.
- Immunisations up to date, in line with UK schedule.
- Signpost to suitable location if any remain outstanding (including BCG).
- Healthy Child Programme (school age) to include offer of school age HPV vaccinations.
- Advise the Pneumovax II vaccine in addition (against pneumococcal infection.) If aged 2-5yrs it is a single dose of Pneumovax II. (It must be given no less than 2 months after the final dose of Pneumococcal conjugate vaccine (PCV) used to vaccinate under 2y olds) If aged over 5yrs - it is a single dose of Pneumovax II (aka PPV 23). Pneumovax II is repeated every 5 years (but it should not be repeated within 5 years).
- Chickenpox can present atypically and in those children who are immuno-compromised, consider VZV vaccine.
- See further advice on immunisations and letter to GP and parents in **Appendix 12**

Social history:

- Check benefits e.g. child benefit, tax credit, PIP, carer's allowance, DLA and rate, carers allowance, housing benefit, universal credit, mobility bus pass when older. There are constant changes - Families can be helped with this e.g. by the family liaison officer in the school, Disabled children's service at social care, or local charities like MENCAP in Barnet or Barnet Carers or Childrens' Centres who often run Welfare/benefit advice drop- ins. **(See Appendix 2 for further help and details of organisations able to provide advice).**
- Check housing, social circumstances, home adaptations, well-being of other family members living in home, other siblings and ask if social workers are involved.
- Any additional help e.g. carers? After school clubs? Access to other services like sport, clubs, library.
- Referral to Disabled children's team (DCT) should be offered.
- Other referrals: if necessary (to consider: a CAF or a MASH referral at any stage (**see Appendix 17**); a multi-professionals or TAC meeting; school nurse monitoring and support; referral to CAMHS for psychological /behavioural support if required **(See Appendix 27).**
- Encourage Healthy Diet. **See Appendix 34** for healthy snack ideas**.**
- Encourage Exercise and Activity. Discuss Exercises and Sports undertaken, and any difficulties.

See Appendix 35 a list of inclusive local clubs and activities.

- For screening prior to participation in competitive sport can be found at http://www.dsmig.org.uk/library/articles/Atlanto%Axial%20-%20British%20Gymnastics.pdf

  - DS Active: https://www.bacdis.org.uk/policy/documents/DSActive.pdf

  - Special Olympics local group – http://www.specialolympicsgb.org.uk/find-a-club/21

As appropriate according to Age and Development (See Appendix 36 for information and resources)**:**

- Menarche and menstrual management
- Pubertal development
- Sexual Health, Relationships, sex education, contraception
- Consider keeping safe from abuse
- Options for medication to suppress periods/ contraception (usually prescribed by GP).
- Consider referral to sexual health/ gynaecology services if particular concern
- Further useful resources on Puberty, Adolescence and Sexual Health (see also **Appendix 36**):

1. The Down Syndrome Association (DSA) has a useful parent information leaflet, produced in collaboration with the Down Syndrome Medical Interest Group (DSMIG): "Puberty, Adolescence and Sexual Health." This also has information about menstrual issues, HPV vaccination, contraception, national screening programmes including cervical screening.

https://www.downs-syndrome.org.uk/for-families-and-carers/health-and-well-being/sexual-health-and-puberty

2. The NSPCC has a useful leaflet on keeping children safe and the PANTS rule:

https://www.nspcc.org.uk/globalassets/documents/advice-and-info/underwear-rule-parents-learning-disabilities-english.pdf

Examination:

- Growth – Measure height and weight carefully. Plot on Down Syndrome chart in notes and in red book (as yet there is no DS chart on EPR.)

  Plot on BMI charts if the child is on or above the 75th centile for weight. If underweight or falling in the lower centiles, consider the possibility of an additional pathology, and if under 2nd centile refer to specialist feeding advice and consider supplementary feeding if growth below the lowest centile.

  If children are overweight/obese this needs a thorough assessment and advice, referral to weight management nurses and guidance about diet and physical activity, also consider referral to dietician. Consider checking TFTs if accelerated weight gain but should in any case be checked annually.

- Cardiac status. Ask about cardiac symptoms. Listen to heart sounds. Ensure cardiac follow up by paediatric cardiologist is in place if appropriate due to previous cardiac history. Arrange assessment by cardiologist with Echocardiogram as teenager, prior to transfer to adult services.

- Neurology – check history as screen for signs of atlanto-axial instability (AAI) or cord compression. Check limbs and spine. See **Appendix 21** for red flags, signs, symptoms, information). X Rays do not have any predictive validity for subsequent acute dislocation/subluxation at the Atlanto-axial joint. Clinical symptoms, often mild, are currently the most useful predictors of future risk and merit an urgent specialist referral (spinal team at GOSH or RNOH). Advise parents of information from the Down's Syndrome Association) with warning signs or new symptoms to look out for which could indicate myelopathy or Cervical Spinal Injury (CSI). · *Neck pain* · *Abnormal head posture* · *Torticollis* · *Reduced Neck Movements* · *Deterioration of gait and/or frequent falls* · *Increasing fatiguability on walking* · *Deterioration of Manipulative skills* *Other signs of progressive myelopathy* · *Increase in muscle weakness* ·

Loss of sensation · Onset of incontinence · Alteration in muscle tone · Decreasing co-ordination · Diminishing kinaesthetic awareness · Pins and needles.

- Musculo-skeletal problems e.g. foot posture, orthotics, scoliosis – check lower limb alignment and foot position when weight bearing e.g. standing, walking and if feet are rolling inwards (valgus ankle) refer to the orthotic department (**see Appendix 25**).

  Check/screen for pain and mobility in joints and limbs – don't forget check fingers for any swelling. (Small but increased incidence of arthritis, leukaemia, hip subluxation/dislocation so worth annually asking for symptoms) (**See Appendix 25**

- ENT – middle ear disease and obstructive sleep apnoea – ensure up to date audiology assessment and report. Refer for a sleep study and ENT referral for persistent symptoms (60% of individuals with Down Syndrome have sleep related upper airway obstruction).

- Dental care

- Eyes – glasses, squint, cataract, blepharitis, keratoconus, nystagmus – ensure up to date ophthalmology review and report. Ensure follow up arranged with Eye clinic and/or Optician.

- ***During annual reviews in Key Stage 4 (14-16yrs): Refer to transition pathways below for further guidance about upcoming transition from children's to adult services.***

Investigations:

- Audiology to be carried out yearly in Key Stage one (5-7yrs) and every 2 years after; more frequently if concerns identified. Screening should be ongoing throughout life, which should be automatic unless the family have repeatedly not brought the child and been discharged. If so, keep referring.

- Ophthalmological (vision and orthoptic) assessment to be carried out yearly in Key Stage one (5-7yrs) and every 2 years after this, as ongoing throughout life. If the child has not had any visual problems an annual vision check by a local optician could be sufficient.

- Thyroid function tests (TFTs) with T4, TSH and TPO (thyroid autoantibodies) every year, more frequently if any suspicion of thyroid disease. Children with mildly raised TSH or presence of antibodies with normal T4 should be tested more frequently; repeat in 6 months. A specialist opinion may be required; the paediatric endocrine specialist at Barnet is Dr Esther Freeman and at Royal Free is Dr Victoria Dublon. **NOTE:** if the child is already under the endocrinology team on thyroxine supplements, leave the monitoring of the TFT's with the endocrine team. Clinicians need to have a low threshold for testing thyroid function if there is any clinical suspicion at times between biochemical testing, as we know around 10% of the DS school age population have uncompensated hypothyroidism.

  Reference for TFTs: Thyroid disorder in Children and Young people with Down Syndrome www.dsmig.org.uk

- Weight and height annually and measured on Down Syndrome specific charts.

- Post pubertal teenager, before school leaving age – arrange assessment by paediatric cardiologist and echocardiogram. An echo can be ordered on EPR. Recommend this should be ordered at or before penultimate review so can see results and act on them prior to finally moving onto adult services.

Include in every report to the GP:

a) Recommended **extra vaccinations (See Appendix 12)** – annual flu vaccine and the extra pneumococcal vaccine; also discuss chickenpox. Letters should be distributed around Autumn to parents and GPs to remind them about these vaccinations due for ALL children with Down Syndrome. Recommend that these children are given the first batches of flu vaccine that is made available for the GPs. Chickenpox can present atypically and in those children who are immuno-compromised, consider VZV vaccine.

b) Every review by the community paediatrician, GP and/or paediatric physiotherapist should include asking about symptoms of **atlanto-axial instability** and documenting findings on that day. Consider completing and updating the BGA screening form (note: it documents examination at that time only).

https://www.british-gymnastics.org/technical-information/discipline-updates/disabilities/9316-atlanto-axial-information-pack-1/file **(See Appendix 21)**

c) Thyroid function **(See Appendix 20)**

Venepuncture at age 6months, 1 year and annually thereafter throughout life - To check T4, TSH and thyroid antibodies.

Where the T4 is normal and the child is asymptomatic but there is a mildly raised TSH (less than or equal to 10mu/l) or thyroid antibodies are present re-check after 6months. A specialist opinion may be warranted.

Key professionals and further referrals as needed:

(remember too that children with an EHCP have annual multi-agency reviews)

- **Involve school nurses e.g.** with growth checks, weight management, immunisation catch up (or GP/practice nurse) and cc your reports to school nurse.
- **Weight management nurses and referral**: The healthy weight nurses can be found on the Barnet website **https://barnet.gov.uk/citizen-home/public-health/Children-s-Health-/Weight-management.html**

Review Therapy input:-

- Speech and Language Therapy (SLT); ongoing school based SLT input if mainstream provision according to child's EHCP.
- Occupational therapy (OT) in line with EHCP. OT can offer useful assessment at school entry and other times with regard to having tables, chairs and other equipment at suitable height for short stature and accessibility of toilets/changing facilities. Also advice on providing a box to support feet, writing slope, holders for pens and pencils, special cutlery and scissors and other adaptations. OTs can advise on many aspects of Activities of Daily Living (ADL) support, home and school equipment if necessary and mobilising in school. *Ongoing input to be determined by assessment of need via annual reviews.*
- Physiotherapy and/or Orthotics in line with EHCP. Consider referral to physio for assessment if Joint or leg or back pain; for assessment and advice and possible onward referral to orthotics.
- ***School based programmes*** *sometimes include: group programmes to develop motor skills and activities for daily living (with or without OT intervention), handwriting tools to meet multisensory needs (e.g. handwriting without tears HWT), PE programme (with or without physiotherapy input).*

Review Education Input

- **Annual EHCP review** to monitor progress, use of Down Syndrome Education materials, access to ongoing training, involvement in Barnet LEG (Leading Edge Group) for DS. Access to Educational psychologist (EP) for ongoing support, advice and training. This can include advice on managing behaviour and sharing best practice. Ensure continued multi-agency planning involving parents. Invite paediatrician and school nurse; share any concerns over behaviour, communication etc., consider dual diagnosis.
- **Access to specialist peripatetic teachers** – Advisory **Teacher** for **Visual Impairment** or Advisory teacher for hearing impairment if wears hearing aids. (Specialist team, education and skills, North London Business Park, **Specialist.Team@barnet.gov.uk**) **(See Appendix 2 and 31)**

Other Services

- **Bedwetting service (over 7yr):** Paediatric nocturnal enuresis senior nurse. The service covers the Barnet areas and children are seen from the age of 7 years up to 19 years, offering clinic appointments for new referrals, as well as regular telephone support. Phone no: 020 7794 0500 ext. 54206. Email: **RF-TR.PaedNocturnalEnuresisServiceFAX@nhs.net**
- **Barnet CAMHS in Schools Team** or Children and Young People's (CYP) Wellbeing Team referral form - https://www.barnet.gov.uk/citizen-home/children-young-people-and-families/forms/Barnet-CAMHS-in-Schools-Team-or-Children-and-Young-People-s-CYP-Wellbeing-Team-referral-form.html

- **SCAN** (Service for Children and Adolescents with neurodevelopmental needs - a subservice of **CAMHS**) – run by psychiatrist Dr Mark Carter, Tel: 0208 702 4500 and mark.carter1@nhs.net
- **SENDIASS** Very useful for guidance around all issues EHCP/High needs funding/DLA etc. and host many useful conferences. https://www.barnet.gov.uk/citizen-home/children-young-people-and-families/parental-support/barnet-send-information-advice-and-support-service.html
- **Relationships/PHSE** – leaflets and information from Nottingham special school, written by head teacher David Stewart (see **Appendix 36**). Specialist school nurses can also be contacted to advise and support around relationships and also transition work, for those children in mainstream in particular. In special schools there is a dedicated school nurse who can work alongside family and school staff but ALL schools have an allocated school nurse.
- **LD Nurses (learning disability):** In many hospitals there are LD nurses who can help support the child and family if they are coming in for appointments or procedures or an admission. Schools are also helpful in preparing a child for this too. Always worth checking with the relevant hospital what is available to support students.
- **Integrated Learning Disabilities (LD) Team in Barnet for adults** – (**Appendix 35**) Consultants are Dr Eileen McNamara and Dr Andrew Leggate, consultant LD psychiatrists, the team also have specialist learning disability nurses, speech and language therapists, psychologists, physiotherapists and social workers. There is standardised referral form. Contact details are: Consultant Psychiatrist, Barnet Learning Disabilities Service, London Borough of Barnet, Adults and Communities, 8th Floor, Barnet House, 1255 High Road, London N20 0EJ. Tel: 0208 359 6173. Email: Marie.Theodorou@barnet.gov.uk

  Email form back to: **BLDSIntegratedDuty@barnet.gov.uk** or by secure email to **BLDS@barnet.gcsx.gov.uk** and attach any documents/reports to help us understand the person's needs. All referrals are discussed by Team Leaders and you will hear back within 10 working days. If you have not provided sufficient information, the referral form will be returned for more information.

- **Transition planning** – see below

TRANSITION PLANNING FOR HEALTH (PAEDIATRIC TO ADULT TRANSITION) 14YR+

What is transition and transition planning? (See Appendix 36 for Resources for transition planning)

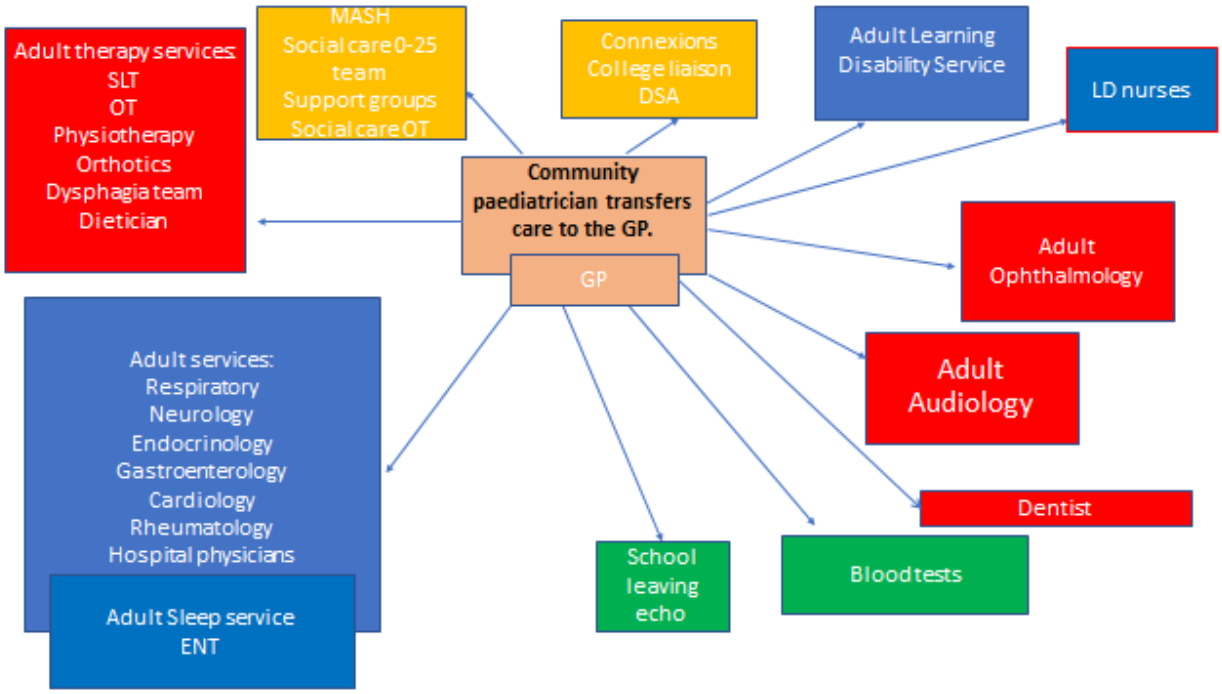
Transition planning should begin at the latest by the age of 13/14 (Year 9 in school) although parents may wish to raise concerns before this and children can be involved in the gradual development of independence from the age of about 6/7. ***The health plan will be part of a wider transition plan*** that school, outside organisations, education, social care initiate and review annually from year 9. This plan will evolve over time as the young person explores preferences and opportunities and will need to be reviewed at regular intervals.

Parents and carers need to be clearly aware of the transition plans and have a named professional contact during the transition period. Transfer of care should be to the GP and/or adult specialist services for physical health interventions and to learning disability services for mental health, behavioural or epilepsy related interventions.

https://www.bacdis.org.uk/policy/documents/transition_moving-on-well.pdf is an excellent document with lots of valuable information and resources with support groups and websites that parents, young people and schools/colleges may find useful.

In terms of health, transition from community paediatric and specialist paediatric care will occur from aged 16 years onwards, depending on local service policies and this can be confusing. E.g. the epilepsy team will transfer to adult neurology at aged 16 years, the community paediatrician will review annually until they leave school (this may be 19 years if they are in a special school), adult orthopaedic services or LD services will be from 18 years, the paediatric sleep service at the Evelina is up to 17yrs. It is always worth checking each service's guidance. Many paediatric specialist teams will do their own transition planning and referrals e.g. the paediatric epilepsy clinic runs joint clinics with the adult neurology doctors to prepare for transition. School nurses, SENCOs, social care and specialist nurses can all be involved and support this smooth process.

This integrated pathway is essential to outline the anticipated care a person with Down Syndrome may receive in adulthood form the multi-disciplinary and/or multi-agency care team. It incorporates both mental health and physical health needs. People with Down Syndrome on the whole do not have medical problems different from those in the general population but some medical conditions are overrepresented and most of these are treatable disorders that need to be recognised, diagnosed and treated accordingly.



All the therapies (physiotherapy, SLT, OT and the dysphagia team) form the Barnet Children's Integrated Therapies.

Annual health check by GP - Directed Enhanced Service (DES) from age 14 years:

In 2010 the DSA surveyed its members to find out about their experiences of adult annual health checks. It was found that health checks were not being conducted in line with official guidance and basic checks critical for people with Down Syndrome were being missed.

DSA developed an adult Health Book to be used by people with Down Syndrome at their annual health check and other GP appointments. The Health Book was launched in March 2014 and is currently sent to all members with Down Syndrome over the age of 14.

The DSA therefore produced an area on its website specifically for GPs to be used in conjunction with the Health Book. **(See Appendix 39)**

https://www.downs-syndrome.org.uk/for-professionals/health-medical/annual-health-check-information-for-gps/

and

https://www.downs-syndrome.org.uk/for-families-and-carers/health-and-well-being/annual-health-checks/

The annual health check for people with learning disabilities is a **Directed Enhanced Service (DES).** This is a special service or activity provided by GP practices that has been negotiated nationally. Practices can choose whether or not to provide this service. The Learning Disability DES was introduced in 2008 to improve healthcare and provide annual health checks for adults on the local authority learning disability register. To participate in this DES, staff from the GP practice need to attend a multi-professional education session run by their local Trust. The GP practice is then paid a sum of money for every annual health check undertaken. If the GP practice is not offering this, please make enquiries with the practice manager and GPs as to why, and discuss with your paediatrician .

Who can have one?

Annual health checks have been extended to include anyone with learning disabilities aged 14 years or above. So anyone with Down syndrome aged 14 years or over can have an annual health check.

All of DSA's members with Down Syndrome who are 14 years old or over will be sent a free copy of the Health Book.

How to get an annual health check

- The GP may get in touch with the person with Down Syndrome to offer an annual health check but this doesn't always happen.
- A person with Down Syndrome and/or a supporter can ask their GP for an annual health check. You do not need to be known to social services to ask for an annual health check. The community paediatrician will also notify the GP via letter, at their 13/14 year review, using a specific letter by our team **(See Appendix 32).**

How long should an annual health check be?

Guidance from the Royal College of GPs suggests half an hour with your GP and half an hour with the Practice nurse.

What areas of health should be looked at as part of the annual health check?

DSA has produced a check list for GPs which contains information about what should be included as part of a comprehensive and thorough annual health check. This includes a list of checks that everyone with a learning disability should undergo as part of an annual health check and a list of checks specific to people with Down Syndrome.

https://www.downs-syndrome.org.uk/for-professionals/health-medical/annual-health-check-information-for-gps/

Health Book: **https://www.downs-syndrome.org.uk/download-package/health-book/** And "Eliciting a case history"

DSA has also produced an excellent factsheet for GPs and other professionals on "How to elicit a history" and discusses difficulties and strategies to help.

It is important to try and get at least some of the history from the person with Down Syndrome if possible. Family members/supporters may not be aware of some of the symptoms, may under or overestimate the significance or severity of a symptom, or may not realize the impact the illness is having on the person with Down Syndrome.

It is also important to try and establish how the illness is affecting the person's functioning and behaviour (e.g. What is the baseline? How do they usually act or function? Are they acting or functioning differently?)

Some of the Health professionals that are involved:

- Cardiology – clinical review may be indicated for cardiac symptoms or new murmurs. However, routine referral to congenital cardiology is not indicated. It is important for those children who have a cardiac condition or previous surgery, to document if ***prophylactic antibiotics*** are recommended by the child's cardiologist for non-cardiac surgery and dental procedures. (GP or Community paediatrician to verify with consultant cardiologist if needed).
- Ongoing hearing surveillance is essential/audiology
- Ongoing vision surveillance is essential/ophthalmology/optician
- Ongoing dental surveillance is essential/dentist
- Adult endocrine team and/or paediatric endocrine services
- GP for ongoing annual surveillance.
- Adult learning disabilities team - specialist learning disability and mental health needs including: challenging behaviour, autism spectrum disorder, complex physical disability, mental health conditions, epilepsy, dementia, concerns around eating and drinking.
- Learning disability acute liaison nurse (hospital based)

- Primary care liaison nurses - Barnet have two dedicated GP Liaison nurses working closely with practices to raise awareness and provide support, in conjunction with the local community learning disability team which also runs health check training for practices alongside GP leads for learning Disabilities.
- Community paediatrician until reached the age of transition to adult services (usually the last review is the year the young person leaves school).

Strategies for health professionals during transition:

- Every clinic letter to GPs should include a transition summary – 'Transition issues reviewed today were as follows…' – or enclose a copy of any updated transition plan summary if used.
- A portfolio of parent, paediatrician and therapy reports can be helpful when the young person moves into adult services, along with multi-agency reports as appropriate.
- Consider using up-to-date communications technology to keep in touch with young people, e.g. a nurse could text a young person to remind them about medication to start promoting independence.

You can download the following here: (**See Appendix 39**)

https://www.downs-syndrome.org.uk/download-package/health-book/

- Health Book 2018 - a complete copy or individual pages
- Covering letter for your GP (2015)
- Covering letter for a PWDS (person with Down Syndrome) 14-17 years old (2015)
- Covering letter for PWDS 18+ years old (2015)
- Checklist of things should be included as part of a comprehensive and thorough Annual Health Check.

Referrals for GP to consider:

- Cardiology – clinical review may be indicated for cardiac symptoms or new murmurs. However, routine referral to congenital cardiology is not indicated (unless this has not been documented by the paediatric service e.g. new arrival in UK).
- Ongoing hearing surveillance is essential
- GP & Practice Nurse for ongoing annual surveillance DES.
- Ongoing surveillance of Vision
- Adult endocrine team if already under paediatric endocrine services
- Ensure Transfer from paediatric to adult specialty services

Other professionals to consider linking in with:

Health:

- Adult learning disabilities team - specialist learning disability and mental health needs including: challenging behaviour, autism spectrum disorder, complex physical disability, mental health conditions, epilepsy, dementia, concerns around eating and drinking.
- Learning disability acute liaison nurse

- Primary care liaison nurses

Education:

Responsibility for providing information, advice and guidance services to young people passed to local authorities; schools and colleges. The Barnet Multi-Agency Preparation for Adulthood (PfA) details the planning process to support transition from adolescence into adulthood for young people with complex learning. It is available on the Barnet Local offer https://www.barnetlocaloffer.org.uk/documents/669-preparing-for-adulthood-protocol.pdf

The post 16 Education and Skills team can provide information about including details of supported internships, email jasmine.west@barnet.gov.uk and sharon.glover@barnet.gov.uk**.**

Social care:

0-25 Disability Service Social Work team:

Social workers from the 0-25 Disability Service Social Work team cover a range of roles; the transition social worker (based in adult services) takes the lead, liaising with social workers from children's disability or looked-after (in care) children's teams.

- attend the annual transition planning meetings (from age 14) in school; and
- assess and organise provision to meet the care needs of the young person and their family.

Some children and young people with Down Syndrome may meet the criteria for the 0-25 Disability Service Social Work team. The team offers a service to children and young people who have a diagnosed severe/profound disability or diagnosed chronic health condition resulting in severe and profound disability. Your child needs to meet the eligibility Criteria to access a service offered by the 0-25 Disability Service Social Work team.

For the eligibility criteria please click on the document link that can be found on the Local Offer webpage: https://www.barnet.gov.uk/children-and-families/children-and-young-people-disabilities/0-25-disability-service

Annual Health Checks for ADULTS with Down Syndrome

Checklist: This checklist of things that should be included as part of a comprehensive and thorough Annual Health Check, specific for adults with DS, can be downloaded.

https://www.downs-syndrome.org.uk/for-professionals/health-medical/annual-health-check-information-for-gps/

The Royal College of GPs have also produced a more generic annual health checklist for people with learning disabilities - step by step toolkit. In the resources section there is also a pre-health check questionnaire for people with a learning disability.

http://www.rcgp.org.uk/clinical-and-research/toolkits/health-check-toolkit.aspx

The GP Practice should pass on a **Pre-Health Check Questionnaire**. This will help prepare the patient and carer for their health check appointment, reduce anxiety and improve effectiveness of appointment.

Hopefully, through the annual Enhanced Reviews the GP has undertaken, since the young person turned 14 years of age, means there is a strong doctor-patient relationship already built up, the young person knows the practice, GP and the practice nurse and understands what happens at these appointments already. This is an ideal scenario but there may be times where this has not happened e.g. if the person has moved GPs and so these guidelines and checklists are extremely important to read and use.

How long will the Health Check take?

The appointment should be carried across two separate 30 minute appointments. One with the practice nurse followed with an appointment with the patient's usual doctor.

Blood Tests

Try and arrange any routine blood tests at least 1 week before the health check. Some patients may find blood tests difficult and will require extra explanation and support.

Tests in adulthood include **Thyroid function tests** (every year throughout life) and possibly the following according to clinical need:

• Full blood count (FBC) • C-reactive protein • Urea and electrolytes (Kidney function) • Liver function Tests • Random glucose and glycosylated haemoglobin (HbA1c) • Lithium and anti-epilepsy drug (AED) levels - check level before morning dose ("trough level") • Calcium and vitamin D levels if on AED, poor sun exposure or from a black or ethnic minority • FSH in women who have not had a period for 6 months • Consider prostate specific antigen in men over 50 years.

ROYAL COLLEGE OF GPs: Syndrome Specific Medical health check guide – Down Syndrome

The survival of people with Down Syndrome has improved dramatically in the past few decades, largely as a result of improved surgical repair of congenital heart defects. The median age at death is now the mid-50s, compared with less than 10 years of age in the 1970s. Respiratory infection and dementia are now leading causes of death in adults with Down Syndrome. People with Down Syndrome generally do well with consistent schedules and can blossom in a setting of predictable routine. This also includes dietary habits and physical activity that prevent obesity.

Resources Managing the care of adults with Down Syndrome, Clinical Review, BMJ 2014: http://www.bmj.com/content/349/bmj.g5596

History

As with all people with LD focus on an assessment of:

• eyesight and hearing • eating +/-feeding • bowel and bladder function • behavioural problems and decline in skills. The differential diagnosis for a decline in skills includes: depression, changes to routines, life events, hypothyroidism, sleep apnoea, hearing loss, vision loss, dementia, seizure disorder, developmental regression.

Important causes of unexplained weight loss include: coeliac disease and gastroesophageal reflux or dyspepsia, and swallowing problems.

Well over 50% of people with Down Syndrome have significant hearing impairment (HI), which can range from mild to profound. Sensorineural and/ or conductive loss may be present at any age. If undetected it is likely to be a significant preventable cause of HI. The main cause of conductive loss is persistent otitis media with effusion (OME) (glue ear).

About two thirds have problems affecting their eyesight e.g. refractive errors, cataract, glaucoma and keratoconus.

Obesity is widespread in people with Down Syndrome (89-95%), likely due to lower activity levels and a lower metabolic rate, making exercise and energy restriction critical in maintaining a healthy weight.

One third, if not the majority of those with Down Syndrome, have obstructive sleep apnoea (OSA), which may due a small jaw and upper airways combined with macroglossia, as well as blocked nose and most of all obesity. OSA can occur at any age and cause daytime sleepiness, behavioural change, loss of skills and other symptoms suggestive of depression or dementia. Complete an Epworth sleepiness score and refer for sleep studies. Weight loss if obese as well as CPAP mask overnight can dramatically improve the symptoms of OSA and the wellbeing of patients.

Pneumonia, aspiration pneumonia and flu are common causes for admission and the second most common cause of death of people with Down Syndrome. All adults with Down Syndrome are eligible for Influenza and Pneumococcal immunisation.

Swallowing difficulties (dysphagia) can present with coughing, gagging, sighing, burping, or throat clearing during mealtimes, and cause choking with aspiration. Evaluation consists of a modified barium swallow study in conjunction with a SALT assessment.

Gastro-oesophageal reflux is also common in people with Down Syndrome. Like dysphagia, it can present with weight loss, vomiting, decline in skills or behavioural changes.

Mental health problems affect 25-30%, mostly depression, anxiety, obsessive compulsive tendencies, and behavioural issues. Depression is common in older adults, often triggered by bereavement or changes in their living situation. Discriminating depression from dementia can be difficult but is important, since the former as amenable to medical therapy. Symptoms more suggestive of depression include withdrawal and decreased appetite and speech. Autism is ten times more common than in the general population; often requiring specialist input.

People with Down Syndrome have an increased risk of Alzheimer's dementia, with an earlier onset than in the general population. The prevalence is 10-22% in their 40s; 2025% in their 50s; and 40-77% in those over 60 years, contributing to one third of deaths. Although donepizil and memantine are increasingly used, there is currently no good evidence demonstrating their effectiveness in this population. They appear to be beneficial for some patients, however, hypotension, bradycardia or ataxia may require their discontinuation in some.

Women with Down Syndrome have an earlier menopause: around 44 years on average.

Down Syndrome is an independent risk factor for osteoporosis, further increased by early menopause, anti-epileptic medication and other risk factors. There is a high risk of fractures in the over 50s.

Hypothyroidism affects 15-37%, increasing with age. Hyperthyroidism is also more common than in the general population.

Diabetes: Increased prevalence of Type 1 diabetes and Type 2 Diabetes associated with obesity. The onset of type 2 diabetes is often at a younger age than the general population and can present with subtle symptoms.

Skin conditions: Dry skin and eczema are particularly common and are managed in the usual way.

Cervical spine: Atlanto-axial instability has mostly been described in children. In adults, degenerative changes and cervical spondylosis are more common, with a prevalence of 35-70%. Routine cervical spine X-ray is not recommended, but we need to be alert to signs of spinal stenosis with cord compression and assess these promptly.

Congenital heart disease is common and usually treated surgically in early childhood. In adults, consider the possibility of acquired valve disease, specifically mitral valve prolapse (in 45%, often with mitral regurgitation) and aortic regurgitation. It may be asymptomatic and a murmur may not always be audible. The incidence of coronary artery disease in adults with Down Syndrome is decreased compared with the general population.

Cancer – with the exception of childhood leukaemia, the incidence of cancer - whether hematologic or solid tumours - is also decreased in all age groups with Down Syndrome. Full blood counts frequently show leukopenia, macrocytosis and mild polycythaemia, which do not appear to be of clinical relevance, but B12-deficiency and hypothyroidism should be excluded and the rare possibility of adult leukaemia be borne in mind.

Examination

Full assessment by **optician/optometrist at least every 2 years**. If examination is difficult, refer to specialist optician or ophthalmologist for assessment.

Otoscopy annually - gentle examination as short auditory canals. **Auditory assessment every 2 years** has been recommended (including auditory thresholds, impedance testing).

Dental - **Dental Review at least annually**, as periodontal disease is common.

Respiratory - Examine nose for blockage, the oral cavity, and lungs for lower airway disease.

Sleep - ask about daytime sleepiness and sleep apnoea. Consider Epworth sleepiness score and sleep studies.

Cardiovascular - Auscultation of the heart annually**.** A single Echocardiogram should be performed in adult life if there are no concerns. Echocardiogram and cardiac opinion should be arranged for new murmurs and signs of cardiac failure. Adults with a pre-existing structural abnormality should be informed if applicable prophylactic antibiotic protocols.

Gastrointestinal-

Look for signs of oesophageal reflux. Ask about swallowing problems and aspiration.

Ask for signs and symptoms of Coeliac Disease annually - Coeliac antibody test in those with suspicious symptoms or signs: disordered bowel function with loose stools or new onset constipation, abdominal distension, general unhappiness and misery, arthritis, rash suggesting dermatitis herpetiformis. Coeliac antibody test in those with existing thyroid disease, diabetes or anaemia.

Endocrine - Thyroid function blood tests (TFTs) including thyroid antibodies every 1 year. ¨ Check TFTs if weight gain or loss, generally unwell, possible diagnosis of depression or dementia. ¨ Consider HbA1c annually (diabetes defined as greater than 48 mmol/mol) and finger prick blood glucose.

Menopause –

Ask women over 40 about hot flushes and menopausal symptoms.

Osteoporosis screening should start in their 40s. Screen early especially in the presence of risk factors, such as poor mobility or non-weight bearing status, antipsychotic or anti-epileptic medication, poor nutritional status, or early menopause.

Mental Health –

From the age of 40, ask about symptoms of dementia, which include: loss of skills and independence, no longer remembering or managing routines, need for prompting, appearing confused, change in behaviour, also urinary and/or faecal incontinence, ataxia, seizures, impaired mobility. Ask family members and/or carers about these symptoms.

<u>The differential diagnosis of a decline in skills and change of behaviour includes:</u>
• Hypothyroidism
• Sleep apnoea or other sleep problems
• GORD or coeliac disease
• Depression or other mental health problems
• Hearing or visual loss
• Dementia
• Iatrogenic (medication related) causes
• Seizures
• Environmental changes such as routine or life event such as bereavement
• Abuse

Orthopaedic - Ask about signs of spinal stenosis associated with atlanto-axial instability, which may be acute or chronic, such as: hyperreflexia, ataxia, clonus, unsteadiness, deterioration in bladder or bowel control, or quadriparesis, and consider urgent neurosurgical assessment if present.

APPENDICES

Appendix 1 (p45): Intake Child Development Team (CDT) form (also has contact details for referrals/teams) - Who we are, where we are and what do we do?

Appendix 2 (p47): Support groups (DS+non-DS specific), Training/Resources for professionals, Barnet organisations.

Appendix 3 (p53): Red flags for feeding, recommended positioning and the paediatric complex needs and dysphagia speech and language therapy (SLT) service. Leaflets for parents.

Appendix 4 (p58): Haematology guidance

Appendix 5 (p59): Homecare/community paediatric nurses referral form

Appendix 6 (p60): Nutrition and dietetics service (including enteral feeding) – leaflets and referral forms

Appendix 7 (p61): Infographic: Top tips for triaging and treating kids with DS

Appendix 8 (p62): DS specific Growth charts and Inserts for red book (child health record)

Appendix 9 (p64): Pre-school Teaching Team Down Syndrome Advisor's Parents letter (Pre-school support teacher)

Appendix 10 (p65): Barnet Breastfeeding Support Referral form

Appendix 11 (p66): Parent's letter for sharing

Appendix 12 (p68): Unusual or recurrent infections and guidance on immunisations with GP and parent letter/template.

Appendix 13 (p73): Sleep, sleep disorders, use of melatonin, referrals to sleep services, support and resources, research and information about oximetry screening, red flags/when to worry.

Appendix 14 (p78): Constipation, Coeliac screening (including HLA typing) and gastroenterological complications

Appendix 15 (p81): a) Neurophysiology (EEG) referral form and melatonin guidance (for EEG usage)

b) Infantile spasms – what to look out for, recognition and treatment and support groups

Appendix 16 (p84): Criteria for RSV prophylaxis

Appendix 17 (p85): Referral to Family services/ 0-25 Disability Service Social Work team/ MASH

Appendix 18 (p87): Neonatal guidelines (DSMIG, 2018-9)

Appendix 19 (p88): Paediatric physiotherapy services

Appendix 20 (p89): Thyroid guidance (DSMIG, updated 2020)

Appendix 21 (p91): Atlanto-axial instability info., leaflets for parents, screening test/form for health professionals

Appendix 22 (p94): Dental information and referral form

Appendix 23 (p96): Hearing and audiology pathway

Appendix 24 (p97): Ophthalmology pathway

Appendix 25 (p99): Musculoskeletal complications and Referral form for Orthotics

Appendix 26a) (p100): Speech and Language therapy

Appendix 26b) (p101) Oromotor exercises – research and practical information

Appendix 27 (p104): CAMHS information, referral and Referral form for CAMHS. Support/IAPT for parents.

Appendix 28 (p108): Occupational therapy (OT) services – child development team OT and social care OT and criteria for paediatric occupational therapy referral. Hand exercises and example of an OT plan.

Appendix 29 (p115): School nursing referral information

Appendix 30 (p116): Fluid and food thickeners – information and letter for parents and schools

Appendix 31a0 (p118): Education – professionals that can support and provide training

Appendix 31b) (p122): Which type of school is best for children and young people with Down Syndrome?

Appendix 32 (p124): Letter to GP about Learning Disabilities Directed Enhanced Services (DES)

Appendix 33 (p127): Managing behavior

Appendix 34a) (p128): Nutritional advice and snack ideas with low sugar

Appendix 34b) (p131): Nutrivene- D and UK perspective

Appendix 35 (p132): Exercise, healthy lifestyle with access and participation

Appendix 36 (p135): Sex and relationship education and pupils with additional needs

Appendix 37 (p138): Integrated Learning Disabilities (LD) Team in Barnet for adults

Appendix 38 (p139): Resources for transition child to adult services

Appendix 39 (p141): Health checklists for people with learning disability and Letters from DSA for members to use

Appendix 40 (p145): Down Syndrome Checklists - Ages birth to 5 years, Ages 5-12 years, Ages 14 years to Adult

Appendix 1: Barnet Child development team referral form – (Sept 2020).

https://wwc.barnet.gov.uk/working-children-barnet/practitioner-guidance/child-development-service/child-development-service

BARNET LONDON BOROUGH — with — Cambridge Education | Royal Free London NHS Foundation Trust | NHS Central London Community Healthcare NHS Trust | NELFT NHS NHS Foundation Trust

Barnet Child Development Service Referral Form

Referrals to (please circle / embolden / highlight as appropriate):
Speech & Language Therapy, Dysphagia, Physiotherapy, Occupational Therapy, Pre-School Teaching Team, BEAM, Specialist Team (Advisory Teachers), Childrens Continuing Care Team, Specialist Childrens Nursing, Neurodevelopmental Paediatrics

SEND COMPLETED FORM TO APPROPRIATE TEAMS (addresses / emails overleaf).
If appropriate the referral will be shared/discussed within a multi professional meeting

Please write clearly and in black ink. Attach all relevant reports and observations. Continue on an additional sheet if necessary.
Incomplete forms and missing information will delay the referrals being accepted

NOTE ABOUT FAMILY ADDRESS, GP ADDRESS and IMPACT ON SERVICES:

If family live out of borough they will not see the Barnet Preschool Teaching Team (PsTT) and will be referred by the hospital team or community team to their local PsTT (also known as portage) service. If the GP is in Barnet, regardless of which borough the family lives in, then their health needs will be met by Barnet teams e.g. community paediatricians, therapists, audiology etc. For education services like PsTT or the SEND team (special educational needs and disability), that comes from the borough of residence, regardless of where their GP is based. Parents need to be aware that living in one borough with a GP in another is complicated and often means services are less joined up and harder to access at times, so if at all possible it is recommended to have the GP and the home post code in the SAME borough.

Who we are, where we are and what do we do?

Developmental Paediatrics	Child Health HQ, Edgware Community Hospital, Burnt Oak Broadway, Edgware, HA8 0AD	020 7794 0500 ext. 26457 email: rf-tr.childdevreferrals@nhs.net
Pre-School Teaching Team	Early Years Centre, Oakleigh Road North, London, N20 0DH	020 8361 2456 ext. 1
Children's Integrated Therapies including Speech & Language Therapy, Physiotherapy & Occupational Therapy (Health).	3rd floor Westgate House, Edgware Community Hospital, Burnt Oak Broadway, Edgware, HA8 0AD.	0300 300 1821 email: nem-tr.BarnetCIT@nhs.net

Developmental paediatrics: this refers to a community based paediatrician (children's doctor) who specialises in children and young people (0-18yrs) who have developmental and possible health needs that need ongoing care. We work in a multidisciplinary group (i.e. with other professionals in the community) to support the child and family as a whole and liaise closely too with hospital services if needed. We aim to have appointments in community settings and to ensure you have the same doctor for most of these appointments to enable continuity.

Pre-school teaching team (Barnet): this refers to an early intervention service for children with complex Special Educational Needs and Disabilities. They offer mainly home-based teaching support to children under the age of 5 who live in the London Borough of Barnet. The Pre-school Teaching team is a registered Portage Service. The Pre-school Teaching Team offers intervention to children who are showing some delays or difficulties in their development. We aim to work together with parents and carers to help children make developmental progress. From the information available at the multi-agency referral meeting, a decision will have been made that the Pre-school Teaching Team could have a role to play in supporting a child.

Children's Integrated Therapies

https://www.nelft.nhs.uk/barnet-childrens-integrated-therapies/

The Children's Integrated Therapies (CIT) service offers both integrated and single therapies dependent upon need and will provide specialist assessment, treatment and management for those children that meet the criteria for the service. The CIT service offers universal services in the form of groups in Children's Centres and Schools, targeted services offering early intervention and blocks of therapeutic intervention and specialist services requiring trans-disciplinary interventions and specialist services such as dysphagia.

The team works with children and parents/carers in schools, Children's centres, clinics and their homes to make an assessment of need and then to deliver therapy accordingly. Children and young people who have an Education and Health Care Plan (EHCP) will continue to have therapy according to the recommendations set out in the plan.

The CIT team work with colleagues in education and social care to deliver an integrated service for children and young people and will share information only to support the care outcomes for the Child or Young Person.

The service runs groups in Children's centres which offer a pre referral assessment for under 5 year olds, please contact your local Children's Centre for further information (https://www.barnet.gov.uk/citizen-home/children-young-people-and-families/fyi-families-and-young-peoples-information-service.html)

Contact our service in Barnet:

Single Point of Access (SPA)
3rd Floor, Westgate House
Edgware Community Hospital
Burnt Oak Lane
Edgware, HA8 0AD

Tel: 0300 300 1821
Service email address: **nem-tr.BarnetCIT@nhs.net**

Referrals

Referrals are accepted from parents/guardians and healthcare, education and social care professionals.

Referrals forms should be posted or emailed to the service at the address above.

Appendix 2: Support groups, Training/Resources for professionals, Barnet organisations

For professionals:

DSMIG

Down Syndrome Medical Interest Group. A group of clinicians with a special interest in Down Syndrome, involved in training, and in producing and reviewing national surveillance guidelines www.dsmig.org.uk.

Down's Syndrome Association (DSA) Tell it right, start it right campaign:

https:/www.downs-syndrome.org.uk/about/campaigns/tell-it-right-start-it-right/tell-it-right-information-pack/

Training and support for delivering a positive diagnosis. Advice and training available for all those involved in delivering a diagnosis of T21.

References and useful resources for families

For Parents:

Down's Syndrome Association (DSA)
Helping people with Down Syndrome to live full and rewarding lives, focusing solely on all aspects of living successfully with Down syndrome.
Helpline: 0333 1212 300 offers information, support and advice to people with Down Syndrome, their families and the people that support them. www.dsa-uk.com

Email: info@downs-syndrome.org.uk

They also can provide the red book Down Syndrome inserts and a new parent pack if you call them and register with them. Multiple online resources covering health, education, support, benefits – and a phone line.

Down's Heart Group

A small charity offering support and information (and support line) relating to heart conditions associated with Down Syndrome. https://dhg.org.uk/ There is also an e-learning package designed to empower parents who have a child with Down Syndrome who are facing congenital heart surgery https://dhg.org.uk/information/ Tel: 0300 102 1644 Email: **info@dhg.org.uk**

Down Syndrome International
A UK based international disabled people's organisation, comprising a membership of individuals and organisations from all over the world, committed to improving quality of life for people with Down Syndrome, promoting their right to be included on a full and equal basis with others.
https://www.ds-int.org/world-down-syndrome-congress
https://www.ds-int.org/Blogs/wdsd-updates

World Down Syndrome Day https://www.worlddownsyndromeday2.org/about-wdsd
www.ds-int.org

Mosaicism in Down Syndrome

In Down Syndrome, mosaicism means that some cells (rather than ALL) of the body have trisomy 21 and some have the typical number of chromosomes. This affects about 2% of those with Down Syndrome. Little research in this group to predict longer term outcomes e.g. with Speech and language or cognition and what research is available is quite mixed.

- International Mosaic Down Syndrome Association
  www.imdsa.org
- Mosaic Down Syndrome
  www.mosaicdownsyndrome.com

Diagnosis - supporting parents and relatives

- Looking forward to your baby {Down's Syndrome Association] https://www.downs-syndrome.org.uk/

Support for professionals in delivering a positive diagnosis

- Tell it Right, Start it Right [Down's Syndrome Association]

Support for parents in telling friends and family

- Down Syndrome: A leaflet for friends and family [Down's Syndrome Association] Information and Support for all
- Positive about Down Syndrome [Positive About Down Syndrome] https://positiveaboutdownsyndrome.co.uk/

Benefits and financial help:

www.downs-syndrome.org.uk/for-families-and-carers/benefits-and-financial-help/detailed-benefit-guides/disability-living-allowance/

Barnet Local Offer (www.barnetlocaloffer.org.uk)
Includes information on the ***Disability Access Fund (DAF)/Early Years SEND Inclusion Funding (SENIF)*** to support children with disabilities or special education needs, by aiding access to Early Years places by for example supporting providers in making reasonable adjustments to their provision through equipment or training. (If you receive Disability Living Allowance (DLA) then you would also qualify for this extra funding).

The Family fund

UK's largest charity providing grants for families raising disabled or seriously ill children and young people.

www.familyfund.org.uk

Local Barnet organisations:

Barnet Local Offer (www.barnetlocaloffer.org.uk)
This is the Local Authority's website where all local resources for supporting children and young people are listed. It is well worth being familiar with its pages and to revisit from time to time, as the website develops. Relevant pages on inclusion, promoting independence, support in school and different levels of expertise.

Barnet MENCAP offer a very supportive drop-in facility for families of children with likely developmental problems.
www.barnetmencap.org.uk

Barnet Carers https://barnetcarers.org/ 0208 3439698

Barnet Carers Centre was established in 1996 and is a network partner of Carers Trust. We are an independent charity based in North Finchley. The Centre offers advice, information, emotional and practical support for all informal carers who live or work in the London Borough of Barnet. We provide carers' assessments, activities, counselling, training, help with form filling, outings and a lot more.

Barnet Parent Carer Forum http://www.barnetpcf.org.uk/

We are a voluntary group of enthusiastic, committed parents and family carers in the London Borough of Barnet working with the local authority to ensure that the voices of our children and young people and their families are heard. If you want to be involved in shaping services for our young people then please join us – the wider our representation the stronger our voice! c/o Barnet Parent Carer Forum, Barnet Mencap, 35 Hendon Lane, Finchley, N3 1RT . Telephone 07468 029 705. Email info@barnetpcf.org.uk

Barnet Parent Carer Forum is part of the National Network of Parent Carer Forums (NNPCF) whose membership is made up of all Parent Carer Forums in England. NNPCF representatives, who are all parent carers, work with a broad range of organisations including Department of Education, Department of Health, Council for Disabled Children, British Academy of Childhood Disability and IPSEA. To find out more go to www.nnpcf.org.uk

Barnet Leading Edge Group (LEG): The Barnet Leading Edge Group for children and young people with Down syndrome are a group of parents and professionals who meet once a term. We want to help Barnet take a strategic lead to help our early years settings, schools and further education colleges to improve outcomes for our children, young people and their families. We study best practice and latest research and also use the expertise of the parents and professionals in the leading edge group. We provide guidelines and training for schools and early years settings. When possible we research to try and find out the best ways to help our children make progress and have successful educational placements. We work effectively together to influence practice in educational settings. We all have different roles and support the group according to our different perspectives. If you would like to join the group, or would like more information please contact sarah.geiger@barnet.gov.uk.

Supports children and young people (CYP) with DS in primary and secondary schools by outlining best practice for schools (levels of expertise); this focuses on training, planning, curriculum, social, emotional and behaviour needs as well as personal support needs, transition and activities. The group organizes training and every two years we hold a DS conference open for all families and professionals in Barnet.
https://www.barnetlocaloffer.org.uk/pages/home/information-and-advice/how-to-get-help/barnet%20leading%20edge%20groups/barnet%20down%20syndrome%20leading%20edge%20group

The BIG-DS hub (Barnet Integrated Group for Down Syndrome): This refers to the hub at Underhill Children's centre for all Barnet preschool children with DS – integrating health, therapy and educational needs all in one place. Further information: "Barnet's Novel Approach to Integrated Care for children with Down Syndrome", by Soor A., Rachamim E., Petsas A., Redman S. (2019). https://5f2fe3253cd1dfa0d089-bf8b2cdb6a1dc2999fecbc372702016c.ssl.cf3.rackcdn.com/uploads/ckeditor/attachments/4646/Barnet_DS_Poster.pdf

Children's Centres: Most of the local Children's Centres offer a range of very good and supportive behavioural support courses for parents to attend. These really do make a difference.

0-25 Disability Service Social Work team. Some children and young people with Down Syndrome may meet the criteria for th0-25 team. They offer service to children and young people who have a diagnosed severe/profound disability or diagnosed chronic health condition resulting in severe and profound disability. Your child needs to meet the eligibility Criteria to access a service offered by the 0-25 Disabilities Service. For the eligibility criteria please click on the document link that can be found on the Local Offer webpage: https://www.barnet.gov.uk/children-and-families/children-and-young-people-disabilities/0-25-disability-service

Support groups in UK (DS-Specific)

Positive about Down Syndrome

https://positiveaboutdownsyndrome.co.uk/

#NobodyToldMe A collection of personal experiences written by young people with Down syndrome, their friends and family. #NobodyToldMe challenges outdated perceptions and attitudes towards those with Down Syndrome by showing the reality of our lives.

https://positiveaboutdownsyndrome.co.uk/nobodytoldme/

The Ups of Downs https://upsofdowns.co.uk/

Tel: 07814929306 **Email: info@upsofdowns.co.uk**

Established in 2006, and based in Leamington Spa, The Ups of Downs has been celebrating Down Syndrome in Warwickshire and surrounding counties for the last 13 years and works with more than 60 families. Our children are aged from birth to 15 years and meet regularly with children of their own age to work on essential skills in a fun and engaging way.

https://upsofdowns.co.uk/thischildcan/

The exhibition showcases children and young people with Down Syndrome and the many talents they have, aiming to demystify the condition and challenge outdated images.

Future of Downs

Support, chat and information for parents of children with Down Syndrome. Also an active Facebook group.

www.futureofdowns.com

Downright Excellent

Enabling children in London with Down Syndrome to maximise their potential as individuals and equally participating members of society through, especially but not exclusively: educational programmes, quality play, education and support for parents and education and support for siblings.

Provides weekly speech and language and occupational therapy sessions at the Sundial Centre in Hoxton for children aged 0-15 years old. (Friday mornings 0-4yr olds and Saturday mornings for ages 5-15) Based in London E7 7RU

www.downrightexcellent.org

Up on Downs

Up on Downs is a parent run organisation which supports families with Down Syndrome in Hertfordshire.

www.upondowns.com

Down Syndrome Scotland

www.dsscotland.org.uk

Down's South London

A South London parent-run charity offering unique, specialist early intervention therapy for babies and young children with Down Syndrome and local support network for families. Free early intervention multidisciplinary (MDT) therapy provision for children with DS from birth to 6 years and their families in their South London catchment area.

www.downssouthlondon.org

DS Achieve

We empower families to enable their children with Down Syndrome to fulfill their potential. A Hertfordshire based organisation providing Hertfordshire-based families: Our little Achievers group for children 5 and under, Our Young Achievers programme for primary school-age children and training events and special events.www.dsachieve.org

Wouldn't change a thing

The mums in this video and the dad who created it (https://twitter.com/5ushi) met online and got together to show the world just how ordinary and fun life with the condition is and how they "Wouldn't Change a Thing".

https://www.wouldntchangeathing.org/

https://www.youtube.com/watch?v=Biex1XR_mpo

The Down Syndrome Research Foundation UK (DSRF-UK)

A national charity formed by parents of children with Down Syndrome who want greater emphasis placed on best scientific research, innovation and best evidence-based interventions, in addition to supporting the human rights of people with Down Syndrome and their families, through advocacy. www.dsrf-uk.org

Support groups/organisations around the UK (not DS-specific)

Scope
www.scope.org.uk
Supporting disabled people and their families through practical information and support, particularly at the time of diagnosis and in a child's early years.
6 Market Road, London N7 9PW 020 7619 7100

Sense
www.sense.org.uk
Supporting and campaigning for deaf blind people
0300 330 9257

The Counselling Directory
www.counselling-directory.org.uk

Care for the Family
Positive Parenting Courses – "there is something very special about meeting other parents/carers on one of these courses, with the ability and benefits of sharing ideas and experiences with others." Usually six 2-hour sessions, led by experienced and trained facilitators. The Early Years, The Primary Years , The Teenage Years, Dads, Special Needs, Handling Anger in the Family, Quidz In – helping kids manage money, How to Drug Proof Your Kids. Parentalk is a DVD led parenting course, Digital Parenting online resources as well as the Positive Parenting courses.

www.careforthefamily.org.uk

SNAP charity (Special Needs and Parents):

https://www.snapcharity.org/ SNAP Helpline:01277 211300

An Essex charity for families with children and young people who have any special need or disability. SNAP's aims are to inform, encourage and support parents and carers so that they can grow in strength and knowledge and

become better equipped to give the best possible help to their children. Also a large useful directory for parents on their website.

Cerebra

A national charity helping children with brain conditions and their families discover a better life together. E.g. advice on education and transport, financial support, Sleep, toilet training and continence, getting help, getting out etc.

www.cerebra.org.uk

The Family fund

UK's largest charity providing grants for families raising disabled or seriously ill children and young people.

www.familyfund.org.uk

The Newlife Charity

A national charity providing equipment for disabled and terminally ill children.

www.newlifecharity.co.uk

Homestart

Local community network of trained volunteers and expert support helping families with young children through their challenging times, working with families across the UK. At the heart of each Home-Start's work is home visiting volunteer support.

In Barnet – www.homestartbarnet.org Tel: 020 8372 0674 Email: admin@homestartbarnet.org

www.home-start.org.uk

ADDISS – The National Attention Deficit Disorder Information and Support Service

Provides people-friendly information and resources about ADHD and related learning and behavioural difficulties, to anyone who needs assistance. Bookstore available too with a wide range of resources, tel: 020 8952 2800, or email: info@addiss.co.ukBased in Edgware in Barnet. Also runs parenting support groups, courses for parents and training for professionals.

www.addiss.co.uk

SENDIASS

Very useful for guidance around all issues EHCP/High needs funding/DLA etc and host many useful conferences.

https://www.barnet.gov.uk/citizen-home/children-young-people-and-families/parental-support/barnet-send-information-advice-and-support-service.html

Makaton Charity

Training courses for carers and professionals, resources to download for home and school.

www.makaton.org

www.wetalkmakaton.org Sign of the Week.

email: info@makaton.org 01276606760

Contact A Family
www.cafamily.org.uk
Supporting the families of disabled children whatever their condition or disability
209-211 City Road, London, EC1V 1JN 020 7608 8700

Appendix 3 –Paediatric complex needs and dysphagia speech and language therapy (SLT)

Red flags for feeding, recommended positioning.

To be clear, the paediatric dysphagia service (PDS) are speech and language therapists who specialise in feeding (over communication) – other SLTs focus on communication and not feeding. So they are the same team with different specialisms.

Background: Feeding difficulties are common in babies with DS, therefore it is essential that mothers are provided with advice and support regardless of the method of feeding. Infants with DS are at increased risk of having hypotonia, which can impact on feeding tolerance. Other factors which can impact on feeding include heart, reflux and respiratory problems, all of which can delay the progression to full oral feeding. It is important that a speech and language therapist considers the following factors during assessment:

- Gestational birth age, i.e. if the baby has been born premature, then they will have increased risk of a delay in developing competent oral feeding skills

- Assessment of early oral reflexes, i.e. rooting reflex, gag, bite reflex and suck -swallow reflex - with a clear evaluation of oral secretion management. For sucking, assessment of the sequential nature of the patterns observed, and the type of suck pattern, e.g. disorganized, dysfunctional, etc., need to be evaluated

- Intra oral pressure

- Muscle tone

- Infant tolerance of different positions for feeding

- Infant responsiveness to carer's communication, and overall responsiveness to daily care activities

- Physiological stability during NGT feeds, and /or oral feeds

- Behavioural organization during feeding

Contact details:

Paediatric Dysphagia Service, Westgate House, Edgware Community Hospital, Burnt Oak Broadway, HA8 0AD. Tel 0208 732 6913

In Barnet Neonatal unit (NNU, Starlight) – the SLT/dysphagia team can be contacted via NNU 02082165160. Many babies with Down Syndrome will be seen by a specialist feeding therapist whilst in hospital, who then lets local community services know about the assessment and plans.

Letter for professionals and parents:

Within the Down Syndrome population there is an increased likelihood of childhood difficulties with eating, drinking and swallowing, in particular oral-motor difficulties and sensory challenges are common. Co-morbid health conditions can further increase the likelihood of feeding difficulties.

Factors to consider:

Structural differences

- Low tone and open posture of lips can cause the anterior loss of fluids/food
- A relatively larger tongue and/or less mobile tongue can cause difficulties manipulating and moving food within the mouth
- Solids can become stuck in a high palate
- Low tone in facial muscles can make it more difficult to effectively chew and/or may mean early fatigue when chewing

Poor sensory awareness can mean that the child is not fully aware of where food is within mouth or when they have chewed sufficiently to swallow, or they may have a hypersensitive gag reflex.

Infant reflexes last longer than typical- e.g. thrusting tongue forward and pushing food out of mouth or clamping down when presented with a spoon.

Jaw and tongue are unstable or uncoordinated causing food to fall to the back of the mouth prompting gagging or choking.

New referrals

As the evidence base suggests that children with Down Syndrome are more likely to have feeding difficulties there is a lower referral criteria threshold for this population. The following list suggests symptoms that would be of particular concern and would be best explored following a referral.

The RED FLAGS:

- Coughing or choking with food or fluids
- Back arching, turning away and refusing bottle/breast or when presented with spoon
- Airway/breathing sounding congested or more congested when eating and drinking
- Wet/gurgly voice when eating or drinking
- Wet sounding cough when eating or drinking
- Changes in facial colour, alertness, breathing when eating and drinking
- Frequent chest infections, particularly if not during season for respiratory illnesses
- Development of respiratory symptoms such as wheezing
- Prolonged feeding times
- Difficulties with texture progression (e.g.. only accepting thin puree)
- Frequent vomiting when eating and drinking (the possibility of reflux should also be discussed with the child's doctor)

Children previously known to the service

The service is currently operating using an *episodic care* model, when a child is agreed to have a safe management plan in place they will be discharged. Written eating and drinking guidelines will be provided describing the management plan. It is expected that some of these children will need to be referred back to the service for another episode of care if changes to the management plan need to be made (e.g.. due to skill development).

All discharge summaries or reports contain the following advice wording to parents/carers and professionals. An immediate referral should be made if concerns are raised of this nature. We are happy to discuss individual cases and if a referral is warranted.

If any of the signs listed below are observed, please request re-referral to the PDS team and seek medical advice: ***the red flags***

- *Coughing or choking with food or fluids*
- *Airway/breathing sounding congested or more congested when eating and drinking*
- *Wet/gurgly voice when eating or drinking*
- *Changes in facial colour, alertness, breathing when eating and drinking*
- *Frequent chest infections, particularly if not during season for respiratory illnesses*
- *Development of respiratory symptoms such as wheezing*

When children previously known to the service who have dietary modifications in place start at a new educational or care setting a referral will most likely be required to ensure staff at the new setting are able to fully implement dietary modifications. Written eating and drinking guidelines will be provided to the new setting describing the management plan. This will contain in the case of fluids a 'recipe' of the correct ratio or fluid to thickener powder and in the case of foods the appropriate testing methods and example foods.

Children with longer term dietary modifications in place, especially those on thickened fluids should be referred for a reassessment before these modifications are ceased.

Other specific information:

Videofluoroscopy - Barnet children can access videofluoroscopy through a referral from the SLT/dysphagia therapist to the radiology department at the Royal Free hospital or through a referral by the Barnet SLT/dysphagia therapist to the SLT/dysphagia team at GOSH. Generally both services they will accept all SLT referrals where there is a clinical assessment/recommendations. They usually see children within 4-12 weeks.

Oro-desensitisation programmes can be helpful for tolerance of teeth cleaning/ acceptance of feeding as sometimes used for those non-oral children e.g. neonates/ children with PEGs and to reduce the impact of negative oral experiences during/after a period of invasive medical interventions. This is done through messy play as children need to desensitise through their other senses of touch/sight /smell and the oral acceptance of new foods is the last step to eating. This is not achieved by the adult putting food /non-food items in the child's mouth. SLTs do not use these programmes to improve the acceptance of textures/foods or increase the range of foods eaten.

Therapeutic feeding – high-risk infants like babies with DS: Breast and bottle feeding

Some general advice is as follows to improve feeding and reduce aspiration. It needs to be given before parents go home from hospital. Some families will start bottle feeding at home, even if they were exclusively breastfeeding on discharge, before they have seen the health visitor or the SLT/Dysphagia team – so they need to know the safest way to bottle feed in the meantime.

Positioning – **Left side elevated side lying** (i.e. head above the level of the rest of the body, not horizontal side-lie position) with **pacing by having teat (avoid silicone teat) horizontal and lowering.**

· Maintain alignment during breast feeds keeping tummy to tummy.

· Bottle feeds to be paced and be in a side-lying position to improve protection.

· Give breaks in feeds if breathing sounds get noisier.

· Provide expressed milk in the bottle if possible - potential damage from aspiration (usually silent) is higher if formula fed compared to breastfed, due to the protective nature of breast milk.

Don't increase flow of the teat to increase weight gain

Use slow-flow teats (not silicone)

Always check the mode of feeding at every visit.

But it is important to speak to the dysphagia team if concerned and to assess each baby individually.

Our lead for infant assessments is: Speech and Language Therapist, Paediatric Dysphagia Service, Children's Outpatients, Edgware Community Hospital, Burnt Oak, HA8 0AD. Tel 0208 732 6913.

Strategies for feeding infants with DS -

LOW-RISK INFANTS	HIGH-RISK INFANTS
Start with: • **Level 1 bottle nipple** • **Standard cradle hold**	Start with: • **Ultra Preemie bottle nipple** (slowest bottle nipple available) • **Side-lying position** with **horizontal milk flow** • **External pacing**

As needed (i.e. if the infant displays any decline in physiological stability or engagement during PO feeds) implement the following compensations, in the following order, until a suitable option is found:
1. Slower flowing bottle nipple
• Preemie (first)
• Ultra Preemie (second)
2. Horizontal milk flow
• Side-lying position OR
• Semi-upright position
• Avoid holding the infant in a reclined/ supine position.
3. External pacing
	As able (i.e. provided infant is showing no decline in physiological stability or engagement during PO feeds), consider trialing the following (one at a time):
	• Remove **external pacing**
	• Transition to **standard cradle hold**
	• Gradually **increase flow**
	  • Preemie nipple (first)
	  • Level 1 nipple (second)

https://www.brighamandwomens.org/assets/BWH/pediatric-newborn-medicine/pdfs/feeding-cpg---final-06-06-2016.pdf

Given that fluids flow more slowly when a bottle is held horizontally vs vertically, the use of horizontal milk flow may be used to assist the infant to regulate milk flow (reducing bolus size) and assist with suck-swallow-breath coordination. It is easiest to achieve horizontal milk flow if the infant is positioned in a side-lying position or in a supported upright position for PO feeds (figure 1). Avoid feeding infants in a reclined/ supine position. The transition to standard cradle hold (semi-reclined) position should be made when tolerated by the infant. In addition, given that most infants are held in a side-lying position when breastfeeding, the use of a side-lying position when bottle feeding may assist with transition to breastfeeding. Supportive positioning can assist in facilitating a flexed position, which is most conducive to effective sucking.

For breastfed infants, support is provided by the mother's torso and arms. It is suggested that the infant is unwrapped to allow skin to skin contact and assist the infant to latch effectively without extending their neck or stretching their mother's nipple.

For bottle fed infants, some level of support is provided by the feeder's torso and arms. However, given that the presence of the bottle obstructs the closeness of the infant and feeder, many infants benefit from being firmly swaddled during bottle feeds. This can make handling easier for the feeder and less stressful for the infant.

FIGURE 1: Side-lying (a-c) and upright (d) positioning for feeding

External pacing is a strategy that may be used if an infant is having difficulty self-coordinating sucking, swallowing, and breathing. External pacing involves either/ both: □ Tipping the bottle down, to reduce the amount of milk in the nipple and slow milk flow □ Removing the nipple from the infant's mouth, to impose a break in sucking to allow the infant to catch their breath. (Figure 2). External pacing may be performed on a schedule (e.g. every 3 sucks) or on demand (i.e. cue based).

FIGURE 2: External pacing for feeding (bottle is tipped down to slow liquid flow)

Leaflet for parents: Feeding Difficulties in Children with Down Syndrome Frequently Asked Questions (FAQ), Carolina Dysphagia centre.

http://feeding.com/wp-content/uploads/2015/10/Down-Syndrome-Feeding-Difficulties-FAQ_CPD.pdf

Appendix 4: Haematology guidance

Haematology

Neonates with DS have recognised differences in their blood cell morphology and counts, which are usually mild and benign and resolve spontaneously by approximately 3 weeks.
(https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2480572/)

Polycythaemia – Approximately 20% of individuals with DS will develop Polycythaemia (Haematocrit 0.65) as a result of increased intrauterine erythropoiesis. In cases where there is an antenatal diagnosis of DS, avoid delayed cord clamping. For management refer to the local guidelines for 'Polycythaemia'.

Thrombocytopaenia – 50% of babies with DS tend to have a platelet count <150 x 109/L but it is important to consider other causes of thrombocytopaenia e.g. Sepsis and IUGR. This tends to be asymptomatic and other than regular monitoring does not require further intervention.

Transient Abnormal Myelopoiesis (TAM)/ Transient Leukaemia of Down Syndrome (TL-DS) – TAM is a disease entity unique to DS and is defined as the morphological detection of blasts at less than 3 months of age. TAM has been reported to occur in 5-30% of neonates with Down Syndrome.

The pathogenesis of TAM is complex and underpinned by mutations in the haemaopoietic transcription factor gene GATA 1, predisposing the individual to impaired Megakaryocytic differentiation and uncontrolled proliferation of megakaryoblasts. The blasts are prevalent in the peripheral blood as opposed to bone marrow, indicating that they are derived from tissues of fetal haematopoiesis e.g. the fetal liver.

It is usually asymptomatic and spontaneously resolves by 3 months of age although some can develop severe disease including hydrops fetalis, liver fibrosis, renal disease and cardiopulmonary failure. Clinical features include hepatosplenomegaly, rash and pleural/ pericardial effusions. Later development of Acute Myeloid Leukaemia (AML) occurs in some.

A FBC and peripheral blood film should be obtained on day 2-3 of life, with a request for a Haematologist experienced at reviewing neonatal blood films to report the film and comment on the peripheral blast percentage if present. If the blast percentage is >10% and/or there are clinical features suggestive of TAM, urgently discuss with the Paediatric Haematologist on-call at Great Ormond Street Hospital. Furthermore, a blood sample should be sent for GATA1 mutation (discuss with Haematology at GOSH). If a peripheral blast cell percentage was not performed in the first 3 days of life or there is significant IUGR (blast cell percentage may be suppressed) the neonate will still be at risk of TAM in the first 4-8 weeks of life and be monitored closely (Discuss this with GOSH so there is a unified plan for monitoring).

If TAM is associated with clinical features, monitor closely until there is resolution of symptoms, thereafter monitor FBC and blood film 3 monthly up until 2 years and 6 monthly until the age of 4 years. Likewise if asymptomatic but diagnosed with TAM, monitor FBC and blood film 3 monthly up until 2 years and 6 monthly until the age of 4 years because 20-23% of those with resolved TAM will develop Myeloid Leukaemia of Down Syndrome (ML-DS) in the first 4 years of life.

For haematology advice at Barnet:

Currently based on other pathways and on the DSMIG guidance, we are not doing annual FBC and blood films. If these tests are required for a clinical reason, and you are requesting a FBC, it is probably worth asking for a blood film routinely to avoid having to re-bleed later for a film if needed. For any haematology concerns, discuss with the consultant haematologist about the need for a blood film review and ongoing management. **Barnet hospital also has a paediatric haematology clinic run by Dr Maxene Lissack**

Appendix 5 – homecare/community paediatric nurses:

NB: some children will be referred to the Barnet homecare team but some will be referred to the Royal Free community nursing team, depending on their postcode. See map further down to check.

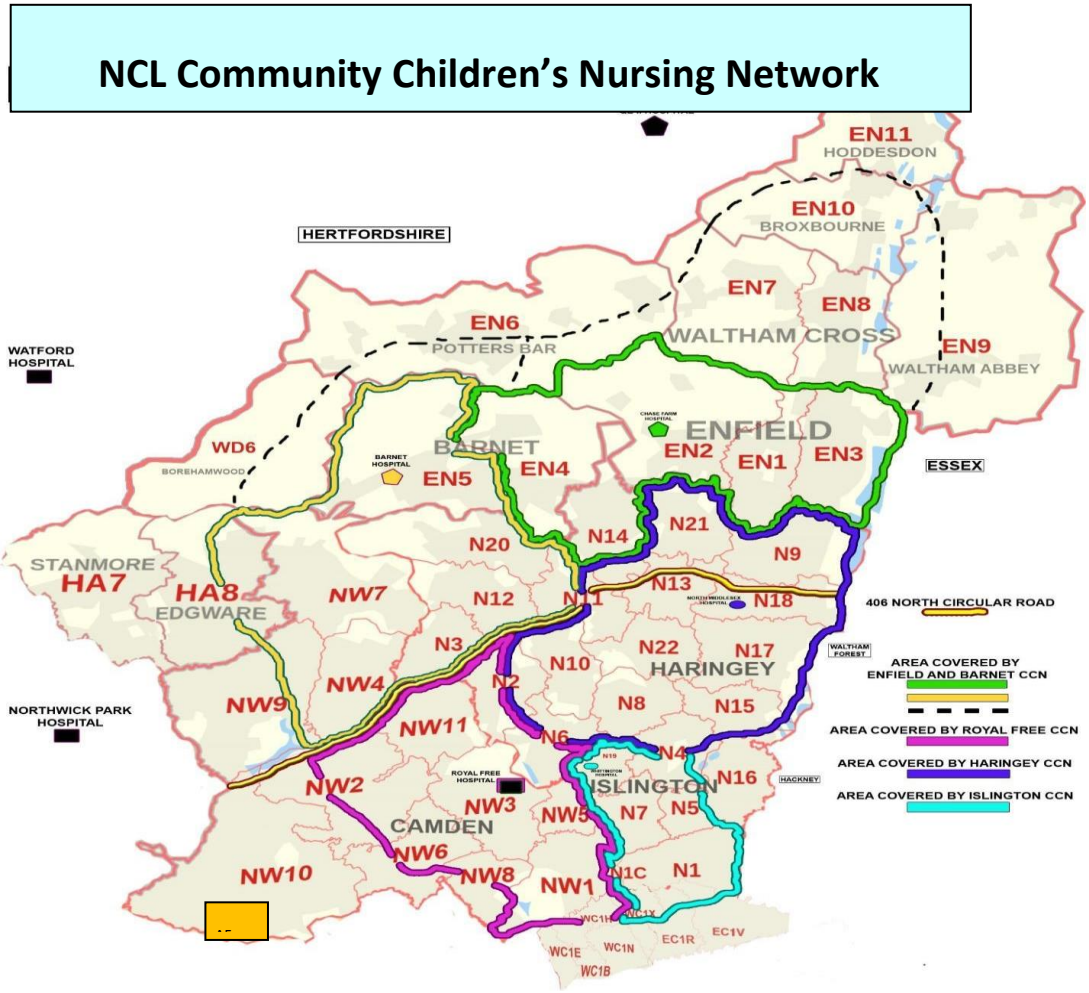
Contact details for Community Children's Nursing (CCN) referrals within North Central London

- **Islington** refer to the Islington CCN team. Mon-Fri 8-6, Sat & Sun 8-4. Telephone: 020 3316 1950
- **Camden and South Barnet:** (NW2 NW11) Refer to the Royal Free Hospital CCN Team. Mon-Fri 8-6, Sat 8-4. Telephone: 020 7830 2571 rf.communitychildrensnurses@nhs.net
- **Haringey:** refer to the **North Middlesex Hospital** CCN team. Mon-Sun 9-5. Telephone: 0208 **887 3301** **Email:** northmid.ChildrensCommunityNurses@nhs.net (No Fax)

Enfield: and there **post code begins with an E** they should be referred to the Chase Farm Hospital Home Care Team. Mon-Sun 9-5. Telephone: 020 8375 1992. **Email:** rf-tr.ChildrensHomecareTeam@nhs.net (No Fax) If the **postcode begins with an N (In Enfield) they should be referred to the North Middlesex Hospital CCN team**. Mon-Sun 9-5. Telephone: 0208 887 3301 Email: northmid.childrenscommunitynurses@nhs.net

- **Barnet:** Barnet Hospital refer to the Barnet Home Care Team. Mon-Sun 9-5. Telephone: 020 8216 5242 **Email:** rf-tr.ChildrensHomecareTeam@nhs.net
- **Watford CCN:** Telephone: 01442454667 – Email ccnteam@nhs.net
- **Northwick Park:** Harrow CCN: 0208 869 3914 **Email:** LNWH-tr.harrowccn@nhs.net

Email relevant team for their referral form and criteria.



Appendix 6 – Nutrition and dietetics service – leaflets and referral forms

Barnet paediatric dietetic (general) service: only accept referrals from Paediatric consultants and do not accept referrals for patients with the following conditions.

1. **Simple overweight / obesity, *unless have a comorbidity e.g. Down Syndrome* / Autism**

2. **Fussy eaters (if no faltering growth)**
   Please refer back to GP to be seen by Health Visitors / Children's Centres.

3. **General Weaning Advice**
   Please refer back to GP to be seen by Health Visitors / Children's Centres.

4. **Iron Deficiency Anaemia**

5. **Constipation**

6. **Eating disorders**

The following forms can be found here:

Referrals can be made online using the EPR system ("dietician – paediatric form) or in writing.
https://www.clch.nhs.uk/about-us/publications/referral-forms

New home enteral feeders (HEFT) (this is a different part of the dietetic service).

Note: Some children with DS who also have a significant cardiac history as well may well have a period of non-oral feeding/ NGT (nasogastric tube) feed - some children go on to have PEG (gastrostomy) and these children need to be seen by both SLT (Dysphagia team/speech and language therapist) and specialist HEFT (home enteral feeding) Dietitian.

Children's Dietetics home enteral feeding referral form, https://www.clch.nhs.uk/about-us/publications/referral-forms)

Parent leaflet:

https://www.clch.nhs.uk/application/files/8115/1370/0300/Paediatric_Service_leaflet.pdf

Appendix 7 – Infographic: Top tips for triaging and treating kids with DS

Most kids with Down's Syndrome (trisomy 21) have some physiological and behavioural differences that make it difficult to assess how sick they actually are.

1. Poor temp control:
may not develop a fever at all, or may be hypothermic instead

2. Weak immune system:
Infections that usually cause only minor illnesses can be dangerous to kids with DS. Amy (in the photo below) spent a week ventilated in PICU when she had chicken pox!

3. Mottle easily:
Kids with DS have poor control of SVR, and get mottled ("corn beefy") with temperature change as well as sepsis, making assessment tricky.

4. Co-morbidities common
Remember cardiac problems, GORD, coeliac and autism (& don't forget the drug history)

5. Leukaemia is more common
and may present atypically

Top tips for triaging & treating kids with Down's Syndrome

6. Ask what's normal for this individual child
Assessing levels of alertness, responsiveness, tone etc. can all be difficult if you don't know the individual child at baseline. Ask parents: they know their child best!

7. Narrow tubes, thicker mucus
Kids with DS get more chest & ear infections, and generally produce more snot!

8. Explain and reassure
Kids with DS often have sensory processing difficulties and can be very wary of new sensations: BP cuffs and sats probes may be terrifying. Take time to explain and reassure.

9. Beware of atypical presentations of serious illness
Sepsis can present atypically (as well as leukaemia, see #5)
- e.g. chest infections/ pneumonia with sepsis presenting as D&V

10. Optimise communication strategies
Speech & language development lags behind understanding, so kids with DS often understand more than they can express. They're often great visual learners (but have poor short-term auditory memory and fluctuating hearing loss) so use sign, pictures and gestures. Speak slowly, clearly and maintain eye contact. Allow for sensory processing delay of several seconds: don't hurry a reply

Don't panic! Just don't forget the extra chromosome

MOUNTAIN MEDICINE
BANGOR EMERGENCY DEPT

Appendix 8 – DS specific Growth charts and Inserts for red book (Personal Child Health Record (PCHR))

GIRLS BOYS Down syndrome 0-18 years

Down Syndrome Medical Interest Group

RCPCH Royal College of Paediatrics and Child Health

Note: Children with significant cardiac disease or other major pathology were excluded from the study population. In addition, data for those born before 37 completed weeks were excluded up to age two. The charts are therefore representative of healthy children with Down Syndrome living in the UK and Republic of Ireland. The charts were commissioned by the UK Down Syndrome Medical Interest Group (DSMIG).

As many older children with Down Syndrome are overweight we have included on the charts a weight-height BMI conversion chart appropriate for children with Down Syndrome age over 2 years.

Further Information

RCPCH/DSMIG Growth Chart Fact Sheet – 2011
Explains why we need special charts for children with Down Syndrome and how to use the charts to monitor children's growth, including premature babies and older infants and children. It also includes some advice on growth in puberty and over-weight and obesity.

DSMIG Guidelines Basic Medical Surveillance Essential for people with Down Syndrome: Growth
Gives more information about growth monitoring for children with Down Syndrome and is part of a set of Medical Surveillance Guidelines for people with Down Syndrome produced by the Down Syndrome Medical Interest Group.

Ordering - Copies of the Growth Charts can be ordered from Harlow Printing. All other enquiries about obtaining the charts should be directed to: Harlow Printing Ltd, Maxwell Street, South Shields, Tyne & Wear NE33 4PU. Tel: 0191 455 4286. Fax: 0191 427 0195.Email: sales@harlowprinting.co.uk

Electronic Growth Charts - DSMIG has been designated by the MRC as sub-licensee for the data. Anyone wishing to produce an electronic chart needs a licence from DSMIG to do so.

Individuals/organisations wishing to produce an electronic Down Syndrome growth chart can download an Licence Application Questionnaire 2019 and Licence Charges 2018.

Email: **info@dsmig.org.uk** for further information.

https://www.dsmig.org.uk/information-resources/growth-charts/

https://www.healthforallchildren.com/wp-content/uploads/2013/04/A5-Downs-Instrucs-chartsfull-copy.pdf

App for parents and professionals to plot growth in Down Syndrome: http://www.medcalc.com/growth/

Personal Child Health Record (PCHR): The fifth edition of this 30 page insert for the 'Red Book' was launched in January 2020. It contains additional information for parents and professionals that will help them maintain the health and well-being of babies born with Down Syndrome.

Areas covered are:

- General information
- Expected developmental progress
- Possible health problems
- Suggested schedule of health checks
- Advice about immunisation, feeding and growth
- Down specific growth charts
- Sources of additional help and advice

The 2020 fifth edition can be downloaded here:

https://www.dsmig.org.uk/information-resources/personal-child-health-record-pchr/

https://www.healthforallchildren.com/wp-content/uploads/2020/02/A5-Downs-charts.pdf

Ordering - Copies of the insert can be ordered from Harlow Printing. All other enquiries about obtaining the insert should be directed to: Harlow Printing Ltd, Maxwell Street, South Shields, Tyne & Wear NE33 4PU. Tel: 0191 455 4286. Fax: 0191 427 0195. Email: sales@harlowprinting.co.uk

***The R*edbook**

https://www.eredbook.org.uk/

The red book (PCHR) is going digital – there is an app available for parents/carers and professionals on both Apple Store and Google Play. The DS inserts are currently paper versions but will be adapted for online access to be incorporated into the digital e-version (Nov 2020).

Appendix 9 - **Pre-school Teaching Team Down Syndrome advisor's Parents letter (Pre-school support teacher)**

BIG DS Hub team

Pre-school Teaching Team Down Syndrome advisor Pre-school Teaching Team:
Telephone 07522352668
02083612456 Ext. 1
e-mail sandra.redman@pstt.barnetmail.net

Helena Goodfellow Pre-school Teaching Team:
Telephone 07850937182
02083612456 Ext. 1
e-mail helena.goodfellow@pstt.barnetmail.net

Ella Rachamim Community Paediatrician
e-mail erachamim@nhs.net

Helen Murrell Speech and language therapist-feeding
03005551201 ext. 52883
Telephone 07718249208
e-mail helen.murrell3@nhs.net

Appendix 10: Barnet Breastfeeding Support and Referral form

Breastfeeding has huge benefits in children with DS if it can be established, in a positive and supportive way. Not only to reduce infections (particularly respiratory and gut) but also to help with jaw development/our chewing and speech muscle development and if the baby is at risk of aspirating (some of the babies had swallowing difficulties) then breastmilk is "safer" for the lungs than formula milk. We need to give support and practical help for families so they can make informed decisions, and not make any assumptions or judgments based on the child's additional special needs.

In Barnet, the Breastfeeding Support Service can also provide home visits for mums who meet any of the following criteria:

1) Mum has had a caesarean (within 6 weeks and not out and about) or;

2) They have another child under 4 at home or;

3) Mum won't leave home for cultural & religious reasons (i.e. "40 day rest period")

The Breastfeeding Support Service wants mothers and professionals to know that they not only offer support with exclusive breastfeeding but also offers support to mothers:

- on stopping breastfeeding - both practically and counselling if mother needs
- on how to keep one breastfeed going, even if the other feeds are not breastmilk/breastfeeds
- who are expressing breastmilk and giving it by bottles
- who start to supplement with formula after breastfeeding or who are mix feeding with both breast and formula milk.

Support groups and drop-ins run in children's centres throughout the borough.

Please email for further information or to make a referral: **CLCHT.Breastfeedingsupport@nhs.net**

Appendix 11 – A letter from a Barnet parent to share (2019)

A note from the other side

"The decision to have a third baby was one made out of pure love. We have two other children whose cuteness and joy was just addicting. We wanted more. I conceived easily and the excitement was overwhelming. I made plans and daydreamed about my future on a daily basis.

I had a straightforward pregnancy. At the 12 week scan, I was given a 1 in 1728 chance of Down Syndrome—negligible. Everything was going to plan. However, because I kept insisting his movements didn't feel normal to me and because the baby was measuring small, I was induced at 38 weeks.

The birth was easy: one and a half pushes and he was out. My heart burst with joy and my husband was in tears snapping a thousand photos of the moment our son was born. The midwife lifted him onto me, but I immediately noticed he wasn't breathing and started vigorously stroking his back. They whisked him away and a medical team rushed in; I was calm. Then the paediatrician asked, "did anything come up on your scans? I see traits of trisomy 21."

And there it was, like a bomb at a picnic—Down Syndrome.

He had almond shaped eyes, a low nasal bridge, a large protruding tongue, a single palmar crease, and there was a space between his big toe and his other toes. My husband insisted, almost pleaded, that he had just been born, he needs a few minutes to "air out." She explained to us that only a genetic test would confirm, but that she was fairly certain he had Down Syndrome. He was taken to the neonatal unit for oxygen and tests and my husband and I were left in the labour room—babyless— watching our lives fall apart. I couldn't come up for air. Life had failed me.

Later that day, I stood over the incubator staring at this baby covered in wires. The nurse said, "congratulations, he's gorgeous." Her comment was so far from my reality. I couldn't see cause for celebration - only the promise of a lifelong burden. He didn't look cute to me, he looked like a diagnosis. I had more dark thoughts than I'd care to admit. Where was MY baby? I didn't want this baby. I was petrified about the future, I couldn't think ahead to the next half hour without feeling sick. Our lives were over, our futures shattered by his inevitable dependency.

I can't pin-point exactly when things started to change. For us, there wasn't a single moment. There were a series of turned corners—mini battles won. Surprisingly, what had felt would be a perpetual armageddon, was more of a short dark tunnel. At the end of that tunnel is a life that looks so much like the one we wanted when we decided to have another baby; It's sunny, warm and sweet. Perhaps most surprisingly, our new life has gifted us with so much meaning.

Our son is helping us do the work we've always wanted to do. Since I was a child, I've yearned to be better and have always felt disappointed in myself when my actions didn't match the goodness I wanted to unlock inside of me. But, as with all things, the work it takes to become a better human is often so uncomfortable. Becoming the best, most beautiful version of ourselves, both inside and out, hurts! My baby boy has forced me to grow, slowly inching me towards the person I've always wanted to be. He's already started washing our eyes of prejudice—prejudice we didn't even know I had. Where I once could only see Downs in him, I now sometimes catch myself looking at him and I can't see it at all. It's so bizarre. I know it's there, but my eyes don't see it. I find myself more often looking at people for what they really are, seeing beauty where I would subconsciously see difference. Our world has become so much more inclusive, positive and beautiful in the most genuine way. We are learning to judge someone's worth by their essence, not their academic or financial success. Although I'd like to think my husband and I already had that benevolence in our hearts, our reaction to his diagnosis showed us that we didn't. He is helping me achieve something I desperately wanted, but was too weak and afraid to do it on my own. For that alone, I am so grateful.

Our son has also brought immense emotional depth to our family. Our children adore him in a way we didn't know was possible. It's like the purest part of their souls recognise each other. When I chose to become pregnant, I knew I wanted to give them a sibling, but I had no idea I would be giving them so much more. Their relationship has an exceptional amount of tenderness. It's more than I've ever dreamed could exist between siblings. We are watching our children develop empathy, acceptance and love in ways we were not equipped to teach them. In turn, they bring out the joy and adventure in their baby brother and intuitively push him to his limits, edging his development forward. We have a different dimension of love in our family and it's wonderful.

He has unified us, not just our nuclear family, but our extended family as well. He's solidified our friendships, and brought out the very best in everyone we know. It's been a journey for everyone, and like us, everyone around us is finding their best selves. It's as if he's a flame, lighting up people's souls. I feel a sense of honour to be the mother of a "soul-lighter." After all, isn't that what most parents want for their child, for them to make a meaningful difference in the world? Somehow, along the way, I've lost sight of what is REALLY meaningful. I don't know when I started valuing titles like doctor, lawyer and CEO more than soul-lighter. The fears we have about the future and what his achievements will be often reflects the need to work on a flaw in our values, not a fault in him. We are still novices on this journey, but we are learning.

In the first few weeks after he was born, I wouldn't have wanted to trade the utopian plans I had made while I was pregnant for the promise of a more enriched life—not at the cost of the difficulties I envisioned would accompany a DS diagnosis. We do still face some difficulties, including complex health issues. Sometimes looking too far into the future can still seem daunting and I have days where I don't want to be different, where the unknown tickles my anxiety. But, my husband and I are facing these challenges. Once we found a doctor we trusted, and we started learning about DS and overcoming our own archaic views, the hills we have to climb became less steep. Once the love for our son hit us, the fear for our future became less sharp. But, our journey is not always linear. Living a life where we value inner beauty versus outward achievements, where we thrive on diversity instead of uniformity, is harder than it looks! However, overcoming ourselves to cope with the medical issues, to address our flaws, and to rise up and face life head on—with love—has added a new dimension to our lives that we wouldn't want to live without. With each summit we conquer the view becomes more breathtaking. We are finding that we like ourselves more now that we did before our son was born. Our family is stronger, deeper and braver. Our love is more fierce and our hearts are more generous. Our challenges have forced us to grow into people we are prouder to be. In a way, we are now grateful for the challenges we feared so much when he was born.

Though this unexpected turn in our path initially felt like we had fallen off a cliff, sometimes it takes falling off a cliff to realise you have been growing wings."

Appendix 12 – Unusual or recurrent infections (based on Nottingham guidelines), guidance on standard and additional immunisations, GP and parent letter/template

Background:

Vulnerability to URTIs – 30% increased risk of death from sepsis (Garrison, 2005) – Impaired immune competence: • Reduced T and B lymphocyte subpopulations • Reduced neutrophil chemotaxis • Thymic abnormalities. • Alterations of Ig subclasses.

Note for recurrent Respiratory infections - ***a lot of Down Syndrome aspiration is silent and this is the difficulty in detecting it on history alone. Certainly if any child with Down Syndrome has above average respiratory issues compared with a child without Down Syndrome, then aspiration MUST be sought and do not hold back on videofluoroscopy (advice from the Brompton respiratory physicians 2018)***

Prophylactic antibiotics

If significant infection history, it may still be appropriate to commence prophylactic antibiotics even when immunological tests are normal. These should be considered in children with frequent infections either to be used throughout the year or just September to April.

Options – e.g. azithromycin 10mg/kg od 3 days per week.
The need for prophylactic antibiotics should be reviewed at each visit.
If stopping, suggest choosing to do this in late spring/early summer.

General management: Consider using double the length of the usual antibiotic course.
Maximise immunity by ensuring appropriate vaccines have been given (as per childhood schedule and any additional vaccines – see below).

Immunological investigations: Immunoglobulins, Functional Antibodies, Prevnar (pneumococcal) Antibodies and lymphocyte subsets are sometimes done routinely in some DS pathways/boroughs at the 12m review. In Barnet/RFH we are planning to have a low threshold for immune testing and discussing with our immunology teams and not test routinely in every child.

E.g. we would test at any time if - with ≥ 4 infections in 6 months requiring GP visits/ill-health > 5 days or admission for sepsis or there was an unusual infection.

Timing of immunology blood tests is at least 1 month after completion of the 13month routine Hib/MenC/PCV booster immunisations.

IMMUNISATIONS:

In addition to the normal UK immunisations schedule - https://www.gov.uk/government/publications/pre-school-vaccinations-a-guide-to-vaccinations-from-2-to-5-years -

1) **Annual influenza vaccine** via GP/practice nurse (from 6 months to 2 years this is the inactivated injected form, after 2 years it is the nasal flu vaccine) for every person with Down Syndrome AND their household members. https://www.nhs.uk/conditions/vaccinations/child-flu-vaccine/

For further information/poster -
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/735239/Which_flu_vaccine_should_children_flu_vaccine_2018_.pdf

2) **Pneumococcal vaccines** – Babies in the UK are given the PCV (pneumococcal conjugate vaccine, also known as Prevenar 13) routinely as part of the UK immunization program i.e. Babies born on or after the 1 January

2020 have 2 injections, which are usually given at 12 weeks old and 1 year old. Babies born before this date will continue to be offered 3 doses, at 8 and 16 weeks and a booster at 1 year.

An additional pneumococcal immunisation is now universally agreed (from Autumn 2019 onwards) for ***every*** child with Down Syndrome and not only those at "high-risk:" Via GP/practice nurse.

Age 2-5yrs: single dose of Pneumovax II (also known as PPV 23 as it protects against 23 different pneumococcal strains).
Age >5 years: a single dose of Pneumovax II which lasts 5 years and then needs repeating.
The PPV vaccine is not effective under 2 years of age, hence why they receive the PCV.

Pneumovax II (PPV23) needs to be REPEATED EVERY 5 YEARS until 65 years of age (but should not be repeated within 5 years of the last one). (Green book on Immunisation for "at-risk" groups) but should not be repeated within 5 years.

If pneumococcal antibodies are tested (based on a clinical reason for checking) and still low despite recent Pneumovax II, please discuss with an immunology consultant locally or at GOSH.

Parental information: Pneumovax (aka PPV): https://www.medicines.org.uk/emc/files/pil.1061.pdf

(As discussed with Dr Elliman, Clinical lead for National NIPE & NBS Screening Programmes, Public Health England and Professor Helen Bedford, Senior Lecturer in Children's Health with the Centre for Epidemiology and Biostatistics at the UCL Institute of Child Health 2019).

Include in every report to the GP about the recommended extra vaccinations **(Appendix 12)** – annual flu vaccine and the extra pneumococcal vaccine. (There will also be routine letters being distributed around Autumn to GPs to remind them about these vaccinations due for ALL children with Down Syndrome). Ideally too, ensure that these children are given the first batches of flu vaccine that is made available for the GPs.

Also have a statement at the end of each report about the increased risk of infection and that in Down Syndrome these infections can sometimes present atypically. There is information in the new insert for the PHCR/red book about this as well.

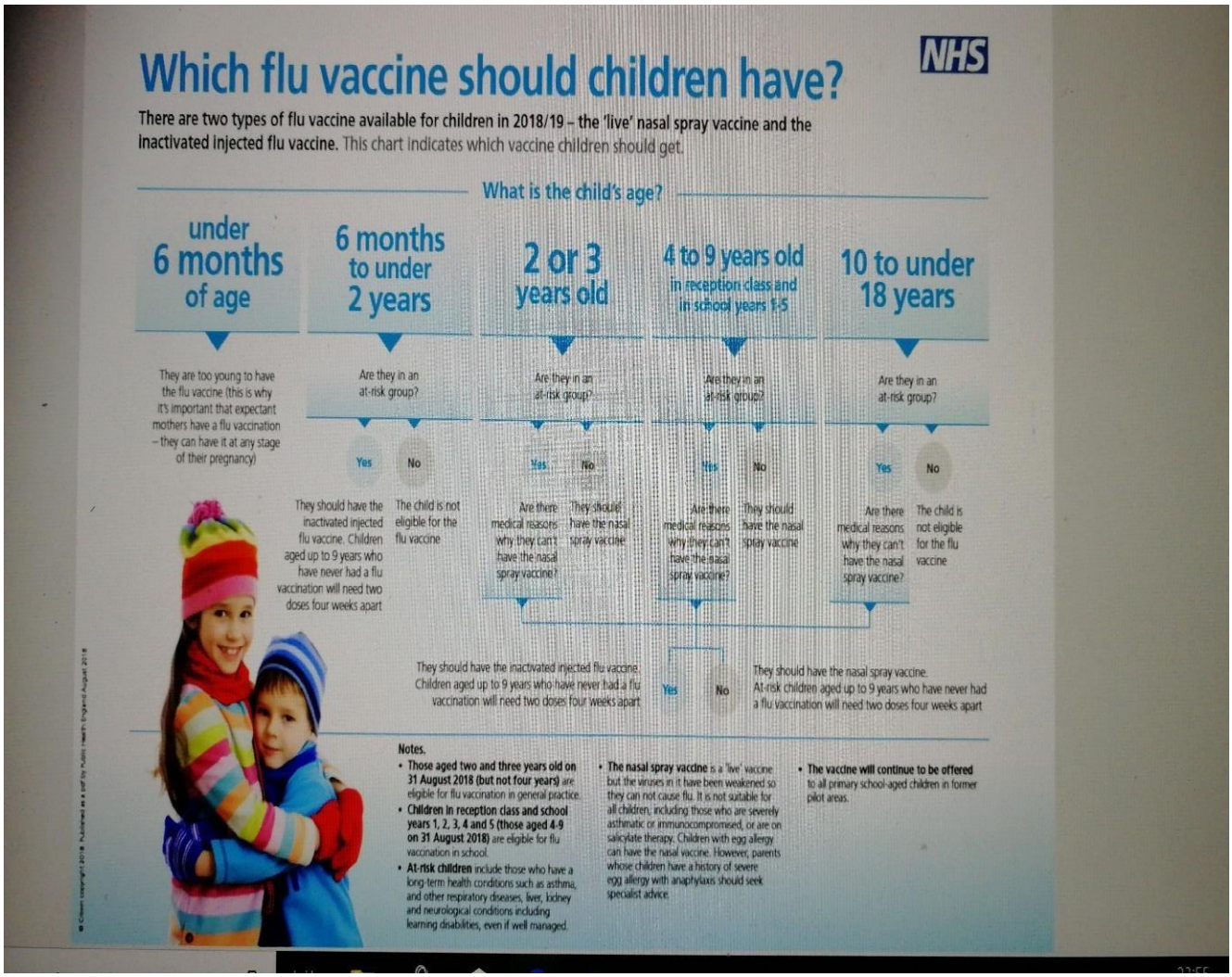
Chickenpox and vaccines:
Vaccines for children with Down Syndrome are under review (2019) and more guidance will be published, including e.g. the VZV vaccine against chickenpox. For now, professionals need to have a low threshold to consider this vaccine if evidence of immunocompromise, as there have been serious cases of VZV pneumonitis in DS. Also inform GP and parents, that sometimes children with Down Syndrome don't show the typical signs and symptoms of chickenpox as other children, so professionals need to consider chickenpox even if it presents in an atypical way, be aware of the complications and monitor them more closely.

Further research:

Archives of Diseases of Childhood (Nov. 2018) Towards Evidence based medicine for paediatricians: Do children with Down syndrome benefit from extra vaccine?

All children with Down Syndrome should have annual influenza vaccines from 6 months of age.
23 valent pneumococcal vaccine from 2 years.
Consideration should be given to meningococcal ACWC (and Meningococcal B if not already given.)
Long term immunogenicity of vaccines unknown in this group and may require boosters
Recurrent vaccine preventable diseases may have negative impact on long term outcome.

Poster – which flu vaccine should children have (2018)



Royal Free London NHS
NHS Foundation Trust

Edgware Community Hospital, Child Health HQ, Burnt Oak Broadway, Burnt Oak, Edgware HA8 0AD

Letter to GP Date:

Dear Dr

Immunisation and Infection: Recommendations for Children with Down Syndrome (Revised Oct. 2020)

Re: Name:

Date of birth:

Address:

NHS number:

MRN Number

We are writing with regard to your patient who has Down Syndrome.

Children with Down Syndrome are at increased risk of infections, such as pneumonia and sepsis, secondary to altered immune function. Furthermore, there is often a suboptimal antibody response to vaccination, and children with Down Syndrome may not be able to maintain appropriate long-term immunity. We recommend the following advice in line with guidance by the national Down Syndrome Medical Interest Group (DSMIG.)

1.Children with Down Syndrome should receive all the immunisations in the normal UK schedule.

In addition, the following immunisations are recommended in children with Down Syndrome,

2. Annual influenza vaccine before the winter months (injectable vaccine for infants). Influenza vaccine should also be considered for carers and family members.

3. Pneumococcal polysaccharide vaccine (PPV 23, also known as Pneumovax II), which is protective against 23 strains, is now recommended for all children with Down Syndrome over 2 years of age. It is not effective in children under 2 years of age.

4. Varicella vaccine if there is any suggestion of lowered immunity

5. If antibiotics are prescribed, double the length of usual antibiotic course should be considered.

Yours sincerely,

Dr Christine Jenkins **&** **Dr Ella Rachamim**

MB BS BSc FRCPCH FRCP DRCOG DCH MRCGP **MB BS BSc MRCPCH**

Consultant Paediatrician, Community Child Health Specialty Doctor in Community Paediatrics

c.c. Parents/Carers for information

Royal Free London NHS
NHS Foundation Trust

Edgware Community Hospital, Child Health HQ, Burnt Oak Broadway, Burnt Oak, Edgware HA8 0AD

Letter to Parents/Carers

Date:

Dear Parents/ Carers,

We enclose a copy of a letter we have sent to your GP regarding immunisations for your child.

Many children with Down Syndrome have lowered immunity and are more prone to infections which can sometimes be serious. It is therefore recommended that they have:

1. Influenza (flu) vaccine every year.
   Influenza vaccine should also be considered for carers and family members.

2. Pneumococcal polysaccharide vaccine (PPV 23, also called Pneumovacc II) if over 2 years of age.

3. All the immunisations in the normal UK schedule.

If you would like your child to have the additional vaccines, please take this letter to your GP surgery and make an appointment with the practice nurse or health visitor to discuss further.

Yours sincerely,

Dr Christine Jenkins **&** **Dr Ella Rachamim**
MB BS BSc FRCPCH FRCP DRCOG DCH MRCGP **MB BS BSc MRCPCH**
Consultant Paediatrician, Community Child Health Specialty Doctor in Community Paediatrics

c.c. GP for information

(Revised Oct. 2020)

Appendix 13 – Sleep, sleep disorders, use of melatonin, referrals to sleep services, support and resources, research and information about oximetry screening, red flags.

Sleep issues – how big is the problem?

All children with Down Syndrome have, at some stage in their lives, and for some - throughout their lives - a degree of sleep disordered breathing. Yet, sleep issues are often under recognised by physicians and parents because they underestimate these problems and/or assume that they are part of the DS features. For instance, approximately 69% of parents reported that their child with DS did not have sleep issues, but 57% had an abnormal polysomnogram [Shott et al 2006].

Background and overnight oximetry screening:

As such we have had to adopt a pragmatic approach and screening for this disorder is now an accepted approach in the UK and a good sleep history, taken at every contact.

Sleep history – to be taken at every contact:

1) **15 minute sleep consultation:** A targeted sleep history is an enlightening part of a consultation with many children, **the following three questions are suggested as a screening exercise** in this excellent article by Jess Turnbull and Mike Farquhar "Fifteen-minute consultation on problems in the healthy child: sleep".

Does your child have any difficulty getting to sleep or staying asleep?
Does your child do anything unusual in the night?
Is your child unusually sleepy in the daytime?

If concerns are apparent more specific history can be gathered:

Does your child have any difficulty getting to sleep or staying asleep?

Does your child do anything unusual in the night?

Is your child unusually sleepy in the daytime?

When is bedtime?

What do you do in the hour leading up to bedtime?

How long does your child take to fall asleep after 'lights out'?

Where does your child fall asleep?

Does anybody need to be with the child while he/she is falling asleep?

Does your child sleep through, once asleep?

Does your child snore, have you noticed pauses in breathing when asleep?

Is your child restless in sleep?

What time does your child wake in the morning?

Is your child tired in the daytime? Does he/she fall asleep during activities?

What effect is this having on your family?

Any excessive sweating?

Daytime mouth-breathing?

2) Another sleep questionnaire that is quick and useful to use is the BEARS questionnaire

	TODDLER/PRESCHOOL (2-5 YEARS)	SCHOOL-AGED (6-12 YEARS)	ADOLESCENT (13-18 YEARS)
BEDTIME PROBLEMS	Does your child have any problems going to bed? Falling asleep?	Does your child have any problems at bedtime? (P) Do you have any problems going to bed? (C)	Do you have any problems falling asleep at bedtime? (C)
EXCESSIVE DAYTIME SLEEPINESS	Does your child seem overtired or sleepy a lot during the day? Does he/she still take naps?	Does your child have difficulty waking in the morning, seem sleepy during the day or take naps? (P) Do you feel tired a lot? (C)	Do you feel sleepy a lot during the day? In school? While driving? (C)
AWAKENINGS DURING THE NIGHT	Does your child wake up a lot at night?	Does your child seem to wake up a lot at night? Any sleepwalking or nightmares? (P) Do you wake up a lot at night? Have trouble getting back to sleep? (C)	Do you wake up a lot at night? Have trouble getting back to sleep? (C)
REGULARITY AND DURATION OF SLEEP	Does your child have a regular bedtime and wake time? What are they?	What time does your child go to bed and get up on school days? Weekends? Do you think he/she is getting enough sleep? (P)	What time do you usually go to bed on school nights? Weekends? How much sleep do you usually get? (C)
SNORING	Does your child snore a lot or have difficult breathing at night?	Does your child have loud or nightly snoring or any breathing difficulties at night? (P)	Does your teenager snore loudly or nightly? (P)

(P) Parent-directed question (C) Child-directed question

A note on Restlessness – this is often missed – do they have "itchy" legs, "growing pains" in their legs, or constantly re-positioning themselves, sleep in strange positions – consider restless leg syndrome as a cause and check their ferritin (total body iron stores). Low iron levels can cause restless legs, often missed or misdiagnosed as growing pains or restlessness only. Ferritin above 50 is what is advised by The Evelina sleep team (in adults they want it above 75) – simple to treat and may make a huge difference.
Restlessness is a common theme amongst children with DS and reported by parents. It is something that needs further research on, some are calling it "restless syndrome" (2020) and more work into managing it is advocated.

<u>Home overnight oximetry:</u>

Home overnight oximetry is a screening tool but recent studies show that in Down Syndrome it can be useful. They all have abnormal sleep studies and we would only do that if we were concerned about significant OSA (obstructive sleep apnoea) with sleep disruption and the ENT (ear, nose and throat) required definitive evidence before proceeding with adenotonsillectomy. Many children with Down Syndrome in due course require an ENT review for tonsils and adenoids.

Pragmatically, we reserve our respiratory polysomnography (PSG) for those who are failing their screen and are having secondary sequelae (consequences) from their OSA. This information is sometimes required to show the ENT surgeon that an airway review and intervention is required.

Sometimes we will embark on CPAP (continuous positive airways pressure) trials. But they are notoriously difficult in this group of children who are so often averse to having equipment strapped to their face.

So then - what is a normal trace? There is the concept that normal saturations (SATS)may miss arousals - a self-correction of a decreasing saturation by disturbance of sleep architecture before the machine picks up a dip. In a non-Down Syndrome child ***WITH*** symptoms of OSA or sleep disruption we may look at this further. But for a child with Down Syndrome we probably should accept the normal screening test as reassuring - even if the trace is not necessarily a perfect straight line in that normal range. (<u>Discussion (Dec. 2018) with Dr Colin Wallis, Paediatric Respiratory consultant and clinical lead at GOSH, our tertiary referral centre).</u>

Research papers and presentations:

This presentation explains the use of oximetry screening in children with Down Syndrome:
http://wdsc2018.org.uk/wp-content/uploads/2018/09/Cathy-Hill.pdf
Home oximetry to screen for obstructive sleep apnoea in Down Syndrome
Catherine M Hill, Heather E Elphick, Michael Farquhar, Paul Gringras, Ruth M Pickering, Ruth N Kingshott, Jane Martin, Janine Reynolds, Anna Joyce, Johanna C Gavlak, Hazel J Evans.

https://adc.bmj.com/content/103/10/962

Summary
High prevalence of OSA in young children with Down Syndrome supporting the need for regular screening • Pulse oximetry could provide an accessible screening method for OSA and halve the number of children needing detailed diagnostic studies • We propose that all children with Down Syndrome have regular screening with Masimo pulse oximetry ideally in the home setting in the early years • This would require training and standardisation but the use of the delta 12s index provides a simple threshold screening criteria for the less experienced clinician.

Arch Dis Child. 2018 Nov 19. pii: archdischild-2018-315676. doi: 10.1136/archdischild-2018-315676.

Cardiorespiratory sleep studies at home: experience in research and clinical cohorts.

Kingshott RN1, Gahleitner F2, Elphick HE1, Gringras P3, Farquhar M3, Pickering RM4, Martin J5, Reynolds J1, Joyce A3, Gavlak JC2, Evans HJ#2, Hill CM#2,4.

http://wdsc2018.org.uk/wp-content/uploads/2018/09/Cathy-Hill.pdf
http://www.bprs.co.uk/documents/RCPCH_sleep_resp_cont_disorders.pdf
https://www.southampton.ac.uk/medicine/about/staff/cmh2.page

RCPCH recommendations regarding screening with oximetry in the community.

In the UK, due to limited resources, the most common type of sleep study performed in most respiratory centres is not the PSG, but respiratory polygraphy studies which don't include EEG and thus don't have sleep stages.

1) All children with Down Syndrome should be offered screening for SRBD, using at least oximetry; suggested screening ages are at least once in infancy then annually until age 3-5 years.

2) Children with Down Syndrome with abnormalities on screening for SRBD, or where there is a clinical suspicion of a false negative screening test, should have polysomnography, including oximetry, airflow, effort and CO2 measurement. Video should be included if possible.

3) If significant SRBD with hypoxia is present in children with Down syndrome, then appropriate treatment should be offered.

4) Further research is needed on the benefits and risks of screening for SRBD in Down Syndrome.

Conclusions

Children with Down Syndrome are at high risk of SRBD and nocturnal hypoxaemia, and the high incidence of congenital heart disease in these children makes the development of pulmonary hypertension a significant risk.

SRBD may be difficult to identify symptoms in this group. Adenotonsillectomy may have a lower rate of success, but is still indicated. Other interventions including CPAP are effective but may be difficult to institute.

APPLYING THIS TO BARNET AND ROYAL FREE SETTINGS:

Note that at Barnet and royal free hospitals and community settings we have a nelcor, not a masimo, and cannot use a delta 12s index. we also do not have cardiorespiratory polygraphy including respiratory movements, nasal pressure flow, pulse oximetry, body position and motion. We have HPO – home pulse oximetry. THEREFORE THIS RESEARCH IS CONVINCING AND WE ARE INCLUDING SCREENING (HPO) IN OUR PATHWAY BUT IT IS NOT A TRUE COPY OF THE RESEARCH. The Massimo has the ability to use signal extraction technology for reliable data, in simple terms this means the "wobble" factor is removed, unfortunately the nelcor oximetry machine does not have this. Discussing with the company it is not something that is available and it cannot produce a delta 12s figure. Further research is being undertaken by the team in Southampton, with Professor Cathy Hill, to plan an intervention trial and also to trial the cost-effectiveness of the proposed screening approach.``

Note: There is no evidence about how long screening should continue in these children. We have arbitrarily taken 3-5 years as including the period of highest risk of OSA. If screening tests are negative up to this age it would seem reasonable not to undertake further tests subsequently unless there are suggestive symptoms.

Currently it is best practice to discuss overnight oximetry traces with either local paediatrician with interest in respiratory or GOSH. Remember it is not only the number of desaturations but what the baseline saturations are doing, they should be in the mid-90's at rest and not in the low 90's. Don't forget to ask parents to video the sleep noises and patterns – this can be invaluable.

Sleep referrals:

GOSH is our main centre for referrals.

Sometimes we can also refer to the Sleep Service at The Evelina Children's hospital – these are both specialist tertiary referral services, which aids in the management of children with complex sleep problems.

Referrals are usually only accepted from NHS consultant paediatricians or child and adolescent mental health services but not from GPs or health visitors. This is because a significant proportion of sleep problems in children can be identified and managed successfully at a primary or secondary care level. Children can be referred for an initial assessment up to the age of 16. New referrals of young people aged 17 or over should usually be made to the adult sleep medicine department at Guy's Hospital.

To refer to GOSH – write a letter to the relevant team. This can be sent by email or post.

To refer to the Evelina - To make a referral, download and fill in the referral checklist for sleep medicine (PDF 1.29Mb) and email to: gst-tr.ELCHPaedNeuroReferrals@nhs.net.

https://www.evelinalondon.nhs.uk/our-services/hospital/sleep-medicine-department/referrals.aspx

AT GOSH or the Evelina sleep service there are sleep and respiratory paediatric specialists who are happy to advise. By referring to the Sleep Service there (consultant in paediatric sleep medicine) they will assess, consider a PSG and refer to the ENT team as needed and arrange follow up – both teams work closely together.

What about after an adenotonsillectomy – can OSA return in DS?
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4515186/#R6

55/108 (51%) who had undergone adenotonsillectomy (AT) for OSA continued to have sleep problems specifically in night awakenings (e.g., need parents in room to sleep), restless sleep, snoring, and daytime sleepiness. Interestingly,

the AT group also reported more issues with falling asleep while watching television. ***Our results suggest that children with DS who undergo AT for OSA continue to have sleep problems suggesting that ongoing monitoring of sleep issues is needed in this population. It is possible that AT is much less effective in treating OSA in DS compared to typically developing population*** [Merrell & Shott, 2007] possibly due to macroglossia, glossoptosis, recurrent enlargement of the adenoid tonsils, and enlarged lingual tonsils [Shott et al., 2004]. These surgical options are most often curative (95%) of sleep issues in the typically developing population [Nieminen et al., 2000; Schechter, 2002; Shott & Donnelly, 2004].

Other useful resources and support:

Infant Sleep Information Service (ISIS) – provides research evidence about biologically normal sleep for human babies. www.basisonline.org Very valuable leaflets for parents and understanding of normal sleep.

Children's Sleep Charity: www.thechildrenssleepcharity.org.uk

Leaflets on bedtime routine, relaxation before bed, creating a calm bedroom, sleep and diet.

info@thechildrenssleepcharity.org.uk Tel: 01302 751416

Cerebra: 01267 244210 or e-mail us at sleep@cerebra.org.uk

https://www.cerebra.org.uk/help-and-information/sleep-service/sleep-information/

https://w3.cerebra.org.uk/help-and-information/sleep-service/

Contact a family: https://contact.org.uk/media/1183103/helping_your_child_sleep.pdf

Down Syndrome Association (DSA): https://www.downs-syndrome.org.uk/for-families-and-carers/health-and-well-being/sleep-problems-in-people-with-downs-syndrome/

SCOPE: https://www.scope.org.uk/child-sleep-services

British Sleep Society: http://www.sleepsociety.org.uk/

Sleep Apnoea Trust: http://www.sleep-apnoea-trust.org/

Raising Children Network – www.raisingchildren.net.au – parental info. on "normal" sleep at different ages.

Leaflet for parents on melatonin in general:
https://www.medicinesforchildren.org.uk/melatonin-sleep-disorders

For use of melatonin (outside of use for an EEG investigation):

Sleep onset insomnia (initiated under specialist supervision), NOT for overnight wakenings.
Delayed sleep phase syndrome (initiated under specialist supervision)

By mouth using modified-release tablets

- **For Child**

Initially 2–3 mg daily for 1–2 weeks, then increased if necessary to 4–6 mg daily, dose to be taken 30-60 minutes before desired sleep time/bedtime; maximum 10 mg per day.

Usually prescribed by a paediatrician and GP can continue if effective.

Appendix 14 – Constipation, Coeliac screening (including HLA typing) and gastroenterological complications

Background –

There are a number of conditions that are more common in Down Syndrome. These include gastro-oesophageal reflux disease (GORD), hirschsprung's disease, pyloric stenosis, duodenal atresia, aspiration, coeliac disease, constipation and food allergies. This presentation gives an excellent overview and covers everyone is considerable detail. https://www.dsmig.org.uk/wp-content/uploads/2017/12/RCPCH-SIG-Gastrointestinal-manifestations-of-Down-syndrome.pdf

In particular, these 3 conditions need to be highlighted as the most common and also ones that need to be assessed and managed at every patient review by clinicians:

GORD – signs, symptoms, red flags, investigations, management, when to refer.

Coeliac disease – symptoms, signs, investigations and management, when to refer.

Constipation – recognition, management and behavioural interventions. As this is often a major issue for many, the slides have been copied out below:

Constipation:

Stooling issues and DS

• Constipation Prevalence 20-36% – Increased with hypotonia, communication and behaviour issues, supplementary feeds. Constipation can happen early on due to low muscle tone, poor mobility, diet and inadequate fluid intake etc or even short segment Hirschprungs. Need to exclude organic disease. Need to check for and manage possible overflow +/- stool withholding which are common issues.

• Diarrhoea: often due to overflow. But could be due to stimulant laxatives. If infective is associated with initial pyrexia. Consider gut dysbiosis associated with lactose intolerance/malabsorption.

Triggers for constipation:

• Varies between children

– Elucidate in the history: age of onset.

– Parental expectations: address them in the treatment strategy.

• Also consider: pain (e.g. a fissure) • Fever/dehydration • Dietary intake (in terms of fibre content) • Psychological issues and expression of distress • Toilet training/aversion • Other medicines, other conditions • Family history of constipation.

NICE recommended treatment

• Investigate children with red flags

• For faecal impaction – NICE: Polyethylene glycol 3350 + electrolytes (e.g. Movicol Paediatric Plain) • Escalating dose regimen (= first-line treatment). • Adjust the dose of Movicol according to response. • Risk of increased overflow (consider impact on school). • Review soon • Reduce the dose of Movicol when disimpaction is achieved – Maintenance dose might be half disimpaction dose. • BUT....

• Add stimulant (senna/picosulphate) if Movicol alone does not work (but can cause overflow++).

• Substitute a stimulant laxative if Movicol is not tolerated. • Add another laxative such as lactulose (toddlers) or bisacodyl (older children) if stools are hard.

• Medication may be needed for weeks/months. • Children who are toilet training should remain on laxatives until toilet training is well established. • Gradually reduce the dose over a period of months in response to stool consistency and frequency; and increase if symptoms relapse. • 20-30% children with DS may require laxatives for several years.

Also…. • Laxatives are only half the story….. • Increase fibre content (to normal). • Ensure adequate hydration • Increase exercise levels (all evidence based).

• Positive behavioural interventions/rewards suited to the child's level. • Explain that treatment may take years. • Addressing the underlying trigger – Understanding of parents – Fear of toilets in younger children – Access to school toilets in school age children. • Early reassessment and reinforcement of initial messages is also key.

• Other resources: Social stories/school nurse/health visitor/continence nurse

Testing for Coeliac disease:

Currently the consensus in the UK is to have a low threshold for testing for coeliac disease in any child with Down Syndrome. This means a blood test for Coeliac antibodies (TTG) AND a total immunoglobulin A (IgA) at the same time. IgA can sometimes be deficient in the general population and this is what is tested when the lab looks for the coeliac test (TTG) so this can lead to a false negative result if you don't know the IgA levels. If levels of IgA are low, then the tests need to be repeated looking for Gliadin antibodies using IgG. This can be discussed with your local lab and immunology team.

The one piece of information that is vital to this testing is "how much gluten is the child on?" The test will not be accurate if the child is not on enough gluten leading up to and during the test. He/She MUST be on gluten and it must not be removed, otherwise this invalidates the test, and not only that but the child needs to be on a sufficient amount regularly to validate the test. Many times the coeliac might be negative but it can develop later on in life so it needs to be remembered and tested for throughout childhood and adulthood.

In view of this, and that clinicians end up testing at random times, with different "thresholds'' for testing, with undue worry for parents about when and if their child will get coeliac – there is another school of thought about testing. It is feasible to do an HLA typing test (one blood test) anytime, which is not dependent on gluten intake nor age nor the IgA status and get a result that either puts the child into a group where they "are at higher risk of getting coeliac at some stage but may not" or a group which means "they will not develop coeliac." Thereby, this means those in the 2nd group do not need random testing and parents can be reassured their child won't develop coeliac. The first group needs testing with a low threshold for symptoms but MUST NOT come off gluten at this stage. They still may never develop coeliac and so it is about informing this group they have a higher but not complete risk of getting coeliac in their lifetime.

HLA pathway:

STATEMENT: Doctors would not put anyone on a gluten free diet until a secure diagnosis is made.

The HLA test is about the *potential* to develop coeliac disease (CD) when positive and does not indicate that someone actually has CD. So in fact it's more useful sometimes if it's a negative, as it makes it extremely unlikely to develop coeliac disease. The other two blood tests (TTG and Anti endomysial antibody) are the ones that tell you about if someone has it or not.

To be clear, the HLA test is independent of the amount of gluten in the diet but the TTG/EMA accuracy is dependent on adequate gluten intake at the time of testing and on a normal total IgA.

We would plan to test for HLA typing at 6 months with the first TFTs (recommended as per thyroid guidance 2020, DSMIG). If the result shows HLA DQ2 or DQ8 – then this means the child has the potential to develop coeliac disease, but it is not definite at all.

If the HLA markers are -ve , it is extremely unlikely this child will develop coeliac disease in their lifetime.
In theory you could *avoid repeatedly testing* them with TTG tests every few years etc. because you know that their HLA test is negative.

If their HLA tests are +VE and the TTG are negative (and they've been consuming adequate amounts of gluten in the run up to the test) then the **person again doesn't have coeliac disease at that time** but **would need repeat screening / TTG testing in 2-3 years if they remain asymptomatic and continue to be screened.**

If HLA tests +VE and TTG positive then refer to paediatric gastroenterology please or your nearest paediatric gastroenterologist.

Do remember:

- If they have not been on sufficient gluten, the TTG/EMA test may be falsely reassuring or if the baby is IgA deficient the TTG/EMA test may also be falsely reassuring, so worth a discussion with the paediatric gastroenterologist if this is a concern.
- The HLA test is a one off screening test, for like, and is irrespective of gluten intake.

Serology testing (no HLA available):

Screening for coeliac disease with TTG when symptomatic or on routine screening or if have a very low threshold for testing: If HLA has not been done, but the TTG test is positive (IgA normal), this needs repeating with EMA (endomysial antibodies) within a few weeks and a referral made to paediatric gastroenterology.

Once referral made, the waiting time is usually about 4 weeks and the paediatric dieticians will contact the family. The child must NOT stop gluten until directed by the gastroenterologist/dietician team.

Discussion with Dr Daniel Crespi, paediatric gastroenterologist Royal Free hospital (2020):

I've put more information re coeliac diagnosis here with the link below and the key recommendations as well as a nice summary link below as well:

https://www.espghan.org/dam/jcr:bebe51d4-8cde-4d20-90d1-815b4a6c76a9/2019_ESPGHAN_guidelines_for_diagnosing_coeliac_disease.pdf

Key recommendations for diagnosing celiac disease (CD):

- § If CD is suspected, measurement of total serum IgA and IgA-antibodies against transglutaminase 2 (TGA-IgA) is superior to other combinations
- § We recommend against deamidated gliadin peptide antibodies (DGP-IgG/IgA) for initial testing
- § Only if total IgA is low/undetectable, an IgG-based test is indicated
- § If TGA-IgA is ≥10 times the upper limit of normal (10× ULN) and the family agrees, the no-biopsy diagnosis may be applied, provided endomysial antibodies (EMA-IgA) will test positive in a second blood sample. HLA DQ2-/DQ8 determination and symptoms are not obligatory criteria
- § In children with positive TGA-IgA <10× ULN at least 4 biopsies from the distal duodenum and at least 1 from the bulb should be taken

https://www.espghan.org/dam/jcr:a82023ac-c7e6-45f9-8864-fe5ee5c37058/2020_New_Guidelines_for_the_Diagnosis_of_Paediatric_Coeliac_Disease._ESPGHAN_Advice_Guide.pdf

There is a plan being put forward towards HLA testing being available to all infants with Down Syndrome (2020).

Appendix 15:

a) Neurophysiology referral form (EEG) and melatonin guidance (EEG usage)

Department of Clinical Neurophysiology
Royal Free London NHS Foundation Trust
Pond Street
London NW3 2QG

Tel: 020 7830 2072
Tel: 020 7794 0500
Internal extension: 33255/33256
Email for forms and requests to: rfh-tr.Neurophysiology@nhs.net
Sometimes melatonin is needed to help children go to sleep, so we can capture part of the EEG when asleep and part of it when awake, which helps us with diagnosing and our assessment. Here is the melatonin protocol:

ROYAL FREE HAMPSTEAD NHS TRUST
NEUROPHYSIOLOGY DEPARTMENT

PROTOCOL FOR MELATONIN SLEEP EEG

Melatonin to be prescribed during outpatient consultation and parent/guardian to collect melatonin prior to the day of test. Parent/guardian to bring EEG referral to the EEG department and make an appointment for melatonin sleep EEG at which time information sheet is issued along with appointment.

Melatonin is prescribed using standard AGE-related (rather than weight-related) doses as follows:

2.5mg – 5mg for under 5's;
5mg-10mg for over 5's;
10mg for over 10's.

The prescribing clinician should prescribe two doses of melatonin, in case one dose is not enough.

No fasting is required prior to administration of melatonin.

Melatonin is administered to patient by parent/guardian 30 minutes before appointment time.
On arrival at the EEG department clinical physiologist checks the time melatonin was taken and dose given, then applies electrodes and ensures the patient is comfortable.
Lighting is dimmed and the "silence" sign displayed prominently in the waiting area. Receptionist is instructed to maintain a peaceful atmosphere in the department.

The patient is allowed to sleep for a minimum of 30 minutes with some awake EEG included at the end of the recording.
.
If the patient has not fallen asleep within 30 minutes of electrode application, the parent/guardian may administer a second dose of melatonin if deemed appropriate.
If, after having had a second dose of melatonin, the patient does not fall asleep within 30 minutes, the recording should be terminated.

Neurophysiology Team."

Appendix 15 b): Infantile Spasms (IS)

Infantile spasms (IS) is a rare condition that occurs in young children, usually under the age of one. The condition is also known as West syndrome. Around 400 children a year are diagnosed with infantile spasms in the UK. The average age of onset is around four months, but some children may experience spasms as early as one month, and a few may begin as late as two years.

A child experiencing infantile spasms (IS) seizures has a chaotic brainwave pattern, detectable on an EEG, which can be associated with loss of skills and brain damage. It is incredibly important, therefore, to recognise that a child has IS as soon as possible, because medication can be given that may control the spasms.

The longer the spasms continue before they are treated and controlled, the greater the risk that development will be affected. If spasms are stopped quickly, children have a better chance of good development.

What does a spasm look like?

Infantile spasms often have a very subtle appearance that makes it difficult to identify as a serious problem. The spasms can look similar to common disorders such as colic or reflux, or a baby's normal 'startle' reflex.

The typical pattern is a sudden bending forward and stiffening of the body, arms and legs. Sometimes, the episodes are different, with the arms and legs being flung outwards. Usually, they affect both sides of the body equally. Typically, each episode lasts just one or two seconds, followed by a pause for a few seconds, then a further spasm. However, a child having infantile spasms may just have little head drops that do not appear to be anything serious.

What should you do?

If a child is thought to have infantile spasms, they need urgent referral to a paediatrician, and probably discussion with, or review by, a neurologist. If you suspect a child is having IS seizures, try to capture them on film and go to your nearest children's A&E department.

To diagnose IS in a child with suspicious movement patterns, their brainwaves need to be assessed with an EEG test (electroencephalogram). The EEG is a test that measures electrical activity in the brain by placing a series of small electrodes on the child's scalp and connecting them to a computer. It often involves taking a video of the child's movements at the same time (video-EEG) to correlate any seizure episodes or movements that might cause an artefact on the trace.

How can infantile spasms be treated?

Infantile spasms do not generally respond to the types of anti-epileptic drugs (AEDs) used to treat most other forms of epilepsy. Two types of medication have proved to be most effective and they are likely to be recommended, singly or in combination, as the initial treatment.

1. Hormonal treatment with ACTH or prednisolone
2. Treatment with vigabatrin (Sabril)

Other options for the treatment and management of IS include a ketogenic diet, epilepsy surgery and other AEDs. More information about the treatment of IS can be found in this guide:

https://ukinfantilespasmstrust.org/ukistwp/wp-content/uploads/2018/11/UKIST-Information-Guide.pdf

https://ukinfantilespasmstrust.org/

Online support group

Parents worried about infantile spasms can access advice and support through our Facebook support group

Facebook information page

(www.childneurologyfoundation.org)

Appendix 16: Criteria for RSV prophylaxis

Clinics run across hospital sites by neonatal sister or community sister. Infant is identified as needing RSV prophylaxis (sometimes referred to as Synergis) will be contacted to come in for these clinics usually starting from October of that year. Assistance from **Principal Pharmacist W&C**, **Royal Free London**, **Bleep 1412 Ext 36443.**

Information for parents – RSV prophylaxis is not a vaccine as such but an immunoglobulin that is given to babies just before the winter season (around October) to prevent the baby getting RSV (respiratory syncytial virus) which causes Bronchiolitis. The baby is given an injection every month they get an injection to cover the RSV season (winter period). The immunoglobulin is called Synergis or Palivizumab. Normally infants only need one course during the first year of life, sometimes they get it two years in a row.
RSV is one of the viruses that causes bronchiolitis and is predominantly only seen from October to February each year. Most children get it and are ok but many do get admitted, especially if they have an underlying medical serious condition or were born very prematurely or have lung disease.
After infancy, it does not cause such big issues, more like a cough and cold but not bronchiolitis which is mainly something in the first year of life, maybe up to 18m or so.

We have criteria based on extensive evidence as they are worldwide studies. They have produced yearly criteria for which children should receive immunoglobulin therapy, i.e. monthly injections, to try and prevent them catching RSV during their first winter.

It is usually given in babies with Down Syndrome who have a significant heart abnormality, meaning they have a significant right to left shunt (i.e. blood going wrong way / shunting) and are usually on medications too. Other reasons could be for example on respiratory grounds in a baby with chronic lung disease or an ongoing daily oxygen requirement. It is rarely given after the first year.

Further research and information:

In the "green book" immunisation guidance can be found here: PLEASE NOTE THIS ADVICE CHANGES YEARLY AND NEEDS UPDATING AND CHECKING YEARLY.

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/458469/Green_Book_Chapter_27a_v2_0W.PDF

At the time of writing this pathway, some research indicates that all children with DS should have Palivizumab due to their increased risk of bronchiolitis/LRTI, hospital admissions and morbidity accompanied with this, even without congenital heart disease or chronic lung disease. This needs further local and national evaluation and discussion with Public Health England. Paes B, Mitra S

Palivizumab for children with Down Syndrome: is the time right for a universal recommendation?

Archives of Disease in Childhood Published Online First: 27 December 2018.

Appendix 17: Children's Social care, 0-25 Disability Service Social Work team, Short Breaks and Safeguarding

Short Breaks

Family Services have a Short Break offer available to children and young people, with Down's Syndrome, up to their 19th birthday. The current offer for families in Barnet is as follows:

- 15 days or 90 hours (using the Barnet approved provider list) or
- £1200 Funding via a pre-paid card to allow families choice and flexibility of services. (Subject to a 0-25 service funding policy and Short Breaks written agreement).

Further information, including how to apply, can be found on the Short Breaks page on the Local Offer website as follows: https://www.barnet.gov.uk/children-and-families/children-and-young-people-disabilities/disabled-childrens-activities-short

The 0-25 Disability Service Social Work team.

Some children and young people with Down Syndrome may meet the criteria for the 0-25 Disability Service Social Work team.
The team offers a service to children and young people who have a diagnosed severe/profound disability or diagnosed chronic health condition resulting in severe and profound disability.

Your child needs to meet the eligibility Criteria to access a service offered by the 0-25 Disabilities Service. For the eligibility criteria please click on the document link that can be found on the Local Offer webpage:
https://www.barnet.gov.uk/children-and-families/children-and-young-people-disabilities/0-25-disability-service

if a child or young person meets the criteria of the 0 - 25 Disability Service for a social work service, an assessment can be undertaken. This assessment will provide detailed information about the needs of the child and family which will help develop a plan of support for the child/young person. if required, a package of support may be offered which may include Direct Payments

We provide a statutory safeguarding role for children and assess families where there are safeguarding concerns or where the parents may be struggling. We provide a statutory safeguarding role for adults 18 – 25 who have disabilities. We support children, young people and their families through transitions to adulthood.

We liaise with other agencies such as housing, education, health and occupational therapy. We contribute to Educational Health Care Plans and Continuing Care assessments or Continuing Health care Assessments

We provide advice and can direct families to national and local voluntary services

For children 0 - 18 families can self-refer or be referred by another agency they are in contact with such as a GP or a health worker.

Referrals are made via the Barnet Multi Agency Safeguarding Hub (MASH) on 0208 359 4066 or email mash@barnet.gov.ukExternal link. For adults 18-25 referrals are usually made via Barnet Social Care Direct 0208 359 5000 or email socialcaredirect@barnet.gov.uk.

https://www.barnet.gov.uk/children-and-families/keeping-children-safe/worried-about-safety-child

Mencap

Children's Social Care commissions advisory services for parents of children with disabilities, provided by Barnet Mencap. This includes advice, signposting and support in applications for things like blue badges, disability related housing issues and disability living allowance. Parenting Programmes for parents of children with disabilities are also provided by Barnet Mencap.
Both services can be accessed by going direct to Barnet Mencap. https://www.barnetmencap.org.uk/what-we-offer/children-and-family/0-25-advice-support/#

Early Help Offer (0-19 service)

We provide help and support to children, young people and their families from before birth up to the age of 19 (or 25 if they have special educational needs or a disability).
All families face challenges and sometimes need support. Early Help is about providing this support as soon as possible to tackle difficulties for children, young people and families before they become more serious. We work with the whole family and the child is at the centre of all we do.
Every family has strengths and Early Help can work with you to build on these. We can involve a range of professionals that will work together so you only have to give your information once.
There are three hub localities throughout Barnet if you prefer to register in person rather than online. Further information is available via:

www.Barnet.gov.uk/0-19

www.barnetyouth.uk

Young Carers

London Borough of Barnet also commission services for adult and young carers too:
Barnet Young Carers - http://barnetyoungcarers.org.uk/

Barnet Carers Centre - https://barnetcarers.org/

MASH (multiagency safeguarding hub)

If you believe a child is at risk of immediate harm please call the Police on 999
If you feel you have urgent welfare concerns about children or young people that require and immediate response, phone the Multi-Agency Safeguarding Hub (MASH) on 020 8359 4066.

The MASH team are available Monday to Thursday 9 am to 5.15 pm and Friday 9 am to 5 pm.

Outside of these hours you should report any concerns that need an immediate response to our emergency duty team on 020 8359 2000. If you are worried that a child may be suffering, or may be at risk of harm, you should complete a safeguarding concern referral.

https://www.barnet.gov.uk/children-and-families/keeping-children-safe/worried-about-safety-child

Appendix 18 – Neonatal guidelines from DSMIG (2018-9)

https://www.dsmig.org.uk/wp-content/uploads/2019/01/Neonatal-Guidelines-amended-7-1-18-NB-edit-26.9.18-new-address-2019.pdf

Appendix 19: Paediatric physiotherapy services

Conversation with senior paediatric physiotherapist Clare Andrews (2018):

Initial appointment at around the 3 months. Children are then reviewed on a 2-3 month basis for the first year and then once their physical progression is clear the frequency can be reduced in agreement with parents.
Once independent walking has been achieved they are assessed to their current need for orthotics / footwear with a referral to orthotics if required.
Once independent walking is achieved children are discharged from physiotherapy with advice on activities - normal activities that can be achieved in the home / community environment (parks soft play etc.) We encourage participation in physical activity to support development of physical skills albeit on a recognised slower attainment of motor milestones.
Referrals to Orthotics, OT etc occurs as needs indicate.

Children with Down Syndrome who have an additional / associated disorder, or significant or outside of typically expected achievement times for physical skills attainment may be reviewed more frequently and for longer. Some children stay on as they transition into schools - this is a small number.

Part of pre-discharge assessment is to review foot posture - we make it clear of what we are looking out for and that needs for orthotics can change as a child grows bigger / heavier. We encourage parents to review their child's foot posture when thinking of buying new shoes."

Appendix 20 – Thyroid guidance (updated 2020)

- Thyroid function

Venepuncture at age 6months, 1 year and annually thereafter throughout life - To check T4, TSH and thyroid antibodies. (Guidance changed in Winter 2019 to annual testing and starting at 6 months).

Where the T4 is normal and the child is asymptomatic but there is a mildly raised TSH (less than or equal to 10mu/l) or thyroid antibodies are present re-check after 6months. A specialist opinion may be warranted.

Have a low threshold for testing thyroid function at other times if clinically indicated e.g. lethargy and/or changes in affect, cognition, growth, or weight. Testing should be continued throughout life.

If a child is already under the endocrinology team on Thyroxine supplements, please leave monitoring of TFT's with the endocrine team.

Health Series: Thyroid Disorder – a guide for parents

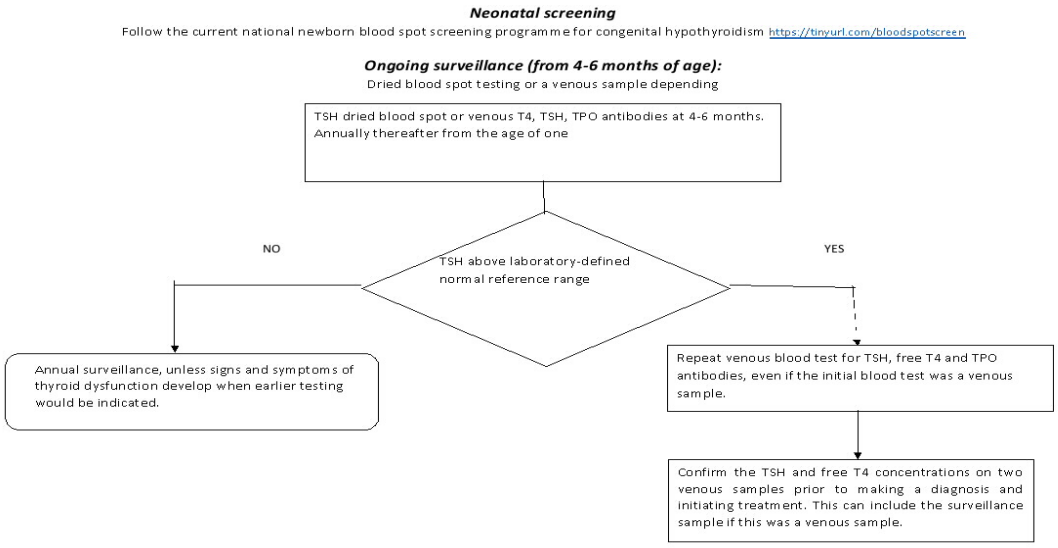
https://www.downs-syndrome.org.uk/for-families-and-carers/health-and-well-being/thyroid/?gclid=Cj0KCQiA-4nuBRCnARIsAHwyuPp9TM9xbaTBxigbs-5kE3_mY892H5oHzMnadmztHFGgPmvMVgje9lsaAuk4EALw_wcB

Thyroid disorder – a guide for professionals

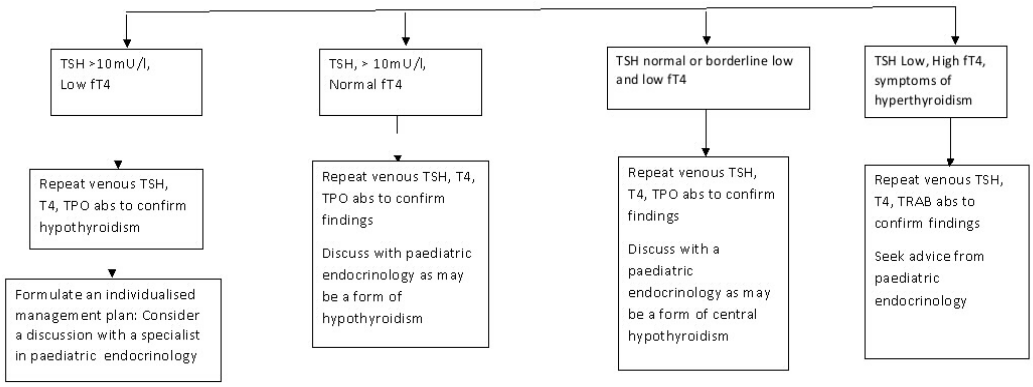
https://www.downs-syndrome.org.uk/for-professionals/health-medical/annual-health-check-information-for-gps/

https://www.dsmig.org.uk/information-resources/guidance-for-essential-medical-surveillance/

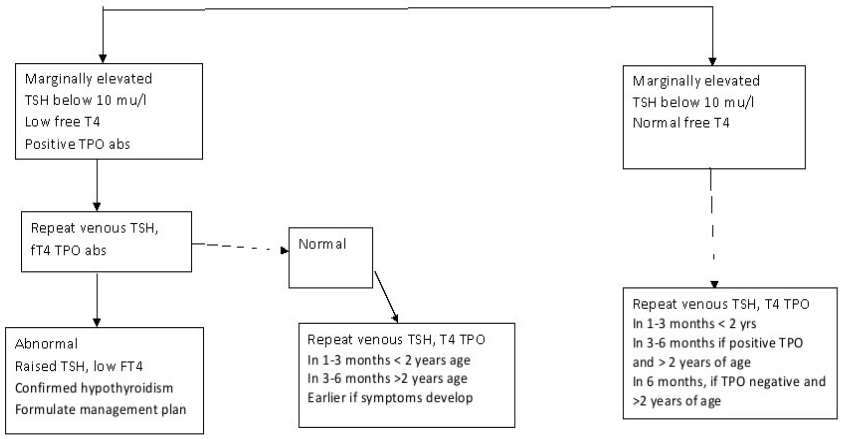
https://www.dsmig.org.uk/wp-content/uploads/2019/01/guideline-thyroid-6.pdf



Abnormal Repeat blood tests requiring immediate action



Blood tests Marginally Abnormal



Return to annual surveillance if three consecutive repeat tests show TSH and free T4 remain stable and there are no signs and/or symptoms suggestive of thyroid dysfunction.

Appendix 21 – Atlanto-axial instability

Screening tests for health professionals with form to complete

At each clinic attendance ensure parents are aware of the 'red flags' for cervical spine instability, and that they should seek immediate medical help if they are present.

· Neck pain · Abnormal head posture · Torticollis · Reduced Neck Movements · Deterioration of gait and/or frequent falls · Increasing fatigability on walking · Deterioration of Manipulative skills Other signs of progressive myelopathy · Increase in muscle weakness · Loss of sensation · Onset of incontinence · Alteration in muscle tone · Decreasing co-ordination · Diminishing kinaesthetic awareness · Pins and needles.

For parents and carers: https://www.downs-syndrome.org.uk/download-package/neck-instability/

For GPs and health professionals: https://www.downs-syndrome.org.uk/for-professionals/health-medical/annual-health-check-information-for-gps/

Sudden dislocation of the neck **probably** occurs more commonly in people with Down Syndrome than in the rest of the population although it must be **stressed** that it is still **very rare.**

If a person with Down Syndrome does not have any of the symptoms already discussed, there is **probably** no reason for worry about them taking part in everyday routine sporting activities. However, no activity is risk free and so we have to be aware of the risks and make an informed decision about taking part in an activity. It's a balancing act involving a decision about what is acceptable risk to you and a compromise between a person's freedom to take part being weighed up against protecting them from possible injury.

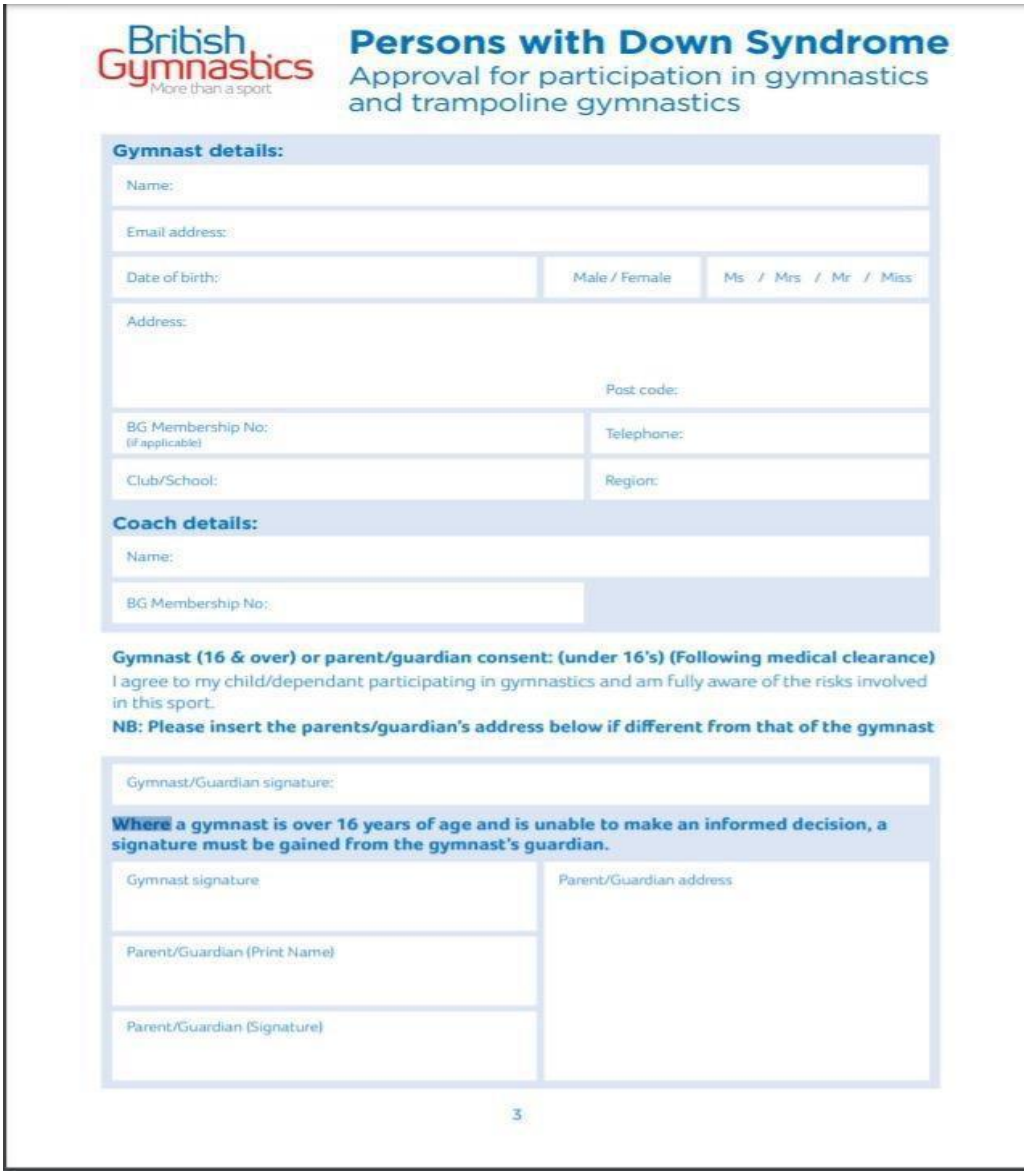
There are sports (e.g. trampolining, gymnastics, boxing, diving, rugby and horse riding) that **may** carry with them more of a risk **just as they do for anyone**. Prior to taking part in such activities, it is strongly advisable to ask a GP, paediatrician or chartered physiotherapist to screen a person with Down Syndrome using the simple screening test developed by the British Gymnastics Association. You can download information about the screening test: https://www.british-gymnastics.org/technical-information/discipline-updates/disabilities

https://www.british-gymnastics.org/technical-information/discipline-updates/disabilities/9316-atlanto-axial-information-pack-1/file

It does not specify how often this screening test needs to be done and the form updated. It is also very upsetting for parents and children if they are invited to for example a trampolining party and the venue refuses to let their child join in, unless they have a medical letter stating this is ok or the screening form above filled in. GPs are sometimes also worried about "signing-off" the form without medical expertise in this area, again causing anxiety for parents and it can be hard to access the community paediatrician with potentially such short notice or physiotherapist. This has been something discussed at the Leading Edge Group (LEG) for DS in Barnet, by the parental representatives. The screening test and form are simple and any health professional who knows the child and can screen with the questions and tests the form and information describes, can sign this form. This could be the physiotherapist, paediatrician, GP, school nurse and so on. Ideally too, every review by the community paediatrician and/or paediatric physiotherapist (although most children are not being seen once they start walking by this team) would not only check about symptoms of atlanto-axial instability but also complete and update the screening form. This is something all health professionals need to address and work towards.

It must be stressed that even if no symptoms are picked up by screening, this just means at the moment in time when screening took place, the evidence did not indicate that a person currently had neck instability. If you are all clear after a screening test you can still go on to develop neck instability.
There are no reliable screening tests to help us to predict those who might subsequently go on to develop a problem with their neck. This is why we all have to be aware of the warning signs that indicate that a person might be at risk

of neck dislocation. If there is greater awareness, then people are more likely to consult with a doctor before any permanent damage happens and early treatment can take place.



British Gymnastics
More than a sport

Persons with Down Syndrome

Approval for participation in gymnastics and trampoline gymnastics

Gymnast details:

Name:		
Email address:		
Date of birth:	Male / Female	Ms / Mrs / Mr / Miss
Address: Post code:		
BG Membership No: (if applicable)	Telephone:	
Club/School:	Region:	

Coach details:

Name:	
BG Membership No:	

Gymnast (16 & over) or parent/guardian consent: (under 16's) (Following medical clearance)

I agree to my child/dependant participating in gymnastics and am fully aware of the risks involved in this sport.

NB: Please insert the parents/guardian's address below if different from that of the gymnast

Gymnast/Guardian signature:	
Where a gymnast is over 16 years of age and is unable to make an informed decision, a signature must be gained from the gymnast's guardian.	
Gymnast signature	Parent/Guardian address
Parent/Guardian (Print Name)	
Parent/Guardian (Signature)	

3

A qualified medical practitioner or chartered physiotherapist must complete the following tests and questions (delete as appropriate):

1. Does the person show evidence of progressive Myopathy? Yes / No
2. Does the person have poor head/neck muscular control? Yes / No
3. Does the person's neck flexion allow the chin to rest on their chest? Yes / No

Name:

Designation:

Address:

Practice stamp:

Signature:

If a gymnast has a positive test (Yes) for any of the first two questions or a negative test (No) for question three, the individual will be excluded from participation in all gymnastics activity within British Gymnastics recognised environments.

For BG Office Use:

Received by BG Office: Date:

Signature:

Approved: Yes ☐ No ☐ (Tick appropriate)

Action required/notes:

4

Appendix 22: Dental information and referral form

DSMIG guidance on dental care:

https://www.dsmig.org.uk/information-resources/by-topic/dental/

https://www.bspd.co.uk/Patients/Dental-Check-by-One.

In Barnet we refer to the Whittington Health Paediatric Dental service.
"The best time so see a patient is as soon as teeth come through. The British Society of Paediatric Dentistry recommendation is at age 1. It would be ideal if we saw them directly in the Community services as there are some considerations to their care that need to be taken into account and High street Dentists are not always ready to support parents on their needs. If when they are older, the dentist believes they can be treated in normal high street the patient will be referred out of the service. Your team can make the referral directly to our service online. It would ideally be picked up and placed in a Senior Dental Officer diary.
On an initial appointment to the dentist the parents will be informed about the assessment, prevention advice and diet recommendations. Obviously an oral exam is performed as well. Discussion about fluid thickeners, timing of medication and feeds will also be relevant to dental care, and timetabling these to optimise dental care (reducing acidity). In addition, advice about palatal shape, tongue positioning and other anatomical issues would be discussed with parents by the senior dental officer." (Discussion with Maria Noguerado, Senior Dental Officer in Paediatric Dentistry, 2019)

Referral to be made at 12 month review.

Paediatric Dentistry referral form (Children 15 years old and younger)

https://www.whittington.nhs.uk/mini-apps/default.asp?page=Paediatric_Dentistry/Default.aspx

There is also a leaflet online. https://www.whittington.nhs.uk/default.asp?c=10989

The referral will be triaged and family sent to one of the clinics around Barnet.

There is another form that can be downloaded too for those older than 15 years.

Paediatric Dentistry

We specialise in the dental treatment of children who cannot be treated in general (or "high street") dental services.

Examples include young children that have

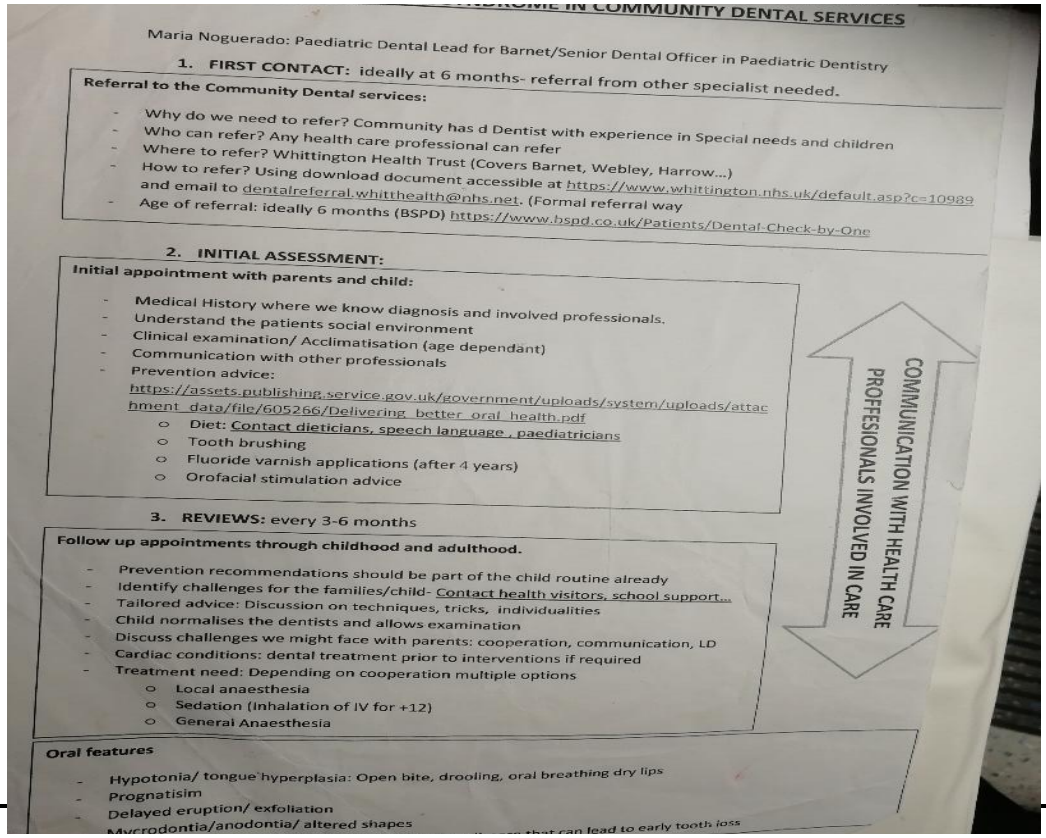
- severe anxiety and not able to cooperate, or who may need a general anaesthetic
- physical or learning disabilities
- medical conditions that require special provision
- 'Looked after' children

Access to this specialist service is by referral only.

How to make an appointment

If you are already a patient of our service, you can contact our head office on 020 3317 2353 to arrange a suitable appointment.

If you have been referred to our service, we will contact you to arrange an appointment.



IN COMMUNITY DENTAL SERVICES

Maria Noguerado: Paediatric Dental Lead for Barnet/Senior Dental Officer in Paediatric Dentistry

1. **FIRST CONTACT:** ideally at 6 months- referral from other specialist needed.

Referral to the Community Dental services:

- Why do we need to refer? Community has d Dentist with experience in Special needs and children
- Who can refer? Any health care professional can refer
- Where to refer? Whittington Health Trust (Covers Barnet, Webley, Harrow…)
- How to refer? Using download document accessible at https://www.whittington.nhs.uk/default.asp?c=10989 and email to dentalreferral.whitthealth@nhs.net. (Formal referral way
- Age of referral: ideally 6 months (BSPD) https://www.bspd.co.uk/Patients/Dental-Check-by-One

2. **INITIAL ASSESSMENT:**

Initial appointment with parents and child:

- Medical History where we know diagnosis and involved professionals.
- Understand the patients social environment
- Clinical examination/ Acclimatisation (age dependant)
- Communication with other professionals
- Prevention advice:
  https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/605266/Delivering_better_oral_health.pdf
  - Diet: Contact dieticians, speech language , paediatricians
  - Tooth brushing
  - Fluoride varnish applications (after 4 years)
  - Orofacial stimulation advice

3. **REVIEWS:** every 3-6 months

Follow up appointments through childhood and adulthood.

- Prevention recommendations should be part of the child routine already
- Identify challenges for the families/child- Contact health visitors, school support…
- Tailored advice: Discussion on techniques, tricks, individualities
- Child normalises the dentists and allows examination
- Discuss challenges we might face with parents: cooperation, communication, LD
- Cardiac conditions: dental treatment prior to interventions if required
- Treatment need: Depending on cooperation multiple options
  - Local anaesthesia
  - Sedation (Inhalation of IV for +12)
  - Generai Anaesthesia

COMMUNICATION WITH HEALTH CARE PROFFESIONALS INVOLVED IN CARE

Oral features

- Hypotonia/ tongue hyperplasia: Open bite, drooling, oral breathing dry lips
- Prognatisim
- Delayed eruption/ exfoliation
- Mycrodontia/anodontia/ altered shapes

…that can lead to early tooth loss

Oro-desensitisation programmes can be helpful for tolerance of teeth cleaning e.g. neonates/ children with PEGs and to reduce the impact of negative oral experiences during/after a period of invasive medical interventions. This is done through messy play as children need to desensitise through their other senses of touch/sight /smell and the oral acceptance of new foods is the last steps to eating. Dentist needs to work with the paediatric Dysphagia team.

Oromotor exercises and dental outcomes**: see Appendix 26b.**

Appendix 23: Hearing and audiology pathway

DSMIG guidance: https://www.dsmig.org.uk/wp-content/uploads/2019/01/guideline-hear-8.pdf

Best-Practice-Guidance-for-the-management-of-hearing-issues-in-people-with-Down-Syndrome

Barnet checklist: From Consultant in paediatric audiovestibular medicine.

Background:

Possibly more than 50% of children with Down Syndrome have at least some degree of hearing loss. Some of those children/ young people require some treatment as it can have an impact on their speech and language development or ability to hear well in the classroom.

Some of the hearing losses might not be obvious to parents or teachers and will require an assessment. These hearing losses might be only temporary, but some can be permanent and so the children and young people with Down Syndrome require regular hearing assessments until they leave school. Therefore we would like to see children::

Between 8 and 10 months
between 15 and 18 months
every year between the age of 2 and 5 years
every 2 years from the age of 5 yrs on until …… leaves school / education.

Bone conduction hearing aids (BAHA) are something being considered e.g. a child who has recurrent "glue ear" and is only intermittently hearing what is going around him/her as it is fluctuating and this would therefore affect speech development. BAHA can be useful whilst adopting the "watch and wait" model of care or waiting for any operation for the hearing like grommets. This can be discussed with the local audiology team.

Contact details and referrals:

2ND TIER SERVICE FOR CHILDREN OVER 6 MONTHS OF AGE ONLY: Referrals is via their referral form (email to request one).

Paediatric Audiology & Audiovestibular Medicine, Children's Services (Management)
Edgware Community Hospital
Edgware, HA8 0AD
Tel. 020 – 3316 8080
email: paediatric.audiology@nhs.net

CHILDREN <6 MONTHS NEED TO BE SENT TO THE SERVICE AT ROYAL NATIONAL ENT HOSPITAL FOR THE BARNET AREA

Some children are also seen at the Royal National ENT and Dental hospitals:

Royal National ENT and Eastman Dental Hospitals, Huntley Street, London, WC1E 6DG.Email: Uclh.paediatric.audiology@nhs.net 020 3456 5160 or 020 3456 5144.

Children Hearing Aid Department (CHAD) – For repairs and lost hearing aids, batteries and mould enquiries - email at uclh.enquiry.chad.rntne@nhs.net

If you are unable to use email, please call 020 3456 5160 or 020 3456 5144.

Address is : Paediatric Audiology CHAD Team The Royal National ENTED 47-49 Huntley Street London WC1E 6DG.

You may find helpful information and interactive multimedia videos provided by: https://www.ndcs.org.uk; https://c2hearonline.com

Cochlear Implant enquiries - Email: uclh.enquiry.cirepairs@nhs.net

https://www.uclh.nhs.uk/OurServices/ServiceA-Z/ENTS/Pages/Home.aspx

Appendix 24 – Ophthalmology pathway

The Down Syndrome Medical Interest Group provides evidence-based guidelines for many of the health problems that can affect children. This is part of the guidance on vision:
Distance and near functioning vision should be checked at every review whenever developmentally possible and a prescription for near correction or bifocals considered at all ages www.dsmig.org.ukhttps://www.dsmig.org.uk/wp-content/uploads/2015/09/Guideline-vision-revision-2012.pdf

Many hospitals routinely refer to ophthalmology after the baby is born, either following an admission to the neonatal unit or at the postnatal baby check by the paediatrician or midwife. Either way, there MUST be clear documentation that the eyes have been checked formally for cataracts, squints, nystagmus and visual behavior. Any concerns identified refer immediately.

If the baby has not been referred routinely after birth, in Barnet we have decided to refer routinely to ophthalmology at the 12 month review in order for the child to be seen at 18 months by the Paediatric Ophthalmology team at Barnet hospital. DSMIG guidelines say to refer around age 2-3 years, but in discussion with the team they would like to see these infants within the 2nd year of life and not wait till 2yrs+. Referral by letter to Consultant Ophthalmologist at Barnet hospital (discuss with the team directly if you have urgent concerns or want the child to be seen urgently, do not just send a letter as it may not be triaged as urgent without contacting the consultant ophthalmologist).

Community paediatrician to check vision, visual behaviour and development at ***every*** review including checking for cataracts, nystagmus, squints and refer earlier if any concerns.

https://www.dsmig.org.uk/wp-content/uploads/2015/09/Guideline-vision-revision-2012.pdf

Research updates:

There is some discussion about bifocals from the age of 2 in children with Down Syndrome.
"So now we prescribe bifocals routinely for all children with Down Syndrome who have the focusing defect once their long or short sight is corrected. Almost all of the children take to bifocals very readily, and most make their own choice to wear their bifocals all of the time. The children are clearly demonstrating to us that they benefit from bifocals."
Our criterion is that, if a child is old enough to sit at a table and do near tasks (whether work or play), he or she is old enough for bifocals.
"Once we started to fit bifocals routinely, we found something quite unexpected. Some of the children began to focus accurately over the top of their bifocal (using just the part of the lens that corrects long or short sight). After, on average, two years of wear, they were able to come out of bifocals and return to ordinary lenses. Quite what is happening, we don't yet know, but it is clear that the bifocals are 'teaching' the children to use their own focusing. So far, 40% have stopped needing bifocals, and none have 'relapsed' into needing then again. What the above outcomes of our research tell us is this: it was never the case that the children couldn't focus properly; it was the case that they didn't. When they wore their bifocals they learned how to do it by themselves. Why 25% of children with Down Syndrome do it anyway, and how the bifocals teach others to do so, we simply don't know." Maggie Woodhouse, Cardiff University.

Poster to share with parents and schools:

Down's Syndrome Awareness Week

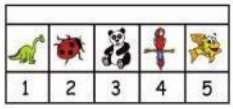
18th - 24th March 2013

People with Down's syndrome see the world differently – their world lacks fine details and sharp contrasts. In order to compensate for their poorer visual acuity we can make the world around them big and bold.

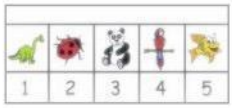
Think BIG, Think **BOLD**

- It is widely recognised that children with Down's Syndrome (DS) prefer a learning style that is predominantly hands on and visual.
- Reduced visual acuity (clearness of vision) affects 100% of people with Down's Syndrome.

You and I may see this:



A child with DS will see this:



Reduced Visual Acuity in the Class Room

- As children become more proficient in reading the text in books and worksheets get smaller. Making reading, worksheet and fine detailed tasks more difficult from upper primary and beyond.
- This may impact their ability to stay on track and may result in not completing tasks and becoming frustrated.

Strategies for Overcoming vision difficulties

- Move child's desk, or seat closer to the front or close to focal point.
- Do not use books with thin blue lines;

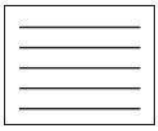
Normal vision:

Feint blue lines.

Child with DS sees this:

No lines.

Child with DS needs this:



Lines bold & well spaced.

Whiteboard

- Use larger text and emphasize key words in different colours but avoid blue and green together.
- Reduce the text to be copied or provide printed version on desk.

Worksheets

- Increase the contrast i.e. bold black on white.
- Text no smaller that 18pt.
- Uncluttered and less detailed.
- Sentences and paragraphs well spaced.
- Avoid colour photos photocopied in black and white.

Letter formation and written tasks

- Use only felt pen – do not use graphite pencils.
- Always use bold well spaced lines.

DOWN'S SYNDROME ASSOCIATION
A Registered Charity No. 1061474

Down's Syndrome Association,
Langdon Down Centre,
2a Langdon Park,
Teddington, Middlesex, TW11 9PS

Tel: 0333 1212 300
Fax: 020 8614 5127
Email: info@downs-syndrome.org.uk

For more information please visit our website – www.downs-syndrome.org.uk

Appendix 25 – Musculoskeletal complications and Referral form for Orthotics

Background:

"Musculoskeletal complications of Down Syndrome (DS) are common but infrequently reported. The combination of ligamentous laxity and low muscle tone contributes to increased risk of a number of musculoskeletal disorders and a delay in acquisition of motor milestones. The combination of ligamentous laxity and low muscle tone contributes to an increased risk of a number of musculoskeletal disorders, such as C-spine instability, hip instability, scoliosis and foot problems.

A delay in acquisition of motor milestones and lower levels of physical activity in children with DS have been observed.[5] Reduced physical activity contributes to the development of lower bone mass, obesity, and a failure to develop or maintain maximum possible muscle strength. Inappropriately low expectations of physical activity and motor function from family, healthcare workers and self-feed into this cycle. Conversely, however, over-attributing motor difficulties to low tone and hypermobility may lead to missed pathology and misdiagnoses."

"Children with DS are at increased risk of a number of potentially debilitating musculoskeletal (MSK) problems. These conditions can present in variable manners or be completely asymptomatic. Pes planus is common; therefore, early consideration of orthotics and lifelong appropriate supportive footwear should be considered. Delayed ambulation is frequently noted. A significant proportion of children with DS have arthritis; however, despite a high prevalence, it is often missed, leading to delayed diagnosis. An annual musculoskeletal assessment for all children with DS could potentially enable early detection of problems, allowing for timely multidisciplinary team intervention and better clinical outcomes." Worth checking for any swellings or pain in digits which might indicate a rheumatological condition and consider a hip examination too and MSK exam. Take history seriously.

Musculoskeletal anomalies in children with Down Syndrome: an observational study

Archives of Disease in Childhood Published Online First: 24 November 2018. doi: 10.1136/archdischild-2018-315751. Foley C, Killeen OG

Orthotics:

Research has shown that two thirds of children with DS have inversion etc and benefit from Orthotics. This above research suggested that 91% of children with Down Syndrome have pes planus (flat feet).

"Children with Down Syndrome as a result of having normal to mild low tone have a higher incidence of foot pronation and requirement of orthotic. This does not mean that every child needs insoles and Piedro boots. Far from it. A good ankle boot (including insole) can be purchased from regular good shoe shops. Foot posture needs to be assessed and provided for on an individual basis. Physiotherapists review foot posture once they are up and walking (just prior to their discharge) so their orthotic need for referral is covered during this period.
Part of pre-discharge assessment is to review foot posture - physiotherapists make it clear of what we are looking out for and that needs for orthotics can change as a child grows bigger / heavier. They also encourage parents to review their child's foot posture when thinking of buying new shoes. " Claire Andrews, Barnet senior paediatric physiotherapist.

Referrals to orthotics- Children's Surgical Appliance Form

Orthotics Service, Oak Lane Clinic, Oak Lane, East Finchley, London N2 8LT. Telephone: 020 8349 7057/Fax: 020 8371 9447

Email: CLCHT.OrthoticsBarnet@nhs.net (email for a form) or can write a referral letter directly.

Good practice to discuss with the child's physiotherapist, if they have one, first.

In the special schools in Barnet the paediatric orthotist comes in to schools so it can be something to mention on your form or referral letter or to discuss with the school physiotherapist or school nurse

Appendix 26a: Speech and Language Therapy (SLT)

www.downs-syndrome.org.uk/for-families-and-carers/growing-up/speech-and-language

www.downs-syndrome.org.uk/for families-and-carers/growing-up/early-communication/

At the 2 year review, refer to Speech and language therapy if not already known to them (sometimes they will have been known by the paediatric dysphagia team which is run by speech and language therapists with a feeding specialism but they also need to be referred to the other part of their team, the Speech and Language service). **Use form from Appendix 1.**

Makaton signing through BIG-DS (Barnet Integrated Group for Down Syndrome) at PsTT weekly Underhill groups or other local signing groups, usually in children's centres.

Ensure Child known to Inclusive Education team/Educational psychologist (through PsTT usually) but can also refer by letter to Barnet based SEN and EP teams, separately.

If concerns about social communication (a small number of children with DS can have a dual diagnosis with ASD), discuss with other professionals and family about referral to TASC forum (Team Assessing Social Communication) and usually the child's community paediatrician takes the lead here (referral via TASC form or through child development team referral, can also discuss with the lead for the ASD pathway at Barnet CDT, **see Appendix 1** for contact details and forms).

If health visitor has concerns – they need to directly liaise with our paediatric SLT team.

Books: *Helping Children to Speak: Down Syndrome Through the Primary School Years (March 2020*) by Karen Massey

A book that aims to help parents - and professionals - support their child with Down Syndrome's communication skills through the Primary School years, from age 3 to age 11. It is written after several years of real-life therapy, training and research. The book includes stories, goals, therapy techniques and top tips.

The Hanen Program: The Hanen Program® for Parents of Children with Language Delays

This program is well-known and some SLTs use or refer to it. The Hanen Centre began its work with a focus on early language intervention for children with language delays. There are several programs for different children and for parents and for professionals to access. Programs such as: http://www.hanen.org/About-Us/What-We-Do/Early-Childhood-Language-Delays.aspx and http://www.hanen.org/Programs/For-Parents/It-Takes-Two-to-Talk.aspx

The *It Takes Two to Talk* Program is designed specifically for parents of young children (birth to 5 years of age) who have been identified as having a language delay. In a small, personalized group setting, parents learn practical strategies to help their children learn language naturally throughout their day together.

The SCERTS® Model: https://scerts.com/

SCERTS® is an innovative educational model for working with children with autism spectrum disorder (ASD) and their families *(for those CYP who have a dual diagnosis of DS and ASD).* It provides specific guidelines for helping a child become a competent and confident social communicator, while preventing problem behaviors that interfere with learning and the development of relationships. It also is designed to help families, educators and therapists work cooperatively as a team, in a carefully coordinated manner, to maximize progress in supporting a child. The acronym "SCERTS" refers to the focus on: "SC" - Social Communication – the development of spontaneous, functional communication, emotional expression and secure and trusting relationships with children and adults. "ER" - Emotional Regulation – the development of the ability to maintain a well-regulated emotional state to cope with everyday stress, and to be most available for learning and interacting. "TS" – Transactional Support – the development and implementation of supports to help partners respond to the person's needs and interests, modify the environment, and provide tools to enhance learning. Specific plans are developed to provide educational and emotional support to families, and to foster teamwork among professionals. (Prizant, Wetherby, Rubin & Laurent, 2007)

Appendix 26b: Oromotor exercises – MDT (multidisciplinary) approach

What are oromotor exercises?

Oromotor exercises are things like encouraging blowing, sucking, holding lollipop sticks between lips to gain lip closure, encouraging tongue movements to reduce protrusion, stroking of the cheek, breastfeeding, and many more. It is a big commitment from parents and little guidance out there that is free for all, and to pay for the "therapist/therapy/resources/courses" is incredibly expensive (hundreds of pounds) and not at all available for the majority of our parents (but it is available to search for "Talk Tools" so parents ask us about it).
We do not also have a clear policy on what we can and cannot show parents and advise, especially with the lack of real evidence based research. It's also costly in terms of time and training.

Research - pros and cons:

Fundamentally, there is no overall evidence based research that shows improved communication/speech with oromotor exercises. However, there are some arguments for benefits of oromotor exercises - and this is around the actual anatomy of the jaw/palate/tongue/chewing muscles. In other European countries, like Spain, our specialist dentist mentioned there is a dental/feeding/SLT combined approach to show parents these oromotor exercises and continue this from newborn onwards. In her experience, and research she has looked into, there is evidence for some improvements in jaw and palate formation, and probably also reduction in tongue protrusion and improvements in mastication, leading to a change (even if subtle) is some of the underdeveloped mid-face that the children have (breastfeeding also has a positive effect on these changes too). This potentially leads to fewer dental complications in the future (which is a common problem in DS) and less risk of sleep apnoea because of the change in palate shape/mid-face.

Oro-desensitisation

On the issue of desensitising and oro-motor aversion – these exercises again are definitely not evidence-based therapy for this. They potentially could help but could also potentially worsen things, if done in the wrong way. Could the oromotor exercises and equipment techniques used be somehow useful in “Desensitising" some of the children to something in their mouth which helps e.g. with dental care or on the other hand, could these exercises and equipment actually cause further dental/food aversion? Currently, Barnet paediatric dysphagia team have a clear position here: Oro-desensitisation programmes can be helpful for tolerance of teeth cleaning e.g. neonates/ children with PEGs and to reduce the impact of negative oral experiences during/after a period of invasive medical interventions. This is done through messy play as children need to desensitise through their other senses of touch/sight /smell, oral acceptance of new foods is the final step to eating. Dentist needs to work with the Dysphagia team of Speech and language therapists **(see Appendix 3).**

Oromotor exercises on anatomy/dental effects:

Using an evidence-based approach, the current evidence highlights the contraindications to using non-functional oromotor activities to improve speech and feeding. However, following an oro-motor subgroup of relevant professionals being developed, we are looking into the different options, research and advice. It needs to be evidence based and also discussed individually with parents as it is not a “one-approach” fits all. The paediatric specialist dentist, preschool support team and community paediatrician as well as the dysphagia team plan to produce some parental leaflets and exercises, which can be given to some families (as decided by the community paediatrician) where it may be helpful. There is evidence to suggest these exercises could help with jaw/facial changes in anatomy which could have an improved impact on e.g. sleep apnoea or teeth development (also clear evidence for breastfeeding helping with this). This is a different outcome to improving speech or chewing/mastication and needs proper training and understanding by parents and professionals.

Research examples: **The effect of oro-motor exercise (ORE) on swallowing in children: an evidence-based systematic review.** ***Arvedson et al, Developmental medicine and child neurology, May 2010.*** “There is insufficient evidence to determine the effects of ORE on children with sensorimotor deficits and swallowing problems.”

Managing eating and drinking difficulties (dysphagia) with children who have learning disabilities: What is effective? Authors are Celia Harding and Helen Cockerill. Clinical Child Psychology and Psychiatry 20(3) · Jan 2014.

People who work with children who have neurological and learning disabilities frequently need to manage the health and emotional risks associated with eating, drinking and swallowing (dysphagia). Some approaches can support children to develop oral feeding competence or to maximise their ability to maintain some oral intake supplemented with tube feeding. However, some clinicians feel that oral-motor exercises can support eating and drinking skills as well as speech and language development, whereas there is little evidence to support this. The implied "beneficial" association between oral-motor exercises, speech and swallowing skills gives a false impression in terms of future outcomes for parents and carers of children with learning disabilities. This paper considers oral-motor approaches in the remediation of dysphagia and the need for a cultural shift away from this view. Realistic and useful outcomes for people with learning disabilities need to be an essential part of therapeutic intervention.

Myofunctional therapy and prefabricated functional appliances: an overview of the history and evidence. Wishney, Morgan; Darendeliler, M Ali; Dalci, Oyku. Australian dental journal; Mar 2019

Abstract: Malocclusion represents the clinically observable endpoint of numerous genetic and environmental influences. Oral Myofunctional Therapy (OMT) aims to treat malocclusions by improving the oral environment through re-education of musculature and respiratory patterns. However, a more recent application of OMT for the treatment of OSA suggests some benefits although more research is needed to clarify this effect.

Effects of an oral-pharyngeal motor training programme on children with obstructive sleep apnea syndrome in Hong Kong: A retrospective pilot study. Cheng S.Y.; Kwong S.H.W.; Pang W.M.; Wan L.Y. Hong Kong Journal of Occupational Therapy; Dec 2017; vol. 30; p. 1-5Dec 2017.

"The findings of this study support the role of occupational therapist in oromotor training modalities to improve the respiratory function for children with OSA in Hong Kong."

Summary of Oromotor subgroup meetings and outcome (2019):

Attended by: SLTs- Dysphagia team (hospital and community-based) Community Paediatricians, SLT-communication, Health visiting, Breastfeeding support/coordinator, Paediatric senior Dentist, PsTT DS advisor.
Background: This was set up to try and get more of a consensus of oromotor function and exercises as there are different opinions, research is available but sometimes scanty, there are different levels of skill and different perspectives but our parents are asking about it and we need to find some common ground which we ALL adhere too and not confuse parents further.
Summary: So from a medical and dental perspective, there is a reasonable argument to propose we teach/encourage parents to do these regular oromotor exercises (with auditing)- BUT we cannot say this improves speech and communication skills or oro-desensitisation. The research is scanty and not specific enough, in our group of children, so Barnet could be the pioneers, in fact, even discussing this puts Barnet ahead of the game in this field.

Take home messages and future plans:

1) ***Breastfeeding has clear benefits with these anatomical changes mentioned above e.g. jaw development, with oro-desensitisation, with less risk of lung damage from aspiration (as a result of issues with the baby's swallow.*** All professionals need to encourage breastfeeding in our families and arm them with information and practical support, without judgement nor pressure. But we must try, as it is sometimes easier to assume a baby with Down Syndrome won't be able to breastfeed or we ourselves don't know if they can - so seek advice/training and seek out others who can help.
2) ***Dental and PsTT teams to develop a simple pamphlet***/leaflet for parents to have, using bits of equipment that is available to all and does not need to be brought from any particular website. e.g. bubbles, lollipop or tongue depressor sticks, straws. Some exercises require no equipment e.g. using your hand to stroke the cheeks or your finger to encourage sensation within the mouth and cheeks.
3) ***Training opportunities*** and developments.
4) ***Communication with parents:*** We need to be absolutely clear we are not forcing or suggesting parents are wrong

for *not* doing these exercises, as with all therapies. We also need to be very careful we explain to individual parents what the leaflets mean and reason behind them with the commitment involved, and maybe it is not for every family for various reasons and so each member of the subgroup, in particular the lead paediatrician, needs to really think about this aspect at every contact with the family. Paediatrician's role here: It will need some paediatric approval to go ahead and suggest parents to try these, at least to start with. This is to ensure we are clear with parents about the issues raised above, the research and evidence and the objectives and it is consistent. What we want to avoid is e.g. a parent who perhaps misunderstood this and who could potentially be too over-vigorous with the exercises causing more damage than good in the longer term. This requires professionals to ensure we have tried our very best to communicate all of this clearly and documented it. This is going to be the lead paediatrician's role for the foreseeable future. Once the leaflets are developed by members of the sub-group, the role can be re-evaluated and audited, to see it can be expanded appropriately to other professionals. *Please, if questions,* discuss with professionals who care for your child.

5) There may be an opportunity to do some of these exercises in the BIG-DS hub at Underhill children's centre, therefore with supervision and support, perhaps an age-appropriate communal snack time, but this is a longer-term project involving more time, training, equipment and storage etc.

Further reading, courses, books:
There were a number of really useful documents and articles, in particular the extensive research put together by Celia Harding (Dysphagia team, Royal Free hospital) whose document can be requested, plus some articles from Pre-school Teaching Team Down Syndrome advisor (PsTT lead for DS) and from our paediatric dentist who remains super helpful with all of these plans.

Books:
"*Nobody ever told me that!*" by Diane Bahr, Everything from bottles and breathing to Healthy Speech Development.
"Down Syndrome, Current Perspectives" by Richard Newton, Shiela Puri and Liz Marder.

Additional articles:
https://library.down-syndrome.org/en-gb/research-practice/11/1/development-oral-motor-control-language/
https://www.arktherapeutic.com/blog/oral-sensitivities-and-low-tone-in-children-with-down-syndrome/
https://www.downsyndromecentre.ie/lip-exercises-to-strengthen-weak-muscle-tone-in-cheeks/
https://www.downsyndromecentre.ie/tongue-exercises/
http://www.three21wellness.org/feeding-issues-for-children-with-down-syndrome/

What else is out there?

Talk Tools: This is not supported by the NHS and our therapists, the evidence is incomplete at present. There are ongoing discussions and more research into this area and in Barnet we have set up an oromotor subgroup to examine this area further. Talktools is an expensive program that is private and many parents ask about it so here are the links, but to reiterate we are not promoting it. There may be some evidence for some use for improving dentition, mastication (chewing), tongue protrusion and palate shape and our specialist paediatric dentist is involved with us to promote these positive outcomes.

Talk Tools promote Oral Placement Therapy (OPT) which uses a hierarchical based approach to improve speech clarity and feeding skills in individuals of all ages and across diagnoses. The techniques focus on motor movement activities to improve phonation, resonation, and speech clarity. OPT is combined with a tactile-sensory approach to aid a variety of speech and feeding issues. OPT involves the use of therapy tools to train and transition muscle movements for speech production. Oral Placement Therapy is a speech therapy which utilizes a combination of: (1) auditory stimulation, (2) visual stimulation and (3) tactile stimulation to the mouth to improve speech clarity. Talk Tools explain that OPT is only a small part of a comprehensive speech and language program and should not be done in isolation. The activities are carefully selected to stimulate the same movements used in the targeted speech production. They can be completed in under 15 minutes and can be used to refocus attention and concentration from a sensory processing perspective. https://talktools.com/

Appendix 27 – CAMHS services, SCAN and Referral forms

IAPT for parents (Improving Access to Psychological Therapies)

http://www.behcamhs.nhs.uk/professionals/barnet-camhs.htm

CAMHS is the Child and Adolescent Mental Health Service

SCAN is Service for Children and Adolescents with Neurodevelopmental Difficulties

Barnet CAMHS is the Child and Adolescent Mental Health Service in the London Borough of Barnet, providing multi-disciplinary assessment and treatment of children and young people with mental health or severe emotional and behavioural difficulties. Barnet CAMHS is an NHS service consisting of seven teams which work closely together, with all referrals to Barnet CAMHS coming through a service called CAMHS ACCESS. To find out more about making a referral to Barnet CAMHS, click here.

Barnet CAMHS includes the following teams and services:

CAMHS Access and Generic Team (East and West Barnet)

CAMHS Access provides a central point of referral for professionals to refer young people with mental health concerns. These referrals may then be discussed with the young person, their family, or the referrer in order for the Access team to gather all the relevant information and send the referral to the most appropriate team as quickly as possible, or for signposting for other support in the borough.

Generic CAMHS provides assessment, treatment and support to children and young people aged 0-18 years and their families for a range of mental health, behavioural and emotional well-being needs. The service offers a range of individual, family and group based interventions. There are two Generic CAMHS teams within Barnet (East and West).

These services are provided by Barnet, Enfield and Haringey Mental Health NHS Trust (with clinics based at Oak Lane, Holly Oak, Barnet General Hospital and Redhill Clinic and in community locations) and Tavistock clinic and Royal Free NHS Foundation.

Paediatric Liaison

The paediatric liaison team provide specialist mental health provision and consultation for young people and families who are in-patients or out-patients under the care of the paediatric and neonatal services at Barnet Hospital. Focus is on improving identification, engagement and providing early, brief and some longer-term interventions to reduce the high levels of psychiatric morbidity in young people with long-term physical illnesses, life threatening medical conditions and in those with medical unexplained symptoms. The team also provide support for staff and families in the case of child deaths, early parent work and support in neonatal units where babies have extreme prematurity or complex medical problems. Paediatric Liaison team run parent groups on neonatal units and have a specific SLA for the Diabetes service, providing input within multidisciplinary clinics; meetings and 1/1 work with this client group. The team provide induction and training for paediatrics around paediatric mental health topics, consultation to the paediatric and neonatal units around complex cases, and act as a liaison between CAMHS and the hospital. The team regularly provide liaison input to enhance the safe care, assessment and follow up of young people with self-harm who present to A and E and the ward. We provide clinical presence and consultation at all three weekly psychosocial meetings on the ward and in A and E.

Barnet Adolescent Service (BAS)

Barnet Adolescent Service (BAS) are a specialist team working with young people between the ages of 13 and 17 facing complex, severe or chronic mental health issues. Often these young people find it hard to engage with other services and may be at a higher risk, with complex presentations including chronic self-harm and psychosis. BAS consists of a multi-disciplinary team which includes Psychiatrists, Psychotherapists, Psychologists, family therapists, nurses and adolescence mental health workers. Most of the team's work is based around talking - this may be with the young person or with members of their family, and/or in a group. Some young people may be offered medication after a psychiatric assessment.

Service for Children and Adolescents with Neurodevelopmental-difficulties (SCAN)

- SCAN are a multidisciplinary team (consisting of Psychiatry, Clinical Psychology, Child Psychotherapy, Family Therapy, Counselling Psychology, Nursing) providing a full CAMHS provision to children and adolescents with moderate to severe neurodevelopmental difficulties and comorbid mental health problems. Referrals are accepted when mental health problems are identified in accordance with the CAMHS referral criteria and when the child or adolescent attends one of the special schools in Barnet. Under particular circumstances referrals are also accepted from special educational units within mainstream education. SCAN clients have chronic and life-long difficulties and will often be re-referred through-childhood, or they require long term monitoring of medication, as their difficulties are generally linked to their disabilities. The majority of clients receive a general initial assessment, although some may require complex specialist diagnostic assessments involving several clinicians and other services (such as a Paediatrician, for example). A range of short or long term treatments are offered as would be expected from a multidisciplinary team. However, all assessment and treatment work is increased in complexity due to the comorbid neurodevelopmental difficulties and mental health problems, requiring more resources to assess, diagnose, treat and liaise with the many professionals involved with the client and their family. A great deal of anxiety and risk surround our client group and the team has to be able to respond quickly and flexibly to safely support families in need. SCAN offer consultation and joint assessments to other CAMHS team in Barnet and foster good links with the special schools, Children with Disabilities Service, the voluntary sector and the community paediatricians. Alongside this assessment and treatment we offer support to parents who are frequently suffering from the stress and low mood that can come with parenting a child with a mental health problem and a major disability. The service contact is Tel: 0208 702 4500.

Barnet CAMHS in Specialist Schools

A team of Child and Adolescent Mental Health professionals support young people in Barnet's Specialist schools (Pavilion, Meadway and Oak Hill Campus).

Barnet Primary and Secondary Project

This CAMH service to schools is now being delivered by our partners in the local authority.

Following the changes in the Child & Adolescent Mental Health Service (CAMHS) to schools this year Barnet Local Authority will be providing CAMHS in School's service rather than the Barnet, Enfield and Haringey Mental Health Trust.

For the service to be able to work with your child we require your consent for Barnet CAMHS in School Service to process the information provided in the current referral form, and permission for the information to be shared with other relevant agencies. Please see below for the Permission for CAMHS in school consent form;

Permission for CAMHS in school

CAMHS in School Leaflet

Looked After Children/Adoption Services

This CAMH service to Looked After Children (LAC) and Adopted Children is now being delivered by our partners in the local authority.

Useful links

Barnet Council Local Offer

A London Borough of Barnet website helping young people with Special Educational Needs and/or disabilities and their families find the information they are looking for?

https://kooth.com

Kooth, from XenZone, is an online counselling and emotional well-being platform for children and young people, accessible through mobile, tablet and desktop and free at the point of use.

Young Minds; What is CAMHS Leaflet

Making a referral to CAMHS

Barnet, Enfield and Haringey each have a CAMHS Access service, which provides a central point of referral for professionals to refer young people with mental health concerns. These referrals may then be discussed with the young person, their family, or the referrer in order for the Access team to gather all the relevant information and send the referral to the most appropriate team as quickly as possible, or for signposting for other support in the borough.

Download the Barnet, Enfield and Haringey CAMHS services referral form here.

The form should then be sent to the appropriate CAMHS service: **beh-tr.camhsreferral@nhs.net**

Barnet

CAMHS Referrals Administrator, Holly Oak, Edgware Community Hospital, Burnt Oak Broadway, Middlesex, HA8 OAD.
E-mail address: beh-tr.Barnetcamhsreferrals@nhs.net and Tel:02087024194.

Barnet CAMHS in Schools Team or Children and Young People's (CYP) Wellbeing Team referral form

Please use this form for all Barnet Local Authority, CAMHS IN SCHOOLS or Children & Young People's (CYP) Wellbeing Provision REFERRALS.

https://www.barnet.gov.uk/citizen-home/children-young-people-and-families/forms/Barnet-CAMHS-in-Schools-Team-or-Children-and-Young-People-s-CYP-Wellbeing-Team-referral-form.html

For parents:

IAPT Barnet: helps people manage and overcome anxiety and depression through psychological therapies.

Contact details: First Floor of Westgate House, Edgware Community Hospital, Burnt Oak Broadway, Edgware, HA8 0AD

Service Tel: 020 8702 5309
Service E-mail: lets-talk-barnet@nhs.net

What we offer

Let's Talk Barnet IAPT (Improving Access to Psychological Therapies) offers assessments and short term therapy for people with mild to moderate low mood or anxiety. We offer face to face Cognitive Behaviour Therapy and Counselling, as well as Guided Self Help – these are shorter appointments, usually over the telephone, and focus on practical ways for people to manage their difficulties. We work together with Twining Enterprise to offer individualised Employment Support, and along with the Multilingual Wellbeing Service, offer a range of community wellbeing workshops focusing on topics such as stress management and sleep hygiene. Our team includes:

- **Psychological Wellbeing Practitioners (PWPs)** who are skilled at helping people find practical ways to manage their difficulties.
- **CBT Therapists** who are trained to deliver individual and group cognitive behavioural therapy.
- **Counsellors** who are trained to provide an opportunity to talk about day-to-day difficulties as well as difficulties from the past.

Therapy can take place over the phone, or face-to-face. We offer assessments and therapy in English and Farsi, with interpreters available on request for other languages.

Who the service is for

Let's Talk Barnet IAPT (Improving Access to Psychological Therapies) offers free and confidential talking therapies to people aged 16 and over, with a Barnet GP. Common difficulties that we can treat in IAPT include:

- Mild to moderate low mood
- Sleeping problems
- Stress
- Generalised Anxiety
- Social Anxiety
- Panic
- Agoraphobia
- Specific Phobias
- Obsessive Compulsive Disorder
- Post-Traumatic Stress Disorder
- Health Anxiety

We offer therapy over the phone, at our base at Westgate House based on the Edgware Community Hospital Site, and in some GP surgeries and community venues, including Finchley Memorial Hospital.

How to access our service

People can refer themselves to us directly by visiting us online at: lets-talk-iapt.nhs.uk.

On our website there is an online referral form, as well as a printable form which can be completed and sent to us in the post or emailed to lets-talk-barnet@nhs.net.

Please note that Barnet, Enfield and Haringey Mental Health NHS Trust provides IAPT services for Barnet and Enfield. IAPT Haringey is provided by Whittington Health NHS Trust.

Associated Services

For other services that may be of interest, please visit: www.communitybarnet.org.uk.

NHS.UK IAPT service finder - https://beta.nhs.uk/find-a-psychological-therapies-service/

Appendix 28 – Occupational therapy (OT) services

Appendix covers:

Child development team OT – hand skills in Down Syndrome and recommendations with an example of an OT individualized plan and helpful resources,

Criteria for paediatric occupational therapy referral and

Social care OT.

There are two types of OT referrals/services –

A) The child development team OT (CYPOT – children's and young people's OT)

B) The social care team OT.

A) Paediatric occupational therapy referral – the main referral form needs to be used (Appendix 1) - Children and Young People Occupational Therapy, Westgate House, Edgware Community Hospital, Burnt Oak Broadway, HA8 0AD. Tel: 0300 300 1821. Email: nem-tr.BarnetCIT@nhs.net

There are criteria for referrals to be accepted:

Occupational Therapy (CDT) Referral Criteria

A referral should be made to the Barnet Occupational Therapy (Health) Team when there is a functional concern regarding the child's ability to participate in the occupational performance areas:

- Play/leisure activities
- Self-care
- Nursery/school life

The definition of function is "age appropriate daily activities".

The reason for referral on the referral form must therefore indicate more than one functional concern, relevant to the child's age such as:

- Difficulty with using cutlery
- Dressing/undressing
- Making light snacks/breakfast
- Participating in P.E. lessons or sporting activities
- Handling play items
- Physically manipulating/using school tools (such as scissors/glue sticks/writing tools).

Please note that our O.T. service does not accept referrals that only state the child is referred for:

- Fine motor difficulties
- Behavioural problems
- Sensory processing difficulties
- Developmental Coordination Disorder (DCD)/Dyspraxia diagnosis.

These referrals will be returned to the referrer. The reason for referral must specify how these difficulties above are impacting on the child's ability to perform daily activities (i.e. functional concerns).

We also do not accept referrals where only handwriting difficulties are highlighted and there are no other functional concerns identified. If there are handwriting concerns, then we would expect a school to be able to provide handwriting intervention. For older children with persistent handwriting difficulties, alternative means of recording work or compensatory strategies should be considered by the school.

HAND SKILLS FOR CHILDREN WITH DOWN SYNDROME

Children with Down Syndrome are often referred to Occupational Therapy with concerns regarding their hand skills, particularly problems in the development of handwriting. Despite individual differences in learning abilities, there are some physical characteristics of the hands that are specific to the Down Syndrome population and these have an impact on the development of hand skills.

The hands of Down Syndrome people tend to be 10-30% shorter than the average population, and the fingers also tend to be relatively short. Bone ossification (hardening) tends to be a slower process and in some cases, deformities or absences of the digits can occur. Children with Down Syndrome may have difficulty with opposition as the thumb may be set lower on the hand and the fingers tend to be shorter. Pincer grasp (thumb tip to index finger tip) tends to develop late in children with Down Syndrome.

The bones in our hands are arranged in a particular way to enable our hand to form arches along both its length (longitudinal) and the breadth (transverse). These arches provide the curve of your palm that allow you to mould your hand around objects and enable your thumb to oppose (move around in an arc) to touch your fingers. The stability of these arches relies upon the small muscles of the hands (intrinsics). In a child with Down Syndrome these muscles are often hypotonic (low tone) and this will affect the child's ability to stabilise the fingers. Tone refers to the amount of resistance a muscle has to passive stretching. Instability of the fingers and decreased strength of the muscles of the thumb may affect the ability of children with Down Syndrome to hold, rotate and translate objects necessary in manipulation.

Function of the hand however relies on more than just the anatomical structures mentioned. Good hand skills are dependent on arm movement and stability, vision, sensation, motor planning and organisation to achieve function.

Inability to adapt grip forces to accommodate changes in the friction of object surfaces is related to poor sensory processing. People with Down Syndrome often have thick, dry that becomes rough with increasing age, therefore inhibiting the sensation of light touch in the fingers. The quality of touch discrimination will determine how effectively the child grasps and releases objects.

Children need to be encouraged to hold and explore toys with their hands to increase their understanding of their environment. The hands are also needed to bring toys to the mouth, which aids early and crucial exploration of their world and helps develop oral motor skills. The ability to engage in playful interaction using the hands is an important part of social development and understanding yourself in relation to other people and your environment.

Activities to improve overall muscle tone and shoulder stability as well as eye-hand coordination are important to include in play. Eye-hand coordination tasks should start with large objects and progress down to those that require increased precision. Objects that provide varied tactile (touch) input should be included, i.e. objects of different size, shape, texture, weight, temperature.

As your child moves from nursery into reception there are many activity ideas you can incorporate into home and school routines that will help maximise your child's hand skills.

Activities to Develop Postural Stability

1. 'Animal walks' incorporating walking on hands and knees.
2. Push-pull games such as 'row-row-row your boat'.
3. Wall push-ups – see if the child can 'push the wall down' (with straight arms).
4. Pushing heavy objects such as furniture around the room.
5. Pushing objects in a toy trolley or a pram.
6. Putting books up on a shelf.
7. Carrying heavy objects where safe, e.g. shopping bags, library books, etc.
8. Working on a vertical surface, e.g. painting at an easel or tape paper to a wall surface for colouring and pasting activities.

9. Working on a vertical surface, e.g. painting at an easel or tape paper to a wall surface for colouring and pasting activities.
10. Playing with magnets on the fridge.
11. Playing with stickers on a large mirror.
12. Encourage child to wipe vertical surfaces – windows or blackboard.
13. Hanging/climbing on playground apparatus.
14. Jumping games.

Activities to Develop Hand Strength

1. Use Playdoh or plasticine activities; encourage the child to squeeze the 'dough' in their hand and roll and pinch it into different shapes.
2. Encourage the use of a sponge in the bath, or water play to squeeze.
3. Squeeze soft balls such as juggling balls or rolled-up socks in the hands.
4. Let the child try opening containers with screw on lids.
5. Wringing out sponges or cloths.
6. Push and pull games such as Lego/Duplo blocks, pop beads, stickle bricks.
7. Scrunching up paper into balls to throw at the target.
8. Folding heavy paper or card into different shapes.
9. Squeezing glue pens.
10. Trigger toys such as water pistols, plant sprayers.
11. Wind-up toys that provide resistance.
12. Push button toys.
13. Playing the keyboard/toy piano/organ.

Activities to promote bilateral integration (using both hands together)

1. Nursery rhymes that have hand actions.
2. Ball games.
3. Threading.
4. Cutting and pasting.
5. Cooking / baking tasks – mixing ingredients.
6. Simple sewing cards.
7. Hole punching.
8. Playing musical instruments that require two hands, e.g. drum, tambourine.
9. Posting objects into containers /shape sorters.
10. Taking lids on / off containers.
11. Water play – pouring and filling containers.
12. Practicing dressing self or dolls.
13. Finger puppets.

Activities to Develop Pincer Grasp

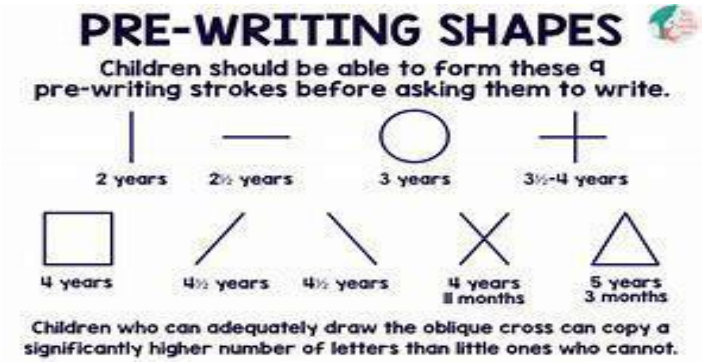
1. Use an eye dropper with coloured water to make pictures.
2. Pinch along a length of Playdoh with thumb and index finger.
3. Picking up small objects such as beads, cotton wool, coins, small sweets, raisins – show your child which fingers to use and help them achieve this.
4. Threading activities.
5. Tearing paper into strips.
6. Squeeze open clothes pegs and place on container.
7. Peg boards.
8. Fuzzy felts.
9. Play with pick-up sticks, toothpicks, straws
10. Bending pipe cleaners.

Activities to Promote Sensory Awareness

1. Identifying objects in a bag or pocket without looking.
2. Messy play with finger paint, shaving foam, sand, clay, lentils, etc.
3. Hide toys in a box of foam or dried lentils / pasta and ask the child to try and find them.
4. Cooking / baking activities using hands to mix ingredients.
5. Make collages using various textures, e.g. wool, pasta, seeds, leaves.
6. Play games blindfolded or with eyes closed, e.g. identify or find body parts using hands – nose, ears, eyebrows, fingernails on another person.
7. Explore fabric books that have different textured pictures.
8. Vibrating pull string toys and bouncing toys provide strong input to the muscles and joints, as well as the skin.

Prewriting Activities

In order to hold a pencil in a tripod grasp, the child will need to have acquired a pincer grasp as well as the ability to stabilise the thumb and fingers against the pencil whilst the hand moves across the page. This is a very complex task that requires a high level of eye-hand coordination and is affected by many factors such as cognitive abilities, attention, posture, muscle tone and sensory processing. Before a child can learn to write letters, there are several stages in perceiving, copying and forming shapes that need to be mastered. There are activities you can do to help your child with writing / drawing tasks.



1. To help your child assume a correct pencil grasp, physically position their fingers on the pencil and gently hold them while you draw. Encourage the child to look at how you are holding your pencil and try to copy.
2. Use large barrel pencils or markers as these are easier to hold.
3. Use rubber grippers on pencils if your child's fingers often slip.
4. Try tracing over lines or shapes with markers or just using fingers. Simultaneously, describe the direction you are moving, e.g. 'up, down and around'.
5. Draw shapes in sand, paint and shaving foam to add strong visual and tactile input using fingers or tools.
6. Make stencils out of cardboard and have the child draw around them to make pictures. Stock Blu-tac underneath so they don't slip.
7. Draw between lines to help learn concepts of up, down, left, right and diagonals. Start with wide spaces and narrow the channel as pencil control improves.
8. Make shapes with Playdoh. Later, progress on to letters.
9. Dot-to-dot activities – use a star to indicate the start point and directionality.
10. Work on large surfaces so the whole arm and body 'feels' the direction of movement required to make a shape.
11. Work on a vertical surface to encourage wrist extension and to develop strength of the arches of the hand.
12. When learning a new concept, combine verbal instructions with an actual demonstration and 'hands-on' approach to maximise information intake.
13. Before a child can form letters, they need to have mastered some prewriting forms. These are horizontal lines (=), vertical lines (II), circles (O), squares (□), crosses (+), diagonal lines (/ \) and oblique crosses (X). These forms incorporate all the pencil movements required to form letters correctly. Many children find it difficult to learn diagonals so try using different media to reinforce the direction of movement.
14. Try simple mazes which incorporate different actions, angled, diagonal and curved pathways.
15. Colour changing pens are often motivational to get children to trace over shapes or letters and provide a visual reward for correct responses.

E.g. of an individual Occupational therapy plan for a school age child and Recommendations

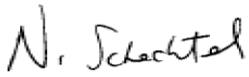
1. Hand strength and endurance –Muscle strength of the hands and fingers increases as children grow and participate in everyday activities. Activities such as climbing, playing with toys or scribbling with crayons all help to develop and strengthen the muscles of the hands and fingers. Hand and finger strength is important as it is required for many everyday activities such as doing up buttons and zips, climbing monkey bars or cutting up a piece of steak at mealtimes. It also helps to develop the endurance to complete activities such as writing a full page. Grip strength refers to whole hand strength. Pinch strength involves the thumb and index finger (and the middle finger if required). See the link below for activities to promote the strength and endurance for a firmer, more consistent grasp of the pencil. These activities should be completed 3-5 times per week, for 5-10 minutes to see functional changes occur in the short term. **https://www.rch.org.au/uploadedFiles/Main/Content/ot/InfoSheet_E.pdf**
2. Facilitate a more mature pencil grasp – the above strengthening program will help with this but also using smaller, broken crayons, placing small items in an ice cube tray with your 'pinching' fingers (thumb and forefinger), scrunching tissue paper with fingertips, popping bubble wrap, putting coins in a piggy bank and using connector blocks develops the ability to isolate the thumb and forefinger for a mature pencil grasp.
3. Practice pre-writing patterns - this can be done when drawing or playing with crayons. It is important to ensure that all vertical lines start at the top and finish at the bottom, horizontal lines start at the left and finish on the right and circles start at the top and travel anti-clockwise. These basic patterns will help lay the foundation for the directionality of future writing.
4. Easi-loop or Spring-loaded scissors – these help to introduce cutting skills. These particular scissors reduce the demands of opening and closing the scissors repeatedly, which can be challenging if hand strength is lower. These can be found at: https://www.amazon.co.uk/HAKACC-Children-Preschool-Pre-School-Child-Safe/dp/B074MXSKRF/ref=sr_1_2_sspa?keywords=childrens+scissors&qid=1557399030&s=gateway&sr=8-2-spons&psc=1

5. Cutting technique – Start out beginning to learn to open and close the scissors to make snips on paper and using the helper hand to hold the paper whilst trying to make the snips.
6. Seated position – when seated at the table, try to adopt an ideal seated posture to prevent postural fatigue which can impact attention, focus and stability for fine motor activities (e.g. handwriting). Aim to sit upright, with feet flat on the floor and hips, knees and elbows all at 90 degrees. Shoulders shoulder be relaxed and forearms supported on the table (not hovering in the air).
7. Pencil grip – a pencil grip can help support finger placement on the pencil (e.g. reducing thumb wrapping around the pencil) for a more functional pencil grasp, reducing potential pain/fatigue when writing. The following pencil grips could be really beneficial:

https://www.amazon.co.uk/Pathways-Learning-GGH03-Grotto-Grips/dp/B000NNM3HM/ref=asc_df_B000NNM3HM/?tag=googshopuk-21&linkCode=df0&hvadid=207965462628&hvpos=1o1&hvnetw=g&hvrand=291812489013184905&hvpone=&hvptwo=&hvqmt=&hvdev=c&hvdvcmdl=&hvlocint=&hvlocphy=9044936&hvtargid=pla-349290587000&psc=1

8. Caring cutlery: it is recommended to utilise Caring Cutlery to promote independent use of utensils when eating. This is available to purchase at http://www.completecareshop.co.uk/categories-disability-aids/29/caring_cutlery_range.html or at Amazon.

Occupational Therapy Input:
Please note: In order to maximise the effectiveness of Occupational Therapy advice and recommendations within the educational environment, all school visits for children by OT must be attended by a designated Teacher or Education Support Assistant who is familiar with the child. In this way, the Occupational Therapist will be able to share information and work as a part of the team to support the child at school. Occupational Therapy would not work in isolation with children unless specifically indicated.



Nicola Schechtel, **Children and Young People's Occupational Therapist** (CYPOT)

Other useful resources:

- www.royalfree.nhs.uk/services/services-a-z/occupational-therapy-services-for-children-and-young-people/
- https://www.facebook.com/groups/helpingkidswrite
- **Video on sensory processing & auditory processing: on the Positive about Down Syndrome (PODS) facebook group:** "An overview about sensory processing and info around sound sensitivity, covering the following topics: The Ear, ENT & DS, Sensory Processing, Auditory Processing and Strategies to help."

  https://www.facebook.com/DSUKPADSPods/videos/361724548525065
- https://ot4kids.thinkific.com/ Private online courses for parents and teachers to learn the Sensory and Motor Fundamentals to improve children's pencil control through easy, fun activities. Courses aim to help parents and teachers be clear and confident where their child needs to start and how to begin developing their pencil control to write. Examples are the 5-part online mini-series informing families about sensory processing, core stability and fine motor skills and treatment activities and the 4-week program where the OT goes through different activities in a progress pathway, with weekly live Q and As to support parents directly and access to a private facebook group for the families on the course to get support, designed for preschoolers and children getting ready for reception.

B) Disabled Children's Occupational Therapy Team (Social care occupational therapy services)

Contact: Multi Agency Safeguarding Hub (MASH), Tel: 020 8359 4066. Email: mash@barnet.gov.uk We provide a community-based assessment service to children and young people under 18 years of age who have permanent and substantial needs (or such needs that are likely to continue beyond 12 months) arising from their disability. We provide these services through our 0-25 Disability Service Children's Occupational Therapy Team:

- advice on managing difficulties caused by disability or loss of ability
- advice to assist carers in the daily management of a child/young person
- advice on moving and handling at home
- equipment to help with daily living and personal care, such as bathing and using the toilet
- minor adaptations to the home, e.g. grab rails, stair rails and ramps
- major adaptations such as lifts, bathrooms and showers
- recommend re-housing if the current property is unsuitable and cannot be adapted

How we do this

- we will visit the child at home to carry out an assessment of needs
- during the assessment identify what the child/young person and family want to be able to do in their daily activities
- we aim to build up a good relationship with the child/young person and family, to work with the child/young person to problem solve and make a plan of action
- a copy of the assessment is provided with an opportunity for feedback from child/young person and the family

How is a child referred to us - A young person / parent can self-refer to the team or ask their health professional or social worker to do so on their behalf. Priority is given to those children with the highest degree of need.

https://www.barnet.gov.uk/children-and-families/keeping-children-safe/worried-about-safety-child

Is there a charge for services? The assessment and minor adaptations are free of charge. Any equipment provided will be on a long-term loan, normally also free of charge.

- if you own your own property or are a private tenant - you may qualify for a Disability Facilities Grant to fund the work
- if you live in council properties - the council will arrange for the adaptations. You do not need to be financially assessed
- if you live in a Housing Association property - the Housing Association will pay for the adaptation or they can apply for a Disabled Facilities Grant.

Barnet Care and Repair Agency can offer assistance in applying for available grants or other funding to pay for the work, including loans or equity release - see contact details.

Who else do we work with? The Occupational Therapy team work in partnership with a range of health professionals including social workers, Adult Occupational Therapy and Transition Services, Housing and Environmental Health Officers.

Appendix 29 – School nursing referral information

Our school nursing teams require the following information to accept a referral:

- patient name
- patient address
- patient contact details
- patient date of birth
- GP details
- name of the school they attend
- details of any relevant health issues

Referrals to the school nursing service are usually made directly to the school nursing team attached to the school.

Contacting the Barnet team

South School Nursing Team
Oak Lane Clinic
Oak Lane
East Finchley
N2 8LT

West School Nurse team (Mill Hill Clinic)
School Nursing Team
Millway Medical Practice
Hartley Avenue
London
NW7 2HX

Phone: 020 8959 0888

North School Nurse Team (Vale Drive Clinic)
North School Nursing Team
Vale Drive Clinic
Vale Drive
Barnet
Hertfordshire
EN5 2ED

Phone: 020 8447 3500

Appendix 30: Fluid and food thickeners - information

Letter providing information about the new IDDSI (International Dysphagia Diet Standardisation Initiative) guidelines and how this relates to thickening fluids.

The resources are freely available to download or print at (https://iddsi.org/resources/ under consumer resources paediatrics) with a helpful information sheet of suitable foods for each 'stage' and foods to avoid.

If a parent appears unsure or confused in any way about the food their child should be eating or thickness of drinks please contact us to arrange a face to face review. Often around weaning, parents will need more intensive support and it may be a slower process, with thickeners for clear fluids for example or bottled milk and also with medications, this can be less convenient and need additional support.

In may be that the child has been discharged by the paediatric dysphagia team but remains on thickeners for their fluids – it is always worth reviewing the long term need for these at the annual reviews and referring back for a review by the team, after discussion with parents and the school.

It is important that schools understand what the thickeners are achieving and reasons behind their recommendation, how to make up the feeds and have it documented in the ***child's school health plan.***

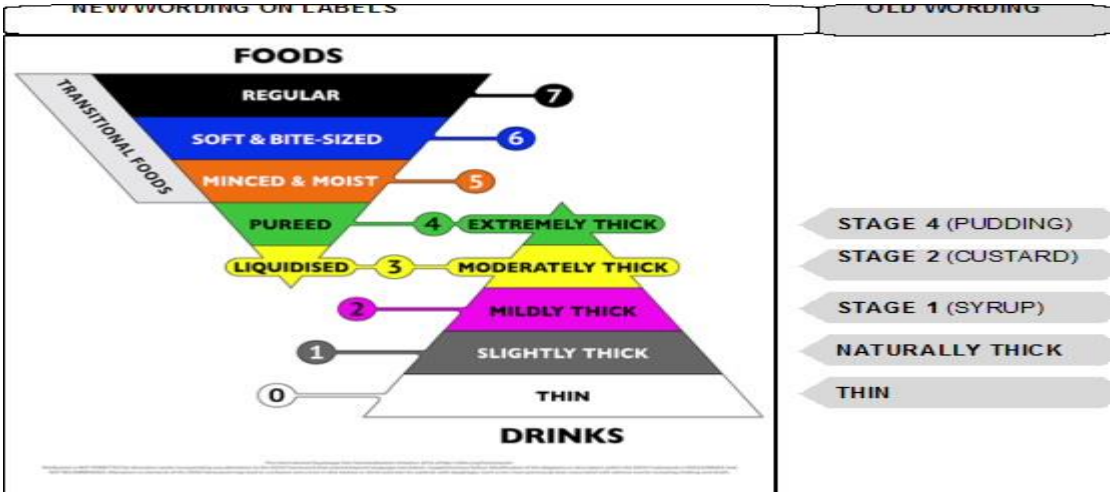
Children's Integrated Therapies
Edgware Community Hospital
3rd Floor, Westgate House
Burnt Oak Broadway
Edgware
HA8 0AD
Contact: 0300 300 1821
Email :nem-tr.barnetCIT@nhs.net

Dear Parent / Carer / Staff member

RE: Change in descriptors for thickening products

We are writing to you to alert you to the imminent change in the way the thickening products on the market will be describing different consistencies from April 2019. You may or may not already be aware of this.
As part of an international roll-out, the terms used to describe the level that your child has his/her thickened drinks will be changing. You will mainly notice these changes on your child's written reports and possibly the instructions on the thickener product that you use. However, **this will not change** what you are currently doing, unless otherwise advised by your child's Speech and Language Therapist (SLT).

Please see diagram below to aid your understanding of how this will change:



The measurements for the thickener you currently use will **remain the same** as you have discussed and agreed upon with your SLT. Please note: some manufacturers may have changed their packaging to reflect these changes already.

We hope this is clear. If you have any questions or concerns about this, please contact your local SLT who will be happy to discuss this more with you.

Kind regards,
The NELFT SLT Paediatric Dysphagia team.

Appendix 31: Education:

Educational support, training and information

Down Syndrome Training (Barnet) – run by Sarah Geiger (Educational Psychologist) and Pre-school Teaching Team Down Syndrome advisor (PsTT) and open to teachers/nursery staff and parents. (***See Barnet Local Offer*** for more dates/information). Well worth going – simple and practical ways to support children within the classroom, to maximise their learning. These days are absolutely vital for anyone in the Education setting and for parents.

Only a few examples of what you can learn:

a) Behaviour: a range of strategies for avoidance behaviour, appealing alternative to misbehaviour, understanding the amount of concentration needed for a task and what is manageable, use visuals to depict the school rules, give the child or young person a job in the class to help.

b) How to support reading for language and more: focus on reading is important because children with DS learn to read words before saying them, so unlike other children in the class they need a "whole word" approach to build up meaningful sight vocabulary by being taught to read whole words. Of course, children can learn the basic understanding of phonics to support later reading development but the main teaching focus needs to focus on building up the child's sight vocabulary. Reading then develops articulation, understanding of grammar and sentence structure, to name a few skills.

c)

d) Visual support: one simple example could be to use Big Pens and Bold Lines (www.downs-syndrome.org.uk/about/campaigns/vision/visual-acuity-thing-big-think-bold/). On the workbooks to support all children with Down Syndrome who often have subtle visual impairment issues even if they do not wear glasses, also ways to encourage independence, consider where they sit in class and so on.

Email sarah.geiger@barnet.gov.uk if you (or your school) would like to be on the mailing list

Downs Syndrome Levels of Expertise written by Barnet Down Syndrome Leading Edge group

The levels of expertise are a concise summary of what schools can do to support children and young people. They present three levels that schools can use for checking their offer and planning next steps. Bronze is level one and details standards of practice for schools to make sure they have a good offer for their pupils with Down Syndrome. Level two, silver, outlines a more developed offer of support and expertise. Gold, level three, outlines excellent practice for children and young people with Down Syndrome

These levels provides an ongoing Education Framework to support children and young people with Down Syndrome in primary and secondary schools. The document outlines the best practice for schools in supporting children and young people with Down Syndrome.

It focuses on:

- Planning,
- Curriculum,
- Social, emotional and behaviour needs,
- Personal support needs
- Transition/Activities

Here's the link to our document:

https://5f2fe3253cd1dfa0d089-bf8b2cdb6a1dc2999fecbc372702016c.ssl.cf3.rackcdn.com/uploads/ckeditor/attachments/4256/Levels_of_Expertise_July_review_2018_FINAL_LO_version.pdf

Schudio TV – What is Down's Syndrome? This short, video-based online free course provides an introduction to Down's Syndrome and dispels some of the most popular myths. https://www.schudio.tv/collections

"We created SchudioTV to provide teachers, school leaders and staff easy, affordable access to a range of high-quality, inspirational online courses. The journey started when our youngest son started school. Arran has Down's Syndrome and his school couldn't access the training they needed to support his education simply because they couldn't afford it. I'd love to quickly tell you the full story!" Our aim is for you to access the training you need without it costing the earth and, wherever possible for free.

DSEI – Down Syndrome Education International

(also affiliated to Down Syndrome Education International, Down Syndrome Education USA and Down Syndrome Education Enterprises CIC)

It aims to help children from infancy to adulthood improve outcome. It has strategies to help speech development, reading, language, maths and has advice for health issues that affect cognitive outcome; focusing on improving early intervention and education. Started in 1987 by Professor Sue Buckley OBE who is one of the world's leading researchers in the education and development of children with Down Syndrome.

https://www.dseinternational.org/en-gb/ *An international charity that supports scientific research and delivers evidence-based advice and information to improve outcomes for children with Down Syndrome worldwide. Facebook and Twitter groups too. Research, resources and training and consulting services to offer parents and professionals expert, evidence-based advice and guidance on early intervention and education for children with Down Syndrome. Also provide accessible* ***online training*** *and support.* *hello@dseenterprises.org*

There are online resources and teaching materials offering detailed information and practical guidance for parents and professionals. This charity also offers advice and online training courses and consulting and training services offering expert guidance and support to parents, therapists and teachers worldwide.

E.g. of Resources: See and Learn Speech, See and Learn Language and Reading, See and Learn Numbers, A reading and language intervention for children with Down Syndrome (RLI), Down Syndrome Issues and Information, videos. (www.down-syndrome.org/en-us/resources/

Reading:

Children and young people with Down syndrome often they learn to read before they learn to speak or to write, reading makes language visible. This can used so it can be hugely supportive and confidence building, with the right support and experience from teachers, families and others. Reading is often a huge focus in class, and for a child with Down Syndrome this can be hugely beneficial.

We recommend:

1. See and Learn https://www.seeandlearn.org/en-gb/
2. A Reading and Language Intervention for Children with Down Syndrome (RLI)

The Reading and Language Intervention for Children with Down Syndrome (RLI) is a teaching programme designed to improve reading and language outcomes for children with Down syndrome. It supplements and supports regular teaching with daily one-to-one intervention sessions. The intervention sessions follow a consistent format within which instruction is carefully targeted to the individual student. https://www.down-syndrome.org/en-gb/resources/teaching/rli/

Maths for Life
https://www.themathsmum.co.uk/maths-and-down-syndrome
The Maths Mum® talks about maths and Down Syndrome.

Why is it important for someone with DS to learn maths? Children and adults with Down Syndrome need to understand maths to be able to live an independent life. They need to be able to deal with money, time, weights and measures and do simple calculations. Technology today can support them, like the rest of us, but a calculator is only useful if you know how to use it and can gauge if the answer it gives is sensible.

What are the key challenges? The way maths is traditionally taught in schools weighs heavily on the use of memory… short term, long term and working memory. We know that Down Syndrome is typically associated with a poor short term memory and therefore we need to adapt and develop new ways to teach our children to compensate for this. We know that visual memory is a strength and it is essential that we capitalise on this and use visual maths aids to support learning. We know that our children are achieving more and more and, with today's early intervention, they have the potential to keep pushing the boundaries. And as The Maths Mum® I have a professional and personal reason to help this to happen.

When should I start teaching maths to my child? From birth! Honestly, maths should be an integrated part of life from the beginning. From the singing of nursery rhymes such as "One, two, three, four, five… once I caught a fish alive" to counting fingers and toes, from the learning 'more' as your first Makaton sign to understanding more and less. Mathematical words like big, small, slow, fast, tall, short as well as colours and shapes all form part of the pre-number skills needed in maths. It is never too young to start introducing these words and concepts… Would you like the big car or the small car? Which one is the red block? Modelling with things that you find in the toy box and around the house. Maths is based on the ability to be able to tell what is 'the same' and what is 'different' so it is always useful to point out things that are the same and things that are different starting with obvious differences such as colour and size but then looking at more subtle differences like spotty socks versus stripy socks.

https://www.themathsmum.co.uk/overview-of-key-stages and https://www.themathsmum.co.uk/options-for-help
https://www.themathsmum.co.uk/free-downloads
email: contact@themathsmum.co.uk

Educational professionals that can be accessed to support students and families:

Educational Psychology in Barnet: Barnet Education and Learning Service
2 Bristol Avenue, Colindale, London, NW9 4EW.

The Barnet educational psychology team provides psychological services to children and young people aged 2 to 25, their families and the people who work with them. Educational psychologists (EPs) work in a range of education and care contexts. The team values early intervention and prevention.

Our EPs can be used for a range of work including assessment, promoting psychological well-being, inclusion and raising standards across the full range of age and abilities.

EPs support schools and educational settings to provide effective identification of Special Educational Needs (SEN), implement appropriate SEN support and deliver high quality provision to meet the diverse range of needs that make up the school or community setting.

Inclusion Advisory Team (used to be called High Incidence Support Team (HIST)) – includes specialists with a range of experience and expertise in SEN and inclusion covering early years and all Key Stages. IAT provides specialist support from advisory teachers and experienced SEN professionals and consists of Advisory Teachers for: Speech, Language and Communication Needs (SLCN), Social, Emotional and Mental Health Needs (SEMH), Literacy Difficulties. They offer advice on identification and assessment, advice and training on strategies and interventions, strategic and systemic support relevant to the area of need, staff coaching, bespoke and evidence based training. Also provide Advisory Teachers for whole school SEND reviews, assistance with policy development and guidelines, support in developing your SEND systems and procedures, support to new SENCOs.
www.barnetwithcambridge.co.uk/send-and-inclusion/inclusion-advisory-team
Also the Barnet Educational Psychology and SEMH team has developed a school coping with anxiety pack and information for schools for children who may become anxious about an aspect of school life, which may become overwhelming and sometimes that anxiety can generalise to other aspects of school life.

Peripatetic Teachers – specialist teams for Visual, Hearing or multi-sensory Impairment:
These specialised qualified teachers support any child or young people with a significant visual (not correctable with glasses) or hearing impairment (any diagnosed hearing loss). They offer guidance, advice and support to schools and families in order to maximise opportunities for learning and inclusion so that children and young people with a sensory impairment can reach their potential. Barnet also has a Multi-Sensory Impairment Specialist Teacher who works closely with children with both a hearing and visual impairment to support them and their families.
Barnet also has some specialist nurseries for preschool children with complex needs i.e. Acorn Assessment Centre in Colindale School and also at Oakleigh School, Kingfisher ASD (autism) provision at Livingstone Primary school, Summerside Hearing Impairment Nursery, (Specialist Team, Education and Skills, specialist.team@barnet.gov.uk and tel: 020 83597624).
There are two main primary Special schools (Northway and Oakleigh) and two main secondary specialist schools (Mapledown and Oak Lodge).

SENCOs (special educational needs coordinators)– Area SENCOs for pre-school children in a non-school based nursery. School SENCOs in every Barnet school. SENCOs can access the SENCO zone.

Appendix 31b

Which type of school is best for children and young people with Down Syndrome?

The Barnet Leading Edge Group for Children and Young People with Down Syndrome have produced the "What school?" paper below, which can also be downloaded here: **https://5f2fe3253cd1dfa0d089-bf8b2cdb6a1dc2999fecbc372702016c.ssl.cf3.rackcdn.com/uploads/ckeditor/attachments/5855/What_school_for_Children_and_Young_People_with_Down_Syndrome.pdf**

What is the purpose of this Information?

This document gives information about school placements for children and young people with Down Syndrome. We have summarised the available research to help inform parents and professionals. We believe every family has the right to decide what type of school is right for their child. It can be hard for parents to weigh up the challenges and opportunities experienced, and to decide between mainstream and special needs schools. Parents may, or may not, find our information about research useful. They need to think about their own child and what an educational setting may offer. It is important that professionals in schools and the Local Authority are aware of research about school type so that they can provide advice and make informed choices. We want our families, and our schools of all types, to have information so that they can best support their children and young people with Down Syndrome.

Which type of school is best for children and young people with Down Syndrome?

There is a lot of research about the best school type for children and young people with Down Syndrome; some is of good quality and some is no better than offering an opinion. In 2012, de Graaf, van Hove and Haveman set out to look at studies published over a 40-year period and written in many languages. They looked very carefully at the quality of the research and found 133 relevant studies. The results of their systematic review was that mainstream classroom placement resulted in the better development of language and other academic skills. This happened even after they took account of the effects of selective placement. Children and young people in special needs schools did not have better self-help skills. There were no significant differences for behaviour and self-competence. In the UK, Buckley, Bird and Archer (2006) looked at children and young people aged from five years old through secondary school. Their research compared the same group of children over their school life. The children and young people had been matched for cognitive ability, behaviour, development and socio-economic factors, so the comparison of progress between the children and young people in mainstream and special settings was a fair one. The language and other academic benefits of mainstream placement were greater than expected. The gains for the included teenagers were in expressive language, literacy and, to a smaller extent, numeracy and general academic attainments. The average progress gain for expressive language was 2 years and 6 months; and for literacy, 3 years and 4 months. These age-related scores are based on norms for typically developing children who are expected to progress 12 months in the measures during a school year. This means that the teenagers in mainstream school gained the equivalent of 5-6 years more progress than expected in spoken language and in literacy when compared with the teenagers educated in special classrooms. The published research is plentiful and clearly concludes that, as a group, our children's academic, language and social progress is enhanced in a mainstream environment. This is not a criticism of the special school offer; it seems the benefit is due to our children's response to the children they are learning alongside.

There are some helpful resources for families. For example Contact https://www.contact.org.uk/advice-and-support/education-learning/admissionsand-school-choice/finding-the-right-school/, the Down's Syndrome Association https://www.downs-syndrome.org.uk/for-families-and-carers/education/ and Down Syndrome Education International https://library.down-syndrome.org/en-gb/news-update/02/2/supporting-social-inclusion-students-down-syndromemainstream-education/

Is the research quality good?

The methods and participant size of published educational research contrasts with medical trials and research. Randomised research control trials are much less frequent for education studies and use of effect sizes are limited to systematic review and meta-analyses. The research is clear and coherent, and there is very little conflicting research. Children and young people with Down Syndrome are not all the same, however research shows that most children with Down Syndrome are likely to benefit from going to school with their typically developing peers. We recommend schools that educate our children alongside typically developing children, this is more likely to happen in a mainstream environment. We are not criticising special-needs schools, or parents who choose a special needs school for their child. We really value our special needs schools in Barnet. We are grateful for the support they provide to our community and the Leading Edge group. The advantage that mainstream schools have is that they can offer a learning environment that includes typically developing peers, this has been found to be particularly supportive for children and young people with Down Syndrome. It supports the development of academic skills including reading, language and socially appropriate behaviour. The research shows that being educated with typically developing children is important for our children's progress.

Are there any cautions about mainstream?

De Graaf, van Hove, and Haveman (2012) found that many studies reported that placement in a mainstream setting was not enough, there needs to be support and modelling for interactions between children. This is because many children with Down Syndrome respond more to social initiation than to initiating social contact themselves. It was found that children with Down Syndrome were generally well accepted by their peers. Not all mainstream schools offer most of our children's education to be spent alongside their typically developing peers. The Buckley research showed that children and young people need friends who are typically developing and also friends with similar needs to themselves. In the same way, special schools need to have ways for their children to interact with typically developing children. In both types of setting opportunities for the development of intimate best friendships needs to be organised in and outside school. When first approached some mainstream schools may be preoccupied by the syndrome rather than the child and may be daunted by their own lack of experience or support. Most schools begin to see past that, to the child and their needs. The breakdown of a placement in one mainstream setting does not mean that another mainstream school won't be able to meet the child's needs. Parents of secondary age pupils will want to know how secondary schools support their pupils in year 9 and onwards. Inclusion in GCSEs, entry-level qualifications, vocational options, and work-experience is important. Secondary schools also vary in what they offer their pupils from age 16+. Some schools offer only A levels while others offer other certificates. Choice of courses has led to the growth of 16+ departments in our local special school and nationally.

Is mainstream school only better for abler children and young people with Down Syndrome?

In 2007, Buckley, Bird and Sacks described how education could change the developmental profile of our children and young people with Down Syndrome. Cognitive ability can influence the outcome of a school placement, and de Graaf, van Hove, and Haveman (2013) carefully analysed this in their review of placement and progress in the Netherlands. De Graaf found that children and young people with severe learning difficulties (IQs assessed as 35-50) in mainstream schools made more academic progress than those in special schools who had more moderate difficulties (IQs assessed as 50+). When change was measured they found that a child's cognitive ability was influenced by school experience.

What about the other children and young people in mainstream classes?

Research shows that the whole school often benefits from including students with disabilities. Some pupils in every classroom will benefit from strategies developed to meet the learning needs of a pupil with Down Syndrome. Best outcomes are achieved when appropriate support is provided to teachers to fully include the pupil in the class. A whole cohort of children will grow up knowing at least one person with a disability. Research, such as a meta-analysis of research studies by Armstrong in 2017, shows that that direct and extended positive contact is one of the key factors in reducing disability hate crime. Leigers (2015) found that pupils needed practical information to

support non-disabled peers' communication and work with peers with disabilities and that presenting only factual information could have negative results.

What about the gap between the learning of children and young people with Down syndrome and typically developing children?

The gap in skills and learning between children with Down Syndrome and their typically developing peers will grow with age. Children with Down Syndrome usually progress about 4-5 months in a year; they make progress but at a slower rate than typically developing children. By secondary school, the gap may be quite significant. But this gap is because of developmental differences, and it is not a reason, in itself, to choose a special school placement. The gap is always there and it makes considerable demands on planning for the school. People with Down Syndrome do not plateau or stop learning new skills in their teenage or adult years. They will continue to make steady progress and continue learning throughout their lives if given the opportunity to do so. Many students with Down Syndrome reach the end of Year 11 and go on to postschool training or college. Work experience is very important in helping young people with Down syndrome to make choices about their life after school. Young people with Down syndrome face greater challenges in leaving school and making the transition to adult life than their peers, and more planning is likely to be needed than for other young people.

What happens if I want my child to go to a special school?

Choosing between mainstream and special school can feel like one of the biggest decisions a parent may face. They may make this decision because of the quality of the special needs school offer, because they feel their child's needs cannot be met in the mainstream environment, or because they have had difficult experiences in a mainstream setting. Many parents experience difficulties and heartache about their children's school placement, we are not telling parents what to choose or criticizing choices made. The research summarised within this document can be used to help parents and professionals to support their child, irrespective of the educational setting.

Summary

Children are not defined by their Down Syndrome, and a school that focuses on their strengths, needs and development will help them progress. Our children have complex needs and schools need support and training to know how best to support them. The Barnet Leading Edge Group for children and young people with Down syndrome has written a Levels of Expertise guidance document that summarises the key ways for schools of all types to support our children and young people it is available on the Barnet Local Offer. Our recommendation is that a child or young person should be given every opportunity to be educated alongside their typically developing peers unless there are clear reasons why this is not in the child's best interests.

Research References

Armstrong, M., Morris, C., Abraham, C., & Tarrant, M. (2017). Interventions utilising contact with people with disabilities to improve children's attitudes towards disability: A systematic review and meta-analysis. Disability and Health Journal, 10(1), 11-22. Buckley S.J., Bird G., Sacks B., Archer T. (2006).

A comparison of mainstream and special education for teenagers with Down syndrome: Implications for parents and teachers. Down Syndrome Research and Practice. 9(3), 54-67. Buckley, S., Bird, G., Sacks, B. & Archer, T. (2007).

Mainstream or special education for teenagers with Down syndrome. In Jean-Adolphe Rondal & Alberto RasoreQuartino (Eds.). Therapies and Rehabilitation in Down Syndrome. Chichester: Wiley. Dolva, A., Gustavsson, A., Borell, L. & Hemmingsson, H. (2011).

Facilitating peer interaction - support to children with Down syndrome in mainstream schools. European Journal of Special Needs Education, 26, 2, 201-213. Carr, J. (2012).

Six weeks to 45 years: A longitudinal study of a population with Down syndrome. Journal of Applied Research in Intellectual Disabilities, 25, 414- 422. Efthymiou, E. & Kington, A. (2017).

The development of inclusive learning relationships in mainstream settings: a multimodal perspective. Cogent Education, 4, 1-22. Graaf, G. De, Hove, G. Van, and Haveman, M. (2012)

Effects of regular versus special school placement on students with Down syndrome: a systematic review of studies. In A. van den Bosch & E Dubois (Eds.) New Developments in Down Syndrome Research. Nova Science Publishers. Graaf, G. De, Hove, G. Van, and Haveman, M. (2013).

More Academics in Regular Schools? The Effect of Regular Versus Special School Placement on Academic Skills in Dutch Primary School Students with Down Syndrome. Journal of Intellectual Disability Research, 57, 23-28. Leigers, K. L., & Myers, C. T. (2015).

Effect of duration of peer awareness education on attitudes toward students with disabilities: A systematic review. Journal of Occupational Therapy, Schools, & Early Intervention, 8(1), 79-96. MacMillan, M., Tarrant, M., Abraham, C., & Morris, C. (2014).

The association between children's contact with people with disabilities and their attitudes towards disability: a systematic review. Developmental Medicine and Child Neurology, 56(6), 529-546.

Appendix 32 – Learning Disabilities Directed Enhanced Services (Barnet letter to GPs - template)

Royal Free London NHS
NHS Foundation Trust

Edgware Community Hospital, Child Health HQ, Burnt Oak Broadway, Burnt Oak, Edgware HA8 0AD

Letter to GP Date:

Dear Dr

Re: Name, Date of birth, Address, NHS number, MRN Number

I am writing to begin the process of transitioning (patient's name) care to you when he/she becomes 18. As part of the Learning Disabilities Directed Enhanced Services, it is encouraged that GP led annual health checks are initiated at the age of 14. These will take place alongside my own health checks until the age of 18 to facilitate a smooth transfer of care.

I have been looking after (patients name) in the community for X number of years. He/she has Down Syndrome and attends (X) school.

His/her comorbidities include:

Medications include:

There are a number of published guidelines to help you with your annual health checks.

- https://www.rcgp.org.uk/clinical-and research/resources/toolkits/health-check-toolkit.aspx
- These also include the Royal College of General Practitioners Syndrome Specific Medical Health Check for Down Syndrome (*Resources Managing the care of adults with Down Syndrome,* Clinical Review, BMJ 2014: http://www.bmj.com/content/349/bmj.g5596)
- The Down Syndrome Association Annual Health Checks for Adults with Down Syndrome Checklist (https://www.downs-syndrome.org.uk/for-professionals/health-medical/annual-health-check-information-for-gps/).

In addition, the Down Syndrome Association has produced a health book which is given to parents of children aged 14 and over with a section of the health book specifically for GPs to complete. It is designed to make annual health checks more accessible to adults with DS, provide structure to the consultation and support effective communication. https://www.downs-syndrome.org.uk/download-package/health-book/

Please also consider referring (patient's name) to the adult learning disability partnership and consultant Psychiatrist at Barnet House for their future mental health and emotional well-being.

If you have any questions or feel that I can be of assistance in any way in facilitating (patient's name) transition to adult services please do get in touch. I'd be happy to help in any way I can.

Yours sincerely,

Dr Christine Jenkins **&** **Dr Ella Rachamim**

MB BS BSc FRCPCH FRCP DRCOG DCH MRCGP **MB BS BSc MRCPCH**

Consultant Paediatrician, Community Child Health Specialty Doctor in Community Paediatrics

Enclose: Last clinic letter

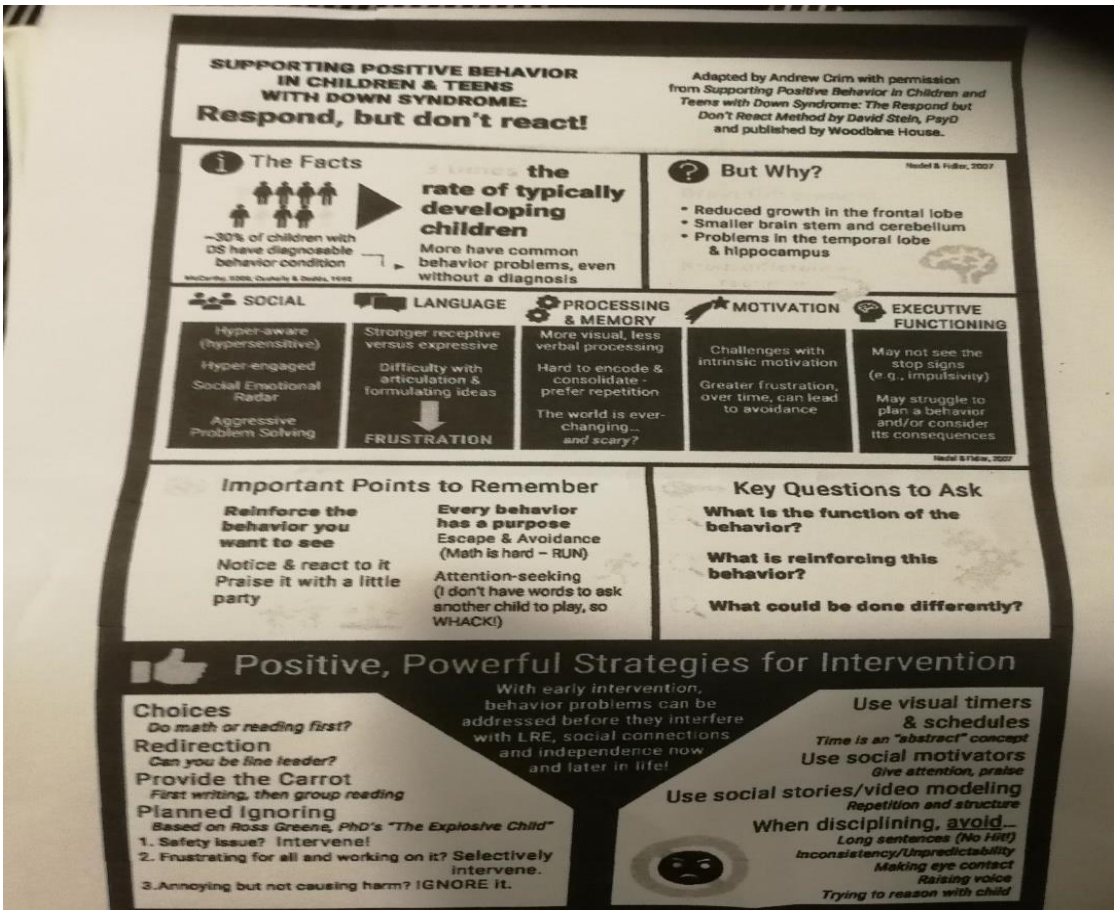
CC: Parents/carers, Young person, School nurse, School SENCO **and** others relevant to young person e.g. transitional social worker, CAMHS and so on.

Appendix 33: Managing behaviour

Here are some excellent resources to help parents and teachers to determine if the "behavioural problem" has become significant, discussing some of the common behaviour concerns, how parents and caregivers could approach behaviour issues including considering medical causes as well as situational, environmental and emotional causes:-

- www.downs-syndrome.org.uk/for-families-and-carers/supporting-behaviour-positively.
- Supporting Positive Behaviour in Children and Teens with Down Syndrome, The Respond But Don't React Method, 2016 by David Stein.
- Achieving Best Behaviour for children with Developmental Disabilities: A step-by-step workbook for Parents and Carers, Jessica Kingsley 2005.
- Down's Syndrome Association
- Barnet Local Offer page
- **Parenting Support Manuals**: There are several parenting manuals which are recommended for families to refer to and which can be purchased online via Amazon: 1**, 2, 3 Magic by Thomas Phelan**, or **The Incredible Years by Carolyn Webster Stratton**.

Supporting Behaviour Positively – Using the ABC model (Antecedents, Behaviour and Consequences) to work out triggers, accurate descriptions of the behaviour and working out what the behaviour means, and consequences of the behaviour. Work together to provide Positive Behavioural Support with a mixture of proactive and reactive strategies e.g. to diffuse undesirable behaviours and take away its power, to ignore and redirect, to respond and not react, to understand the learning strengths and challenges in this group of children and young people.



Appendix 34a: Nutritional advice and snack ideas with low sugar

From Laura Southern, nutritionist: Laura Southern DipION mBANT CNHC

www.londonfoodtherapy.com

The main thing to remember is that it's best NOT to snack! (easier said than done, I know!) - Weight control/ loss is achieved by eating just 3 meals a day, with large gaps between the meals. The time we're NOT eating is more important that what we're eating (within reason).

We understand this is difficult, especially with pester power etc. Before they hand out a snack parents need (to try) to get in the habit of asking a few questions:

1. Is my child genuinely hungry? (perhaps been a long time since last meal/ long time till next meal)

2. Will this snack provide some extra nutrients to my child's diet (i.e. increase their vitamins, protein, good fat quota etc.)

3. Has my child already had a lot of sugar/ processed food in their diet today?

4. Is my child just bored?

5. Am I using this snack to keep them quiet (we've all been there!!)

The idea really is to try and ensure that snacks provide extra nutrition that might be missing from the child's diet, rather than just as a way of giving the child 'nice' food as a treat or reward (there is time for this, but shouldn't be the habit).

There is good information out there now, more and more, for everyone to access. Things I get asked about include: how to read a label to find the hidden sugars, how to reduce and replace the sugar, and what children need for optimum nutrition, snack and meal ideas, specific nutrition for children in all their life stages, specific nutrients for children's growing brains and how certain foods can have a positive and negative effect on mood, concentration and focus.

Reducing Sugar in Your Child's Diet

Top 20 snack ideas

1. Corn thins/ corn cakes/ rice cakes with 100% peanut butter
2. Apple slices with 100% almond butter
3. Cucumber/ carrot/ red pepper sticks with hummus
4. Homemade popcorn with cinnamon
5. Mix of raw unsalted nuts (cashew nuts and pistachio nuts popular with children)
6. Strawberries/ raspberries/ Satsuma pieces dipped in melted high cocoa solids (e.g. 70%) chocolate
7. Pot of natural yoghurt with fresh fruit and/or nuts
8. 1-2 falafels with hummus
9. Packet of Itsu seaweed thins (or other seaweed crisps)
10. Bowl/pot/bag of olives
11. Slice of rye, wholemeal, pitta bread with cheese/nut butter/hummus
12. Steamed edamame beans

13. Snack box with nuts, seeds and chocolate chips
14. Babybel/cheese portion with piece of fruit
15. Mug/flask of soup (vegetable, miso, chicken)
16. Bag of lentil or tortilla chips (with hummus or mashed avocado)
17. Homemade smoothie ice cream (see recipe)
18. Homemade almond biscuits (see recipe)
19. Slice of banana and pear bread (see recipe)
20. Roasted chickpeas (see recipe)

T**op 10 breakfast ideas**

1. Cereal mix – use a base of Rude Health puffed oats and Kallo puffed rice, add toppings – e.g. nuts, pumpkin seeds, pomegranate seeds, coconut chips, few raisins, berries etc
2. Porridge, use almond butter, berries or tiny bit black strap molasses Wholemeal toast with nut butter/ cream cheese
3. Mini wholemeal pitta bread filled with hard-boiled egg/ or hummus/ tomato/ cheese etc.
4. Cereal mix with Low Sugar Cheerios or Whole Earth Cornflakes
5. Natural yoghurt with mushed up berries
6. Scrambled eggs with rye bread
7. Homemade granola (see recipe)
8. Bircher Muesli (see recipe)
9. Blueberry and almond pancakes (see recipe)
10. Slice of banana and pear loaf (see recipe) with butter

Top 10 packed lunches (cold)

Ensure ice packs/ kept out of sun/ fridge if possible

1. 2 Chicken drumsticks, pot sweetcorn, cucumber sticks, 2 oat cakes, 2 unsulphured dried apricots, pear
2. Hard-boiled egg, brown pitta bread, pot with hummus, baby corn and carrot sticks, frozen yoghurt tube
3. 1-2 salmon rissoles, 3 cold boiled new potatoes (or potato salad), pot sweetcorn, small box raisins
4. Large pot rice salad (brown rice, onions, red peppers, chickpeas, sultanas, garlic, tomato or soy sauce), plum, frozen yoghurt tube
5. Tinned tuna and cucumber sandwich (wholemeal bread/pitta), small pot/bag kale crisps, piece of cheese, Satsuma
6. Mini lamb koftes, pot of hummus, spelt wrap, cherry tomatoes, cucumber, pot of mixed berries
7. Large pot quinoa/ lentil salad (quinoa/ lentils, onions, celery, carrots,

peas, ginger, honey, soy), 2 dates, pot of mixed seeds (pumpkin, sunflower, pinenuts) and dried coconut

8. Pot of tinned salmon, cream cheese and sweetcorn mix, 2 corncakes, pot of roasted chickpeas (see recipe), frozen yoghurt tube, apple

9. 1-2 cold baked sausages, brown pitta bread, sugar snap peas, baby corn, small bag home made popcorn

10. Slice of Spanish omelette (tortilla), carrot and cucumber sticks, piece of cheese, pot of coconut pieces.

Appendix 34b – Nutrivene- D and UK perspective

Nutrivene - D

UK perspective and guidance from DSMIG (2018): Dr Jill Ellis, a paediatrician and member of the UK DSMIG, was the lead researcher in the UK on a trial to see if it works.

Here is the journal Paper:
Supplementation with antioxidants and folinic acid for children with Down Syndrome: randomised controlled trial.

Objectives To assess whether supplementation with antioxidants, folinic acid, or both improves the psychomotor and language development of children with Down Syndrome. Design Randomised controlled trial with two by two factorial design. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2267988/> and <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2267988/>

Jill Ellis talks about it on You tube:

Here is the Down's Syndrome Association statement:
Targeted Nutritional Therapy | Down's Syndrome Association<https://www.downs-syndrome.org.uk/about/where-we-stand/targeted-nutritional-therapy/>
<https://www.downs-syndrome.org.uk/about/where-we-stand/targeted-nutritional-therapy/>

So in conclusion, we do not support this treatment and do not believe it has any benefits in the short or long term, supported by our own UK based research trials.

Dr Ella Rachamim
Community paediatrician

(2018 conversation and DSMIG Winter conference)

Appendix 35: Sports, clubs, groups, days out - with access and participation

Groups for children with special needs, including sports are vital. Things change all the time so it is worth checking and doing your own research too.

Chickenshed Inclusive Theatre

Chickenshed is an inclusive theatre company based in Southgate, North London. They celebrate diversity and are fabulous for creating a range of musical, dance and theatre opportunities for children, young people and adults. These include:

* Planet Play - sensory shows aimed at babies

* Tales from the Shed - engaging shows with puppets and music for 0-7 year olds during holiday periods

* Children's and Youth Theatre - after-school inclusive drama clubs from age 5 (get on the waiting list early as possible, as it's very popular!)

See https://www.chickenshed.org.uk/

North London United is a weekly Football Club for children and young people with Down Syndrome, in partnership with the Arsenal Community Hub.

See http://www.nlunited.co.uk/

Icandance nurtures creativity, learning and wellbeing in children and young people with disabilities through dance and movement. Weekly classes in Hampstead - and an opportunity to perform at the annual show (previously at arts depot, in future at the newly restored Alexandra Palace!) See https://www.icandance.org.uk/

DSA Active offer various short-term initiatives, from BMX biking to tennis. Get on their mailing list to hear about upcoming opportunities. DS Active is a sports programme for people with Down Syndrome administered by the Down's Syndrome Association (DSA). DS Active currently have over 40 football sessions and 20 tennis programmes that run over England and Wales. All of the programmes are easily accessible and cater for ALL ages and ability. DS Active was created in response to the awareness of the sedentary lifestyles of many children and adults with Down Syndrome and the subsequent health problems including obesity, resulting from lack of exercise and participation in sport. **Phone: 0333 1212 300** Email: dsactive@downs-syndrome.org.uk Down's Syndrome Association for further resources and training.

https://www.bacdis.org.uk/policy/documents/DSActive.pdf

IPOP provides opportunities for children and young people of all abilities to play and socialise together, offering support/info to families and raising awareness of inclusive provision. Services include enabling play-workers (1:1 support to attend mainstream play/leisure activities), swimming (weekly sessions at Finchley Lido) and family activities and trips. **See https://ipopsupport.org.uk/**

(Some of these services are accessed through the short breaks scheme - there may be other things of interest there. See Barnet's local offer page for details).

Barnet Mencap run 'Open Door'- a weekly playgroup for under-fives where parents can also access support/advice with carefully considered toys and experienced staff. They also organise adhoc events e.g. soft play and drama workshops for older kids and young people. Worth subscribing to their mailing list:
email projectsupport@barnetmencap.org.uk

The Challenge Playgroup in Muswell Hill is run weekly for children with additional needs and for their siblings, parents and carers. Great toys, very welcoming and even massage on offer while your child is looked after!

Play group at St James church in New Barnet for children with additional needs (Discuss with PsTT for further details)

Unity is Norwood's recreational service for children with disabilities between the ages of 5-18. Unity offers a wide range of programmes including weekly after school clubs, play schemes during the summer, winter and spring school holidays and one residential holiday a year. Email: info@norwood.org.uk Tel: 020 8809 8809

For family days out, also worth keeping an eye out for:

* ZSL's annual 'Special Children's Days' at London Zoo and Whipsnade.

* relaxed performances at local arts centres arts depot and Jackson's Lane (both of which also occasionally commission work aimed at CYP with SEND), and the West End! - and local cinemas e.g. Phoenix in East Finchley and Picturehouse in Crouch End. These are becoming increasingly commonplace.

* SEND activities increasingly commonplace at many of London's larger museums, often free.

EVERYBODY is a new social enterprise which connects families of children with additional needs towards better cultural participation – by combining community development and creative inclusion consultancy for the cultural sector (2019), started by one of the Barnet parents.

GLL: **GLL** exists to make community services and spaces better for everyone and to improve the health and wellbeing of local communities. https://www.gll.org/b2b

It operates local leisure centres under the brand name 'Better'. It's worth checking what is available at your local Better centre. For example, in Barnet it might be the Finchley Lido leisure centre, who have launched supervised inclusive gym sessions (with an experienced fitness instructor), targeting adults (16+) with a disability.

Or contact Barnet Parent Carer Forum or Barnet MENCAP for current information:

info@barnetpcf.org.uk
T: 07468 029 705
W: BarnetPCF.org.uk
Barnet Mencap, 35 Hendon Lane Finchley, London N3 1RT

Special Olympics

In every corner of the earth, Special Olympics is changing the lives of people with intellectual disabilities, building an inclusive world – one that celebrates ALL abilities – in sports, schools and in the workplace.

www.specialolympics.org

Special Olympics local group – http://www.specialolympicsgb.org.uk/find-a-club/21

Herts disability sports Hub

https://www.hertsdisabilitysportsfoundation.com/

Saracens
- Rugby training. Monday 5-6pm Allianz Park
- Athletics for Special Needs students at Allianz Park
https://www.saracenssportfoundation.org/our-programmes/disability/

Pedal Power: Cycling with provision of specialist bicycles. Finsbury Park, mixed days tues, thurs, sat. https://pedal-power.co.uk/

Tottenham Hotspur foundation - Football, mixed levels for students with learning disabilities.
https://www.tottenhamhotspur.com/the-club/foundation/about-us/

Otters & Barracudas Swimming clubs - at the weekend in Borehamwood and Potters Bar.
Otters: Saturday, 4.30-5.30, The Venue, Borehamwood
https://otterswimming.com/
Barracudas: Sunday, 11.30-12.30, Furzefield Leisure Centre, Potters Bar
http://www.barracudasc.co.uk/

Guppies swimming training - at Willesden Sports Centre. Tues 6pm & 7pm term time. https://www.brent.gov.uk/services-for-residents/children-and-family-support/the-brent-local-offer/send-local-offer-directory/sea-urchins-and-guppy-swimming-clubs-at-willesden-sports-centre/

Electric Eels (Maidenhead) - DS special swim club. https://electriceels.org.uk/

Special needs gymnastics - Heartlands School, Wood Green, https://www.lagad.co.uk/

Jump start Jonny. Aerobics on the internet, https://www.jumpstartjonny.co.uk/home

Disability Ice Hockey - Werewolfs Streatham - https://werewolvesoflondon.org.uk/

The Gold Trust based at The Shire Golf Club - https://theshirelondon.com/

PHAB Club - Clubs and overnight holidays for kids with and without disabilities. Nationwide. https://www.phab.org.uk/

Brownies, Guides - https://www.girlguiding.org.uk/

Scouts, Cubs - https://www.scouts.org.uk/

Happy Days at Northway - Playscheme for Children with SEN at Northway special school for Northway students (Barnet).

Horse Riding - **Riding for the Disabled**, https://www.rda.org.uk/
The Stables in Barnet. http://thestableshorseactivitycentre.org.uk/
Penniwell - http://www.penniwellsrda.com/

Electric Umbrella Dance https://www.electricumbrella.co.uk/

SOTO Finchley - Something Out The Ordinary – Performing Arts Opportunities For Children, Young People & Vulnerable Adults. Disability dance group. https://www.sotocic.org/

Unitas Youth Zone in Barnet – huge range of activities to young people aged 8-19 (or 25 with a disability) including dance, boxing, wall climbing, cooking, gaming…..and more! It is open to all young people for a £5/year membership, then a nominal 50p/session entry which includes all equipment needed for the activities. They are also able to get hot meal for £1. They also offer a session on a Sunday specifically for children with a disability and their families. www.unitasyouthzone.org

Lagad run a disability gymnastics classes (not just DS) - this was on Saturday afternoons at Heartlands school (Haringey) but this may have changed.

See https://www.lagad.co.uk/disability-gymnastics

Appendix 36:

Sex and relationship education (SRE) and pupils with additional needs

Do school policies for social and relationship education really meet the needs of pupils, asks Head ***David Stewart****, and what happens in the real world of the classroom?*

Every child, whether they are in a mainstream or special educational setting, has a right to a sex and relationship education (SRE) which supports them and prepares them for the realities of life. Parents of children with additional needs have identified that they wish schools to work with them on what is seen as a difficult aspect of their child's life. Citizenship education assumes that young people have a good grasp of self-worth and respect for others, and anti-discrimination legislation demands that pupils with special needs are not disadvantaged in terms of access to the full curriculum. While there may seem to be no shortage of reasons for ensuring that these pupils receive appropriate SRE education, evidence would suggest that the reality is very patchy.

Small scale research in individual authorities paints a picture of very mixed practice. There is no doubt that in some schools there will be exemplary practice. However, this is often down to a particular member of staff who has a passion for SRE. What happens if they leave or retire? Is the whole school signed up to this education?

In other schools, both special and mainstream, some pupils appear to receive almost nothing at all; it is not uncommon to hear comments such as "It is difficult for us discussing issues such as masturbation being a faith school." Some schools might have a written policy but no clear guidance on who is teaching what. So often the role of covering SRE is given to teaching assistants who may have had no training in special education or sex education. Even if they have been on training courses, they have no authority in the school to change practice or timetabling.

Staff often identify lack of resources or training as key problems, and there can also be a lack of support from senior leadership. Governors who have a responsibility for this area of the curriculum may not question what is being provided for pupils with additional needs. While there is every hope that future OFSTED inspections will question access for all pupils, I think there are some key areas for schools to consider now:

- does the SRE policy reflect all the needs of pupils? There are many situations in school which are not necessarily covered by the policy, so how are these monitored and assessed? For instance, with issues of personal and intimate care, staff may have a degree of uncertainty about what is deemed appropriate. Are behaviours excused due to disability? There can be a real danger that pupils are not provided with the appropriate boundaries
- rather than working in isolation, schools should set up support groups including relevant agencies and individuals. Indeed, for 25 years, my school has had a sex and relationship monitoring group. Members include staff, governors, parents, and colleagues from health, police and educational psychology. They work with staff on the delivery of the education and provide training for parents on a wide range of issues. They have also produced a series of booklets for pupils and parents to support their work
- when should sex and relationship education begin? In the early years, children should be given clear guidance about dignity and modesty, and they need to have a suitable vocabulary to help them understand their bodies. At this age, opportunities to make choices must be introduced. They need to know that they can say no. From an early age, children need to develop the skills which will help them keep safe. If they are not encouraged to do this, what happens when they find themselves in a problematic situation aged sixteen and they do not have the skills to make decisions and be assertive?
- work with parents is essential. If one is talking about masturbation being a private activity, i.e. in the young person's bedroom, then discussion with parents is essential. Parents often feel isolated concerning this area of their child's life, and this is a topic they feel less inclined to talk to other parents about. They need a forum where they can feel comfortable and realise that there are other parents who are dealing with similar issues and can often offer support and advice

- there is a need for on-going training and professional development. I would always recommend a general all staff training to begin with. While many staff members may not be involved in direct teaching of SRE, they will encounter a wide range of issues during the course of the school day and their reactions and responses to situations can be as powerful as formal teaching. If it has been agreed that a pupil should be dealt with in a particular way, then all staff need to have signed up to this. Staff will have a wide range of views, but they also have a duty to support the pupil with appropriate education. Too often schools simply respond to a crisis rather than having thought through possible scenarios and appropriate responses in advance
- education should be prophylactic. Pupils need to understand what is happening to them as they grow up. Social stories which prepare for periods or wet dreams can dispel a great deal of anxiety. For those pupils who dislike change, the changes of adolescence can be particularly traumatic
- issues of friendships and relationships need very sensitive handling, and young people need to know what the social rules are. Children with additional needs can feel very isolated and have little opportunity for friendship, let alone relationships. While responsibility for this area of a child's life is not just the school's, clearly, a school is in a good position to support pupils in the development of friendships.

This is not an area of choice for schools; it is one of absolute duty. Schools must support some of the most vulnerable children and young people in society and help them to have happy, safe and fulfilled lives.

Further information

David S Stewart OBE is Head Teacher of Shepherd School, Nottingham and Head Teacher Designate of Oak Field School. He is also a member of the PSHE Association, the subject association for all professionals working in personal, social and health education

www.pshe-association.org.uk

https://senmagazine.co.uk/articles/articles/senarticles/sex-and-relationship-education-and-pupils-with-additional-needs

https://www.theguardian.com/education/2018/aug/07/sex-education-special-needs-schools-vulnerable

file:///C:/Users/ellar/AppData/Local/Packages/Microsoft.MicrosoftEdge_8wekyb3d8bbwe/TempState/Downloads/spe_26_27_28%20(1).pdf

USEFUL RESOURCES

Teaching Children with Down Syndrome About Their Bodies, Boundaries and Sexuality: A Guide for Parents and Professionals – Terri Couwenhoven

The Autism-Friendly Guide to Periods (2019) Robyn Steward

http://www.oakfieldsportscollege.org.uk/uploads/POLICIES/other/SRE%20Booklet%20Order%20Form.pdf

A Series of Information Booklets for Parents On:

§ Menstruation § Male Masturbation § Female Masturbation § HIV & AIDS § Protecting Your Child § A Planned Dependent Life & Sexuality § Loss (also suitable for younger children) § Smearing § Your Child's Right (an introduction to Sex Education for parents) § Your Child's Right 2 - FAQ

Booklets for Young People on: 'Feeling Grown Up'

§ Female Masturbation § Male Masturbation § Menstruation at Home § Menstruation at School § Wet Dreams § Use of Public Toilets

ALL BOOKLETS £2.50 each plus postage & packaging

For further information and purchase, please contact: Oak Field School and Sports College, Wigman Road, Bilborough Nottingham, NG8 3HW Tel: 0115 915 3265 Fax: 0115 915 3264 Email: admin@oakfield.nottingham.sch.uk

Bodyworks flyer - http://www.oakfieldsportscollege.org.uk/uploads/POLICIES/other/BodyWorks%20Flyer.pdf

Living your life (Brook, www.brook.org.uk)

SHARE Special: an SRE curriculum for young people with special needs (Me-and-Us, www.me-and-us.co.uk)

Sexuality & Learning Disability: A Resource for Staff (FPA, www.fpa.org.uk)

Bodyworks (Oak Field School, www.oakfieldsportscollege.org.uk/uploads/ BodyWorks.pdf)

Sex and Relationship Education: a programme for learners with ASD (City of Nottingham, www.fionaspeirs.co.uk)

Exploring sexual and social understanding and Sex (both Bild, www.bild.org.uk)

How it is; an image vocabulary for children about: feelings, rights and safety, personal care and sexuality (Triangle, www.triangle.org.uk)

SNAP charity (Special Needs and Parents):

https://www.snapcharity.org/

https://www.snapcharity.org/wp-content/uploads/2018/09/Puberty_Sept_2018.pdf

At the SNAP Centre and on the SNAP helpline we are often asked for help with this particular issue, puberty. It seems that although sex and relationship education (SRE) is part of the National Curriculum, this is often not delivered at the correct time for a child with special needs or not differentiated to the appropriate level. Mainstream schools can usually only lesson plan with age appropriate material, which may not match the level of the child with special needs at that time.

Periods/Menses:

Preparation Is Key:

It's advisable not to wait until your daughter gets her first bleed before you talk to her about periods. Girls can begin their periods from the age of 9 and sometimes earlier, it is, therefore important to have an ongoing conversation about changes to her body such as her growing taller, needing to buy new clothes and her body shape changing. This will lay the foundation to talking to her about beginning her period.

Discussing menstruation before it happens reduces levels of anxiety and avoids it seeming like a crisis or a scary event when it does happen.

Talk to your daughter's school and ask them what they teach and how they teach the subject of puberty and menstruation. This can be useful for both you as the parent and the school, so together you can educate your daughter in a structured way that she will understand.

After your daughter begins her period preparation is still important. Keeping a diary of her menstrual cycle can help to plan ahead allowing you both to be prepared emotionally and practically for her monthly bleed.

How Period Pants Can Help?

It can be a worry as a parent how your daughter will cope with changing her period protection, especially if she is at school or without you. It may be that your daughter is also anxious about changing and disposing of a pad or tampon in a public bathroom. WUKA's Period Pants can be worn up to 8 hours on lighter days meaning that your daughter may not need to change her pants whilst out and about. Some girls may find a pad irritating against their skin, especially those who may have sensory issues. Wearing WUKA's Period Pants (or similar "period pants") alleviates the above concerns as the pad is secure inside the pants, meaning that they fit and feel like a pair ordinary of pants. They are made from soft, breathable and moisture wicking materials which contain no harmful chemicals.

https://wuka.co.uk/blogs/periods-a-z/learningdifficultiesandperiods

Appendix 37: Integrated Learning Disabilities (LD) Team in Barnet for adults

For a referral form please contact:

Barnet Learning Disabilities Service, Barnet House, 1255 High Road, London N20 0EJ,

Or by email to BLDSIntegratedDuty@barnet.gov.uk.

To return the referral form, it can be posted or emailed by secure email to BLDS@barnet.gcsx.gov.uk and attach any documents/reports to help us understand the person's needs.

All referrals are discussed by Team Leaders and you will hear from us within 10 working days. If you have not provided sufficient information, the referral form will be returned to you for more information.

Appendix 38: Resources for transition child to adult services:

Barnet Multi-Agency Preparation for Adulthood (PfA) - Protocol First Review 2020-2023: The planning process to support transition from adolescence into adulthood for young people with complex learning difficulties, disabilities, additional needs or mental health needs. https://www.barnetlocaloffer.org.uk/documents/669-preparing-for-adulthood-protocol.pdf

BACDIS: https://www.bacdis.org.uk/policy/documents/transition_moving-on-well.pdf is an excellent document with lots of valuable information and resources with support groups and websites that parents, young people and schools/colleges may find useful.

Youth Health Talk: www.youthhealthtalk.org and Transition Information Network

Transition information Network: www.transitioninfonetwork.org.uk are useful resources of information and good practice for young people, families and professionals.

Expert Patients Programme16: can help adults with long-term health conditions develop confidence in taking control of their own health needs; the Supporting Parents Programme is available at: www.expertpatients.co.uk

The transition social worker needs to work in partnership with the young person and family to agree how they prepare for the process of transition and how the young person will be supported to have a lead voice in planning and reviews

NSF: Multidisciplinary working is emphasised in the **National Service Framework for Long-term Conditions**, published by the Department of Health in 2005; it underlines the importance of maintaining independence and social and psychological wellbeing, including personal care, equipment, (assistive technology) and housing planned around individual needs.

The Transforming Care Prevention and Support (TCaPS) service is an NHS England Accelerator site initiative. Using a keyworker model the service provides flexible early intervention and crisis prevention support for young people and their families rated green and/or amber on the At Risk of Admission registers. It includes funding for Personal Health Budgets (PHBs) which have been particularly successful in supporting the needs of people with autism and learning disability.

Other general resources:

- Transition to adult care: Ready Steady Go
  https://www.what0-18.nhs.uk/health-for-young-people/long-term-medical-conditions/transition-and-moving-to-adult-services
- NICE guidelines: Transition from children's to adults' services 2016
  https://www.nice.org.uk/guidance/ng43
- Scottish Guidance on transitions 2017
  https://scottishtransitions.org.uk/summary-download/
- Royal college of Physicians acute care tool kit
  https://www.rcplondon.ac.uk/guidelines-policy/acute-care-toolkit-13-acute-care-adolescents-and-young-adults
- Preparing for Adulthood
  https://www.preparingforadulthood.org.uk/

- Top Tips for professionals who support young people to participate in their EHC
  https://natspec.org.uk/wp-content/uploads/2017/04/Top-Tips-for-Professionals-who-support-CYP-to-participate-in-their-EHCP.pdf
- From the Pond into the Sea – CQC report 2014
  https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report.pdf
- Transitions moving on well DoH
  www.bacdis.org.uk/policy/documents/transition_moving-on-well.pdf

Down syndrome specific

- Education Rights Series Factsheet 1 Young people over 16 with SEND 2016.pdf
  https://www.downs-syndrome.org.uk/download-package/education-rights-series-2/
- Listen To Me – 13+ Transition: resources to help students make decisions about their future Easy Read booklet
  https://www.downs-syndrome.org.uk/download-package/listen-to-me-13-transition-resources-to-help-students-make-decisions-about-their-future-easy-read-booklet/
- Down's syndrome Health Check book
  https://www.downs-syndrome.org.uk/for-people-with-downs-syndrome/health/health-book/
- Connecting employers and employees with Down's Syndrome
  http://www.dsworkfit.org.uk/
    - Stories of young adults with Down syndrome
      Beth's story narrated by her mother https://youtu.be/TaSxI_5ests

Appendix 39: Health checklists for people with learning disability and letters from DSA for members to use

Health checks for people with learning disabilities toolkit:

https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/health-check-toolkit.aspx

People with learning disabilities (LD) have poorer physical and mental health than other people and die younger. Many of these deaths are avoidable and not inevitable. Annual Health Checks can identify undetected health conditions early, ensure the appropriateness of ongoing treatments and establish trust and continuity care. GPs and practice nurses have the much needed generalist skills to help people with LD get timely access to increasing complex health systems.

Resources Managing the care of adults with Down Syndrome, Clinical Review, BMJ 2014: http://www.bmj.com/content/349/bmj.g5596

'How to' section of the 'Understanding Intellectual Disability & Health' website
http://www.intellectualdisability.info

General Medical Council (GMC) – Learning Disabilities: **http://www.gmc-uk.org/learningdisabilities/**

Down's Syndrome Association
A Registered Charity No. 1061474

This guide and checklist from the DSA: **Down Syndrome Specific Checklist, health book, GP info.**

https://www.downs-syndrome.org.uk/for-professionals/health-medical/annual-health-check-information-for-gps/

https://www.downs-syndrome.org.uk/for-families-and-carers/health-and-well-being/annual-health-checks/

https://www.downs-syndrome.org.uk/download-package/health-book/

File	Download
Health Book 2018	Download
Covering letter for GP 2015.pdf	Download
Covering letter for PWDS 14 to 17 years+ 2015.pdf	Download
Covering letter for PWDS 18+ 2015.pdf	Download
Check List.pdf	Download

Letters from DSA for members to use

Letter for DSA member: 14years +

Down's Syndrome Association
A Registered Charity No. 1061474

Dear DSA Member,

We are writing to you to tell you that you can now ask your GP for a free health check every year. Until last year only people over 18 years old could ask for a health check. Now the rules have changed and anyone over the age of 14 years old can have a free health check.

After you have asked your GP for a health check they will send you some questions to answer about your health. Your family can help you answer these questions.

When you have your health check you will see the nurse who works with your GP for about half an hour. You will see your GP for about half an hour as well. This may happen on the same day or different days.

We have made this Health Book to help you and your GP look at all the things that need to be looked at to make sure you stay healthy.

You can take the Health Book with you every time you go to see your GP, especially when you have an Annual Health Check.

The front part of the Health Book is for you and your family to fill out. At the back of the Health Book there is a list of things for your doctor to think about.

You can download extra pages for your Health Book at: http://www.downssyndrome.org.uk/for-families-and-carers/health-and-well-being/annual-healthchecks/

Don't forget to take a look at the information about health on our website http://www.downs-syndrome.org.uk/for-people-with-downs-syndrome/

Please let us know what you think about the Health Book by sending an email to info@downs-syndrome.org.uk

Yours faithfully

Stuart Mills Information Officer

Letter for your GP: Covering letter 14years to 17years+

Down's Syndrome Association
A Registered Charity No. 1061474

Dear GP,

The Down's Syndrome Association has produced this Health Book for your patient with Down Syndrome. The primary purpose of the Health Book is to increase the number of people with Down Syndrome (from 14 years upwards) accessing annual health checks and to provide GPs with information they may find helpful. It may also be used at routine appointments to support effective communication between you and your patient with Down Syndrome.

If your patient has come to you for an annual health check with their Health Book, please take a look at the section of the Health Book for GPs. In conjunction with the Health Book, we have set up a website for GP's (www.dshealth.org) containing up to date information about health conditions that are more common in people with Down Syndrome. We hope that you will find the site useful.

Your patient may have had an annual health check this year. If this is the case, they will have brought their Health Book with them today for your ease of reference during a routine appointment.

It is very important that this Health Book continues to be a useful tool to ensure that the health needs of people with Down Syndrome are met. Please send any comments/questions about the Health Book or about health issues in people with Down Syndrome to info@downs-syndrome.org.uk

Thank you for your support, it is very much appreciated.

Yours faithfully

Stuart Mills Information Officer

Letter to DSA Member and can be sent to GP: Covering letter 18yrs +

Down's Syndrome Association
A Registered Charity No. 1061474

Dear DSA Member,

We are writing to tell you that that you can ask your GP for a free health check every year.

After you have asked your GP for a health check they will send you some questions to answer about your health. You can ask someone to help you answer these questions if you need to.

When you have your health check you will see the nurse who works with your GP for about half an hour. You will then see your GP for about half an hour. This may happen on the same day or different days.

We have made this Health Book to help you and your GP look at all the things that need to be looked at to make sure you stay healthy.

The front part of the Health Book is for you and your family to fill out. At the back of the Health Book there is a list of things for your doctor to think about.

You can take the Health Book with you every time you go to see your GP, especially when you have an Annual Health Check.

You can download extra pages for your Health Book at: http://www.downssyndrome.org.uk/for-families-and-carers/health-and-well-being/annual-healthchecks/

Don't forget to take a look at the information about health on our website http://www.downs-syndrome.org.uk/for-people-with-downs-syndrome/

Please let us know what you think about the Health Book by sending an email to info@downs-syndrome.org.uk

Yours faithfully

Stuart Mills Information Officer

Appendix 40

Down Syndrome Checklists

The following are suggested ages for health checks. Check at other times if there are parental or other reasons for concern.

Ages birth to 5 years	Neonatal	3months	6 months	1 year	2 years	3 years	4 years	5 years
Completed	Date	Date	Date	Date	Date	Date	Date	Date
Confirm diagnosis with chromosomes (if not confirmed, important to identify translocations for recurrence risk counseling)								
Screen for hypothyroidism (newborn screen, on Guthrie test only)								
Observe for any signs of gastrointestinal malformations (duodenal atresia, malrotation, Hirschsprung's disease)								
Monitor for signs of poor feeding or aspiration or GORD, early referral for a paediatric dysphagia assessment, treat GORD.								
Check for cataracts and nystagmus, refer immediately ifvision concerns								
Check hearing at birth through the National Hearing Screening program and refer for specialist help as needed								
Echocardiogram in all infants (immediately if concerns, ideally before discharge from hospital, otherwise by 6-8 weeks)								
If **stridor or other signs of airway anomaly**, refer for evaluation								
FBC in newborn to check for transient myeloproliferative disorder or polycythemia, if present, manage per specialty input.								
Discuss and refer to **Early Intervention Services** (community paediatrics, physiotherapy, preschool teaching team and paediatric dysphagia team as a minimum) using Child Development Team referral form AND inform health visiting.								
Liaise with **neonatal outreach nurses** for follow up (Barnet) after discharge								
Review appointment with **neonatal consultant**								
Consider Genetic Counseling referral (if not already obtained)								
Refer parents to **support groups and literature (**Down Syndrome Association, Down Syndrome inserts for Red Book, See Appendix 2)								
Address questions about **alternative therapies** (see pathway/ask for help)								
Consider a **children's social care** referral for Early Help (MASH) etc								
Encourage all **routine immunisations** as per UK schedule								
Consider **RSV prevention** if fulfills current RFH/National criteria								
Community paediatric appointment by 3 months, then 6m, 1year and annually after that								
Repeat **thyroid screening** (TSH, T4 and thyroid antibodies) at 6 months, 12 months, then yearly								
Vigilant attention to **middle ear effusion**. If canals preclude exam, consult ENT for microscopic examinations (every 3-6 months)								
Review **growth** (use DS specific growth charts)								
Discuss **development** with particular focus on feeding, language, social, and gross motor skills and services to optimize, vision and hearing. If not walking by 3 years of age – consider hip Xray.								
Ask about any **abnormal movements** that parents are concerned about, consider referral, EEG and ask for videos.								
Refer to **Ophthalmology** by 6 months, follow-up at 12 months then yearly.								
Refer to **audiology** services for review at 9-12m, and then yearly								
Review access to **support groups and Early Intervention** services at all well child visits – pre-school teaching team, physiotherapy.								
Ensure **health visiting** involvement								
Support for **DLA** (e.g. via MENCAP) and check benefits and welfare rights.								
Ensure follow-up for **prior diagnosed health issues** (e.g.cardiac, GI, haematology, respiratory etc at local and tertiary levels)								
Check chest health and review infection history: admissions, antibiotic courses – consider antibiotic prophylaxis, respiratory referral, chest X-ray and/or immunology testing.								

Thyroid Screening (TSH, T4 and thyroid autoantibodies) at 6 and 12 months, then yearly								
Consider **HLA testing** (to define potential for coeliac disease) from 6months as becomes available (irrespective of gluten intake)								
Repeat **FBC** at 6 months if born prematurely – low threshold for annual FBC is clinically indicated								
Consider Iron studies (ferritin and iron studies), FBC, Vitamin D levels at 6m, 12m and yearly if medical need or dietary concerns, only as clinically indicated and not routine.								
Review signs and symptoms of **coeliac disease** - very low threshold for testing for coeliac antibodies with a total IgA if the child is on enough gluten for the test to be valid (need for repeat testing if symptoms persist is unclear at this time but consider rescreen if new symptoms emerge).								
E**ducate families** on symptoms related to atlanto-axial instability and seeking medical help, potential risk of contact sports/gymnastics, and perform neurologic /musculoskeletal examination yearly.								
Monitor for symptoms of **obstructive sleep apnoea (sleep disordered breathing)**. Referral for a formal sleep study/review if any symptoms on routine questioning to GOSH or Evelina Sleep centres. **Repeat** as indicated.								
Routine overnight oximetry screening recommended at 6m, 12m and yearly till 3-5 years of age for any child ***without*** symptoms through the homecare nurses.								
Discuss transition from **early intervention program to preschool** that will often occur at age three.								
Discuss transition from **preschool to school** that occurs at age four.								
Consider health and therapy referrals as needed e.g. OT, orthotics, enuresis service, health visiting, school nursing, weight management team, CAMHS.								
Pneumococcal polysaccharide vaccine (PPV23) to all children and young people, after the age of 2 years, then repeated 5 yearly (5 year gap between doses).								
Annual flu vaccine from age 6m (injection 6m to 2 years and nasal from 2 years) and the household contacts too								

Ages 5-12 years	**6 years**	**7 years**	**8 years**	**9 years**	**10 years**	**11 years**	**12 years**	**13 years**
Completed	Date	Date	Date	Date	Date	Date	Date:	Date:
Ensure follow-up for all **prior diagnosed health issues** (local and tertiary) e.g. Cardiac, GI, Haematology, Respiratory, ENT								
Community paediatric appointment at least annually								
Monitor **growth** (DS-specific charts) Height Weight BMI								
Review **diet, nutrition, healthy eating for dental care**								
Consider referral to dietician if appropriate								
Exercise and interests - specific emphasis on lifestyle to prevent obesity.								
Review Gross Motor skills ? requires physiotherapy Orthotics								
Review fine motor skills ?requires OT assessment Especially at transition to primary and secondary school								
Consider health and therapy referrals as needed e.g. OT, orthotics, enuresis service, school nursing, weight management team, CAMHS. Consider a **children's social care** referral for Early Help or the Children's Disability team (MASH) etc Support for **DLA** (e.g. via MENCAP) and check benefits and welfare rights.								
Annual **hearing screening**								

Annual **vision screening**								
Annual **thyroid screening** (TSH, T4 and thyroid autoantibodies) and refer if abnormal as per guidelines.								
Consider Iron studies (ferritin and iron studies), FBC, Vitamin D levels yearly if medical need or dietary concerns, only as clinically indicated and not routine.								
Check chest health and review infection history: admissions, antibiotic courses – consider antibiotic prophylaxis, respiratory referral, chest X-ray and/or immunology testing.								
Encourage all **routine immunisations** as per UK schedule								
Consider repeat screen for **coeliac disease** - review signs and symptoms of **coeliac disease** - very low threshold for testing for coeliac antibodies with a total IgA if the child is on enough gluten for the test to be valid. (Check if HLA typing available)								
Educate families on symptoms of atlanto- axial instability; perform **neurologic/musculoskeletal examination** yearly								
Monitor for symptoms of **obstructive sleep apnoea (sleep disordered breathing)**. Referral for a formal sleep study/review if any symptoms on routine questioning to GOSH or Evelina Sleep centres. **Repeat** as indicated.								
Annual flu vaccine from age 6m (injection 6m to 2 years and nasal from 2 years) and the household contacts too								
Pneumococcal polysaccharide vaccine (PPV23) to all children and young people, after the age of 2 years, then repeated 5 yearly (5 year gap between doses).								
Discuss **development** with particular focus on language and social skills and services to optimize.								
Liaison with school services (Inclusion lead / SENCO) and therapy services.								
Discuss **behaviour,** referral for evaluation and support if challenging								
Discuss **social communication**, referral for evaluation and support								
Discuss **menstrual hygiene** management; contraception								

Ages 14 years to Adult	**14 years**	**15 years**	**16 years**	**17 years**	**18 years+**
Completed	Date	Date	Date	Date	Date
Ensure follow-up for all **prior diagnosed health issues** (local and tertiary) e.g. Cardiac, GI, Haematology, Respiratory, ENT					
Community paediatric appointment at least annually					
Directed Enhanced Service (DES) from age 14yrs by GPs (annual review), send letter to GP about this and refer to Down's Syndrome Association checklists and booklets.					
Monitor **growth** (DS-specific charts) Height Weight BMI					
Review **diet, nutrition, healthy eating for dental care**					
Consider referral to dietician if appropriate					
Exercise and interests - specific emphasis on lifestyle to prevent obesity.					
For obesity, check consequences of obesity e.g. lipid profile, BP, HbA1c					
Review Gross Motor skills ? requires physiotherapy Orthotics					
Review fine motor skills ?requires OT assessment Especially at transition to secondary school and sixth form					
Consider health and therapy referrals as needed e.g. OT, orthotics, enuresis service, school nursing, weight management team, CAMHS. Consider a **children's social care** referral for Early Help or the Children's Disability					

team (MASH) etc Support for **DLA** (e.g. via MENCAP) and check benefits and welfare rights.					
Annual **hearing screening**					
Annual **vision screening**					
Annual **thyroid screening** (TSH, T4 and thyroid autoantibodies) and refer if abnormal as per guidelines.					
Consider Iron studies (ferritin and iron studies), FBC, Vitamin D levels yearly if medical need or dietary concerns, only as clinically indicated and not routine.					
Check chest health and review infection history: admissions, antibiotic courses – consider antibiotic prophylaxis, respiratory referral, chest X-ray and/or immunology testing.					
Encourage all **routine immunisations** as per UK schedule					
Consider repeat screen for **coeliac disease** - review signs and symptoms of **coeliac disease** - very low threshold for testing for coeliac antibodies with a total IgA if the child is on enough gluten for the test to be valid. (Check if HLA typing available)					
Educate families on symptoms of myelopathy and, related to atlanto- axial instability, perform **neurologic and muskuloskeletal examination** yearly – also enquire about any pain or any joint swellings?					
Monitor for symptoms of **obstructive sleep apnoea (sleep disordered breathing)**. Referral for a formal sleep study/review if any symptoms on routine questioning to GOSH or Evelina Sleep centres. **Repeat** as indicated.					
Annual flu vaccine from age 6m (injection 6m to 2 years and nasal from 2 years) and the household contacts too					
Pneumococcal polysaccharide vaccine (PPV23) to all children and young people, after the age of 2 years, then repeated 5 yearly (5 year gap between doses).					
Discuss **development** with particular focus on language and social skills and services to optimize.					
Liaison with school services (Inclusion lead / SENCO) and therapy services.					
Discuss **behaviour,** referral for evaluation and support if challenging					
Discuss **social communication**, referral for evaluation and support					
Discuss **menstrual hygiene, sexuality**, self-care, sexual health/PSHE, contraception.					
Discuss **parents' goals** for child (e.g., academic, self-help, athletic, social) **and child's progress**, ensure supports to optimize					
Discuss **behavior and social communication**, referral for evaluation and supports if challenging					
Discuss **transition issues**, group homes, settings, and other community supported employment					
One-off school leaving **echocardiogram**					
Transition planning with education, health, social care, families, young person. Send letter to GP about this and refer to Down's Syndrome Association checklists and booklets.					
Consider additional referrals around transition to adult services e.g. adult neurology, adult mental health (Learning Disability team), LD nurses in community, adult cardiology.					
Annual health checks for adults by the GP (checklists available from the RCGP and DSA websites and a personal health book) – no further community paediatric checks once leaves full-time education – this is 18 years if in mainstream or 19 years if in a special school					

Bull MJ and the American Academy of Pediatrics Committee on Genetics.

Health Supervision for Children With Down Syndrome. Pediatrics. 2011;128(2):393-406

Adapted by Dr Ella Rachamim, 10th Nov 2020 for Barnet Combined Care Pathway (RFH NHS Trust)

List of abbreviations

AAI – Atlanto-Axial Instability

ADL – Activities of Daily Living

AED – Anti-Epileptic Drug

ARC – Antenatal Results and Choices

ASD – Atrial Septal Defect

ASD – Autism Spectrum Disorder

AVSD – Atrio-Ventricular Septal Defect

BGH – Barnet General Hospital

BP – Blood Pressure

CAF – Common Assessment Framework

CAMH – Child and Adolescent Mental Health Service

CAMHS – Child and Adolescent Mental Health Service

CBT – Cognitive Behavioural Therapy

CDC – Child Development Clinic

CDT – Child Development Team

CHD – Congenital Heart Disease

CIT – Combined Integrated Therapies

CTG – Cardiotocography

CVS – Chorionic Villus Sampling

CXR – Chest X-Ray

CYP – Children and Young People

CYPOT - Children and Young People's Occupational Therapist

DCT – Disabled Children's Team

DES – Directed Enhanced Review

DLA – Disability Living Allowance

DS – Down Syndrome

DSA – Down's Syndrome Association

DSMIG – Down Syndrome Medical Interest Group

DS LEG – Barnet Leading Edge Group for Children and Young People with Down syndrome

ECG – Electrocardiogram

Echo – Echocardiogram

EEG – Electroencephalogram

EGH – Edgware General Hospital

EHCP – Education, Health and Care Plan

ENT – Ear, Nose and Throat

EP – Educational Psychologist

EPR – Electronic Patient Record (computer system)

FBC – Full Blood Count

FMU – Fetal Medicine Unit

FSH – Follicular Stimulating Hormone

GORD – Gastro-Oesophageal Reflux Disease

GOSH – Great Ormond Street Hospital

HbA1c – glycated Haemoglobin

HI – Hearing Impaired

Hib – Haemophilus Vaccine

HLA – Human Leukocyte Antigen

HPV – Human Papillomavirus

HQ – Head Quarters

HV – Health Visitor

HWT – Handwriting Without Tears

IAG - Information, Advice and Guidance

IAPT – Improving Access to Psychological Therapies

IFT – Infant Feeding Team

IgA – total Immunoglobulin A

LD – Learning Disability

LEG – Leading Edge Group

MASH – Multi-Agency Safeguarding Hub

MAT – Multi-Agency Team

MDT – Multi-Disciplinary Team

Men C- Meningococcal C

ML-DS – Myeloid Leukaemia in Down Syndrome

NELFT – North East London Foundation Trust

NGT – Naso-Gastric Tube

NHS –National Hearing Screening

NICE – National Institute for Clinical Excellence

NIPE – Neonatal Infant Physical Exam

NIPT – Non-Invasive Prenatal Testing

NNU – Neonatal Unit

NSPCC – National Society for the Prevention of Cruelty to Children

OME – Otitis Media with Effusion

ORE – Oromotor Exercise

OSA – Obstructive Sleep Apnoea

OT – Occupational Therapist/Therapy

PCHR – Personal Child Health Record

PCV – Pneumococcal Conjugate Vaccine

PDA – Patent Ductus Arteriosus

PE – Physical Exercise

PIP – Personal Independence Payment

PPI - Proton Pump Inhibitor

PPV23 – Pneumococcal Polysaccharide Vaccine

PSG - Polysomnography

PSHE – Personal, Social, Health and Economic education

PsTT – Pre-School Teaching Team

PVD – Pulmonary Vascular Disease

PWP - Psychological Wellbeing Practitioner

QRS – QRS complex or interval on an ECG

RFH – Royal Free Hospital

RNOH – Royal National Orthopedic Hospital

SAL – Speech and Language

SALT – Speech and Language Therapy/therapist/Team

SCAN – Service for Children and Adolescents with Neuro-developmental difficulties

SCBU – Special Care Baby Unit

SDB – Sleep Disordered Breathing

SEN – Special Educational Needs

SENCO - Special Educational Needs Coordinator

SEND– Special Educational Needs and Disabilities

SENDIASS – Special Educational Needs and Disabilities Information Advice and Support Services

SENIF – Special Educational Needs Inclusion Funding

SLT – Speech and Language Therapist

SOGS – Schedule of Growing Skills

SPA – Single Point of Access

SRE – Sex and Relationship Education

SW – Social Worker

T4 – Thyroxine (thyroid hormone)

TAM – Transient Abnormal Myelopoiesis

TASC – Team for Assessing Social Communication

TFT – Thyroid Function Test

The BIG-DS – Barnet Integrated Groups for preschoolers with Down Syndrome

ToD – Teachers of the Deaf/Teachers of the hearing impaired

TPO – Thyroid Peroxidase auto-antibodies

TSH – Thyroid Stimulating Hormone

TTG – Tissue Transglutaminase antibody

TVI – Teachers of students with Visual Impairments

UCLH – University College London Hospital

USS – Ultrasound

VFF/VFSS – Videofluoroscopy

VI – Visually Impaired

VSD – Ventricular Septal Defect