This is absolutely life changing for all children and adults who have Down’s Syndrome, this will also make a huge difference for babies yet to be born.

No one ever tells you just how amazing your child will be when he/she is born, you are just filled with fear; fear of the unknown, fear for your baby on how will society view my child, will he/she live, your met with such low expectations doom and gloom sombre looks and whispers.

When in reality you are a mother and father of a beautiful baby who just wants to nurture and love their baby just as any other parent does.

By having the care pathway it gives you hope, something we as parents need in those very precious early days.

You need a clear view of what to expect in the future and to know that your beautiful baby will be ok.

So thank you for listening to us I don’t think you realise just how much this means

Local Parent (Vicky Abbott) of a child with Down’s Syndrome

Pathway development

This pathway was developed in partnership with parents, carers, health professionals and People with Down’s Syndrome. This pathway will be regularly reviewed and updated, further information can be found at www.hullccg.nhs.uk/downssyndromehull.

If there are any errors or changes that should be made please email corrections to NHS Hull CCG HULLCCG.contactus@nhs.net or through our website www.hullccg.nhs.uk/downssyndromehull.

If the error presents a significant clinical risk please contact NHS Hull CCG on Telephone: 01482 344700 or email – Angela.ward14@nhs.net

If you would like to be involved in the future development of this pathway please email contact details to HULLCCG.contactus@nhs.net
Introduction

Please refer to Glossary of terms, if required, at the back of this document

Any person who has Down’s Syndrome is a person first. As with any other child or adult, they will have their own unique personality and attributes. It is important to remember that despite someone having Down’s Syndrome, this alone does not define them.

Down’s Syndrome is the commonest autosomal anomaly, present in 1 in 600-700 live births. In the majority of cases (95%) there is an extra chromosome, 47 chromosomes rather than 46. The extra chromosome being number 21. In 2.5% there is mosaicism where only some of the cells have the extra Chromosome.

In Hull and East Yorkshire there are approximately five live births per year of babies who are diagnosed with Down’s Syndrome.

Some families know that their child is going to be born with Down’s Syndrome due to screening processes, while other families have no indication that their child will have Down’s Syndrome until they receive a diagnosis after birth. Even though everyone who has Down’s Syndrome is different, there are some clinical features present at birth, and some health conditions they may be more prone to.

What is a care pathway?

A care pathway aims to have:
- 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 clinical care pathway and clinical guideline for children with Down’s Syndrome. Input has been sought from parent/carers and other services closely involved with the care of these children. The transition to adult services from children’s services is often a time of anxiety for people, however this pathway is designed to make this process clearer and can give people assurance that there are processes in place for both children and adults. This pathway will enable people to navigate their way through health services to ensure no one who has Down’s Syndrome gets ‘left behind’. It is effectively putting all the health information pertinent for people with Down’s Syndrome in one place.

Multidisciplinary representatives from Community Services, Hull and East Yorkshire Hospitals, education, Humber Teaching TNHS Trust, Community Paediatricians within City Health Care Partnership, other local services, and parents, set up a pathway group to produce a clinical pathway emphasising the need for information and engagement with families. Services for adults who have learning disabilities have also been involved in the development of this pathway, and links to their easy read resources have been used to support the pathway.

This pathway does not replace those services that all children and adults have access to: e.g. GP services, midwifery, health visiting, school nursing (now the 0-19 years service in Hull), 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’s Syndrome because of some common health difficulties experienced by some people who have Down’s Syndrome.

These guidelines are largely based on work done by Down’s Syndrome Medical Interest Group (DSMIG, UK and Ireland) who have produced guidelines for basic medical surveillance in children with a diagnosis of Down’s Syndrome. These guidelines and a wide range of other health information can be found at www.dsmig.org.uk. The Down’s Syndrome Association have a lot of useful information relating to health and wellbeing and other important issues for people who have Down’s Syndrome, and their families. www.downs-syndrome.org.uk

We would also like to acknowledge the work done by Nottingham Down’s Syndrome Children’s Services team led by Elizabeth Marder and we have utilised their guidelines for this pathway. We have also used the Grampian and Leicestershire Down’s Syndrome pathways as reference tools. Further acknowledgements can be found at the back of this Pathway.

The pathway and guideline has been co-produced with parents/carers/ service users and professionals to ensure the information is accurate, and is driven by those who will benefit the most from using it.

Consent from parents and carers should be obtained prior to referral and notification of needs within the pathway as per local policy. Clarification regarding consent arrangements for each service should be sought.
Antenatal screening

Antenatal Screening for Down's Syndrome to be offered to all pregnant women booking up to 20 weeks gestation

Screening method depends on gestation date of test
- Combined Screening Approx. 11+1 to 14+2
- Quadruple Test Approx. 14+2 to 20

Previous baby with Down’s Syndrome
Woman offered appointment with screening coordinator or deputy to discuss options which will include screening and prenatal diagnosis

Low Chance
> 1:50
Baby has a lower chance of having Down’s syndrome if the test result is higher than 1 in 150

High Chance
< 1:150
Woman informed by telephone and offered face to face appointment with screening coordinator or screening midwife
Downright Special information pack to be given

Options discussed
Including prenatal diagnosis to ascertain diagnosis

Anomalies on ultrasound scan consistent with baby possibly having Down's Syndrome

Normal QFPCR / Karyotype
Woman notified by pre-agreed method

Woman opts for prenatal diagnosis (amniocentesis/CVS)

Antenatal care will be dependent on maternal and foetal health and will form part of an individual Care plan

Birth of baby
Newborn and Infant Physical Examination (NIPE)

Information pack given.
Referral to Downright Special Network.
Infant Feeding Coordinator notified.
Appointment offered with a Neonatologist.
Woman’s GP and 0-19 years’ Service notified in Hull. Inform East Riding Heath Visitor
Down’s Syndrome Health Visitor Champion allocated
Health visitor notified to prepare for introduction to the family

Down’s Syndrome QFPCR/ Karyotype
Positive Diagnosis
- Result given by screening coordinator or deputy. Parents are notified by previously agreed method which is often by telephone.
- An appointment to discuss options face to face should be offered within 24 hours.
- Plan of care discussed, agreed with woman and documented diagnosis

Pathway provided by Hull and East Yorkshire Hospitals Trust Neonatal Screening Co-ordinator, June 2017
Useful links and contacts

Information about the tests for Down’s Syndrome
- Screening test for you and your baby
  [Public Health England, NHS Screening Programmes]
- Screening for Down’s, Edwards’ and Patau’s syndromes
  [NHS Choices]

Information about screening results
- Screening for Down’s, Edwards’ and Patau’s syndromes
  [NHS Choices]

Information and contacts for positive diagnosis
- Looking forward to your baby
  [Down’s Syndrome Association]

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’s Syndrome: A leaflet for friends and family
  [Down’s Syndrome Association]

Information and Support for all
- Positive about Down’s Syndrome
  [Positive About Down’s Syndrome]

Antenatal and Newborn Screening Co-ordinator
01482 382737

East Riding Early Support Panel
01482 392227 or 01482 392218
eyst@eastriding.gov.uk

Downright Special (Hull & East Riding Down Syndrome Support Group)
01482 420160
enquiries@downrightspecial.co.uk

Antenatal screening guidance

In England all pregnant women under 20 weeks gestation are offered screening for Down’s Syndrome at their booking appointment by the community midwife or booking midwife.

The decision whether to accept or decline screening is up to the woman, and enough time should be given to enable them to come to a decision

Prenatal diagnostic tests
Some women decline screening for Down’s Syndrome. If however the woman has accepted screening and gets a higher chance result or if an ultrasound scan suggests the baby may have an increased chance of Down’s Syndrome, even if the woman has declined screening, further testing (prenatal diagnosis) will be discussed and offered.

The decision whether to accept or decline further testing is up to the woman, and enough time should be given to talk through the options and come to a decision

Further information about these tests can be found on NHS choices website;
https://www.nhs.uk/conditions/chorionic-villus-sampling-cvs/
https://www.nhs.uk/conditions/Amniocentesis/

Communicating diagnosis/results
At the point of prenatal diagnosis, agreement should be made between the woman and the health professional (usually the Screening Coordinator or Deputy) to establish how the results will be communicated. Results will usually be given over the phone with the opportunity to discuss face to face, however the woman will always have a choice as to how she wants to receive results.

Support
If a diagnosis is made antenatally, choices available to a woman and a personalised plan of care will be discussed. Information about Down’s Syndrome including local and national support organisations such as the Down’s Syndrome Association and Downright Special Network will be offered.

Contact will be made with the 0-19 years Service in Hull or the Early Support Panel / Health Visitor in the East Riding; and the child will be allocated a Health Visitor and a Down’s Syndrome Champion. A referral to Downright Special with consent may also be made.

Counselling
Being told that a baby may have Down’s syndrome can be difficult news. Information and time should be offered to allow a woman and her partner to discuss the impact of the diagnosis upon them and their family, and obtain the necessary support from services available to them.
**Diagnostic pathway**

**Birth of baby**

- **Down’s Syndrome suspected**
  - Clinical features present (see below)

**Karyotyping**
- **With parent’s consent**
  - Send to Hull Pathology Service transport via hospital systems
  - Notify laboratory by phone
  - Request transport via BLOODFAST to ensure arrival at Leeds

**Down’s Syndrome confirmed by antenatal testing and screening**

- **Karyotyping**
  - **Negative result**
    - Normal Karyotype
  - **Positive result**
    - Definitive diagnosis of Down’s Syndrome

  - To be given to the parents by the Consultant Paediatrician

**Baby does not have Down’s Syndrome**

- Information pack given
- Referral to Downright Special Network
- Infant Feeding Co-ordinator notified at Hull Royal Infirmary
- Appointment offered with a Neonatologist.
- Woman’s GP and 0-19 years Service notified, or East Riding Health Visiting Service
- Hull Down’s Syndrome Champion allocated
- Health visitor notified to prepare for antenatal contact at home or in hospital ASAP
- Referral to Portage Service
- Referral to East Riding Early Support Panel

**Clinical features at birth**

**General**
- Poor feeding
- Flat occiput (back of head)
- Short broad hands
- Single transverse palmar crease (crease across palm of hand)
- Low muscle tone
- Short neck

**Facial and eyes**
- Prominent epicanthic folds (skin fold in upper eyelid)
- Upward slant of eyes
- Brushfield spots in the iris
- Low set small ears
- Flat nasal bridge
- Congenital cataract
- Glaucoma
- Tongue may protrude from mouth

**Abdomen**
- Hirschsprung’s disease (bowel problem)
- Intrahepatic biliary hypoplasia (liver problem)
- Duodenal atresia/stenosis (intestine problem)

**Limbs**
- Short incurved little fingers
- Sandal gap between first and second toes
- Dislocation of knee
- Hip problems

**Heart and blood**
- Atrial and ventricular septal defects
- Congenital leukaemia – (commonly AML and acute megakaryoblastic leukaemia)
- Mild Pancytopenia (reduction in blood cells)
- Neutropenia (low levels of a type of white blood cell)
- Transient abnormal myelopoiesis (abnormal number of certain blood cells)
- Polycythaemia (increased number of certain cells)
Useful links and contacts

Health Visiting Teams
Hull 01482 336634 or 01482 344301

East Riding
South Holderness (Hedon/Withernsea)
Tel: (01482) 344455
email: Hnf-tr.Southhondernessisphteam@nhs.net

North Holderness (Beverley/Hornsea)
Tel: (01482) 677618
Email: Hnf-tr.Northholdernessisphteam@nhs.net

Haltemprice (Cottingham, Hessle, Brough and surrounding villages)
Tel: (01482) 335010
email: Hnf-tr.Haltempriceisphteam@nhs.net

Goole (Goole, Howden and Snadth)
Tel: (01456) 752931
Email: Hnf-Tr.Gooleisphpteam@nhs.net

East Riding Early Support Panel
01482 392227 or 01482 392218
eyst@eastriding.gov.uk

Downright Special
01482 420160
enquiries@dowrightspecial.co.uk

Diagnosis pathway guidance

Chromosomal blood samples should be taken with consent from Parents and sent to Hull Pathology Service to be transported by hospital systems. It is essential to telephone the laboratory to inform them of the imminent arrival of the sample and to request transport by ‘Bloodfast’ and not the shuttle system. This would ensure the sample arrives at Leeds Cytogenic Laboratory the same day, and testing can be started as soon as possible, preferably that day or the day after. Sending a sample by shuttle can add unnecessary delay. Non urgent samples or a very low likelihood of a positive diagnosis may be sent routinely if clinically appropriate.

Diagnosis and disclosure
Parents should be told of diagnosis as soon as possible, preferably by a senior Paediatrician and the responsible Consultant. Chromosome analysis should be requested urgently, but advice of the likely diagnosis should not be delayed to wait for the results.

Medical history and examination
Routine neonatal examination should pay particular attention to common complications of Down’s Syndrome such as bowel atresias, Hirschsprung’s disease, cardiac defects and cataracts. Chromosomes: Ask for a rapid FISH test first and full test as soon as possible. Two millimetres of blood (less may be possible) in a lithium heparin bottle and send to lab straight away or store specimens in fridge if out of hours. Full blood count (FBC): Minor abnormalities in a blood count are commonly seen and should be managed as for any other baby. Transient abnormal myelopoiesis (TAM) is reported to occur in 10% of babies with Down’s Syndrome and may need advice from the Paediatric Haematologist. Thyroid screening: Routine Newborn screen is satisfactory, but it is necessary to chase and record the result. Thyroid screening will need to take place routinely throughout life.

Clinical cardiac assessment: This should be performed by a senior paediatric trainee or Consultant prior to the baby leaving the hospital and should include a physical examination. If cardiac murmur is present, then prior to discharge baby must be reviewed by the Neonatal Consultant and an echocardiogram take place before discharge. If a baby is asymptomatic and antenatal scans are normal then a scan should be arranged within first 8 weeks of life as an outpatient.

Postnatally, all babies should have oxygen saturation monitoring whilst still in hospital on the post-natal ward or Special Care Baby Unit. If there is no murmur present, antenatal scans were normal, and the oxygen saturations have remained satisfactory, then follow up with the Paediatric Cardiologist can be arranged as an Outpatient.

Note: All babies with a significant left to right shunt should be referred for RSV prophylaxis in flu season. Neonatal Hearing Screen: Check this has been done and record the result.

Infant Feeding Co-ordinators should be notified of the birth of a baby who has Down’s Syndrome regardless of the chosen/preferred method of feeding. This will enable the Co-ordinators to support the parent/s to establish feeding, as we know that babies who have Down’s Syndrome can be poor feeders for a variety of reasons including sleepiness, jaw/tongue/ muscle tone/co-ordination issues.

Referrals/notifications to be arranged by neonatal team
The 0-19 Years Service should be contacted if the child is from Hull, or the health visiting team in the East Riding, as soon as it is identified that a baby may have Down’s Syndrome. The Children’s Community Nursing Team may also be contacted for further support and advice if there is a nursing need present.

The Health Visitor will, wherever possible, visit the child and family in hospital (NICU/SCBU/Post-natal ward) prior to discharge.

A comprehensive medical assessment according to the guidelines must be carried out prior to discharge. A Neonatal discharge letter for babies requiring inpatient treatment will be sent to the GP and named Health Visitor with a copy attached to the Community Paediatrician referral. Referral to be made to Community Paediatricians (on discharge) by the acute Paediatrician/Consultant or Neonatologist. Copies should be sent to the GP and Health Visitor.

Referral to Portage Service with consent from parents and notification to the local authority SEND Team.
Down's Syndrome Pathway - Hull

Post diagnostic pathway

If not already done, notify Infant Feeding Co-ordinators of birth, to support initiation of feeding.

Definitive diagnosis of Down's Syndrome with personalised plan in place
  e.g. referrals to doctors or specialists to meet their individual needs

Information for Parents
  Downright Special referral made. 0-19 years service
  Down's Syndrome Champion Health Visitor to be allocated if in Hull, early support panel and Health visitor in the East Riding, and provide support and monitoring.

Children's growth should be plotted on growth charts (centiles) specific to children with Down's Syndrome.
These are to be kept in the personal child health record (Red Book)

Screening and management by specialist services
  Cardiology, Ophthalmology, Audiology
  Other Specialist Services (see guidance notes P.9)
  Referral to IPASS (Hull), SaPTS (East Riding)
  Hearing Impairment team if hearing impaired

Referral to Community Paediatrician by Consultant Paediatrician in hospital/Neonatologist who discharges baby from hospital after birth (or after receiving treatment on SCBU/NICU)

Education
  Identify any additional support for learning needs.
  Portage Referral IPASS Referral for physical difficulties and / or visual impairment, or SaPTS in the East Riding

Health Visitor to notify local authority of special needs in line with local SEND strategy

Personalised Care Plan in place
  Regular review and reassessment of needs undertaken by Down’s Syndrome Health Visitor Champion, 0-19 years Service Nurses if in Hull, and Paediatrician with involvement of specialist services as required/ detailed in personal plan.
  Begin Educational Health Care Plan (EHCP) preparation as soon as possible, and definitely before second birthday.
  Early support panel in the East Riding to maintain links and continue involvement

Ongoing health monitoring through screening and review by Community Paediatrician
  Cardiology, ophthalmology, audiology
  other specialist services (see guidance notes)

Referral to Community Paediatrician by Consultant Paediatrician in hospital/Neonatologist who discharges baby from hospital after birth (or after receiving treatment on SCBU/NICU)

Schedule of health checks
  Refer to Down's Syndrome Medical Interest Group schedule in attached guidance notes including what requires consideration, and when
  This can be found on page 21 (www.dsmig.org.uk)

Transition from children’s to adult services to be considered as part of the personalised care planning throughout childhood by 0-19 Years Service in Hull– (Health Visitor/School Nurse in the East Riding), with Paediatrician, Specialist Services, Community Team for Learning Disability & CAMHS (where appropriate), Education Services, Social Care where appropriate, and family.
  Adult Social Care to be invited to transition meetings to prepare for smooth transfer to adult services. If there is unmet need as transition takes place, invite adult CTLD to transition meeting.

Cardiology, Ophthalmology, Audiology
Other Specialist Services
  (see guidance notes)

Ongoing health monitoring through screening and review by Community Paediatrician
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  Adult Social Care to be invited to transition meetings to prepare for smooth transfer to adult services. If there is unmet need as transition takes place, invite adult CTLD to transition meeting.
Useful links and contacts

Family and Setting Support Team (offering Portage)
Hull 01482 616667
East Riding 01482 392189

Community Paediatricians
(Single point of Access)
01482 221261

East Riding Integrated Specialist Public Health Nursing Service (Beverley Office)
01482 677618

Children’s Community Team Learning Disabilities (CTLD) Hull
01482 303688

Child and Adolescent Mental Health Contact Point
Hull 01482 303688
East Riding 01482 303810

Adult Community Learning Disability Team
Hull 01482 336740
East Riding 01377208800

NB- Occasionally numbers may change without us knowing – please refer to organisations website if necessary.

Post diagnosis guidance

First Year
The family will receive ongoing support and visits from their named Health Visitor from the 0-19 Years Service, in Hull and from Health Visiting and Early Support in the East Riding. The family will receive ongoing support and follow-up from hospital Consultant/acute Paediatrician, at the Consultant’s discretion (generally only if medically required).

The family will be invited to attend an initial appointment with the Community Paediatrician, this will include Portage and education provision.

Referrals and introductions will be made to other members of the Team by the 0-19/Health Visiting Service/Community Paediatrician/Early Support Panel.

Initial visits – Health Visiting Team (0-19 Years Service)
This initial visit should be done in the hospital prior to discharge. If the baby has been discharged early, it may be arranged for the home. The purpose of this initial visit is to give the parents written and verbal information about Down’s Syndrome. Information about services in Hull and the East Riding of Yorkshire and an opportunity to talk about the diagnosis and to ask questions. Notification to the LA of the clinics additional needs to be done by Health Visitor Champion / Health Visitor /Early Support Panel.

Information to be gathered prior to initial visit: In addition to the usual information you would need for a first visit, it would be useful to consider the following.
- Confirm that the parents are ready to meet the named Health visitor
- Was the child expected to have Down’s Syndrome?
- What do the family already know about Down’s Syndrome?
- Is the chromosome result available? If not when will it be?
- Associated health/feeding difficulties e.g. are they discharged home with tube feeding. (if so, has a competency training pack been completed? Is there adequate supplies and arrangements for consumables)

Information to be given to the family on first visit:
- Downright special welcome pack which includes:
  - Personal Child Health Record (PCHR) inserts, these need to be obtained as soon as possible to ensure child growth is plotted on appropriate charts specific for Down’s Syndrome
  - Information about Down’s Syndrome Association (DSA) Parent’s leaflet
  - Parents Folder (if available)
  - Department of Health early start materials – Down’s Syndrome Booklet
  - Encourage access to community Child Health clinics for weighing, and advice around development and general child health

Follow up visit (within 1st month of life)
This usually takes place at home, but may need to be in the hospital if the child is still inpatient

General discussion and provision of further information regarding Down’s Syndrome and the locally available services (e.g. Downright special)
Appendix 9

Specific Down’s Syndrome literature from the Down’s Syndrome Association to be given to the family.

Offer the family the opportunity to meet with other families if not already had contact with Downright Special.

Confirm that the Neonatal team have:
- Arranged the following investigations and completed a discharge letter to the GP and Health Visitor.
- Echocardiogram done or booked through Outpatients with paediatric cardiologist (follow-up arranged if necessary)
- Hearing Screen
- Karyotype and, if parents not aware of result, when and how will this be communicated with them
- GP informed

Notes for the Down’s Syndrome Champion / 0-19 years Service / Health Visitors / School Nurse
The following guidance should be followed in all children who have Down’s Syndrome.
Pre-School – At least annual review with the Community Paediatrician
Disability Living Allowance: The family will have a right to apply with support from agencies.
Multi-agency review meeting arranged around 2 ½ -3 years of age if not done before. - Request for Education, Health and Care Plan preparation and assessment to be made. The 0-19 Years Service to organise this if not already taken place.
Ongoing support from the named Down’s Syndrome Champion continues in addition to universal services that all children receive. Support around transition (when starting primary and secondary school)

School age – Transition planning with wider 0-19 Years Service
At least annual review by local Community Paediatrician
Attendance at Transition Review in year 9. Invite Transition Nurse to multi-agency meetings

School Leavers
Review by community Paediatrician and preparation of a comprehensive report introduction to Adult Learning Disabilities Team where appropriate. Transition Nurse for Learning Disability to support young person to smoothly transition to adult services. Social Care to be involved where appropriate.
**Paediatrician review schedule & checklists**

### 3 Month Review
- Full history and clinical examination
- Feeding and Gastro Oesophageal Reflux (GOR) symptoms.
- Discuss bowels
- Cardiac assessment, checking ECHO reported - referral to Cardiology if necessary
- Hearing and vision
- Immunity and infections
- Discuss immunisation
- Is there a 0-19 years Down’s Syndrome Champion in place?
- Discuss family life & adjustment to diagnosis. Refer for support if needed. Downright Special/KIDS involved

### 6 Month Review
- Same Clinical Examination as 3 months
- Discuss immunisation. Encourage routine primary immunisation and Influenza vaccine
- Check hearing results are known and write letter to Child Hearing Assessment Centre (CHAC) to ensure appointment IPASS Referral
- Letter to SALT and explain to family the child will be seen at approx. age 9 months
- Infancy Oximetry test (Appendix 4) Page 18
- Check SEND team are aware of child (Down’s Syndrome Health Visitor Champion and Local Authority) Physiotherapy referral if needed if concerns about extreme hypotonia Page 19
- Check hips, knees, foot position. Is there Scoliosis or Perthes?

### 1 Year Review
- Any parental concern?
- Same clinical assessment and examination including abdomen, cardiovascular, neurological, ENT, (middle ear problems, airway obstruction, squint, cataract, nystagmus, blepharitis, nasolacrimal duct obstruction. Refer where indicated. Discuss development and health. Plot growth on Down’s Syndrome specific charts, and in red book. Authority/Physiotherapy referral if needed if concerns about extreme hypotonia Page 19 Refer to orthotics
- Discuss respiratory, cardiac, bowel symptoms (low threshold for investigation of coeliac disease)
- Unusual or recurrent infections and sleep related upper airway obstruction symptoms. Refer to ENT if symptoms present.
- Discuss therapy and educational input and consider referrals to specialist dentist and orthotics for boots. Check Portage arrangement are in place
- Are the family aware they can apply for Disability Living Allowance if not already in receipt of this? Refer to parenting support.
- Cervical spine and atlanto-axia instability discussion and give leaflet,
- Investigations: See DSMIG schedule (Appendix 8) Thyroid, Coeliac screen, Audiology. Annual Oximetry test - Appendix 4 (page18)
- Check hips, knees, foot position. Is there Scoliosis or Perthes?

### 2 Year Review
- Any parental concern? Same clinical assessment and examination as previous reviews, with particular attention to growth (plot on DS chart), ENT cardiovascular, neurological/signs of cervical spine instability or cord compression.
- Foot posture
- Behaviour, consider co-morbidities / dual diagnosis, or emerging concerns.
- Dental care- referral to specialist dental team indicated?
- Early education, plans under way? Contact SEND team or HV Down’s Syndrome Champion if not. If there is indication of dual diagnosis of Autistic Spectrum disorder – refer to CAMHS present
- Investigations: See DSMIG schedule (Appendix 8) Thyroid, Coeliac screen, Audiology. Annual Oximetry test - Appendix 4 (page18)
- Refer to Paediatric Ophthalmology Service (appendix 2 page 16)
- Hip screening. If not weight bearing, request hip x-ray and ensure physiotherapy input.
**3 Year Review**

- Any parental concern?
- Repeat full clinical assessment and examination as previous reviews, with particular attention to growth (plot on DS chart), ENT, cardiovascular, neurological/signs of cervical spine instability or cord compression
- Developmental progress and general health. Bowels, thyroid symptoms and coeliac symptoms
- Sleep related upper airway obstruction. Perform sleep study and/or refer to ENT if symptomatic.
- Discuss behaviour. Consider referral to CTLD if behaviour not responded to universal advice from 0-19 years service, consider dual diagnosis
- Orthopaedic checklist. Hips, knee position, foot posture. Is there scoliosis or Perthes?
- Dental care discussion
- Immunisations and annual influenza and Pneumovax II if in ‘at risk group’
- Investigations: See DSMIG schedule (Appendix 8) Thyroid, Coeliac screen, Audiology. Annual oximetry test (Appendix 8) page 18

**4 Year Review**

- As for 3 year review. As for other reviews. Ensure DSMIG (appendix 8) checks are continuing as per schedule. (Investigations, thyroid, coeliac etc).
- Is there continued involvement with the 0-19 Years Service for school transition? If not, contact Health Visitor/School Nurse
- Annual Oximetry test (Appendix 4) Page 21
- Discuss behaviour. Consider referral to CTLD if behaviour not responded to universal advice from 0-19 years service. Consider dual diagnosis

**5 Year Review & Annual Review**

- As for other reviews, repeat full clinical examination. Ensure DSMIG (appendix 8) checks are continuing as per schedule. (Investigations, thyroid, coeliac etc).
- Unusual or recurrent infections and sleep related upper airway obstruction. Refer to ENT if symptoms present. (appendix 4)
- Discuss therapy and educational input and consider referrals to specialist dentist and orthotics for boots.
- Are the family aware they can apply for Disability Living Allowance if not already in receipt of this?
- Discuss immunisation and influenza annual vaccine
- Discussion about puberty, sex and relationship education when the time is appropriate at annual review. If extra support required, consider referral to CTLD.
- Transition to CTLD if behaviour not responded to universal advice from 0-19 years service. Consider dual diagnosis.

**School Leaver Review**

- Repeat full clinical examination.
- Discuss behaviour
- Self care, independence, personal hygiene, sex and relationship education. Refer for support to Learning Disability Team where indicated.
- Testicular Check
- Dental care - referral to specialist dental team indicated?
- Discuss immunisation and annual influenza vaccine.
- Consider referral to the Community Learning Disability Service for support with behaviour that has not responded to the universal advice given by the 0-19 Years Service on a needs led basis.
- Transition to CTLD for adults. Correspondence to be sent, notifying of transition.
Care pathway for adults with Down’s Syndrome

- Adult with Down’s Syndrome who has not transitioned from children’s services with a plan in place.
  - Primary Care GP Baseline assessments and health checks. Prior to referral to rule out physical ill health e.g. urine infection.
  - Young adult transitions into adult services with plan in place, supported by the Hull Learning Disability Transition Nurse where there is unmet need.

- Behavioural distress, nursing need, mental health need, social care, psychology or therapy need present?
  - If appropriate, short term piece of work to address issue and either discharge, or referral to Intensive.

- Access to acute health services to be supported by the Learning Disability Liaison Nurse for care episodes. The Hospital Communication Handbook should be used as a support. A Communication Passport to help people to care for individuals will be used. This should include baseline presentation to enable health professionals to assess condition.

- Referral to the Community Learning Disability Service for assessment.
  - Referral to palliative care team where appropriate.

- Annual Health Check with GP or other health care professional. From age 14 years, a ‘Health Check Booklet’ will be given to anyone who has a learning disability to fill in before the check. A Health Action Plan will be given after the annual health check. For further information see http://www.chcpcic.org.uk/pages/wellbeing-service.

- Access to ‘Let’s Talk’ service with support in place.

- If symptomatic of Dementia, referral to be made to the combined Down’s Syndrome Dementia clinic. See page 14.


Personalisation of care, individual method of communication, access, and capacity to consent to treatment, must all be considered on an individual basis.

All people who have a learning disability have access to the same services as everyone else. Professionals can also refer or signpost in to other services that exist just for people with a learning disability.
Useful links and contacts

Adult Community Learning Disability Team (CTLD)
Hull 01482 336740
East Riding 01377 208800

Health needs for adults with Down’s Syndrome

The following conditions are more prevalent in adults who have Down’s Syndrome, therefore screening and a lower threshold for further investigation is important.

- Obesity
- Hearing impairment
- Gastro-oesophageal reflux
- Eye problems
- Osteoporosis
- Lower immunity hence more infections
- Diabetes Mellitus
- Dementia and Alzheimer’s Disease
- Hypothyroidism
- Constipation
- Hypermobility and joint problems
- Teeth/Dental problems
- Coeliac
- Spinal problems
- Cardiac difficulties

‘Annual Health Checks’ should include the assessment and discussion about the following:

- Thyroid Function Test
- Cardiovascular examination
- Sleep discussion, including somnolence. Possible sleep apnoea assessment if indicated
- Throat and neck examination
- Vision and hearing check (or confirmation these are being checked)
- Immunisations – including Influenza and Pneumococcal Vaccination
- Communication needs
- Medication review
- Lifestyle factors such as smoking, alcohol consumption, nutrition and exercise
- Sexual health
- Foot care
- Continence
- Weight, height, blood pressure and heart rate
- Mental health and emotional wellbeing, including mood and anxiety
- Well woman awareness (cervical and breast care screening)
- Well man awareness (testicular and prostate health)

Please Note

A person with Down’s Syndrome can develop any medical condition as with the general population. The following information is highlighted as we know there is a higher incidence of those conditions listed occurring in people who have Down’s Syndrome.

Everyone with Down’s Syndrome is entitled to an annual Health Check with their GP or primary care team. This will ensure that all the physical health needs are reviewed regularly. If, however, in the interim period there are any concerns regarding these, or any other health needs, conducting a GP consultation is recommended.

Consideration should also be given to the carer’s health and wellbeing.
Hull & East Riding Down’s Syndrome and Dementia Clinic

Jointly run by Psychology & Psychiatry

Referral to Dementia clinic
Internal or external referral due to concerns in memory or changes in behaviour

Referral to Nursing
To begin physical health checks

Dependant on results may not need to attend dementia clinic

Referral to Occupational Therapy
For functional assessment if applicable

Initial Clinical Psychology Assessment and OT Assessment

Initial Dementia Clinic Appointment
With relevant professionals

Clinical Psychology Reassessments
After 6 months
With OT assessments and Dementia clinic appointment

Further Assessment

Dementia diagnosed

No Dementia

Discharge from Clinic to be re-referred if necessary

Prevalence rates increase to 30 – 75% in people aged 60 – 69 with Down’s Syndrome (BPS 2015)

British Psychological Society (BPS) and Royal College of Psychiatrists 2015 Dementia and people with intellectual disabilities: Guidance on the assessment diagnosis, interventions and support of people with intellectual disabilities who develop dementia BPS Leicester
Down’s Syndrome Dementia

The community learning disability team work systematically as a multi-disciplinary team. We work with clients, carers and family in different environments including the family home, day service, supported living and residential settings. The health professionals in the team offer training to internal and external sources to support care of clients.

**Psychology**
- Talking therapies e.g. loss, negative experiences
- Anxiety management
- Anger management
- Mood problems
- Psychometric testing
- Positive behavioural support plan
- Psycho education
- Relationships
- Supervision and consultation
- Assessment and formulation

**Speech and Language Therapy**
- Dysphagia assessment
- Dysphagia intervention
- Communication assessment
- Communication passports
- Communication and behaviour work
- Intensive interaction
- Reminiscence work i.e. memory books, life story work
- Carer support and advice
- Communication friendly environments
- Staff training
- Advance care planning

**Occupational Therapy**
- Moving and handling assessment
- Postural management
- Specialist seating
- Developing independence
- Sensory profile
- Environment adaptations
- Equipment provision
- Volunteering or employment
- Personal care
- Daily living skills assessment
- Visual supports e.g. daily routine, activity plans
- Meaningful occupation
- Budgeting
- Travel practice
- Behavioural interventions e.g. mindfulness, sensory strategies, anger management
- Assessment and interventions relating to leisure, social activities and education

**Physiotherapy**
- Mobility assessment
- Postural management
- Transfers
- Seating
- Exercise advice
- Tone management
- Abdominal massage for chronic constipation
- Falls assessments
- Chest care at end of life

**Epilepsy**
- If seizures are suspected we provide assessment, diagnosis and treatment of epilepsy from specialist nurses and consultant neurologist.
- Each individual will have individualised epilepsy management plans which if required will include rescue medication.
- We look at medication management and optimisation providing ongoing support and advice for carers and families as appropriate to the individual.
- Epilepsy awareness and administration of rescue medication training is available for carers if required.
- We also work closely with our colleagues in palliative care to manage the individual's epilepsy at the end of life as there can be complex adjustments required to medications.

**Nursing**
- Health screening: routine and as part of the national screening programs
- Health Facilitation: health action planning
- In depth nursing assessments: to consider holistic needs and strengths
- Health promotion of any relevant health issues, inclusive of addressing health inequalities and making reasonable adjustments
- Total bowel management assessments
- Functional analysis of behaviour
- Relationship guidance
- Anger management
- Training for families, carers, providers and individuals re: health related topics
- Advocating for individuals
- Joint working with other health, education and social care as part of young person’s education and health care plan when in transition
- Medication optimisation
- Desensitisation in relation to treatments: dental, hospital, bloods and any health investigations.
- Intergenergy working within acute and primary care
- Social inclusion opportunities: friendship groups, RED disco, etc.
- Developing independence
- Continuing health care applications
- End of life support

**IST**
- The learning disability intensive support team is a multidisciplinary team comprised of Occupational Therapists, Speech and Language Therapist, Nursing, Psychologist and Healthcare assistants. They typically work with complex clients who range of interventions aimed at supporting people in the community.
Appendix 1 – Audiology for children’s services

- Children’s Audiology Clinics
  - No Clear Response
  - Clear Response
    - Targeted hearing follow ups at 8-9 months (Behavioural audiometry + Imped +
      Paediatrician Specialist Nurses Health Visitors referring)

- Close monitoring/ Ear Nose Throat referral/HA
  - Hearing loss
    - Satisfactory
      - Pre-school age monitoring at 12/12, 18/12, 3 & 4 years if required
    - Unsatisfactory
      - School age monitoring yearly until 18 years of age if required

- Neonatal Hearing Screen
  - Audiology needs will be assessed by adult services as need identified and will be monitored through annual health check

If a person transitions with hearing impairment they will remain with Audiology Services
Appendix 2 Guidelines for referral to ophthalmology service

Children with Down’s Syndrome are very likely to develop vision problems of one sort or another throughout life so it is especially important that the visual behaviour of children is checked regularly. Look for signs of squint, nystagmus, change in visual behaviour with time and any other parental concern.

If in doubt - refer to Ophthalmology.

The recommended structure devised by Down’s Syndrome Medical Interest Group (Down’s Syndrome MIG) 2000 for ophthalmic screening is as follows

Birth to 6 weeks
- Check visual behaviour
- Check red reflex for congenital cataract and other congenital abnormality such as coloboma of the iris
- Refer urgently to ophthalmology if problem identified/suspected at this stage

3 month review
- Check visual behaviour and red reflex as above
- Refer to ophthalmology if any concerns are raised

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

1 year review
- Check as above
- Problems with naso lacrimal duct may be a problem so consider referral for this if parents are concerned
- At age 18/12 an alert on system 1 to alert Health Visitors of need to refer to Orthoptic Screening for routine review. Attendance at a local screening clinic will be followed by a referral to an ophthalmologist regardless of outcome.

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

3 and 4 year review
- Checks as above including squint
- Check that referral and attendance at the eye clinic has taken place.
- If unclear then refer to ophthalmology.

Ongoing
- Repeat vision test at least annually.
Appendix 3 Speech and Language

Clinical advice includes:

- Feeding
- Hearing (assessment/levels and type of loss)
- Specific communication profile and learning style
- Language through play
- Speech sound development
- Signing (access to training)
- Down’s Syndrome Educational Checklists
- Language through reading/See and Learn
- Jolly phonics
- Talktools
- Numicon

Reasons for discharge include

- Treatment to be followed up out of area
- Treatment no longer wanted
- Treatment no longer appropriate
- Treatment complete

Care pathway for children with Down’s Syndrome from birth to 18 years

Referred to Speech and Language by Parents or professional

Pre-school Service

Mainstream Service

Special School Service

Initial assessment provided, including a case history

Parents and settings provided with advice and recommendations

Signposted to training

Episode of care to be implemented by SLT/SLTA

Targeted interventions implemented by parents/setting

Review planned or initiated by parents or setting

Advice on request with clear guidance on re-accessing the service

Pathway provided by Speech and Language Therapy Service, May 2017
Appendix 4

Sleep-related upper airway obstruction (SRUAO) or Sleep related breathing disorder (SRBD)

The RCPCH Working Party on Sleep Physiology and Respiratory Control Disorders in childhood reported that:

- Children with Down’s 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 on 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.

They recommended the following:

- All children with Down’s 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.
- Children with Down’s 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.
- If significant SRBD with hypoxia is present in children with Down’s Syndrome, then appropriate treatment should be offered.
- Further research is needed on the benefits and risks of screening for SRBD and Down’s Syndrome.
- It is acknowledged in the report that “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.

Symptoms to consider include:

- Snoring
- Sleep disturbance
- Mouth breathing and halitosis
- Restless sleep
- Chronic rhinorrhoea
- Subcostal and sternal recession
- Odd sleep positions, such as hanging over the bed or sleeping upright with head extended to optimise the upper airway
- Swallowing difficulties
- Recurrent upper respiratory tract infections
- Nausea and vomiting
- Daytime sleepiness
- Persistent or secondary enuresis
- Nocturnal sweating
- Cyanosis
- Apnoea
Appendix 5

Down’s Syndrome Physiotherapy Pathway
For Community & Acute Services for Children

Child referred to community service (medical referral)

Is child under 2 with Hull GP?

Triage

Physiotherapy assessment of child development and motor skills review Down Syndrome – child development chart and identify key areas of development

Milestone development in line with Down Syndrome

Milestones below those expected for child with Down Syndrome or concerns regarding significant hypermobility/ poor joint stability

Liaison with Paediatric Consultant and referral for hip x-ray/ orthopaedic opinion

Assessment and consideration of provision of equipment to aid independence e.g. walking assessment. Consideration of Rifton pacer / Kaye walker

Assessment of foot posture - consideration of orthotic provision e.g. AFO/DAFO/Piedro boot/EVAs

Education and advice to parents/carers regarding Down Syndrome Child Development and how to aid their child’s independence.

Education and advice to parents/carers regarding Down Syndrome child development and how to aid their child’s independence.

Advice regarding cervical spine instability.

Advice regarding cervical spine instability.

Create early intervention Physiotherapy management programme in liaison with parents/carers and all multi-disciplines involved with the child.

Monitor motor skill progression and gradually reduce level of physiotherapy input once child independently walking – monitor progress using Gross Motor Function Scale

Education and advice to parents/carers regarding Down Syndrome Child Development and how to aid their child’s independence.

Discharge – parent can access service again via Downright Special or medical referral

Child attends Downright Special Physiotherapy drop in session (half termly)

Refer on to Physiotherapy Team HEY

Child referred to community service (medical referral)
Appendix 6
Down Syndrome
Occupational Therapy
Pathway

- Child referred to community OT via GP, Consultant or Physiotherapy

- Referral screened

- Referral accepted and placed on departments waiting list if it meets the service referral and priority criteria

- Occupational therapy assessment of child’s level of development and functional skills

- Milestones below those expected for child with Down Syndrome e.g child unable to sit or mobilise independently

- OT intervention includes recommendation for specialist equipment to assist with positioning, development of sitting, moving and handling bathing, feeding etc.

- Education and advice to parents/carers/nursery/school on how to promote development of their child’s functional independence skills

- Liaison with other professionals involved Early Support meetings

- Implement Occupational Therapy programme in liaison with parents/carers and all professionals involved with the child.

- Review OT programme, specialist equipment and provide advice on child’s

- Milestones at expected Level. OT to provide advice, support, signpost to other services and discharge

- Discharge at the end of the episode of care when OT input is no longer required. Parent can access service again via GP or Consultant

- Referral not accepted as fails to meet criteria referrer informed or signposted to another service eg Wheelchairs Service, Social Services OT

Version 2 October 2018
Appendix 7 - Downright Special Service Provision

Downright Special is a charity which provides support to families with children with Down’s Syndrome in Hull and East Yorkshire. This support covers a variety of areas, as follows:

Antenatal support
- Our information packs are stocked in the Antenatal Clinic at Hull Royal Infirmary, Women and Children’s Hospital, for distribution to families with an antenatal diagnosis of Down’s Syndrome, or those with a high probability of such a diagnosis.
- Our volunteers are available to talk to families in such a situation, if required.

Neonatal support
- We have been involved in providing training to midwives, neonatal nurses and Paediatricians regarding early support and communication of diagnosis.
- Our new baby information packs are available to all families with new babies who happen to have Down’s Syndrome. These include our information DVD, leaflets regarding Downright Special and information provided by the national Down’s Syndrome Association.
- When and if families wish us to do so, our volunteers can visit to provide information and support. Families can either contact us directly or referrals can be made by other services, with the families consent for them to do so.

Health
Families of children with specific health needs can be put in touch with other families in a similar situation.
- Information regarding health issues is available via our website.
- We have provided training to the team at the Eye Clinic and have been involved in discussions to shape the service provided to children with Down’s Syndrome. A leaflet is available for parents which gives further information about vision, eye clinic and related topics.
- We are able to provide training to other health care professionals, including information about Down’s Syndrome in general and how to get the best out of a consultation with a child with Down’s Syndrome.
- We work closely with the community and hospital physiotherapy teams. We have provided training for parents regarding physiotherapy issues and physiotherapists visit our sessions to provide support to families.
- We deliver training sessions for parents and professionals alongside members of the speech and language therapy team, who also visit our educational sessions to enable sharing of best practice.
- Health Visitors visit Downright Special monthly to give further input around health, development and growth.

Early Years Support
- Our Downright Special Friday sessions are for children from birth to 5 years old and offer an excellent chance for parents to meet each other and to enjoy their babies and young children in a relaxed environment.

- Through our baby group we provide an introduction to signing, speech sound production, communication skills and sensory stimulation.

Education
- Our specialist teachers provide support to children, teachers and teaching assistants in both the pre-school and school settings. This includes advising on annual reviews, special educational provision and target-setting for Individual Education Plans (IEPs).
- Schools are provided with an education pack which includes valuable resources used to support the specific learning profiles of children with Down’s Syndrome.
- We deliver training to teachers and teaching assistants regarding specific techniques used in teaching children with Down’s Syndrome.
- Each Friday our specialist teachers deliver targeted small group lessons within our group session. These have the added bonus of providing on-going training and support to parents and teaching assistants.

Social
- We host regular social activities for the whole family to allow children with Down’s Syndrome, siblings and parents an opportunity to interact in a relaxed environment.
- Our Friday group session includes both structured and unstructured time for children to develop their social and play skills and for parents to meet other parents.

Information
- Our website provides information regarding a number of issues important to families with children with Down’s Syndrome.
- We have an active Facebook group for parents as well as a Facebook page and Twitter account which provide information to the wider public.
- We provide advice, advocacy and support to families in person, over the telephone, by email or social media.

Referral Pathways to Downright Special
- Families are very welcome to self-refer to us, either via telephone (01482 420160) or email (enquiries@downrightspecial.co.uk).
- Those with an antenatal diagnosis can be referred by the antenatal clinic.
- Referrals are made with permission from the family by ante natal and post natal wards, Neonatologists and Midwives.
- Any other health professionals are able to refer to us at any point if, for example, a family moves to the area when their child is older.
- Schools and pre-schools can access our services via telephone or email at any point in the child’s school career.
DOWN SYNDROME - SUGGESTED SCHEDULE OF HEALTH CHECKS

The following are suggested ages for health checks. Check at any other time if there are parental or other concerns.

<table>
<thead>
<tr>
<th></th>
<th>Birth - 6 weeks</th>
<th>Special checks under 2 years</th>
<th>Preschool checks</th>
<th>School age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thyroid blood tests</td>
<td><em>Newborn</em> routine heel prick - blood spot test</td>
<td><em>From age 1 year</em> thyroid function should be discussed annually using results of either • Annual fingerprick TSH test OR • 2 yearly thyroid blood tests, including thyroid antibodies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eye checks</td>
<td><em>Newborn</em> routine check including congenital cataract check</td>
<td><em>Age 18-24 months:</em> Formal eye and vision examination including check for squint, and refraction for long or short sight</td>
<td><em>Age 4 years:</em> Formal eye and vision examination including check for squint. Refraction and assessment of near and distant vision and visual acuity</td>
<td><em>Repeat vision test every 2 years, or more frequently if recommended by optometrist or ophthalmologist</em></td>
</tr>
</tbody>
</table>

Visual behaviour to be monitored at every review particularly in first year

<table>
<thead>
<tr>
<th>Hearing checks</th>
<th>Universal <em>newborn</em> hearing screen</th>
<th>Full audiological review by <strong>10 months</strong> including hearing test and impedance check</th>
<th>Annual audiological review as before</th>
<th>2 yearly audiological review or more frequently if recommended</th>
</tr>
</thead>
<tbody>
<tr>
<td>Growth monitoring</td>
<td>Length, weight and head circumference should be checked frequently and plotted on Down syndrome growth charts</td>
<td>Height and weight should be checked and plotted on Down syndrome growth charts at least annually while growing. (BMI checked if concern regarding overweight)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heart checks</td>
<td><strong>By age 6 weeks,</strong> formal heart assessment including Echocardiogram</td>
<td><strong>At all ages</strong> low threshold for reviewing heart status if signs or symptoms develop</td>
<td></td>
<td>From adolescence onwards as part of routine health checks listen to heart for signs of acquired heart disease</td>
</tr>
<tr>
<td>Breathing checks</td>
<td>Enquire at every review for uneven breathing during sleep and poor quality sleep. Low threshold for further testing using sleep studies</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blood checks</td>
<td><em>Newborn</em> blood test to check for abnormal blood film</td>
<td>If blood film is abnormal in first 6 weeks, follow up or repeat blood testing may be necessary until age 5</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Detailed recommendations for Medical Surveillance Essentials for children with Down syndrome can be found at www.dsmig.org.uk

Down syndrome insert © DSMIG 2011
A person with Down’s Syndrome can access mainstream services with reasonable adjustments in place.

The team may not be involved continuously, the team works on a needs based system. Once the relevant intervention is complete the individual can be discharged but can access the service again if needs change.
References and Acknowledgements

The development of this pathway and guideline has been facilitated with the support of the following people, services and organisations.

Helen Chamberlain – Principal Physiotherapist Humber Teaching NHS Foundation Trust (HTFT)
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Jane McFarlane – Neonatal Screening Co-ordinator (HEYHT)
Vicky Abbott – Parent
Janette Waddingham – Parent
Anna Daniels – Clinical Trainer, City Healthcare Partnership (CHCP)
Gillian Bowlas – Manager, Downright Special
The Parents and Carers of Downright Special in original focus groups and consultation
Laura Jones – Parent Forum Manager, Yorkshire & Humber KIDS
Lynne Barton – Clinical Manager, 0-19 Years Service, (CHCP)
Suzanne Nicholls - Learning Disability Primary Care Liaison Nurse, Emotional Wellbeing Service, CHCP
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Mick Fletch – Hull Transition Nurse, CTLD, (HTFT)
Colin Hurst, Engagement Manager, NHS Hull CCG
Helen Sall – IPASS, Hull City Council
Childrens Occupational Therapy Team (HTFT)
Jill Atkinson - Antenatal and Newborn Screening Co-ordinator
Leicestershire Partnership NHS Trust Care Down’s Syndrome Care Pathway, 2016
Nottingham Guidelines for the management of children with Down’s Syndrome
NHS Grampian- Down’s Syndrome Care Pathway, 2008

Medical and Surgical Care for Children with Down’s Syndrome: A Guide for parents
Van Dyke et al (Editors)

Early Support Programme Publications (Blue Box)
Information for Parents – Down’s Syndrome
https://www.education.gov.uk/publications/standard/publicationDetail/Page1/ES13
Developmental Journal For Babies and Children with Down’s Syndrome
https://www.education.gov.uk/publications/standard/publicationDetail/Page1/ES49

Personal Child Health Record for Babies with Down’s Syndrome

Down’s Syndrome Medical Interest Group
Children’s Centre
City Hospital Campus
Hucknall Road
Nottingham NG5 1PB
Website: www.dsmig.org.uk

Down’s Syndrome Association
Langdon Down Centre
2a Langdon Park
Teddington TW11 1PS
Tel: 0333 1212 300
Website www.downs-syndrome.org.uk

Parent support, and information on range of issues including health, education and legal issues

Down’s Heart Group
PO Box 4260
Dunstable
Down’s Syndrome LU6 2ZT
Tel: 0300 1021644
Website: www.dhg.org.uk

Parent support group – useful information leaflets on cardiac issues
Glossary of terms, including abbreviations

0-19 Years Service
Hull Health Visitors and School Nurses

ABR
Auditory Brainstem response (relating to audiology/ear/hearing)

AFO
Ankle Foot Orthosis (brace worn on lower leg to support ankle)

Amniocentesis
Test carried out during pregnancy to assess whether the baby may have a genetic or chromosomal condition

Annual Health Check
From age 14 years onwards someone who has Down’s Syndrome should have a thorough annual health check

Audiology
Hearing team

Cardiac/Cardiovascular
Heart/ circulation/blood vessels

Cardiology
Department who deal with health of the heart

Cataract
clouding of the eye lens which can lead to a decrease in vision

CCG
Clinical Commissioning Group

CHCP
City Health Care Partnership

Coeliac disease
lifelong autoimmune disease caused by a reaction to gluten. It can cause diarrhoea, abdominal pain, bloating and the inability to absorb certain nutrients.

Continence
The ability to control bladder and bowel.

CR
Clear response (relating to audiology/ ear/ hearing)

CTLD
Community team for Learning Disability

CVS
Chorionic Villus Sampling

DAFO
Dynamic Ankle Foot Orthosis (brace worn on lower leg to support ankle)

Down’s Syndrome Champion
A nominated professional from the 0-19 Years Service who advises a Health Visitor or School Nurse on supporting a family who have a child with Down’s Syndrome

DSMIG
Down’s Syndrome Medical Interest Group

Early Support
East Riding service that supports children with additional needs

ENT
Ear, nose and throat team based in the hospital.

FBC
Full Blood Count

FISH Test
Fluorescence in situ hybridization test (type of blood test)

Gestation
The length of pregnancy or amount of time a baby is in the uterus (A typical pregnancy gestation is around 38-42 weeks with ‘full term’ being classed as 40 weeks)
GOR
Gastroesophageal reflux – where acid from the stomach leaks up into the oesophagus (gullet).

HA
Hearing Aid

HEY
Hull & East Yorkshire Hospitals

Hirschsprung’s disease
Condition affecting the large intestine and causes problems passing bowel movements.

Hypermobility
Joints are flexible and easily move beyond expected range.

Hypothyroidism
Under active thyroid gland

Imped
Impedance testing (relating to audiology/ear/hearing)

Infant Feeding Co-ordinator
A professional who specialises in supporting people to feed their baby and advises on different feeding techniques and those who may require additional support.

IPASS
Integrated Physical and sensory service (HULL)

Karyotype
Laboratory test done on blood

Makaton
Language programme that uses signs and symbols to help communication. It is designed to support spoken language

NCR
No Clear Response
(relating to audiology/ear/hearing)

NICU
Neonatal Intensive Care Unit

NIPE
Newborn and Infant Physical Examination

Numicon
Multi-sensory approach to teaching maths

OAE
Otoacoustic emission
(relating to audiology/ear/hearing)

Osteoporosis
Medical condition where the bones can become brittle and fragile.

Ophthalmology
Eye/vision team

OT
Occupational Therapy – a team who assess patients and provide therapy, and recommendations

Oximetry test
test used to measure the oxygen levels in the blood. This may be done over night as a ‘sleep study’ to see if the oxygen levels are dropping overnight (which could possibly be due to sleep obstruction or apnoea).

Paediatrician
Doctor who specialises in health of a child

PCHR
Paediatric Child Health Record

Physiotherapy
Team who look at physical movement and function of joints, limbs, muscles, posture and core including strength, gait and balance.

Podiatry
Team who specialise in the assessment and treatment of feet, including their position

Portage
Home-visiting educational service for pre-school children with additional needs. In Hull the Family & Setting Support Team (FASS) offer this service
QFPCR
Quantitative Fluorescence-Polymerase Chain
Reaction; laboratory test done on blood

RSV
Respiratory Syncytial Virus

SALT
Speech & Language Therapy. Team to advise on speech, communication, feeding and swallowing.

SCBU
Special Care Baby Unit

SEND
Special Educational Needs and Disabilities

SLA
Speech & Language Therapy Assistant

TAM
Transient Abnormal Myelopoiesis

Thyroid
Thyroid gland releases important hormones that keep your body functioning at the correct speed

SaPTS
Sensory and Physical Teaching Service