



...building a brighter future for
children with Down Syndrome

Health, Social and Education Directory

for children with
Down Syndrome in
Hull and East Riding (2021/22)

Babies 0 - 18 months

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Health, Social and Education Directory

Babies 0 - 18 months

This directory was co-produced by Downright Special staff and parents who have been in your shoes. It is to provide you with some useful information you might need at this stage in your baby's life. There is a lot of help and support out there but sometimes it can be hard to find or understand. Help available also varies from area to area.

The Hull Down Syndrome Care pathway

(<https://www.hullccg.nhs.uk/downssyndromehull>) is a road map of health care provision for people with Down Syndrome (DS) locally. We wanted to make the care pathway more accessible to you as parents/carers. We also wanted to bring information about health care together with information about the educational, social and emotional support available locally for you and your family. The result is this directory.

We hope this directory will help you to navigate the first 18 months. It might seem overwhelming to read all at once so please don't. Keep this as a document you can refer to as and when you need to know something. If you are somebody that likes to know everything there are many links to explore. If not then just use the main section and forget the rest.

When your child gets older we have separate guides for those next ages and stages.

If you feel upset or frightened by any of this information be aware that not all children with Down syndrome (DS) will need support in all these areas and many children grow up to lead healthy lives.

Also remember that you are never alone in this experience and parents of other children with DS will fall over themselves to help and support you.

Above all else consider these very wise words written by a young person with DS.

// But the first, most important thing I want you to always remember: everyone with Down Syndrome is a new and different person and it isn't the most important thing about them! //

Can I Tell You About Down Syndrome?
Elizabeth Elliott, 2016

This directory is alphabetical. It explains what your family can expect in terms of health, education and social support in the first 18 months of your child's life, and what additional support you can seek should you wish.

There are many commonalities between children with DS but your baby is an individual with unique needs and circumstances therefore the information in the directory is just a guide, there may be variations for your child. For example your child may be receiving specialist care for bowel or heart conditions which is not included in the information below. Geographical variations in services may also occur as Downright Special (DRS) supports children in Hull, East Riding, Lincolnshire and North Yorkshire Local authorities. Look at the "Local Offer" section on your own council website for specific information about local services for children with a disability.

DS is a cause of learning disability (sometimes now called intellectual disability). People with learning disability have the right to access mainstream health care, for example from their GP or hospital throughout their lives as would any citizen. Health care providers are legally obligated to make "reasonable adjustments" to make this care accessible.

When the word "review" is used below it means appointments your baby will have with a Paediatrician to monitor their health. These will be more regular when your child is younger and reduce in frequency, depending on need, as they grow. Your baby will remain under the care of the Neonatology Team paediatricians at the Hospital (HRI) after discharge. They will conduct the early reviews. At some point around 1yr -18 months of age, care will be transferred to the Community paediatric medical service (also based at HRI) who will then conduct the reviews. There is likely to be some overlap where both these teams are involved. The care and support described in the directory **is in addition** to the care any UK baby would receive (universal services) for example health visiting and GP provision and does not replace this.

On the tables below

1 = Taken from Down Syndrome Medical Interest Group Green insert

2 = Taken from Hull DS Care pathway

Subject/ category (Alphabetical)	Monitoring, treatment, help or support.	Who helps ?
<p>Benefits</p> <p>Your child may be eligible for Disability Living Allowance (DLA) from 3 months of age.</p>	<ul style="list-style-type: none"> ■ Downright Special (DRS) staff member Louise can help with your application form as can your Health Visitor (HV). ■ Once DLA is in place you may fit the criteria to claim Carer's Allowance depending on your personal circumstances. 	<p>Louise, Downright Special staff member louise@downrightspecial.co.uk</p> <p>Your own HV.</p> <p>Official and unofficial online and peer sources of advice, see links on P8.</p>
<p>Bladder</p> <p>Dry by day a little later than a typically developing child.</p>	<ul style="list-style-type: none"> ■ Most Children with DS achieve daytime urinary continence at between 36-50 months¹. ■ Gradually introducing elements of toilet training early (around 9 months) gives more time to learn the skills needed even when readiness to achieve continence is not yet apparent. ■ DRS run a toilet training workshop for all parents which includes bowel management advice. 	<p>Your own HV can give general potty training advice.</p> <p>Reputable online sources of advice, see links on P8.</p> <p>DRS workshop would be advertised via Facebook or by e-mail invitations to parents.</p>

<p>Bowels</p> <p>Constipation is common.</p>	<ul style="list-style-type: none"> ■ In most cases there is no underlying problem and this can be managed as with any child with advice from GP or HV¹. ■ If constipation present from birth, is severe or persists despite measures discuss with your GP¹ or paediatrician. ■ Bowel discussion to take place at each paediatrician review. ■ Bowel control not expected till 36 months of age on average¹. ■ Pro-active management of constipation is encouraged. Follow the links on p8 for reputable online sources of advice on this. ■ DRS run a toilet training workshop for parents which includes bowel management advice. 	<p>GP</p> <p>Your own HV or the HV that visits Downright Special group.</p> <p>Neonatologist or Community Paediatrician (contact details P29).</p> <p>Reputable online sources of advice, see links on P8</p> <p>DRS workshop would be advertised via Facebook or by e-mail invitations to parents</p>
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<p>Breathing</p> <p>Can be prone to nasal congestion and respiratory infection which affects breathing.</p> <p>Also common is obstructive sleep apnoea¹ (OSA) Sleep apnoea is one kind of sleep related breathing disorder (SRBD).</p>	<ul style="list-style-type: none"> ■ Nasal suction or saline drops/spray can help with congestion¹ ■ An overnight oximetry check (to measure oxygen levels in the blood whilst sleeping, at home) is recommended at around 6 months, then to be repeated annually². ■ Discussion about sleep quality and breathing during sleep at each paediatric review^{1&2}. ■ See "infection" section on p19 for respiratory infection information 	<p>Oximetry arranged by Neonatology at 6 month review. Referral made to an Ear, nose and throat (ENT) specialist if any concerns. Possible further sleep studies may then be conducted.</p> <p>Discussion with Neonatology/Community paediatrics at each review.</p>
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<p>Childcare</p>	<ul style="list-style-type: none"> ■ Babies with Down Syndrome are able to access childcare at a Nursery or a childminder in the same way as typically developing children. ■ Working parents can find the early years challenging in terms of juggling work with health events and appointments however many families manage this successfully ■ Downright Special have an Early Years outreach worker who can support the childcare setting with recommendations and resources. They can also support you with advice while you choose a setting. ■ Downright Special can put you in touch with other working parents if you would like to talk this over. 	<p>See Link on P9 for some online parent stories</p> <p>Speak to Laura at Friday morning sessions or email Laura@downrightspecial.co.uk</p>
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<p>Dual diagnosis</p> <p>The term “dual diagnosis” in the DS community means a diagnosis of DS and Autism (ASD). Estimates vary but it is now thought that around 10% of people with DS have diagnosable autism. This can become apparent from an early age (toddlerhood) or later in childhood.</p>	<ul style="list-style-type: none"> ■ Social communication difficulties is a term you may hear. This is not the same as a diagnosis of autism (this cannot be given by a single professional) but a description of some specific developmental differences SALT may have noticed in your child (as compared to typical DS development). ■ Share concerns or ask questions of any professionals involved in your child’s care (particularly Speech and Language Therapy) including your Downright Special group teacher. ■ An additional diagnosis can be frightening and isolating for families. Downright Special staff can link you with others with similar experiences and offer bespoke educational provision if a need is identified 	<p>Speech and Language Therapy (see contact P13)</p> <p>Downright Special teaching staff</p> <p>Portage (contact details P26)</p> <p>Health visitor (contact details P29)</p> <p>Community Paediatrician (contact details P29)</p>
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Additional information and contacts by category.

Benefits

The charity Cerebra produce a guide to successfully claiming DLA
<https://cerebra.org.uk/get-advice-support/>

The Down's Syndrome association website has comprehensive benefits information. They also have a benefits advisor you can e-mail or call. <https://www.downs-syndrome.org.uk/about-downs-syndrome/lifes-journey/benefits-finance/>

Government advice on eligibility for carer's allowance <https://www.gov.uk/carers-allowance>

The charity "Contact a family" have online guides, calculators and a helpline.
<https://contact.org.uk/advice-and-support/benefits-financial-help/>

Peer support private Facebook group, DLA for children: advice and support. DLA for children, advice and support. <https://www.facebook.com/groups/518450451568106>

Bladder

One page guide of top tips for starting toilet training children with DS
<https://www.bbuk.org.uk/wp-content/uploads/2019/08/Top-tips-for-potty-training.pdf>

Bladder and Bowel UK have other information about training readiness and ideas
<https://www.bbuk.org.uk/toilet-training-resources/>

ERIC (children's bowel and bladder charity) Guides to potty training children with additional needs. <https://www.eric.org.uk/potty-training-children-with-additional-needs>

Bowels

Advice about understanding and managing constipation including information about specific conditions that can occur in children with DS such as Hirshsprungs and anal/rectal malformation. Continence helpline with specialist advisors.
<https://www.bbuk.org.uk/bowel-resources/>

Comprehensive source of Information and advice about managing and treating constipation in children.
<https://www.eric.org.uk/Pages/Category/bowel-problems>

Breathing

Appendix 4 of Hull Down Syndrome Care Pathway lists some signs and symptoms of SRBD.

<https://www.hullccg.nhs.uk/wp-content/uploads/2018/05/201803-dsp-pathway-document-vs.-1.0.pdf>

Page 5 of this information booklet has further information about Obstructive sleep Apnoea (OSA)

https://www.downs-syndrome.org.uk/wp-content/uploads/2020/06/Managing-Sleep-Problems-In-Children-21st-March-KP-28th-June-SM_DSMIG.pdf

Childcare

This website has some first hand stories from American working parents

<http://downsyndromepregnancy.org/working-moms/>

Dual diagnosis

This DSA website explains dual diagnosis of DS and Autism.

<https://www.downs-syndrome.org.uk/about-downs-syndrome/life-journey/complex-needs-autism/>

The Down Syndrome Research foundation website has information about dual diagnosis and some signposts to other sources.

<https://www.dsrf.org/information/autism/>

Subject	Monitoring, treatment, help or support.	Who helps ?
<p>Emotional wellbeing</p> <p>(Parents and siblings) Coming to terms with a diagnosis can be an emotionally challenging time for new parents, often likened to a grieving process. It is normal to find this difficult at the same time as loving your baby unconditionally.</p>	<ul style="list-style-type: none"> ■ Talk to your HV or GP ■ Self refer to local emotional wellbeing services who can assess your needs and refer you for appropriate support ■ Downright special Friday groups are an opportunity to speak to other parents about your feelings. Whilst we wholeheartedly celebrate the unique gift that is DS we recognise that having a baby with additional needs can be an unexpected and significant adjustment. We aim to provide a safe space where parents are free to express any thoughts they have about coping with their child's diagnosis. You can also talk to a member of staff without judgement, in confidence, many of whom are themselves parents of a child with DS. ■ There are many online resources or communities that deal with the process of coming to terms with a diagnosis. ■ DRS have a resource borrowing library which includes many books written by parents describing first hand the diagnosis of their child and their DS journey ■ DRS Social events are an opportunity for siblings to meet and befriend other siblings of children with DS. 	<p>GP, HV</p> <p>Hull-Let's talk (link below). East Riding emotional wellbeing service (link P11).</p> <p>Staff and peers at DRS by phone, in person at Friday group sessions or at Social events.</p> <p>Online self and peer help-see links P11.</p> <p>Downright Special resource library ask louise@downrightspecial to join online or browse at friday sessions</p> <p>Invitations to events are via Facebook and e-mail.</p>

Additional information and contacts by category.

Emotional wellbeing

PADS (Positive about Down syndrome). Peer support on Facebook. Split by age group so you can join a group just for parents of babies 0-18 months. A Social forum but also a useful place to ask for advice or support from other parents. PADS website page <https://positiveaboutdownsyndrome.co.uk/the-journey-begins/> has stories written by parents about their own experiences of pregnancy, birth, diagnosis and early years.

The Down's Syndrome Research Foundation (dsrf-uk.org) have a section on their website for new parents <https://www.dsrf-uk.org/parents-carers/new-parents/>

The Down's syndrome association has new parent stories and videos on their website <https://www.downs-syndrome.org.uk/about-downs-syndrome/pregnancy-and-baby/new-parent-stories/>

The DSA new parent pack has some advice regarding siblings in the "congratulations on the birth of your baby" leaflet and there is also a leaflet that you can give to family members to explain Down syndrome and how you might be feeling.

<https://www.downs-syndrome.org.uk/about-downs-syndrome/pregnancy-and-baby/you-and-your-baby/>

DownSyndromePregnancy.org have a selection of excellent publications which you can download. We also have some in our resource library. They give insightful advice about coping with diagnosis including ideas for what to say to family and friends and practical advice about navigating other people's comments or reactions.

<http://downsyndromepregnancy.org/books/>

It is vital that you also consider self-care as part of your role as a new parent. If you feel you need professional talking therapy you can self-refer to the Wellbeing services below who will make an initial assessment of your needs and either provide appropriate support or refer you for more specialist help. These Universal services can be used to provide emotional support around experiences of new parenting and adjusting to diagnosis.

In East Riding-East Riding Emotional Wellbeing Service,
NHS Talking Therapies <https://humberews.co.uk/can-we-help-you/>
In Hull-Make a Referral - Let's Talk - Hull Depression & Anxiety Services
<https://www.letstalkhull.co.uk/pages/make-a-referral>

The affinity website offers online advice about emotional wellbeing and peer support for parents of children with disabilities including coming to terms with diagnosis and signposting to sources of professional help.
<https://www.affinityhub.uk/1/Welcome.html>

Subject	Monitoring, treatment, help or support.	Who helps ?
<p>Feeding</p> <p>May have feeding difficulties in the first weeks.</p> <p>Breast feeding may be harder to establish but can definitely be successful.</p> <p>Issues may emerge at later stages e.g. moving to solids¹</p>	<ul style="list-style-type: none"> ■ Your HV can provide advice on feeding (breast or bottle) and about weaning onto solids ¹. ■ Other parents have found breastfeeding peer support groups helpful ■ Speech and Language Therapy (SALT) can provide specialist advice following assessment about feeding and swallowing issues². ■ An Occupational Therapist (OT) can help with specialist equipment/advice regarding independence skills when feeding such as special seating or cutlery if typical DS milestones are not being met² ■ Feeding and gastro-oesophageal reflux symptoms are discussed at the 3 month review ² 	<p>Your own HV. A DS Champion Health Visitor attends DRS Friday sessions each month.</p> <p>Online and in person peer support, links P13</p> <p>Referral to SALT can be made by a professional, DRS or by yourself (contact P13)</p> <p>OT referral made via GP, Neonatologist, Community Paediatrician or Physiotherapist ².</p> <p>3 month review is with neonatologist</p> <p>Downright Special resource library is a source of information-ask a staff member or browse the library at Friday sessions</p>

Additional information and contacts by category.

Feeding

Integrated Paediatric Therapy Service (Humber Teaching NHS Foundation Trust)
<https://www.humber.nhs.uk/services/integrated-paediatric-therapy-service.htm>
 Speech and Language Therapy (SALT) 01482 692929 (option 3) or
 e-mail hnf-tr.sltadmin@nhs.net

Occupational Therapy (OT).
 East Riding 01482 478898 (Beverley) or 01405 608233 (Goole).
 Hull 01482 692929 (option 4)

Feeding, drinking and weaning advice and tips
<https://www.downs-syndrome.org.uk/wp-content/uploads/2021/04/Comms-Series-Feeding.pdf>
<https://www.downs-syndrome.org.uk/wp-content/uploads/2021/02/30.04.2020-Drinking-Straw.pdf>

Some recommendations for teat/bottle options
<https://downssyndromeassociation.wordpress.com/2013/07/23/new-parents-feeding-bottles/>

Tips for adapting breastfeeding for babies with DS
<https://www.breastfeedingnetwork.org.uk/downs-syndrome-and-breastfeeding/>

Canadian booklet providing advice about different holds with tips
<https://cdss.ca/wp-content/uploads/2016/05/CDSS-Breastfeeding-a-Baby-With-Down-Syndrome-ENGLISH.pdf>

Information about breast and bottle feeding babies with Heart conditions
<https://dhg.org.uk/information/feeding-problems/#:~:text=%20Feeding%20Problems%20%201%20Weight.%20Make%20sure,hole%20in%20the%20teat%20is%20big...%20More>

Comprehensive booklet by Down Syndrome Ireland about feeding and weaning babies with DS including some information about tube feeding.
https://downsyndrome.ie/wp-content/uploads/2018/03/feeding_oral_development.pdf

Hull peer breastfeeding support group
 To refer yourself to either project either talk to your midwife or health visitor or contact their office on 01482 497 811.

Subject	Monitoring, treatment, help or support.	Who helps ?
<p>Growth</p> <p>Babies and Children with DS require different charts to monitor their growth as they tend to have smaller than average stature.</p>	<ul style="list-style-type: none"> ■ Ensure your child has the (green) Down Syndrome Medical Interest Group (DSMIG) growth charts in their "red book" to replace the standard charts. It is important that your baby's growth is plotted on these charts. Your HV should provide these at the initial visit (in home or hospital) 2. ■ Your HV also makes a follow up visit within first month of life. ■ A DS HV Champion pays a monthly visit to DRS Friday sessions. Both are opportunities to weigh your baby and seek input about health, development and growth2. ■ Regular attendance at the usual baby weighing clinics is encouraged 2 	<p>Your own HV (Link to the charts and DSMIG online information also provided P15)</p> <p>A HV DS Champion visits the group one Friday in every month</p>

Additional information and contacts by category.

Growth

Fact sheet about why children with DS need different growth charts

<https://www.dsmig.org.uk/wp-content/uploads/2015/10/Chart-Fact-Sheet-A4-4pp.pdf>

The "Red book" Green insert containing the growth charts can be downloaded here, however this should be provided by HV.

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

Subject	Monitoring, treatment, help or support.	Who helps ?
<p>Hearing</p> <p>Prone to minor hearing difficulties for example Glue Ear. Most hearing loss is mild or temporary. Important to identify early to minimise the effect on speech and language development¹.</p>	<ul style="list-style-type: none"> ■ Hearing screen at birth. If no clear response baby referred to paediatric audiology. If clear response then still expect follow ups to monitor at 8-9 months following referral by community paediatrician, specialist nurse or HV². ■ The 3 month review should include a hearing check. At 6 month review the hearing results should be known/checked and appointments arranged as necessary². ■ After 10 months full audiological review annually is recommended (more frequently if needed) whilst pre-school age¹. ■ Expect an ear examination at 1yr review with close monitoring if hearing loss apparent and possible ENT referral¹. After that even if hearing satisfactory still expect pre-school monitoring at 18mths². ■ Treatment for hearing impairment is with hearing aids or grommet insertion. ■ Children with hearing loss/aids may be referred to I-pass (Integrated Physical and Sensory Service-Hull) or SaPTS (Sensory and Physical Teaching Service-East Riding) by Neonatology or Audiology to support parents/child with communication, to monitor progress and offer advice/training to nursery. Level/frequency of support depends on individually assessed need. 	<p>Neonatology screen at birth</p> <p>Neonatology and/or community paediatrics conduct 3 month, 6 month and 1yr. reviews and make referrals to audiology</p> <p>Paediatric Audiology (contact details P18)</p> <p>Paediatric Audiology</p> <p>Online advice and information about hearing loss and treatment options, links P18</p> <p>Ipass and SaPTS contact/links P18</p>

Heart

Around half of babies with DS are born with a heart condition. Some more serious than others. It is important to identify early (in the first 2 months) as treatment may be needed¹

- All babies to have a formal heart exam including an Electro Cardiogram (ECG, a simple, quick test to check heart rhythm and activity) by 6wks of age with a low threshold for reviewing if there are signs or symptoms¹.
- If a murmur is present an echo cardiogram (ultrasound scan of the heart) to take place before discharge from hospital.
- If baby is asymptomatic or heart was normal on the neonatal scan then the echo cardiogram can occur within the 1st 8 weeks of life (at an outpatient appointment).
- A Cardiac assessment to take place at the 3 month review, including checking the echo cardiogram results, with referral to cardiology if needed²
- Treatment if needed is likely to be surgery and/or medication. The age surgery takes place varies according to what is appropriate for the child. This usually happens in Leeds. Most conditions are operable with excellent success rates.
- DRS staff can link you with other parents whose children have had similar conditions and/or experienced surgery.

Neonatology/
Paediatric cardiology.

See links P18 for further information about echo cardiogram and electrocardiogram (ECG) procedures

Neonatology and/or community paediatrics conduct 3 month review

See links P18 for further information about heart conditions, treatment and support groups.

DRS Peer support. Ask a staff member to put you in touch with other families.

Additional information and contacts by category.

Hearing

Paediatric Audiology Service (PAS). Hull and East Yorkshire Hospitals NHS Trust.
01482 623072.

http://eastridinglocaloffer.org.uk/directory/?category=Health_All&entry=paediatric_audiology_service_pas

In Hull-Integrated physical and Sensory Service (iPass) www.ipass.org.uk

In East Riding-The sensory and physical teaching service (SaPTS)

http://www.eastridinglocaloffer.org.uk/directory/?EntryId124=433003&entry=the_sensory_and_physical_teaching_service_sapts

This Down's Syndrome Association website explains common hearing conditions and treatment options with links to further leaflets about hearing.

<https://www.downs-syndrome.org.uk/about-downs-syndrome/health-and-wellbeing/ears-nose-throat-and-teeth/>

National Deaf Children's Society leaflet on hearing loss and DS

https://www.ndcs.org.uk/information-and-support/childhood-deafness/causes-of-deafness/downs-syndrome/?gclid=EAlaIqobChMly734kPTP7QIVV OvtCh0N1whsEAAYAiAAEgLJWvD_BwE

Heart

Paediatric cardiology (this is the general paediatrics number) 01482 607872

Link to electrocardiogram (ECG) explanation

<https://www.nhs.uk/conditions/electrocardiogram/>

Link to echo cardiogram explanation <https://www.nhs.uk/conditions/echocardiogram/>

Down's heart group is an excellent source of information and explanation and can provide support to families.

<https://dhg.org.uk/>

The DSA guide to Cardiac conditions explains the different congenital (from birth) conditions in simple terms and treatment options

<https://www.downs-syndrome.org.uk/wp-content/uploads/2020/05/19.05.Cardiac-Conditions.pdf>

Subject	Monitoring, treatment, help or support.	Who helps ?
<p>Immunisations</p> <p>Can be more susceptible to infections (see below). Very important to have all regular childhood immunisations¹.</p>	<ul style="list-style-type: none"> ■ Routine vaccinations and immunity will be discussed at the 3mth and 6mth review². ■ Flu vaccination recommended from 6 months of age then annually¹. ■ Some children e.g. those with a heart condition may require extra vaccinations, discuss with a professional in charge of their care². 	<p>Neonatology conduct reviews</p> <p>HV/GP for routine childhood immunisations and annual Flu jab.</p> <p>See links P20 for additional vaccine information</p>

<p>Infection</p> <p>Can be more vulnerable to chest and other infections.</p>	<ul style="list-style-type: none"> ■ Be aware that babies with DS may not always display typical signs/symptoms when unwell. Seek urgent medical advice early if you are concerned about a change from your baby's usual presentation. You know them best. ■ Page 16 of your "red book" green insert is an Infection alert. This page is designed for you to show to medical professionals if you feel concerned. ■ Immunity and infections are discussed at the 3mth review. ■ Unusual or recurrent infections are discussed at the 1yr review. Immune function may be checked. 	<p>Self-help. Have to hand should your baby become unwell : The alert on P16 of your red book green insert and/or "Tips for triaging" sheet (link P20) to make health professionals aware of possible atypical presentation in children with DS.</p> <p>Neonatology/ Community paediatrics conduct reviews</p> <p>See links P20 for further information about infections</p>
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Additional information and contacts by category.

Immunisations

One page summary of relevant universal and additional vaccines.

<https://www.dsmig.org.uk/wp-content/uploads/2015/10/keypoints-immunisation.pdf>

Longer explanation of routine and additional vaccines on P13 of this publication

<https://www.downs-syndrome.org.uk/wp-content/uploads/2020/05/Immunisation.pdf>

Infection

“Tips for Triaging”. Single sheet alert aimed at medical professionals treating children with DS which could be carried by parents.

https://d29e30c9-ac68-433c-8256-f6f9c1d4a9ec.filesusr.com/ugd/bbd630_62856d4c8cb940279397c2d308aa6f07.pdf

This booklet has further information about what a respiratory tract infection is and tips on avoiding infection

https://www.downs-syndrome.org.uk/wp-content/uploads/2020/05/Respiratory-infections-4th-April-KP-3rd-July-SM_DSMIG.pdf

This is a short article clearly explaining the reasons for increased infection risk in people with DS and outlines simple measures to reduce risk.

<https://www.downs-syndrome.org.uk/wp-content/uploads/2020/05/DSA-Journal-141-Spring-Summer-DSMIG-pages.pdf>

Subject	Monitoring, treatment, help or support.	Who helps ?
<p>LD Register</p> <p>DS is a cause of learning disability (LD), sometimes known as intellectual disability.</p>	<ul style="list-style-type: none"> Ask your GP (or reception) if your child can be placed on their practice LD Register (also known as QOF register). This may or may not be done automatically. There is no urgency to do this but it is important. DRS have a template letter you can use if you wish to request this in writing. 	<p>See links P22 which explain the GPs LD register and reasons for registering. Downright Special have a template letter you can use (ask staff member Sam. sam@downrightspecial.co.uk).</p> <p>Further links P22 to explain the term "learning disability".</p>

<p>Mobility and movement</p> <p>Movement milestones may be met later 1</p> <p>Children with DS walk alone between 13 and 48 months1</p>	<ul style="list-style-type: none"> Possible referral to physiotherapy (physio) at 6 month or 1 yr review if there are concerns about hypotonia (low muscle tone/floppiness). A check of hip/knee foot position and foot posture made at 1yr review. Referral may be made to orthotics or podiatry (for shoe inserts or supportive footwear) if there is a need. A Physio visits Downright Special Friday sessions once per half term to assess and provide advice or make referrals. 	<p>Neonatology and/or Community paediatric service conduct reviews.</p> <p>Paediatric Physiotherapy Service (contact P22)</p> <p>Orthotics (contact P22) Podiatry (contact P22)</p> <p>A Paediatric Physiotherapist at a DRS Friday session</p>
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Additional information and contacts by category.

LD Register

Brief explanation of the LD Register on this webpage
<https://www.downs-syndrome.org.uk/about-downs-syndrome/health-and-wellbeing/#annualhealthchecks>

Information about joining the register in other formats for example easy read and video

<https://www.mencap.org.uk/advice-and-support/health/dont-miss-out/dont-miss-out-join-learning-disability-register>

Explanation of the term "learning disability"

<https://www.mencap.org.uk/learning-disability-explained/what-learning-disability>

Mobility and movement

Integrated Paediatric Therapy Service (Humber Teaching NHS Foundation Trust)
<https://www.humber.nhs.uk/services/integrated-paediatric-therapy-service.htm>
 Physiotherapy 01482 336774

Orthotics (boots, splints, shoe inserts) 01482 605317

Podiatry. 01482 247111. Musculo-skeletal issues (under 13s Hull only) or routine podiatry (HULL or ER) including supportive shoe insoles and inserts. This is the general CHCP number, podiatry is option 0 (the last option given on the list). Referral can be made by any medical health professional such as for example GP, HV. Review is then made by a podiatrist at a clinic to either accept/decline the referral.

www.chcpcic.org.uk/chcp-services/podiatry-service

An easy to read fun booklet with some physiotherapy advice and activity suggestions for infants with DS

https://positiveaboutdownsyndrome.co.uk/tummy-time/?fbclid=IwAR3EWXo6kh6pz1IZ0qF0fIF9zgWrbh5XQ9X1nubgnGWcB_21ghcD1hZ18io

Subject	Monitoring, treatment, help or support.	Who helps ?
<p>Social and social care</p> <p>The birth of a baby with Down Syndrome can affect the extended family. Connecting with others raising a child with additional needs is the single thing parents/carers report as having the biggest impact, making them feel confident, comforted, informed and supported. You are now a member of the DS "Community": local, national, and global, face to face and virtual. Welcome.</p> <p>You will also receive support and advice from your Local Authority</p>	<ul style="list-style-type: none"> ■ If your child has specific medical condition/s DRS can put you in touch with a local family with similar experiences. ■ DRS host regular social events such as soft play sessions and parties. Events are free. Siblings and close relatives welcome. ■ DRS have a closed facebook group for parents and close relatives. ■ There are many popular online communities, see links below recommended by other parents ■ In Hull, KIDS provide a befriending service for parents who have recently discovered their child has a disability. ■ In Hull, KIDS run early years sensory and play groups for children with additional needs. You can refer yourself. ■ In East Riding there may be portage group sessions at children's centres and some children's centre's have sensory rooms available to book. ■ If you feel that you are struggling to cope as a family, to receive the support you need or to access suitable services or support for your child seek advice from your health visitor or Early help (SEND) and the Children's Disability Team (Hull) or the 0-25 SEND Team (East Riding). You can look on the "Local offer" section of your council website. 	<p>Ask a DRS staff member</p> <p>You will be notified of events if you are on our e-mailing list or via social media.</p> <p>Apply to join us via facebook</p> <p>Online/social media see links P25</p> <p>KIDS befriending service and play groups-see links P25.</p> <p>Ask your HV, Portage worker or your local children's Centre.</p> <p>Ask your HV or Portage worker or see links to the Local Offer websites P25.</p> <p>See links in information section P25.</p>

<p>Speech, Language and development (including signing)</p> <p>Speech and language developmental milestones may be met later ¹</p> <p>Use of Signing to augment early communication is recommended. Makaton is a trademark name of a widely used type of signing. DRS use Makaton.</p>	<ul style="list-style-type: none"> ■ Your baby will be seen by Speech and Language Therapy (SALT) around 9 months following referral (arising from 6 month review².) ■ You can also self-refer to SALT (under age 2.6 you need to speak with a therapist before making referral) ■ DRS staff also liaise with SALT (with parental consent) to ensure timely referral. ■ SALT run signing courses. Special Stars Foundation run signing courses. There are online Makaton groups and courses. Mr Tumble or You Tube is a good place to start. Focus on core vocabulary. ■ DRS run weekly (school term time) small group lessons to build social and communication skills. Signing is taught in the sessions. DRS have signing books and DVDs in our resource library ■ Portage is a home visiting early educational service for children aged 0-5 with additional needs. A named individual will support your baby's development. A health professional can refer you e.g. Paediatrician or HV. You can also self-refer. ■ If your baby attends nursery or childminder our DRS Early Years Outreach Teacher (Laura Nichols) can advise nursery on how best to support in the setting. 	<p>Neonatology refer to SALT (see contacts P26).</p> <p>SALT. Contact numbers and e-mail P26</p> <p>Downright Special staff</p> <p>Local and Online signing resources links P26</p> <p>Downright Special.</p> <p>Portage teams Hull and East Riding (see contacts P26) or speak to Katie Bewell, Downright Special staff member on Friday mornings (Hull Portage).</p> <p>Speak to Laura at Friday morning sessions or email Laura@downrightspecial.co.uk</p>
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Additional information and contacts by category.

Social and Social Care

PADS (Positive about Down syndrome). Peer support on Facebook. Split by age group. Group just for parents of babies 0-18 months. A Social forum and a useful place to ask for advice or support from other parents. <https://positiveaboutdownsyndrome.co.uk/>

Special stars is a local charity supporting people with Learning Disability that run events and activities, provide parent training (including Makaton) and loan/sell sensory and specialist play equipment <https://www.heyspecialstars.co.uk/>

Parents United Hull. (Supported by Hull City Council Early Years Inclusion Team) A parent support group that meets bi-monthly. Call 01482 318 318 for details.

Wouldn't Change a Thing. Positive advocacy and campaign group challenging negative perceptions of DS. <https://www.wouldntchangeathing.org/>. Also on Facebook.

Coraline and us. Blog following a family and their daughter with DS.

<https://www.coralineandus.com/>

Instagram recommendations

@downrightwonderful

@ahtharpe

@chisnikic

@abigail_the_advocate

For Hull parents (or Hull GP) KIDS parent befriending service.

<https://www.kids.org.uk/hull-befriending>. KIDS also run play and sensory groups for children with additional needs <https://www.kids.org.uk/hull-sensory-group>

Your Local Council must outline in one place (a website) all services available for children with Disability. This is called "The Local Offer" and includes details of local health, education and social services. It can be a very useful source of information. Hull Local offer 0-5 Early Years page.

<https://hull.mylocaloffer.org/s4s/WhereILive/Council?pagelId=3018>

Hull Local offer includes information about Early Help (SEND) family support and the Children's Disability Team for children with complex needs and disabilities in Hull.

<https://hull.mylocaloffer.org/s4s/WhereILive/Council?pagelId=2983>

East Riding Local offer <http://www.eastridinglocaloffer.org.uk/> includes information about the 0-25 SEND Team. The role of the team is to support children and young people with special educational needs and disability and their families to access the support they need.

http://www.eastridinglocaloffer.org.uk/directory/?category=Care%20and%20Support_All&entry=0_to_25_send_team

Speech, language and development

Integrated Paediatric Therapy Service (Humber Teaching NHS Foundation Trust)
<https://www.humber.nhs.uk/services/integrated-paediatric-therapy-service.htm>
 Speech and Language Therapy (SALT) 01482 692929 (option 3) or e-mail
hnf-tr.sltadmin@nhs.net

Portage

East Riding-part of the Early Years Support Team. 01482 392220 eyst@eastriding.gov.uk
<http://eastridinglocaloffer.org.uk/care-and-support/early-years-and-childcare/portage/>
 Hull. 01482 616 667.
<https://hull.mylocaloffer.org/s4s/WhereLLive/Council?pagelId=3042&id=b8250496-88f2-4a9c-b30c-a6d400f10416>

Two comprehensive Down Syndrome Education International publications covering Development in children with DS age 0-5. Available as a pay to download pdf files. Also available from DRS resource library.

<https://store.dseenterprises.org/collections/ebooks/products/an-overview-of-the-development-of-infants-with-down-syndrome-0-5-years-pdf-ebook>

<https://store.dseenterprises.org/collections/ebooks/products/speech-and-language-development-for-infants-with-down-syndrome-0-5-years-pdf-ebook>

The DSA website has a page about Speech and language development in babies with DS, information, simple activity ideas and a description of the role of the Speech and Language Therapist with your child.

<https://www.downs-syndrome.org.uk/about-downs-syndrome/lifes-journey/speech-language-and-communication/>
<https://www.downs-syndrome.org.uk/wp-content/uploads/2021/07/SALT-babies-preschool-30.6.21.pdf>

Singing Hands. Online or DVD sing and sign performers who also do live tours
<https://singinghands.co.uk/>

Special Stars is a local charity that offers subsidised Makaton training from time to time
<https://www.heyspecialstars.co.uk/pages/events>

Makaton with Lucinda is a simple and accessible way for all the family to start signing, on Facebook and You Tube

Makaton with Lucinda | Facebook

https://www.youtube.com/channel/UCVR4-zug_Upe9pWcz1jRalw

The Makaton charity can link you with online or face to face local tutors and sells resources <https://www.makaton.org/>

Subject	Monitoring, treatment, help or support.	Who helps ?
<p>Thyroid</p> <p>A gland that releases hormones to keep the body functioning². Underactive thyroid is more common at all ages in people with DS than in the general population¹</p>	<ul style="list-style-type: none"> ■ A Routine Newborn screen is done in hospital (heel prick). ■ A blood test is required to check thyroid function. 1st one to be at around 4-6 months¹. After this an annual blood test recommended for monitoring as symptoms not always apparent in individuals with DS. Blood can be taken from a vein or sometimes by a fingerprick ¹. ■ Treatment for thyroid conditions is with medication 	<p>Arranged by Neonatology at 3 or 6 month review.</p>

<p>Vision</p> <p>Prone to vision difficulties. Important to identify early to minimise effect on development¹.</p> <p>Most people with DS wear glasses.</p>	<ul style="list-style-type: none"> ■ Expect baby to follow objects with eyes at around 1.5-6 months of age¹ ■ Vision checked at 3 mth, 6mth and 1yr reviews. Child referred to paediatric ophthalmology if indicated or concerns². ■ If child has 'visual impairment' or a vision condition e.g. Nystagmus the eye hospital can refer to I-pass (Hull) or SApts (East Riding). NB-Wearing glasses alone is not a vision condition. I-pass and SaPTS assess child and provide advice and training to parents and/or nursery. Level/frequency of support would depend on individual need. ■ A DRS/eye hospital leaflet is available explaining vision in children with DS ■ Reputable online sources of advice and information 	<p>Neonatology and/or community paediatrics conduct 3 month, 6 month and 1 yr reviews and make referrals to ophthalmology (this is at the Eye Hospital at HRI).</p> <p>I-pass and SaPTS links below</p> <p>Ask Downright Special staff for an eye hospital leaflet.</p> <p>Links to online sources see P28.</p>
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Additional information and contacts by category.

Thyroid

Basic factual information

<https://www.downs-syndrome.org.uk/for-families-and-carers/health-and-well-being/thyroid/>

Vision

Ophthalmology (Eye hospital, children's department)

<https://www.hey.nhs.uk/ophthalmology/>. 01482 816605, leave a message.

In Hull. Integrated physical and Sensory Service www.ipass.org.uk

In East Riding. The sensory and physical teaching service (SaPTS)

<http://www.eastridinglocaloffer.org.uk/education/education-support/the-sensory-and-physical-teaching-service-sapts/>

General information about vision and DS with links to further detailed information.

<https://www.downs-syndrome.org.uk/about-downs-syndrome/health-and-wellbeing/eyes/>

A downloadable Down Syndrome Association publication which contains information from Maggie Woodhouse, a world leading expert in vision and Down Syndrome at the Down Syndrome Vision Research Unit at Cardiff University. Contains tips about selecting glasses.

https://www.downs-syndrome.org.uk/wp-content/uploads/2020/06/Children-vision-eye-tests-glasses-21st-March-KP-27th-June-SM_DSMIG.pdf

Information from Cardiff University specialist Down Syndrome eye department

<https://www.cardiff.ac.uk/downs-syndrome-vision-research-unit/get-advice/for-parents>

Additional General information and contacts

Neonatology-Hull Royal Infirmary [01482 607875](tel:01482607875)

Community Paediatrics Medical Service- [01482 315588](tel:01482315588)

Health Visiting

Hull. Specialist Public Health Nursing Services 0-19 Integrated Public Health Nursing

[01482 344301/336634](tel:01482344301336634)

or e-mail hull.cypcommunityservice@nhs.net

East Riding. Integrated Specialist Public Health Nursing Service (ISPHN). 6 regional teams across the East Riding, the various telephone numbers are on the link here

<https://www.humber.nhs.uk/Services/integrated-specialist-public-health-nursing-service-isphns.htm>

Downright Special. [01482 420160](tel:01482420160)

Other useful numbers:

If you find some useful help or advice in the first 0-18 months that is not mentioned in our guide please share it with us so you can pass it on to future parents.

We try to keep this guide up to date annually but if you find a faulty link, number or a service that is unhelpful or no longer available please help by telling us (sam@downrightspecial.co.uk). This is version 1. of this document all information correct as of August 2021.