

Health Services in Leeds for **Children with Down syndrome**



A Parents' Guide June 2020

This booklet provides information about the services you may access in Leeds. It can be translated in to different languages by going to:

<https://www.leedsth.nhs.uk/patients-visitors/our-hospitals/leeds-childrens-hospital/a-z-of-children-hospital-leaflets/> and searching for 'Down syndrome'.

Use the orange Browsealoud icon and click the globe to translate in to your chosen language. Please be aware that Browsealoud may not always translate accurately.

We hope it will help you understand:

- the roles of health professionals that you and your child may meet
- what to expect from the different health services
- how to contact each service if you need them, from when your child receives a diagnosis up to the time they leave school

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Introduction

Congratulations on the birth of your baby!

Enjoy getting to know your new baby; they need the same things that all babies need – love, care, food, sleep and opportunity. Every baby is unique and your baby will have characteristics of other members of your family.

Other things will happen in good time, and you will be your baby's best representative – you know what is important for you, for them and for your family.

Your journey with your child may be different to what you expected and for some people, this may seem overwhelming at times. However there are services to support your child and your family through that journey and to enable your child achieve their fullest potential.



Services in Leeds

Health care services for children are provided by two different health organisations; the hospital team at Leeds Teaching Hospitals Trust and within the community, Leeds Community Healthcare Trust.

Community services aim to provide care in your local area of the city, so our community child health doctors (paediatrics), therapies and other health services are delivered from three 'Hubs', depending on the postcode of your child's GP.

These hubs are ICAN (Integrated services for Children with Additional Needs) East, South and West.

As health professionals, our job is to work with you so you can help your child achieve the things that are important to them: you are the expert on your child and family.

Please tell us what your priorities are so that we can help you work towards your child's goals.

People you may meet

The professionals that you may come across are:

Hospital-based services

At birth your baby will be cared for by neonatologists.

Some families whose baby has more complex medical issues may be supported by the Neonatal Outreach Nursing team.

If your baby needs immediate medical attention within the hospital they will be cared for by a general paediatrician. In addition, depending on your child's needs they may be cared for by specialist paediatricians based within the hospital, e.g. paediatric cardiologist.

All families resident in Leeds are invited to a Developmental Baby Massage group run by Physiotherapists and Occupational Therapists (see page 8). This can be accessed until your baby is four months old.

Community-based services

- General Practitioner (GP)
- Midwife
- 0-19 Public Health Integrated Nursing Service (formerly Health Visitors and School Nurses)
- Community Paediatrician
- Speech and Language Therapist
(for advice and support around communication and where appropriate, for feeding and swallowing)
- Physiotherapist
- Occupational Therapist
- Audiology (hearing)
- Ophthalmology (vision)
- Special Needs Dentist



What can you expect to happen before you leave hospital (or soon after your baby is born)?

An experienced paediatrician will examine your baby, undertaking the normal baby checks, making sure that your baby does not have serious health issues or a heart condition:

- **Genetic tests:** As soon as the doctors consider that your baby may have Down syndrome they will request a blood test to confirm the diagnosis. A preliminary result is available within 2 working days (so may take longer if it is the weekend or a bank holiday) but the detailed results may take up to three weeks.
- **Heart scan:** Your baby may have a heart scan soon after birth if the doctors are concerned that your baby has a heart disorder. However even if this is normal, your baby should see a heart specialist and have a repeat heart scan by 6 weeks. This is because babies with Down syndrome have a 40-60% likelihood of having a heart condition (Congenital heart disorder).
- **Blood tests:** All children with Down syndrome will have full blood tests and blood film within the first three days, to make sure that they are not at risk of a serious blood disorder. Additional tests may be advised depending on your child's medical needs.
- **Newborn hearing screen** (offered to all newborns). Sometimes the results are not definitive in the new-born period, however, it is really important that your baby has any recommended follow up hearing tests. We know that babies with Down syndrome have a higher incidence of hearing loss which can result in language delay.
- **Feeding:** It is quite common for babies with Down syndrome to take some time to establish feeding. If you wish to breast feed your baby, you should do so, unless you are advised of a medical reason not to.

If your baby is having difficulty in establishing breast or bottle-feeding, the midwives and a speech therapist who specialises in feeding can support you. Some babies may go home with a naso-gastric tube (feeding tube) and may need medications to help with feeding. You can also seek support with breast feeding from your 0-19 Specialist Public Health Nurse

If your baby has no immediate health issues they will be discharged home as soon as you are ready. The hospital paediatricians will request the community paediatricians and arrange to see you and your baby.

You should be provided with the specific Down syndrome inserts for your parent held child health record book (Red Book - 5th edition February 2020).

Details of the local Down syndrome parent support groups are included at the end of this booklet.

The role of your GP



GPs are primary care doctors that provide the first point of contact for any health related issues. Your baby's GP will review your baby at 4-8 weeks for a 6 week review.

If you have any health concerns regarding your child, do make an appointment with your GP.

Midwife



Maternity care in Leeds is provided by Leeds Teaching Hospitals NHS Trust and your GP will refer you to the Midwifery Team. Becoming a parent is an important and exciting experience and the team will ensure you have the right maternity support and care around you. The Community Midwife will undertake a risk assessment and discuss the choices of place of birth that are available.

Midwives work with you at all stages of pregnancy, birth and the early postnatal period from the time you realise you are pregnant. If you find out during pregnancy that your baby has Down syndrome, the team of Obstetricians and Midwives in the Fetal Medicine Unit provides specialist care and support.

Midwives will support you throughout your birth and the period after your baby is born. Community Midwives will visit at home until you are ready to be transferred to the care of the Public Health Integrated Nursing Team (see pages 7 and 8).

How do I contact the Midwife Team?

If you need to speak to a midwife urgently, please call the Maternity Assessment Centre:

LGI - **0113 392 6731** or St James's - **0113 206 5781**

If you have a general query about any aspect of your care please contact your named community midwife. You will be given their contact details early in your pregnancy. Please allow a few days for a response as not all midwives work full time.

Community Midwifery Office **0113 206 6241**

Monday to Friday 9am - 4.30pm, Saturday to Sunday 9am - 1pm

0-19 Public Health Integrated Nursing Service



What do the 0-19 Public Health Integrated Nursing Service do?

Health Visitors and School Nurses have come together to form the 0-19 Public Health Integrated Nursing Service.

The team work with children from 0-19 years old and can offer support on a wide range of issues from pregnancy through to young adulthood.

In the early years of your child's life, a member of the 0-19 Public Health Integrated Nursing Service can support you with:

- parenting strategies
- building positive relationships
- linking to Understanding your Baby booklet
- breast feeding and weaning
- sleep
- nutrition and eating advice
- maternal mood
- community support
- social, emotional and environmental issues affecting parents and children
- behaviour
- play
- toilet training
- signposting to Leeds City Council housing service



The 0-19 Public Health Integrated Nursing Service can make or advise about referral to other specialist services if appropriate and may help you liaise with other professionals. They weigh and measure children and fill in the growth charts in your child's Personal Child Health Record ('red book').

The service also runs well baby clinics and breast feeding support groups across the city where you are able to talk to a member of the team. These timetables can be found in your child's red book or on the Leeds Community Healthcare website.

Children with Down syndrome grow at different rates to other children, so there is a separate red book insert which you should be given by either your named 0-19 Public Health Integrated Nurse or Paediatrician. These inserts also provide useful information on typical health checks and the developmental milestones of children with Down syndrome.

When should my child see a member of the 0-19 Public Health Integrated Nursing Service?

Parents can contact their named 0-19 Specialist Public Health Nurse at any time. There are certain points at which the health visiting team will make contact with every child in Leeds:

- Antenatal visits from the 30th week in pregnancy.
- Birth visits when your baby is between 10 and 14 days old.
- 6-8 weeks of age.
- 8-12 months and 2-2.5 years old physical and developmental checks.
- 4-5 years: questionnaire prior to your child starting primary school about your child's health to see if there is any support you or your child may need. In reception class, your child's height, weight and vision will be checked.
- 10-11 years: weight and height check in line with the National Child Measurement Programme.
- 11-19 years: a range of support for emotional health, weight management and healthy relationships to help young people throughout their school life reach their full potential. Extra support is available for those with long term illnesses and other needs.
- 19-25 years: ongoing support for families of young people up to the age of 25 who have additional needs.



Further support is also on hand for families when they need it, including breastfeeding, bed wetting, emotional difficulties, oral health, bereavement and bullying. We also work with local health and social care services to support families who have additional needs. Some examples include if your child has a special education need or disability (SEND), a medical condition or there may be concerns about the safety of your child. We will work to make sure your child is safe and get the services and care they need.

How do I contact the 0-19 Public Health Integrated Nursing Service?

The 0-19 Public Health Integrated Nursing Service in Leeds work out of bases at local health centres.

Telephone: **0113 843 5683**, Monday to Friday 8.30am to 5pm

There is also an on the day pre-bookable extended hours service where you can speak with a 0-19 Specialist Public Health Nurse between 5pm and 7.45pm.

www.leedscommunityhealthcare.nhs.uk/0-19team/

You can find up to date and relevant information on their Facebook page:

@019PublicHealthIntegratedNursingServiceLeeds

Developmental Baby Massage



What is developmental baby massage?

In Leeds, the developmental baby massage group is offered to all babies under four months of age who are known to have, or who are at risk of developmental difficulties and who have a Leeds GP. This is an opportunity to look at how baby massage can help your baby, as well as time to talk to the professionals and other parents in the group. It is co-ordinated by the therapy team at Leeds General Infirmary.

The team will talk about positioning for play and daily family activities, and massage strokes to enjoy with your baby. They can signpost you to community Occupational Therapy / Physiotherapy clinics that are available for ongoing support.

A member of the community therapy team will also contact you during this early period to answer any questions you may have and help to signpost you to any other services / information you need.



For babies born outside Leeds, or who were born at home, you may not have discussed baby massage with any professionals. Please contact your child's community or hospital Paediatrician who can advise about a referral to the group.

How do I contact the Developmental Baby Massage Group?

Tel: **0113 392 6610** (LGI Therapy Department)

Community Paediatricians



What do Community Paediatricians do?

Community Paediatricians are specialist doctors caring for children with additional medical and developmental needs. They will monitor your child's health needs as outlined in the Health surveillance guidance for all children with Down syndrome, by the Down Syndrome Medical Interest Group (DSMIG) UK and Ireland.

Your child may also be under other doctors in the hospital if they need to see a specific specialist, e.g. respiratory team, cardiologist etc.

If your child has a problem that needs immediate attention, you should take your child to see their GP or for more urgent issues, go to your nearest Accident and Emergency hospital.

Before each Community Paediatric appointment, you will be sent a questionnaire to fill in at home. This will help focus on any areas of importance for you and your child so that you can discuss them with the paediatrician.

When should my child see a Community Paediatrician?

■ 0-1 months old

If you know before your baby is born that they have Down syndrome, you may be referred to a Community Paediatrician during your pregnancy, so that you can start to access any support you may need. If your baby is diagnosed at birth, you will be referred to a Community Paediatrician by the hospital doctor once the diagnosis is confirmed. The Community Paediatrician may visit you on the ward, or you will be offered an appointment within two weeks of the referral being received.

You will have time to talk about any questions you may have, and how you are feeling as new parents.

The Community Paediatrician will discuss with you the various checks on your baby's health that may be needed, for example, blood tests, general health check, heart screening, and hearing test.

The Community Paediatrician, along with your named 0-19 Public Health Integrated Nurse will discuss your family's needs and the types of support that are available locally.

■ 2-3 months old

You will be offered a clinic appointment with the community paediatrician to check on your baby's health, how you are feeling and talk about any questions you may have.

Information about other support or services that are available or referrals that may be needed will be discussed such as: Occupational Therapy; Physiotherapy; Speech and Language Therapy (including baby signing); Portage (developmental play activities, see pg18 and 19) and H-EN (Health to Education) referral, which will enable you to access different services within the Education department.



■ Up to 1 year old

Your baby will be offered an appointment with the community paediatrician approximately every 3 – 4 months as agreed with your doctor, and depending on you / your baby's needs.

■ Your baby will be offered a blood test to check their thyroid function, between 4 to 6 months, and then every year from the age of one, as we know that thyroid problems occur more commonly in people who have Down syndrome.

■ 1 – 3 years old

Your baby will be seen approximately every six months unless you agree otherwise with your paediatrician. At each appointment, the doctor will check on your baby's health and development, and may make recommendations or referrals to other services if needed. You will be sent a questionnaire to fill in at home which will help you get the most out of your appointment.



■ 3 years old to leaving school

Your child will be seen on a yearly basis unless otherwise agreed. You will still be sent a questionnaire to fill in at home which will help you get the most out of your appointment.

■ Child Development Team Assessment (CDA)

Some children who have more complex health, developmental or social needs may meet the criteria for a CDA at your local Child Development Teams. Your paediatrician will be able to discuss this with you.

How do I contact the Community Paediatrician?

The Community Paediatricians are based at the following locations:

St George's Centre (South Leeds)

Reginald Centre (East, North East Leeds),

Wortley Beck Health Centre (West, North West Leeds)

They can be contacted on the ICAN central number **0113 843 3620**

<https://www.leedscommunityhealthcare.nhs.uk/ican/>

Speech and Language Therapists



What do Speech and Language Therapists (SLT) do?

Speech and language therapists specialise in assessing children's understanding and communication skills. Some SLTs also specialise in assessing eating and drinking skills. SLTs can advise about things you can do to help your child improve in these areas.

Most children with Down syndrome are keen to communicate, however, they can experience difficulties with understanding words, as well as using words and / or sounds clearly to communicate.

As children with Down Syndrome are generally very good visual learners, using additional visual supports of signing (e.g. Makaton) and /or symbols (such as pictures/photos) is recommended to help children learn to communicate more effectively. It is important to remember that research shows signing, such as Makaton, does not discourage any child from talking. Instead it builds on the natural ways children learn to communicate and gives your child a way of expressing themselves before they are ready or able to use spoken words.

When should my child see SLT?

If you haven't already been referred to SLT, but would like to know more about early communication, you can self-refer or ask your Health Visitor, GP or Paediatrician to refer your child (see information on page 10).

Following referral to SLT your child will be seen for an initial assessment and be offered subsequent contacts on a 4-6 monthly basis up to the age of 2 years, depending on the needs of you and your child.

Families may also be offered 6 sessions of the Makaton baby signing programme, run by the Children's Speech and Language Therapy Team.

Early communication

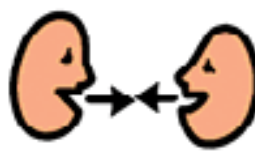
Early communication between you and your child is very important, and communication can mean many different things!



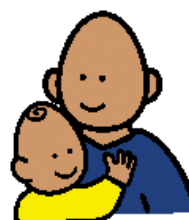
Singing



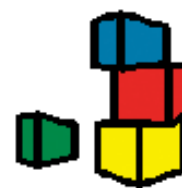
Eye contact



Copying sounds



Talking about everyday activities



Sharing fun time!

For children over 2 years

The service offers an episode of care approach. Children will be seen in clinic by a speech and language therapist for one session to offer advice and resources to support communication development.

Some children will also be offered a block of therapy focusing on specific communication targets. At the end of these sessions, the SLT will give a support plan of ideas to continue to work on and your child will be discharged from the service. Your child can be re-referred to SLT once the recommendations have been completed or if you have ongoing concerns about your child's communication development.

What can I do to support my child's speech and language development?

Once your child has been seen, the SLT service offer different training courses to help you promote your child's communication and language skills.

Current courses on offer are as follows, and your SLT will recommend the appropriate course for you:

- **Makaton Level 1 and 2 workshop** (2 days)
- **Intensive Interaction course** (2 x ½ days)

Hearing loss has a significant impact on the speech and language development of children. Make sure your child has had their hearing checked - see Audiology section for further details.

Check out our toolkit of resources on the website for lots of ideas about developing communication skills!

www.leedscommunityhealthcare.nhs.uk/cslt
(follow Toolkit link)

Your SLT will recommend relevant sections to look at.

What if I'm concerned about my child's eating and drinking?



Discuss your concerns with your Health Visitor, GP or paediatrician and they can refer your child to a specialist speech and language therapy feeding team.

It is important that the referrer discusses and agrees the referral with your child's GP or paediatrician before we see your child to gain medical consent for the referral (this can be verbal e.g. on phone).

The referral form is on our website **www.leedscommunityhealthcare.nhs.uk/cslt** - see Feeding Difficulties section.

How do I contact the Speech and Language therapy service?

The service has an open referral system which means any health or education professional can refer with parental consent. Parents can also refer their child to the service themselves.

Referrers can access the referral form from our webpage **www.leedscommunityhealthcare.nhs.uk/cslt** - follow 'Access and referral information'; there are separate forms for parents and professionals to refer.

Alternatively, you can contact our central admin team on **0113 843 3650**.

Physiotherapists (Physio) and Occupational Therapists (OT)

What do Physiotherapists and Occupational Therapists do?

Physiotherapists look at how your child learns the “big movements” (*gross motor skills*) – sitting, crawling, walking etc.

Occupational Therapists look at the activities your child does to participate in everyday life, e.g. *dressing, playing, eating, having a bath and using the toilet*. They also work closely alongside the physiotherapists to look at how your child develops the fine motor movements of their hands (*fine motor skills*).



Children with Down syndrome often have low muscle tone (*floppy muscles*) and are extra flexible (*hypermobile*). This can affect how they learn to move between positions and develop their movement skills. Children with Down syndrome generally take longer to reach developmental milestones and may need different levels of support as they grow up.

When should my child see Physiotherapy and / or OT?

■ 0 years to starting school

You may have attended Developmental Baby Massage and already met a Physiotherapist or OT. As your baby grows and develops, if you can see that your child is making progress with their movement skills and is starting to join in with daily activities which fit with the stage of their development, then you don't have to see a Physiotherapist or OT again during this period. If other professionals working with your child have identified concerns, you may wish to opt in to discuss this.



Please access the online resources at any time, however, if you have specific concerns which have not been resolved by this information, you can opt in to one of our clinics. If other professionals working with your child have identified concerns, you may wish to opt in to discuss these.



Check out our advice leaflets on the website for ideas about developing motor skills, hand skills and what to look for in everyday, high street baby equipment e.g. bath seats, highchairs, footwear.

www.leedscommunityhealthcare.nhs.uk/ican
(select 'Physiotherapy' or 'Occupational Therapy')

Opt-in sessions with the OT / Physio are available across the city, where therapists can assess your child's needs and provide advice on how to develop:

- gross motor skills (big movements e.g. sitting, walking etc.)
- fine motor skills (hand movements) e.g. using a spoon, mark making and handling toys etc
- daily living activities / equipment e.g. seating to enable your child to sit well while learning to feed themselves

Before attending, think about what you would like your child to achieve. We will work with you to agree a goal(s) to aim for, look at what activities may help, and what changes you could make to your child's daily play, home and nursery routines that will help your child achieve their goal(s).



We would advise you book an appointment if:

- Your child is unable to sit independently, or unable to sit without support for more than a couple of minutes at 12 months old.
- Your child is 18 months old and can't stay standing for 5 minutes when helped to stand against a support.
- You have not been able to find the right equipment or technique to help your child achieve an everyday activity, for example, to enable/ allow your child to sit safely in a high chair to eat or play.
- Your child is not making progress with specific gross or fine motor skills or everyday activities and you would like further support to develop these e.g. stairs, using cutlery.

The clinics alternate in the three hubs; St George's Centre (South), Leeds Mencap at The Vinery (East) and Wortley Beck (West), but you can attend any clinic if you have something you would like to discuss. The details are on our website, or are available through Leeds Mencap, Sunshine and Smiles or via the Paediatrician.

If you are concerned about your child's foot posture, and its impact on their standing and walking skills, please look at our leaflet on the website for information about supportive footwear. Alternatively, book an appointment at our opt in clinic to discuss with a physiotherapist. They will advise you if specialist footwear is needed, and refer on to the Orthotic service.



What if I'm worried my child isn't progressing?

Children whose movement skills are more delayed than is typical, or who are not making progress may be referred directly to physio by their paediatrician. Alternatively, if parents attend an opt-in clinic and the therapist and parents agree that further physiotherapy sessions are necessary, this will be organised within the child's local hub.

Any child with Down syndrome who is developing movement skills within a typical range for Down syndrome is seen on this pathway, whether they have self-referred or been seen initially via the Child Development Team. You can opt in as often as you feel you need if you have not been able to resolve your concerns by accessing our online information.

■ 5 years old to leaving school

Once children are in full time school, referrals to physiotherapy and occupational therapy can be made as detailed below, depending on specific goals being identified on the referral. Examples may be around functional ability (child / family wants to, but is unable to complete certain activities), or participation (wants to but is unable to join in something they want to do with their friends or family) at home or at school.

OT

Parents, schools or other health professionals can refer directly to OT for school-aged children.

Physio

If your child has been seen by physio in the past, parents can contact physio directly (see below). If your child has not previously been seen by physio, your GP or paediatrician can make a referral.

All referrals to ICAN services should be made on the ICAN referral form (link to ICAN page of LCH website) highlighting the difficulties the child is experiencing and the impact upon their day to day participation. Parental consent for the referral is required.

How do I contact Physiotherapy and OT?

0113 843 3620

Text for hard of hearing **07984 547 923**

Children under 5 years old

Parents directly contact our central admin team on **0113 843 3620**.

They can advise you when the next available appointments are in the opt-in clinic.

Children over 5 years old

Please contact the admin team to discuss how to refer your child.

Further information about our services and online resources can be found at:

<https://www.leedscommunityhealthcare.nhs.uk/our-services-a-z>

then select Physiotherapy or Occupational Therapy.

The ICAN general referral form can be found at:

<https://www.leedscommunityhealthcare.nhs.uk/ican/referrals>

Audiology (hearing)



What do Audiologists do?

The audiology teams are involved in checking your child's hearing and managing any hearing loss that your child may have.

In Leeds there are two audiology teams that may be involved in your child's hearing care:

- The **hospital audiology team** are located at the Hearing and Balance Centre at Leeds General Infirmary and provide hearing care for any children that have hearing aids.
- The **community audiology team** are involved with the ongoing monitoring of children that may be at risk of developing hearing loss at any stage in their childhood. This includes children with Down syndrome. This ongoing monitoring is carried out at a number of health centres in Leeds



If your child has persistent hearing difficulties he or she may be referred from the community audiology team to the hospital audiology team and/or to an Ear, Nose and Throat Surgeon (ENT) at the hospital.

Your child may also be referred to a specialist community paediatrician who can arrange for investigations to be carried out to try and determine why your child may have a hearing loss.

Why should my child have their hearing tested?

Babies and children with Down syndrome are more likely to have hearing loss - both *conductive* (where the problem is in the middle ear) and *sensorineural* (where the problem is with the nerves that help with hearing).

It is really important to monitor your child's hearing by formal testing as research has shown that our perception of a child's hearing is not a good indicator of the child's hearing abilities. Hearing loss has a significant impact on the speech and language development of children.

When should my child have their hearing tested?

■ At birth

All children (including those with Down syndrome) should be offered a new-born hearing screen by 4 weeks of age. This screen is carried out by a separate team at the maternity units based at Leeds General Infirmary and St James's Hospital. The hearing screen is normally done before your baby leaves hospital. If your baby was born at home or was not screened before you left

hospital, you should receive an appointment to attend one of the two hospitals for the hearing screen.

Sometimes the results of the newborn screen are not clear. If this is the case, even if it is in just one ear, it is really important for your baby's hearing to be checked again, so you will be offered another appointment for more detailed tests with the hospital audiology team. This appointment is very important, as we know that hearing loss in new-born babies with Down syndrome occurs in approximately 15% of babies, compared to 0.25% in the general population.

■ 6 – 10 months old

If your baby's new born hearing screen is normal, your baby will be invited for a further routine hearing check with the community audiology team, initially at 7 to 10 months of age.

■ 1 – 2 years old

Every six months.

■ 2 years to school leaving

At least annually throughout school-age years.

These assessments will be in the community clinics unless your child has hearing aids. If your child has hearing aids they will be seen in the hospital.

NOTE: It is important at any age to consider hearing loss as a potential factor to challenging behaviour or poor school performance. If you are worried about your child's hearing in between the appointments, please contact the audiology department.

How do I contact Audiology?

Tel: **0113 843 3620**

(Monday to Friday 8.30am to 5pm)

Text for hard of hearing **07984 547 923**

Answer phone: **0113 855 5267**

(24hrs, seven days per week)

The audiology referral form can be found at:

<https://www.leedscommunityhealthcare.nhs.uk/ican/referrals>

Further information and resources can be found at:

<https://www.leedscommunityhealthcare.nhs.uk/our-services-a-z/audiology-ican/>

Ophthalmology (Children's eye service)



What is the Ophthalmology service?

The professionals within the Ophthalmology Team include the Orthoptist, Optometrist and Ophthalmologists.

Orthoptists specialise in testing children's vision, testing the muscles of the eyes and assessing how well your child uses their eyes together.

Optometrists carry out glasses tests and look at the health of the back of the eye.

Ophthalmologists are eye doctors / surgeons.

Children with Down syndrome have a higher likelihood of sight problems than the general population, therefore it is important that they have regular vision checks.

When should my child see the Ophthalmology team?

The following is an outline of the timings of eye tests for children with Down syndrome in Leeds.

■ At birth

All children will have an eye examination by a Paediatrician before they leave the hospital. This looks for any congenital abnormalities of the eyes e.g. cataracts etc.

■ 6 weeks of age

All children will have a further check at 6 weeks of age with their GP.

■ 6 weeks of age to 18 months

Your child's vision will be monitored by the paediatrician. Where there are concerns, e.g. a squint or other abnormalities of gaze, visual behaviour or attention should be referred to ophthalmology. If you are worried, do tell your paediatrician.

■ 18 - 24 months of age

All children with Down syndrome should have an Orthoptist assessment, who will test your child's vision and examine how the eyes work together. The Optometrist will examine the health of the back of the eye and also see if there is any sign that glasses may be needed.



■ 4 years of age

A further appointment with the Orthoptist and Optometrist should be offered. The tests carried out at the 18-24 month checks will be repeated. At this age your child's ability to focus on near objects will also be checked.

If your child does not need any active treatment, you will be offered a test with the Orthoptist and Optometrist every 2 years. This may be in the community or with the high street ophthalmic opticians.

Your child should have their eyes checked at least every two years throughout their life, including adulthood as eye problems are more common in people with Down syndrome and can appear at any stage.

How do I contact Ophthalmology?

Tel: **0113 843 3620**

(Monday to Friday 8.30am to 4.30pm)

Text for hard of hearing **07984 547 923**

Dentist



When should my child see a dentist?

Your child should be registered with a dentist as early as possible in their life, and definitely before their first birthday.

If you are struggling to find a dentist, or your child is having difficulties having a dental assessment, please discuss this with your paediatrician. There is a dental service specifically for children with additional needs that your child can be referred to.

How do I contact a dentist?

Check out local NHS dental practices in your area.

Find a dentist at www.nhs.uk/Service-Search/Dentist/LocationSearch/3

Portage

What does a Portage Worker do?

Portage is a home visiting teaching service for families of pre-school children with additional needs. Portage works in partnership with parents / carers to support their child's development. Portage empowers parents / carers to become teachers of their own children, in their own homes with support from a trained Portage Home Visitor. Portage Home Visitors will also work closely with other professionals involved with your child's care to incorporate specialist advice in to play and development at home.



When should my child access Portage?

Children can be referred to Barnardo's Portage Service between the ages of birth and two and a half years old if they have a delay in two areas of their development. Parents / carers or any other professional working with the family can refer as long as they have the parent / carer's consent. Please contact the Portage team to check if your child meets the criteria.

How do I contact Portage?

Tel: 0113 272 0832

<https://www.portage.org.uk/barnardos-leeds-portage-service>

Resources and Information

Local Authority resources

Leeds City Council have produced a number of One Minute Guides (OMG) to their services. Some of the most relevant are listed here, or visit www.leeds.gov.uk/residents/Pages/One-Minute-Guides.aspx for a full list.

- Portage leaflet
<https://www.portage.org.uk/barnardos-leeds-portage-service>
- Children and Family Act / Education Health and Care Plan (EHCP)
- SCOPE Cluster Working
- SCOPE Sleep right
<https://www.scope.org.uk/family-services/sleep-right/>
- Leeds Local Offer
- Early Help
- Early Start Service
- EYFFI (Early Years Funding For Inclusion)
- FEEE (Free Early Education Entitlement)
- Safe Sleeping
- School Admissions
- SEND IASS (Special Educational Needs and Disabilities Information and Support Service)
- SENIT (Special Educational Needs and Inclusion Team)
- Short Breaks
- Supporting Pupils at School with Medical Conditions
- Third Sector

Local support groups

Sunshine and Smiles

<https://sunshineandsmiles.org.uk>

Mob: 07725 041 601

Email: hello@sunshineandsmiles.org.uk

Hawthorn Family Support Centre (Mencap)

The Vinery Centre

20 Vinery Terrace

Leeds LS9 9LU

www.leedsmencap.org.uk/support-for-young-people/hawthorn-family-support-centre

Tel: 0113 235 1331

Email: kath.surtees@leedsmencap.org.uk

Bradford Down Syndrome Training and Support Service Ltd

<http://www.downsyndromebradford.com/>

Tel: Wendy Uttley 01274 561 308

Email: office@downsyndromebradford.co.uk

Wakefield and District Down Syndrome Support Group

www.downsyndrome-wakefield.net

Tel: 07814 367 594

Email: info@downsyndrome-wakefield.co.uk

SNAPS (Special Needs and Parent Support)

www.snapsyorkshire.org

Email: dean@snapsyorkshire.org or 07964 847 775 (Penny Field site)

jo@snapsyorkshire.org or 07738 287 024 (Broomfield site)

Mobile: 07964 847 775

The Down's Syndrome Association (DSA) have produced a number of parent information leaflets which can be found on their website here www.downs-syndrome.org.uk/for-new-parents/ and here www.downs-syndrome.org.uk/for-families-and-carers

The Down Syndrome Medical Interest Group (DSMIG) UK have a useful information and resource section on their website for further information on health surveillance and health issues - www.dsmig.org.uk

Some families may be entitled to claim certain benefits. Further information is available at www.gov.uk/browse/benefits. Your health visitor will be able to support you to look at what is right for you.

Family information

The Family Information Service

<https://familyinformation.leeds.gov.uk/>
tel: 0113 247 4386

Leeds SEND Information Advice Support Service

Technorth
9 Harrogate Road
Chapel Allerton
Leeds LS7 3NB
<https://familyinformation.leeds.gov.uk/sendias-site/sendias>
Helpline: 0113 378 5020 (Mon-Fri 10am to 3pm)

Leeds Local Offer

www.leeds.gov.uk and search for 'local offer'

Leeds City Council Inclusive Sport Programme

<https://active.leeds.gov.uk/classesandactivities/sports> then look for the 'Disability Sports' section
Customer Contact Centre - tel: 0113 378 8001 email: ActiveLeeds@leeds.gov.uk

Changing Places

www.leeds.gov.uk and search 'changing places'

National resources

Down's syndrome association

www.downs-syndrome.org.uk

Down's Heart Group

www.dhg.org.uk

Down Syndrome Educational Trust

www.dseinternational.org

Babywalkers leaflet produced by Bliss – the premature baby society www.bliss.org.uk
Search for 'babywalkers'

Contact a Family

www.cafamily.org.uk

With thanks to the services who have supplied information for this pathway, the families and staff at Sunshine and Smiles Family Support Group and Leeds Mencap Family Support Group.

Help us get it right

If you have a complaint, concern, comment or compliment please let us know by speaking to a member of our staff. We learn from your feedback and use the information to improve and develop our services.

If you would like to talk to someone outside the service contact the **Patient Experience Team** on **0113 220 8585**, Monday to Friday 9.30am to 4.30pm or email lch.pet@nhs.net

We can make this information available in Braille, large print, audio or other languages on request.

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www.leedscommunityhealthcare.nhs.uk