You don't know what you don't know

Little orange book of knowledge



DSUK
Down Syndrome UK

Positive About Down Syndrome

Compiled by Nicola Enoch

This publication was created as an online resource as there are many hyperlinks, however at the request of parents, we have also created this printed version. The latest version is available via DSUK's website.

All information is provided in good faith for guidance and reference purposes only. If you have any medical concerns about your child, please always seek professional medical advice.



Welcome & many congratulations on the birth of your baby!

Positive about Down syndrome is here to help you! Our **New Parents page on Facebook** is exclusively for new parents, like yourself, to provide somewhere where you can meet other new parents, ask any questions at all, share experiences, write openly and honestly about your feelings, impart any concerns or worries you have, post photos of your beautiful babies, and show off how gorgeous they are!

We would love to post to you a copy of our book **#NobodyToldMe The truth about Down syndrome**. Please advise your address and we will send out a copy with our love. You can order additional copies for friends & family on our website www.downsyndromeuk.co.uk



We are very aware from our own experiences, that in the early days you may feel somewhat overwhelmed – potentially coming to terms with the news little one has Down syndrome, and perhaps feeling unsure about what that entails, what your baby's future will look like and indeed your own and that of your family. Some new parents find themselves without any information or support, whilst others are bamboozled with information from medical professionals about actual or potential health concerns. There's obviously loads of information online but we wanted to provide you with a one stop overview about some of the services your little one will be able to access, language you may not be familiar with and offer any help we can. If you take away just one message please let it be – you're not alone, we understand and we care, and we're here to guide and help you...

We have a super supportive team of admins all here to help, all parents of a child or young person with Down syndrome, so we absolutely understand where you are coming from and equally importantly, where you're going! Some, like me discovered little one has Down syndrome after birth and struggled big time as shared in my **TEDx talk**, others knew in advance. We know that there is no right or wrong emotion, and that no question is a silly question. We also have a wonderful team of experts on hand to offer their extensive experience and knowledge.

So, sit down, take a deep breath, and know that you've got this! We're here to help you every step of the way and are honoured to be a part of the amazing journey you are embarking on – the road may sometimes be a little bumpy but the views are amazing – enjoy the ride!

Nicola and the team at PADS

Early days

Take time to enjoy your baby!



Assuming little one has no particular medical needs, life with a newborn baby with Down syndrome is really not that different to life with any newborn baby. Your baby needs to be loved and cared for as any other baby.

There is a growth chart for babies with Down syndrome that we can send to you and that we recommend is used for the initial year. Thereafter, we want to be encouraging parents and doctors to ensure your child is thriving and growing.

Some mums are told that little one is not able to breast feed because they have Down syndrome – we know otherwise! Our experience shows that for most mums who want to breast feed that is absolutely achievable. For those babies who may be very prem, requiring heart surgery and/or struggling to feed, it may be suggested that baby is fed via an NG tube (Nasogastric), where a narrow feeding NG tube is placed through little one's nose down into their stomach. Breast milk can be fed to baby via the NG tube and many mums have been able to exclusively breast feed. We have published **the experiences of some of our new mums**, and we have a **closed group** where you can chat with them and others who are happy to answer questions and share their experiences.

You're not alone!

All children develop skills in their own time, with some quicker to meet milestones in certain areas than other children, this is also true of children with Down syndrome.

We know that for all children with Down syndrome there will be a delay in expressive (spoken) language, so we strongly recommend introducing signing from an early age.

Most families use Makaton, some Signalong, these are forms of sign language – you just sign key words and are used as a bridge to communication, until little one is speaking.



You can pick up signs on CBeebies' Mr Tumble and there are lots of great resources on You Tube, in particular Singing Hands. We have a **#PADSPod** on introducing signing which hopefully explains more. PADS regularly runs online baby signing courses for new parents.

Have high expectations – talk to your little one, tell them what you're doing and sing to them, cuddle and love them – baby days fly by so quickly, so enjoy! And make sure you take lots and lots of photos and videos!

Services across the country vary enormously. Your Health Visitor, GP or Paediatrician should be able to refer you to many of the services. Do take a look on your local authority's website under the 'Local Offer' as this is where there should be information about services available in your locality.

We know that children with Down syndrome benefit from early intervention to support and encourage development and we acknowledge many families do not have access to specialist support to encourage development through play and targeted activities, so offer PADS Early development Groups (PEGS).

These consist of online video recordings by specialists in the Down syndrome arena together with highly experienced early development leaders. We recommend our families consider accessing these from about 6 months of age and they progress through to when little one starts school!

We also offer online Physiotherapy support sessions– suitable from birth.

We do not want to overwhelm you with information but hope that this guide is something you can refer to as required. Don't feel compelled to read it from start to finish, but rather know it's here, as and when, as indeed are we - we're online to help answer any questions as and when you think of them. We're very aware that 'You don't know what you don't know', so wanted to ensure 'You do know what you need to know'!

Knowledge is power!

Don't worry about remembering everything – we're going nowhere!



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Frequently used acronyms

DLA	Disability Living Allowance
ENT	Ear Nose and Throat
NICU/NNU	Neonatal Intensive Care Unit and Neonatal Unit
OT	Occupational Therapy
PICU	Paediatric Intensive Care Unit
PT	Physiotherapy
S&LT or SALT	Speech and Language Therapy
SCBU	Special Care Baby Unit



Cardiology

All matters relating to the heart. It is estimated approximately 50% of babies with Down syndrome have a heart defect. Of these about 15-20% require surgery, the rest tend to self-resolve. It is not known how this compares to the typical population, since other babies do not have the checks that babies with Down syndrome routinely do.

All babies with Down syndrome should undergo an echocardiogram (ultrasound scan of the heart) within the first 6 weeks. Sometimes we hear of parents being advised a doctor has listened to the heart and cannot hear any defects but not everything can be detected via this method, so an echocardiogram must always be conducted.

There are many great sources of information that we recommend you use for specific information regarding heart defects, these are listed in our booklet **The Lived Experience – Heart Surgery Experiences.** We hope the experiences shared provide some reassurance and answer some questions.

PADS organises Heart Buddies to those families whose little one is due to undergo any heart surgery – connecting you with another family whose child has recently undergone the same procedure and if possible a family whose child underwent surgery at the same hospital. To request a PADS Heart Buddy contact our Heart Buddies Coordinator by emailing **heartbuddies@downsyndromeuk.co.uk**



Dieticians Service

Some babies, children and young people with Down syndrome may initially struggle to eat certain foods, or they may not be able to eat enough food for normal growth and development. The majority of babies go onto tolerate and manage all foods. A Paediatric Dietitian will work with you to help improve symptoms and achieve optimal nutrition.

We have produced **The Living Experience – Feeding issues with babies with Down syndrome** to provide an insight and share parents' tips and advice.

Overview of Service

Children's dieticians work with children with significant feeding issues or failure to gain weight, including children who require feeding interventions such a an NG (nasogastric) Tube or PEG (percutaneous endoscopic gastrostomy) feeding. Dieticians support feeding issues giving advice on specialist diets and supplements. Dieticians will monitor weight gain and dietary intake.

Frequency

When required depending on your child's need.

When to expect service to start/end

From when a feeding issue is identified until it is resolved.

Referral/Contact Details

Referrals can only be made via health care professionals such as GP, S&LT or Paediatrician.

Health Visitor

Health Visitors are qualified registered nurses or midwives who have additional training and qualifications. Their additional training enables them to assess the health needs of children from birth to 5, their families and the wider community to promote good health and prevent illness.

Health Visitors provide support to all families, not just those with a baby with Down syndrome. For those with a little one with Down syndrome, some areas have a Health Visitor who has more knowledge and experience around Down syndrome. The experience of our parents is that a good Health Visitor can be a wonderful advocate for you and your family and should be able to signpost you to local services and support.

The role of Health Visiting varies considerably from area to area, and occasionally there may be a specialist component to the role.

The day-to-day work of Health Visitors typically includes providing ante-natal and post-natal support, supporting parents in bringing up their young children, assessing a child's growth and development needs and supporting the child and their family.

Frequency

From birth as required depending on need of your family.

When to expect service to start/end

Health Visitors often become involved antenatally and support your family until your child goes to school.

Referral/Contact Details

Your Health Visitor's contact details should be within your Red book or contact your GP.

Occupational Therapy

Occupational therapy aims to improve someone's ability to do everyday tasks.

An occupational therapist (OT) will work with you to ascertain what equipment your child may need to make life easier and to aid their development. OTs work with families at home, in nurseries and schools.

An Occupational Therapist (OT) will work on activities and provide equipment to help promote development across a range of skills, often focusing on Fine Motor Skills these involve the small muscles of the body that enable functions such as writing, grasping small objects and fastening clothing.

There are OTs who specialise in sensory processing development and on our New Parents page, we are fortunate enough to have Munira Adenwalla who specialises in this area.

Some examples of the tasks and skills OTs might provide support on as your little one grows up: Self-care routines like getting dressed (fine motor skills and motor planning); writing and copying notes (fine motor skills, hand-eye coordination); holding and controlling a pencil, using scissors (fine motor skills, motor planning).

In the early days an OT may provide your little one with a seat for the bath, a seat (often a Tumble Form) for everyday activities and a high chair for eating at.





Frequency

As with all service provision, this can vary depending on local arrangements for your area, and your child's needs.

When to expect service to start/end

As with all service provision, this can vary depending on local arrangements for your area, and your child's needs. In many areas, OTs work with a family on a particular aspect and then discharge the child and you have to reapply for further support, so always worth thinking ahead of potential need as there is often a waiting list/delay between requesting and receiving support.

Referral/Contact Details

Parents or health professionals can refer directly to the service for an assessment.

Ophthalmology/ Optometry

Simply put – all matters relating to the eyes and vision!

Optometrists, ophthalmologists, and opticians are all professionals who specialise in eye care. An optometrist is an eye doctor that can examine, diagnose, and treat your eyes. An ophthalmologist is a medical doctor who can perform medical and surgical interventions for eye conditions.

On PADS New Parents page, we have the wonderful Maggie Woodhouse OBE, who is widely regarded as The Expert in eye care for folk with Down syndrome. We have a list of trained optometrists recommended by Maggie who you can visit across the country for specialist advice and support. We also hold Information Sharing Sessions on Eyecare, run by Maggie, these can be found on our **website**.

Trust in her, she will surprise you.

Overview of Service

Paediatric ophthalmology provide eye and vision screening tests and ongoing reviews. Tests vary depending on need.

When to expect service to start/end

Baby will receive the newborn routine examination and then a follow up at 6-8 weeks. Maggie recommends that babies with Down syndrome should see an orthoptist and optometrist before the age of 1 in order to get a good baseline assessment. This will ideally be done with eye drops to ensure a thorough check of the health of the eyes. If any issues are identified with the health of an eye your child will be referred to an ophthalmologist.

Frequency

Since eyes can change rapidly in children with Down syndrome, they should have 6 monthly eye examinations until they are 4 years old; and then regular ongoing reviews for all children with Down syndrome every two years if there are no defects or at least annually for children wearing spectacles. Children with a squint may need more frequent clinic visits.

Referral/Contact Details

Referral/Contact Details Referrals can only be made via health care professionals such as GP or Paediatrician

Paediatric Audiology

Paediatric Audiology is a specialist clinical service which aims to identify and manage hearing impairment/loss in children.

Babies and children with Down syndrome can be more prone to glue ear which can affect hearing, especially during winter months. Often an audiologist will provide a hearing aid which may be on a temporary basis until baby's ear tubes grow and the glue ear resolves.

Paediatric audiology conducts various tests to establish the extent, site and cause of hearing and balance problems. The service provides and manages hearing aids for those children that require them.

Frequency

Annually or as required.

When to expect service to start/end

All children have a hearing test as part of the newborn screening. It's worth noting that the vast majority of little ones with Down syndrome seem to fail this initial test but go on to pass subsequent more thorough tests. For children with Down syndrome, it is recommended that they should have a further review by 10 months and then annually, unless recommended otherwise.

Referral/Contact Details

Referrals can only be made via health care professionals such as GP, Community Paediatrician, or following failed Newborn Hearing Screening. If you have concerns regarding your child's hearing contact your Community Paediatrician.

Paediatrician

A Paediatrician is a doctor who works exclusively with children.

You should have a named paediatrician who your child will see on a regular basis through their childhood. The paediatrician should give you advice and information on all medical matters to do with your child having Down syndrome. They will refer you to other health professionals and should ensure your child has any checks and tests needed. Paediatricians may be based in the community or at a larger hospital. They oversee the whole child and their care needs and will be able to refer on as required, so they should be your first point of contact for all matters to do with health, apart from routine issues when you should still see your GP.

We would expect your child to access their paediatrician at least every 6 months in the early years, but this does depend on need.

When to expect service to start/end

Generally families see a Paediatrician by 3 months of age, and a frequency of every 3 months is common practice until aged 1, then it goes to annual assessments unless the need is greater. Most are available for anything in the interim by email or phone.



Physiotherapy

A physiotherapist will work with you to help your child develop physical skills through showing you activities and exercises for your little one to do at home, as part of everyday play. Physiotherapists work with children and their families at home as well as in nurseries and schools.

Children with Down syndrome can have low muscle tone, which is often referred to as hypotonia or floppiness. All children will be affected differently, some may have it quite mildly whilst others will be more noticeably affected.

Some children with Down syndrome can have increased flexibility of some of their joints – hypermobility. However, it is important that slower development should not be dismissed as 'typical for Down syndrome' without proper assessment. There can be many things that cause slower gross development, and it is ok to ask about these.

We highly recommend tummy time from the delivery room if possible, skin to skin on mum or dad's chest. Our publication **The Lived Experience - Physiotherapy** advice for your baby with Down syndrome will hopefully give you some ideas.

Gross motor skills enable us to do things that involve using the large muscles in the torso, arms and legs to complete whole-body movements, e.g. rolling over, sitting up, crawling and walking. Fine motor skills involve the small muscles of the body that enable functions such as writing, grasping small objects and fastening clothing.

We recommend a publication called **Gross Motor Skills in Children with Down Syndrome: A Guide for Parents and Professionals** by Patricia C. Winders and **Fine motor skills for children with Down syndrome** by Maryanne Bruni.

These can often be purchased second hand on Amazon for less than £10.

Since many families have limited, if any, regular access to specialist physiotherapy, we have introduced online Physiotherapy support sessions. These sessions are available from birth, email **info@downsyndromeuk.co.uk** for further information.

We recommend Gympanzees as a great source of information and activities you can do at home.

When to expect service to start/end

This varies enormously across the country, some areas start this service from a few weeks old, others much later. On our new parents page, we have a couple of physiotherapists to provide general advice. We recommend starting tummy time from birth.

Referral/Contact Details

Your Paediatrician, GP or Health Visitor should be able to provide you with more information.

Enjoy every moment with your baby – it goes so fast



Portage also known as Home Teaching

Portage is a home visiting educational service to support pre-school children with special educational needs to learn through play. Portage supports families to learn together through playing together. A good portage worker will assess where your child is at and work with you to target areas of development through particular activities. Some portage workers loan equipment and resources to families to use at home. Portage can support with the transition into pre-school settings, offering support both to the child and the childcare setting on targets and development.

The Down syndrome development journal is an excellent resource many families find helpful as a guide to their child's development.

Some areas do not offer portage or there may be a delay until you access, so we suggest investigating what your local Children's Centre offers, many have active Facebook groups. You can also establish if you can connect with a Family Support Worker to establish what else is available in your area.

Frequency

Services available can vary depending on your child's needs and availability of service provision in your area.

When to expect service to start/end

The Portage service is often based within the Local Authority as it is an education resource rather than a health service. Availability of these services does vary area to area, so contact your local authority's Special Educational Need Department (SEND) for more information.



Referral/Contact Details

Referrals can often be made to the service via health visitors, GP, Paediatrician, other professionals or directly by parents. Referrals require parental permission.

Early Development Groups

PADS realises many families do not have access to specialist support to encourage development through play and targeted activities, so offer PEGS – PADS Early development Groups – online video recordings by specialists in the Down syndrome arena together with highly experienced early development teachers. These sessions start from the September or January after your child has reached 6 months, through to starting school. Please email **info@downsyndromeuk.co.uk** for further information, and/or to register your interest.

Speech and Language Therapy (S&LT)

includes support around feeding

We recommend introducing Makaton signing as soon as possible and we run an online baby signing course that you can access when you are ready. We also recommend introducing speech sound cards from around 4 months – **Speech and Language - Down Syndrome UK.**

If you planned to breastfeed your baby before they were born, please don't change your mind just because they have Down syndrome. We have plenty of parents on the page who can offer advice and share their experiences around breast feeding and have published **The Lived Experience – Breastfeeding** and **A Guide to Breastfeeding a child with Down syndrome** for your information and encouragement.

Some babies may have difficulties with bottle feeding – always ask your Health visitor or midwife for support. A baby requiring heart surgery may tire easily and so need assistance with feeding via an ng (Nasogastric) tube. It is possible for breast milk to be fed via the tube. If baby is exclusively tube fed please ensure you receive advice from an S&LT around exercises to aid oral motor development.

As well as providing support around speech and language (communication), therapists also provide support and care for children who have difficulties with eating and swallowing - this is known as dysphagia.

Aspirating can be an issue and parents need to be more vigilant. This is when milk trickles the 'wrong way' into the lungs and can cause pneumonia. Fluids may need to be thickened and the swallow properly assessed if this is an issue. Babies do not

always cough if this happens, so be sure baby is alert and well supported when feeding. We run Information Sharing Sessions on Dysphagia to give you an insight into such feeding issues including tips how to help baby, to book onto these please take a look at our website. Reflux can be more of an issue than in babies without Down syndrome and may require an ultrasound to assess as baby may not always make a fuss.

A baby with Down syndrome can feed as well as any other baby. However, some children may have issues when introducing weaning – and your Health Visitor may suggest specialist help from a S&LT. The S&LT may assess your child to ensure they are feeding well and that all food is going into their stomach rather than airways.

All our children should receive support from Speech and Language Therapists to help develop their speech, language, and communication. Often parents source and fund independent therapists if the local provision is not adequate, you can search on the website ASLTIP.

We can help recommend therapists with extensive experience too. Many local Down syndrome charities provide subsidised access to independent specialist S&LTs.

Frequency

This article by Down syndrome education international sets out recommended frequency.

When to expect service to start/end

As with all service provision, this can vary depending on local arrangements for your area, and your child's needs. We recommend starting to sign with little one from when they are a few weeks old and to introduce speech sounds (phonics) from around 9 months.

Referral/Contact Details

Parents or health professionals can refer directly to the service for an assessment.



Don’t be overwhelmed,
one step at a time...



General advice

Get referrals in early as many can take a long time to come through. Find out who your baby's paediatrician will be and the best way to contact them - usually via a secretary. Keep your baby's records in a folder because they will form evidence when you come to complete forms for DLA, nursery and school provision. It is a sad fact that parents who are able to keep on top of the appointments and who are better informed often seem to receive better care and more timely interventions. Familiarise yourself with who's who and make a list of who you would like to see, keep in regular contact and don't be afraid to chase and chase and chase. You are your child's advocate and now is the time to set aside any shyness and 'not wanting to make a fuss' attitude, respectfully showing the professionals that you know what baby needs and you will make sure they get it.

PADS has developed a referral list for you to complete for your convenience, which you can find at the end of this book; parents find it handy to have all names and numbers in one place.

Try and develop a good relationship with your GP if possible, as they remain the primary healthcare giver and should be contacted first if baby is unwell or if there is something you need. From our experience, babies with Down syndrome do have a higher risk of developing lung infections in the first few years and therefore you need to be more vigilant and seek advice sooner than perhaps you otherwise would. Do not be worried about being seen as a 'fussy parent', anything that concerns you should be taken seriously and be properly explored.

Have high expectations!

Your baby is not so different from other kids, yes there may be some extra medical issues and you may have to wait longer to see little one reach the same milestones, but unless there is a known issue you should assume that your child will get there in their own time and generally with support. If you feel baby is not making satisfactory progress then speak to your GP or Paediatrician and see if there is a reason for this because it may well be something is being overlooked that needs addressing - for example poor nutrition, food intolerance, poor sleep and constipation can combine together to slow baby's development. If baby does not seem responsive, are they due another hearing test? Be expectant of progress and vigilant to anything holding them back.

Your choice!

Your child will require extra appointments, and this can be overwhelming at times. Take your time and review every once in a while who you think you and your child benefit from seeing.

If you really feel a particular professional is not addressing your child's needs and/or you don't get on, you can sometimes request to change.

Ask!

Always ask for clarification or a clearer explanation if you don't understand something. If you have an appointment think of all the questions you have and write them down before you go so you don't forget. Doctors can be very quick to explain and move on to their next patient, but this is your child's chance and so make sure you understand what has been said and that you agree with any plans or suggestions as it can be harder to question later.

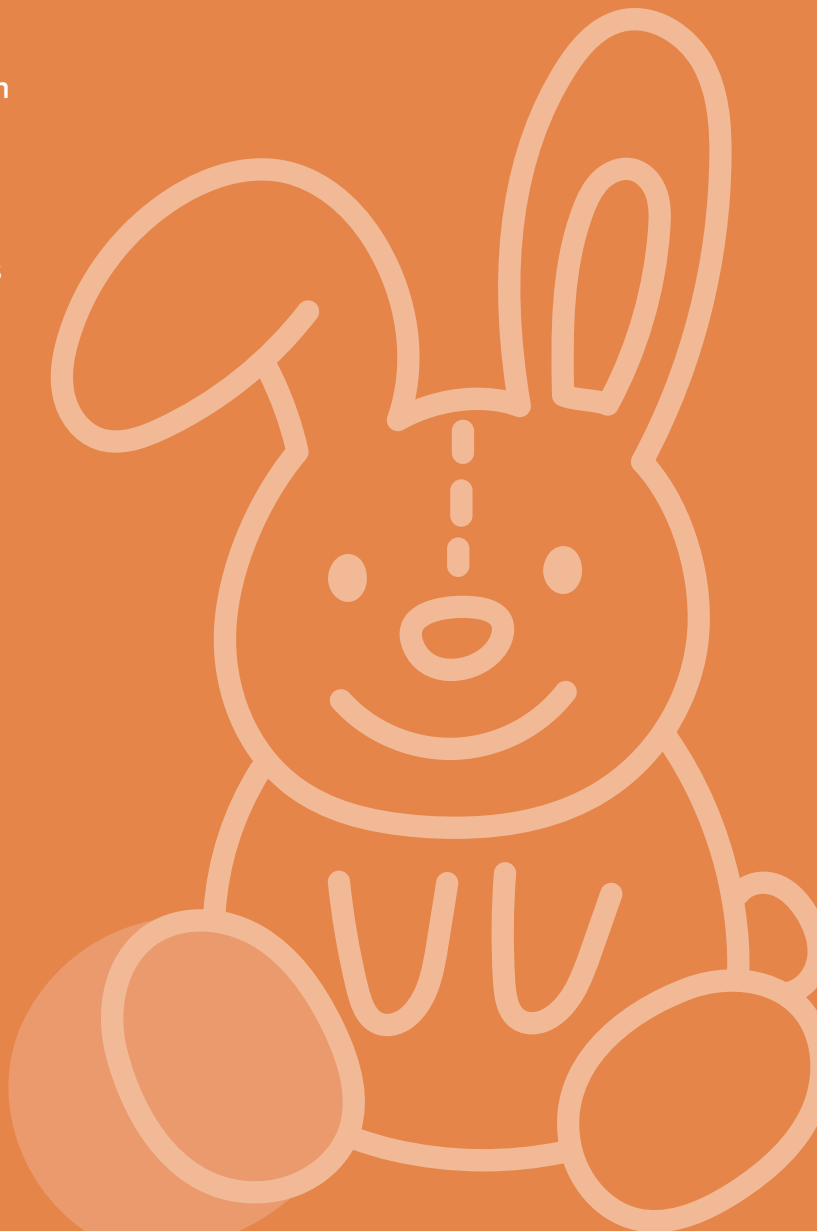
Notebook/Diary

Some families find it helpful to have one book in which they write down notes from medical appointments, jot down things they want to ask next time they see a particular specialist. A few of our children have more complex medical needs and parents report having a diary exclusively for recording notes whilst in hospital, and/or at appointments is very useful.

You'll look back & wonder what all the worry was about

Toileting

At PADS we promote introducing sitting on the potty from when little one is starting to wean. **We have a wonderful group called #pants4school toilet training, we recommend you joining** from c5/6 months old. This advocates a 4 step programme to toilet training as this is very achievable for the majority of our children to be toilet trained alongside their peers. Many families recommend sitting little one on a potty to aid with constipation.



Communication

Language

You will in the fullness of time discover we live in a society that sadly has much discriminatory language. PADS is working hard to challenge and address this, and we strongly advocate the use of chance not risk when giving screening results, and the use of person first language – a baby has Down syndrome and is not a Down's baby. We encourage medical practitioners and indeed others to see the person first and that each baby should be seen as an individual.

Makaton Signing

Makaton is a well-established and fun way of helping your baby communicate used by many of our families as a bridge until speech starts. Some families use Signalong instead of Makaton – worth finding out which your local nursery uses.

Maybe look at attending a signing course or learn some basic signs from **Singing Hands** and **BBC's Mr Tumble**. As a baby the most useful signs are probably 'more', 'milk' and 'biscuit' - you don't need to know much to get going – learn a few signs and repeat them often throughout the day and one day your baby will sign 'more' back and you will see that they did get it after all!

PADS offers the opportunity for new parents to access a 6 weeks online course of baby Makaton signing sessions at a subsidised rate. We also arrange an introduction to **Makaton online training course** for nurseries/childminders, as well as a 6 week course for Grandparents!

For more information, please email: **info@downsyndromeuk.co.uk**

Financial support

In general, the services and resources PADS provide are subsidised in order to make them both sustainable and affordable. We would not want anyone's financial circumstances to exclude them from accessing any, so if anyone cannot afford to financially contribute, please contact info@downsyndromeuk.co.uk and we will discreetly

ensure you are included.

Disability Living Allowance (DLA)

Everyone with Down syndrome should qualify for DLA. DLA is a non-means tested allowance - it is not influenced by your income or savings and is paid into your bank account on behalf of your child. If your baby has significant health needs early on, such as an NG tube, cardiac issues etc, then it is worth trying to claim early, otherwise we find most claimants are more successful after a year.

From the age of 0-3 years is potentially awarded at 3 different rates for Personal Care – low, middle and high. At 3 years of age, you can apply for the Mobility Care element.

The DLA is a depressing form for parents - it is not a form where we celebrate success and achievement but think more closely about the needs baby has that are over and above their typical peers. For example, baby may wake more frequently during the night, they may need closer monitoring at night, they may need repositioning often as they are unable to make themselves comfortable, they may need more help with feeding. If this is your first baby, you may find it helpful to complete the form with a friend who has children because they may be able to see the additional care needs more clearly as they compare their typical experience of development and milestones. This is an important form because it can help secure

financial support that you may need to cover possible extra expenses that your child has. The form itself is a massive turn off but remember this is YOUR CHILD's money which is payable to them to help them achieve their potential - let that be your motivation!!

It is common for DLA requests to be denied but do not give up, gather more information, and seek help from those experienced in this area. On our New Parents page, we have a lot of advice and information to help you. We regularly hold information sharing sessions on applying for DLA. Many support groups assist families to complete their DLA form as do Citizens Advice and some health visitors. If your child receives middle or higher rate, then you may also be eligible for **Carer's Allowance** (depending on your income) and if the child receives DLA this may increase **Universal Credits**.

Our **Disability Living Allowance (DLA) service** provides parents with expert guidance and support to navigate the application process for this essential benefit. Led by one of our specialists, our regular drop-in sessions empower families with the information they need to access financial support for their child's additional needs.

Neonatal Leave and Pay

If your baby ends up needing special medical care in the first month after birth, you can now get up to 12 weeks of paid leave on top of your usual maternity, paternity, or adoption leave. This is called **Neonatal Care Leave**, and it's meant to help parents be there for their little ones without stressing about work or money.



Peer support

Our super supportive, very welcoming and nurturing New Parents page will provide you with a safe space in which you can ask any question, share any concern or worry, as well as celebrate little one's arrival and general gorgeousness!

In addition, we are delighted to be able to provide our families with access to other support:

Counsellor

PADS subsidises the cost of a wonderful independent professional counsellor, Sue, for those who perhaps are struggling around discovering little one has Down syndrome and feel they may benefit from a chat with someone completely independent of friends, family and our community. We arrange small group and individual sessions, please please contact info@downsyndromeuk.co.uk for further information.

PADS Family

For many, PADS becomes like a second family. We are here not only to support parents, but we also have a closed **group exclusively for Grandparents**, and we run regular Makaton online training sessions developed for PADS Grandparents.

We have a **closed group just for Dads**, it tends to be quiet but is there for anyone who wants to connect with other dads. We also have a WhatsApp group for dads.

We suggest that you encourage all friends and family to follow our social media to gain an insight into the reality of having Down syndrome in modern Britain.

Please email **info@downsyndromeuk.co.uk** for more information.

Facebook **Twitter**

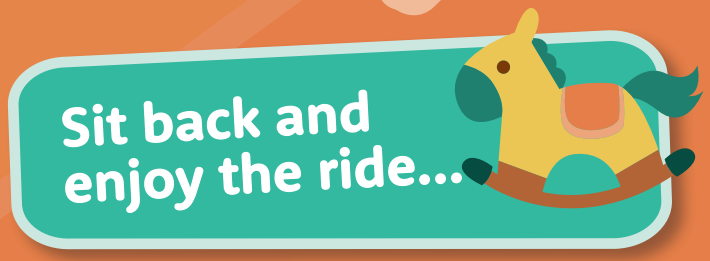
Instagram **TikTok**

PADSFit
Putting Parents First

We cannot look after anyone else if we don't look after ourselves.

PADSFit is a place to find out information about all the fitness, health and well-being projects PADS has to offer. You'll find posts inviting you to join Yoga sessions, running or waking challenges set by other PADS members and up to date information about how to join TomFit - a half an hour weekly HIIT session prepared and run by Tom Enoch.

So, whether you fancy keeping yourself motivated to run regularly by sharing your runs with other runners, being inspired to get out walking or on your bike, or want to tap into the yoga/HIIT sessions we regularly offer, then this is the place for you. Please do as much or as little as you want. The group is for fun and friendship and there is no pressure to do anything you don't want to.



Local support

Local Down syndrome Support Groups

Alongside national organisations such as Positive About Down syndrome, there are many smaller local groups who provide a variety of services and support.

Their details can be found on our support group map.

downsyndromeuk.co.uk/supportgroups



Medical info

Bowels

Babies and children with Down syndrome can be more predisposed to bowel issues. Some may have had surgery for duodenal atresia or Hirschsprung's disease, some may be more prone to constipation or looser stools. If you have any concerns, keep any eye on baby's nappy and record when they do a poo and its consistency or if baby was distressed passing it. This information can help formulate what is 'normal' for your baby and whether intervention is needed to better manage issues. **Constipation is a relatively common issue** and baby may need medication to help keep the poos soft and easier to pass. This is not always easy to get exactly right and so a 'poo diary' is a helpful way to accurately record information so that a proper plan can be made.

Constipation can worsen when weaning and is best if caught early before it stretches the bowel and causes more problems.

Our publication **The Lived Experience - Hirschprung's Disease/ARMs** may be insightful, and we have **a closed group for parents** of children with the condition.



Infantile Spasms

Infantile spasms (IS) is a rare but serious form of epilepsy, which occurs mostly in babies under the age of one (although occasionally in children with Down syndrome it can begin later).

IS affects around 400 children a year, and around 3% of children with Down syndrome. IS is caused by chaotic electrical activity in the brain. This activity can result in a range of symptoms, the most obvious being spasms, which are a form of seizure. Spasms normally happen in clusters, with a pause of a few seconds between each one. They can look like a head drop, or an exaggerated startle reflex. Some children may also begin to slow down in their development or lose skills. This is less likely if the spasms are caught early.

IS also causes chaotic brain activity which can be seen on a test called an EEG (electroencephalogram). You may hear IS being referred to as West syndrome – this is the combination of spasms, loss of skills, and chaotic brain activity.

The single most important thing you can do to protect your child is to be aware of what IS looks like so that you can take prompt action if your child has spasms. UKIST has an awareness video on their website which all parents of young children with Down syndrome should watch. IS can look quite subtle but can have big consequences, including increased learning disability and an increased likelihood of seizures in the future. Quick diagnosis and treatment of IS gives your child the best chance of a good outcome.

Guidelines are that children with suspected IS should have an EEG within 3 days. Many forms of epilepsy do not require the same rapid diagnosis and treatment of IS. An example of clinical guidelines from Sheffield Children's Hospital are on our website, and you may wish to share these.

Our publication Lived Experience: Infantile Spasms includes many useful links to publications and organisations for further support.

Remember: there are several things that can cause worrying movements, most of which are not serious. However, if you have any concerns that your child is experiencing spasms you should seek expert advice as it is a medical emergency. It is not the time to worry about making a fuss!



Diagnostic overshadowing

This is when having Down syndrome is used to explain away potential issues. For example, baby may not be settling at night and waking several times, the doctor advises this is because baby has Down syndrome and this is a common issue, when in fact baby may have silent reflux, which is causing pain, they may have food intolerances causing discomfort, or they may be constipated. Do not be fobbed off but be politely persistent if you feel there is an issue. All problems are best if caught early and properly managed so don't be afraid to be bold and have confidence in what you feel. If you suspect a medical professional is guilty of diagnostic overshadowing, ask them what course of action they would be considering if little one didn't have Down syndrome. You are the expert in your baby and if something doesn't seem right then tell someone!

To learn more, take a look at our **resource on diagnostic overshadowing**.

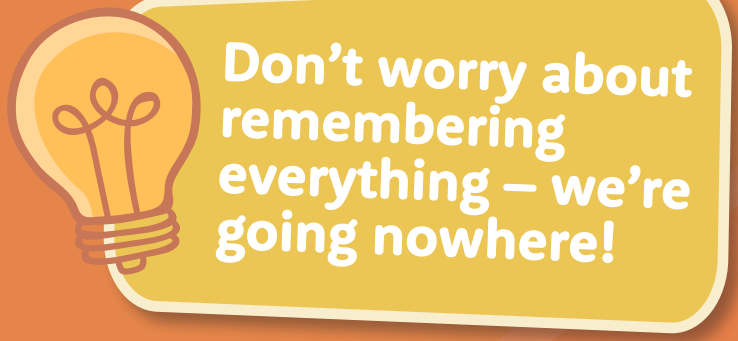


The future...

Down Syndrome UK

PADS is an initiative created and run by Down Syndrome UK, a registered charity, run by parents for parents (registered number 1184564).

Whilst PADS works primarily in maternity care and with expectant/new parents, we have many other strings to our bow! As your little one grows up, you will have access to a wide range of resources, support groups, expert advice and training that we provide.



Fundraising

At PADS we aim to enlighten, educate and empower parents and professionals to ensure our children and young people have every opportunity to flourish and thrive. We subsidise the services and resources we provide to parents and fund literature into maternity units to reach new and expectant parents. We also campaign and lobby parliamentarians and policy makers to improve the care and support our families receive, particularly in maternity services. **We are always grateful for any support families** can give – from shopping via **easyfundraising** to running a marathon! We believe we make a huge difference on a day to day basis at the coal face and always welcome any fundraising opportunities as well as more friends and families to help run and contribute to PADS on a **voluntary basis.**

Here is a guide to all our Facebook groups/pages that in time you may find helpful:

Great Expectations

A warm welcome awaits any expectant woman in the UK who has had a high chance/ confirmed result of baby having Down syndrome. Members have described the group as 'honest, refreshing, completely non-judgmental' and 'my favourite place on social media'.

Our admin team comprises of mums with a range of experiences around discovering their baby has Down syndrome. We also have three wonderful mums who are midwives, a neonatal nurse mum and an auntie who is a paediatric nurse with extensive cardiology experience, all on hand to answer general questions about pregnancy.

Dads to be

We realise dads to be can sometimes feel a little overlooked and neglected, so this group is exclusively for those dads in the UK whose partner is expecting a baby with a high chance/confirmed result of having Down syndrome.

A small team of dads are on hand to share their own experiences, offer support and answer any questions.

Primary

A group for parents of pupils with Down syndrome in the UK of primary age (4-11 years) providing Support Training & Resources.

Muslim Mums

A closed group exclusively for mums of a child/young person with Down syndrome. This group is about providing support to all Muslim mums.

Dads

A group exclusively for dads in the UK of a child with Down syndrome aged 0-5 years. A chance for the dads to meet and chat with other dads, to share experiences and perhaps exchange ideas, discuss any worries and celebrate achievements.

New parents

One of the most wonderfully supportive and caring groups you will find on Facebook! We welcome parents of babies with Down syndrome, from birth through to 18 months of age. The youngest member to join to date is 3 hours old! Any question can be asked, any concern expressed, any celebration shared, all are welcomed by a completely non-judgemental group of parents providing the best peer support whilst potentially creating friends for life.

We are very fortunate to have some experts in their field on hand, to offer advice and share their wisdom. These include Maggie Woodhouse OBE – leading eye care expert working extensively with children with Down syndrome; June Rogers MBE – the expert on all issues toileting for children with Down syndrome, Jenny Rawling of the UK Infantile Spasms Trust, along with Donna Murphy a highly experienced paediatric physiotherapist working with infants and children with Down syndrome. We have recently added specialist speech and language therapists Nicole Murray and Becky Baxter to strengthen our team along with Munira Adenwalla an OT specialising in sensory processing.

Breastfeeding

Several mums who are lactation consultants and others who are very happy to help any mum who would like some support and advice around breastfeeding their baby with Down syndrome. PADS has a Breastfeeding Supporter, Sarah, who has extensive experience and knowledge around breastfeeding.

Contact **breastfeeding@downsyndromeuk.co.uk** for more details.

Grandparents

We know the important role grandparents play in all our lives and so have a wonderfully supportive group exclusively for UK based grandparents.

Preschoolers

Open to families who graduate from our New Parents group, currently has families from across the UK with a child with Down syndrome, aged 18-36 months.

PADSFit

At PADS we take a holistic approach – acknowledging the importance of mental and physical wellbeing of parents and carers. This group is open to PADS members who wish to encourage and support each other around mental and physical wellbeing. We have monthly challenges for those who enjoy running, walking, swimming, cycling or crawling, as well as details of our weekly yoga and HIIT sessions.

Professionals preschool

A group for all professionals who work with a child/children with Down syndrome in any preschool setting, includes nursery staff, childminders, S&LTs, OTs etc.

Professionals primary

A group for all professionals who work with a pupil with Down syndrome in primary school, including teachers, TAs, SENCos, OTs, S&LTs...

Professionals secondary

A group for all professionals who work with a student with Down syndrome in mainstream secondary school, including teachers, TAs, SENCos, OTs, S&LTs...

Parents secondary

In conjunction with Future of Downs, this group is open to parents of a child/young person aged 9+ in the UK.

DSUK 16+

A group for parent/carers of young people and adults with Down syndrome in the UK to ask advice, share tips, offer encouragement and general peer support.

Healthcare professionals

We welcome, midwives, obstetricians, neonatal practitioners, health visitors, doulas - all professionals working in and beyond maternity services who care for new & expectant parents of a little one with Down syndrome in the UK.

Parents in education

We love to collaborate with parents who are professionals working in education.

Parents in healthcare

We love to collaborate with parents who are professionals working in health care.

Optometrists

Created with Maggie Woodhouse OBE to disseminate best practise, and to encourage eye care professionals across the UK to increase their knowledge of eye care for folk with Down syndrome.

Research

At DSUK we are very keen to encourage and support research so have created a group where those conducting research and seeking UK based respondents can promote and look to recruit parents who are members of the group.

DSUK Network - Parent support groups

Created in February 2015 this group is for those who are actively involved in running a local Down syndrome support group in the UK. We hold an annual conference, disseminate information, encourage and support each other whilst aiming to share best practise to support our families across the UK.

Reaching out

We are keen to extend our reach to families of all faiths, cultures, and social demographic backgrounds. This group aims to reach those from diverse backgrounds to ensure we reach as many families as possible with a child with Down syndrome.

DSUK Pants4School Toilet Training 0-5

This hugely successful group is for both the parents of and professionals working with children with Down syndrome aged under 5, to encourage and support the child to be out of nappies and become toilet trained.

Toileting 5+

For parents and professionals working with children aged 5+ around toileting issues.

Hirschprung's disease

A group exclusively for parents and carers of children and young people with Down syndrome who have Hirschprung's Disease or other anorectal malformations who are wanting information and support specifically around toilet training.

PADS Cares - Parents

For those PADS members who have sadly lost a child or pregnancy with Down syndrome.

PADS Cares - Grandparents

For those grieving grandparents who have sadly lost a child or pregnancy with Down syndrome.

PADS Cares - Children with leukaemia and Down syndrome

For parents and carers of children and young people with leukaemia and Down syndrome.

Bilingual

For families who speak a second language at home.


Be prepared to
laugh every day

Routine health care/recommended frequency

Blood tests	Newborn routine heel prick blood test to confirm Down syndrome
Thyroid	Blood test every 4-6 months Blood test every year from age 1 year
Blood Disorders	By 3 days, full blood count and blood film
Vision	Newborn routine check including congenital cataract check plus follow up at 6-8 weeks Before age of 1 see an orthoptist and optometrist to get a good baseline assessment At least 6 monthly visits until 4 years old
Hearing	Newborn hearing screen By 10 months full audiological review Annual/bi-annual audiological review
Heart	By 6 weeks, formal heart assessment including echocardiogram
Sleep apnea	Home sleep study recommended by age of 1 and annual study conducted each year until 5 years old

Source: Down Syndrome Insert DSMIG 2020, The Royal College of Paediatrics and Child Health and Maggie Woodhouse MBE.

DSUK recommendations

Provision of early intervention services vary enormously across the country.

Birth+

Physiotherapy input primarily skin to skin and tummy time.

Online Physiotherapy sessions start from newborn.

Speech & language intervention may be required around feeding from birth.

Makaton signing, PADS Makaton signing for babies course is suitable for parents when they have the time and headspace to attend and enjoy.

4 months+

Communication specialist intervention from 4 months.

Speech sound production activities from 4 months.

6 months+

PEGS - PADS Early Development Groups start from when baby is 6 months old.

Toilet training – we suggest starting to sit baby on the potty from when they are becoming strong enough to sit. Our 4 step toilet training programme starts with making potty visits part of the everyday routine.

Child's directory of medical contacts

Child's name: Date of birth:

NHS number: Weight at birth:

AUDIOLOGY (Hearing)

Name: Tel:

Hospital: Email:

CARDIOLOGY (Heart)

Name: Tel:

Hospital: Email:

DIETICIAN (Feeding)

Name: Tel:

Email:

HEALTH VISITOR (General health related support)

Name: Tel:

Email:

OCCUPATIONAL THERAPY (Support around equipment)

Name: Tel:

Email:

OPHTHALMOLOGY (Vision)

Name: Tel:

Hospital: Email:

PAEDIATRICIAN (Specialist children's doctor)

Name: Tel:

Hospital: Email:

PHYSIOTHERAPY (Support around physical development)

Name: Tel:

Email:

PORTAGE (Home teaching service)

Name: Tel:

Email:

SPEECH AND LANGUAGE THERAPY (Feeding and communication)

Name: Tel:

Email:

Little orange book of knowledge



This guide is intended for new parents in the UK of a baby with Down syndrome.

It is not exhaustive but a starting point - your baby will teach you so much and we hope this guide will help to fill in some of the gaps.

DSUK
Down Syndrome UK

Positive About Down Syndrome

For more information and to download resources visit
www.downsyndromeuk.co.uk
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