



DOWN SYNDROME  
CHESHIRE



*MATERNITY PACK*

**BOOK OF INFORMATION FOR NEW PARENTS**



HELLO.

Welcome to our book of  
Information for new parents.

## Congratulations on your new arrival!

Welcome to Down Syndrome Cheshire. Our charity began in 2007 when a group of parents, who all had babies with Down syndrome, got together to support one another. Since then, the charity has grown to help around 300 children and adults with Down syndrome and their families as well as informing education and health professionals and our wider community.

The arrival of a new child can be a joyful but unsettling time for many parents. This booklet provides you with some information about what Down syndrome is and what it might mean for you and your family.

Everyone is different and we feel emotions at different times so read the information when you feel ready to do so. This is your personal journey with your beautiful new baby.

*"My son Ben has Down syndrome, and I can remember very clearly the emotions I felt the day he was born. I was on a roller coaster where one minute I was utterly delighted and the next I felt sheer panic."*

**Sarah, Mum of Ben**





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# We Are Here For You: Introducing Our Key Support Staff

You will meet many health and education professionals who can support you and your beautiful new baby. At Down Syndrome Cheshire we're here for you and have experienced members of staff on hand to offer practical support and guide you towards getting the help and information you and your baby might need. These staff include:

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**Lawrence Caygill**  
*CEO*

Lawrence is likely to be one of your first points of contact at Down Syndrome Cheshire. He oversees all our services which include family support and events, education advocacy and training, therapies and professional services, life skills and employability, social care and supported accommodation.

**You can contact Lawrence by emailing**  
[lawrence@dscheshire.org.uk](mailto:lawrence@dscheshire.org.uk)



**Rebecca Goodier**  
*Family Support Worker*

Rebecca organises all our family support events and is on hand to offer advice, information and to signpost you to relevant services. In the early days, Rebecca is available to come and visit you at your home to meet you and your baby and answer any questions you may have. Rebecca is mum to Jamie, who has Down syndrome.

**You can contact Rebecca by emailing**  
[rebecca@dscheshire.org.uk](mailto:rebecca@dscheshire.org.uk)



**Yvonne Edwardson**  
*Education Advocate*

Yvonne is an Education Advocate specialising in early years. She arranges our Cheeky Monkey baby and pre-school play sessions, Makaton training and is on hand for any questions you might have about your baby's early learning development. Yvonne has a wealth of experience in the education sector and is mum to Libby, who has Down syndrome.

**You can contact Yvonne by emailing**  
**[yvonne@dscheshire.org.uk](mailto:yvonne@dscheshire.org.uk)**



**Amanda Holland**  
*Speech and Language Therapist*

Your baby's communication journey begins as soon as they are born and Amanda is available to support and advise you about your child's speech and language development.

**You can contact Amanda by emailing**  
**[amanda@dscheshire.org.uk](mailto:amanda@dscheshire.org.uk)**

# We All Follow Our Charity Values

## AMBITIOUS

We create opportunities to exceed expectations.

## SUPPORTIVE

We provide well informed, tailored support to families.

## TRUSTED

We always tell the truth.

## DEDICATED

We strive to consistently provide high-quality services.

## CARING

We care and celebrate what matters to you.

*"The day after our child was born, a representative from Down Syndrome Cheshire visited our house with an information pack and contact details should we require any help or assistance. This was much appreciated as we did not have a pre-natal diagnosis of Down Syndrome. The support we have received to date has been invaluable, particularly the Makaton classes. The family days provide an opportunity for parents to give and receive advice and our children to play with their peers on an equal footing."*

**Joanne, Mum of Rueben**





# Questions You May Have

Whether you were expecting your baby to be born with Down syndrome or if the news is unexpected, there may be questions you need answering. Use this section of the booklet when the time is right for you.

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## **What is a syndrome?**

A syndrome is a group of symptoms that consistently occur together, or a condition that is characterised by a set of associated symptoms. Not every person with a syndrome will have every single listed symptom.

## **What is Down syndrome?**

Down syndrome is a life-long condition that causes delays in learning and development. It occurs because your baby's cells contain an extra chromosome 21. It is named after the English doctor John Langdon Down who was the first person to categorise the common features of people who have the syndrome.

## **What health conditions are most common with Down syndrome?**

There are some conditions that are common with people who have Down syndrome although it is worth noting that not every person will experience them and many of these conditions also affect the general population. Heart problems, decreased muscle tone, hearing and visual impairments can occur. Other common conditions can include thyroid function, immune system development, frequent coughs and colds and gastrointestinal conditions.

## **Will my baby have heart problems because they have Down syndrome?**

Around 50 per cent of babies with Down syndrome have heart problems that can be minor or more serious. Less than one in five have a serious heart problem.

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Our website has a wealth of information about Down syndrome and can be visited at [www.dscheshire.org.uk](http://www.dscheshire.org.uk). We would also recommend looking at the Down's Syndrome Association website [www.downs-syndrome-org.uk](http://www.downs-syndrome-org.uk) or phoning their helpline (10am – 4pm) 0333 1212 300.

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### **What health checks will my baby with Down syndrome receive?**

There are basic minimum health checks that babies and children with Down syndrome should be given. All new parents are provided with an insert for their Personal Child Health Record (PCHR), also known as the “red book”. We can provide you with a copy of this. Please email [rebecca@dscheshire.org.uk](mailto:rebecca@dscheshire.org.uk).

### **Can my baby with Down syndrome grow up to lead a healthy and active life?**

Absolutely. From an early age, children will benefit from making healthy food choices and being encouraged to take part in physical activity. There may be some factors that people with Down syndrome may need to overcome when it comes to maintaining a healthy weight such as a lower metabolic rate and hormonal conditions. Your GP or learning disability nurse will be on hand to support you.

### **What does the future hold for my baby with Down syndrome?**

Generally, people with Down syndrome are living longer and achieving more than ever before. With the right support, people with Down syndrome are living independently, forming relationships, becoming role models, and gaining employment.

# Your Feelings

It's perfectly normal to feel overwhelmed at the birth of your new baby and you may experience a mixture of emotions ranging from joy and wonder to denial, anger and even sadness for the loss of the baby you thought you were having. You may feel scared about the future and worried about what other people may say or do. There is no right or wrong way to feel and our team are here to support you.

Looking after yourselves is incredibly important even though it is difficult to find the time between feeding, nappy changing and visitors! Here are some strategies that might help:

## **Talk**

To a friend, relative, support worker or another parent. Our Family Support Worker Rebecca is always available for a chat and can put you in contact with other parents who may have gone through similar emotions as you. Our regular Cheeky Monkey baby groups and family days out are a great opportunity to meet up regularly with other mums, dads, grandparents, and siblings.

## **Rest**

Take every opportunity to look after your own wellbeing and rest as regularly as you can. Accept offers of help where you can and prioritise what needs to be done versus what can wait. Having a newborn is exhausting, so cut yourself some slack on housework and chores.

## **Get information**

Knowledge about Down syndrome can feel empowering and reassuring for some and overwhelming to others so take it at your own pace.

## **Enjoy your baby**

Make the most of this precious time. Cuddle your beautiful bundle of joy and take photos.

## **Ignore unhelpful comments**

Even if from well-meaning people close to you!

If you feel that you or a family member may need additional support coping with your feelings, please don't hesitate to contact our Family Support Worker Rebecca who will put you in touch with someone who can help.



*"Jack was diagnosed with Trisomy 21 shortly after birth. We were called into a private room at the neonatal unit and that's when we were told Jack had Down syndrome. Instead of giving us positives we got all negatives and even a sorry about his diagnosis but that didn't change my feelings. They asked me how I felt about the diagnosis and I replied, am I supposed to feel any different?"*





# Celebrating Your New Arrival

Telling friends, family and work colleagues may feel daunting. Only you know when and how it is best to tell people and often that will depend on the individual and the relationship you have with them.

You might feel comfortable sharing your news with everyone you know straight away or may rather tell only close family and friends to begin with until you have come to terms with the news yourself. It might be that they do not know very much about Down syndrome so you can share this booklet with them or point them in the direction of our website for further information [www.dscheshire.org.uk](http://www.dscheshire.org.uk). Grandparents and siblings are always very welcome to come to our Cheeky Monkey play group and to our family events.

If your new baby has brothers or sisters, you are the best person to decide how much information you want to give them about their new sibling. It is likely to depend on their age and level of understanding.

Key messages you may want to pass on to them are:

- **The baby has Down syndrome by chance**
- **You can't catch Down syndrome**
- **You are very important in the new baby's life**
- **We love you very much and we love the baby too**

Unfortunately, some people don't react in the way that you might expect or may share or say something inappropriate. It is unlikely anyone is trying to be intentionally hurtful. Some people just haven't been educated about Down syndrome or any disability for that matter! Try not to take things to heart (easier said than done) and remind yourself of the positive comments you have had from others.

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*"We welcomed our second set of twins in 2018. Twelve hours after they were born and before I'd even seen them, we were told by the consultant that one of our babies had Down syndrome. The shock was huge! We cried buckets! The thing that worried me the most was what their twin relationship would be like. Fast forward three years and I realise now I couldn't have been more wrong. They have a wonderful bond and they've loved each other from the start."*

Jon, Dad of Louisa and Elyse

# Feeding Your Baby

Deciding how to feed your baby is one of the biggest decisions all new parents have to make. And while you might have one plan in mind, your baby may have another. Finding the right method, or combination, for you and your baby may take a little time and require some support.

Breastfeeding helps babies with Down syndrome in the following ways:

- **Close body contact**
- **Speech development**
- **Less infection and illnesses**
- **Less constipation**
- **Lower risk of sudden infant death syndrome (SIDS)**

Sometimes babies feed easily and sometimes it can be more challenging to feed a baby with Down syndrome. The extra challenges can include:

- **Weak suck due to low muscle tone**
- **Sleepiness**
- **Tongue staying up in the roof of the mouth**
- **Small mouth and jaw**

However, with patience and perseverance, many babies with Down syndrome do learn to breastfeed successfully. The following tips may help you overcome some of the common issues above:

- **Frequent feeding**
- **Expressing in-between feeds**
- **Expressing a little before latching**
- **Compressing your breast whilst feeding**
- **Lots of patience!**

If you bottle feed from day one, combi feed (give baby both breastmilk and a bottle) or move from breast to bottle, make sure you hold baby very close to you while giving a bottle to ensure plenty of skin-to-skin contact. This will provide your son or daughter with sensory stimulation too.

Bottle feeding also gives you the option to share feeding duties with a partner, grandparent or friend. If you feel you do need additional support or advice, please speak to your midwife, health visitor or healthcare specialist.

# Your Baby's Development

Your baby will amaze and delight you every day and it's important to remember that they are on their own individual development journey.

**Involve your baby in everyday life and activities** by playing and interacting as you would with any baby. It is important to remember that most of your baby's behaviour is due to being a baby rather than having Down syndrome!

Your child with Down syndrome will learn to walk, talk and be toilet trained but will meet these milestones in their own time which may be later than children who do not have Down syndrome.

**Communication is incredibly important** for your baby which is why we run a specific baby and toddler group so that parents and babies can begin to learn Makaton which uses signs and symbols to aid communication. We also lead Makaton training sessions for parents and carers. Our education advocate Yvonne can explain more about the importance of Makaton and communication for babies. You can contact her by emailing [yvonne@dscheshire.org.uk](mailto:yvonne@dscheshire.org.uk).

**Early intervention for speech and language development is incredibly important** for your child and our speech and language therapist Amanda can advise you about this. You can contact her by emailing [amanda@dscheshire.org.uk](mailto:amanda@dscheshire.org.uk).

**Getting out and about** and experiencing new sights, sounds and people is wonderful stimulation for your baby. Our Family Support Worker Rebecca regularly arranges activities and family days out that will benefit your baby and the whole family. To find out about events and activities run by Down Syndrome Cheshire visit our website [www.dscheshire.org.uk](http://www.dscheshire.org.uk) or email [rebecca@dscheshire.org.uk](mailto:rebecca@dscheshire.org.uk).

As your child moves through each new stage of development you may decide you would like to know more about Down syndrome and how you can support your daughter or son. We run free training sessions for parents and carers on topics such as: **Toileting and continence, Behaviour, Learning profile of children with Down's syndrome, Makaton, Portage.**

We also work with teachers, teaching assistants, midwives, health visitors and paediatricians and the wider community to inform them about the profile of people who have Down syndrome.

# Services To Support You And Your Baby

Keeping track of the services that exist to support your baby can be overwhelming so here's a brief guide. Please be aware that not all services are required for all babies and all at once! If you feel that your baby or pre-schooler needs support in a specific area, then have a chat with your Health Visitor or paediatrician. Our Family Support Worker Rebecca can also signpost you to the help you need.

## **Health Visitor**

If you already have an older child then you will have previously been supported by a Health Visitor as they exist for all families, not just those who have a baby born with Down syndrome. A Health Visitor will help assess the health needs of your baby from birth and should be able to signpost you to relevant local services and support. Please see the next section of this booklet for questions you may wish to ask your Health Visitor.

## **Paediatrician**

Otherwise known as a children's doctor, your baby will have a named paediatrician who they will see regularly throughout their childhood (usually every 6 months). They will give your child medical advice and will refer them to specialist health professionals.

## **Speech and Language Therapy**

Speech and language therapists provide communication support as well as care for children who have difficulties with swallowing and eating. We recommend introducing Makaton signing to aid communication and run free courses for parents and carers. We also employ a speech and language therapist who can offer advice and practical support to you and your baby. You can contact Amanda by emailing [amanda@dscheshire.org.uk](mailto:amanda@dscheshire.org.uk).

## **Occupational Therapy (OT)**

OTs work with families at home, in nurseries and schools. The purpose of occupational therapy is to improve your child's ability to do everyday tasks such as getting dressed. The therapist may provide useful equipment and work on activities with your child which often focus on Fine Motor Skills. Parents or health professionals can refer directly to the service.

## **Physiotherapy**

To develop your child's physical skills, they may be referred to a physiotherapist who will show you activities and exercises for you to build into everyday life. Youngsters with Down syndrome can have low muscle tone which is also known as hypotonia whilst others can have increased flexibility of some of their joints (hypermobility).

## **Education Advocacy**

Your baby's learning journey starts from the moment they are born and their development during the early years is incredibly important. Our early years specialist Education Advocate Yvonne can talk to you about your child's learning development and answer any questions you might have. We also run Cheeky Monkey sessions for babies and their parents/ carers, siblings and grandparents. These sessions encourage learning through play as well as sing and sign activities run by our specialist speech therapist. You can email our education team [education@dscheshire.org.uk](mailto:education@dscheshire.org.uk)

## **Cardiology**

This medical service is for all matters relating to your baby's heart. An echocardiogram (scan of the heart) is given to all babies who have Down syndrome within the first six weeks of their life. Around 50 per cent of babies with Down syndrome have heart problems. Depending on the nature of the heart concern some may require treatment whilst others need regular monitoring. Advances of medical intervention has significantly improved over the years, and these are now seen as straight forward routine procedures.

## **Dieticians**

Dieticians will monitor weight and dietary intake and see children who have feeding issues, weight loss or gain. They also support babies who fail to gain weight including those who require feeding interventions such as an NG (nasogastric) Tube or PEG (percutaneous endoscopic gastrostomy). You will be provided with a specific growth chart for your baby. If you have not already received one, then please contact us and we will arrange to have one sent out to you.

## **Ophthalmology**

This service is for all matters concerning your baby's eyes and vision. An ophthalmologist will examine, diagnose, and treat eyes. At between 6-8 weeks your baby will receive the new-born routine eye examination and it is recommended that you seek an appointment with an optometrist before your baby is 1 year old so than any issues can be referred to the service.



## **Audiology**

Your baby will have a hearing test as part of their new-born screening and it's recommended that your baby should have a further hearing review at 10 months. Glue ear which causes hearing loss can be more common in babies and children with Down syndrome particularly during the winter months. If your baby is found to have a hearing impairment/ loss, then they will be supported by the clinical audiology service.

## **Family support**

Your baby's wellbeing depends on the health and happiness of your whole family and our Family Support Worker Rebecca is available for you all. Whether you would like information and advice, a home visit, to join in with our family activities or just fancy a chat, Rebecca can be contacted by phone on 07518 590300 or by emailing [rebecca@dscheshire.org.uk](mailto:rebecca@dscheshire.org.uk).

# BENEFITS

There are a variety of benefits you may be eligible for now your new baby has arrived.

These include:

- **Child benefit: helpline 0300 200 3100**
- **Universal Credit (UC): administered by DWP, call 0800 3285644**
- **Tax credits: administered by HMRC**
- **Disability Living Allowance: administered by DWP, call 0800 121 4600**
- **Carers Allowance: Carers Allowance Unit 0800 731 0297**

The Down's Syndrome Association (DSA) employ a Helpline Benefits Advisor who you can contact Monday & Thursday 10am-4pm, Tues & Weds 10am-12.30pm on 0333 1212 300 or by email: [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk).



*"My name is Laura and I've been a midwife since 2007. My son Milo was born in 2012 with Down syndrome. I had a very difficult pregnancy with him and naively thought that Down syndrome would never affect me as I was only 27. It was a lonely and vulnerable time. I've learnt so much since then and with the help of Down Syndrome Cheshire I am now so privileged to be able to be a support to families who would otherwise be left feeling lost and isolated following a diagnosis without the invaluable information and contact details that we can now provide. Helping to update fellow professionals on how to provide a diagnosis and what support to give is also an invaluable part of my role. The icing on the cake is that I get to be one of the first people to enjoy a new-born cuddle and get to watch the babies grow and develop over the years. Utterly priceless. Going home to my own gorgeous son at the end of my shifts and listening to him telling me about his day makes it all worthwhile, he lives for the moment and we're enjoying the scenic route in life that he's taking us on!"*

Laura, Mum of Milo

# Topics To Discuss With Your Health Visitor Or Social Worker

Below is a list of useful things you might want to discuss with your Health Visitor/ Social Worker about professional services that might be available to you. You may not need all of these, but it is worth asking about each service as they are important for our children.

- **How does my child receive physiotherapy?**
- **How does my child get referred to a speech and language therapist?**
- **Does my child need occupational therapy?**
- **How do I get Portage or specialist play support for my child?**

Administration questions to ask your Health Visitor/ Social Worker

- **Am I entitled to claim for Disability Living Allowance?**
- **Should I become registered as a Carer?**
- **How do I contact a family in a similar situation?**
- **Would my child be entitled to have access to the Short Break Individual Payments Fund?**
- **Should I get any additional vaccinations for my child?**
- **Can I get my child registered on the Learning Disability Register?**

If you have any questions, please don't hesitate to contact us either by emailing [admin@dscheshire.org.uk](mailto:admin@dscheshire.org.uk) or calling 07518 590300.

# USEFUL CONTACTS

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## **Down Syndrome Cheshire (DSC)**

We are a local charity supporting people with Down syndrome and their families in Cheshire.

**Tel:** 01606 246171/ 07518 590300

**Email:** [admin@dscheshire.org.uk](mailto:admin@dscheshire.org.uk)

**Website:** [www.dscheshire.org.uk](http://www.dscheshire.org.uk)

## **The Down Syndrome Association (DSA)**

The DSA provides information and support on all aspects of living with Down syndrome.

**Tel:** 0333 121 2300

**Email:** [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk)

**Website:** [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)

## **Down's Heart Group (DHG)**

Support and information to those who have a family member with Down syndrome and heart problems.

**Tel:** 0844 288 4800

**Email:** [info@dhg.org.uk](mailto:info@dhg.org.uk)

**Website:** [www.dhg.org.uk](http://www.dhg.org.uk)

## **Equality Advisory Service**

Providing advice and information on behalf of the Equality and Human Rights Commission.

**Tel:** 0808 800 0082

**Website:** [www.equalityadvisoryservice.com](http://www.equalityadvisoryservice.com)

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### **Parent Carer Forum Cheshire West and Chester**

A voluntary group of Parents and Carers who have children/young people with special education needs (SEND) in Cheshire West and Chester.

**Website:** [www.pcfcheshirewest.org](http://www.pcfcheshirewest.org)

**Email:** [contact.pcfcwac@gmail.com](mailto:contact.pcfcwac@gmail.com)

### **Parent Carer Forum Cheshire East**

A voluntary group of Parents and Carers who have children/ young people with special education needs (SEND) in Cheshire East.

**Email:** [cheshireeastpcf@gmail.com](mailto:cheshireeastpcf@gmail.com)

**Website:** [www.pcfce.org](http://www.pcfce.org)

### **Parent Carer Forum Warrington**

A voluntary group of Parents and Carers who have children/ young people with special education needs (SEND) in Warrington.

**Email:** [devofficer@warrpac.org](mailto:devofficer@warrpac.org)

**Website:** [www.warrpac.org](http://www.warrpac.org)

### **Parent Carer Forum Halton**

A voluntary group of Parents and Carers who have children/ young people with special education needs (SEND) in Halton.

**Email:** [haltonsendcarersforum@gmail.com](mailto:haltonsendcarersforum@gmail.com)

**Website:** [haltonsendcarersforum.org.uk](http://haltonsendcarersforum.org.uk)





Proud  
Sister



Extra  
chromosome  
Extra  
cute











DOWN SYNDROME  
CHESHIRE

Empowering people with Down syndrome  
to live the life they choose