

A booklet for new parents
about what to expect in the
first few months

Welcoming your Baby with Down's Syndrome



For more information or to obtain
any of our other publications
please visit www.dsscotland.org.uk

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Health Checks

Like all babies, your baby will have routine health checks carried out by a paediatrician shortly after birth. Babies born with Down's syndrome have some additional health checks so that you can feel confident that your baby is progressing well, and they get the right support they need at the right times.



Babies with Down's syndrome have similar health issues to all babies but there are some health conditions that are more common in babies with Down's syndrome and your child should receive regular screening for these each year. There are additional inserts for your baby's red book that tell you more about these.

Personal Child Health Record (PCHR) insert for babies and children with Down's syndrome

You should have received a Personal Child Health Record (PCHR) for your baby, (referred to as the 'Red Book') from your midwife or health visitor.



This is given to all UK parents and carers and will be the main record of your child's health and development. You keep hold of the record book and take it along with you to each health appointment your child has so that health professionals can update it each time they see your child.

You will also be given additional inserts for your red book specifically for babies born with Down's syndrome which are produced by Down's Syndrome Medical Interest Group (DSMIG UK). These inserts contain details of the basic minimum health checks for your baby from now up to the age of 18 years and gives you information about health aspects and the health checks your baby will receive, alongside a specific graph to plot your baby's growth. You can view and download this [here](#).

If you didn't receive a copy of the insert, your health visitor can get a copy for you from Harlow Printing Ltd, their contact details can be found [here](#).

Our Family Support Team can also support your health visitor with information regarding development of babies with Down's syndrome.

It is really important that you attend all the health appointments scheduled for your baby and that they receive the health checks as recommended to support their development; these appointments can also ensure that any health concerns can be picked up early and that your child gets the right support at the right time which can help you feel confident that your baby is progressing well.

If you have any questions or would like more information about health checks or conditions associated with Down's syndrome our Family Support Team are available to chat and provide support in relation to any aspects of your baby's health. Please get in touch by emailing familysupportservice@dsscotland.org.uk or call our helpline on **0300 030 2121**.

If you have specific concerns about your baby's health, we recommend that you contact your health visitor, GP or paediatrician in the first instance.

Scottish Allied Health Professional (AHP) Pathway for Children with Down's syndrome aged 0-3 years

At this early stage of their development, children with Down's syndrome can have additional support needs which include managing low muscle tone, feeding difficulties and delayed speech development and parents/carers should be supported with targeted intervention from relevant AHPs. This national care pathway will guide you and your child up to age 3 and enables you to access specialist AHP services at the appropriate time and be signposted to appropriate interventions which support your child's early development.



Alongside the Scottish Government and Allied Health Professionals we created these postcards which are designed to help you identify when you and your baby may need extra support from a specialist professional. These are included in our Baby Packs, if you can also access them on our website.

All AHP services have an open access policy, meaning that anyone can make a request for assistance at any time for a specific need. These postcards are intended to complement that policy by supporting you and paediatric staff to identify concerns.

These postcards should be used alongside the information in the Personal Child Health Record (PCHR) insert for children with Down's syndrome which your health visitor provides for you.

If you would like more information about these postcards and how to use them please get in touch with our Family Support team on familysupportservice@dsscotland.org.uk or call 0300 030 2121.

Feeding

All babies tend to lose up to 10% of their birth weight in the first few days and it may take your baby longer to regain this weight and put on more weight. Your Health Visitor will help you to monitor this and you can plot your baby's weight gain on the Down's syndrome growth chart in your personal child health record (the inserts mentioned earlier). If you do not have the growth chart, please ask your Health visitor or contact our Family Support Team on familysupportservice@dsscotland.org.uk or call 0300 030 2121.



If your baby has low muscle tone, they may find it more difficult to latch onto the breast or bottle teat correctly and to coordinate sucking, swallowing and breathing. In addition, they may find it harder to be able to maintain a seal on the breast or bottle teat but keeping some gentle upward pressure on their chin may help.

Although some babies wake up and clearly show that they are hungry, some babies are very sleepy and need to be gently woken so that they can feed. Making a soft noise or rubbing your baby's hands and feet can help to rouse your baby ready for a feed.

As your baby may need to make more effort to feed, or may be too sleepy, you may find that they tire quickly before they have had enough milk. Burping and continual gentle stimulation can help them to stay awake for longer whilst feeding and help to ensure that they are getting enough nutrition. If you are breastfeeding, changing breasts several times may help and there are a variety of feeding positions which may make feeding easier and more comfortable for you both.

More information can be found on our leaflet 'Help with Feeding your Baby' which is available in our Resources Hub.



Breast milk is understood to have very beneficial properties for a baby's development and many babies with Down's syndrome can successfully learn how to breastfeed. Other babies partly breastfeed and supplement this with expressed milk or formula. Babies fed through nasal gastric tubes can also be given expressed breast milk.

If you would like support, and/or like to talk to another family who have gone through this before, our Family Support Team are here for you.

We have resources available on Feeding Oral Development and Breastfeeding your baby with Down's syndrome – these resources can be downloaded from our Resources Hub on our website.

Sleeping

In the first few weeks after they are born your baby will sleep for around 16 hours or more each day, this will gradually reduce to about 13 hours by age 2 and continue to reduce as they get older. Initially, your baby will spend about an equal amount of time sleeping during the day and at night. This will change as your baby gets older so that less time is spent asleep during the day and most sleep occurs at night.



It's fair to say though that sleep can be an issue for lots of parents of young children. In a way it is surprising that so many young babies and children do get into good night settling patterns as it is a complex process. Some babies with Down's syndrome can find it difficult to settle to sleep and can be restless and wriggle about once asleep. We do know from research that proportionally more children with Down's syndrome have sleep issues than children without Down's syndrome.

There are several aspects of sleep that are important. The first is learning to settle and stay asleep in your bed for a length of time at night. The next is the quality of sleep you get, which is dependent on two main types of sleep – Rapid Eye Movement (REM) and non-REM. REM sleep is used by the brain actively and is very important for learning. It is used by the brain and body to rest, to repair and rebuild cells and to strengthen your immune system. During non-REM sleep in children, growth is also promoted by the release of growth hormone.

Initially babies have a different sleep pattern and settle more quickly into REM sleep, which is the sleep in which we assimilate the information we are learning. So, it's not surprising that babies need lots of that type of sleep. By the time you are one year old you will have pretty much an adult pattern with periods of REM and non-REM sleep that come in cycles through the night, approximately every 90 minutes. As you progress through childhood you need less sleep and children usually drop their daytime naps by 5 years of age and should be aiming for about 8-10 hours of sleep overnight.

Most parents can have difficulty around settling their child to sleep. The key to good settling is a clear sleep programme or good 'sleep hygiene', as professionals will refer to it. This involves making sure your baby/child has a secure and warm bed, where they feel safe, that they have had enough, but not too much, food before bedtime. There is often a routine of a relaxing bath, and/or massage, and then a short familiar routine of a story or music to settle. Parents too must feel secure about leaving their baby to settle, and sometimes this can be difficult if your child may have had a previous or on-going illness that makes you more wary of leaving them alone. It is important that your child learns to self soothe, re-settle themselves and not be dependent on you being there. We all, as a normal part of the sleep pattern, have short awakenings through the night, though some of us won't even be aware of them. If your child has not learned to self soothe and settle then this short awakening will turn into a lengthy re-settling job for you, the very tired parent, and unfortunately re-enforces your child's need for you to help.

Sleep issues in Children with Down's syndrome

We know that around 50% of children with Down's syndrome experience some difficulty sleeping which can be behaviour related but can also be due to a physical cause, and it is important that you get the right help if you think your child is experiencing sleep difficulties. Your first port of call should be your child's health visitor or paediatrician; they can make a referral for your child to be assessed by professionals with experience of sleep issues. Sleep signs or difficulties you are concerned about should not just be put down to the fact that your child has Down's syndrome. If you have worries or concerns about your child's sleep and getting appropriate support for this, remember our Family Support team are here to help.

As with all information, it's easier to read about than to carry out the practical task, and that is why, if you are encountering problems, early support to achieve a good sleep pattern for your child is so important.



Some sleep issues can be improved with good sleep habits the links and information below can help you with establishing these; however, some sleep issues may be more complex and need investigation and possibly intervention.

The sleep support services available from Cerebra are there for you to speak to someone about sleep concerns you have and they are able to offer support and advice on what you need to do.

If you would like to talk to someone about your baby's sleep pattern, or would like to talk to another parent about sleeping and routines please contact the Family Support Service. We also have some resources about sleep that you can download from our website.

Development

With any new baby, thinking about how they are going to develop is most probably one of the top questions. Like all babies, little ones with Down's syndrome need a lot of care and attention. New parents often worry if they need to treat their baby differently if they have with Down's syndrome.



Unless they have a significant health concern, then there would be no reason why they cannot be treated the same. Babies with Down's syndrome need an environment that is rich in learning activities with lots of opportunities to interact with and explore their environment. The range of skills they can develop with your guidance and encouragement will be far greater than what can they could achieve on their own.

Spend time playing and enjoying time with your baby through talking, singing, cuddling, and massage. The insert for your little red book gives you some ideas of when milestones may be reached but remember every child is unique.

Holding and Moving at Birth

Most children with Down's syndrome are born with low muscle tone, known as hypotonia which can make them floppy and it may take them longer to gain head control, roll over, sit up and use their hands to grasp objects, however, each child will be affected differently, some children are affected very mildly, whereas in others it can be far more noticeable.



This is nothing to be overly concerned about and should not stop you cuddling your baby. Just take extra care to support their head and posture. If you have any concerns speak to your Health Visitor in the first instance and our Family Support team are here to support you with information and guidance with any aspect of your child's health and development you may need.

Learning Profile

Children with Down's syndrome tend to have an uneven learning profile and developmental milestones may be reached later, and, sometimes, children may appear to slow down in one area whilst making progress in another. The specific learning styles and individual needs of each child are unique and should always be considered when planning new learning activities.



Our Developing Early Skills booklet gives you more information about the development and learning profile of children with Down's syndrome and has lots of ideas for supporting their early development. You can download this from our website.

Disability Living Allowance

From 3 months onwards, you can apply for Disability Living Allowance (DLA) from the Department of Work and Pensions (DWP). This is help with the additional costs that you may have in bringing up your child with Down's syndrome.



In our experience, unless your baby has a significant health need, you are best to apply when your baby is around 9 months – 1 year old. You can find out more about DLA [here](#).

If you would like to talk about your baby's development our [Family Support Team](#) are here to help with support and information, and link to other professionals where appropriate. The team can also help if you have any questions about financial support and help with further information or applying for welfare benefits.

Early Communication Support

Makaton For Babies

We run Makaton Sign Sharing For Babies and Families workshops four times a year. Each block consists of six sessions, which will run weekly.



The groups are led by Katy Lironi, Down's Syndrome Scotland Makaton Tutor and ABC (Achieving Better Communication) tutor. The sessions are for parents and carer members with their babies of up to 1 year old (upper age limit negotiable). Sessions incorporate Makaton sign sharing, oral motor exercises and songs with Makaton. It is hoped babies can join in the sessions, but don't worry if they fall asleep or need fed during the session, there is plenty still to be learned!

All the sessions are recorded so if you are unable to commit to the day or timeslot you can access the sessions via these recording. You can find out more about these sessions [here](#).

ABC First Steps

Our ABC First Steps sessions are the earliest stage of our ABC Programme for children aged 0 to around 3.

These groups are delivered weekly online. The sessions are fun, interactive, inclusive for the whole family – siblings and grandparents are welcome to join in too!

ABC First Steps sessions help babies, toddlers and young children to focus on the sounds of language and introduce oral motor exercises in a fun way that parents and carers can continue out with the sessions.

Parents tell us that, as much as their children, they enjoy the opportunity for social interaction and making connections with other parents with children at the same age and stage of development.

You can find out more about ABC First Steps [here](#).



Additional Resources

- **Oral Feeding Development**
- **Breastfeeding your Baby with Down's Syndrome**
- **Managing Sleep Problems in Children**
- **Cerebra Sleep Cards**
- **Cerebra Sleep Guide**
- **Developing Early Skills Booklet**

This booklet is designed for new parents to give them information about what to expect in the first few months.

Down's Syndrome Scotland provides information and support to families, carers and professionals who care for and work with people with Down's syndrome.

If you would like to access further support or information please call us on 0300 030 2121 or email familysupportservices@dsscotland.org.uk.

For further information visit:

www.dsscotland.org.uk




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