Supporting children with Down syndrome: growth, feeding and development

People with Down syndrome have a genetic variation - Down syndrome is not a disease. Whilst they share some common features, they are all unique individuals with their own abilities, needs, interests and aspirations.

This Good Practice Point was co-developed and informed by a panel of experts by experience. The iHV values and acknowledges the expertise and important contribution of all those involved.

Please read this Good Practice Point in conjunction with the Good Practice Point on Supporting Babies and Children with Down Syndrome and their Families - https://bit.ly/3OTTom7

What families with lived experience say:

"Our health visitor was amazing – she came and saw me every day for the first week, then came every few days for the next few weeks. Not just to check on Amos and I, but also to make sure that my husband and children were all coping too. She supported me with getting Amos to breastfeed (which took a long 12 weeks) and took me to the local baby café, where we received expert help. She made me tea and told me my baby was perfect and beautiful. It was just what I needed and without her I think we would have found it all much more daunting. She was an absolute lifeline".

Emma, mum to a boy who happens to have Down syndrome, as well as a cheeky smile and an infectious laugh.

The Down syndrome* inserts for the Personal Child Health Record (red book) contain charts which follow the usual developmental progress of children with Down syndrome. By understanding what is usual for a child with Down syndrome, you will be able to recognise any additional conditions at an early stage.

Growth

Babies with Down syndrome can sometimes gain weight slower than other babies[1]. There are specific growth charts for children with Down syndrome as their growth follows a different trajectory[2].

Growth charts for children with Down syndrome can be ordered via this link[2]: https://bit.ly/3KwmX9W.

Parents may find "baby weighing" a difficult time as babies with Down syndrome can have difficulty maintaining weight - and being around other typically developing babies can present different emotions and feelings for parents. All parents are different, some parents will prefer to attend the standard child health clinic and enjoy meeting other parents and the social part of being weighed together, whereas others may feel uncomfortable at first and prefer for their baby to be weighed at home. As parental confidence grows, please do not forget to invite them to clinic.

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The information in this GPP version was reviewed on 23/02/2024.

Breastfeeding*

(content provided by Sarah Edwards from the Breastfeeding Network - BfN)[3].

Further information available here: https://bit.ly/3XrL5Rp

Breastfeeding a baby with Down syndrome is not only possible, it also provides important benefits to both women - or birthing parent - and their baby:

1. Breastmilk boosts any baby's immune system and contains anti-infective factors including antibodies. This is especially important for babies with Down syndrome since they are prone to respiratory and viral infections.
2. Babies with Down syndrome can have low muscle tone. The specific sucking action needed during breastfeeding will help strengthen baby's lips, tongue and face. This can also help later on for eating other foods and speech development.
3. Breastmilk contains all of the nutrients, calories and fluids any baby needs, but it is also much more than just nutrition. It provides baby with comfort and warmth, and the physical closeness when breastfeeding helps create a special bond between parents and their baby.

The first days and weeks of breastfeeding are a time for parents and their baby to get to know each other and learn together how to breastfeed effectively.

There are some specific physical characteristics of babies with Down syndrome that may have an impact on a mother's breastfeeding journey[4]. Every baby is unique so not all of the challenges mentioned here will be relevant to every baby. If there are initial difficulties with breastfeeding, then early support can make all the difference. Feeding babies expressed breast milk in the early days can enable more time to establish effective breastfeeding.

Hints and tips for breastfeeding a baby with Down syndrome[5]

Low muscle tone: Babies with Down syndrome can have low muscle tone and so may have trouble attaching effectively to the breast and staying there for a full feed. Some babies might also have trouble coordinating their sucking, swallowing and breathing and may gulp or splutter as they feed. They might get less milk for their efforts and they often get tired quickly. This generally improves with practice and time. The act of breastfeeding will actually help strengthen facial muscles and, as babies get stronger and learn to breastfeed more effectively, they will be able to take more milk at each feed. As well as the breastfeeding positions that people commonly use, there is also a position called Dancer Hand position that can sometimes help by providing babies with gentle support for their head and chin when they go to attach to the breast (contact Breastfeeding Network for details if unsure https://bit.ly/3ALF4DW).

Sleepy babies: Some babies with Down syndrome can be very sleepy or tire more quickly, especially if they have any issues with their heart. Helping parents make sure that their baby is in a comfortable and well-supported position can also help by meaning their baby doesn't get tired so quickly and that they get more milk for their efforts. Gentle hand expression before breastfeeding can help encourage the let down reflex, starting the flow of milk before the baby is put to the breast. This way the baby doesn't expend so much energy sucking without the milk flowing.

Tongue thrust: Some babies with Down syndrome have a tongue that sticks out more than usual which can make breastfeeding harder. This can be managed by trying to position baby in a way that encourages them to open their mouth really wide and to keep their tongue down, and touching their bottom lip when they go to attach onto the breast. The following top tips can help:

- When starting a feed, press gently on their baby's chin to help open their mouth wider as they go to latch on.
- Between feeds, try simple tongue exercises such as encouraging their baby to suck on a clean finger before feeding.

These can sometimes help their baby to coordinate their sucking and get their tongue in the right place before starting to feed.

Parents may be interested to read:

Julia's Way – Breastfeeding and Down's Syndrome – free download: https://bit.ly/2rbySFI

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Introducing complementary foods

Babies with Down syndrome should be introduced to solid foods, including finger foods, at the same time and in the same way as other babies. It may take them a bit longer to coordinate the actions needed for eating solids.

Current guidelines from all UK health departments suggest that infants do not need food other than milk until about 6 months of age. They can then be offered different textures and flavours from different food sources to provide a varied healthy diet.

(see Good Practice Points: Complementary feeding and baby-led weaning, available: https://bit.ly/3Hkocqm.

Down's Syndrome Association[6]:

- Straw drinking: https://bit.ly/3Jua40E
- Biting and chewing: https://bit.ly/3Jua40E

Development

There is no such thing as a "typical" child with Down syndrome. Like all children, babies and children with Down syndrome will have a wide range of developmental abilities. They all have some level of learning disability. This means that there are often delays in reaching developmental milestones in some areas, for example for speech and language, and motor development. Whereas other areas of development, like reading, toileting and social interaction, may be areas of strength for some children[7]. Advances in intervention have meant that very many children can enjoy a mainstream education in primary and secondary school[8].

Development and health reviews

It can be helpful, both for now and later, to monitor child development in the Down syndrome development journal. The health visiting service can support parents by connecting them to the Council for Disabled Children's Downs Syndrome Development Journal, which sets out charts to enable families to record what their child is able to do as time passes and they learn new things[9]. https://bit.ly/2QFeKGD

Children with Down syndrome should receive all the universal health reviews offered as part of each nation's child health programme. In England, the High Impact Area guidance for the 2-2½ year review states that:

> *"Where a child already has an identified disability or developmental delay, health visiting teams will need to agree with parents whether they wish to complete the ASQ-3™ (British English) questionnaire as part of their child's 2 year review. Much rests on health visitors' professional judgement and their skill in working sensitively and collaboratively with families to agree the best approach. Parents are experts in their child's development and are key players in the review, sharing information about their children's development with their health visitor or community nursery nurse by completing a short questionnaire. Combined with the clinical judgement of the health professional, a rounded picture of a child's development can be made to identify the child's progress, strengths and needs, with an agreed plan to address any needs going forward."*

Early language and communication

A really important aspect of early intervention for children with Down syndrome is learning to sign. Signing has many advantages including: bypassing the potential fluctuating hearing loss that children with Down syndrome can experience; encouraging language development even if a child is late to speak; giving a way for a child to communicate before they can speak clearly; it is also FUN and a natural extension of what we do anyway, for example, waving goodbye.

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Child development resources:

- Makaton - https://bit.ly/2XzCI7H
- Singing Hands - https://bit.ly/33eEnRn
- Something Special on CBeebies - https://bbc.in/2O6TU13
- Signalong - https://bit.ly/2ObsKWI

Early intervention

If a Portage service is available in your area, please make sure that parents are aware and are able to access this valuable service.

iHV's expert panel of parents recommended the following books and downloads:

- Gross Motor Skills in Children with Down Syndrome: A Guide for Parents and Professionals[10].
- Fine Motor Skills for Children with Down Syndrome: A Guide for Parents and Professionals (Topics in Down Syndrome)[11].
- Supporting Positive Behavior in Children and Teens with Down's Syndrome, Revised Edition: The Respond but Don't React Method[12].
- Sleep problems[13] https://bit.ly/44jDuXC
- Classroom Language Skills for Children with Down Syndrome: A Guide for Parents and Teachers (Topics in Down Syndrome)[14].

Potty training

Potty training children with additional needs can be done in much the same way as teaching a child without additional needs.

- ERIC contains useful resources for parents[15]:
  - ERIC's Guide for Children with Additional Needs: https://bit.ly/44Bt5Xt
- One Step at a Time: A parent's guide to toilet skills for children with special needs: https://bit.ly/35t2Svh
- Pants4School - Toilet training with Down Syndrome: https://bit.ly/3T5mRMp

Managing minor illnesses and knowing when to seek urgent medical care

Most children with Down's syndrome have some physiological and behavioural differences that can make it more difficult to assess the severity of illness. This infographic provides some useful advice[16]: https://bit.ly/3KxFDpZ

Remember to signpost parents to iHV Parent Tips on Managing minor illnesses[17]: https://bit.ly/2pEoAgH.

Benefits

Health visitors can support families to access benefit entitlements. Disability Living Allowance is currently available from birth, for care, and from three years, for mobility (benefit entitlement can change, so please always check the most up-to-date advice before sharing information with parents). Further information is available at:

- Gov.uk: Help if you have a disabled child: https://bit.ly/2pJslSe
- Down's Syndrome Association - Benefits for Babies guide: https://bit.ly/44fElsb

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Good Practice Points for Health Visitors

The Down Syndrome Act 2022[18] became law in April 2022. The act represents a significant opportunity to improve the life outcomes of people with Down syndrome, and to raise the understanding and awareness of the specific needs of people with Down syndrome.

Everyone with Down syndrome should receive early support to meet their needs, and families and carers should receive the help they need to enable them to guide their child's development.

iHV's expert panel offered the following advice to support health visitors to meet the needs of babies and children with Down syndrome and their families:

- Recognise that every family is different and will deal with issues in different ways.
- Acknowledge concerns and respond to questions, including those that might appear unimportant or trivial – this does not mean that they are unimportant to the family asking them.
- Continuity of health visitor is important – families value "being known" and receiving personalised care.
- Don't forget to include all the usual universal health visiting support and advice – sometimes these can get overlooked (e.g. safer sleep advice, accident prevention, oral health, immunisations, etc).
- Make sure you are familiar with the local offer for children with Special Educational Needs and Disabilities (SEND) and support parents to access local resources and groups that suit their individual needs and preferences.

Further reading:
Emond A. Editor. Health for all Children. 5th ed. U.K.: Oxford University Press; 2019.

*In this Good Practice Point the words Down's syndrome and Down syndrome are used interchangeably depending on the use of terms within the research or organisation that is cited.

We refer to breastfeeding and breastmilk but recognise terms such as chestfeeding, bodyfeeding, nursing, lactation, or providing human milk may be more preferable for and accurate to some of the families we support.

While we refer to women in this report, we recognise that some transgender men, gender-diverse people, and people who are intersex may be affected by some of the same issues. We also recognise that people who are trans, gender-diverse or intersex have specific needs, experiences and health issues that need addressing. The use of the term "women" in this report is not intended to exclude other groups or overlook the challenges they face.

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