



The Down Syndrome Association Gauteng

CONGRATULATIONS ON THE BIRTH OF YOUR BABY



A GUIDE FOR NEW PARENTS



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GETTING THE NEWS

Many parents find out their baby has Down syndrome soon after the birth, but some new parents will already know that they are going to have a baby with Down syndrome.

Each parent will experience different feelings when they learn their baby has Down syndrome. Parents have said it helps to try and focus on the here and now. It's easy to get carried away with thinking about your baby's future. As the days and weeks pass, and you get to know your baby, you will begin to see them as a unique person with their own character.

'The one piece of advice we would give, is not only enjoy your baby, but look forward to enjoying your toddler, child, teenager and adult with always worrying about what you "should" be doing or what the future may bring.'

There is a lot of information on the internet about Down syndrome. It is tempting to want to read as widely as possible to ensure you feel you are armed with the facts.

Some parents say that reading factual information from reliable sources lessened their worries about the future and helped to guide their expectations. Other parents may find they prefer to leave reading about Down syndrome until their baby is a little older and life has settled into a routine.

WHAT IS DOWN SYNDROME?

Down syndrome is a genetic condition, caused by the presence of an extra chromosome in the baby's cells, that results in some level of learning disability and a range of physical characteristics. The learning disability affects a child's ability to learn compared with other children of their age; it does not mean they cannot learn.

Chromosomes are tiny particles, which are present in every cell in every tissue of our bodies. Most people have two copies of all chromosomes, but people with Down syndrome have three copies of chromosome 21, hence the medical name 'trisomy 21'.

Every day, between one and two babies are born somewhere in the world, which means that one baby in 1000 has the condition.

People with Down syndrome are born in every country in the world to parents of all races, religions and socio-economic backgrounds.

Anyone can have a child with Down syndrome. As far as we know, nothing done before or during pregnancy causes the condition.

WHAT WILL MY BABY BE LIKE?

First and foremost, your baby has the same needs as all babies. They will eat, sleep and cry and will need love and cuddles like any other. The most important thing that you need to know about Down syndrome is that everyone with the condition is a unique individual.

People with Down syndrome have more in common with their families than with each other. Just like the rest of the population they will inherit their families' characteristics.

Children with Down syndrome generally need more time to reach developmental milestones and they will need some additional support to learn new skills as well as extra help when they go to school. The way the condition effects a person's development, learning and health varies widely.

The level of support a person with Down syndrome needs as they grow up and throughout their lives will be different from person to person.

Every day, between one and two babies are born somewhere in the world, which means that one baby in 1000 has the condition.

Understandably, particularly if your new baby is a first child, you may be worried about whether something your baby is doing (or not doing)

is because they have Down syndrome rather than just because they are a baby. It is likely that whatever behaviour you are seeing in your baby has nothing to do with their condition. However, as a new parent it is natural to have some worries.

SHOULD I BE DOING ANYTHING SPECIAL OR DIFFERENT WITH MY BABY?

In the early weeks and months enjoy and get to know your baby. Have fun talking to them, showing them the world and responding to their efforts to communicate.



FEEDING AND BREASTFEEDING

'I was informed before my baby was born that she would never breastfeed. It took some doing, a mixture between breastfeeding and expressed breastfeeding, but she fed for sure!

'I had always intended to breastfeed and when I was told after the birth that my daughter had Down syndrome, I was even more determined that she would have the very best start in life that I could give her. '

'My baby was tube fed for a few weeks until she learnt to breastfeed. She was breastfed for 22 months.'

Almost all mothers who want to can breastfeed or provide breast milk for their baby. For some mothers breastfeeding is established easily, but others may find it takes a little more time, patience, and perseverance. Support should be available to help you if you want to breastfeed your child. Many hospitals employ a lactation consultant or have midwives with a particular interest in feeding.

Some babies will become better at feeding as they grow older and will be able to be fully breastfed. Some mothers choose not to breastfeed or find that because of their circumstances, breastfeeding is not right for them.

A few babies have medical problems which affect feeding. Babies with gastro-intestinal tract (GI tract) disorders who need an operation will not be allowed to feed at first and will get nutrients intravenously.

Some babies with heart conditions may be unable to feed immediately because they are tired or breathless; mothers of these babies can express breast milk by hand or pump to build up their milk supply. Their milk can be given to their babies by naso-gastric tube when the babies are well enough. With patience, and following surgery for any medical conditions, these babies can often fully breastfeed eventually.

WEANING

Babies with Down syndrome should be introduced to solids at the same time and in the same way as other babies. It may take them a bit longer to co-ordinate the actions needed for eating solids.

- Introduce your child to finger foods as you would any other child, offering different textures and flavours.
- Give your child choices and let them touch and play with different foods.
- You may have to give your child a new food gradually and on a number of occasions before they will eat it.

Your child's speech and language therapist can give you advice about feeding.

HEALTH

Babies and young children with Down syndrome have the same health needs as any child. You should take your baby for routine health checks and immunisations in the usual way.

Babies with Down syndrome can be fit and healthy and have no more health issues than any other child. However, we know they may have some additional health needs that could affect their growth.

Just over half of children born with Down syndrome have a heart challenge. Sometimes a baby will need an operation, either soon after they are born or when they are older and stronger.

They can pick up coughs more easily than other children and their narrow ear and nose passageways may become blocked more often.

It is a good thing that we know some health conditions are more common in babies and children with Down syndrome because screening for these conditions can take place and any problem picked up and treated.

The Down Syndrome Medical Interest Group UK: -

Basic Minimum Health Checks that All Babies and Children with Down syndrome should receive as a matter of course.

- The following are suggested ages for health checks.
- Check at any other time if there are parental or other concerns.
- If you feel that your child hasn't had the right health checks, show the list to your GP or Paediatrician.

	BIRTH – 6 WEEKS	SPECIAL CHECKS UNDER 2 YEARS	PRESCHOOL CHECKS	SCHOOL AGE
THYROID BLOOD TESTS	New-born routine heel prick – blood spot test	From age 1-year thyroid function should be discussed annually using results of either <ul style="list-style-type: none"> ▪ Annual fingerprick TSH test OR ▪ 2 yearly thyroid blood tests, including thyroid antibodies 		
EYE CHECKS	New-born routine check including congenital cataract check	Age 18-24 months: Formal eye and vision examination including check for squint, and refraction for long or short sight	Age 4 years: Formal eye and vision examination including check for squint. Refraction and assessment of near and distant vision and visual acuity	Repeat vision test every 2 years, or more frequently if recommended by optometrist or ophthalmologist
Visual behaviour to be monitored at every review particularly in first year				
HEARING CHECKS	Universal new-born hearing screen	Full audiological review by 10 months including hearing test and impedance check	Annual audiological review as before	2 yearly audiological review or more frequently if recommended
GROWTH MONITORING	Length, weight and head circumference should be checked frequently and plotted on Down syndrome growth charts		Height and weight should be checked and plotted on Down syndrome growth charts at least annually while growing. (BMI checked if concern regarding overweight)	
HEART CHECKS	By age 6 weeks, formal heart assessment including Echocardiogram	At all ages low threshold for reviewing heart status if signs or symptoms develop		From adolescence onwards as part of routine health checks listen to heart for signs of acquired heart disease
BREATHING CHECKS	Enquire at every review for uneven breathing during sleep and poor-quality sleep. Low threshold for further testing using sleep studies			
BLOOD CHECKS	New-born blood test to check for abnormal blood film	If blood film is abnormal in first 6 weeks, follow up or repeat blood testing may be necessary until age 5		

Detailed recommendations for Medical Surveillance Essentials for children with Down syndrome can be found at: www.dsmig.org.uk

Children with Down syndrome tend to grow more slowly and are usually shorter than other children. Sometimes parents of babies and young children have been told by a health professional that their child is failing to thrive. In some of these cases the children are actually doing fine, but alarm bells have been raised because the health professional is using a generic growth chart rather than the growth chart for children with Down syndrome.

In common with all babies, babies with Down syndrome lose up to 10% of their birth weight in the first three or four days. It may take them longer than other babies to regain this weight.

Each child with Down syndrome is different but generally their development is slower than that of other children.

SUPPORT AND ADVICE ABOUT YOUR CHILD'S DEVELOPMENT (EARLY INTERVENTION)

You may have heard or read about 'Early Intervention' for children with Down syndrome. This may sound a little daunting, but it needn't be. Early intervention is an umbrella term for a collection of services that can help babies and toddlers whose development is delayed. The focus of early intervention is on helping children learn skills that are usually learnt in the first three years of life.

Early intervention services for children with Down syndrome typically include speech and language therapy, physiotherapy as well as occupational therapy. What is available for families and how services are delivered will be different from place to place. Talk to your child's paediatrician or GP about making the necessary referrals for you.

Ideally, your child should be seen by:

A speech & language therapist from around the age of six months. If your baby finds feeding and swallowing difficult, you may need to ask for an earlier appointment with a speech and language therapist. A paediatric physiotherapist in the first three months of life and an occupational therapist when they are a little older.

Sometimes it will not be possible to see these professionals within the timescales suggested here. However, if you have any worries about how your child is getting on, ask for appointments to be brought forward.

The level of support from professionals will depend on the individual needs of your child. There are no hard and fast rules about how much support a child with Down syndrome should receive.

WHAT IS LIFE LIKE FOR FAMILIES?

On a day-to-day basis life for families with babies and young children with Down syndrome brings with it the same hopes, joys, highs and lows as other families.

You might find it reassuring to read about the experiences of other families.

There are a growing number of blogs by parents of babies and children with Down syndrome.

In the early months and years, it is likely you will have many appointments with health professionals to discuss your child's health and development. It can be difficult to get the balance right so your needs and the needs of other family members are addressed. With regular discussion about your child's development, what they can and can't do at a given age, it can be very easy to just focus on what is special or different about your child.

It's worth remembering that to some extent, all young children have to learn to fit in with what is going on around them! While 'special' activities help, they are unlikely to be the main influence on your child's development. The most important experiences for a child with Down syndrome come from being a member of a happy, loving and active family and from doing all the things that families normally do.

'There is no single "right" set of approaches – every child with Down syndrome is an individual and what works for some does not necessarily work for all. Life's journey is long (and unexpected and wonderful) and learning takes place over many years. Just seek out the people who work well with your child, make them feel good about themselves and have the ability to see things from their perspective.'

BROTHERS AND SISTERS

It's fine to talk to your other children about their new brother or sister with Down syndrome. As a parent, you are best placed to decide how much information is appropriate to give your other children. Much will depend on their age, their level of understanding and their curiosity. They may not understand or remember all the information, so follow their lead, keep listening and answer their questions.

Your children will follow your example. If you treat Down syndrome as just one aspect of your baby's life, your children will too. It is now very common for children with Down syndrome to go to their local mainstream nursery and primary school. Your children may already have a classmate or know of someone in their school with Down syndrome.

WHAT IS LIFE LIKE FOR PEOPLE WITH DOWN SYNDROME?

The quality of life, life expectancy and inclusion in the community for people with Down syndrome have gradually been transformed as education and support have improved. There are now more opportunities for people with Down syndrome to lead the lives they want to; however, we know there is still a lot work to do to ensure that people with Down syndrome have many of the same life chances the general population take for granted.

