

The Down Syndrome Association Gauteng (TDSAG)

TDSAG Website: <a href="https://tdsag.co.za">https://tdsag.co.za</a>

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# DOWN SYNDROME: DEVELOPMENTAL MILESTONES HEALTH ISSUES



There is no such thing as a typical child with Down syndrome.

Children born with Down syndrome are as different from each other as are all children.

However, by and large, their development is slower than that of most children.

The guides which follow give 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 problems at an early stage.



Not Disabled, Differently Abled



Acknowledgement: DSMIG - UK

### **CHILD DEVELOPMENT: MOVING**



ACTIVITY	CHILDREN WITH DOWN SYNDROME		TYPICAL CHILDREN	
	AVERAGE AGE	RANGE	AVERAGE AGE	RANGE
Holds head steady when sitting	5 months	3 – 5 months	3 months	1 – 4 months
Rolls over	8 months	4 – 12 months	5 months	2 – 10 months
Sits alone	9 months	6 – 16 months	7 months	5 – 9 months
Stands alone	18 months	12 – 38 months	11 months	9 – 16 months
Walks alone	23 months	13 – 48 months	12 months	9 – 17 months





ACTIVITY	CHILDREN WITH DOWN SYNDROME		TYPICAL CHILDREN	
	AVERAGE AGE	RANGE	AVERAGE AGE	RANGE
Follows objects with eyes	3 months	1.5 – 6 months	1.5 months	1 – 3 months
Reaches out and grasps objects	6 months	4 – 11 months	4 months	2 – 6 months
Passes objects hand to hand	8 months	6 – 12 months	5.5 months	4 – 8 months
Builds a tower of 2 cubes	30 months	14 – 32 months	15 months	10 – 19 months
Copies a circle	48 months	36 – 60 months+	30 months	24 – 40 months

### **CHILD DEVELOPMENT: WORDS**



ACTIVITY	CHILDREN WITH DOWN SYNDROME		TYPICAL CHILDREN	
	AVERAGE AGE	RANGE	AVERAGE AGE	RANGE
Responds to sounds	1 months	0.5 – 1.5 months	0 month	0 – 1 month
Babbles "Da-da" and "Ma-ma"	7 months	4 – 8 months	4 months	2 – 6 months
Responds to simple instructions	16 months	12 – 24 months	10 months	6 – 14 months
First words spoken with meaning	18 months	13 – 36 months	14 months	10 – 23 months
2-Word phrases	30 months	18 – 60 months+	20 months	15 – 30 months

# CHILD DEVELOPMENT: RESPONDING TO PEOPLE



ACTIVITY	CHILDREN WITH	CHILDREN WITH DOWN SYNDROME		TYPICAL CHILDREN	
	AVERAGE AGE	RANGE	AVERAGE AGE	RANGE	
Smiles when talked to	2 months	1.5 – 4 months	1 month	1 – 2 months	
Plays peek-a-boo	11 months	9 – 16 months	8 months	5 – 13 months	
Drinks from an ordinary cup	20 months	12 – 30 months	12 months	9 – 17 months	
Dry by day	36 months	18 – 50 months+	24 months	14 – 36 months	
Bowel control	36 months	20 – 60 months+	24 months	16 – 48 months	

## **DOWN SYNDROME - HEALTH ISSUES**

Children who have Down syndrome have health issues that can affect any child. However, some health issues occur more often in children with Down syndrome. It can sometimes be hard to recognise the health problems and therefore it is recommended to have some extra health checks (see next section) to identify and manage the condition as soon as possible.

#### Heart

About half of all children who have Down syndrome are born with a heart problem. It is important to identify these in the first 2 months, as early treatment may be needed. It is recommended that all children must have a thorough heart examination, including an echocardiogram, by six weeks of age to enable prompt treatment.

#### **Blood**

Children who have Down syndrome should have their blood count and blood film checked within the first three days of birth, to identify any serious blood disorders. A few may need treatment or on-going checks.

#### **Vision and Hearing**

Children who have Down syndrome are more prone to have difficulties with their hearing and vision. It is important to identify these early on, so that appropriate help can be given to minimise the effect of a hearing or visual impairment on your child's development.

#### **Thyroid**

The thyroid gland is more frequently underactive in children who have Down syndrome. The symptoms of thyroid disorders can be difficult to spot. An underactive thyroid can affect your child's growth, learning and general health. Treatment is simple and effective. It is recommended that your child has an annual blood test to identify the condition early on.

### **DOWN SYNDROME - HEALTH ISSUES**

#### **Constipation**

Constipation is common in children who have Down syndrome. In most cases it is not due to any underlying bowel condition and can be managed as it would be in any child. If constipation is present since birth, or is severe and persists despite simple measures, then discuss your concerns with your doctor.

#### **Toilet training**

Children who have Down syndrome are usually toilet trained by the age of 3.5 - 4 years old. If your child is still in nappies at 4 years old then they need to be seen by a medical specialist to make sure that their bladder and kidneys are working properly.

#### **Coeliac Disease**

Although Coeliac disease (sensitivity to a protein in wheat, called gluten) can occur more frequently in children with Down syndrome, routine screening is currently not recommended. Symptoms of Coeliac disease include bowel problems, tiredness or a change in behaviour. There should be a low threshold for checking for Coeliac disease and, if your child has symptoms seek advice from your doctor.

#### **Breathing**

Babies often have nasal congestion. Saline drops and nasal suction can sometimes help. Sleep apnoea occurs more commonly in children with Down syndrome. Symptoms of sleep apnoea include gasping momentarily stopping to breathe or snoring whilst sleeping. It is recommended for all children with Down syndrome to have their oxygen levels checked overnight, whilst asleep, at around the age of six months and then once a year until the age of 5. This is an easy procedure which can be done at home. This is to ensure that their breathing pattern and oxygen levels are normal.

### **DOWN SYNDROME - HEALTH ISSUES**

#### **Infections**

Children with Down syndrome are more vulnerable to chest infections and other serious infections. They may not show the same signs and symptoms as other children. If you are worried that your child may have a serious infection seek urgent medical advice so that a serious illness such as sepsis or pneumonia can be identified and treated early. Your child should receive all childhood immunisations, including the flu vaccine every year and Pneumovax II at 2 years of age.

#### Teeth

Baby and permanent teeth often come late and in a different order compared to other children. Gum and teeth infections can occur more commonly and can be serious. Children should brush their teeth twice a day and visit a dentist every six months.

#### **Arthritis**

Children who have Down syndrome are more commonly affected by arthritis. They may not easily express the pain that they are experiencing. A change in your child's ability to perform daily living activities, e.g., in their handwriting or walking abilities may be an indication of early onset arthritis. Seek advice from your doctor if your child is experiencing any of these difficulties or if you are concerned.

#### **Neck Instability**

Neck instability can occur at any age in children with Down syndrome and though this is rare, it can be very serious. Routine neck X-ray screening does not help to detect the problem. Children with neck instability, usually have warning symptoms e.g., neck pain, holding their head or neck in an odd position or a change in their motor skills or continence. If your child develops any of these symptoms, seek an urgent medical assessment.

#### Other conditions

Those discussed above are some of the most common. Any concerns you may have about your child's health should be discussed with your own health professional.

## **DOWN SYNDROME - FEEDING**

Many babies with Down syndrome feed just as well as other babies. Some babies may have feeding difficulties, in the first few weeks, especially if they have additional health issues.

If you had decided to breast feed your baby before he | she was born don't change your mind just because he | she has Down syndrome. Most mothers who want to, do breast feed their babies successfully although it may take longer to establish. You may find it helpful to express breast milk for a time and use this to feed your baby. You can go back to breast feeding, if and when your baby is able to manage to breast feed. Your health professional or a breast-feeding expert will be able to advise you about these issues. Breast feeding support groups are available and provide use information, some of it specifically about feeding babies with Down syndrome.

#### The most common feeding issues are:

- Your baby falls asleep soon after starting feeding so doesn't take enough;
- Your baby may have a weak suck;
- Your baby's coordination of sucking, breathing and swallowing has not yet matured so she/he gets tired and distressed and again, he | she ends up not getting enough milk.

These issues usually get better after the first few weeks but understandably can be very worrying for parents at the time. If your baby is experiencing these issues, you can help by feeding little and often until feeding settles down to normal. You may even need to wake your baby up at night to feed. Some children may have issues with feeding at later stages of development, for example when moving on to solids. If this happens your health professional will be able to advise and you may need more specialist help from a Speech & Language Therapist.

Remember though, many babies and children with Down syndrome feed just as well as other children.

# **DOWN SYNDROME – IMMUNISATIONS & CHILD HEALTH CHECKS**

#### **Immunisations**

Children who have Down syndrome may be particularly susceptible to infections and it is very important they have the same immunisations as everyone else.

For some children, particularly those with heart problems, additional immunisations may be recommended, for instance to protect against seasonal flu and some respiratory infections. You can discuss this with your GP or Paediatrician.

#### Child health checks

Your child should be included in just the same way as other children in your area. It is also advisable for children with Down syndrome to have a few extra tests or checks.

The next page tells you in the first column what sort of extra health checks (thyroid, eyes, hearing, growth, heart, breathing, blood) are needed. The other four columns tell you at what age these should be carried out.

Details are given about the actual tests or procedures advised. Your GP or Paediatrician will be able to explain these to you.

However, if you think that your child has missed out on one of these checks take this booklet along to your GP or Paediatrician and ask if you can have the checks carried out.

# **DOWN SYNDROME – SUGGESTED SCHEDULE OF HEALTH CHECKS**

	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  * 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			



