Summary

- Many children with Down syndrome have a normal life span.
- A large percentage of babies with Down syndrome are born with a congenital heart defect.
- Some babies with Down syndrome are born with conditions that affect the stomach and gastrointestinal system.
- Have your child’s hearing, eyesight, thyroid function, teeth and gums checked regularly.

There are a number of significant health and medical issues that are more common in people with Down syndrome. In the past, the medical conditions associated with Down syndrome were responsible for a reduced life span. Today, advances in surgical and medical treatments mean that many people with Down syndrome will not have any more ongoing health issues than anyone else.

Babies with Down syndrome are more likely to have heart defects, gastrointestinal tract problems and lax (loose) joints, especially the hip joint.

Many people with Down syndrome have lower immunity than the general population. This means that, especially in early and older years, extra care may be needed to ensure that common medical ailments like colds and other infections are promptly attended to so they do not develop into more serious health issues. Antibiotics can prevent the risk of serious side effects, such as pneumonia or gastroenteritis.

If your baby with Down syndrome is born with a heart problem

A large percentage of babies with Down syndrome are born with a congenital heart defect. This is a problem with the structure of the heart. The most common congenital heart defect for people with Down syndrome is an atrioventricular septal defect (often referred to as a ‘hole in the heart’, although there may be more than one hole).

Babies are checked for heart problems at birth, and then examined again at six weeks of age. The seriousness of a heart defect usually depends on how much it affects the way blood flows around the body. In some cases, heart defects will cause no problems and eventually heal themselves. However, more commonly, heart surgery is required.

If your baby is born with a heart problem:

- Mild forms will cause little trouble and will be self-correcting.
- More complex heart problems will be operated on in the first few months of your baby’s birth.
- Only the more severe cases are inoperable and will shorten your baby’s life.

Gastrointestinal issues

Some babies with Down syndrome are born with conditions that affect the stomach and gastrointestinal system. Some of these conditions are evident at birth, and may require surgery straight away. Others are picked up due to feeding difficulties.

A relatively high proportion of babies with Down syndrome have reflux in the early days. Constipation is also common in people with Down syndrome. This can be made worse by low muscle tone in the stomach muscles.

People with Down syndrome are more likely than the general population to develop coeliac disease, which is an intolerance to gluten. Routine blood tests are used to screen for this, and if coeliac disease is suspected, a biopsy is taken from the small intestine to confirm the diagnosis. Treatment is a diet free from gluten for life. Many people in the community have coeliac disease and a wide range of gluten-free products are today available in most

betterhealth.vic.gov.au
Down syndrome and thyroid conditions

An over-active or under-active thyroid gland is caused by hormone imbalances or deficiencies. If left untreated, it can affect physical and mental wellbeing. The most common condition for people with Down syndrome is an under-active thyroid, which is known as hypothyroidism. The symptoms of this condition include:

- Lethargy
- Lack of concentration
- Weight gain
- Dry coarse skin
- Memory impairment
- Intolerance of cold.

Newborn babies with Down syndrome are tested for thyroid conditions. Ongoing screening should be done at least every two years throughout life as the onset is gradual. Treatment is a thyroid supplement in tablet form.

Down syndrome and leukaemia

While leukaemia is more common in children with Down syndrome than in the general population, only around 1 in 100 children with Down syndrome will develop the disease. Onset is usually between the ages of one and four years. A particular form of transient leukaemia can occur in newborns with Down syndrome, in which the changes to blood and bone marrow associated with leukaemia appear, but then disappear again without treatment.

Upper respiratory tract

Children with Down syndrome tend to have relatively narrow nasal passages. As a result, some children may be more prone to coughs and colds than other children, especially in early childhood and at times when there is an increase in mixing with other children, such as starting playgroup, pre-school or primary school. Older people are also more susceptible to chronic respiratory conditions.

Sometimes, upper airway obstruction can lead to disrupted sleep patterns and resulting fatigue, stress and behaviour issues. Sleep apnoea can be identified by surveying sleep patterns. Treatment may involve the removal of tonsils and adenoids.

Down syndrome and ears

Children with Down syndrome tend to have narrower Eustachian tubes than the general population. Eustachian tubes are the part of the ear that drain fluid from the middle ear.

Narrow Eustachian tubes may mean that the fluid cannot be drained easily, which can lead to blockages that cause ear infections and hearing loss. Blocked Eustachian tubes can also develop into a condition called ‘glue ear’. Glue ear often clears up spontaneously as a child grows and the tubes enlarge naturally. However, the problem may be recurrent throughout childhood. If it becomes a persistent problem, it can be treated by surgery to insert tiny plastic tubes, called ‘grommets’, into the ear that allow the fluid to drain.

For people with Down syndrome, hearing loss has been a significant health issue in the past. This was due partly to untreated ear issues in early life. It is less of an issue today with more consistent monitoring. Hearing should be monitored at least every two years throughout life. People with Down syndrome experience some degree of hearing loss with ageing, as do the general population.

Down syndrome and eyes

Visual defects are common but correctable and people with Down syndrome should have their vision checked regularly throughout life. Both long and short-sightedness are more common than in the general population. A decline in sight with ageing occurs at the same rate as in the general population.

Other conditions that occur more commonly include:

- Squints
- Nystagmus – involuntary movements of the eye that blurs vision
• Cataracts – a clouding of the lens inside the eye
• Keratoconus – vision becomes impaired because the cornea changes shape.

**Down syndrome and teeth and gums**
The milk teeth of children with Down syndrome appear later than in other children, and they tend to keep them for longer, which results in increased wear and tear. Adult teeth may be irregularly spaced. Gum disease is more common in people with Down syndrome and regular dental check-ups are advisable. Ongoing and specific instruction may be necessary to maintain good oral hygiene.

**Down syndrome and skin and hair**
The majority of people with Down syndrome have dry skin and hair, and routine monitoring for associated irritation, inflammation and infection is advisable. There is also increased likelihood of a number of common skin and hair disorders, such as atopic dermatitis, fungal and yeast infections, impetigo, eczema and alopecia.

**Down syndrome and growth**
People with Down syndrome grow more slowly than others. They are usually short in stature and may be prone to weight gain, partly as a result of metabolic differences. A physically active lifestyle is recommended for general health and to combat this tendency.

**Neck problems**
In a small minority of children, there is increased mobility of the atlanto-axial joint. This is the joint that connects the two neck bones directly under the skull (known as the atlas and axis). This condition is known as atlanto-axial instability. In rare cases, this can lead to dislocation of the two bones, which can cause compression of the spinal cord. This usually occurs gradually, but can also occur suddenly.

Signs of spinal cord compression include:
• Neck pain
• Restricted neck movement
• Unsteadiness in walking
• Deterioration in bowel and bladder control.

**Down syndrome and reduced muscle tone**
Your baby may have reduced muscle tone (hypertonia). Muscles can be strengthened through:
• Exercising and stimulating your baby
• Handling and tickling your baby
• Helping your baby into a sitting position.

A physiotherapist can provide help and assistance. Exercise will also help to stimulate your baby’s circulation and will reduce the risk of chest infections.

Low muscle tone can lead to problems with the structure of the foot, poor gait and mobility issues. These can be corrected by the use of good supporting footwear and orthotics.

Muscle tone usually improves as the child grows older.

**Reduced expression of pain**
People with Down syndrome do not always localise pain very well and may also not be able to clearly express the level of pain they may be experiencing. Care should be taken not to underestimate the discomfort a person may be feeling. The level of complaint may not adequately reflect the serious nature of a health or medical issue.

**Where to get help**
• Your doctor
• Down Syndrome Victoria Tel.1300 658 873
• Better Start for Children with Disability Tel. 1800 242 636

betterhealth.vic.gov.au
Things to remember

- Many children with Down syndrome have a normal life span.
- A large percentage of babies with Down syndrome are born with a congenital heart defect.
- Some babies with Down syndrome are born with conditions that affect the stomach and gastrointestinal system.
- Have your child’s hearing, eyesight, thyroid function, teeth and gums checked regularly.

This page has been produced in consultation with and approved by:

Down Syndrome Association of Victoria

Content on this website is provided for information purposes only. Information about a therapy, service, product or treatment does not in any way endorse or support such therapy, service, product or treatment and is not intended to replace advice from your doctor or other registered health professional. The information and materials contained on this website are not intended to constitute a comprehensive guide concerning all aspects of the therapy, product or treatment described on the website. All users are urged to always seek advice from a registered health care professional for diagnosis and answers to their medical questions and to ascertain whether the particular therapy, service, product or treatment described on the website is suitable in their circumstances. The State of Victoria and the Department of Health & Human Services shall not bear any liability for reliance by any user on the materials contained on this website.

For the latest updates and more information, visit www.betterhealth.vic.gov.au