



Informing, Empowering and Changing Lives Training Conference 2014

Introduction to Down's Syndrome

Compiled by Claire Fisher, with contributions by the parents of WDDSSG

Down's syndrome is a genetic condition

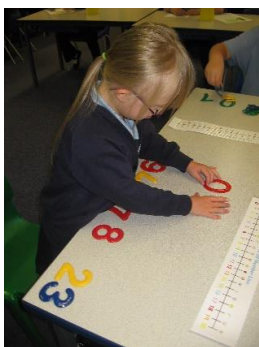
Down's syndrome is caused by an extra copy of chromosome 21. This can happen in three different ways. In the majority of cases people with Down's syndrome have an extra copy of chromosome 21 in every cell in their body (trisomy 21). In 3-4% of cases, the extra chromosome attaches to another chromosome pair – this is called translocation. Mosaic Down's syndrome occurs in 1-2% of people with Down's syndrome and is where some of the cells in the body have an extra copy of chromosome 21 and some do not.



Anyone can have a baby with Down's syndrome, although the risk does increase with age. It is almost always diagnosed at birth or before. There may be indications of Down's syndrome in pre-natal scanning, but they are not always present. There is now a blood test which, combined with a scan in the early days of pregnancy, can predict the risk of a having a baby with Down's syndrome. A mother who is assessed as having a high risk may be offered an amniocentesis during pregnancy to discover if the baby does have Down's syndrome. Different physical features of a new-born baby with Down's syndrome are often detected by the Paediatricians who will order a blood test to investigate the genetic makeup of the child. This will confirm the Down's syndrome, and the families will be told what type of Down's syndrome their child has.

For every 1 000 babies born, one will have Down's syndrome. There are about 750 babies born with Down's syndrome in the UK each year.

People with Down's syndrome have a wide range of abilities



All people with Down's syndrome will have some intellectual disability. In childhood this will show as developmental delay. All children with Down's syndrome will develop at different rates, and they may not be equally delayed in all areas. They may need to be taught how to do new skills rather than just learning them naturally as a typically developing child would do. Effective interventions (such as Portage) can make a difference to the rate an individual with Down's syndrome learns. A child with Down's syndrome may need to be taught in a different way at school in order to access the same curriculum as their peers.

A child with Down's syndrome has the same basic needs as any other child. They need to be loved by their parents, included in their family and community, and be treated with respect. As they grow, they need to be included in decisions about their life, and have the same rights as other adults in their community.

Adults with Down's syndrome will mostly need some form of extra support to live independently, though some may need full time support. The range of mental ability in an adult with Down's syndrome varies hugely. Some may be able to work in their community, others may choose supported work, and some may not be able to work. It is not possible to predict the future level of cognitive ability from facial features in a baby nor medical conditions and it is something that becomes apparent over a long period of time.

Children with Down's syndrome often are visual learners and reading is one of their strengths. There are various reading schemes designed to help with this. Numeracy is often a weakness. However, as all children with Down's syndrome are different, this will not be true for everyone. Children with Down's syndrome often have severe speech and language delay. Their understanding is often much better than their spoken language. This can lead to frustrations and can affect all aspects of their lives. Children with Down's syndrome in Wakefield are taught Makaton sign language from an early age, and this enables them to communicate effectively to encourage them to speak.



Thomas Raddings and Sarah Shutt hold numerous European and World records for swimming for a person with Down's syndrome

All children with Down's syndrome are unique and their strengths will vary from person to person. It is helpful to be positive and look at what the child can do and not what they struggle with. Children should be praised for what they do achieve and not compared to their peers.

People with Down's syndrome may have additional healthcare needs

Children with Down's syndrome are at greater risk of a number of childhood illnesses and disorders. All of these can occur in other children, but they are more common in children with Down's syndrome. For some children the additional health care needs may require a significant amount of medical attention and for others it may simply be regular observation by the health professionals.



Around 50% of babies with Down's syndrome will be born with a congenital heart defect. Many of these will be repaired through surgery, but for some babies the heart cannot be fully repaired. Some of our children require a number of open heart surgeries throughout their childhood and into adult life. All children with Down's syndrome are sent for full heart scans within the first few weeks of birth so the medical professionals are fully informed if there are any heart problems.

Children with Down's syndrome are less resistant to infections and may need extra help to recover due to lowered immune systems. It is common for our young children to spend most of the winter fighting colds and viruses, and due to small airways may seem to constantly have a runny nose. Children with Down's syndrome may need extra time off school to recover from their illnesses.



Children with Down's syndrome are 10 to 20 fold more likely to develop leukaemia. With appropriate treatment, many children with Down's syndrome and leukaemia can be successfully treated. Thyroid disorders are more common in children with Down's syndrome, and most will undergo regular testing of their thyroid levels.

Around 80% of children with Down's syndrome experience some degree of hearing loss. Glue ear and ear infections are common, and many of our children have grommets fitted. Hearing loss can be more severe and some of our children wear hearing aids or Baha bands to help them with their hearing. Mild hearing loss in a child with Down's syndrome reduces the ability of a child to discriminate between similar sounding words (e.g. pat and bat). The inability to hear correctly will also affect speech and language development.

People with Down's syndrome are more likely to have problems with their vision. Short sightedness, long sightedness, astigmatism, and squints are common. A child with Down's syndrome may also experience delays in developing focusing, depth perception, and sharpness of vision. Glasses are frequently worn by people with Down's syndrome, however many people with Down's syndrome find glasses uncomfortable as they do not fit over their nose properly. It is possible to buy Erin's world glasses which are designed with people with Down's syndrome in mind.



Many children with Down's syndrome have trouble sleeping at night, or are very early risers. There are members of our group who are up before 4:30 every morning with their child. There are a range of reasons why a child may not sleep, including sleep apnoea or a lack of melatonin (which is the body's hormone which regulates sleep). However, sometimes no reason can be found for the reduced sleep. Poor sleep can lead to other behavioural problems and may impair learning.

People with Down's syndrome often have low muscle tone (hypotonia) and the degree to which this affects them varies from person to person. Some children will walk only slightly later than their peers whereas some children with Down's syndrome will not walk until they are three or four years old. Low muscle tone makes it harder for children with Down's syndrome to use their muscles and uses more energy for the same activity, when compared to a child without Down's syndrome. Children with Down's syndrome feel as if their muscles are very heavy and they tire easily. Many children with Down's syndrome will use a special needs pram or a wheelchair for walking long distances for many years after they first learnt to walk.



Every person with Down's syndrome is unique

Everyone born with Down's syndrome has an extra chromosome, but the effect of this extra genetic material varies widely. All people with Down's syndrome will experience some learning disability. Some children will progress in the lower range of abilities in their mainstream school, and others will have moderate to severe learning difficulties. People with Down's syndrome will often have common facial features, but will look more like their parents or siblings than other people with Down's syndrome. All children develop at varying rates and will have strengths and weaknesses in different areas. The number of additional medical needs and the impact of these will also vary from



person to person. Stereotypes also exist around personality traits – for example, “they are all so loving” is a common phrase that WDDSSG members encounter. People with Down's syndrome have a full range of emotions, just as everyone else does. People with Down's syndrome are unique individuals, who get all of their genetic material from their parents. They will have inherited their personalities from a combination of their genetic material and will be influenced by the environment they grow up in. People with Down's syndrome should be treated as individuals and their needs addressed by knowing the person, and not making assumptions based on the fact they have Down's syndrome.

“When you've met one person with Down's syndrome, you've met one person with Down's syndrome”