An introduction to Down syndrome

What is Down syndrome?

Down syndrome, also known as Down's syndrome or Trisomy 21, is a naturally occurring genetic difference caused by an extra chromosome in a person's cells. Babies with Down syndrome are born in every country to parents of all ages, races, religions and backgrounds. Whilst the likelihood of having a baby with Down syndrome increases with a woman's age, the average age of a mother with a baby with Down syndrome is 29.

How can Down syndrome affect a person?

Although people with Down syndrome share some common physical characteristics, a child with Down syndrome will look more like their family members than others who have the condition. People with Down syndrome are unique individuals with different personalities and abilities, just like everyone else. People with Down syndrome have some degree of learning disability which affects their ability to learn, it does not mean that they cannot learn. Children with Down syndrome may take longer to learn skills such as sitting, standing, walking, and talking, they will master them when they are ready and able.

Living with Down syndrome

Like everyone else, children with Down syndrome are entitled to a place in mainstream education, and more young people with Down syndrome now leave home, have relationships, work and lead largely independent lives. Children and young people will receive support through their education and families are eligible to financial support.

Health and Wellbeing

People with Down syndrome can be more prone to some common health conditions but, like the rest of society, benefit from medical advancements and subsequently live longer and healthier lives. In the 1960's life expectancy for someone with Down syndrome was 15 years of age, today this has risen to 60+ and increasing. Routine heart surgery means that those babies who require surgery generally do very well and are often home within a week.

Useful information

It is estimated there are approximately 40,000 people with Down syndrome in the UK.

Approximately 1 in 800 babies born in the UK has Down syndrome.

It is worth stating that 99% of individuals with Down syndrome report being happy and 94% of their siblings express pride in their brother or sister with Down syndrome! Furthermore, another study shows that divorce rates are significantly lower for families of children with Down syndrome compared to couples with non-disabled children and families of children with other disabilities.

The Down syndrome community is a diverse, vibrant and supportive network who care for and support each other from discovering baby has Down syndrome through to adulthood.

For further information and support about Down syndrome please visit: **www.positiveaboutdownsyndrome.co.uk** and **www.downsyndromeuk.co.uk**

People with Down syndrome have an extra chromosome, they have the same needs as everyone else, to be accepted, valued and respected.

Talking about Down syndrome

Good Practice Guidelines

It is vital to be factually accurate and inoffensive to people with Down syndrome, their families, friends and associates when speaking about any issue regarding Down syndrome.

An individual with Down syndrome is an **individual first** and foremost. The emphasis should be on the **person**, not the disability.

If there is a requirement to refer to someone having the condition, always use person first language; so 'Jack has Down syndrome', never 'he's a Down's boy'. Please consider if necessary to constantly refer to someone as having Down syndrome. Please look at the person, not their genetic make-up!

Please describe people without disabilities as **"typically developing"** rather than "normal."

Avoid the use of stereotypes and generalisations, eg "They are ...." Consider and view each person an individual.

Medical language benchmarks against a medically defined 'norm', much medical terminology is insulting and disrespectful to people with Down syndrome, so we advocate the use of difference instead of abnormality, disorder or anomaly.

When talking about Down syndrome, words which should not be used include:

'**Risk**' – in accordance with NHS guidelines, the word chance is used in antenatal screening, when talking about the likelihood of a baby having Down syndrome, the definition of risk is 'exposure to the chance of injury or loss; a hazard or dangerous chance'. None of which should be associated with this condition.

'Suffering' – no one suffers from having Down syndrome, the definition of suffering includes 'endure, agonize, deteriorate, disadvantage'. Down syndrome is simply a part of someone's genetic make up.

'**Burden**' – this outdated reference does not reflect the reality. People with Down syndrome are valued, loved members of their families and communities.

Common Myths about Down syndrome

Myth: Individuals with Down syndrome are always happy.

People with Down syndrome experience the same range of moods and emotions as everyone else in the population.

Myth: People with Down syndrome are all so friendly and loving.

This is a gross generalisation about what "all" people with Down syndrome are like. The assumption that all people with Down syndrome are loving and want to hug can lead to the encouragement of inappropriate social behaviour. It can also lead to strangers behaving in a way that we would not accept for typically developing children unfamiliar to them.

Myth: People with Down syndrome suffer.

Down syndrome is not a disease and people with Down syndrome do not 'suffer', people live with Down syndrome.

Myth: Children with Down syndrome should be educated in special schools.

Inclusive education benefits not only the child with Down syndrome but also leads to greater understanding about difference and diversity resulting in less prejudice within the local community and ultimately in society at large. Research shows that children with Down syndrome do better academically and socially in inclusive settings.

Myth: People with Down syndrome all look the same.

While children with Down syndrome share certain physical characteristics, these will vary from child to child. A person with Down syndrome will look more like his or her close family than someone else with the condition. He or she will also be most strongly influenced by their family and their lived experiences.

Myth: People with Down syndrome don’t live very long

This myth comes from the past, however, the average life expectancy today is increasing with many people with Down syndrome living into their 60’s and beyond. This is largely due to the advances in medicine, particularly the ability to detect and treat heart defects, and the changes in attitudes within the medical profession.

Myth: People with Down syndrome cannot read or write.

In the past, the public perception of people with Down syndrome was that they were incapable of learning and therefore did not receive any sort of formal education. Now we know that people with Down syndrome are very capable of lifelong learning; many people with Down syndrome are visual learners so for them reading can be a particular strength.

Myth: Down syndrome is a spectrum.

People either have Down syndrome or they do not, they do not therefore have it mild or more severe. In line with the general population, everyone with Down syndrome has a range of different strengths and weaknesses.   It is estimated approximately. 15% of children with Down syndrome will have autism spectrum disorder (ASD) or attention deficit hyperactivity disorder (ADHD).

Myth: You can predict the future for someone with Down syndrome.

No one knows the future for any child, a very small percentage will become brain surgeons or astronauts, the majority will lead ordinary lives and there are some people who will face various challenges. People with Down syndrome are no different—some will excel, the majority will lead full and rewarding lives, while others encounter challenges. As with all children, those born into caring families will be loved; families accept and adjust as they do with any family member who may need some extra support, time or effort.

Myth: People with Down syndrome cannot achieve normal life goals.

Every year, more young people with Down syndrome than ever before are living in the community, gaining qualifications and experience as well as succeeding in a wide variety of jobs. People with Down syndrome date, socialise, form ongoing relationships, and get married.

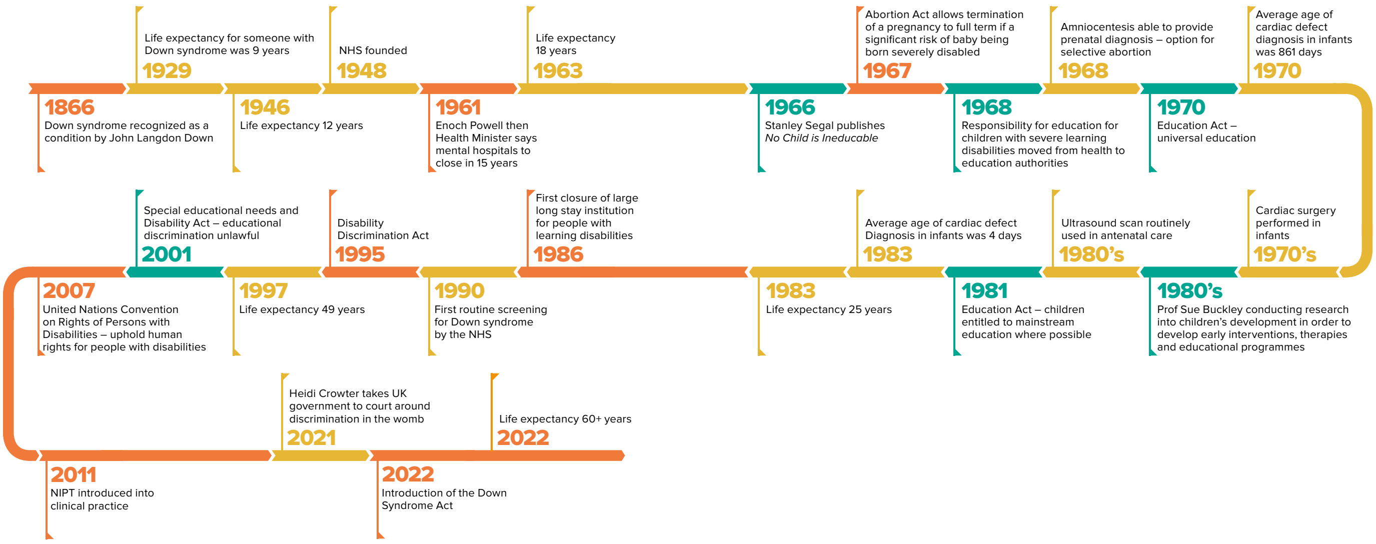
Background history

Only fifty or so years ago people with Down syndrome were often placed in institutions where they lived their lives, unloved, uneducated and unstimulated. Expectations were low and they received little if any in the way of support, education and social experiences. Research has increased our knowledge about the capabilities of people with Down syndrome and advances in health care, early intervention, education and family support have vastly improved the quality of life for young people with Down syndrome and their families.

Most young people growing up with Down syndrome today will lead ordinary lives in their community. Some people with Down syndrome may need very little help to live independently while some may require a lot more support.

Down syndrome timeline

🟩 **Education** 🟧 **Social** 🟨 **Health**



1866 Down syndrome recognized as a condition by John Langdon Down

1929 Life expectancy for someone with Down syndrome was 9 years

1946 Life expectancy 12 years

1948 NHS founded

1961 Enoch Powell then Health Minister says mental hospitals to close in 15 years

1963 Life expectancy 18 years

1966 Stanley Segal publishes *No Child is Ineducable*

1967 Abortion Act allows termination of a pregnancy to full term if a significant risk of baby being born severely disabled

1968 Responsibility for education for children with severe learning disabilities moved from health to education authorities

1968 Amniocentesis able to provide prenatal diagnosis – option for selective abortion

1970 Education Act – universal education

1970 Average age of cardiac defect diagnosis in infants was 861 days

1970's Cardiac surgery performed in infants

1980's Prof Sue Buckley conducting research into children's development in order to develop early interventions, therapies and educational programmes

1980's Ultrasound scan routinely used in antenatal care

1981 Education Act – children entitled to mainstream education where possible

1983 Average age of cardiac defect Diagnosis in infants was 4 days

1983 Life expectancy 25 years

1986 First closure of large long stay institution for people with learning disabilities

1990 First routine screening for Down syndrome by the NHS

1995 Disability Discrimination Act

1997 Life expectancy 49 years

2001 Special educational needs and Disability Act – educational discrimination unlawful

2007 United Nations Convention on Rights of Persons with Disabilities – uphold human rights for people with disabilities

2011 NIPT introduced into clinical practice

2021 Heidi Crowter takes UK government to court around discrimination in the womb

2022 Introduction of the Down Syndrome Act

2022 Life expectancy 60+ years