



Down's Syndrome Awareness Week 16-22 March 2020

***'To Aspire, Endeavour and
Thrive Together.'***

Our Values



T **GETHER** **MOTIVATION** **OPTIMISM** **UNDERSTAND & ACCEPT** **BELIEVE**
★ **DETERMINATION** ★ **DIFFERENCE** ★★★★★★

TEAMWORK **INSPIRE** **teamwork** **STRONG** ★
CHALLENGE YOURSELF **WORK ETHIC**

ASPIRE **WE VALUE OUR STAFF** **TARGETS**

PREPARE FOR SUCCESS **LOVE to learn** **RESPECTFUL**

VISION **To aspire, endeavour and thrive together.** *Be kind* **PRIDE**

ALWAYS STRIVE TO IMPROVE **Plan for YOUR**

remain **optimistic** **THRIVE** **FUTURE**

SUPPORT **HIGHEST EXPECTATIONS** **PARENTS CARERS** **PREPARE TO THRIVE**

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What is Down's Syndrome?



Down's syndrome is caused by the presence of an extra chromosome in a baby's cells. In the majority of cases, Down's syndrome is not an inherited condition. Down's syndrome usually occurs because of a chance happening at the time of conception.

How many people does it affect?



- For every 1,000 babies born, one will have Down's syndrome.
- About 750 babies with Down's syndrome are born in the UK each year.
- Down's syndrome affects people of all ages, races, religious and economic situations.
- There are approximately 40,000 people with Down's syndrome living in the UK.

How long have we known about it?



- It is believed that people with Down's syndrome have always existed. However, it was not until 1866 that the English doctor, John Langdon Down published a description of the condition, which subsequently took his name.
- In 1959 Professor Jérôme Lejeune proved that Down's syndrome is a chromosomal irregularity. Instead of 46 chromosomes usually present in each cell, Lejeune noted 47 in the cells of people with Down's syndrome. It was later determined that this additional chromosomal material results in the physical characteristics associated with the condition and the different course in development.

Can people with Down's syndrome lead a 'normal' life?



- People with Down's syndrome, like all adults, have the right to get married. It is important that young people with Down's syndrome receive education in the area of relationships and sexuality. As in other areas of learning, they may need more support with this than some of their peers.
- Women and men with Down's syndrome can be parents. However, many couples with learning disabilities decide for themselves not to have children because of the responsibility and hard work involved, or for financial reasons. Where one parent has Down's syndrome, there is a 35% to 50% chance that the child would inherit the syndrome. This chance is even higher where both parents have Down's syndrome. There is also a high chance that pregnancy would end in miscarriage. Women with Down's syndrome are also more likely than other women to have a premature baby, or to need a caesarian section.

How have attitudes changed towards people with Down's syndrome?



- In the early part of the last century legislation was introduced which led to the incarceration of thousands of people with learning disabilities in institutions known as long stay hospitals. Parents were made to feel ashamed of their children with learning disabilities and were routinely told to “Put him away and forget him”.
- The 1944 Education Act advocated a selection process to decide which children were deemed “educable”. Children with Down's syndrome were deemed “ineducable” and therefore denied an education. This classification determined that their lives would be spent in institutions or at home with their families who were given no support.
- It was not until the 1971 Education Act that it was officially recognised that no child is “ineducable”, that children with learning disabilities had a legal right to go to school.

How have attitudes changed towards people with Down's syndrome?



- The quality of life, life expectancy and role in the community for people with Down's syndrome have gradually been transformed as education and support have improved. In fact the opportunities for people with Down's syndrome to lead the lives that they want have never been greater. However, we know that we still have work to do to ensure that people with Down's syndrome have many of the same life chances that the general population take for granted.
- Adults with Down's syndrome are leading longer, more healthy, fulfilling and varied lives. Small but increasing numbers are leaving home to live with support in their communities, getting jobs, having busy social lives and enjoying friendships and relationships. Some adults choose to stay with their families and receive a service to meet their needs from Social Services. Alternatively, the person might receive a direct payment from Social Services and they and their family organise their support.

How should we refer to people with Down's syndrome?



- Down's syndrome is not a disease and therefore people with Down's syndrome do not suffer nor are they victims of their condition. Down's syndrome is only a part of the person, they should not be referred to as "a Down's". People with Down's syndrome are all unique individuals and should be acknowledged as a person first and foremost. It is important to think of the person first, e.g. "John is 29 and he has Down's syndrome".



- **Fact or fiction? Children with Down's syndrome are only born to older parents.**
- **Fiction.** 80% of children with Down's syndrome are born to women younger than 35. However, the likelihood of having a child with Down's syndrome does increase with the age of the mother.



- **Fact or fiction? People with Down's syndrome cannot form relationships.**
- **Fiction.** People with Down's syndrome are perfectly capable of forming all types of relationships with people they encounter in their lives, be it friendship, love or a dislike of someone.



- **Fact or fiction? Men and women with Down's syndrome can have children.**
- **Fact.** Women with Down's syndrome can and have had children. It has been recorded that two men with Down's syndrome have been fathers. The information about fertility in people with Down's syndrome is very outdated and based on research in institutions where men and women with learning disabilities were kept apart.



- **Fact or fiction? All people with Down's syndrome will eventually develop Alzheimer's disease (dementia).**
- **Fiction.** Alzheimer's disease is not inevitable in people with Down's syndrome. While all people with Down's syndrome are at risk, many adults with Down's syndrome will not manifest the changes of Alzheimer's disease in their lifetime. Although risk increases with each decade of life, at no point does it come close to reaching 100%.

Meet some adults with Down's syndrome



Karen has just held a party for her friends and family to celebrate the tenth anniversary of moving into her flat. Karen part owns her flat and she has a dedicated team of three staff who support her on a daily basis. A staff member sleeps over each night to make sure that Karen is safe. Karen fills her week with visits to the Gym, college courses in IT, numeracy, crafts and massage, listening to rap music and watching wrestling. Karen travels to and from college on her own using public transport. Karen loves playing football and visiting the Science Museum. Karen finds writing difficult so she dictates her poetry to one of her support workers so that they can write it down for her.

Meet some adults with Down's syndrome



Tom lives in a residential home with other adults with learning disabilities. Support is on hand day and night if Tom needs it. During the week he enjoys going to a day centre and a Mencap social group. Tom is quite active and he enjoys dancing, swimming and table tennis. Tom adores animals, particularly monkeys, and when he feels comfortable he loves to list the things he likes.

Meet some adults with Down's syndrome



Tessy lives with her aunt and she has a little spoken language in Czech and English. She helps her aunt with the cooking and household chores. Tessy loves to make things with her hands and she expresses herself in colours and shapes. During an average week she does yoga, gardening in a herb garden, ceramics classes and glass mosaic classes. Tessy enjoys bird watching, walks and studying nature.

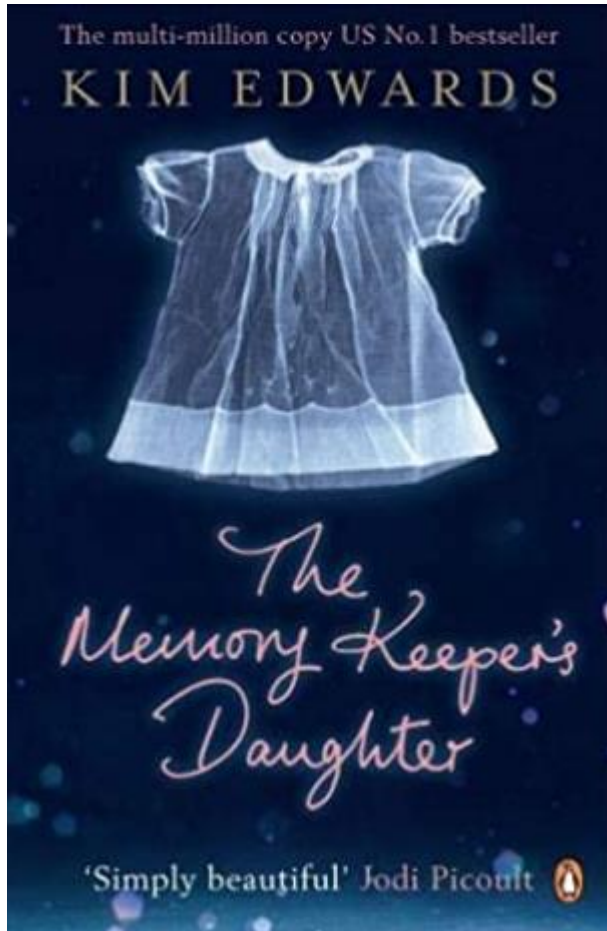
Meet Cameron and Ollie.....



<https://www.youtube.com/watch?v=-gwqNptOHZy>

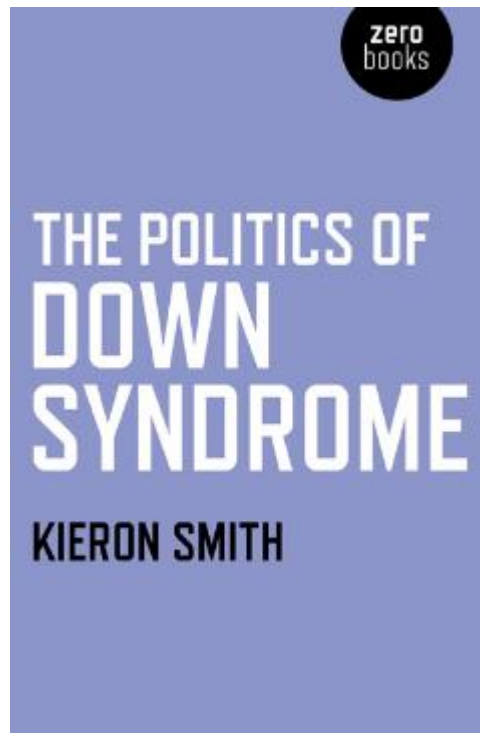
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Suggested further reading...



The Memory Keeper's Daughter, Kim Edwards

Families have secrets they hide even from themselves...It should have been an ordinary birth, the start of an ordinary happy family. But the night Dr David Henry delivers his wife's twins is a night that will haunt five lives for ever. For though David's son is a healthy boy, his daughter has Down's syndrome. Followed by a shocking act of betrayal, the consequences only time will reveal.....



The Politics of Down's Syndrome, Kieron Smith

Are we a more accepting society than ever before? Is there no longer a 'them and us' division between the disabled and 'everybody else'? The Politics of Down Syndrome looks at how we got to where we are, from the racist roots of its identification to the rising number of abortions today. Down's syndrome is the most common form of learning disability, shared by all classes and races, yet it's one we rarely address our feelings about, head on. This book, although direct and questioning, takes a positive view about where we go from here and the opportunity for society to fully enjoy the benefits of being inclusive.