



Positive about Down syndrome

Dear Doctor,

Having Down syndrome is not a problem.

Clearly it is important that language used by medical professionals when communicating with families is considerate and respectful. Can I kindly ask therefore that you review your correspondence in which it refers to my child having Down syndrome as being a 'problem?'

Down syndrome is a genetic difference that a person is born with, and should not be referred to as a problem. It could instead be referenced as diagnosis, reason for referral, or condition; all of which parents

of and people with Down syndrome would consider far more factual and less offensive.

Positive about Down syndrome provides resources to hospitals to ensure expectant and new parents have an understanding of the reality of Down syndrome. PADS works hard to ensure language and attitudes are non-discriminatory or prejudicial. I would be grateful if you would kindly consider and amend future communication to be respectful to my child.

Thank you



Photo: Magdalena Szechman



**Positive about
Down syndrome**

Talking about Down syndrome

Good Practice Guidelines

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

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.