

A terminology guide for health professionals working with individuals with Down syndrome and their families

When speaking about issues relating to Down syndrome to colleagues or the public, or to individuals with Down syndrome and their families, it is important that the language used is both factual and inoffensive, and does not perpetuate negative stereo-typing, or any myths about the condition.

Please consider the following guidelines:

DO NOT say

- 'Risk' of Down syndrome or 'bad/difficult news', when delivering a diagnosis in relation to pre-natal screening and probability assessments
- Downs baby/child/person
- Downs (as an abbreviation) 'He has Downs', 'a study of Downs'
- Suffers from or is a victim of Down syndrome
- Disease, illness or disorder, problem, abnormality or handicap
- Retarded, mentally handicapped, backward
- 'Normal' (if it's necessary to make comparisons to peers) 'A normal child/individual might be expected to....'

Myths

- Individuals with Down syndrome cannot learn or achieve normal life goals
- Individuals with Down syndrome have short lives
- Individuals with Down syndrome are happy/ affectionate/musical/all look the same/have behavioural issues

DO say

- Chance of a baby having Down syndrome
News/unexpected news/result/diagnosis
- Use person first language; a person/baby/child with Down syndrome
- Down syndrome or use DS as an abbreviation if necessary
- Has Down syndrome
- Condition or genetic condition
- Learning/intellectual disability
- Typically developing `A typically developing child/individual might be expected to....'

Facts

- With appropriate support, individuals with Down syndrome are achieving more than ever before; attending mainstream schools, passing exams, gaining employment, getting married, making positive contributions to their communities, and living full, semi-independent adult lives
- With appropriate medical support, individuals with Down syndrome are now living into their fifties, sixties and beyond
- We are all individuals, and people with Down syndrome are no different in their character traits, interests and varying moods, and can experience anxiety and depression just like everyone. There are no behavioural problems unique to Down syndrome