

Stop saying that!

by Leticia Keighley

The world has changed a lot for people with Down syndrome but there is still a long way to go. Outdated stereotypes still persist and parents are often on the receiving end of (sometimes) well-meaning but hurtful assumptions.

Before I became pregnant with my son I knew very little about Down syndrome and was on a steep learning curve from day one. The more I learnt, the more I became aware of what Down syndrome was and was not—and that’s when the comments of others started to grate. It’s hard to hear well-meaning comments that couldn’t be further from the truth and realising how much misunderstanding there is in the wider community about our loved ones.

Knowing that these frustrations couldn’t be mine alone, I decided ask other parents to vent by asking the question – What do you wish people would stop saying about Down syndrome?

And vent they did.

Here’s a list of things that really gets under our skin.

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“She only has a little bit of it”

“You can’t tell”

“It doesn’t look like they have it”

“She doesn’t have it that bad”

“He’ll grow out of it”

”

When other people hear about your child’s diagnosis for the first time, they want to say something positive but often don’t know what to say. They mean well but think that minimising the news somehow will make the parent feel better. It’s frustrating because, as one parent wrote, ‘What you don’t know (is) how I love my child unconditionally and that they are the best thing that ever happened to me.’

It’s also frustrating because there is a misunderstanding in the community that Down syndrome is a spectrum condition, which is isn’t. You either have it or you don’t. There are different levels of independence or intelligence or health, just like in the typical community. These types of comments make Down syndrome feel like a disease or an affliction instead of a part of who our children are.

“He ‘is’ Down syndrome instead of ‘has’
Down syndrome”

“A Downsy”

“A Downs person”

“It’s ok, I know what she is”

“‘They’ and ‘them’”

”

“My uncle’s neighbour’s sister-in-law had one too!”

Prominent in the Down syndrome world, is Person First Language. The idea is that when speaking about a person with Down syndrome it is preferable to say that a person has Down syndrome instead of is Down syndrome. The language in the comments above makes it feel as though a person with Down syndrome is an object rather than a person. It also assumes that everyone with Down syndrome is the same. As one parent commented, ‘They assume everyone with [Down syndrome] is like this one person they met 20 years ago. If you have met one person with [Down syndrome] then you have ONLY met ONE person with [Down syndrome].’

Frustration comes because a lot of stereotypes about Down syndrome persist despite advocates trying to dispel them. Starting a sentence with ‘They all...’ reinforces the generalisations our community is trying very hard to change.

“They’re so happy!”

“They’re all so friendly and loving”

“So cute!”

“You’re lucky because they will always love their mums”

Like the category above, these comments make gross generalisations about what ‘all’ people with Down syndrome are like but it goes even further.

The assumption that people with Down syndrome are happy and loving all the time is frustrating for parents for two reasons.

Firstly, it is wrong because people with Down syndrome have the full range of emotions—just like everyone else. There is also the presumption that negative words and attitudes won't hurt, however a comment from one parent shows how wrong that can be: '...makes my blood boil as my son is an introvert and always has been, like his parents...If they had to witness their 9 [year] old sobbing in the bath saying "I stupid, Mum, I stupid" after bad school times they would never say such ignorant painful...things.'

Secondly, the assumption that all people with Down syndrome are loving and want to hug and kiss all the time 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 typical children unfamiliar to them. As one parent described, 'A couple of times I had total strangers come up to my son and put their hands on him!—patting and hugging him and acting out their "they're such loveable children" belief.'

"I don't know how you do it"

"It must be so hard"

"So how is he really going?"

"They are suffering from Down syndrome"

"They are a burden"

"I'm so sorry"

These comments are just hard, full-stop. Parenting is hard for everyone. For parents of typical children it is accepted that there will be good times and bad times but comments like these presume that our difficult times are all there is to our parenting journey. For a lot of parents, the hardest part of raising a child with Down syndrome is listening to this attitude! As one parent says, 'I have 5 children and he is by far my easiest child.'

Comments such as these also presume that parents are 'putting on a brave face' or 'making the best of it' as though, if the right question is asked, they will tell you the 'truth' which is not the case at all for a lot of people.

"Did you know when you were pregnant?"

"Didn't you have the test?"

Parents were divided as to whether they wanted people to stop saying this. On the one hand, there is the presumption that if a person knew of the diagnosis beforehand, they would not have continued with the pregnancy—which is confronting and offensive to a lot of parents.

However, some parents don't mind being asked this as it gives them an opportunity to announce that they chose this child and reinforces to the questioner that their child is wanted and valued. One parent made the observation, 'In my short experience, answering that question often means any sympathetic (condescending) questions that might have followed are not asked.'

"I can't believe how well he is doing!"

"She has Down syndrome but isn't she cute anyway."

"He won despite having Down syndrome."

This category of comments is sometimes known as 'Inspiration Porn'—the notion that a person with a disability doing ordinary every day things is a surprise and inspiration for able-bodied people to try harder: 'If they can do it, then so can you.' Wrapped up in these comments is the assumption that most people with Down syndrome are not pretty or capable or winners so, if they happen to succeed or look attractive, this must be 'despite' their disability. This is offensive to people with Down syndrome and the people who love them because people with Down syndrome are attractive and are capable of doing every day activities and it shouldn't be headline news if they happen to be successful too!

"You were chosen as his parents"

"God only gives special children to special parents"

"Everything happens for a reason. There must be something you need to learn"

"They are angels from heaven"

A lot of parents find these comments particularly frustrating, especially if they have other children as well. The notion that only one of your children 'came from heaven as a gift' and the rest didn't is not a lovely thought. The other problem with these comments is they (once again) set our children apart as though they are special or other-worldly. I personally don't like hearing that God only gives 'special' children to 'special' parents because there are children with disabilities all over the world that are mistreated, abandoned or abused by their families as well as the society they are unfortunate enough to be born into. It is also incredibly offensive to be told that there must be something to learn from the situation—as though as a child with Down syndrome is some kind of punishment for previous acts or a lesson to be bestowed on others.

Thank you to all the parents who contributed to this article by sharing their most loathed comments with me.