

ASD: telling others about the diagnosis

This is a transcript of the Raising Children Network video available at http://raisingchildren.net.au/articles/asd_telling_others_video.html. Parents share their experiences of telling others about their children's autism spectrum disorder (ASD) diagnosis.

Sandra [*mother of two, two with an ASD*]: You've also got to decide who is important enough in your lives that you want to share this initial piece of information with. Because as you get on, you get more and more robust and then you can tell people and you're not a sobbing mess.

Korrine [*mother of two, two with an ASD*]: I was quite shocked with the responses you get from people. It's almost like your child's died. And you... you... basically people start giving you their condolences.

Alison [*mother of three, one with an ASD*]: It took me a while to come out and tell people. It took me a good, I'd say, six months, you know. I think people wondered what was going on with Flynn and with us, and why we weren't sort of going out as much.

David [*father of two, two with an ASD*]: If you don't feel comfortable with talking to someone about it, you don't have to. It will become easier, and so when *you* feel like you're comfortable talking to people about it, then that's the right time to tell people.

Jerry [*mother of two, one with an ASD*]: I couldn't tell to anybody, even my friends. When they ask me about 'How is Daniel going?', I said, 'Please, don't ask me about Daniel. Later, later I can tell you'.

Elena [*mother of three, two with an ASD*]: My mum was the first person I told and I said, 'Well, he's got autism but it's not autism, it's pervasive developmental disorder. And it kind of made me feel better about it... that it wasn't autism, it was like something a bit better than autism. But really all it is is autism but a higher functioning type of autism. And then I straight away said, 'But they want to reassess him next year'. Um... she said, 'Oh good'. And I think that... her... a lot of people who don't know what autism is (and at that time, I didn't really either), I think, um, people think that the child can grow out of it.

David: When Kingsley was first diagnosed, I found it... it was very emotional and I found it very difficult to talk to people about his condition. And, to be honest, I wasn't really 100 per cent proficient in being able to explain to them just exactly what the problem was.

Carl [*father of two, two with an ASD*]: Everybody at work knows that I have two boys with autism. I take them in there quite often, so... um... they actually all think they're normal kids. And obviously they don't have a full understanding of what autism spectrum disorder is but, um, I think most of them know what autism is.

Sandra: Dad's a very, very strong Christian and his, sort of, um, initial reaction was that a miracle would happen and Kingsley would be cured. And I think, to this day, he still... backs of his mind said that he's just waiting for God to do his work.

Tracey [*mother of two, one with an ASD*]: I didn't find it hard to tell people at all because to me it was like... um... almost like, 'See, there's a reason...'. My mother just thought Jack needed a good smack, um, and then... now she's decided that ok, well, maybe Jack doesn't need a good smack and there's another reason [*smiles*].

Alison: My own mother was fantastic. She was straight into research and everything like that. My other side of the family were... they just didn't want to know. 'Nope, not my grandson'... and, yeah. She had nine kids of her own and 23 grandchildren so that was hard. We started to let people know that this was, um, you know, what's going on and this is what's wrong with Flynn. And, then, you know, finding that we had another friend, an obscure friend who was actually going through the same thing, but had a couple of years on us.

Sandra: I always vividly remember that my mother-in-law actually attends a beautiful little Anglican church and she was telling me this story where she'd told the minister of the church that her grandson, her very first grandchild, had been diagnosed with autism. And the minister had said to her, 'Well, you're just going to have to love him just that little bit more'. And she said turned around to him and said, 'It's not possible because I couldn't love him any more than I do'.
