

## **A Bright Future For Alex**

*Following recent news stories about an increase in the number of mothers who continue with their pregnancies after a positive test for Down's Syndrome in their unborn children **Seán Kelly** met Paola Nono, mother of Alex, an 18-month old boy with Down's Syndrome. She told Seán about what she decided and why.*

**The weather was still cold when I headed out to Ealing in West London to meet Paola Nono and her son Alex. Paola is Italian by birth and Alex is her first child. Between them they give me a grand welcome to their home. Paola is charming and friendly while young Alex has a smile which is frankly irresistible.**

Paola became pregnant relatively late in life. Having lived a single life for nearly 40 years she met James and married him two years later. Initially, Paola was not concerned whether or not she had a child – her view was “If it happens it happens, if it doesn't it doesn't. That's been my attitude to life; you just take what you're dealt with”.

A little while later she did become pregnant. She says she and James did have an idea that there would be an increased risk but she was more concerned that she might miscarry and that this would be her last chance rather than she might have a child with a disability. However, they decided to have the tests because if there was something they would rather know.

The news from the hospital came by 'phone when Paola was alone at home. “They told me it was positive.

Someone you don't know who says, ‘I'm sorry but it's bad news’.” She believes that this could have been handled better. “I don't know why they do that. This is one thing they should change. They could pick up the phone and say ‘come in’.”

Her husband came back from work. She says, "That was the difficult time, telling people". They went back to the Foetal Care Unit at the hospital and saw a counsellor. Paola says things improved from then on. Perhaps this was partly because, at an early stage, Paola felt clear about what she wanted. "I guess it's maternal instinct, I don't know, but something had kicked in, maybe it's the shock reaction.. but suddenly I was feeling, okay, alright, it's Down's Syndrome. So what?"

It sounds like an almost absurd reaction. I remember thinking Down's Syndrome is not really a disability.. you know you think of all the worst things that could happen in life. Really I just felt this was my baby and there was no way I was going to part with him".

Though Paola had found her own certainty it did not come so swiftly for her husband. "The problem suddenly was that James and I were no longer feeling the same way. He couldn't understand my reaction any more than I could understand his. For a few weeks we were both in shock. You obviously react to it in different ways. My reaction was, 'I don't care. Okay, Downs' Syndrome, we'll live with it, we'll cope.'" James needed a more rational approach. Paola says, "He was whirring – what will it be like when Alex goes to school? Would he be able to find a job?"

Paola and James were helped by the Down's Syndrome Association to meet a family with a six year old girl with Down's Syndrome. This reassured James that things were not as dire as he had feared; the family had a fairly normal life. "Then you start talking to people.

Someone said, 'Oh, we've got a friend who adopted a girl with Down's Syndrome and she's 18 now and a brilliant gymnast'. Another said, 'My wife works at the library of a college and there's lots of people with Down's Syndrome there and they're all doing well'."

Paola and James met more families but perhaps in a way the decision came down to Paola's determination to see through

whatever life gave her. She says that, for example, some parents have to cope with their children having leukaemia. "No one wants to have a child with leukaemia but if it happens there is not much you can do about it. I'd rather have a happy child with Down's Syndrome than an unhappy child without".

So they went ahead with the pregnancy and Alex was born. Paola says she has only had positive reactions, from family, from friends and even on the street. She thinks this may be because she and her friends are, in English terms, middle class, but then she is quick to point out that, where she lives, it is very mixed. "The neighbours have been absolutely wonderful.

Everybody adores him". Paola's approach is to tell people that Alex has Down's Syndrome. "Otherwise", she says, "they won't know what's going on". She is aware of the danger of 'carrying a flag' but says, "If you are open there is nothing to hide. If you are comfortable you can put people at ease and they can be comfortable as well".

We speculate together on whether attitudes have improved. Paola believes they have and that they will continue to do so, thanks to children with Down's Syndrome being included in mainstream schools. "That should help. If you went to school with someone with Down's Syndrome you would know what it's like".

She feels that, as a mature mother, perhaps she is better able to cope. "I didn't feel 'why me?', I felt 'why not me?' I am sure we can cope. If anybody can cope we should be able to. We have got the time, we have got the resources, we can help him".

One unexpected source of support was that an unusually high number of children with Down's Syndrome were born in about three months in Ealing. There were eight in all. The health visitor and a worker from Contacta-Family helped to set up a support group. Not all the families wanted to be involved but five still meet regularly. It provides a different peer group for Alex and also gives Paola a

different way to judge his development. The families support each other and Paola sees it as a blessing. "The children are gorgeous".

She hopes that Alex will keep some of the children from the support group as friends as he grows up. Paola is positive about the future. "I wouldn't say there aren't problems but I am positive about the future. I don't spend my days thinking this or that could go wrong. I firmly believe there is a place in Society for people with Down's Syndrome".

*Seán Kelly is publisher of Community Living and Chief Executive of the Elfrida Society.*