

## Speaking from Experience

### *Cystic Fibrosis: Newly diagnosed*

#### Transcript for chapter 2 of 7: Sibling reactions

**Gael (her 12 year old son Reuben has CF)** - I have another little boy, who's nearly five. At the moment, he's aware that Reuben has CF and he talks about it. He's not aware of the full implications as yet. I answer those questions as they come. In some ways I find that it seems harder for me than it was with Reuben. With Reuben, I've just answered those questions directly, because they directly involve him. Whereas now, this is like a third party. It's just become a little more complex. But certainly, I'm going to be as open and honest in exactly the same way with Oliver as questions come up. I think that they're not coming as early, because they're not directly involving him in the same way. I'm not answering as early as I did with Reuben. That's something that, for me, is difficult too, because now he has to deal with this as well. We don't like our children to hurt basically.

**Emma (22 years old. Has CF)** - A lot of younger brothers - I know it's a bit of a generalisation - would maybe not put as much effort and support into their sister. Pretty much focussing on their own life, at such a crucial age. But, he's just been fantastic when I've been in hospital. He sits down and has conversations with me and asks me how I'm really doing. If I was having a coughing fit at home, he'd come and rub my back. He would do anything for me. He'd drop anything. He's amazing.

**Melissa (has a 2 year old son with CF)** - I have a daughter who's five. She had just turned three when Benjamin was born. She copes extremely well with Ben's CF. She said to me when Ben was first diagnosed and I was crying a lot, "What's the matter mum?" I said, "my tummy is sore". "Oh, you can vomit on me". And that was her attitude from the beginning - you'll get over it, you'll be fine. She really keeps a good perspective on things. She's said cute things like, "God got the recipe wrong when he made Benjamin - he put too much salt in." And we have a laugh. It has opened her eyes to a lot of other things. If she sees a dwarf [sic], or if she sees someone who doesn't fit that perfect mould... I think she has a much better understanding. She goes to kinder with a boy who's profoundly deaf. So, she understands that not everybody is made the same.

**Louise (has a brother and sister with CF)** - The idea of CF, to me, was getting a hell of a lot more attention... It's pretty hard to come by attention, being one of seven. But when two kids in the family are sick and they do spend time in hospital, people are going to visit them, spend time with them. I remember thinking that I wished I had CF, just to get a bit of that attention. Not to be sick, but to have the fun [laughs].

**Melissa** - We're very open about it. We don't try to hide it. We don't make an issue of it, but we don't hide the fact that Ben has CF. She does physio on her dolly while we do physio on Ben. If we see anyone on television with CF, we show her. She comes with us to meetings sometimes, where we talk about CF. She's very matter-of-fact about it.

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