



## Speaking from Experience Asthma in Childhood

### Transcript for chapter 5 of 12: Medication issues

**Paul, Vicky and daughter Michelle (who has asthma):** Ventolin is a miraculous drug to me. Even now, when I have attacks and take ventolin, it just takes them away immediately. There's not many medications you can take that have such a dramatic, immediate effect. I'm just so happy that it's available for Michelle.

**Marilyn (has three sons with asthma):** When he was first diagnosed, and on quite high doses of cortisone, five or six times a year, I was most concerned because I knew the side-effects were a lot more severe through a tablet form than it would be through a spray form. In those early days we didn't have the spray forms that we have now. So the only treatment we could use for Matthew was either reliever medication and prednisolon tablets or cortisone. When it was occurring more and more often, I was really getting quite concerned. Would it stunt his growth? Would he be on this for the rest of his life?

**Paul, Vicky and daughter Michelle:** Her medication routine, if you like, is one puff of pulmicort once a day, which is good.

**Paul, Vicky and daughter Michelle:** Yes, 200 micrograms.

**Paul, Vicky and daughter Michelle:** I think when we started it was two puffs twice a day?

**Paul, Vicky and daughter Michelle:** I was two puffs three times a day.

**Paul, Vicky and daughter Michelle:** Two puffs three times a day. So we've been able to reduce it dramatically, which is wonderful from our point of view, because we do worry about what the side-effects are going to be.

**Marilyn:** He has been on preventative medication for many years. Even now, I've got a good rapport with his doctor and I'll sit down and say, "Look, he has been so well for so long, let's take him off his medication and see how he goes." And we've done that at different times of the year, about two or three times, and each time he has been taken off the medication, within one or two weeks he has asthma. So it reaffirms to me that being on the medication is the right answer for Matthew.

**Susan (has three children with asthma):** I constantly try to wean back the medication, but then you have the breakthrough symptoms and then you'd have to 'up' it again. It was this constant juggling act. There's no one solution for someone with asthma. There's often a customised group of medications for that one person. So it was always trying to get it to the lowest side-effects for the maximum benefit of the asthma.

**Lavinia and Geoff (have two daughters with asthma):** For Gem, there has been some side-effects from her medication. So that's another issue that you worry about too. She takes a high calcium diet because she's got some bone thinning from long-term steroid use. But at the same time, you go "Oh my goodness, she can't have the steroids" but then you have to

weigh up this quality of life thing - and she needs them so she needs them. So you just pump in the calcium, and you do other things.

**Lavinia and Geoff:** That's right. When new medication comes along, you try that. Some of them don't have as much steroids in it.

**Marilyn:** Particularly when the boys were small, well-meaning family members, more so than friends, would say to me "You're giving them too much medication. Why do you have to give them all of this? They'll be OK." And I didn't actually take the time, a lot of the time, to explain to them why they needed to take the medication. I was just struggling to cope on my own. So I just would wear it on the back a lot of the time. It often wasn't until they became aware of an asthma attack themselves that they then started to understand that these children needed this medication to keep them alive.

**Paul, Vicky and daughter Michelle:** When Michelle was first diagnosed she would have the spacer just for the periodic problems that she would have. But as soon as there was any severe attack they would automatically switch to a nebuliser. But there has been a change now, away from the nebuliser to only be using the puffer and the spacer. It's just that you have far more puffs, so to speak, per episode and closer together. So that has been easier, and a lot of people get very freaked out and scared off when using a contraption such as a nebuliser. The spacer is obviously very portable and easy to use.

**Susan:** Two year-olds and seven month-olds scream and yell the house down when you put a mask on their face for fifteen minutes, so it was a very depressing time.

**Vladamier (has a son with asthma):** You can make a disease or anything like a breathing problem or a pain much less severe if you can get the person who has got that problem to relax.

**Susan:** When my daughter had very severe asthma it was often two hourly that we had to give those pumps. So the children would often bucket the whole idea of having medication. They got really bored by it and really annoyed with it, because they wanted to get on with their lives. And the interesting thing is that they didn't notice their symptoms -they just kept pushing on with their life, and they were coughing and spluttering and wheezing. So they were running off and doing whatever they wanted to do, and you were always trying to drag them back to give them their medication.

**Paul, Vicky and daughter Michelle:** Whenever we've said that we're trying to reduce her dosage, she has always been happy about that, because I don't think she likes the taste in her mouth.

**Vladamier:** He still goes through spates, I guess as anyone does, where he thinks "I'm back to superman and I can do without it." And he's pulled back into line just by his physical condition. He has now learnt to recognise the warnings early enough before the bad time starts.

**Marilyn:** I found it much easier when the boys were younger and I was in full control of their medication, because I knew that they had exactly what they needed. Now, having to step back and let them take their own medication, I have to also stand back and let them get asthma and see how it feels and help them understand that it's a direct result of not taking



their medication. That's not easy as a parent, but it's part of the learning curve of passing on that ownership from me to them - because it is their condition.

**Matthew (has asthma):** If I go out to the movies with my friends, when I'm a teenager, I have to take my medicine. If I forget it, I might have an asthma attack or something, and mum won't know. So I have to take responsibility with my asthma.

**Gemma (has asthma):** It sort of makes you feel like you can go anywhere and you'll be fine, because you can take care of your asthma and yourself.

**Lavinia and Geoff:** Sometimes she doesn't want to do it all, and we just remind her and have a bit of a chat. And then she gets it all together, and off she goes again and does the right thing. As she grows, things change. Different issues come into it. Like now, we'll probably get "What will my friends think?", whereas we've never really had that before. Before we've had "But it takes too much time!" and "I'm busy, I'm doing such and such." So there's different issues to deal with along the way and it'll be interesting to see what the next issue is and whether we can cope with it.

**Lavinia and Geoff:** Plus we've got different medications now too. We experimenting with other medications, stuff like that. Gemma probably doesn't get the full gist of it, so we need to remind her of why she is taking it.

**Lavinia and Geoff:** Yeah, taking a tablet like the singularair, doesn't really feel like you're treating your asthma. So it's hard to remember that taking that is important, because you're not breathing it in, and into your lungs and getting an instant effect. So it was easy for her to forget that you need to take that each night.

**Vladamier:** We just said "Righto, this is the way to do it. Thousands of other people have done it this way before. The pluses far outweigh the minuses. Let's get on with it.