



## Speaking from Experience *Cystic Fibrosis: Adults*

### Transcript for chapter 2 of 9: Changes in care and treatment

**Julie** - Although she was 19 at the time, thinking about transition, it was still difficult. She easily stayed at the children's hospital. It made her feel like she was in a home away from home.

**Amber and Stephen** - It's all pretty sterile, with lots of nurses and doctors. It was pretty scary initially. But after a few admissions, you got used to how things worked.

**Damien** - I think the transition from paediatric to adult care was a pretty smooth one for me. I was always blessed with really wonderful doctors.

**Amber and Stephen** - You tend to have a relationship with your doctor, as one adult to another. I feel pretty relaxed with all my doctors.

**Stephen** - Within the first few admissions, I'd look around and couldn't believe all the guys and girls who looked very ill. I thought that they must be different from me. I still didn't have that acceptance that I had the same thing.

**Damien** - I grew up with mum and dad giving me percussion, and then the invention of the PEP mask was significant.

**Peter** - These days, there's the PEP mask, there's the flooder valve that people are using, rather than the postural drainage. To each their own. If they get benefit from it, fine. I think exercise programs have increased. There's more awareness than ever now that you need to pursue some form of exercise, to keep the lungs clear.

**Sue A.** - I was on drugs to keep my heart beating steadily and anabolic steroids. They talked a bit about oxygen therapy then, but I freaked a bit thinking that was the end, to be put on to oxygen. I used to spend about three months a year in hospital.

**Jo** - When I was younger, we used to have to follow a low-fat diet, now we follow a high-fat diet. That's helped with weight. We just take more enzymes with our meals to digest the extra fat. So, if there's any advantage to having CF, it's the diet, because you can eat anything you like [laughs].

**Sue B.** - I remember the early days, Viocase, having to mix it up with anything she would eat, like honey. We found tomato juice was actually good. It wasn't very good for the digestive system, it didn't seem to work greatly for her. She continued to have the bowel blockages. Then it went through to medication in capsule form, which worked a lot better. I think they made a big difference to her, health-wise, because it meant that she was taking less medication and had good results with the digestion.