

Being a mother of a young adult with Cystinosis



If I now look back to the past 25 years of taking care for a child with Cystinosis, I think: "Somehow we came through".

So many different and/or difficult aspects have crossed our road and we were more or less successful in dealing with it, this makes me feel surprised and happy about the flexibility of our family. Big issues were: eating problems, solid food has been a problem till he was 10 years old. Dealing with his behaviour, he showed difficult behaviour to compensate his small stature. Try to teach him how to handle annoying and excluding. Give him self-confidence.

But the last and most difficult part has been to teach him to take responsibility for his own life and health.

When he was 16 years old the paediatric nephrologist and I decided to train him to visit the doctor on his own because when he is 18 years old he has to visit the adult care unit. From that moment on he went inside the doctor's chamber and I stayed in the waiting room, only the last 5 minutes of his visit I joined them for an update on his situation. These were the strangest moments of my life. I, who has been responsible for the past 15 years, was now in the waiting room while my son was inside!!! These visits to his doctor were somehow fun for him but that was the only responsibility that he wanted to take. At home I tried to teach him how to take his medicines (dose and x times of the day) and what they were meant for but he was not interested. He wants to live his relaxed life, have fun with his friends and caring for nothing. Until that moment I have taken care for his medication and he wouldn't see the need to change this. My attempts to let him take the medication on his own failed in every way. Finally we visited a psychologist to discuss this problem but this doctor told me that he was too young to take this kind of responsibility. So he has had his transition to the adult care unit where they don't want to speak with the parents but only with the patient himself. I didn't have the chance to inform his new doctor about his compliance problems; he wouldn't let me enter the doctor's chamber. So I decided to make a phone call and explain my sorrows. The kidney function of my son was at that time between 15 and 20% and after some medical test his father decided to donate his kidney. Later we heard that also his doctor was very concerned about my son taking the risk of acute kidney dis-function due to taking his medication very badly. One year after his transplant he has had a mild acute rejection phase, possibly caused by poor compliance. After all I think that this has been the alarm bell he needed to face before he was convinced that medication helped him to stay in a good condition. From that time on he was more careful.

My advice for parents is to start to train them in taking responsibility for their own health from the age of 12 years old. Maybe we started too late with this procedure but on the other hand every child has his/her own character, for this issue: "it takes two to Tango!" When your child doesn't want to work on this subject, all your attempts are useless.

Four years after his transplant my son started a life of his own and moved to a city nearby. Although some starting problems occurred he is doing great!! In the beginning I had to get used to this new situation. Nowadays my function is more a coaching one instead of taking a 100% responsibility. We together discuss his health issues and what can be done, he takes the decision. Finally: our relationship is far better than in the past!! ☺