

About the Lovely Foolishness of Having a Child

By Dr. Beatrix Redemann, Board Member of IACFA (International Association of CF Adults)
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Oops, and there I was—pregnant. Actually it did not strike me quite that surprisingly. It had already dawned on me some time ago that having a child would not be a bad idea at all. I had been ambivalent to this issue for quite awhile, mostly due to the fact that I did not want to compromise my personal freedom, lifestyle, and professional education. My affliction with CF had not been a major factor in this calculation. I figured, if I could work crazy long days of 10-14 hours as a researcher and junior lecturer at medical school or as a general practitioner, I would also have stamina enough to get through a pregnancy.



However, beforehand I made sure that in case of difficulties gynecologists and lung specialists would be under the same roof in case teamwork was needed.

Besides health consideration I also thought some other issues through: My husband and I knowingly produced a healthy carrier of the CF gene, which is possibly putting a burden on our daughter's future when the time comes for her to do her own family planning. However, who can predict what the future holds for CF and how frightening the prospects are going to be 15 years from now with all the progress constantly being made in treatment. In addition, I think that Ainu will be able to handle her carrier status.

More important, in my opinion, is the fact that my daughter might lose me before she reaches adulthood, as one can never entirely predict the progression of an individual CF case. It may be too simple to argue that every day many children lose one or both parents through war, accidents and other mischief. These sort of deaths from injury are more or less unpredictable as opposed to the rather sure outcome of CF in which, statistically speaking, I have an increased chance of dying before the suggested average survival age for women in western countries. There might be people holding the opinion that my husband and I acted irresponsibly by taking this risk. However, from a current perspective, I should be able to survive long enough in relatively good shape to provide Ainu with a capable mother during her growing years.

I think in western high-tech societies currently it is much more of a fundamental decision for women to choose whether or not to have a child at all. There remains the fact that one has to compromise one's own ambitions to pass on one's own genes. This is all the more true when there is the possibility of the child being affected by CF. I am still in a moderate state of disease and able to work full time. However, I realize that my lungs will not improve over time and that more effort will be needed on my part to keep myself in good condition as I get older. Now, having a baby on top of a profession as well as CF makes me wonder how I am going to meet all my commitments according to my desires. One thing I have learned immediately, babies/children are extremely time and energy consuming. On the other hand, they reward a lot of the parents' energy by their mere existence and the joy involved in watching them and taking good care of them.

Of course, it might happen that from a certain point on I will not be able to work full time and also care for both Ainu and my CF and this may pose a financial risk. After I had thought all these issues through I came to the conclusion that I was confident and optimistic enough to go through with a pregnancy and take things as they came, one step at a time. I suppose, it is quite useful for any parent to prepare mentally for all eventualities, meaning to acknowledge the possibility of disaster, as so many things can go wrong from the minute on conception. Having said that, what happened in my case?

A month before I got pregnant I was extremely stressed out and exhausted. I had worked hard in 3 jobs and had seen a lot of patients suffering from bronchitis and flu. Then one of the worst episodes of congestion that I

have ever encountered started. At first I could not walk 5 m without getting into a coughing fit and bringing up a lot of sputum. This episode lasted all in all 8 weeks, as I did not recover as readily as usual, which made me suspect already that something more was going on than one of my usual infection exacerbations (flare-up). I could not afford sick leave and intuition told me it would be unwise to start aggressive i.v. treatment. I could get myself back on track by cutting my work hours, intensifying home treatment and physiotherapy (which I normally do not do at all, if I am honest), and getting rid of my nasal polyposis (under local anesthesia). During that episode I found about my pregnancy. After that I simply felt great and quite energetic.

I had no problems whatsoever with the pregnancy or with my lungs (I am “progressing sufficiently”). All check-ups showed the baby and me in good shape. I decided to continue working until 4 weeks before the calculated birth date, which I almost succeeded in doing. Four weeks before my maternity leave was to begin I encountered another episode of congestion. The baby was already pressing on my lungs and stomach. I had to change my eating habits, eating a lot of small portions, if I did not want to cough my food back up. For safety reasons I decided to be admitted for pulmonary care.

At that point I was extremely low in spirits, as I realized the progression of my condition and in addition had to face a colleague who had no experience with CF care whatsoever. She was nice and we were able to work out the situation. However, I am considering consulting the pediatricians next time I need hospital care here in Finland, a country where they see maybe 9 cases of CF per year. The rest of the time went quite well. I was able to go back to work for the last weeks before maternity leave. Then my baby decided 3.5 weeks prior to the calculated date that she had had enough of staying inside and introduced herself into the world as a healthy and vigilant girl of 49 cm and 2710g.

The birth as such was much easier than I had imagined, although I would not repeat it for the fun of it. I took advantage of epidural anesthesia as the opening labour took unnervingly long. Anesthesia helped me to save strength for the final period (press labour), which took only 12 minutes. Interestingly, I had no respiratory trouble during the birth process at all. Afterwards I was quite exhausted for the next 4 weeks. During that period it was of enormous help that my husband was around as he had still most of his summer vacation left. With regard to my pulmonary condition I felt great the minute the baby was out. Since then my situation has returned to normal and is fortunately not affected by sleep deprivation. I discovered that feeding a baby every 2 hours during the night is worse than being on duty at hospital, but meanwhile she lets me sleep 5-7 hours/night, which is pleasant enough.

For now I am just curious to find out how everything is going to work out within the next few months, as I plan to start working weekend shifts in the spring and return to work full-time in the summer.

In summary, these are steps I took that helped me as I progressed from the decision to go ahead with the pregnancy through the process of giving birth:

- be sure of wanting a child even if it means sacrifices
- organize medical care with close screening of my CF and the ongoing pregnancy in the same clinic
- prepare mentally for the birth procedure and possible post-partum depression
- take care of financial/insurance issues and understand maternity leave regulations (one has to know what one is getting into)
- have a person around the first 2-4 weeks after giving birth
- minimize chest infection/exacerbation risk throughout the time of pregnancy and afterwards (in my case cephalosporine prophylaxis and regular inhalation of bronchodilators like salbutamol and ipratropiumbromide).

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