

Day-to-Day

Thinking About Having Children?



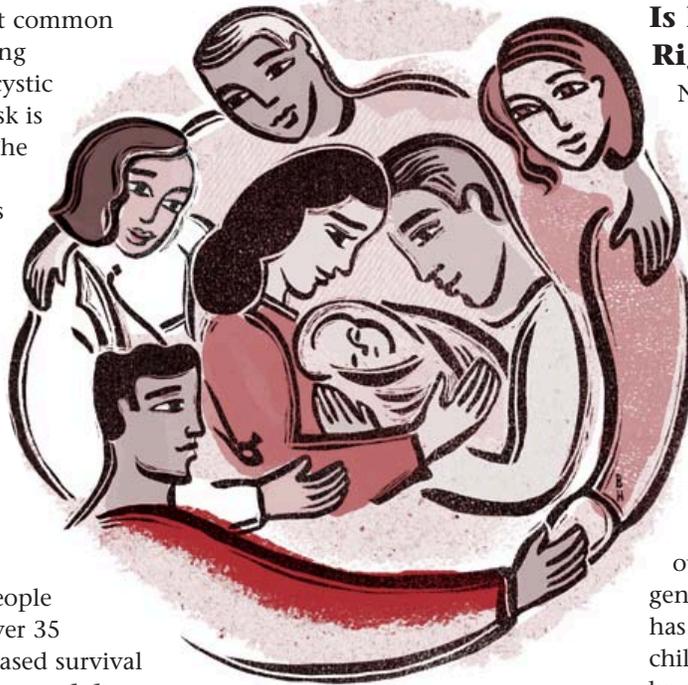
One of the most common questions young women with cystic fibrosis (CF) ask is "Can I have children?" The simple answer is "yes", though it has taken years of improved treatment and careful studies to change people's minds about CF and pregnancy.

Improved CF Treatment

Over the last 35 years, improved treatment has led to:

- Expected survival in people with CF has risen to over 35 years of age. This increased survival means that there are **more adults with CF**. Today, over 40% of all people with CF in the U.S. are older than 18. In the next 10 years, there may be more adults with CF than children with CF.
- **Better health** for people with CF in their 20s and 30s
- **New options for choices**, like whether or not to have children

It has long been known that women with CF can get pregnant. The first reports of women with CF getting pregnant appeared in medical journals in the 1960s. The concern, though, was that pregnancy would lead to bad health effects on the mother and baby. In 1980, an article in the medical journal *Lancet* advised women with CF to avoid pregnancy.



But between 1980 and 2000, *many* women with CF got pregnant!

- In 2000, an article in the medical journal *Chest* reported 92 pregnancies to women with CF in Canada.
- In 2002, an article in the *British Journal of Obstetrics* reported 72 pregnancies in CF in the United Kingdom.

It was a little harder for women with CF to get pregnant. But if the mother's health was good to begin with, things often went well for the mother and baby during pregnancy. These articles found that **women with CF with good lung function and nutrition status could get pregnant and have a healthy baby**.

Is Having Children Right For Me?

Now, the question is not "Can I have children?" but "**Is having children right for me?**" Many things may help you decide:

"Will my child have CF?"

The answer depends more on the father of the child than on you. A child must have two CF genes to have CF. A child gets one gene from the mother and one from the father. A mother with CF will give one CF gene to her child, so you must find out if the child might also get a CF gene from the father. If yes, the child has a chance of having CF. If no, the child will only have one CF gene and be considered a carrier of CF, which usually does not affect health.

Test the father to find out if he is a carrier before getting pregnant!

Lab. tests on blood samples are very good at finding CF genes (though none are perfect).

- If the father is tested using one of these very good tests and found *not* to carry a CF gene, a child's chances of having CF are one in several thousand.
- A child's chances of having CF are 50% if the mother has CF and the father is found to carry a CF gene (about 4% of people are carriers)!

This is why it is vital to test the father **before** getting pregnant. To learn more, ask your CF caregiver or genetic counselor about screening for CF.

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"Is my health good enough for pregnancy?"

Women should have had many months of good health before getting pregnant. Many things affect how well pregnancy is handled. CF affects pregnancy, and pregnancy affects CF.

- The first is **lung function**. You should have an FEV¹ of more than 70% of predicted, though women with an FEV¹ of 50–70% of predicted can still do well. Women with even lower FEV¹ values might do well, but their risk of problems is higher. The state of your lung function is the most important factor that affects both your health and the baby's after delivery. You and your CF caregiver should discuss your CF management before you become pregnant.
- Your **nutrition status** should be good enough to support both you and the baby while pregnant, even if you end up having bad morning sickness and poor appetite. This means having a BMI of 20 kg/m². In general, you should gain a minimum of 20 pounds during the pregnancy. It is also best if you do not have diabetes, since this will raise your risk of problems.
- It is best if you are followed by a high risk obstetrics group who has close communication with your CF team, to minimize problems.

Infection with *Burkholderia cepacia* may lead to more problems during pregnancy.

"What do I expect of my health in the future?"

The factors listed can help you decide how well you might handle being pregnant. But **there is so**



much more to being a parent than just getting through pregnancy and birth! In many ways, the work of being a parent doesn't begin until **after** the child arrives. You must look at your health and decide how well and how long you will be able to care for and parent a child.

To help you decide, talk openly with your CF caregiver. Since pregnancy, and particularly delivery, can complicate your CF, discuss your lung and nutritional health with both your CF team and your obstetrician.

"Will I have lots of help from family and friends?"

You will need time to focus on your health after a child is born. You will need to have help in place for both you and your child **before** your child is born. Women thinking about getting pregnant must talk with their spouse and family first. Then *all* can commit to doing what's needed for you and your child's health.

"How much do I want to have a child?"

Many personal things can affect your choice to have a child. For some, adopting children is the way to balance health and the desire for children.

Ask the Right Question

The question is not "Can I have children?" but "**Is having children right for me?**" Talk openly with your CF caregiver about your health and your future goals. Then you can plan and make the right decision for you!

References

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