As a teenager, you probably have many questions about your sexuality and about how cystic fibrosis (CF) might affect your sexual health. Like many teenagers, these kinds of questions are common:

“Am I changing more slowly than my friends?”

“When will I have my first period?”

“When will I start to fill out?”

“Why am I still not very tall?”

“Why don’t I have signs of a beard yet?”

“Why hasn’t my voice changed?”
Sometimes, you might feel that you are not developing as quickly as your friends. Try to remember that people grow at their own pace. Look around and you will find others your age who do not have cystic fibrosis who have not yet started to develop. The fact remains that puberty begins about 18 months later than the average for individuals with cystic fibrosis. It is not unusual for development to start as late as 15 to 17 years of age for girls, and even later for boys. You can help your development by making sure you are getting enough calories and nutrients — this may require eating a lot more than your friends who do not have cystic fibrosis.

When should I tell my partner that I have cystic fibrosis?

Only you can decide when to tell someone that you have cystic fibrosis; there is no right or wrong time. You may not be comfortable confiding in someone right away, but as the relationship develops, so will opportunities to share your situation. Many people living with cystic fibrosis find lasting, committed relationships. If you are unsure about how to approach the subject with a loved one or partner, speak with your healthcare professional.

How will cystic fibrosis affect my sexual health?

When you feel ready to move into a sexual relationship, you should do your best to make informed choices. Only you can decide when to become sexually active. For the most part, cystic fibrosis will not affect your sexual desire or performance. When you decide the time is right, there is no reason why you cannot enjoy a satisfying sex life with your partner.

Because it affects all secretory glands, cystic fibrosis will influence your sexuality in some respects. You may have noticed that you cough more when exercising. Sexual activity is physical, so you may also cough more when in a sexual situation. You can reassure your partner before it happens that you are okay, you may just need a little break.

Pain may be another issue. Some people with cystic fibrosis experience chest pain, abdominal pain, joint pain or headaches. When you are in pain, you might not feel like having sex. Some positions may be uncomfortable. You will have to try things out to see what feels comfortable. Many people have noted that orgasms reduce their pain, so having sex or masturbation may help relieve pain. When you are not feeling well, you might feel more tired, and your sexual energy might be low. Taking care of your body, exercising and eating well can enhance your sexuality.
Many girls are prone to vaginal yeast infections, regardless of whether they have cystic fibrosis. The symptoms include discomfort, a burning sensation while urinating, uncontrollable itchiness and thick vaginal discharge. These symptoms may be especially strong during and immediately following menstruation.

Women with cystic fibrosis, may be particularly vulnerable to these infections if antibiotics are taken frequently. Symptoms may be more severe when taking extra antibiotics. A prescribed vaginal cream is the best way to get comfort and relief. If the problem is frequent, a change of antibiotics may help but you should talk to your doctor.

If you decide to become sexually active, your partner may find the high salt content of your body provokes vaginal irritations, making intercourse uncomfortable. Using a sterile lubricant may help. A physician or gynaecologist should be able to recommend an appropriate product for you or your partner.

When you become sexually active you should be careful to prevent sexually transmitted infections. Condoms provide excellent protection against sexually transmitted infections such as HIV, chlamydia, syphilis, gonorrhea and others. Remember, the pill does not protect against sexually transmitted infections so always use condoms for intercourse, and practice “safer sex” to prevent the spread of sexually transmitted infections. You are responsible for your body, and you should ensure that both you and your partner are protected.
Both women and men with cystic fibrosis must use contraceptives to avoid an unplanned pregnancy. Even if you have a physical examination, no one can say for sure whether you are fertile or not. A wide variety of contraceptives are available. You and your doctor should decide on the method that is most appropriate for you. Condoms provide fairly good protection against pregnancy, especially if used with a spermicide like contraceptive foam, gel or film. If you are allergic to latex, you can use polyurethane (or the newer polyisoprene) condoms, which are more expensive, but do not contain latex.

For girls with cystic fibrosis, the birth control pill is an excellent means of preventing pregnancy. Your physician can prescribe the pill and advise you of possible side effects. The pill must be taken regularly, so do not forget to take it when staying in a hospital. Other options include the birth control patch, vaginal ring, or the progesterone intrauterine device (IUD).

If you take enzymes regularly and you have no severe diarrhea, constipation, nausea or vomiting, the pill will be absorbed and effective. If you do not take your enzymes regularly or have any of the above-mentioned problems, you might consider the birth control patch or the vaginal ring. Both of these contain the same hormones as the pill. The birth control shot (Depo-Provera) is not recommended for girls with cystic fibrosis because it has been associated with bone density problems. However, the progesterone IUD can be used.

Certain antibiotics can make the pill less effective. Therefore, your CF physician needs to know if you are using the pill. Fortunately, most antibiotics used routinely in treating cystic fibrosis do not interfere with the pill. To be absolutely sure, ask your doctor. If, at some point, you need antibiotics that reduce the effectiveness of the pill, you may need to rely on a different combination of contraceptives.
Will cystic fibrosis affect my ability to have children?

Although you have cystic fibrosis, you probably have higher than a 50 percent chance of being fertile. It will be difficult for you to have a regular menstrual cycle if you are undernourished and do not have a minimum amount of body fat. However, even if your periods are irregular, or you haven’t yet begun menstruating, it’s still possible for you to become pregnant.

When you decide to have a child, your doctor can tell you more about the implications of pregnancy for women with cystic fibrosis. Men with cystic fibrosis can have perfectly normal sexual relations, but in almost all cases, no sperm are ejaculated with the semen during intercourse. You do produce sperm, but the vas deferens tubes, which carry sperm from the testicles, may be blocked or absent — making the passage of sperm impossible. Thanks to reproductive technologies, some men with cystic fibrosis can father children by procedures such as microepididymal sperm aspiration (MESA) or testicular sperm extraction (TESE).

“Although you have cystic fibrosis, you probably have higher than a 50 percent chance of being fertile.”

Talk to a member of your healthcare team if you would like to know if you are fertile. Under no circumstances should you assume you cannot get someone pregnant. A small percentage of men with cystic fibrosis have normal vas deferens. When you start thinking about having a family, talk to your doctor and health care team. A genetic counsellor can also help determine your options for family planning.
How can I connect with other Canadians with cystic fibrosis?

Join the My CF Canada Network, Canada’s first-ever social network designed by CF patients specifically for CF patients to connect and share important information about living with this severe and potentially fatal genetic disease. Canadians with cystic fibrosis can discuss the treatments, programs and services available in their province/region, via video chat and instant message, share stories and personal issues, and receive support for advocacy and fundraising initiatives from a much broader community.

Cystic Fibrosis Canada acknowledges Novartis Pharmaceuticals Canada Inc. for the collaboration that has made the My CF Canada Network possible.

Sign-up today at www.mycfnetwork.com

For more information, visit www.cysticfibrosis.ca

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