

Sexuality, Fertility and Cystic Fibrosis: Information for Adults



...adding tomorrows every day.





Introduction

Sex is a delicate subject that is often difficult to broach, especially with your healthcare team. You probably have some questions about sex, which you may have already discussed with a specialist. Some of your questions may, however, remain unanswered.

This brochure was prepared for adults with cystic fibrosis (CF) who are interested in learning more about certain matters regarding sex. We assumed that if a few people raised the issue, a larger number probably had several questions that needed to be addressed.

This brochure will deal with:

- fertility and the reproductive system
- practical advice about sex
- contraception and STDs
- fungal vaginitis
- stress incontinence

Happy reading!



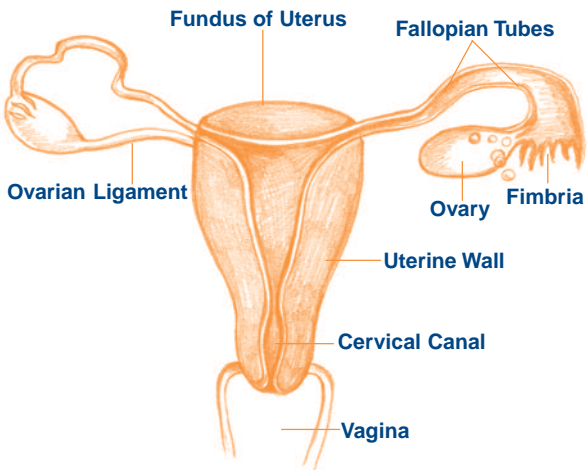
Fertility and the reproductive system

In both men and women, the reproductive system is regulated by sex hormones (progesterone, estrogen, testosterone). It is important to specify that the level of hormones in individuals with CF is entirely normal. Consequently, adults with cystic fibrosis can enjoy a perfectly normal sex life. Since cystic fibrosis can affect mucus viscosity, fertility may, however, be compromised.

IN WOMEN

The fluidity of mucus varies in women. Vaginal mucus is often thicker, making it more difficult for the sperm to travel and for fertilization to take place.

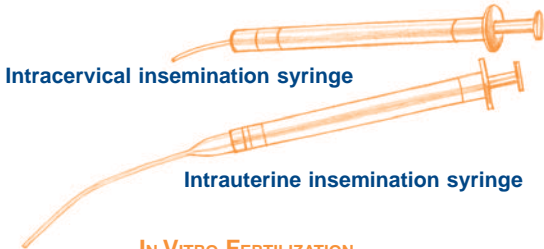
It may take longer for women with cystic fibrosis to become pregnant, although this in no way affects the pregnancy itself or the fetus (85% of couples conceive within the first 12 months after stopping contraception).



It is sometimes necessary to consult a fertility expert if you seem unable to conceive. A variety of tests are performed to determine the causes of infertility. Depending on the case, some of the following options may be available to you.

INSEMINATION

Insemination is a procedure that consists of inserting the sperm into the cervix (intracervical insemination) or directly into the uterus (intrauterine insemination). This technique is used when vaginal or cervical mucus is too thick and prevents the sperm from reaching the fallopian tubes. This technique may or may not be used in combination with ovarian stimulation.



IN VITRO FERTILIZATION

Stimulation of the ovaries

Stimulation of the ovaries is one of the steps of in vitro fertilization. It consists of taking medication (hormones) to stimulate egg production. Ultrasound and blood tests are used to assess the maturity of the eggs. Once mature, they are ready to be retrieved.

Egg collection

To collect the mature eggs, a needle under ultrasound guidance is passed through the vagina into each ovary. The procedure is performed under local anesthesia. The male partner will be asked to produce a sperm sample on

the same day and fertilization will take place in the laboratory. This procedure will produce what is called an embryo.

Embryo transfer

Embryos are usually transferred 48 hours after egg collection. This painless procedure is performed through normal channels. A maximum of three embryos are usually transferred to the uterus. Once this step is completed, medication is usually taken for a period of fifteen days to increase the chances of implantation in the uterus. A pregnancy test is then performed.

*If you want to have children and are planning to get pregnant, talk to your doctor and healthcare team. They will be able to properly advise you. It is important to know that pregnancy as such is not dangerous provided the woman's condition is stable), but requires more rigorous follow-up. Special attention will be placed on lung function, because a decrease in lung function is often observed during pregnancy. Usually, it returns to normal in the months following delivery. It may be recommended that your partner be tested for the gene responsible for CF.

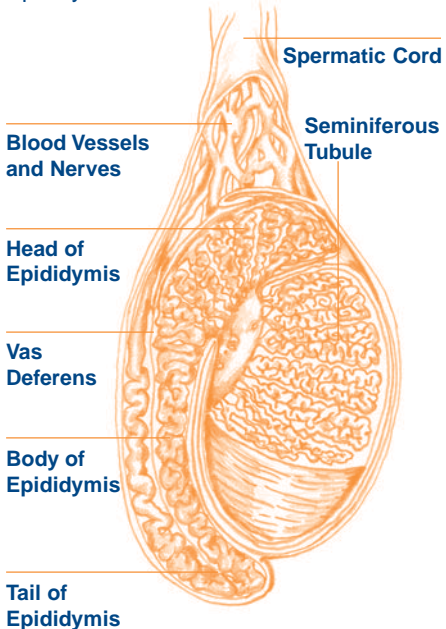
You should also be aware that, if you become pregnant, you should stop taking certain medications. This is why it is important to discuss a planned pregnancy with your doctor. He or she may choose to change your medication. You should also be aware that the first trimester of pregnancy is a critical phase in the development of the fetus. Certain drugs will directly affect fetal development and must be avoided (especially certain antibiotics and natural products whose effects on the fetus have yet to be tested). Several medications, however, pose no risk to the fetus and may be taken throughout pregnancy. This includes vitamins, enzymes and insulin for diabetics. Your doctor and pharmacist are important resource people. Don't hesitate to ask for information if you have any questions.

*If you don't want to have children, you must use contraception. The various methods of contraception are discussed later on in this brochure.

IN MEN

In most cases, men with cystic fibrosis are infertile. It is important to distinguish between sterility (absence of spermatozoa) and infertility. In the case of cystic fibrosis, spermatogenesis is intact, resulting in normal sperm production. The problem occurs in the testicle, where a blockage or absence of the vas deferens may make the passage of sperm impossible. This does not necessarily mean that you are infertile. If you want to know for sure, talk to your doctor about it. He or she will have you undergo a test in which you will be asked to produce a sperm sample. The sperm will be counted and you will be notified of the results within a few days.

Thanks to reproductive technologies, it is possible to extract sperm using either a procedure called microepididymal sperm aspiration (MESA), or testicular sperm extraction (TESE) or percutaneous epididymal sperm aspiration (PESA).



These techniques are appropriate in cases of infertility related to CF because they make it possible for sperm to be extracted directly from the epididymis (fine tubules behind the testis). The technique involves an operation, generally done under local anesthesia, in which the sperm are collected. Once collected, the sperm are not quite motile enough for insemination, as described earlier, but can be used for in vitro fertilization or intracytoplasmic sperm injection (ICSI).

ICSI is another method of assisted conception. In the laboratory, a single sperm is injected directly into the egg. This technique is used when sperm are not sufficiently motile, as is the case in men with cystic fibrosis.

As previously mentioned, sexual function in men with cystic fibrosis is normal and they are perfectly able to have normal sexual relations. The ability to have an erection and to ejaculate is unaffected. It has been observed that men with cystic fibrosis produce less ejaculate, or none at all, and that the semen is clearer than normal, possibly even transparent. For more information on the subject, talk to a member of your healthcare team.

In short, sexual function is normal in both men and women with cystic fibrosis, although the ability to reproduce may be affected.

If an individual with CF wishes to have a child, it is important to know that the child will carry the gene responsible for CF. Your doctor may recommend that your partner be tested to determine whether he or she is a carrier of the gene responsible for CF, which would help predict whether children will be carriers, or at risk of having CF. Meeting with a genetic counselor may be helpful when deciding whether or not to have a family.

Some practical advice

Sex is an essential part of our lives, regardless of our age, sex, health or physical ability. Cystic fibrosis in no way diminishes sexual desire or the need to be intimate with our partner. Moreover, sex is a wonderful source of relaxation, pleasure and fulfillment. Sex also helps satisfy different needs. Some individuals with CF, especially those whose lungs are more seriously affected, worry about shortness of breath or hemoptysis (the expectoration of blood or blood-stained sputum). Under the circumstances, wouldn't abstinence be the best solution? Absolutely not!

Did you know that when you walk or climb stairs, your heart rate can go as high as 107 to 130 beats per minute? During sex, the average heart rate is 117 beats per minute. If you feel fine after climbing two flights of stairs or doing a comparable activity, you are physically fit enough to have sex without worrying about shortness of breath.



The following practical advice, given the right ambiance — music, dinner, clothes and candlelight — will help you fully enjoy your sex life.

- **Be creative.** Don't limit yourself to sexual intercourse. Take your time. Foreplay (ambiance, touching, massage) are equally as important.
- **Avoid anything that may aggravate your symptoms,** such as perfumes, cigarettes and other strong-smelling products.
- As with all physical exercise, **use your short-acting bronchodilator** (Ventolin™, Brycanyl™, Berotec™ . . .) 20 to 30 minutes before having sex.

A FEW POSSIBLE POSITIONS FOR WOMEN WITH CF



- Ideally, do your **physiotherapy exercises to dislodge mucus prior to having sex.**
- **Adopt positions that require less energy and that do not put pressure on your chest.** Use pillows to support your back. If necessary, let your partner play a more active role.
- **Stimulants such as amphetamines can be dangerous.** Marijuana increases your heart rate and the need for oxygen, which can lead to shortness of breath. It is up to you to make the best choice!

A FEW POSSIBLE POSITIONS FOR MEN WITH CF



Contraception and sexually transmitted diseases (STDs)

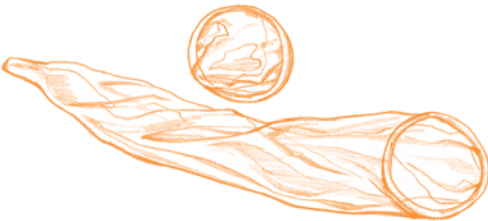
Although men with cystic fibrosis are infertile in most cases, they are not immune from STDs. Women must use contraceptives if they do not wish to become pregnant and they must have protected sex since they are also at risk for contracting STDs.

When choosing a method of birth control, you should consider its effectiveness and how well it is suited to your lifestyle.

THE CONDOM

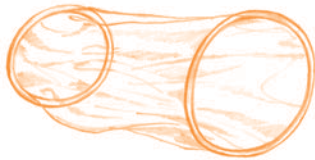
The condom provides both protection from STDs and contraception. When used correctly, the success rate of the condom for birth control is 95%. When used as protection from STDs, the condom is successful almost 100% of the time.

Moreover, it is inexpensive. The condom's one minor drawback is that it may diminish sensitivity. For added pleasure, apply a drop of water-soluble lubricant (e.g. KY jelly™) to the tip of the penis before rolling on the condom. Be watchful of allergies to latex, spermicidal products or lubricants. If you experience any burning or itching with condoms, try changing brands.



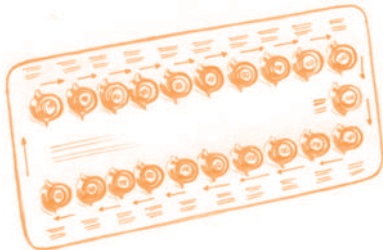
THE FEMALE CONDOM

The female condom is an alternative to the traditional male condom. It offers the same type of protection, but is more costly. It is made of two rings: the first is inserted into the vagina, while the second covers the outer labia. It is less visually appealing than the male condom, but it apparently offers greater pleasure for men than the traditional condom. Since it is made of polyurethane, a flexible plastic, the female condom is suitable for people who are allergic to latex. The success rate of the female condom is 97%.



THE PILL

The birth control pill is an excellent choice for women with cystic fibrosis. *(Most insurance companies will reimburse the cost of oral contraceptives.)* The pill does not offer any protection against STDs. The pill may produce such side effects as headache, heartburn and weight gain. As well, its effectiveness may be decreased when certain antibiotics are taken. Its success rate, when used properly, is 99.5%.



CONTRACEPTIVE INJECTIONS

The use of contraceptive injections like Depo-Provera™ involves an intramuscular injection every three months. It is NOT recommended for women with cystic fibrosis because it increases the risk of osteoporosis, a condition to which cystic fibrosis patients are already predisposed. Women who use Depo-Provera™ do not menstruate. The main side effect, other than the risk of osteoporosis, is weight gain and occasional spotting in the first year of use. Its success rate is 99.7%.

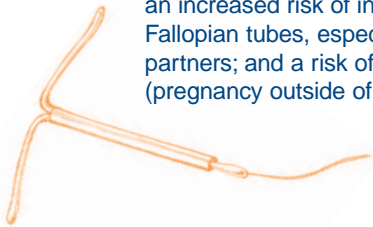


THE PATCH

The patch is an excellent choice for women with cystic fibrosis. The patch is a once-a-week birth control option that is as effective and works on the same principles as the pill. Like the pill it does not offer protection against STDs, and its effectiveness may be decreased when certain antibiotics are taken. However, it has a better compliance rate than the pill, as it only has to be replaced once per week.

THE INTRAUTERINE DEVICE (IUD)

The IUD is a device that is inserted into the uterus by your gynecologist or family doctor. The procedure takes only ten minutes. The IUD is a highly effective means of birth control (99% effective the first year, 98% the second year, 97% the third year, and so on). It can remain inside the uterus for several years. You may experience the following problems: heavier and more painful periods; a risk of spotting or bleeding between periods; an increased risk of infection of the Fallopian tubes, especially with multiple partners; and a risk of ectopic pregnancy (pregnancy outside of the uterus).



THE DIAPHRAGM

The diaphragm is an effective birth control device, but offers no protection against STDs. It is a less popular means of contraception and is not as easy to use as some others. It is recommended that the diaphragm be used in combination with a spermicidal cream or jelly. With perfect use, its success rate is 94%.



NO METHOD

Leaving pregnancy entirely up to chance without birth control is only 15% effective. This method is not consistent with a planned pregnancy. Similarly, use of the withdrawal method, where the male withdraws the penis just before ejaculation, is only 20% successful.

Fungal vaginitis

Fungal vaginitis is an infection caused by *Candida albicans*. This microorganism is normally found in the mouth, the throat, the large intestine and the vagina. It generally grows in warm, moist regions, especially skinfolds and mucus. (*Men are not immune from Candida infections.*) Women with cystic fibrosis are very likely to suffer from fungal vaginitis because of daily doses of antibiotics and corticosteroids (Prednisone™). Certain antibiotics, such as penicillin (e.g. Amoxil™, Cloxacillin™), cephalosporins and tetracyclines, are known to disrupt the vagina's normal acidity and bacterial flora.

The following are signs and symptoms of fungal vaginitis:


- itching
- irritation, discomfort
- pain during intercourse
- pain during urination

**These symptoms are more severe prior to menstruation and are more difficult to treat during pregnancy.*

In men, the symptoms manifest as follows:

- lesions on or irritation of the penis
- itching

**Men may occasionally present symptoms, while their partner has none.*



The conventional treatment for fungal vaginitis is the application of an anti-fungal cream or suppositories for a period of up to seven days. Sometimes, in the case of a serious infection that seems to be resistant to creams, various treatments in the form of oral capsules are required for a longer period of time.

Several healthcare facilities recommend eating yogurt that contains live bacterial cultures when taking antibiotics. It is believed that ingesting these bacteria will enable the body to reestablish its bacterial flora, thereby preventing further infection. Although these data have not been proven scientifically, there's no harm in trying. Since yogurt is an excellent source of calcium, if it doesn't help reestablish your bacterial flora, it will certainly help maintain a high level of calcium in your bones.

Patients who experience fungal vaginitis should schedule an annual examination with a gynecologist or family practitioner. Although no symptoms may be present in cases of chronic infections, treatment is required. It is therefore very important to undergo an annual examination. A visit to your doctor is also a good opportunity to discuss methods of contraception and safe practices, have a PAP test to screen for cervical and uterine cancer, and have a breast examination. Women with CF are not at increased risk for developing cervical or uterine cancer.

Stress incontinence

Another problem that is often experienced by women with cystic fibrosis is stress incontinence.

This type of incontinence is defined as an involuntary discharge of urine when there is no anatomic displacement. It is caused by a sudden increase in abdominal pressure as a result of coughing, for example.


Fortunately, there are a number of exercises, such as Kegel exercises, that can help control this type of incontinence.

Kegel exercises help firm up the perineal muscles, more particularly the pubococcygeal muscle, and increase their elasticity.

To feel this group of muscles, stop urinating in midstream. It is not recommended to practice the exercises described below during urination, as this will increase the risk of urinary infection.

The first Kegel exercise consists in contracting the pubococcygeal muscle for three seconds, relaxing for three seconds, contracting it again, and so on. It may be too difficult to maintain the contraction for three seconds at first. If so, hold it for two seconds to increase the strength of the muscle.

The second exercise is similar to the first, except that the objective is to contract and relax as quickly as possible. This exercise is difficult to perform, especially at first. Don't get discouraged. You will improve with practice and will be able to do the exercises more quickly.



A third exercise inspired by Kegel consists in imagining that the pubococcygeal muscle is an elevator. When the muscle is relaxed, the elevator is at ground level. The exercise involves producing a contraction that will bring the elevator to the first floor, then the second, then the third. Hold the contraction for a few seconds and then gradually release.

All these exercises must be repeated ten times, three times a day. Try them in your car, when you're waiting at a red light or while you're brushing your teeth. Be careful not to contract your gluteal or quad muscles. You want to be sure to work the right muscle group.

When done regularly, Kegel exercises can help control stress incontinence. There is only one side effect: several women have reported increased pleasure during sex after doing the exercises for six weeks; not unpleasant, as side effects go!

In order to live a truly fulfilling life, it is important to communicate. Sex between two people who love each other can be one of the most beautiful forms of expression.

Take the time to savor every moment. You'll find it really pays off.

American and Canadian Cystic Fibrosis Foundations

The American Cystic Fibrosis Foundation is a national, voluntary health organization formed in 1955 whose mission is to assure the development of the means to cure and control cystic fibrosis and to improve the quality of life for those with the disease.

The Canadian Cystic Fibrosis Foundation is a national, voluntary health charity incorporated in 1960. Its mandate is to help those with cystic fibrosis by funding research into improved care and treatment with the goal of finding a cure or effective control for CF.

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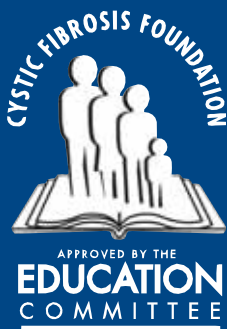
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