

# what they don't tell you

**A young person's guide  
to sexual and reproductive  
health issues in Cystic Fibrosis**

What they don't tell you:

A young person's guide to sexual and reproductive health issues in Cystic Fibrosis.

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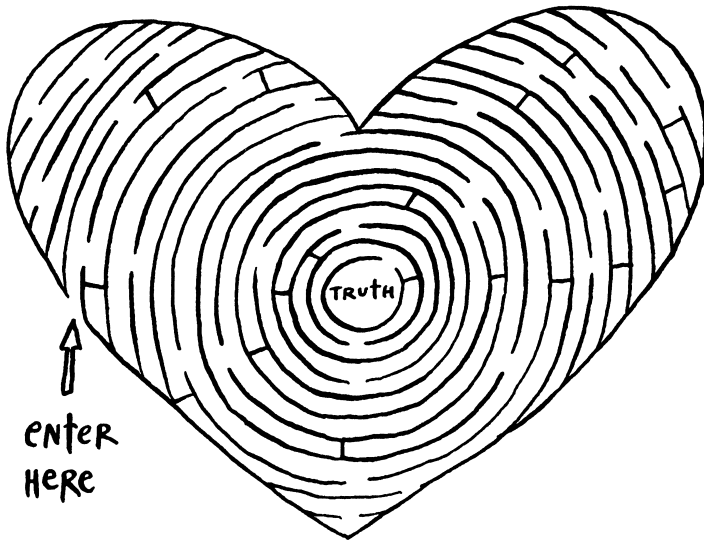
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# what they don't tell you

A young person's guide  
to sexual and reproductive  
health issues in Cystic Fibrosis

This book has been written for young people with Cystic Fibrosis. Your parents, friends and family will probably be interested in reading it too.

Most people find that becoming a young adult involves lots of changes. You might be experiencing a lot more opportunities, but also a lot more uncertainty.

As a young person with Cystic Fibrosis (CF) you might feel that you sometimes have double the troubles. CF can certainly complicate matters. Having CF means that staying well and staying in charge of your life can be hard work – hard work that needs to happen daily. Nobody can do it for you, and we all know it's not much fun.

Even though your life seems complicated enough as it is, it's important to find out about your sexual and reproductive health. Although it may feel like you are surrounded by doctors, you still need to see a general practitioner (GP) or family doctor who will take care of your routine sexual and reproductive health. If you don't have a GP, your CF doctor can help you find one.

Lots of people find it embarrassing to talk about sexual health issues. That's normal. But ignoring your sexual health can have serious consequences.

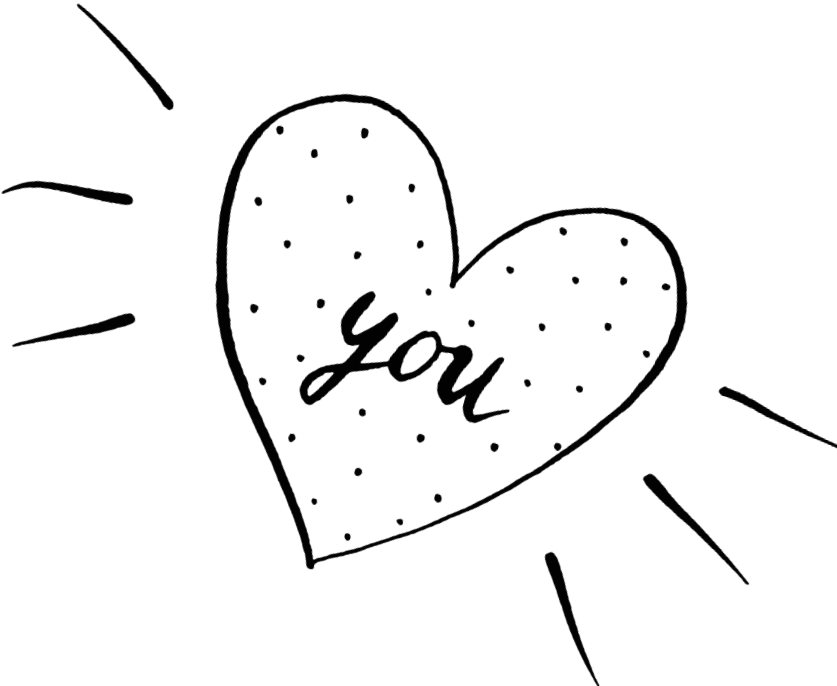
***Talking about and taking care of your sexual and reproductive health now can prevent problems in the future.***

As with other areas of CF care, our knowledge about the impact of CF on sexual and reproductive health is being updated all the time. It's important to stay on top of the latest.

We've written this booklet so that young people with CF can read about the basics and find out where to get more information if you want to.

This booklet includes info about:

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# YOUR GROWTH AND DEVELOPMENT

Despite the dramatic improvements in treatment in recent years, young people with CF still commonly have reduced height and weight compared to people without CF. This can delay the onset of puberty (sexual growth and development).

Good nutrition helps young people to reach their full potential, both in terms of growth and puberty. Your growth spurt in puberty greatly depends on your weight. If you have poor lung health, you may find it hard to gain enough weight to kick-start puberty.

The poorer your lung function and the skinnier you are in adolescence, the more likely it is that your growth and puberty will be delayed.

***Many young people with CF find that their pubertal development is delayed by up to two years.***



If you are a young woman with CF, you might find that the onset of your periods (menarche) is delayed by up to two years. If your lung function is pretty normal, your periods should not be delayed. (The average age of menarche for young women without CF is 12.) Aside from the delayed onset, your periods are expected to be normal as you get older.

The good news is that CF does not affect your hormonal function. The level of sex hormones (progesterone and estrogen in women and testosterone in men) is normal in women and men with CF. Your fertility may be affected (*see the Fertility section of this booklet*), but your sexual functioning will be normal. Men and women with CF can expect a normal sex life.

### **Puberty and your skeletal growth**

Significant delay of growth or sexual development (puberty) needs to be sorted out. Poor growth and delayed puberty are concerning because if your puberty is delayed, so is your production of sex hormones (estrogen and testosterone), which are important in promoting normal growth of your bones.

If you don't have normal growth and development during the teenage years, your bone mineral density may be reduced (called 'osteopenia') or very reduced (called 'osteoporosis'). If you have osteopenia or osteoporosis you will be at greater risk of breaking your bones.

You gain about half your adult bony skeleton during your teenage years, so it is important that your skeletal growth is as good as it can be during this time. Regular physiotherapy (airway clearance), exercise and a good diet that includes lots of calcium-rich foods (like milk and other dairy products) are all important for your bones. If you haven't shown signs of puberty by the age of 14 (and if a girl's period hasn't started by the age of 14), you may require treatment.

Your height and weight will be measured at each clinic visit. There are also special X-rays (DEXA studies) that can measure bone mineral density. These involve only a little more radiation than a routine chest X-ray.



### **Kick-starting your growth**

If your growth is delayed, ask your CF doctor what can be done to speed it up. For some people, taking extra care of their lungs with regular physiotherapy will improve lung function enough so that their growth spurt starts.

For others, nutritional supplements can help them put on weight and get things started. Some people require a gastrostomy to deliver extra nutrition. A small percentage of people benefit from hormones to kick-start their growth spurt. Talk to your CF doctor if you are worried about your growth.

***You can encourage growth and sexual development by putting on weight.***

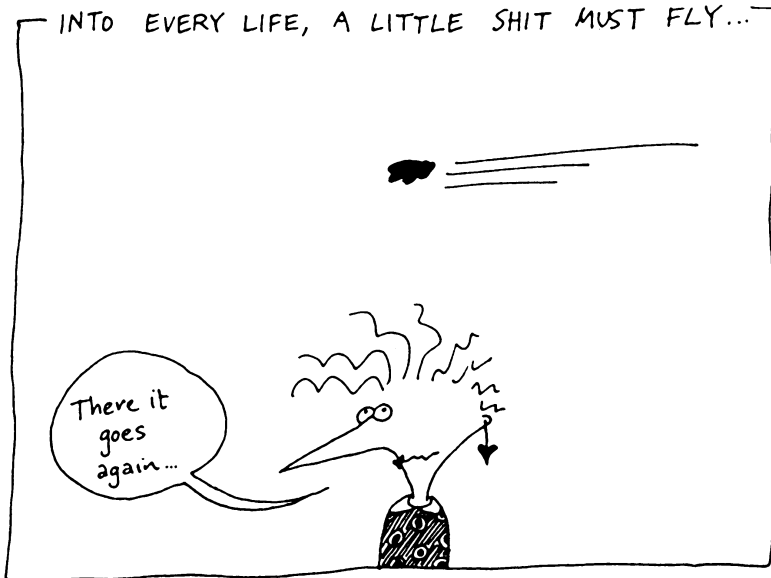


## You and your body image

Young people with reduced height and weight and/or delayed puberty can have a hard time. You may look younger than your friends. Worse, you may be treated as if you are younger than you actually are. Sometimes that's not easy to deal with.

What makes it harder is that there is a lot of pressure to conform to a particular body shape. The advertising industry trades on making you feel like you're not thin, fat, muscly, tall, short, curvy, straight, little, big or good enough. We can all waste a lot of valuable time and energy fretting over the appearance of our bodies and trying to make it look like it 'should'.

The important thing to remember is that your appearance is only one of a range of things that makes you who you are. Make friends with your body and treat it well. Work on your self-esteem. Think of all the good things your body lets you do. Try using your body to do a few fun things: try karate, belly dancing or rock-climbing. Admire how your body works and feels.



# SEXUAL HEALTH AND FUNCTION

## Male anatomy and CF

Men with CF produce sperm normally. The problem in most men with CF is that the vas deferens is blocked or absent. (The vas deferens is the duct or tube that leads sperm from where they are produced in the testes to where they are stored prior to ejaculation.) It is estimated that 98% of men with CF, regardless of the severity of their respiratory or gastro-intestinal disease, have a problem of poor development of the vas deferens. Men with CF are therefore a little like men who have had a vasectomy: sperm are produced normally but have nowhere to go because of the absence of the transport tube.

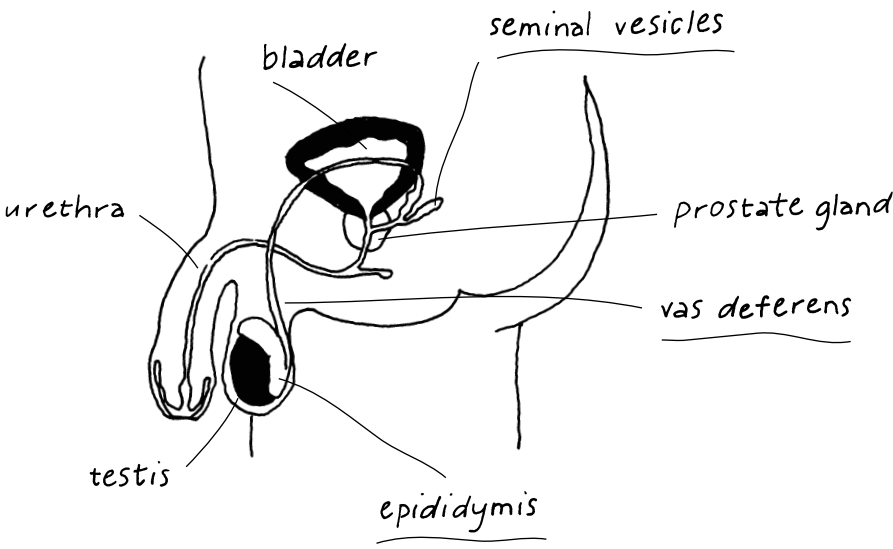
As well as sperm, semen also contains fluid that is made by the glands called seminal vesicles. These glands don't function normally (and are sometimes absent) in men with CF.

This means that men with CF often have a lower semen volume when they ejaculate – less than 1.5 mls (one third of a teaspoon) – in comparison to 3.5 mls (two thirds of a teaspoon) produced by men without CF.

The reduced semen also means that as a young man with CF, you might not experience nocturnal emissions (wet dreams). This is due to the abnormal or absent seminal vesicles.

The good news is that men with CF have normal hormonal function. Your testes produce testosterone (male hormone) normally. Testosterone is responsible for the production of male muscle bulk and sexual feelings and is absorbed directly into the blood – it doesn't need to rely on the defective transport tube. This means that your ability to have erections and sexual intercourse is not affected.

The underlined labels in the diagram below refer to those parts of the male reproductive tract that generally don't develop normally or are absent in men with CF.

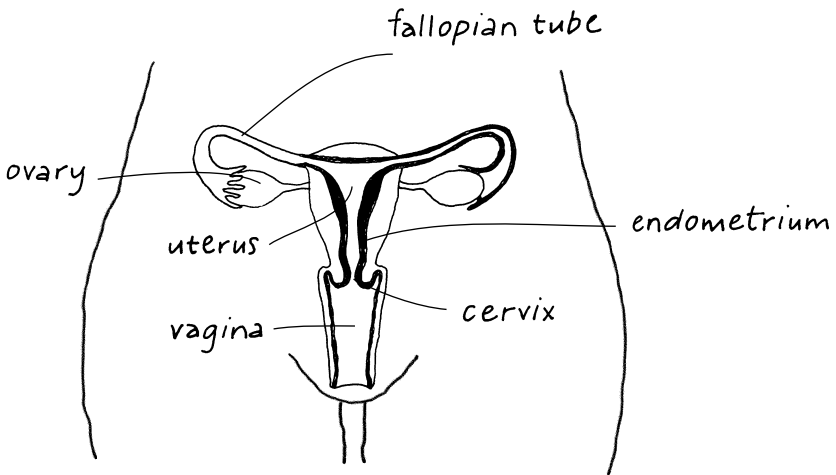


## Female anatomy and CF

In contrast to men with CF, women have anatomically normal reproductive tracts. The ovaries (that hold the 'ova' or 'eggs'), the fallopian tubes (that join the uterus to the ovaries) and the uterus (where the fertilised egg implants itself) are all expected to be normal.

The only reported abnormality in women with CF is that the cervical mucus (in and around your cervix) is thicker and more tenacious. This may reduce the ability of sperm to penetrate the cervix. In days gone by, people thought that women with CF would find it difficult to get pregnant because of this thicker cervical mucus; however, there is little evidence that getting pregnant is a problem for most women with CF.

The good news is that your hormonal function is normal. You produce female sex hormones (progesterone and estrogen normally); your periods are expected to be normal and your ability to have sexual intercourse is not affected.





### Having regular sexual health checks

It's important to have regular checks of your sexual and reproductive health, whether you're sexually active or not. For women this means breast checks and regular pap smears once you have become sexually active. For men this means testicular (testes) checks to identify any lumps. (Cancer of the testis is the most common cancer found in males aged 15 – 35 years of age.) Early diagnosis and treatment of irregularities is important.

*Your GP can show you how to do your own breast or testicular checks.*

### Pap smears

It is recommended that women have a pap smear (also called pap test) every two years once they become sexually active. A pap smear detects cervical irregularities. It's a simple, painless procedure – and an important one – although embarrassing the first few times. A GP or gynaecologist does this test. (*See the People to Talk to section.*)

## Thrush

Many women with CF who take antibiotics report high rates of a fungal or yeast infection of the vagina called candida albicans, fungal vaginitis or thrush. Women without CF who are on antibiotics or have poorly controlled diabetes report the same thing. Men can get fungal infections too, although less commonly than women.

Thrush can cause itching or redness, just plain old discomfort 'down below' or pain when you pass urine. It is caused by a yeast called candida albicans. This lives naturally in your bowel, but can get out of control in the moist parts of your body in certain conditions, particularly when antibiotics are changed.

This is because the antibiotics disrupt the normal balance in the bowel between bacterial and yeast organisms and allows for overgrowth of the yeasts.

You are most likely to get yeast infections after puberty and at times when you change antibiotics, such as during a hospital admission.

Thrush in both women and men is easily treated using antifungal creams or oral medications. If you get yeast infections when you use intravenous antibiotics, you can use antifungal medications during each hospitalisation to try to prevent it happening. Some people need to use these medications each time they change antibiotics.

If you suffer from very frequent infections you might need to use a different antifungal medication, or consider changing from oral to nebulised antibiotics.

A lot of people also use natural remedies to treat thrush. Always check with your CF doctor before taking anything that might conflict with your treatment.

## Urinary incontinence

People with CF often find they release small amounts of urine when they have coughing fits or laughing fits. This unexpected urinary leakage is called urinary incontinence or stress incontinence.

Urinary incontinence is very common in women with CF: about one in four women with CF (including teenagers) experience urinary incontinence regularly. Urinary incontinence can occur in men but is far less common.

All that coughing increases the pressure on the muscles that help to hold urine inside the bladder (the pelvic floor muscles). Some women who have had children also suffer from urinary incontinence because their pelvic floor muscles have been damaged during childbirth.

Wearing panty liners or sanitary napkins can help protect you from unexpected urinary leakage, especially when your chest is bad. However, if it occurs frequently, or you leak larger amounts of urine, the recommended treatment is to do pelvic floor exercises. There are specialist physiotherapists and nurses who can teach you how to do pelvic floor exercises effectively.

As embarrassing as it might feel, you need to report urinary incontinence – especially to your CF doctor or CF physiotherapist or nurse. If you leave it untreated, you might be reluctant to cough and clear your lungs, which may lead to more chest infections. This can happen quite subconsciously.

There are plenty of people you can talk to about this. Start by talking to your CF doctor, physiotherapist, nurse, or GP. *(See the People to Talk to section.)*

# RELATIONSHIPS AND SEX

## Your relationships – CF and you

Having close friends is important for all of us. Sometimes CF gets in the way of friendships and intimate relationships. CF makes huge demands on your time. Your medication, nebuliser pumps, physiotherapy and exercise can really eat into your day – let alone outpatient appointments and hospital stays. Staying overnight at someone's house can be a challenge. It can be hard to keep in touch with the people close to you.

CF can also complicate how you feel about yourself. You might feel like you're different from your healthy friends: that's because you are. CF can give you a very intense experience of life. Sometimes it feels like you can only relate to other people with CF. Even though your friends without CF may not be able to relate to your experiences directly, you'd be surprised to know how many people feel like they're alone – for a variety of reasons.

### EVERY RELATIONSHIP HAS ITS PROBLEMS





Talking to other people with chronic illnesses might be a good idea, to hear what they experience. Talk to your friends, parents and other family members about what's going on for you. Keep talking until someone listens.

If you feel a bit lonely, make a plan for getting connected again. Decide where you will put your energies and passions. Think about your mental health. Try and work out a way to balance all the elements in your life so that you can make time and space for close friends. *(See the People to Talk to section.)*

***Your mental health is an important part of staying well.  
There are lots of people who you can talk to about this.***

### **Sex and CF – deciding not to**

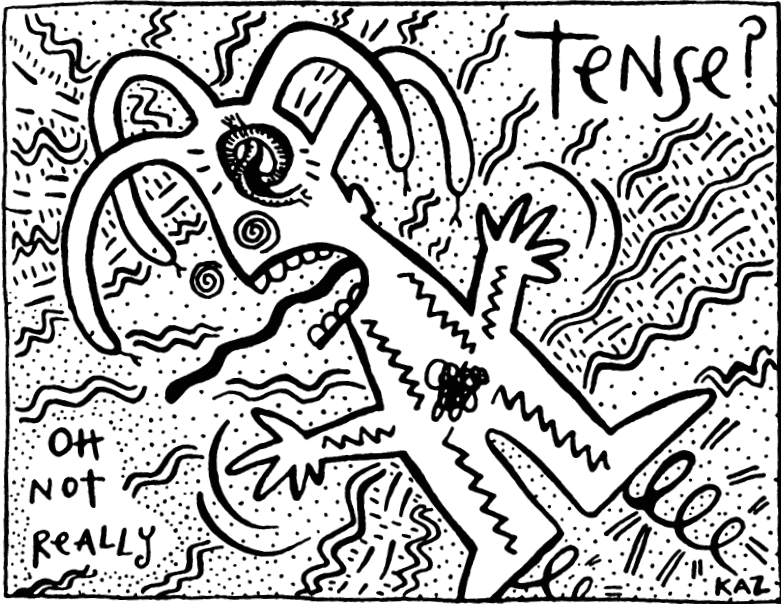
There's a lot of pressure on young people to have sex. TV and movies makes us feel like there's a whole lot of sex going on without us. It's OK to take things slowly or say no. It's your decision. Don't do it if it doesn't feel right.

***Even if you're not having sex at the moment, it's important that you know about safer sex so you make the right choices at the right time.***

### **Having sex**

On average, young men and women with CF start having sex at the same age and stage as young men and women without CF. If it isn't already, a sexual relationship will probably be an important part of your life at some stage in the future.

Sexual intercourse can mean strong physical exertion – some people with CF find they experience shortness of breath and coughing during sex. This is nothing to be embarrassed about. Some people find that doing physiotherapy a few hours before sexual intercourse will lessen the coughing.



You are likely to find that when you are sick or when your respiratory function is low, your interest in sex may be low. This is normal. However, the need for intimacy (physical and emotional closeness) remains the same. Finding ways of being close to the people you love without necessarily being sexually active can be an increasing challenge as your health declines.

***Having CF doesn't mean you can't have a normal sex life.***

### **Safer sex**

Just because you have CF, you're not immune to the risks everyone else faces. If you have decided to have sex, it is vital to practice safer sex. Safer sex means sexual contact that doesn't involve the swapping of blood, semen or vaginal fluids.

Safer sex doesn't just mean preventing unwanted pregnancies. Whether you're fertile or not (*see the Fertility section in this booklet*), gay or straight, you can get sexually transmitted diseases (STDs).

## **Sexually transmitted diseases**

There are heaps of STDs around: the most common STDs found in young people are chlamydia, herpes, genital warts, HIV, gonorrhoea and syphilis. As a young person with CF, you certainly don't want more pain, itches and lumps to take care of, let alone more medications to manage.

You can get tested for STDs and talk about contraception with your local GP, or your gynaecologist (for women) at a community health centre, family planning clinic or sexual health/STD clinic. You can start by talking about contraception and STDs with your CF doctor. *(See the People to Talk to section.)*

## **Contraception – condoms**

Safer sex means choosing a very good barrier contraception. A condom is the best barrier against both unwanted pregnancies and STDs. Young men and women need to get familiar with their use. You can buy condoms cheaply from your chemist or pharmacist. There are instructions on how to use them in the condom packet. You can also get detailed information from family planning and sexual health clinics. *(See the People to Talk to section.)*

Even if you know you can't get pregnant or get someone else pregnant, you still need to use condoms to lower the risk of getting or transmitting STDs.

## **The pill and other contraceptives**

There are various other forms of contraception available that will protect women from unwanted pregnancies (but not STDs). Different factors will determine the most appropriate contraceptive for each woman.

The oral contraceptive pill is the most common form of contraception used by women with CF. There are some situations in which the pill is best avoided. If you have active liver disease, poorly controlled malabsorption, or have permanent intravenous access (eg Portacath), you need to discuss the use of the pill with your CF doctor.

THE NIGHT BEFORE



THE MORNING AFTER



PARTY GIRL



POUTY GIRL



Drugs are metabolised (broken down and absorbed) differently in people with CF. You need to know that if you are on antibiotics, there is a higher chance of failure of the pill, especially when you change antibiotics. To help counteract these factors, women with CF are generally recommended to use a higher dose pill (with 50 micrograms of estrogen). Remember that the pill doesn't protect you from STDs.

***If you are going to go on the pill, make sure you're on a high dose pill.***

If the pill is not right for you, you need to find alternative contraception. Other forms of contraception you can explore include the diaphragm, the IUD and Depo-Provera. (Make sure you check with your doctor or gynaecologist about possible side effects.) Tubal ligation is an option to consider for women who have decided against pregnancy.

It's important to discuss your contraception options with an expert. (*See the People to Talk to section.*) An unwanted pregnancy can create some unwanted nightmares.

You don't want to be in a position where you need to consider termination (abortion) for an unwanted pregnancy. If you do have an unwanted pregnancy, there are a number of health services that will help you with the issues, including termination of pregnancy if this is required. (*See the People to Talk to section.*)

# FERTILITY

## Male fertility

Sadly, the majority of men with CF are infertile. Your testes produce sperm normally, but because the vas deferens is blocked or absent, the sperm can't go anywhere. They are reabsorbed into the blood.

You can have your fertility tested through analysis of your semen. This involves producing ejaculate by masturbation, which is then examined under a microscope to look for motile sperm. It's not as embarrassing as it sounds!

You can ask your CF doctor if you want to find out whether you are infertile or not. This can be a hard thing to face, but it can be better to know one way or the other so you can get your head around it.

It is still possible to father a child and there are some options to explore. These are artificial insemination by donor sperm and microscopic epididymal sperm aspiration (MESA) where sperm are collected by a needle, bypassing the blocked or absent vas deferens tube. (*See the People to Talk to section.*)

## Female fertility

The combination of improved respiratory function, better nutrition and longer survival means that these days, young women with CF have higher fertility rates than previous generations of women. Indeed, the annual number of pregnancies reported to the CF patient registry in the United States doubled between 1986 and 1990, including a significant number of unplanned pregnancies.

The upshot of all this is that if you have sex and don't wish to become pregnant, you need to use contraception. (See the *Contraception section*.) Remember that being on the pill won't protect you from STDs.

On the other hand, if you do wish to get pregnant and you have difficulty getting pregnant, there are a range of things that might help boost your fertility.

Poor fertility can result from poor health. (Poor health can refer to your lung function or your nutritional state.) If you have very poor nutritional status and severe respiratory disease you might experience what is known as 'secondary amenorrhoea' (loss of periods) for some months, or experience 'anovulatory cycles' (you may continue to menstruate, but do not actually release eggs). These are generally features of serious illness. Improving your nutritional status, weight and lung function can help restore your periods and ovulation. If your health is this bad however, pregnancy may not be safe for you.

***In the past, it was thought that women with CF had reduced fertility. However, many women with CF have had children. If you do not want to get pregnant, use contraception.***

## THINKING OF PARENTHOOD

The decision to become a parent is complex enough even without CF to deal with. As a young person with CF, male or female, you have to consider a range of things: your fertility, your health and wellbeing, and genetic issues.

For young women with CF, you will need to specifically think about the effect of pregnancy on your health, as well as the longer term impact of looking after a child. The demands on your time made by a baby or child may mean less time looking after yourself.

You might know already that you aren't fertile, or you aren't healthy enough to cope with the demands of parenting. This is likely to make you feel sad. Some people may feel very sad about this. Similarly, your parents may express sadness that they will never become grandparents to your children.

You may want to think about the role of the children that are already in your life. Many people can have a rewarding and rich experience by involving themselves in the lives of children around them, even without being a biological parent.

These are big things to think about. People without CF may find it hard to understand these complex issues. There are people who can provide you with information to help work through these things. Many people with CF say that talking to other people, whether friends or counsellors, can really help. Psychologists and psychiatrists are trained to help you in tough times such as these. (See the People to Talk to section.)



## Genetics

Knowing whether or not your partner is a carrier of the CF gene is the key to working out the chances of having a child with CF.

As you probably know, if you have CF and your partner is not a carrier, you will not have a child with CF, although all will be carriers of the gene. *(See top panel, page 24.)* If your partner is a carrier, the risk of having a child with CF is 1/2 (one in two) for each pregnancy. *(See middle panel, page 24.)* If you don't know the carrier status of your partner, the chance of them being a carrier is 1/25, with the risk of an affected pregnancy being 1/50.

Genetic counsellors can help you understand these chances and arrange for carrier status testing. Other tests are available in early pregnancy that can identify whether or not the fetus has CF. People have varying beliefs about what these results might mean for them. It's important to talk about these issues in advance, rather than having to confront the consequences later once you are pregnant. *(See the People to Talk to section.)*

### Having a child: the options for men

The decision to have a child is a complex one for all men. There are reproductive options if you want to father a child. These are artificial insemination by donor sperm, and microscopic epididymal sperm aspiration (MESA).

MESA is a surgical technique that involves taking sperm directly from the testes under local or general anaesthetic. The female egg must be retrieved using in-vitro fertilisation (IVF) techniques. The sperm is then used to fertilise the egg, which is then placed into the woman's uterus using standard reproductive biology approaches.

Your CF doctor can talk to you about this and can refer you to a reproductive biology program at a major hospital. *(See the People to Talk to section.)*

# CONCEPTION AND CF

non-CF  
non-carrier  
parent



child A  
carrier



child B  
carrier

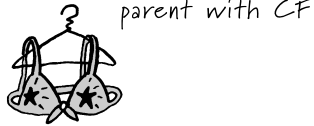


child C  
carrier



child D  
carrier

carrier parent



child A  
carrier



child B  
carrier

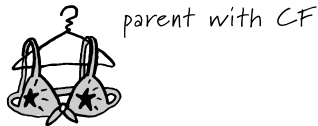


child C  
affected



child D  
affected

parent with CF



child A  
affected



child B  
affected



child C  
affected



child D  
affected

## **Having a child – the issues for women**

The decision to get pregnant is a complex one for all women. CF complicates things even further. Early studies of pregnancy in women with CF reported high rates of complications. However, many women with CF have had successful pregnancies. These days, it is generally the case that women with mild lung disease (lung function greater than 70%) tolerate pregnancy relatively well.

The decision to get pregnant needs to take into account whether pregnancy will make your lung function worse and adversely affect the longer-term course of your illness.

There is the potential for pregnancy to significantly affect the health of any woman with CF, however mild their lung disease before the start of the pregnancy. Generally, pregnancy doesn't affect your long-term health; however, you will need to talk to your CF doctor about the risks associated with pregnancy for you. Sadly, if you have severe lung disease, pregnancy cannot be safely recommended.

Occasionally, women with CF who have severe lung disease and become pregnant unexpectedly, and/or women whose lung function drops severely during their pregnancy, may need to consider termination of pregnancy in order to preserve their own health.

You need to talk about pregnancy with your CF doctor before you start 'trying'. You also need to talk about genetic screening. *(See the People to Talk to section.)* Before you get pregnant you'll also need to see an obstetrician (a specialist in pregnancy) who is likely to discuss with you the risks of poor growth of the baby (called poor 'fetal growth'), premature labour and delivery, as well as the risks to your own health. It is always best to see an obstetrician who has experience with CF.

## BEING PREGNANT

Your CF doctor, an obstetrician, a nutritionist and a physiotherapist all need to be closely involved if you decide to become pregnant. During the pregnancy your medical team will work with the obstetric team. There needs to be close attention to weight gain and respiratory function of the mother, as well as fetal growth. Regular monitoring and early treatment of complications will help minimise the risks associated with pregnancy.

***It is best if pregnancy is a well-planned event.***

If you have a low body weight or find it hard to gain weight during the pregnancy, the baby may be born prematurely or smaller than normal.

If you have diabetes, it needs to be carefully monitored and controlled during the pregnancy. Even if you do not have diabetes you may develop it during your pregnancy. This is called 'gestational' diabetes and will usually resolve once your baby is born. Many women need to take nutritional supplements during pregnancy.

Different approaches to physiotherapy are generally required as the pregnancy progresses.

If you are pregnant you need to discuss your use of antibiotics with your CF doctor. Some antibiotics have potential effects on the growing fetus and your doctor will advise you to avoid them. It is reassuring to know that most CF antibiotics have no effect on the fetus.

When it comes to giving birth, a vaginal delivery is usually encouraged over a caesarean section. A caesarean section is an operation involving pain and restricted movement after birth. This may affect your lung health. Recovery tends to be faster after a vaginal delivery.

Women with CF are, at least in the short-term, able to supply sufficient infant energy through breastfeeding, without reducing the mother's nutritional status. However, the additional energy requirements imposed by breastfeeding for longer periods can be difficult to achieve for most women with CF. You need to consult an expert nutritionist about this. If you are going to breastfeed you need to find out about possible drug transmission through breast milk. *(See the People to Talk to section.)*

## FINDING SOMEONE TO TALK TO

There are lots of people that you can talk to about your sexual and reproductive health. Choosing the right person to talk to is important. If you're not comfortable talking to them or you don't think they're listening to you, go to someone else. You can 'shop around'.

Your CF team may include a specialist doctor such as a gynaecologist (a specialist in women's sexual health) or urologist (a specialist in men's sexual health), or an allied health professional such as a social worker, nurse or physiotherapist.

If you don't feel comfortable talking to someone from the hospital, your general practitioner is a good person to talk to. GPs do routine sexual health screening such as pap smears and breast and testicular checks and will talk about the best form of contraception for you. They also deal with STDs daily. If you don't want to talk to your GP about these issues, they will be happy to refer you to someone else.

***Even though it seems like you're surrounded by doctors, you still need a GP for your routine sexual health care.***

You can also do your own independent research to find an expert in your area of concern. As well as individual specialists there are community and neighbourhood health centres, family planning clinics and sexual health clinics. Look in the phone book or on the web.

Ask around and see who your friends have been to see. You can phone and ask to chat to someone before you decide to make an appointment.

There will be a wider choice of people to talk to in cities and towns. If you live in a rural or regional area you may need to plan ahead and organise an appointment to coincide with your next visit to your city centre.

Make sure the person you are consulting knows about CF. If they don't know the latest in CF care, give them a good grounding and suggest they do some research before you see them.

The details of your discussion don't need to go 'on record' on your patient history at your CF centre. Your CF doctor doesn't have to know that you have consulted someone else, although it is a good idea to keep your CF doctor up to speed about what's going on for you.

***All health professionals have a duty of confidentiality. They aren't allowed to tell your parents what you've been talking about – unless you want them to.***

## PEOPLE TO TALK TO

Here is a list of the type of agencies, services, clinics and individuals you can contact for more information. You can just telephone and make an appointment to attend most of the health services below. You may need a referral from your CF doctor or GP to see a medical specialist.

If you want to, you can take a friend or family member with you to your appointment.

### **Physical growth and sexual development**

- Your CF doctor
- GPs
- Endocrinologists (Hormone specialists)
- Adolescent medicine services

### **Body image and other mental health stuff**

- GPs
- Adolescent medicine services
- Psychologists (Psychologists are trained to talk with people about a wide range of concerns)
- Psychiatrists (Psychiatrists are doctors who have had specialist training in mental health)

- Counsellors at community and neighbourhood health centres
- Peer support programs (Ask your CF service if there is one in your area)
- Social workers, youth workers and ethnic health workers
- Telephone help lines

### **Sexual health**

- GPs
- Adolescent medicine services
- Family planning centres
- Community health centres
- STD clinics



- Gynaecologists (Specialists in female sexual health including yeast infections, pap smears and STDs and infertility)
- Urologists (Specialists in men's sexual and reproductive health)

### **Urinary incontinence**

- Physiotherapists
- Hospital incontinence clinics
- Gynaecologists

### **Unwanted pregnancy**

- Family planning services
- GPs

### **Fertility**

- Your CF doctor
- Gynaecologists
- Obstetricians (Specialists in women's pregnancy and birth issues)
- Urologists (Specialists in men's sexual and reproductive health and men's and women's urinary tracts)
- Other hospital-based reproductive biology units

### **Genetic counselling**

- Genetic counsellors (Attached to all CF services)

### **Being pregnant**

- Your CF doctor
- Genetic counsellor
- Obstetricians (Specialists in women's pregnancy and birth issues)
- Physiotherapists
- Nutritionists

### **About CF**

- CF Australia (The national CF association)
- The community CF association in your State

## OTHER RESOURCES

### **Internet (the world wide web)**

There are many good websites about CF. Most national CF associations and foundations have a website.

There are heaps of good resources on the internet about sexual and reproductive health. Search by combining the words 'young people', with terms such as 'sexual health', 'safer sex', 'contraception' and 'body image'.

There are also a number of excellent online magazines that are dedicated to the issues of young people. Many have information specifically for young gay and lesbian people.

### **Books**

Have a look in the health section of your local bookshop or library; there are lots of good books around.

Everywoman and Every Man (also Every Girl) by Derek Llewellyn-Jones are good starters about puberty, general anatomy and sexual function.

Kaz Cooke has written a number of books that address sex and reproduction in a hilarious way. (Her cartoons illustrate this booklet.) Her books include Real Gorgeous and The Modern Girl's Guide to Safe Sex.

You can read what young people have to say about their own lives in Boys' stuff: boys talking about what matters (Wayne Martino and Maria Pallotta-Chiarolli [Eds]) and Girls' talk: young women speak their hearts and minds (Maria Pallotta-Chiarolli).

glossary

**Airway clearance**

See physiotherapy.

**Anovulatory cycle** Each cycle of female hormones aims to result in the release of an egg ('ovum') ready to be fertilised ('ovulation'). Whether or not one has CF, not all of these cycles will actually result in the release of an ovum. Those cycles that don't result in release of the ovum are called 'anovulatory'.

**Caesarean section** Birth of a baby by an operation on the abdomen rather than through the vagina. Named after the Roman Emperor Caesar who was born this way.

**Cervix** The lowest part of the uterus.

**Chlamydia** A type of sexually transmitted disease that can result in infertility for a woman.

**Depo-Provera** A form of progesterone injected every three months to prevent periods or as a method of contraception.

**DEXA studies** Dual Emission X-ray Absorptiometry: A method of testing the density of bones.

**Diabetes** A condition where the body cannot deal with sugar appropriately.

**Diaphragm** 1. The muscle that separates the chest from the abdomen. It is used to breathe in which explains why the tummy moves in and out with breathing.

2. A form of contraception where a diaphragm, or artificial barrier, is inserted into the vagina to sit over the cervix to prevent sperm from passing.

**Endocrinologist** A doctor who specialises in the treatment of hormone problems.

**Estrogen** A female hormone that is responsible for most of the changes that occur with puberty in females.

**Fertility** The ability to contribute to the conception of a baby. For a male this means the ability to produce sperm and ejaculate; for a woman, this means the ability to produce eggs which can be fertilised and then implanted in the uterus.

**Fetus** A baby developing in the uterus.

**Gastrostomy** A tube that goes through the skin into the stomach, used to give extra feeds.

**GP (General Practitioner)**

Also known as a family doctor, local doctor, or local medical officer.

**Genetic counselling** Discussion with a health professional expert in the understanding of diseases transmitted from parents to children.

**Genital warts** A type of sexually transmitted disease that may come and go, but can't be cured. It still needs to be treated.

**Gestational diabetes** Diabetes that occurs during pregnancy, which may or may not disappear after pregnancy.

**Gonorrhea** A type of sexually transmitted disease that can lead to infertility in a woman if untreated.

**Growth spurt** A period of rapid, accelerated growth caused by hormone changes around the time of puberty.

**Gynaecologist** A doctor who specialises in the conditions affecting the female reproductive tract.

**Herpes** A type of sexually transmitted disease that once caught, may come and go, but cannot be cured.

**HIV (Human Immunodeficiency Virus)** A virus transmitted by sharing body fluids (blood, semen and others), that is, by unprotected sex, sharing needles, or blood transfusion (which is a rare means of transmission now that donors and blood can be checked). This virus causes AIDS.

**IUD (Intra-Uterine Device)** A method of contraception where a small copper device is implanted into the uterus to prevent implantation of a fertilised ovum.

**IVF (In-vitro Fertilisation):** literally 'in glass' fertilisation. A technique of becoming pregnant where an egg is fertilised with sperm in a test tube and then transferred into the woman.

**Malabsorption** Inadequate absorption of food. In CF this is usually a result of failure to sufficiently digest or break down foods into a form that the body can absorb.

**Menarche** The onset of the first ever period.

**Menstruation** (Also known as a 'period' and many other nicknames.) With cycles of female hormones, the lining of the uterus becomes thick and juicy ready for a fertilised egg to implant. If fertilisation does not occur, the lining of the uterus is shed, coming out as a period.

**MESA (Microscopic Epididymal Sperm Aspiration)** Technique of collecting sperm with a needle to bypass blocked or absent transport tubes.

**Motile sperm** Sperm look like microscopic tadpoles, which move about by flicking their tails. Not all do, but those which move are called 'motile', which literally means 'moving'.

**Nocturnal emissions** Sometimes men release semen while asleep. These events are commonly called 'wet dreams'.

**Nutritionist** A health professional specialised in the nutritional content of food and special diets. (Also known as a 'dietitian'.)

**Obstetrician** A doctor who specialises in the care of pregnant women.

**Osteopenia** A condition where the bones are thin.

**Osteoporosis** A condition where the bones are very thin.

**Ovaries** (Singular: ovary) The organs where eggs (ova) are stored and released (ovulation) one-by-one with the cycles in female hormone levels.

**Ovulation** The release of an egg ('ovum') ready to be fertilised.

**Ovum** (Plural: ova) A human egg, which is stored in the female's ovaries. Ova contain genetic information from the mother to join with genetic information from the father to form the new individual.

**Pap smear** (Also known as 'pap test'.) A test where cells are collected from the cervix and looked at under the microscope for changes of cancer or pre-cancer.

**Pelvic floor muscles** Muscles in the pelvis that help to keep pelvic contents in the right place.

**Physiotherapy** (Also known as 'airway clearance'.) Physiotherapy for CF care involves clearance of sputum from the lungs using

physical means such as huffing, positive pressure manoeuvres and exercise, and also training in better use of muscles, movement and posture.

**Portacath** A device implanted by a surgeon to enable medications to reach the biggest veins of the body by simply being injected into a reservoir sitting under the skin. Once implanted, the reservoir (a Portacath is one brand) only needs to be removed if there is a problem with it.

**Primary amenorrhea** The absence of periods, but before they have actually started. That is, delayed menarche.

**Progesterone** A female hormone responsible for the preparation of the uterus for the implantation and development of a fertilised ovum.

**Psychiatrist** A doctor specialised in the assessment and treatment of mental health.

**Psychologist** A non-doctor health professional specialised in the assessment and treatment of mental health.

**Puberty** A period of rapid change caused by changes in hormones. The end result of puberty is adult sexual maturity.

**Secondary amenorrhea**

The absence of periods, but after menarche has occurred.

**Seminal vesicles** Parts of the male anatomy where semen is stored prior to release.

**Sex hormones** Estrogen and progesterone for women and testosterone for men.

**Sexual development** For women, sexual development includes growth of breasts, changes in the vagina and uterus, onset of periods and development of body hair. For men it includes growth of testes, changes in the penis and development of body hair.

**Sperm** Tadpole-like cells made in the testes which carry genetic information from the father. At fertilisation, the sperm joins with the egg (ovum) from the mother, leading to the eventual development of a new individual.

**STDs** Sexually transmitted diseases.

**Syphilis** A sexually transmitted disease which is now uncommon. This disease is treatable with antibiotics but if untreated can eventually lead to severe complications.

**Testes** (Singular: testis. Also known as 'balls', 'testicles' and many other nicknames.) The male organs that sit in the scrotum whose job it is to produce sperm, semen and testosterone.

**Testosterone** A male hormone responsible for growth of testes, changes in the penis, development of body hair, sexual drive, aggression and muscle development. Females have a small amount of testosterone, which leads to the development of body hair.

**The pill** An oral contraceptive. This is the most effective form of contraception taken by women to prevent pregnancy but it does not prevent STDs.

**Thrush** (Also known as 'candida', 'fungal vaginitis'.) A type of infection caused by overgrowth of yeasts. This occurs commonly when antibiotics disturb the normal balance of yeasts that live in the body.

**Urinary incontinence** (Also known as stress incontinence.) Leakage of urine inappropriately which can occur with raised abdominal pressure such as with laughing, coughing.

**Urologist** A surgeon who specialises in conditions of the urinary tract of men and women.

**Uterus** The female organs which sit in the pelvis. This is where the fertilised egg implants and where the fetus grows and develops for nine months.

**Vas deferens** A tube that transports sperm from the testes to the outside. This tube may be blocked or absent in males with CF.

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