

Cystic Fibrosis *our focus*

Urinary incontinence

Factsheet – March 2013

Fighting for a
Life Unlimited

Urinary incontinence

Introduction

Women and girls with cystic fibrosis (CF) are more likely to experience urinary incontinence (UI) than the healthy population. Symptoms of UI in males with cystic fibrosis do occur, but to a lesser degree than in females.

Reports of leakage in men and boys with cystic fibrosis are similar to that of the healthy male population.

Leakage may occur during activities such as coughing, sneezing and laughing. Cough is the major cause of leakage in people with cystic fibrosis. Risk of UI is greater at times of increased cough such as during a chest infection. The amount of leakage may vary from a few drops to emptying the full bladder.

This factsheet explains what urinary incontinence is, how people with cystic fibrosis may be affected, and how it is treated.

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What is urinary incontinence (UI)?

There are two types of incontinence:

- Urge incontinence happens when the muscle of the bladder is over sensitive and there is not enough warning of the need to empty the bladder. Certain drugs (e.g. caffeine) may make the bladder muscle 'twitchy' and cause urge incontinence.
- Stress incontinence happens during actions such as coughing and sneezing and this is the type most commonly reported by patients with chronic cough.

A combination of the two causes can also occur and is known as mixed incontinence.

The pelvic floor

The pelvic floor is made of ligaments and muscles that form a sling which supports the floor of the pelvis. The opening to the bladder (urethra) passes through this sling. The muscles of the pelvic floor must work to keep the urethra closed when you don't want to pass urine.

What happens during coughing?

The abdominal muscles contract strongly during a cough. This increases the pressure on the bladder and pelvic floor. The pelvic floor muscles need to contract with every cough to prevent leakage. This process usually happens automatically.

The reason why people with cystic fibrosis are at increased risk of leakage is not fully understood. Studies show that the muscles are usually strong enough, but sometimes they can't keep up with the intense, prolonged coughing that people with cystic fibrosis experience.

What help is available?

Many people find it embarrassing to talk about urinary incontinence. It is really important to discuss this problem with a member of the CF team as soon as you are aware of the problem. If the problem remains untreated it may get worse. You should not avoid coughing as this can lead to a build up of sputum in the lungs.

Your team may routinely ask at annual review if you have any problems with leakage. The specialist physiotherapist(s) at your CF centre can provide advice about managing symptoms of UI during airway clearance treatment and exercise.

Where necessary a referral can be made to a specialist continence team who will be able to provide advice, assessment and treatment (e.g. pelvic floor exercises). Studies have shown that various methods of training the pelvic floor muscles result in less leakage. Specialist continence advisers can also help you to access equipment such as appropriate pads. The team at your CF clinic can arrange referral to a continence team for you.

Airway clearance and coughing

It is essential that you are able to clear your chest effectively to minimise build up of infected respiratory secretions. It is important that urinary leakage does not interfere with your ability to do this.

Controlled coughing and modifying your airway clearance technique may help to prevent or minimise leakage. Good posture during airway clearance is essential. Research shows that the muscles involved in coughing and control of the pelvic floor work best with the spine straight and in an upright position.

Your physiotherapist can help to select the best airway clearance technique and position for you.

“The Knack”

“The Knack” is a technique where you tighten and lift the pelvic floor muscles before coughing, huffing, sneezing etc to protect against leakage. It is very important that you are performing “the Knack” correctly and lifting the muscles, not pushing downwards. You may need the help of a specialist continence physiotherapist to do this.

It is suggested that all people with cystic fibrosis should practice “the Knack”, whether you leak or not.

Exercise

Exercise is important to maintain fitness and helps to keep your chest clear of secretions.

High impact exercise such as jumping, skipping and running may cause leakage.

Extra care should be taken with these activities during and after puberty as risk of leakage may increase at this time.

For those who leak and wish to exercise on a trampoline, jogging will cause less strain on the pelvic floor muscles than jumping with both feet together. Jogging instead of jumping with a skipping rope is preferable for the same reason.

Talk to your physiotherapist if you intend doing weight training and abdominal toning (sit ups) programmes to ensure you are following a balanced exercise programme.

What do I need to do if I don't leak?

Ensure that you have good posture during airway clearance therapy and coughing. This will help the muscles that control coughing and continence to work most effectively.

Learn how to tighten and lift your pelvic floor muscles and get into the habit of practising “the Knack” routinely.

Ask your physiotherapist if you would like advice about posture, pelvic floor exercises and “the Knack”.

What do I need to do if I leak?

Discuss the problem with a member of your CF team (remember that the problem may be more common than you think and that help is available).

Good posture, pelvic floor exercises and practising “the Knack” may help to control the symptoms of UI. Effective sputum clearance is important and you may find pads useful to contain leakage during airway clearance and coughing. It is important to use pads specially designed for urinary leakage.

If your leakage persists despite using these techniques, continence specialists are available to provide advice, assessment and treatment of leakage and you can be referred to these teams via your CF clinic.

Further information

The Cystic Fibrosis Trust provides information about cystic fibrosis through our factsheets, leaflets and other publications.

Most of our publications are available through our helpline and can be downloaded from our website or ordered using our online publications order form. Visit cysticfibrosis.org.uk/publications.

The Cystic Fibrosis Trust helpline can help you with a range of issues, no matter how big or small. Our trained staff can provide a listening ear, practical advice, welfare/benefits information or direct you to other sources of support. The helpline can be contacted on 0300 373 1000 or helpline@cysticfibrosis.org.uk and is open Monday to Friday, 9am – 5pm.

Calls to 0300 numbers cost no more than 5p per minute from a standard BT residential landline. Charges from other landlines and mobile networks may vary, but will be no more than a standard geographic call and are included in all inclusive minutes and discount schemes. If you are worried about the cost of the call please let us know and we'll call you back.

You can also find more information at our website cysticfibrosis.org.uk.

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More factsheets available at:
cysticfibrosis.org.uk/publications

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The information included in this publication is not intended to replace any advice you may receive from your doctor or CF multidisciplinary team and it is important that you seek medical advice whenever considering a change of treatment.

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