

Children's Services – Parent Information

Stress incontinence in children with Cystic Fibrosis – parents' copy

Introduction

Stress incontinence is a symptom that many people have at some point in their lives. However, it can be more common in children with Cystic Fibrosis. The physiotherapist recommends the advice given in this leaflet and you should be read in conjunction with their instructions.

This leaflet will explain to parents of children with Cystic Fibrosis:

- What is Stress Incontinence
- Anatomy of the Pelvic Floor Muscles
- Why your child may have Stress Incontinence
- How to treat the symptoms
- Management for the future

What is Stress Incontinence?

(SI). It is usually more common in girls than in boys but it can affect any child at any age.

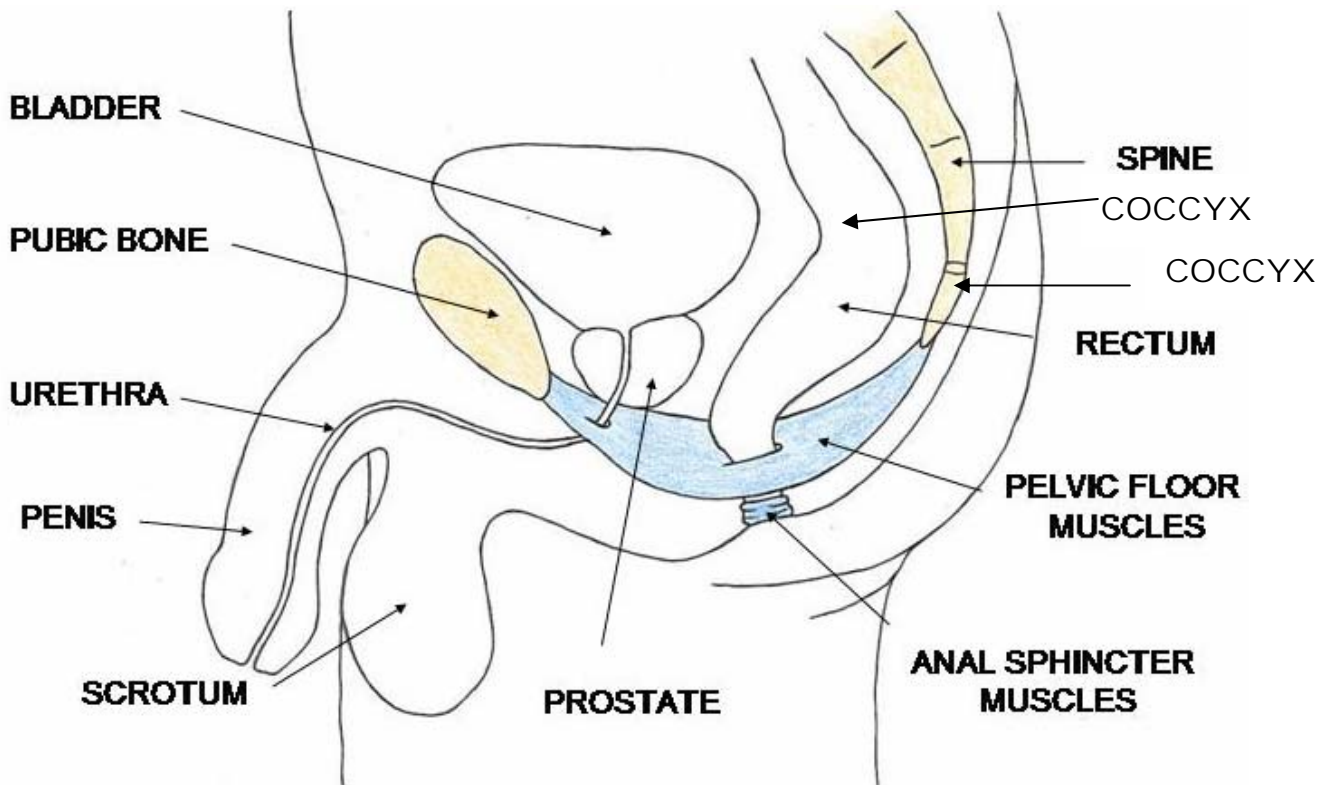
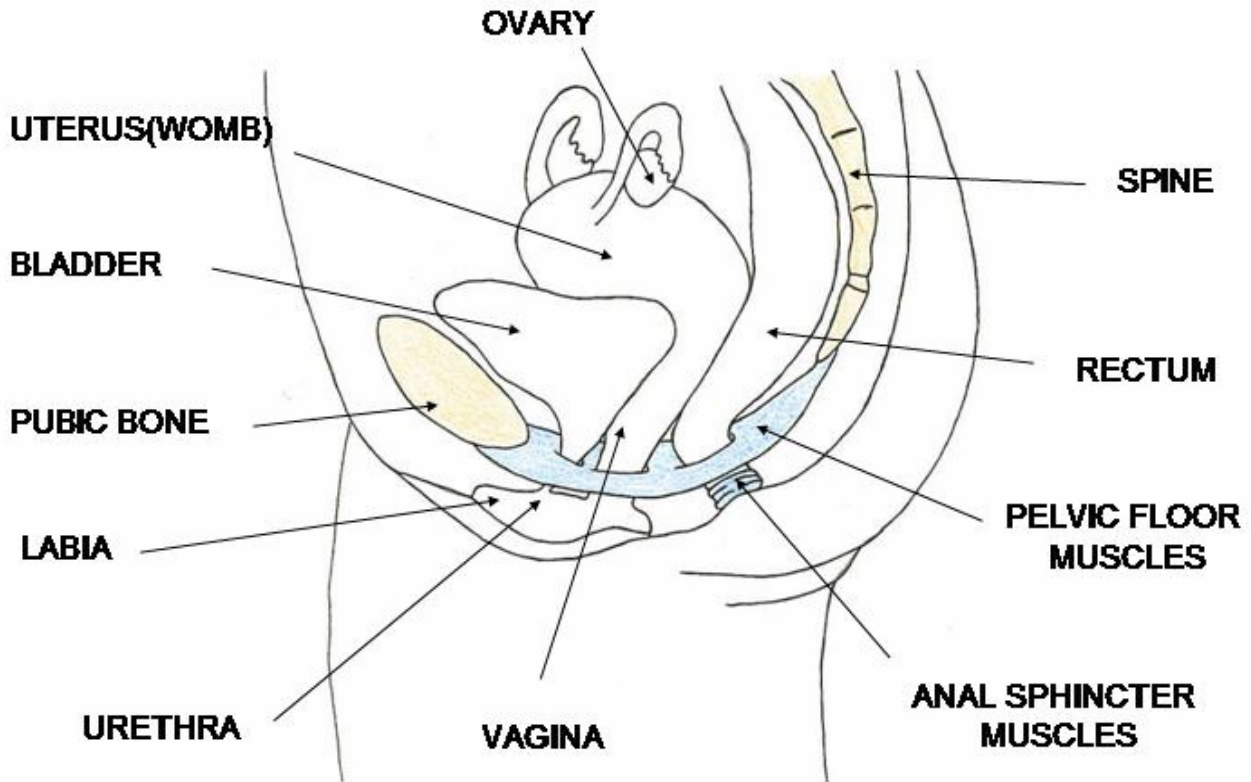
The symptoms are leakage of urine (either a dribble or full emptying of the bladder) during an activity which places 'stress' or pressure on the internal pelvic floor muscles such as coughing, laughing, and jumping etc.

In order to understand why your child has this symptom, it is useful to understand the anatomy of the Pelvic Floor Muscles (PFM) and what happens during these times of 'stress'.

Anatomy of the Pelvic Floor Muscles (PFMs)

The PFMs form a hammock underneath the pelvis to support and control the functions of the bladder and bowel. The muscles attach to the pubic bone at the front, then span backwards and attach to the coccyx (tailbone). The opening to the bladder (urethra), the bowel and in girls, the birth canal (vagina) all pass through these muscles as shown in the following diagrams:

The female and male pelvis, illustrating the location of the pelvic floor muscles:



(Images reproduced with kind permission from Caroline Allen at pelvicsupport.com)

The PFM's support the pelvic organs and abdominal contents especially on standing and on exertion. These muscles are usually strong enough to support and work gently at all times and stop leaking from the bladder. However PFM's also need to be able to work harder when a person exerts pressure during coughing, sneezing or exercising.

If the PFM's are weakened, then they cannot support the bladder and keep the urethra closed so leakage is likely to occur during these activities of coughing, sneezing, laughing or exercising. The weaker the PFM's then the less control there is at other times for example when there is no stress on these muscles and bowel control could also be affected.

Therefore it is important to maintain strength in these muscles to prevent problems occurring or to increase the strength when problems do occur.

Why does my child have Stress Incontinence?

Coughing, huffing and keeping an active lifestyle are very important for any person who has Cystic Fibrosis (CF) so that they can clear the sputum off their chest and maintain a healthy lung function. However these activities do place pressure on the PFM's and over time, occasionally these muscles can get weakened. It is not fully understood why people with CF have an increased risk of getting Stress Incontinence (SI), but during times of a chest infection, the extra pressure on these muscles from coughing means that this is when people start getting symptoms of (SI).

Another common time when SI could occur is during strenuous exercise such as jumping on a trampoline. It is important not to be alarmed if these symptoms occur in your child as your child will be worried also. When symptoms first arise please report this to the CF physiotherapist who will be able to help and offer advice on managing the symptoms.

Pelvic Floor Muscles are just like any other muscles of the body, therefore they should be exercised just as much as any other weak or damaged muscles. The exercise programme given to you by the Physiotherapist will help to maintain and / or improve your child's PFM strength.

How to Treat Stress Incontinence

The Pelvic Floor Muscle Exercises (PFM)

A PFM contraction is performed by closing and drawing up of the front and back passages. It is best performed by imagining you are trying to stop the flow of urine and passing wind. The feeling should be one of "squeeze and lift".

The exercises can be done in lying, sitting or standing; it is easiest on the muscles if done in the lying position (if the muscles are particularly weak) and most difficult in standing (as the muscles have to lift up against gravity). The Physiotherapist will recommend which position is best for your child.

When exercising, **DO NOT**:

1. pull in the tummy muscles too much
2. squeeze the legs together
3. tighten the buttocks
4. hold your breath

Exercise 1 – The quick (fast) contractions

Squeeze the PFM and lift up firmly, then let go completely. Rest a second and then repeat the squeeze again. Aim to build up by practising until your child can perform 10 in a row. This exercise will help your child's muscles to react quickly when they laugh, cough, sneeze, exercise or lift things.

Start with: _____ repetitions.

Exercise 2 – The endurance (slow) contractions

Squeeze and lift up the PFM and this time hold this position while still breathing in and out. Aim to build up to a maximum of 10 repetitions.

Start by holding for _____ breaths and repeat _____ times.

The 'Knack':

This is a term used to describe the contraction of the PFM just before pressure is about to be exerted. This practice is introduced to your child once they have a good technique of muscle contraction i.e. they can "squeeze and lift" their PFM.

Your child is then advised to "squeeze and lift" or contract their PFM before they know they are about to cough / huff / lift something etc. and maintain this contraction whilst they are doing this activity.

How often should these exercises be done?

Your child should do both the fast and slow exercises at least four times a day, but up to 10 times a day is ideal to aim for. Do not do so many exercises that the muscles ache; quality is more important than quantity.

Muscles only develop when they are challenged to work harder than normal and this will be different for everyone. Follow the advice from your physiotherapist but in general, start with a few repetitions and increase the number as the exercise becomes easy.

The most difficult part of these exercises is to remember to do them; you must work a routine out with your child that can accommodate the exercises into their lives and reminding them to do the exercises may not be enough – you may have to do the exercises with them!

Management for the future

If the exercises are performed correctly the symptoms should improve and in some cases, disappear. However, there may be times when the symptoms can reoccur or worsen if your child has a chest infection and their excessive huffing and coughing can cause stress incontinence again.

During these times, please contact the physiotherapist for further advice. However, for the period of time that your child is unwell, he or she may benefit from wearing special pads that absorb urine leakages and provide peace of mind for them, particularly during chest physiotherapy and/ or exercise. You can buy these incontinence pads in most shops where sanitary towels are also sold.

If your child is particularly sporty and feels that they need 'protection' during physical activities, specialist underwear with pads built into the pants may be a better option. Your physiotherapist can provide stockist's details as necessary.

Other tips for a healthy bladder:

Your child should try to avoid passing urine too frequently as this can reduce the capacity of the bladder. They should not go "just in case", only if their bladder feels full.

- Avoid leaving it more than four hours between emptying the bladder.
- Your child should aim to drink the required amount of fluid for his/her size but aim to drink more in hot weather, really dry conditions and after sports.
- Your dietitian will be able to advise you on your child's exact fluid requirements as this is age and size dependent.
- Large volumes of fluids within a short space of time will cause rapid filling of the bladder so drinks should be paced evenly throughout the day (urine should be light straw coloured – too dark and strong smelling means it's too concentrated. Too pale and no smell means they are drinking too much).
- Avoid being constipated as this puts pressure on the bladder.
- Avoid fizzy drinks and drinks that contain caffeine as this can irritate it and cause your child to want to pass urine more often.
- Try to encourage your child to empty his/her bladder fully when they go to the toilet.
- You may have heard of an exercise using the pelvic floor muscles to stop and start the flow of urine. This is no longer recommended as it may interfere with normal bladder emptying.

Other sources of help and advice:

ERIC (Education and Resources for improving Childhood Continence) is a national charity that helps children, young people and families with issues of incontinence and also bedwetting and soiling problems. Their website is www.eric.org.uk and helpline is 0845 370 8008.

CF Trust factsheet on Urinary Incontinence in Cystic Fibrosis – www.cftrust.org.uk

Your contact Physiotherapist is

And can be contacted on.....



We are currently working towards a smoke free site. Smoking is only permitted in the designated smoking areas.

For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169

Help with this leaflet:



If you would like this information in another language, large print or audio format, please ask the department to contact Patient Information: 01223 216032 or patient.information@addenbrookes.nhs.uk

Polish

Jeżeli chciałbyś uzyskać te informacje w innym języku, w dużej czcionce lub w formacie audio, poproś pracownika oddziału o kontakt z biurem Informacji Pacjenta (Patient Information) pod numerem telefonu: 01223 216032 lub pod adresem patient.information@addenbrookes.nhs.uk

Portuguese

Se precisar desta informação noutra língua, em impressão de letras grandes ou formato áudio, por favor peça ao departamento que contacte a secção de Informação aos Doentes (Patient Information) pelo telefone 01223 216032 ou através do e-mail patient.information@addenbrookes.nhs.uk

Arabic

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Cantonese

如您需以另一語言版本、特大字體或錄音形式索取本資料，請要求部門聯絡病人諮詢服務：電話 01223 216032，電郵地址 patient.information@addenbrookes.nhs.uk

Turkish

Eğer bu bilgileri başka bir dilde veya büyük baskılı veya sesli olarak isterseniz, lütfen bulunduğunuz bölümdeki görevlilere söyleyin Hasta Bilgilendirme servisini arasinlar: 01223 216032 veya patient.information@addenbrookes.nhs.uk

Urdu

اگر آپ کو یہ معلومات کسی دیگر زبان میں، بڑے الفاظ میں یا آڈیو طریقہ سے درکار ہوں تو برائے مہربانی اس شعبہ سے پیشینٹ انفارمیشن سے ذیل کے ذریعہ رابطہ کرنے کی درخواست کریں: 01223 216032 یا patient.information@addenbrookes.nhs.uk

Bengali

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