



News

from the York Adult Cystic Fibrosis Unit

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Lung function

What is lung function?

Lung function tests are known by different names; lung function tests (LFTs), respiratory or pulmonary function tests (RFTs or PFTs), 'blows' or spirometry. They measure what's going on with your lungs. They show us whether your airways are open or floppy, whether you have tight airways or sputum stopping the air coming out as fast (obstruction) or whether there isn't as much air getting in and out of the lungs (restriction).

Why do we do lung function?

When you come to clinic or to the ward, lung function is important as part of the picture, along with other measures like weight, the CF team's examination and how you feel. We can see if there are sudden changes which may mean that extra treatment for your chest is needed and we can measure how steady the condition of your lungs is. Some people find it hard to know when their chest is worse and measuring lung function helps us not to miss any problems that need extra treatment.

How do we measure lung function?

We use a machine called a spirometer (pictured below).



Measurements

FEV₁ is the measure we most often discuss with people. FEV₁ is the amount of air blown out in the first second of a fast blow. If it drops it can show that there is sputum in the way or the airways are tight.

Imagine a 3 lane motorway with a start line and a finish line about 100 metres apart. If we count the cars that can get from the start line to the finish line in one second this may be 10 cars. If we then add some road works which block 2 lanes we can still get 10 cars through eventually but less cars will get through in one second. FEV₁ works like this. So when the airways are clear and not tight (like the motorway with all the lanes open) someone may blow one litre of air out in one second and two litres in total (FVC) but if the airways are tight and/or have sputum in them (like the motorway with roadworks) then the amount of air blown out in one second (FEV₁) may drop to half a litre while the total amount of air blown (FVC) may stay at two litres.

Your physio will always try to make sure that we explain what the results of lung function show and will show you your past lung function so that you understand what's been happening with this measure over the last few years.

What is important about lung function?

It's important to remember that lung function is just part of the picture and other things like weight, blood measures, oxygen levels and how you are feeling will help us to make a decision about your treatment. It is normal to have small changes in lung function, this may be due to the time of day, technique, etc.

What keeps lung function more stable?

Unfortunately the things that people tend to see as boring or hard to do are the things that are needed to keep lung function steady:

- **Coming to a regular clinic** This means that we can make sure that you are having the best treatment and pick up on any problems early
- **Taking medication** (tablets, inhalers and nebulisers) that are prescribed...all the time not just when things aren't good
- **Exercise** This improves lung function in people without CF so just think what it does if someone has a chest condition
- **Keeping weight at a good level and steady** When weight drops or is low, your respiratory muscles won't be as strong and your body is less able to deal with infections
- **Physio** (but I would say that, I am a physio!!!)

Tracey

Hello and welcome to the second edition of our newsletter. There have been some big changes to the service we provide here at York Hospital, and we have a lot of ideas and plans for further improvements. We'll be using the newsletter to keep you informed of all the things we're working hard to achieve, and to let you know about interesting updates relating to all aspects of living with cystic fibrosis.

Over the last year we've had a few changes to the faces in the CF team, with the retirement of old friends such as Julie Gray, and the appointment of new ones with Tracey Daniels, specialist CF physiotherapist, joining the team from Leeds. Towards the end of 2011 we also welcomed Sheila our new clinical psychologist to the team and she has become a regular face in outpatients

We may also have a new nurse specialist joining the team later in the year, and we will keep you all informed.

For those of you who have had an inpatient stay you will know we now have free WIFI access, and we have now launched our new website -

www.CFYork.org.uk

If you log on you will see this is very much a work in progress - we need your feedback, and most urgently your pictures! We have introduced a scrolling picture gallery, so please contact the team with any pictures you are proud of - a scene of Yorkshire or any photo or memory you would like to share.

As part of the service for people new to the York unit, we've created new transition packs. They can still be changed and updated so we do need your opinions on what was good or bad - or if you transitioned to an adult service previously, what you would have liked to

know beforehand. Copies of all the new information and handouts will be downloadable from the new website. You'll also find lots of other information on all aspects of our service, and CF care in general.

Our other focus has been the annual assessment or yearly 'MOT'. You may have noticed a few more tests slipping in, like more detailed breathing tests and a longer session with the physiotherapist. We are also changing the way we let you know the results, with a new letter format and the option to receive your results by email.

Finally, we can't know what you want to find out unless you tell us. Please feel free to share any thoughts on how we can improve the newsletter, articles you'd like to see or any other information you think should be in here. Please get in touch!

CF Trust Expert Patient Adviser

In the past few months I have had meetings in York, Hull, Leeds and Sheffield Hospitals to address issues regarding staffing, development and other projects. I have also attended parent meetings in the North West to provide updates on the work of the CF Trust. In particular the CF Trust have been fronting a campaign regarding cuts to specialized staffing posts which have affected some CF services in this region and elsewhere, which I have been involved in.

I sit on the CF Trusts Medical Advisory Committee (MAC) who have recently approved the new Standards of care document. This will be published in the next few weeks so look out for it! You will be able to download it at www.cftrust.org.uk/publications the idea is to inform you about the level of care you should expect from your CF service.

Also, in the coming months the Expert Patient Advisers are having a new and improved role within the CF Trust. We will be known as Clinical care advisers, and will have more involvement with policy, politics and lobbying. We will still need your involvement to help us prioritise what national and local issue we should be working on and addressing. If you have any ideas please let me know! Some examples include transplantation/donation, clinical/hospital care, raising awareness of CF. You can contact me at lmorton@cftrust.org.uk Also don't forget to check out the Expert Patient Advisers face book page at www.facebook.com/epacftrust Lynsey

Clinical Psychology

Hi, my name is Sheila and I am the clinical psychologist who is part of the multidisciplinary CF team. I am also attached to the Department of Psychological Medicine based at York Hospital.

The CF team address all aspects of your health care and treatment which include psychosocial issues. A clinical psychologist works with people who are having difficulties in their life and would like help in coping with them. They use a wide range of psychological methods to help people assess and tackle emotional problems.

Living with CF as well as other life stresses can be difficult. Many people find talking over their problems with someone can be helpful. This might be a friend or relative, or might be one of the CF team who you feel you can talk to. This is often enough but there may be times when you have a complex issue to deal with and need more help than they can offer, or would like to discuss in private. A clinical psychologist can often help at these times.

Seeing a clinical psychologist does not mean there is anything wrong with a person psychologically. It simply means that a person is trying to improve their way of coping with problems and they want to learn new skills. I hope this information is useful and I hope to meet you all soon.

Sheila

Vitamins

Many of you will take vitamin supplements but do you know why?

Vitamins A,D,E,K are known as fat soluble vitamins. In cystic fibrosis low levels of these vitamins can often be found, primarily due to the difficulty many people with CF have absorbing fat, and therefore fat soluble vitamins. There are a number of other mechanisms that can affect vitamin levels so it is not uncommon for pancreatic sufficient have reduced levels also. Your vitamin levels will be measured at your annual review and dependent on the results you may be started on supplements or have your dose altered.

Why are these vitamins important?

Vitamin A: helps keep the skin, teeth, skeletal and soft tissue, mucus membranes, and cells in the eyes healthy. Low vitamin A levels can make you more likely to get infectious diseases and vision problems.

Vitamin D can be produced by your skin on exposure to the sun as well as from some dietary sources. Reduced vitamin D can lead to an increased risk of developing osteoporosis (thinning of the bones) as well as increasing your risk of developing infections.

To keep your vitamin levels within normal ranges it is important to

take any vitamins you have been prescribed daily. They should be taken at a mealtime when enzymes will also be taken (if required) to help improve the amount of vitamin you absorb. Vitamin E acts as an antioxidant, so it protects cells in the body from damage. It may play a role in protecting the lungs therefore can help reduce the progression of lung damage.

Vitamin K: Is involved in bone health and blood clotting. Low vitamin K levels can increase your risk of developing osteoporosis as well as slow down the time it takes for your blood to clot.

Contacting the CF team

If your query is not urgent E-mail:

cystic.fibrosis@york.nhs.uk

Dr Thomas (secretary)	01904 726045
Lynne Cairns	01904 725269
Janice Quarton	01904 726448
Tracey Daniels	01904 725528
Ward 34	01904 726034

Any e-mail that you send to this address will come to the whole CF team and the most appropriate person will respond to you within 24-48 hours during weekdays. Any e-mail sent to the team at the weekend will be responded to on the next week day.

Telephone: If your enquiry is outside of normal working hours, staff on ward 34 at York Hospital may be able to deal with your enquiry or you can leave a message.

In an emergency out of hours: You should seek assistance from either your GP or the A&E department.

The patient satisfaction survey... we're planning to ask you about your experiences and opinions of your CF service at York. We will aim to do this every year so that we can see whether changes we have made to the service are useful and to help us to plan any future improvements. George Bardsley is one of the doctors at York who isn't involved with the CF service. He will work with Lynsey Morton, the expert patient advisor at the CF trust, to complete the survey and report back to the CF team. The CF team will not know who has made each comment and we'd like you to be as honest as possible about what we do well and not so well. The results are really important so that we can continue to improve your CF service (and know not to mess with things that are working well) so we do ask that you take the time to fill in the survey and get it back to George and Lynsey as quickly as possible.