ISSUE 3 MAY 2015

CF NEWSLETTER

NHS Lothian

SCOTTISH ADULT CYSTIC FIBROSIS SERVICE

PEER REVIEW UPDATE

The Scottish Adult CF service underwent Peer review in November 2014. This was a review of the service carried out by the CF Trust in partnership with the British Thoracic Society (BTS). The CF Trust reviews every CF service in the UK every 5 years.

The peer review team were impressed with the quality and organisation of our service, which covers a wide geographical area in Scotland. They have made recommendations about increasing staffing in the CF team, in line with the CF standards of care. We have only seen the draft report so far. However when the full report is published, you will be able to read it on the CF Trust website.

Thank you for those of you who completed a questionnaire or telephone interview of our service. The results were presented to us on the day, and were very positive. It was nice to hear all your appreciative comments about the CF Team. The main areas for improvement were in parking and quality of the food. Both these areas have been discussed with the hospital management and will be discussed again at an MSP visit scheduled for May 2015.

We will let you know when the final report is posted on the CF Trust website.

Helen Rodgers

Director of Scottish Adult CF Service

Welcome to the third issue of our CF Newsletter.

Our aim is to update all patients on all CF service changes, news, research and publications.

We would like to include a patient section in your newsletter. If you would like to contribute please contact us in the CF Office on:

Tel– 0131 537 1762

INSIDE THIS ISSUE:

HOW WE MANAGE YOUR APPOINTMENTS

Out-patient Appointments

We currently have around 185 patients attending the Scottish Adult Cystic Fibrosis service so managing appointments can sometimes be a challenge. We have 12 appointment times available at every clinic where all members of the multi disciplinary team are available to see you. All cystic fibrosis clinic appointments are made according to microbiology status – this means what grows in your sputum.

Therefore it is important that you come to the clinic appointment you have been given. If you miss a clinic appointment we may not be able to give you another appointment for up to 6 weeks. We would like your help in ensuring we review all patients appropriately. Please help by attending your appointments as arranged and when unable to do so, please call/text/message us to rearrange **as soon as possible**.

During January & February 2015:

- 10 people did not attend clinic without letting us know.
- 32 appointments at clinic were not used due to last minute cancellations.

Cancelling on the clinic day can be difficult for us to refill appointments. We know you have times when you cannot make your clinic date, but would appreciate if you could tell us as soon as you can, so we can offer appointments to other patients.

Ward Attenders

If you need to be seen out with clinic appointments please call the cystic fibrosis office to arrange a suitable time. As a large Cystic Fibrosis service we will aim to see you as soon as possible, although this may not be the same day you call. When attending the ward for review we have to consider length of appointment needed, Doctor availability, cross infection and room availability.

Please help us by attending ward times as arranged and letting us know if you cannot make it or are running late. It is also important if you are originally booked for a short appointment (ie. blood test), and you are unwell and need a Doctor review, to let us know in advance so we can arrange a longer slot in our diary for you.

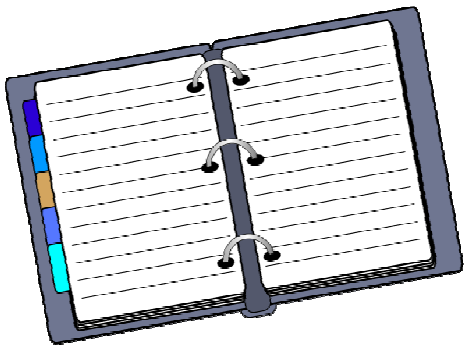
We appreciate your help in keeping your service running smoothly.

Contact details

Cystic Fibrosis Office Tel: 0131 537 1762

CF nurse mobiles: 07770326301 or 07770326302

Clinic A **(on clinic day only)** Tel: 0131 537 1317



WHAT TO BRING INTO HOSPITAL

Admission Checklist

When you are admitted to hospital please remember to bring the following items with you (we appreciate that not all these items will apply to everyone):-

- Your medication (both tablets and nebulised).

- Your nebuliser machine, including the chamber and lead.

- Your physiotherapy airway clearance devices.

- Your sinus clearance equipment

- Your BiPAP machine, tubing, mask / nasal cushions and lead

- Blood glucose monitor (if you use one).

FIFTY SHADES OF FIBRE

– how to get your belly full/pack it in

DIETARY FIBRE: FACTS AND FIGURES

Fibre is made up of the parts of plant foods that are neither digested nor absorbed in the small bowel.

- 18g of fibre per day is recommended for good health
- 70% of men and 90% of women in the UK don't meet this target

Annual review food diary analysis shows that the average fibre intake within our clinic is 8g per day (45% of target)

We would all benefit from increasing our fibre intake, read on to discover why…..

Insoluble fibre – traditionally known as "roughage", moves food along more quickly in your bowel helping to **reduce constipation** and **bloating**.

Good sources are wholegrain foods, for example wholegrain breads and crackers, wholemeal pasta, brown rice, wholegrain breakfast cereals (e.g. Weetabix and Shreddies), grains, seeds and nuts.

Soluble fibre – provides a food source for "friendly" gut bacteria, helping them to increase and produce substances which are thought to **protect** the lining of **the bowel**.

Good sources are oats, beans, peas, lentils, fruits and vegetables (aim for a minimum of 5 portions per day).

Why is a good fibre intake so important in Cystic Fibrosis?

Distal Intestinal Obstruction Syndrome or DIOS (a blockage in the bowel) is a common complication in CF and often requires admission and treatment in hospital. Taking more fibre in your diet, avoiding dehydration and ensuring that you take enough enzymes may help prevent DIOS.

Understanding food labels

Check the nutrition panel to check the fibre content of foods.

- A food containing 3g or more per 100g is a source for fibre.
- A food containing 6g fibre or more per 100g is a high fibre food.

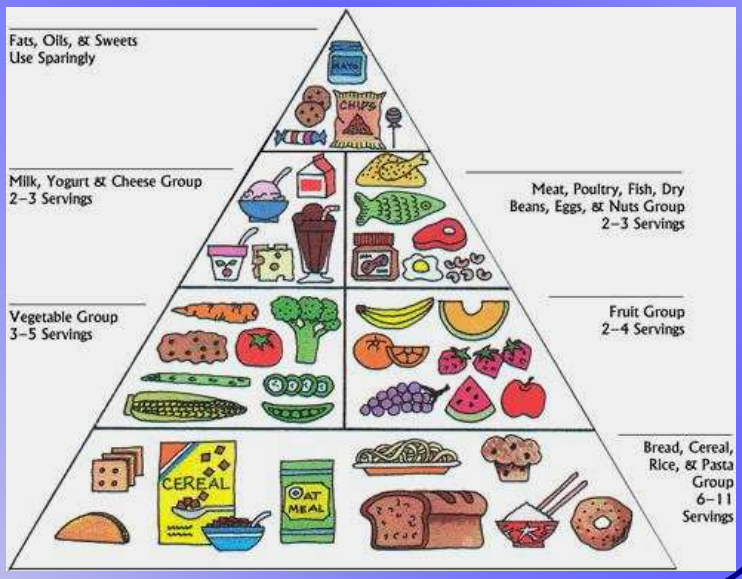
NOTE

IF YOU INCREASE YOUR FIBRE INTAKE, MAKE SURE YOU INCREASE YOUR FLUID INTAKE

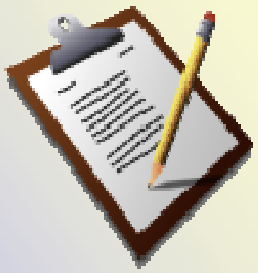
Important!

If you are trying to gain weight, please speak to your dietitian before increasing your fibre intake. High fibre foods help keep you feeling fuller for longer and may reduce your appetite for those important high energy foods and drinks.

INSTEAD OF	TRY	INCREASE IN FIBRE
BREAKFAST		
Special K with full fat milk	Special K plus 1 tablespoon chopped dried apricots with full fat milk	1.3g
White toast, butter & jam	Wholemeal toast, butter & jam	1.2g
Glass fruit juice	Glass fruit smoothie	3g
MAIN MEALS		
White pasta/spaghetti	Wholemeal pasta	5.1g
White rice	Brown Rice	1.2g
Jacket potato - flesh only & butter	Jacket potato with skin & butter	2.6g
Normal casserole	Add 1 tbsp cooked green lentils/serving	1.5g
Chicken Tikka & Rice	Chicken Tikka, Rice and 2 heaped tbps chickpea dahl	3.4g
Fruit crumble & custard	Wholemeal fruit crumble & custard	2g
LIGHT MEALS		
Chicken salad sandwich white bread	Chicken salad sandwich wholemeal bread	1.3g
Cheese on white toast with butter	Baked beans & grated cheese on wholemeal toast with butter	10.5g
Ham salad sandwich white bread	Peanut butter & banana sandwich wholemeal bread	4.2g
Fruit flavour yoghurt	Fruit salad with yoghurt	1.5g
SNACKS		
White scone, butter & jam	Wholemeal scone, butter & jam	1.7g
Crisps	Handful of almonds	0.9g
Crisps	Oatcakes	4g



TRANSITION FEEDBACK & EXPERIENCES



We asked some young adults and parents who had recently transitioned to the Adult CF Service to tell us a little about what this had been like for them.

They have very kindly agreed to share their personal experiences in our CF Newsletter. We really value their contribution – Thank you!

PATIENT 1- From a Transition Patient's Point of View

I have been keeping well and the transition has been smooth. Clinics have been fine and I feel I am handling my CF well. I miss the convenience of attending my local hospital as I am now travelling much more.

PARENT of PATIENT 1- From a Transition Parent's Point of View

As parents, the transition has been more of a challenge as it has put more focus on our relationship with our son. The big question for us is how can we support him to communicate with us that he is indeed well and he has talked about any changes, listened and taken on board information and advice given in clinics.

Our son is a typical teenager in that he does not want to talk about CF which is great but leaves a huge gap that used to be filled by talking things through with the CF nurse. We don't want to keep on asking too many questions or put pressure on him to say everything we would like him to say in clinics. It would have been more reassuring to have a bit more time to build up a relationship with the new team before letting go of attending the clinics altogether. What is difficult to deal with is the change from regular proactive IV's and antibiotics when we were heavily involved, to accepting that everything has been discussed at clinics without us, when it results in fewer prescribed treatments.

At the end of the day , our son appears well. We are learning to trust the professionals and yet not take too much of a back seat as the effects of letting things slide are all too important.

PARENT of PATIENT 2- From a Transition Parent's Point of View

As a parent who has dealt with only the Sick Children's hospital in Edinburgh since my child was diagnosed with cystic fibrosis at 2 weeks old, I faced transition to the adult team at the Western General in Edinburgh, with a sense of loss, fear and uncertainty.

The paediatric team were exceptionally efficient, caring, supportive, always willing to help and I trusted them implicitly with my child's care.

I now had to meet a whole new team and as well as getting to know them and develop trust in them, I had to accept hospital visits would now be very different as adult care focuses on the individual, not the parent's and carers.

I am only too aware and accepting of the fact that my child, now a young adult, has to learn to take care of himself but at 17 this young adult's mind focuses on their important things such as computer gaming, socialising, school exams and cystic fibrosis is far down the list of priorities. Whereas for me, cystic fibrosis is priority as I know without their health, they can't participate in other things.

I have been at every hospital visit throughout the past 17 years and been very involved and felt my input was valid. Now I am expected to take a back seat and expect a teenager, whose mind is elsewhere, to give accurate accounts of how they are feeling. This teenager who finds clinic a nuisance, in his busy schedule and really can't be bothered as he is being a typical teenager who can't be expected to fully understand the consequences neglecting health can bring. I, on the other hand, am only too aware but I am expected to sit outside or not be there at all, while he is seen by the various health professionals.

It is difficult to accept the changes from paediatric to adult care and I find it stressful but I have to encourage self care and autonomous decision making.

I know a young adult of 17 can no longer be taken care of at a children's hospital but as a parent you make multiple transitions throughout a child's life and their cystic fibrosis team has been a constant.

Transition for me is changing from the known to the unknown.

In our last newsletter, we wrote a little about our Parent/Carer Transition Open Evenings, which were set up in 2013 to allow parents/carers the opportunity to ask questions and to share their worries (like the ones mentioned in the personal stories included here) with some of the Adult CF Team. All those who have provided feedback from previous Open Evenings have said that they would recommend this evening to other parents whose child is about to transfer to our service. We have therefore planned another Transition Open Evening for Parents / Carers of those transitioning later this year on:

Wednesday 26th August 2015 at 7pm

If you would like to find out more or suggest any improvements to the transition process, please get in touch with:

Audrey Matthews or Catriona McMullan on (0131) 537 1762.

CF WEBSITE– COMING SOON

We are currently working on a CF Website for the Edinburgh Adult CF service.

Our website will be created on the NHS Lothian website and will provide lots of information on the following:-

- Information and leaflets on the Cystic Fibrosis Service
- Inpatient /Outpatient/ Admission information
- Transition/ New patients information
- Annual reviews
- What to do in an emergency
- Protocols/ policies and other information resources
- Our CF Team
- CF research & latest developments

Keep a look out for the launch of our CF website:

http://www.nhslothian.scot.nhs.uk/Services/A-Z/Pages/default.aspx

PHARMACY UPDATES

Creon 40,000iu

There is a supply problem with Creon 40,000iu. There is stock for now, but if you do find problems getting hold of this product then please get in touch. Most patients will be able to switch to Creon 25,000iu but it would be best to talk this through with the dietitians first. The hospital should have stock for a while if you can't get hold of any from your community pharmacy.

Annual Review

As part of the annual review process the CF pharmacist (Douglas) will contact your GP for a current list of your medication. This helps us to keep our list of medication up to date and to identify any issues that you may wish to discuss with the team about your treatments. We will assume you consent to this process unless you tell us otherwise. Please let us know if you would rather we did not contact your GP without your knowledge.

Butterfly Trust

The Butterfly Trust provides a variety of support services in the community for people affected by Cystic Fibrosis.

They provide advice on the following:

- ◊ **Information and advice**
- ◊ **Benefits and DLA**
- ◊ **Housing**
- ◊ **Employment**
- ◊ **Access to financial support**
- ◊ **Other specialist services**

Website- www.butterflytrust.org.uk

E-mail – info@butterflytrust.org.uk

KNOW YOUR GENOTYPE CAMPAIGN– 2015

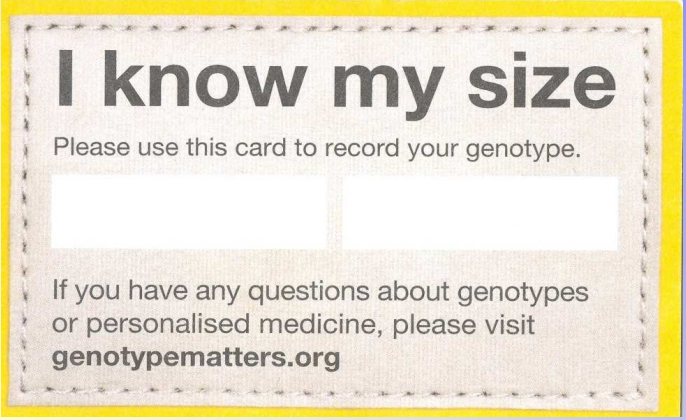
The CF Trust have launched a new website dedicated to helping you discover information that's unique to your genotype.

If you don't know your genotype then ask at your CF Centre at your next visit. If your genotype is already recorded, they will be able to tell you what it is. If it has not yet been identified, then they can arrange a test to find out.

The Cystic Fibrosis Trust will cover the costs of the test, so it won't cost you or your CF centre a penny.

For more information visit:

http://www.genotypematters.org



THE CYSTIC FIBROSIS TEAM

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Dr Maeve Smith	Secretary: (0131) 537 1781

CF Fellow

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Lynne McIntosh	CF Mobiles: 07770 326301/
Julie Robertson	07770 326302

CF Psychologist

Dr Audrey Matthews	Secretary: (0131) 537 1781

CF Pharmacist

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Nicola Duncan	

CF Data Manager

Dawn Wilson	Resp Office: (0131) 537 1108

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