

Dear All,

Firstly, I'd like to thank Lynne Gumery on behalf of the team for her massive contribution to the CF Centre over the years. Her tireless enthusiasm, drive, knowledge and passion for CF are inspirational and set an example to us all. We will be very sorry to lose you, but hope that you enjoy yourself in the States!



'Welcome' to Sarah Hackforth, Rebecca Jones and Sally Round as new members to the CF team. Sarah is a research nurse who will be helping with our CF clinical trials. Becky has joined the dietitians and Sally is Dr Nash's secretary.

On the theme of research, we have further clinical trials just round the corner. One will be an investigation of the effect of tiotropium (long acting, once daily airway 'opener') in CF. Another is the effect of inhaled heparin. Heparin acts to loosen sticky sputum, but may also reduce inflammation in the airways. Glutamine is an antioxidant, with positive effects on patients with other respiratory conditions. We will be trialling oral glutamine with Nottingham CF Centre.

We recently asked you to fill out a questionnaire during the clinic visit to analyse and hopefully improve how we run clinics. Thank you to all those who took part. The team were delighted that 89% of you thought that the quality of service we delivered was 'good' or very good'. We are anxious to improve in all areas and welcome feedback from you.

Unfortunately Kirpal (diabetes nurse specialist) has broken her ankle and will be off work until January 2009. Hope you feel better soon! And finally thank you to Anne Gray and Lisa Hodge for their input with this newsletter.

Best wishes,

Top Tips for Winter 2008

1. You need to have a pneumonia vaccination (Pneumovax) from your GP every 5-10 years. This protects against the commonest type of pneumonia.
2. As with all vaccinations, have them when you are feeling well, or immediately after antibiotics.
3. Allergy to fungal spores is common at this time of year. If you are feeling wheezy, have a tight chest or have a dry, irritable cough, let us know.
4. If you are planning to raise money for charity, the CF Centre Trustees have a 'just giving' web page already running. Please contact alastair326@btinternet.com for details on how to obtain tax back on charitable donations.

The "A" Team

Hi from Liz, Denise, Joe, Ann, Sally and Elaine (A for Admin that is!)

Liz and Denise are available on Mondays, Tuesdays and Wednesdays between 10am and 12 noon to install your laptops to give you TV access and to issue you with a Car Parking Pass whilst you are an inpatient on the ward. They are contactable on: 0121 424 2449 (Liz) and 0121 424 1810 (Denise)

Don't forget you can also book your Annual Review with Denise – so if you think that you are due an appointment please get in touch. Denise is also responsible for inputting data onto the national CF Database. If you haven't signed your consent form or want any further information please do not hesitate to contact her.

Elaine Chapman (CF Centre Manager) is responsible for the typing of travel letters so please contact her.

Joe Watson is our clinic receptionist and the friendly face and voice that you meet when you book into clinic or need to change an appointment over the phone. Joe can be contacted on 0121 424 1693.

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| Elaine Chapman | CF Centre Manager, PA to Dr Whitehouse | 0121 424 2261 or 424 1746 |
| Ann Lane | PA to Dr Honeybourne | 0121 424 3731 |
| Sally Round | PA to Dr Nash | 0121 424 3731 |

Dom Kavanagh - Your Expert Patient Adviser

Let me just introduce myself. I'm Dominic Kavanagh and I was recently appointed CF Expert Patient Adviser (E.P.A.) for the West Midlands & East Midlands regions. I am proud to cover these two regions, as I have lived in various parts of both regions over the last 23 years and was born in Stone, Staffordshire. Hopefully you have seen my poster in at Ward 26 Outpatients here at Heartlands.

I have been attending Heartlands CF adult clinic for five years, ever since I moved to Shropshire. I am 41 years old, married and have an adorable cat, but no children. I am lucky to still work part time for the Cystic Fibrosis Trust as E.P.A., thanks to great treatment and care from my team at Heartlands, my local Consultant at Royal Shrewsbury Hospital, support of family and friends, determination on my part to stick to treatments and stay active with exercise, and it must be said, some luck I am sure. But crucial, I think, is to remain positive as much as possible.

When not working, I enjoy photography, walking, riding my motorbike and drawing and painting and I try to go skiing in winter if I can afford it.



I'm just going to start going to the gym again, because I need to keep myself well and I have noticed how the lack of exercise has made me more breathless!

"What does an Expert Patient Adviser do?", I hear you asking. Well my main role is to represent you, as PwCF and the CF Trust in helping to ensure appropriate and safe care and treatment for all at CF Centres and clinics. There are 7 of us EPAs working throughout the UK, based at home but also frequently on the road attending meetings with hospital CF adult and paediatric teams, attending workshops and conferences which cover issues affecting all people with CF, as well as badgering hospital managers, commissioners, the Government and Department of Health representatives to ensure CF treatment and care is fully understood and properly funded.

Please contact me using the details below, with ideas and any topics you'd like me to cover:

Dominic Kavanagh, (EPA – West Midlands)
Cystic Fibrosis Trust,
11 London Road,
Bromley,
Kent, BR1 1BY

Tel. 0845 859 1057 Mobile: 07767 6128 82

Have you ever wondered how much it costs to look after you in hospital and covering the cost of your treatment at home?.. it's a real eye-opener I can tell you! But as I'm sure you'll agree, we all deserve the best treatment! Oh, if you were wondering.. the seven of us E.P.A.s never actually get together face to face due to cross-infection risk so we email, telephone each other or discuss issues in telephone conferencing sessions. To see the other CF E.P.A.s, check the CF Trust website (www.cftrust.org.uk) because we are all on there!



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"...my main role is to represent you and the CF Trust in helping to ensure appropriate and safe care and treatment for all at CF Centres and clinics"

In the coming months I will cover topics which either affect us all with CF and ones which may only affect certain people with CF. It would be ideal to have some input from you guys out there – tell me what you want to discuss or write about and get involved yourself... put pen to paper or bang away on that keyboard!

At 41 years of age I can relate to a lot of experiences people have with CF, so let's share them. I have a vascular port, a PEG for overnight feeding to sustain my weight, I'm monitoring my blood-sugar at the moment, but don't yet have diabetes. We can talk about these sorts of issues, or work and school related issues, relationships, living away from home, being a student with CF, travel insurance, benefits etc.. Of course I don't know all the answers, but that's where you come in..! Also, I often know a person who does know through my links with the CF Trust!

Keep well and I look forward to hearing from you.

Dom.

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"I'm just going to start going to the gym again, because I need to keep myself well and noticed how lack of exercise has made me more breathless!"

Lynne's Article and picture!

Bon Voyage to Lynne Gumery

We are pleased to wish Lynne Gumery good luck as she embarks on a move to New York State. Lynne has worked at the Heartlands Hospital with adults with Cystic Fibrosis for 27 years and has pioneered the development of the physiotherapy service which we now provide. Her passion and enthusiasm has been inspirational.

Lynne is pictured below with one of our longest serving CF adults, Neville Kennedy in 1987 at a CF conference in Oxford. From left to right Teresa Johnson, Paul Johnson, Lynne Gumery and Neville Kennedy.

Everyone wishes Lynne well for the future and we look forward to seeing her on her return.

Lynne says *"I would like to thank everyone for their good wishes and positive support regarding my adventure to the USA. I know the physiotherapists and multidisciplinary team will continue to provide an excellent standard of care to all the adults attending the CF centre. I will look forward to keeping in touch and hearing your news. If I do not see you personally before I leave I wish you good health and happiness, as always and hope to see you on my visits home. Best wishes", Lynne.*

Footnote....Love the hair Lynne!! Love the specs Neville!



Clinical Nurse Specialist Team

Hello! We would like to start by apologising if you have tried to contact us during the last 6 months by leaving a message on the answer phone in the CF nurses office. We previously had the answering service removed and were unaware that it had been reinstalled when a new telephone system was set up in the Trust!



Following the tiny photo in the last edition (for which the editor has eaten humble pie) we have demanded a proper sized photo this time! Welcome back from maternity leave, Fiona (and sorry you're not in our photo!) Unfortunately Kirpal Marwa, our CF diabetes nurse, has broken her ankle and will be off until January 2009. If you have any concerns regarding your diabetes please contact the CF nurses on our mobile number.

Tobramycin pumps

Once again we would like to remind you to return tobramycin pumps as soon as you have finished your course of IV antibiotics. It appears some pumps have not yet been returned. Please can you check if you have a pump at home and return it as soon as possible. If these pumps are not returned, cystic fibrosis patients are unable to receive once daily tobramycin.

Early discharge

We aim for in patient discharge before 1.00pm in line with Trust policy. We will try to ensure tto's are prescribed and on the ward before 1.00pm. Where possible please arrange to be collected during the morning of your discharge date.

Contact details:

If you need to contact us we have a mobile phone which is on between the hours of 08.30am and 4.30pm Monday - Friday.

We are happy to receive calls or text messages on:

Mobile number - 07971329933

If you have any concerns outside these hours, leave a message on the mobile phone or if it is urgent contact Ward 26 on 0121 4242226 and speak to the nurse in charge.

Concentrate on Calories



Eating well and maintaining a healthy body weight is important for everyone, but particularly if you have cystic fibrosis. Achieving a healthy body weight (BMI ideally 22) will help you to maintain your lung function, withstand chest infections and have a reserve of energy.

Individuals with cystic fibrosis have up to 50% higher energy requirements than those without CF.

Increasing the fat in your diet is the best way to improve your overall energy intake as 1 g of fat contains 9 calories which is more than double the calories in carbohydrate and protein. Don't forget to increase the amount of enzymes you take with fatty food.

6 steps to success

HOW TO GAIN WEIGHT

1. Try to get into a regular routine of 3 meals and 3 snacks daily.

If you do not enjoy eating when you get up in the morning, have a snack mid morning.

1. Try to have protein foods such as meat, fish egg, cheese, beans, lentils or nuts at least 3 times a day.
2. Avoid foods that are low in fat, low sugar or low calorie.
3. Have a least 1 pint of full cream milk daily. This can be used in puddings, drinks or cereals.
4. Have a pudding once or twice every day,
5. Add more calories to your food by adding fat and sugar as often as possible - fry your foods. Spread butter/margarine thickly on bread and adding to potatoes and vegetables. Add cheese to potatoes and soups. Add sugar to cereals and puddings. Spread jam/honey/syrup on toast.

Snacks that contain 250 calories each:

- 2 scoops ice cream
- microwave fries
- 1 slice of toast with thickly spread peanut butter
- packet of Walkers Max crisps
- chocolate bar
- sausage roll
- 2 crackers with cheese and butter
- cream cake

Snacks that contain 450 calories each:

- 100g medium bag peanuts
- chocolate donut
- $\frac{1}{2}$ tub of Pringles
- pot noodle
- bag of toffee popcorn
- Chocolate covered flapjack
- Scandishake (600 calories)



Did You Know?

10% of people with CF develop an allergy to a fungal spore called 'Aspergillus fumigatus'. This problem presents with asthmatic symptoms and sometimes new chest X-ray changes especially at this time of year. We can check for this allergy with a blood test. This condition is treatable with steroids (anti-inflammatory) and itraconazole (anti-fungal).



International Research Links for Heartlands!



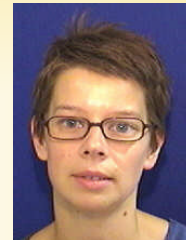
Our centre has been chosen to be one of only 2 adult CF centres in the UK to be part of an exciting new European CF Research Network. This will mean that our centre is at the cutting edge for future research projects, involving several new promising approaches to treatment.

I recently attended the inaugural meeting of the Network at the University of Leuven, near Brussels. The Network will be co-ordinating research amongst selected major CF centres like our own all across Europe. Some studies need large numbers of patients in order to get accurate results and this will be an ideal way to achieve it. The network will also help to ensure that high quality research is carried out. I will be involving the whole CF team in this venture and we hope to start some pivotal studies next year. We will be approaching you to ask for your help!

Dr David Honeybourne

An Introduction to me!

It fills me with trepidation when I'm asked to write something about myself for a newsletter...so I'll be brief! I'm Sarah Hackforth and I'm a Research Nurse who joined the CF team in September.



I've come to work 3 days week carrying out Clinical Trials into new treatments for CF. You will see me wandering around the unit wearing a rather fetching black and red uniform during clinics. I may approach you about taking part in studies along with the Doctors. Please feel free to ask me what studies we are doing in the department...I'm always happy to take time to explain things to you, and if you are interested in taking part then that is even better!

My background was previously as a Specialist Nurse in Infection and Tropical Medicine here at Heartlands, where I also carried out lots of Clinical Trials. When I am not at work, I can be found embracing the joys of parenting, with my 3 energetic boys at home.

Sarah Hackforth

Mind Matters

Seasonal Affective Disorder



So summer is officially over and the winter months are looming. For some this may be the perfect opportunity to hibernate in front of a cosy fire but between 2 and 10% of the population are thought to suffer from a type of winter depression called Seasonal Affective Disorder (SAD). If you have spotted a pattern, over three years or more, where you feel low in mood between September and April, then you may too suffer from some degree of SAD. Other symptoms include anxiety, sleep problems, a lack of energy, overeating, social withdrawal, low libido, irritability.

The exact causes are not fully understood but SAD is rare in people who live closer to the Equator. Therefore, theories suggest that biochemical imbalances caused by a lack of natural sunlight are responsible.

And failing that, if you are thinking of decorating, a psychologist has suggested that the colour green is soothing and helps to create a sense of calm!!!

Good Luck for the months ahead and remember I am here if you are struggling.

Anna

Management Strategies:

- Try to get outside each day
- If possible, sit next to a window when you are inside
- Take regular, moderate exercise preferably outside
- Try to eat a well-balanced diet
- Avoid unnecessary stress and learn relaxation strategies
- Psychotherapy to help accept and cope with symptoms
- In severe cases, antidepressant medication may help
- Phototherapy or Light Therapy for 1-2 hours each day

Useful websites:

Seasonal Affective Disorder Association:

www.sada.org.uk

Mind: www.mind.org.uk

Mental Health Foundation:

www.mentalhealth.org.uk

BUPA: hcd2.bupa.co.uk

New Broadband Facilities



Just to update you all the line has now been installed on unit, we are just waiting for that to be made live and then we can get the router and access points in place.

The benefits will be the use of email facilities ie hotmail and other web-based emails, skype facility and much more.

I would like to take this opportunity of thanking the trustees for financing this, without which it would not be possible.

Lisa
IT



Above: Catherine Miller treating Adrian Duncan with acupuncture

If you would like more information or to discuss whether acupuncture can help you then please contact the physiotherapy team on 0121 424 1780 or catherine.miller@heartofengland.nhs.uk

AcupunctureWhat is it?

Acupuncture forms a part of traditional Chinese medicine, an ancient form of healing that developed over several thousands of years. Acupuncture is a system of medicine that aims to improve and maintain health by the insertion of needles into specific points on the body. Placing needles into the skin at these points stimulates the body to 'rebalance' itself, encouraging homeostasis by activating our own self-healing powers.

Who can it help?

Acupuncture can be used to treat a wide range of conditions. The physiotherapy service offers acupuncture treatment for the relief of sinus pain, nasal congestion and associated frontal headaches which are symptoms commonly reported in adults with CF.

What does it involve?

The acupuncture needles are very fine, single-use disposable needles. Usually 6-8 needles are used, depending on your needs. Most people receiving acupuncture for the first time are concerned that it will hurt. While it should not be painful when the needles are inserted, there is a 'needle sensation' that may be a tingling or feeling of numbness. Sometimes the needles are left in for 10-20 minutes for maximum benefit.

Comments from other CF adults have also been very positive:

"I am pleased that alternative therapies are considered.....I have benefited from this and was happy with the results"

"The acupuncture was great for relaxation and I slept really well afterwards. I would definitely recommend it!"

" I was very sceptical when offered acupuncture as I didn't believe it would work, however after every treatment my oxygen saturation improved, my breathing rate decreased and my sinuses felt better....so I'm very pleased with the results and am no longer a sceptic "

NEW CF WEBSITE

We are also re-launching our new cf centre website (www.heartlandscf.org). The new design will give us much more flexibility and interaction. This will be complete in the next few months.

Patient articles are very important and we are keen to hear off any of you who would like to submit.

Please send your article to the following email addresses.

joanne.barrett@heartofengland.nhs.uk

lisa.hodge@heartofengland.nhs.uk

Laptop Security

Please can you ensure that the tv cables are disconnected from wall and put into safe before going home.

The safe does require the lock to be turned to be locked, please ensure you check that you cannot open before you go home.

Thank you

Social Update - have you heard..?

latest news!

PRESCRIPTION CHARGES

Slow progress in the campaign for free prescriptions



The Government recently announced that they're scrapping prescription charges for cancer patients next year. In addition, they are promising to *eventually* phase out charges for *all* patients with long-term conditions and to consult relevant groups about which conditions to cover... *however* ... there's *still no* timescale for change!

They've already got a good idea of the patient groups affected, as support organisations like the Cystic Fibrosis Trust have been lobbying for years. Plans for consultation were first mentioned months ago, with the emphasis being on finding a "cost-neutral" solution. Consulting the public can be used as a way to delay taking action until funds are available.

Costs for cancer patients' will be recouped through savings made by switching from branded to generic drugs and by increased bulk-buying. The long term promise is that further savings in the NHS drug budget will be ploughed into abolishing charges for everyone with long-term conditions.

So, while other regions move towards reducing charges, England needs to wait a bit longer. The official spirit is willing to change, (in line with the rest of the UK) but the funding is weak!

Free prescriptions for people with CF will happen
..... it's just a matter of *when??*

Anne Gray

Did You Know?

10% of people with CF develop an allergy to a fungal spore called 'Aspergillus fumigatus'. This problem presents with asthmatic symptoms and sometimes new chest X-ray changes especially at this time of year. We can check for this allergy with a blood test. This condition is treatable with steroids (anti-inflammatory) and itraconazole (anti-fungal).