

## Newsletter Launch

Dear All,

I'd like to welcome you to the first edition of the Birmingham Heartlands Hospital CF Unit newsletter. Over the last few months we have several newcomers to the CF Team, including Anna Regan (psychologist), Kirpal Marwa (diabetes nurse specialist) and Ed Nash (CF consultant).



I'm also sorry to say that Joanne Osmond left in April. She was 'head-hunted' for a post at the CF Trust and her new job involves trying to improve the financial situation for all CF Units in the UK, by securing fairer, national funding from the government.

We wish you 'all the best' Jo!

*Jo Whitehouse*  
Consultant Physician

## Clinical Psychologist

Hello. I'm Anna Regan and I've been working here for six months now. Before that, I worked in the field of substance misuse. I have a long interest in working with people with physical health problems and I'm very happy to be part of the team.

We know that living with CF can present many emotional challenges on top of all the usual life difficulties. In addition to demanding treatments, people may also face work and relationship stress, fears about dying, body image concerns and worries about medical procedures. These concerns are all understandable and unsurprisingly people sometimes struggle to cope and become anxious or depressed.

Psychologists are specifically trained to carry out 'talking therapies'. The ultimate aim is to help you better understand and cope with whatever difficulties you are facing. At the first meeting, I will ask you to tell me about your problems and together we agree on how you can best be helped. Treatment is usually between one and six sessions, and each one lasts for fifty minutes.

I work as part of the wider multidisciplinary team but anything you tell me remains confidential except in very rare circumstances. If you would like to see me then you can either refer yourself or speak to another member of the team and they can refer you. If you would like some more information or to ask any questions, please feel free to contact me on 0121 424 2987. I work in the CF service on Tuesdays, Thursdays and Friday afternoon.

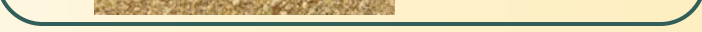
I am trying to introduce myself to as many people as I can and look forward to meeting you all over the coming months.

Bye for now. Anna

## Top 10 Tips for Summer 2008

1. If you are admitted to your local hospital for any reason, please inform us (012142441746 or mobile 07971329933). The reason is that your medical problem may relate to CF. Even if not, the local team **may** still need advice on your CF management. Contacting us ASAP can save you from delays to treatment or even unnecessary surgery.
2. If you are planning to become pregnant, be aware that we run a monthly joint respiratory/obstetrics clinic and are very happy to see patients planning pregnancy in addition to those who have already conceived. This is important as your medication may need to be altered.
3. If you have had an annual review and have not heard about all the results, let us know! (012142441746)
4. Car parking—now FREE if you are an inpatient or main carer visiting.
5. A new clinic starting is a diabetes nurse/dietician—led clinic. This will be led by Kirpal (monthly). If you have any queries about your diabetes control or treatment, contact Kirpal on 0121 4243577 or email [kirpal.marwa@heartofengland.nhs.uk](mailto:kirpal.marwa@heartofengland.nhs.uk).
6. Don't bother with the pre-holiday diet this year
  - a. They don't work (trust me on this one)!
  - b. Lung function is directly proportional to weight, so if you lose weight you lose lung function.
7. If you have transitioned to Heartlands in 2008, make sure that you see the same doctor for the first year. It helps us get to know you and you to know us.
8. If you have *Pseudomonas*, consider attending one of the Monday afternoon or Friday morning clinics, instead of the usual Tuesday/Thursday slots. The Monday/Friday clinics are much less crowded!
9. Make use of Baljit Ahitan, our CF pharmacist. Some of you will have already met her in our clinics. She is a fantastic source of knowledge and help for queries/problems relating to medication (contact details).
10. For up-to-date information on the unit, including research projects you may wish to take part in, try our website at [www.heartlandscf.org.uk](http://www.heartlandscf.org.uk).





# Enjoy the Great British Summer!

As we move into the summer months we all hope the weather will improve and bring us some heat and sun! Summer is also the time of year when many of us choose to take a holiday abroad where we are guaranteed hot weather.

Well, in 3 ways:

- ☀ Vitamin D
- ☀ Salt
- ☀ Hydration



## Salt and Hydration

When you have Cystic Fibrosis you will lose an increased amount of salt when you sweat. Salt is an essential mineral the body needs to help regulate water and fluid balance. If your body becomes low in salt, you can become dehydrated, even if you are drinking plenty of fluids. You therefore need to replace this salt by taking salt tablets and/or adding salt to your food.

### When will I need extra salt?

You will need extra salt if:-

- ☀ The weather is warm
- ☀ If you work in a warm environment, e.g.; leisure centre or factory.
- ☀ If you have a fever
- ☀ When you exercise (if exercising is enough to make you sweat).

### How can I take extra salt?

- ☀ You can add salt to your food to a level of taste you find acceptable.
- ☀ You can take salt tablets.
- ☀ You can also eat salty foods but you may need tablets as well if the weather is very hot.

### How many salt tablets should I take each day?

The usual dose for adults with CF is 4-8 tablets of slow sodium (600mg) daily. These should be taken at regular intervals during the day, e.g.; 2 tablets 3 times per day. If you are in an extremely hot environment you may need more. To compensate for an exercise session 2 tablets may be sufficient. Always drink plenty of fluids as well.

### Remember!

The more you sweat the more salt you need! Drink plenty of fluids, especially in hot weather, after exercising or if you have a high temperature. If you have a kidney problem or high blood pressure, do not follow these guidelines. Discuss the amount of extra salt you should take with your doctor in CF clinic.



Joanne Barrett  
Specialist CF Dietitian



## Vitamin D

One of the good things about more sunshine (we are ever hopeful!) is that it can improve your vitamin D level. By Having short periods of sunlight exposure between the months of April and October in the UK, your body can make vitamin D. Sunshine can also cheer you up - apart from the obvious positive associations we have with a sunny day, the sun can alter your mood chemically and even prevent depression.

### How can I improve my vitamin D levels with sunlight exposure?

UVB light reacts with the skin to produce vitamin D. You need about 15 minutes exposure on your hands and face to make about 2000 units of vitamin D. This exposure needs to be without sun cream, but don't over do it! A sun lamp or sun bed will also have the same effect, but again overuse increases your risk of skin cancer. It is also important not sunbathe if you are taking Ciprofloxacin or Doxycycline as this can make your skin very sensitive to the sun.

### Why is vitamin D important?

Most people with CF are prescribed fat soluble vitamins including vitamin D as without them they would become deficient. Vitamin D is needed to help the body to absorb calcium from the diet and maintain bone strength.

### Did You Know?

**BMI** – stands for Body Mass Index. We use this to measure whether or not your weight is appropriate for your height. It is calculated as weight/ (height X height). The normal range is 20 – 25.



## New Consultant in the CF Team



My name is Ed Nash and I am the new CF consultant at Heartlands. I previously worked in the CF clinic in Bristol and recently spent 12 months in Canada as the clinical and research CF Fellow in the Toronto Adult CF Clinic. I also worked as Lung Transplant Fellow at Toronto General Hospital, one of the largest transplant centres in North America. I am delighted to be appointed as Consultant in the West Midlands Adult CF Centre because the unit has a very good reputation and excellent facilities. My time in the UK and Canada has given me experience in helping to care for patients with CF and I hope to be a useful addition to the already excellent multidisciplinary team.

The compassion and skill that I witnessed in my time in Toronto were inspirational and it was fascinating to see how they looked after CF patients. There were many similarities in their approach, but also differences. They have faced a great number of challenges in dealing with nasty lung infections, and their antibiotic choices for certain bacteria differ to those commonly used in the UK. They carry out lots of research in CF, with many patients happy to get involved with research projects. The patients' view was that research was a

vital part in our improving our understanding of CF, and enables us to try out promising new therapies. I was lucky to be involved in several research projects in Toronto, and part of my role at Heartlands is to further develop the research programme – so expect to be asked to consider taking part in research studies over the next few months!

My time at Toronto General Hospital also showed me the potential benefits of lung transplantation in CF. There are close links between the CF clinic and the transplant programme in Toronto, and they have very good post-transplant survival figures in CF patients. I hope that my experience in transplantation will be useful in giving advice to patients awaiting lung (and liver) transplant, as well as those who have undergone these procedures.

I am really looking forward to getting to meet you, although I'm sure that it will take a while before I get to know you all. Thanks for taking the time to let me introduce myself – I hope to meet you many times in future, although not too many!

## Adult Pharmacy Services



Welcome to the pharmacy section of the CF newsletter. If I have not yet had the pleasure of meeting you, my name is Baljit and I am the CF pharmacist here at Heartlands.

What I would like to do through this section is to keep you all informed on developments in the pharmacy services, and also provide you with information on the medication you may be taking. It goes without saying that if there is anything you would like to see here, any questions you may have, please do not hesitate to get in contact. My contact details are below.

### **Outpatient Boots Pharmacy**

It has now been a year since Boots started to dispense your outpatient prescriptions. Overall, the service has been very well received and I have had some very useful feedback.

If you do have any comments on the current service or suggestions on how you would like to see it develop, I would be very interested in hearing from you.

### **Prescriptions for nebulised Pulmozyme® and TOBI®**

If you are one of the patients for whom we send out regular prescriptions to your community pharmacy, we are looking to change the process over the next couple of months. As you are aware we currently post prescriptions on a regular basis.

We have had feedback from both yourselves and community pharmacists of numerous instances of prescriptions and/or medication supplies building up, either in the pharmacy or your homes.

Just as you order repeat medication from your GP, we would like you to contact us and request further prescriptions. The plan is to have a dedicated email address, as well as a telephone number. I will let you have the contact details in due course.

Baljit Ahitan, CF Pharmacist  
Tel: 0121 424 3914 (direct line)



### **Tobramycin Pumps**

We would like to remind you to return tobramycin pumps as soon as you have finished your course of IV antibiotics. These pumps are on loan only therefore prompt return enables other patients to receive this treatment. Your co-operation is much appreciated. Thank you.



## Marathon Man - by John East

### How to (or maybe not in my case) raise money for Cystic Fibrosis

My name is John and I recently ran the London marathon to raise funds for Cystic Fibrosis for ward 26 Heartland Hospital. My wife Lynne suffers from Cystic Fibrosis and is a great example of the sort of spirit shown by those who have CF. The money raised from events like this has helped enormously with understanding how to treat this disease and as a result the life expectancy of sufferers has increased considerably over the years. Mission completed in 4hrs 11mins and 25secs. Pity I didn't break the 4 hour mark but things didn't go exactly according to plan and by the end it was an achievement to even finish.

The story started about a week before the race when I went to the chiropodist as I was experiencing some discomfort in my little toe. I was told that the cause of the problem was the fact that the arch of my foot had dropped and the extra pressure on the outside of my foot was rotating the metatarsal bone causing the pain. So I was prepared for some discomfort.

At the marathon exhibition I was advised to tape the toe up to avoid a blister, so I did.

Off we go on the big day. After 3 miles I felt the onset of a blister on the sole of my foot. OOPS. So I decided to carry on, with some stupid idea that it might go away if I ignored it. I got to 20 miles when I felt a pain in my foot like that I had trodden on something sharp, a bit like getting a small stone inside the shoe. The shoe then started to turn red. I walked for a bit, stopped for a drink and heard my son Simon shout for me to carry on, so I did. At this time I was approaching the embankment and the noise, encouragement and enthusiasm of the crowd over these last 4 miles was inspiring and pushed me on to the finish. Even if I wanted to stop I don't think they would have let me. So around Big Ben and towards the Wedding Cake I ran, and I saw a sign that said 400 yards to go and half a mile later another said 200 yards to go and then after a further mile I remembered the cameras and showboated the last 5 yards crossing the finish line in 4 hrs 11 mins a personal best thrashing my previous record by a full 4 mins. Fantastic.

I then hobbled to the Medical Centre where it was warm and dry. The Medics said that the blister on the sole of my foot was the biggest that they had seen that day. It was 4 1/2 inches long and 2 1/2 inches wide and was probably caused by me overcompensating trying to protect the toe. I had taped the toe too much and this had caused it to burst on 20 mile. They gave me tea, sympathy and a bit of TLC. I went into the medical centre feeling downhearted and came out feeling a Hero.

Still the most credible achievement on the day is that you collectively gave money approaching £2,000 to Ward 26 of Birmingham Heartlands Hospital.

## CF Outpatients Clinics

Day	AM/PM	Week	Clinic type
<b>Monday</b>	PM	1	Non-pseudomonas
		2	pseudomonas
		3	pseudomonas
		4	pseudomonas
<b>Tuesday</b>	AM	1-4	pseudomonas
<b>Thursday</b>	PM	1	pseudomonas
		2	DM / pseudomonas
		3	Obstetric / pseudomonas
		4	pseudomonas
<b>Friday</b>	AM	1	Cepacia only
		2	pseudomonas (SpR only – urgent slots)
		3	pseudomonas
		4	pseudomonas (SpR only-

### Other clinics held:

- Monday and Wednesday morning Annual Review (Weekly),
- Tuesday PM Transition (bimonthly)
- Thursday PM Diabetic Nurse led (monthly).
- A CF nurse-led clinic is held every Tuesday and Thursday.

Please remember to telephone and let us know if you are unable to attend your hospital appointment, so that another patient can use your clinic slot.

It is important to arrive for your appointment on time unless you are unavoidably delayed. If that happens just let us know. We do realise that many of you travel quite a distance. You will be seen by order of appointment time and not arrival time.

To cancel an appointment/re-arrange an appointment please contact Joanne Watson – Clinic Receptionist on 0121 424 1693.

Elaine Chapman



## Compliments to Ward 26!

The West Midlands Regional Adult Cystic Fibrosis Centre opened its therapy room in September 2007. Since then it has become very popular with both CF adults. This innovative physiotherapy led service offers additional complimentary therapies which included reflexology, Indian head massage, acupuncture and musculoskeletal treatments. Occupational Therapy also offers relaxation sessions using guided imagery or autogenic muscular relaxation.

We are very grateful to Gregg Smith who invited his friend Paul Delves and family to the opening for providing funding towards the running of the therapy service.

All therapies are designed to complement treatments already being received by patients. We believe it is important to look at the "whole" person, taking into account their medical history as well as their lifestyle, before devising a treatment programme tailored to individual needs. We hope this service continues to grow, to enable us to provide a high level of integrated care for all CF adults.



Pictured above (left to right): Dr Honeybourne, Dr Whitehouse, Ian Culligan, Gregg Smith, Lynne Gumery, Andy Szykuta, Aruna Kailey, Joanne Osmond, Joanne Lee, Roisin Delves, Georgia Delves, Paul Delves.

### Feedback from patients so far has been very positive:-

*"Absolutely fantastic experience! Would recommend it to anyone. I am so grateful."*

*"Being the first time I've experienced anything like this, I didn't know what to expect but needless to say I wasn't disappointed, I found it very soothing and relaxing."*

*"Very good idea, very relaxing. Helped a lot, 10 out of 10. Thank you. "*

If you would like more information about any of these complimentary therapies then please contact the CF Physiotherapy team on 0121 424 1780 or 0121 424 1577

## Indian Head Massage ... my recent experience *by Lynne East*



**Aruna Kailey carrying out an Indian Head Massage with Lynne East**

My name is Lynne I am 50 married with one child Simon age 16 and yes I have CF but not diagnosed until 2004, although I have always suffered with chest related problems. I have been treated at Heartlands Hospital shall we say for what seems a life time, the staff have seen me grow old and shall we say I have seen some of them mature quite well!!!!

I have always been game to try new ideas relating to the illness so was well chuffed when I heard the Physio Department were moving into holistic treatments, this sounded much more fun than new drugs with horrendous side effects.

An appointment was made for me and on the due date I arrived a little apprehensive and sceptical of how an Indian head massage could be a relaxing treatment within a hospital environment. I need not have worried! I was greeted by Aruna who led the way to what could only be described as a room totally transformed from the sterile hospital rooms to deep colours soft lights mood music and a wonderful aroma of oil.

Aruna made me feel very comfortable and relaxed as she explained the treatment to me and the benefits that I would experience. With the lights turned low soft music playing and me suitably draped in a towel the massage began, I had chosen Jasmine oil for my treatment. The massage is performed sitting so no need to worry about lying down and coughing, the oil is massaged into your back, shoulders and neck before starting on the head.

The technique is very professional and pleasurable in fact it's a job not to drop off to sleep, Aruna then moves onto the head massaging the oil through the scalp a wonderful experience of massage and pressure points, just one word of warning do not plan to go out the evening as Aruna likes you to sleep with the oil still in your hair, I was a little bit alarmed by this as I looked like a greased monkey, but all I can say is it was well worth it.

I would recommend this treatment to anyone it is so relaxing and you have the feeling of total wellbeing in your own bit of

paradise, I look forward to the next breakthrough in the treatment of CF.

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## The CF Clinical Nurse Specialist Team

Hello, we are the clinical nurse specialists here at the Heartlands Adult Cystic Fibrosis Centre. There are currently six of us working in the nursing team.

The specialist nurses are Christine Evans, Ruth Davies, Josie Hussey, Nicky Gilday and Fiona King.

We would like to welcome Kirpal Marwa to the team. Kirpal has been recently appointed as a diabetes specialist nurse for patients with CF related diabetes. Kirpal will provide education and support on: blood glucose monitoring, starting insulin, insulin regimens, how to adjust your insulin, diabetes and exercise, carbohydrate counting and many more diabetes related issues.

The C.F specialist nursing service provides support to patients whilst on the ward, in the outpatient clinic and in the community. This could include your home, place of work or college.

Our role is to ensure that you receive the highest level of nursing care. This includes providing specific advice support and education tailored to your needs. We can also give support to your family or carers.

The specialist nurses can be your first point of contact if you have any concerns or worries. We have a mobile phone which is on between the hours 8.30 am and 4.30 pm Mon – Friday.

**Mobile number** – 07971329933

If you have any concerns outside these hours, contact Ward 26 on 0121 4242226 and speak to the nurse in charge.

## Social Update - have you heard..?



Here's a few of the many changes to social legislation that you might like to know about ...

### CONCESSIONARY BUS PASSES *(good news!)*

#### Amendments to the Concessionary Fares Scheme

This scheme has provided discounted fares on public transport since April 2006. Eligible people (aged 60+ or disabled) have been able to claim free off-peak travel in their local area. From 1 April 2008, it has been extended to allow free off-peak bus travel in every area of the country.

If you're fed up with rocketing petrol costs and would like a buspass, contact your local council for details. In the West Midlands, the scheme is managed by Centro, the West Midlands Passenger Transport Authority, so contact a local Travel Centre or download a form from their website.

### INCAPACITY BENEFIT *(waiting for news!)*

#### Planned abolition to make way for a new benefit

Employment and Support Allowance starts in October 2008. ESA replaces Incapacity Benefit & incapacity-related Income Support.

#### Who's affected?

- All new claims from 1 October 2008 - no plans yet to switch existing claimants.

#### What's new?

- ① Medical assessment to check what you can do, not just what you can't do - usually by a trained doctor or nurse.
- ① Expectation to take "reasonable steps" to prepare for a return to work and explore any help you may need to do so.
- ① Most severe levels of disability won't need interviews, just written evidence from someone involved in their care.

#### Pros & cons?

We don't know yet until more specific guidelines come out.

### HOUSING BENEFIT *(not-such-good news!)*

#### Changes for tenants in the private rental sector

Private tenants can only claim partial help with rent. The rules changed on 7 April 2008 when Local Housing Allowance (LHA) was introduced. It is the maximum amount of Housing Benefit (HB) payable for privately rented accommodation in a specific area, depending the size of the property and who lives there. Just like HB, all claims for LHA are dealt with by the local Council housing department.

#### Who's affected?

- Private tenants making new claims for help with their rent, from 7 April 2008.
- All private tenants claiming HB will eventually move onto LHA, possibly by April 2009.

#### What's new?

- ① Set formula to fix the maximum amount of benefit payable, in a defined area.
- ① Change to rules about how many bedrooms you can claim for.
- ① More restrictions for tenants under 25 years old

#### Pros & cons?

- ✓ Benefits tenants in the cheaper properties as it's based on the average rent in their area.
- ✗ Penalises some under-25yrs and those in living larger properties who don't qualify for extra rooms.

Anne Gray  
CF Social Worker



We'll want to hear from the first claimants in the new system.  
***Watch this space!***

Tel: 0121 424 2530

Email: [Anne.gray@heartofengland.nhs.uk](mailto:Anne.gray@heartofengland.nhs.uk)



## And finally.....have you heard?



### **BIRMINGHAM TEAM SCOOP TOP HEALTH AND SOCIAL CARE AWARD**

A Project from Heartlands Hospital in Bordesley Green was named a winner in the national Health and Social Care awards last night, which recognises breakthrough ideas from people on the front-line to improve care and access to services.

The project, which scooped the 'Innovative Information and Communications Technology' award, saw the hospital come up with a range of initiatives to improve access to information on Cystic Fibrosis for patients and their families, including a localised website and a touch-screen kiosk for friends and carers.

Having seen off considerable competition earlier in the year to become regional winners of the Health and Social Care Awards, the team successfully saw off two other national finalists to be selected overall winner by the NHS Institute for Innovation and Improvement and the Department of Health.

With other categories such as the 'Peoples Experience Award' and 'Dignity and Care', the 14 awards recognise projects across care and community settings, with many of the winning projects the result of collaboration between health, education, local government and social care professionals.

Other winning ideas from around the UK include a pioneering scheme in Hackney, which trains teenagers to provide sex education to their peers, the winners highlight the scope of ideas emerging across the UK; and an occupational therapist who started a football league for people with mental health issues.

Commenting on their success, Dr David Honeybourne from Birmingham Heartlands Hospital, said; 'with this project, we've cracked something that can really make a difference to the way care is provided. We're keen to share our learning more widely so that others can copy it for themselves. This award is an important step in that process'.

