

Dear All,

Here's hoping that Spring is paving the way for a great summer... Welcome back Kirpal – I hope that your ankle is fixed now. Congratulations to Elaine Chapman on becoming the new CF Centre manager.



Congratulations also to Dr Rifat Rashid on becoming our second CF Centre Fellow, alongside Dr Richard Whitmill.

Since Lynne Gumery left our most senior physio post based on the unit has yet to be filled. However, Paula Agostini has been appointed as the chief physio in respiratory medicine and will have responsibility for our CF physios. She is particularly interested in driving forward physiotherapy research within the unit. Welcome Paula!

In the last few weeks our ward 26 'Code of Conduct' has been revamped. This document is available for you to read in patient room and will be handed out to in-patients and those new to the unit.

The inhaled tiotropium (long-acting airway opener) and nebulised heparin (mucolytic and possible beneficial effects on immune system) research trials are now underway. We are also part of a national psychology in CF study, which is questionnaire-based. Anyone wishing to find out more should contact Sarah Hackforth on telephone number 0121 4242762.

Last but not least Jo Lee (CF physio) has given birth to a beautiful baby girl called Charlotte.

Best wishes,

Jo Whitehouse

Top Tips for Spring 2009

1. Do you ever have a shaky/hungry/nauseous feeling, which is relieved by eating? If so, you may have low blood sugar (hypoglycaemia). These episodes may be the first sign of reduced blood sugar control, which can be treated initially by changes to your diet. If these symptoms are happening to you, please let us know!
2. If you are going abroad let the CF docs and/or Elaine Chapman know because you need a 'fitness to fly' letter outlining all the medication, nebulisers, needles etc...that will be in your luggage. The minimum turn-around time for these letters is 10 days.
3. If you are travelling to a place where there is no fridge available, consider requesting a trial of nebulised hypertonic saline instead of DNase for the trip. Hypertonic saline is a mucolytic taken once daily that does not need to be refrigerated.
4. If you have a different blood testing meter from the one that is used on the ward and you would like to test your own blood sugars, please bring your blood testing strips for your meter.

Don't forget to visit

www.heartlandscf.org

The new website will be going live June 1st



Jo Lee and baby Charlotte

The Administration Team would like to officially welcome Janet Jukes to their team as Medical Secretary/PA to Dr Whitehouse. Her contact number is 0121 424 1746.

This follows the recent appointment of Elaine Chapman to Cystic Fibrosis Centre Manager. She can be contacted on



Did You Know?

Half of all CF patients by the age of 30 years will have CF-related diabetes. Tell tale symptoms may include tiredness, thirst and waking up to urinate at night. Signs include weight loss, increasingly frequent chest infections and sometimes hypoglycaemic episodes (feeling shaky, nausea and hunger – blood sugar reading below 4mmol/l). However many patients have few or no symptoms. This is why your blood sugars are routinely monitored when you are admitted for treatment.

Running Made Easy

It all started in June last year when I spotted *Running Made Easy* in a friend's book case. This was written for me I thought, never having been much of a natural runner and certainly never having entertained putting *running* and *easy* in the same sentence! And so, the fitness programme began. The book guided me through an 8 week plan, which gradually increased the amount of running relative to walking.

During the plan, I was talking to one of our in-patients Nabeeda Naaz who told me that she was entering the Birmingham Women's Adidas 5K Challenge. Thinking this would be a good goal I signed up to take part.

Sunday the 7th September 2008 dawned cool and cloudy. By 9.30am Centennial Square, at the end of Broad Street, was buzzing with keen participants all ready to begin their warm up with some very energetic local gym instructors wearing fluorescent pink lycra!

The run itself was very exhilarating and there was a great atmosphere. Spurred on by the support of my family and some well chosen *Rocky* MP3 tracks I finished the run in just over 31 minutes and felt great (that was until the day after when my leg muscles felt pretty sore!)

So exercise is good for you and it can be fun too!! Hopefully you can see that although as a physio I may nag you about exercising regularly, I do occasionally try to practice what I preach!

There are many benefits of regular exercise for adults with CF including improved fitness of the heart and lungs, muscle and bone strength and sputum clearance and reduced breathlessness. And with all those 'happy hormones' (endorphins) circulating around your body it can help you to feel really good too. For guidance on the types of exercise that might be best for you and how much to do please contact the physiotherapy team.

And finally, very well done to Nabeeda (pictured with me at the finish line) and thanks to everyone who helped me raise £500.00 for the Cystic Fibrosis Trust.



Sarah Cameron, CF specialist physiotherapist

What is Annual Review?

You will be invited to attend for an Annual Review once a year. On the day, you will be seen by the Dietitian, Physiotherapist and CF Nurse. This review gives both you and us an opportunity to discuss your health and to carry out or book any necessary investigations with your consent.

Appointment slots for Annual Review are limited and we would appreciate it if you could let us know in advance if you are unable to attend on the allocated day

The Annual Review usually involves a glucose tolerance test (in non diabetic CF patients) to check for diabetes, other routine bloods and possibly a chest x ray. We will discuss if you need to be referred for an Ultrasound Scan to check your liver or a DEXA Scan to check your bone density. This all sounds very medical but the day is also about you having time to ask about issues pertinent to yourself. For example going to University, starting work, travelling abroad, fertility, pregnancy, transplant, available new treatments or physio techniques, supplemental feedingthe list is endless! You can expect to be here for between 2.5 and 3 hours. (Car Parking is free on Annual Review day).



In a follow up clinic visit, one of the Consultants will go through all your test results with you and will discuss any recommendations for the following year.

Appointment slots for Annual Review are limited so we would appreciate it if you could let us know in advance if you are unable to attend on the allocated day. Your time can then be given to someone else. Unfortunately, in the past, DNA's (non-attenders) have meant that not all patients have been able to be offered an appointment.

If you wish to rearrange your appointment please contact Denise Moore, Annual Review Administrator on 0121 4241810.

We look forward to seeing you at your Annual Review.

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Car Parking Arrangements at Heartlands for CF Patients

We know that parking is a major issue for many of you and have negotiated some concessions for inpatients, outpatients on oxygen therapy and patients attending for annual review.

▶ Free car parking arrangements for oxygen therapy patients (LTOT):

- ① The Admin Team will issue you a swipe card (with a number pertinent only to you) allowing access in /out of the car park.
- ① Access will be via the 'Yardley Green Road' entrance, at the back of the hospital.
- ① You can park in the 6 'disabled' bays, straight ahead, at the rear entrance to the CF centre (1 or 2 may be used by disabled staff members). If these are full, we're allowed to use the 6 disabled bays alongside the Children's Ward - immediately on your right, as you drive through the barrier.
- ① You must display a laminated sign in your windscreen stating 'cystic fibrosis patient attending Ward 26' (as well as your Blue Badge) to avoid getting a penalty notice. You will be given one of these signs when you receive your swipe card.
- ① After you've parked, use your swipe card to get through the sliding doors ahead. You enter the corridor opposite the foot of the stairs leading up to Ward 26 - the lift is on your right.
- ① Your swipe card also allows you access to the front doors of Ward 26. This will be useful 'out of hours,' to avoid having to wait outside for a member of staff to let you in.

▶ Free car parking arrangements for other concessionary patients groups:

- ① **Inpatients:** If you're admitted to hospital, your 'main carer' can get a swipe card so that he/she can visit without paying for parking. Carers should park in the main visitor's car park, **NOT** the disabled bays, unless they hold a Blue Badge in their own right.
- ① **Annual review:** You can get a swipe card so you don't pay parking fees for an extended appointment. If you don't have a Blue Badge, you must park in the main visitors car park.

▶ Car parking arrangements for other concessionary patients groups:

- ① **Outpatients:** (except patients on oxygen therapy/ annual review). You must use the front entrance, on Bordesley Green and park in the main visitor's car park. You will be charged for parking unless you are exempt under the benefits/ low income rules.

Main visitors car park from Yardley Green Road: turn immediately left and go through the first barrier (alongside the labs). Follow the road around the 'staff only' car park and go through a second barrier (alongside the oncology department bungalow) into the main visitor's car park. Cars parked in the 'staff only' car park will receive a penalty notice.

Swipe cards: When we issue your swipe card, you/your 'main carer' must sign for it, agreeing to return it at the end of the required period (after your admission/ annual review). **If you fail to bring it back, it will be de-activated. We will not issue you another one until it is returned.** If the card is lost or stolen, we will inform the Facilities Department who will delete card access from the hospital computer, in order to maintain security. If you do still experience problems, please contact a member of the Admin Team.

Elaine Chapman, *Cystic Fibrosis Centre Manager*

Help with Hospital Travel & Parking Costs

If your income is low or you get certain income-related benefits, you may be entitled to help with the cost of attending hospital.

Travel expenses: patients on benefits/ low income may qualify for full or partial help with the cost of the return journey between home & hospital - for either the cheapest public transport or for petrol expenses, if travelling by car.

Benefits: if you get Income Support/ income-related Jobseekers Allowance/ income-related Employment & Support Allowance, you automatically get full help. **Claim:** bring an official letter, confirming your benefit, to the Hospital Fares Office.

Low income: If you're on other benefits or haven't much money coming in, you be entitled to help under the low income rules.

Claim: get Form **HC1** from the hospital/ Benefits Agency/ Department of Health (0300 123 1002) or apply online (<http://www.nhsbsa.nhs.uk/HealthCosts/2123.aspx>).

If you qualify, you get a certificate, valid for 6-12 months - HC2 (full help) or HC3 (partial help) - bring it to the Hospital Fares Office.

Parking: if you qualify for help with travel costs or get other income benefits (Housing Benefit/Council Tax Benefit) you can park for free - just bring written proof to the Parking Office.

Anne Gray, *Social Worker*

HEARTLANDS CAR PARKING CHARGES

Standard Charges		Multiple Tickets	
Up to: 15 minutes *	FREE	3 DAY TICKET	£7.00
" 1 hour	£2.00	7 day ticket	£14.00
" 2 hours	£3.00	20 exit carnet	£26.00
" 4 hours	£4.00		
" 24 hours	£5.00		

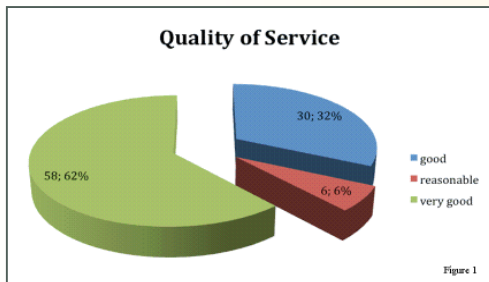
① **Drop Off / Pick Up Only** - Entrance tickets allow FREE exit for up to 15 minutes - just insert your ticket in the exit barrier

Planned improvements to out patient clinics

When I first visited Heartlands I was extremely impressed by the outpatient and inpatient facilities on offer. The CF Trust agrees that facilities at our CF unit are amongst the best in the UK, but there are certain aspects of our service that could be improved. Something that we are working hard on is improving your experience when you attend the CF outpatient clinic. Ideally, we would like you to go straight into a clinic room, be seen by team members without delay and be given the appropriate treatment promptly. We aim to reduce the time that you wait for a room to become available and to minimize the time it takes to be seen by members of the CF team. The first few steps in this process have already taken place and we hope that your clinic experience will improve in the near future.

In this article I will summarize the approach that we have taken to tackling these problems.

First of all, in September 2008, we asked around 100 patients attending outpatients how happy they were with the 'outpatient clinic experience'. The good news from this part of the survey was that the majority of patients were satisfied with the quality of service (Figure 1) and clinic waiting times (Figure 2) once they arrived in the CF centre.



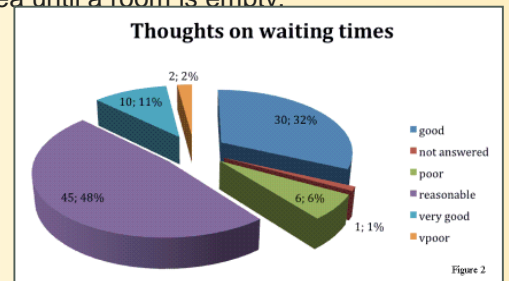
However, 6.6% thought that waiting times were poor and 6.6% also said that quality of service was reasonable (rather than 'good' or 'very good'). The responses showed that most people were generally happy with their clinic experience but that there was room for improvement.

The results of this part of the survey confirmed that car parking was a major problem, with 59% of patients saying that car parking was either 'poor' or 'very poor'. We know that parking is a major problem at Heartlands – the majority of the CF team try to drive to work every day!

We then asked the same 100 patients to record how long it took them to go through each of the steps of their clinic appointment (a 'time mapping exercise'). The information from this exercise showed us that there tends to be a 'bottle-neck' around 2 hours into the clinic, resulting in patients waiting in the clinic area until a room is empty.

2 main problems were identified as causing this 'bottle-neck':

- Patients' appointments were being booked at the wrong intervals. This meant that at certain times during the clinic, patients were arriving faster than the team could deal with.
- Patients were having their height, weight and lung function checked by the technician in one room. This caused delays as only one person could have these essential measurements performed at any one time. We have now installed wall-mounted tape measures and electronic weighing scales in each clinic room.



Please let us know if you have any other suggestions as to ways that we could improve the clinic experience.

Ed Nash, CF Consultant



New Improved Lite bites Menu

Please take a look at our New Improved 'Lite Bites' menu. This is available on the ward as an alternative to the main hospital menu. We hope you like it! We now have panninis and fresh eggs available! It is cooked to order on the ward by the housekeepers. When you are admitted to hospital please let us know if you have any particular food preferences and we will try to accommodate your needs as best we can.

If you would like to be able to make your own drinks in your room, in addition to the ones provided on the tea round, please let a member of staff know and we can provide you with a flask of hot water, tea, coffee and hot chocolate. We can also make smoothies, hot chocolate drinks and milkshakes for you in between meals. But please don't be afraid to ask!

We would value your feedback on the food service we provide – please let us know if you have any ideas for food provision on the ward. The only time we cannot provide this service is when a housekeeper is not on duty. The hospital food policy does not allow food brought in from home or bought from shops to be heated or cooked on the ward.

Jo Barrett, CF specialist dietitian

