



West Midlands Adult Cystic Fibrosis Centre Summer Newsletter 2023

I hope you are enjoying the summer of 2023, despite the rainy weather!

Welcome to Bill Morgan, who is our new CF psychologist as of this week. We are also delighted to announce that Dr Jones gave birth to a baby boy.

There will be two letters for you in the coming weeks. The first is to politely request that you attend face-to-face appointments that are booked for you, or rearrange them as needed. We do need to see you face-to-face in order to monitor your health thoroughly, with the aim of

keeping you well. Whilst home spirometry is excellent, blood tests, weights other investigations such as X-rays and physical examinations are also necessary from time to time.

The second letter will be to talk to you about introducing screening the bowel using a camera test in patients over the age of 40 years old. More information about this is available on Page 4, but please do not hesitate to ask if you have any questions or concerns.

Dr Joanna Whitehouse



Baby Ralph

All change for the dietitians!

There have been some big changes in our team of dietitians recently.

Firstly, Jo has been awarded an National Institute of Health and Care Research (NIHR) doctoral fellowship and started this in July. Jo is looking at researching and developing a diet and physical activity behaviour change intervention, for adults with CF who are overweight on a CFTR modulator. This is in conjunction with the University of Birmingham. If you would like to be involved in working with Jo on this research project, [find out more about how you can be involved here](#). Jo will still be around and you may see her in clinic, but just not as frequently.

Katie is now working in the CF team full time and will be taking a lead on the ward and catering. Katie is who you will see if you are admitted to the ward.

Marathon in October to raise money for [Heartlands Cystic Fibrosis Centre Charity](#). You can support Katie via [JustGiving](#).

Go Katie ! We know you can do it.

Liz and Claire are still part of the team and

will be covering clinics and annual reviews, with Claire being lead dietitian for the team and diabetes.

We are hoping to recruit another dietitian to join the team – watch this space for any updates!



Katie will be running the Rugby Half

European Cystic Fibrosis Society Conference 2023

In June 2023 several members of the CF Team attended the 46th European Cystic Fibrosis Conference in Vienna.

Many of us participated in oral and poster presentations of work and research we completed.

Attending this conference allows us to learn about current research, new treatments, and network with other CF centres and healthcare workers worldwide.



Port flushes

Can we remind anyone with a port to have it flushed every 6 weeks. Your port is at risk of blocking if it is left

longer than 6 weeks. This can be done at home/work/college or you can come to the hospital. Please contact the CF

Nurses on **07971329933** when your flush is due and we can arrange this for you.

Planning a holiday?

If you have a holiday booked, before you go there are a few things to consider. If you think you may need any additional health assessments for travel, please speak to a member of the CF team well in advance of your travel dates and they will be able to advise you. [The CF Trust also have lots of useful information about going on holiday](#)

1. **Travel Letter** – [contact our secretarial team to request a travel letter](#) which will detail your medical conditions and medication. They will need a minimum of 2 weeks' notice.
2. **Travel insurance** – [Organise some travel insurance](#) and apply for a [Global Health Insurance Card](#)



3. **Salt tablets** – if you are going to a hot climate you are likely to need to take some salt tablets or increase your usual dose. [Download our information leaflet on salt supplements and staying hydrated during hot weather here](#)
4. **Diabetes** – if you are diabetic there are a few more things to think about before you set off. [Diabetes UK has lots of useful information about diabetes and travel](#). Alternatively contact our [CF diabetes team](#)
5. **Nebulisers** – these may require a travel adapter plug. If you have any questions about physiotherapy equipment, [please contact the CF Physiotherapy team](#)

6. **Medication** – plan ahead and ensure you have enough supply of all your treatments for the holidays if you are planning on travelling

You can find out more about [flying with a lung condition including information about flight assessments](#) and [travelling with oxygen here](#).

We hope you have a lovely time!



Virtual exercise classes

We continue to offer weekly group virtual exercise classes, open to all. We can also offer 1-2-1 sessions. If you are

interested in finding out more please contact Rob on **07772137613** or email **uhb-tr.wmcfspiro@nhs.net**.



Home spirometry

Please remember to complete a home spirometry (also called a 'lung function test') before your virtual clinic appointments. This helps us and you to get

the most out of virtual clinic reviews. To find out more about how to use your home spirometer and when we would advise not to complete a test.



Sputum samples

You all know how much we, the CF physio team, love sputum! Sending sputum samples to check for bugs remains vital, whether or not you are taking modulators such as Kaftrio. Cough swabs can't be sent for all tests and are much less accurate.

If you are someone who cannot often cough up sputum for a sample at

clinic, but occasionally do at home, we can give you a sputum sample by post pack. This will mean you can post us a sample if and when you are ever able to cough up anything at home.

Please contact us on **07772137613** or email **catherine.brown@uhb.nhs.uk** to find out more.



Physiotherapy

We are really pleased to introduce Stacy Ojo. Stacy has joined our team in the role of Admin Assistant. She joined our team after five years as an executive assistant, even though she began her career as a nursery teacher. Stacy is a lifelong learner, who is dedicated to her work and enjoys helping people.



CF social work

We know the cost of living crisis hasn't gone away. Please do not hesitate to get in touch if you're struggling to manage financially as we can try to help by looking at income maximisation and grants that might help with energy costs.

Please contact the CF Social Workers for more information on **07740066704** or **0121 424 2998** or by email: **cfsocialworkers.email@uhb.nhs.uk**



Psychology Service News

Hello. I hope you're managing to get out this summer between the showers!

I'd like to introduce myself to those I haven't yet met – I'm Bill Morgan, the new CF Psychologist. My background has been in adult mental health, but for the last three years I've been working for a national homeless charity.

I've been working at the Centre for one day a week since September but have been

focussing on inpatients. From the start of August I've been up to three days a week, and will now hopefully see more of you in annual reviews and clinics, as well as on the ward.

I'm very excited at having more time in the role and getting to work with more of you. We're now in the process of recruiting another psychologist to work with me, so hopefully we'll soon have a full psychology team again.



Bowel cancer and cystic fibrosis

As people with cystic fibrosis live longer, we expect to see new trends in health data, with many positive developments but also new health challenges such as cancer.

International Registry data has shown an increased rate of bowel cancer, which is occurring earlier in people with cystic fibrosis. It has also shown an increased risk of other types of cancer,

like skin and lymphoma, in people who have had a transplant.

We don't know if the increased risk is due to lifestyle factors or to do with CFTR (the gene affected in people with CF), but the increased risk is approximately 6 times that of the general population.

As a CF service we would like to offer a colonoscopy for large bowel cancer

screening to all our patients over the age of 40 years. If you have had transplant, will be contacting you to offer this from the age of 30 years onwards. Please do not hesitate to ask if you have any questions.

[You can find out more about bowel cancer risk and cystic fibrosis here.](#)

Pharmacy update

CF Pharmacist Shradha will be undertaking annual reviews in the CF annual review clinics. Shradha will review all the medication you are prescribed and provide information and advice on your medicines. You will also have an opportunity to discuss the treatments you are taking and address any concerns.

It is summer holiday season - please plan ahead and ensure you have enough supply of all your treatments for the holidays if you are planning on travelling. We would like to share contact details for our

homecare providers with you.

Lloyds Homecare (Kaftrio, Kalydeco, Symkevi, Colobreathe) – **03452636148**

Sciensus Homecare (Tobi pod, Brmaitob, Vantobra) – **03331039499**

You can contact Shradha Shah, our CF Pharmacist if you have any questions about any of your treatments on **0121 424 1732**.

