



Easter Newsletter

April 2022

HAPPY EASTER!

Dear All,

Spring has finally arrived and I'm so pleased to see many of you in person again. Virtual clinics have been a lifeline since 2020, helping us to care for you, but some assessments cannot be done virtually and I urge you to attend in person when you are sent appointments to do so. Our capacity is likely to remain reduced due to COVID infection control restrictions, therefore please let us know if you cannot attend so that someone else may use the slot.

The Heartlands Cystic Fibrosis Centre Charity supports our adult patients attending this centre. Whilst we are recruiting for replacement CF psychologists, the charity has offered to support you with financial aid for psychology/counselling sessions, local to you, if you need this aspect of the service. Please get in touch via our social work team, Jacqui Wainwright (jacqui.wainwright@nhs.net) and Kaywane Wickham (Kaywane.wickham@nhs.net) or call the CF nurse specialist mobile (07971 329933) if you are interested in this support.

Best wishes to you all,

Jo Whitehouse, Neil Patel, Rifat Rashid,

Laura Jones

Social Work

We know that the rapidly increasing cost of living will make managing the weekly budget harder and if you need financial guidance and support or someone to talk things over with, please don't hesitate to contact either myself, Jacqui or Kaywane on either 07740066704 or 07774017067 or you can email us at cfsocialworkersemail@uhb.nhs.uk. We are also here to support with employment and training queries and benefits advice. Please don't hesitate to get in touch; we are here to support you

All the best,

Jacqui & Kaywane.

jacqui.wainwright@nhs.net

Kaywane.wickham@nhs.net

CFHealthHub

Would you be interested in joining almost 160 of the adults with CF at Heartlands who already have access to a personalised app to monitor your health trends? The CFHealthHub app is free to download and the content will be individualised for you. CFHealthHub enables you to add your weight and spirometry measurements to view in simple, easy to understand graphs, as well as helping you track your nebuliser use, if you wish, with the use of a brand new eTrack device. If you have any questions or would like any further information about CFHealthHub, please get in touch with me on 07928 655952 or jocelyn.choyce@heartofengland.nhs.uk

Best wishes,

Jocelyn

Dietitians

If you have experienced a change in your weight recently, and would like some advice on how to manage this, we are able to provide individualised nutritional advice on a one to one basis either by phone or face to face at a pre-arranged appointment. Please give us a call on 07794 375776 or 07867 143787

Fruit and Vegetables are an important part of everyone's diet. We recently had 2 student dietitians who produced some resources for patients to highlight the nutritional benefits of including fruit and vegetables in our daily diet. Check out this information on our website and our information board in clinic.

Please follow us on twitter for more useful food and nutrition info **@CF_dietitians**

Happy Easter!

Jo, Claire, Liz and Katie

Physiotherapy

Hello from the Physio team!



STAFFING:

Since our last newsletter physio Nicky Rogers has gone on maternity leave, we are thrilled to tell you she and Adam had a beautiful baby girl called Jessica in January, mum and baby are doing well.

We are really pleased to announce that Physio Charlotte Morby has joined the CF physio team in a permanent position. Some of you may remember Charlotte as she completed a rotation with us back in 2019/2020.

Charlotte is a wonderful asset to the team so we are so pleased she is now having a permanent position with us.

EXERCISE:

We hope you are all enjoying the beautiful spring sunshine. This is the time to dust those trainers/ walking boots off and get out there and enjoy some fresh air and exercise! If any of you would like to get moving but have any questions or concerns please do get in touch, we will happily offer advice or do 1:1 exercise session with anyone who needs a confidence boost.

Heartlands Cystic Fibrosis Centre Charity managed to secure a fantastic grant for home exercise equipment last year, we still have some exercise bikes and weights available, get in touch if you would like to have either!

We continue to run our virtual exercise classes, now via a website called 'Beam clinics' where we can host live sessions and also hold a library of saved videos- please log in and check it out- and keep an eye out for any new classes or educational videos (see website for how to join)

SPIROMETRY:

A reminder- please complete your spirometry before a virtual clinic appointment (unless there is a reason not to, for example, chest pain). The results really do help inform our discussion in the clinic and significantly improves the quality of the virtual review. If you have any issues completing your spirometry before your virtual clinic please contact our team.

STERILIZING EQUIPMENT:

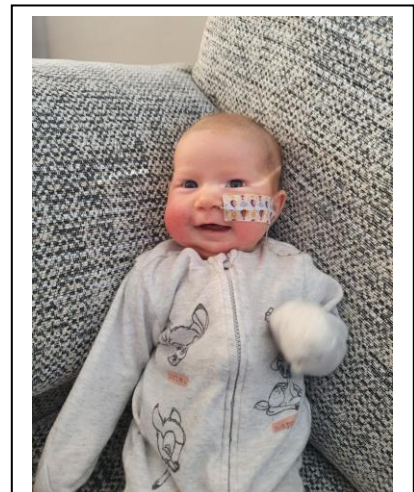
Washing and sterilising your physiotherapy equipment is essential but can be a huge burden. We are hoping to use some charitable funds to purchase some baby bottle steam sterilisers, these can be used to sterilise your equipment after washing and negate the need to boil the parts in a pan. We hope this will help make the process easier for you. Let us know if you have baby bottle steriliser recommendations or if you would like one of the ones we buy with charitable money



Best wishes

Your CF Physio team

07772137613 or 01214241780



CF Specialist Nurses

ANNUAL REVIEW

We are excited that annual reviews are now face to face again in our outpatient clinic. You will receive an appointment around your birthday month. We will now be able to carry out annual review tests such as spirometry, send sputum/cough swab samples, obtain bloods, screen for diabetes and arrange an x-ray on the day. You will meet the CF specialist physio, dietitian, social worker and nurse to discuss how your year has been. We will all give you information and/or advice which is tailored to you. We look forward to seeing you for your annual review.

FREESTYLE LIBRE

We now offer an alternative to the glucose tolerance test at annual review. It is called Freestyle libre which is inserted in the upper arm for 7-14 days. By using your smart phone this small device transmits information on blood glucose levels direct to our computer screen via the libreview app. It provides a much improved overall assessment of your blood glucose levels and along with keeping a food diary allows for us/the dietitians to give you personalised advice.

TRAVEL LETTERS

Holidays abroad are possible again – hooray! If you need a travel letter or medication list please contact the CF secretaries on:

0121 42 41669 (Robbie-Leigh)

0121 42 41746 (Pat)

0121 42 43007 (Hosanna)

You will need to phone at least 2 weeks in advance if possible. Please have your medication list ready.

You will need to check with each individual country regarding their COVID travel rules. This can be found on the Government website.

CLINIC APPOINTMENTS

As you know we are offering both virtual and face to face clinic appointments. We are no longer able to change a face to face appointment to a virtual for the same day. This is for operational reasons. If it is necessary to change your face to face appointment the clinic receptionist will rebook you for another day.

Christine, Fiona, Josie, Nicky and Ruth



Diabetes

IDEA-CF – IMPROVING DIABETES EDUCATION IN ADULTS WITH CF

IDEA-CF is our new online structured education programme for those with CF related diabetes (CFRD). It aims to give you the knowledge and confidence to take control of your diabetes. The course is run by the CF diabetes nurse and CF dietitians.

There are 3 sessions which are delivered every 2-3 weeks over a 6 week period and there will be 6-8 patients in the group. If you don't want your camera on it's fine to turn it off!

There are some forms and questionnaires to complete before and after the course and during the course it is advised you complete the 3 on-line assessments. These assessments help form the basis of the virtual sessions.

Sessions are delivered on Tuesday or Wednesday 1-3pm and all 3 need to be attended. We are also looking to deliver Saturday morning sessions too.

If you are interested in attending please speak to the dietitians or CF diabetes nurse

LIBRE CLINICS

Libre clinics are running on a Tuesday afternoon with our CF Diabetes Specialist Nurse and CF Specialist Diabetes Dietitian. The aim of these clinics is to help support you with your diabetes control and making the most of the features of Libre. Everyone will be offered an appointment but if you have any concerns with your diabetes control you can phone the diabetes team at any time. At the moment you may receive a letter that informs you of a respiratory appointment but this is actually for a Libre appointment. Nazma our assistant will contact you before the appointment to ensure you are able to attend. Don't forget to annotate the Libre with your food intake and insulin doses – this can be done via the log book on the app.

CF Diabetes Specialist Nurse, Harbinder Sunsoa– 07772137600 or 0121 424 3577

CF Diabetes Specialist Dietitian, Claire Roden – 07794375776 or 0121 424 1796

Best wishes
Claire and Harbinder

