

HAPPY EASTER!

Dear All,

I cannot believe that a year has gone by since our first national 'lockdown' and that the world has changed so much. For many of you the start of Kaftrio has been a high point in an otherwise very difficult 12 months.

At the West Midlands CF Adult Centre we have embraced 'virtual' clinics, although the ward has remained open for CF patients throughout the pandemic. I'd really like to know how you find virtual clinics and how we could/should incorporate these into your care. Please feel free to contact us with your thoughts about clinics.

Clearly it is not advisable to offer virtual care solely and we hope to start some face to face clinics in April, please see www.heartlandscf.org for more information. Thinking about vaccinations, if any of you are having issues with either obtaining a vaccine or concerns about having one, I'd urge you to get in touch, via the CF Nurses.

Best wishes to you all,

Jo Whitehouse, Neil Patel, Rifat Rashid

CF Nurses

Many of you may have started new medications Kaftrio and Symkevi. Just to remind you that you will need to have a blood test to monitor your liver function every 3 months for the first 12 months. This can be done at your GP practice or the hospital. A CF nurse will contact you to arrange this blood test.

We are restarting annual reviews from 12 th April. These will be carried out virtually in a similar way to the current clinics. Your annual review will be either a Monday or Thursday morning or last 1 – 1 1/2 hours. During this time you will see several members of the CF team. We look forward to speaking to you soon.

The CF Nurses

Social Work

We miss seeing you and hope you are keeping well. Please get in touch if you have any queries with returning to work after shielding or any general financial worries. We now also have access to CF charity crisis funds we can support you to apply for if needed. Don't hesitate to get in touch for more information.

All the best,

Jacqui & Kaywane.

Our contact details: 07740066704 or 07774017067

jacqui.wainwright@nhs.net

Kaywane.wickham@nhs.net

Physiotherapy

The Physio team continue to run virtual exercise classes. We currently have an exercise bike /spin class, a stretch/body conditioning class and a cardio /boxercise class. We are also starting some 1 to 1 sessions to help build confidence and fitness in individuals with a view to joining one of the classes or carrying on independent exercise. We can also provide some equipment (such as exercise bikes) to facilitate participation in the classes, thanks to funds raised by the Heartlands Cystic Fibrosis Centre Charity. Please contact the Physiotherapy team if you would like to be added to our email list to take part or to get more information. We remain available for any Airway clearance, general exercise and nebulised medication queries that you may have. Best Wishes,

The Physio Team

Dietitians

Research has shown that most people do gain some weight when they start on CFTR modulators, which may mean adjusting your diet in order to continue to maintain healthy weight (BMI 20-25kg/m2).

Sign up to our 'Refresh – Eating Well on CFTR Modulators' webinar to find out more about how you can introduce healthy eating principles into your diet to help you manage your weight.



Tuesday 18th May

To register, email joanne.barrett2@nhs.net or Katie.marsden4@nhs.net or phone 0121 4242 1796

Jo, Liz and Katie

CF Health Hub

Would you be interested in joining almost 140 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

Jocelyn Choyce

Pharmacy

2020 was fantastic year for the CF community with the approval of Kaftrio by NHS England! Recently NHS England have expanded access to 'off label' gene modulators for patients with cystic fibrosis not previously eligible for gene modulators. Wishing all our

patients a Happy Easter! Best Wishes

Pharmacy Team

HEARTLANDS CYSTIC FIBROSIS CENTRE CHARITY

reg charity number 1074745

Trying to exercise at home? Our charity can provide free equipment for any patient who does not have his at home - please email Jane Mulvale at heartlandscfcentre.nhs@gmail.com for further details. Easter is a time for those special treats, but if you are you currently struggling to buy even basic food, or pay an everyday utility bill, our charity has a special fund to help support our patients in financial crisis. Applications for assistance can be made, in the strictest confidence, by contacting jacqui.wainwright@heartofengland.nhs.uk

Psychology

Hi Everyone

It's been such a difficult year for so many reasons. Feeling anxious or being low in mood, energy and motivation are quite normal human responses to the threat you have all been under. We have lost our usual routines, which give us structure and satisfaction and missed the simple joy of seeing others.

Hopefully, life will get easier very soon as restrictions are eased and the weather improves. If you do struggle though, please do not hesitate to contact Georgina or myself on 0121 424 2987/0121 424 2530. We have missed you and are really looking forward to seeing you face to face when normal clinics resume. Very best wishes

Anna & Georgina

Diabetes

If you are already using Freestyle Libre, you will be eligible for Freestyle Libre 2. This brings added advantages such as alarms and not being necessary to do a finger prick blood glucose measurement, if the sensor indicates a low reading. If you have Freestyle 1, contact me to arrange a prescription of Freestyle Libre 2

Harbinder

