



West Midlands Adult Cystic Fibrosis Centre Newsletter

December 2022

Merry Christmas
and a Happy New Year!

From your Cystic Fibrosis team.

Kaftrio monitoring

Many of you have benefited from being able to take Kaftrio, however it is important that we continue to monitor you on a regular basis, even if you are feeling well. This is to ensure that you do not suffer from any adverse effects from Kaftrio but also that we are not missing any subtle deterioration in your health.

We would like to therefore remind

everyone that as a minimum we need to measure two home spirometry readings, as well as two hospital spirometry readings, every year.

We also need an up-to-date weight every three months. If you do not have a home spirometer or are having technical issues with it, then please let the physiotherapists know.

Kaftrio is a new drug and although we are hopeful that the positive effects will last for the foreseeable future, there are a lot of unknowns and therefore it is important that we continue to keep monitoring patients to ensure we are able to safely prescribe it.

Are you a woman with Cystic Fibrosis (CF) thinking about having a baby?

We offer pre-pregnancy counselling for all women considering pregnancy to discuss how your CF may be affected by becoming pregnant, in particular any medication changes that may be required. For those of you with CF-related diabetes or impaired glucose tolerance, you will be referred to pre-conception diabetes clinic. Understanding the impact your diabetes will have on pregnancy and how it will be managed is important to minimise the

risk of complications. All pregnant women with diabetes will be closely monitored and managed by the antenatal diabetes service, in close liaison with the CF Diabetes team.

What to do if you have an unplanned pregnancy?

Please let us know as soon as possible so that we can review your medications with you and discontinue any treatments that are not safe during pregnancy.

Pregnancy and maternity services available at

Birmingham Heartlands Hospital

All pregnant women are invited to attend a monthly face-to-face CF antenatal clinic, which will take place in Ward 26, Outpatients. You will be reviewed by both our consultant obstetrician and CF consultant, along with the CF multidisciplinary team.



Merry Christmas


from your CF Physiotherapy team!

It is very important that equipment is serviced regularly to ensure that it is working correctly and that it is safe for continued use. Electrical equipment that requires testing includes:

- eflows, PARI TurboBOYS, Portaneb-50s, TENS machines, 'Vest' machines
- Non-invasive ventilation (NIV) devices

need to be booked in in advance, so please call us ahead of clinic if you are bringing your NIV (the service for an NIV is a bit longer ~90 mins). The I-neb nebuliser device is serviced by the manufacturers.

Please bring any electrical devices that you have at home that are due for testing to the

clinic (as shown by the date on the green and white '**NEXT TEST DUE**' sticker fixed to the device). If there is no '**NEXT TEST DUE**' sticker fixed to a device, please bring it to clinic anyway and we will organise for it to be assessed by the medical engineers. If you have any queries regarding the information above, please contact the CF physiotherapists on  **07772137613**.

Preparing for your virtual clinic appointment

Please ensure you are in a suitable environment where you feel comfortable discussing your health with the CF team via video or phone.

If you would like to speak to the consultant or any member of the team privately, please do not hesitate to

mention this during the consultation. Please could we kindly remind you to use your home spirometer and weigh yourself prior to your virtual clinic appointment, as it is an essential part of our assessment. If you need a refresher on how to use it, please contact the Physiotherapy team.




Traveling to your face-to-face appointments

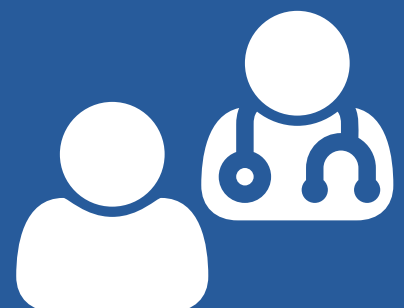
We are delighted that we are now able to see more of you face-to-face in clinics since COVID-19 restrictions have been lifted. To allow us to keep the face-to-face clinic running smoothly and on time, and give you the time and attention we would like, it is important that you arrive on time for your appointment.

We appreciate that many of you travel long distances to come to your appointments and that parking at the hospital can be quite busy now that outpatient services and visiting have opened up again, so please allow extra

time to navigate busy traffic and road works, and to find space in the car park. If you have any concerns regarding the cost of travelling to your appointments, please scan the QR code to see if you are eligible to claim back travel expenses.

If you are unable to make your appointments, please respond to the text reminders as soon as possible or call outpatient reception on  **0121 424 1693** to allow the appointment to be taken by someone else who may be unwell and in need of an urgent review with the team.

<https://www.uhb.nhs.uk/getting-here/help-with-travel-costs.htm>



Rising costs of living



We know that patients are increasingly worried about the rising costs of living and the financial burden of living with a lifelong condition. We can support patients by signposting them to charities, including CF Trust, who are currently providing support with increasing costs of living. Additionally, the Heartlands CF charity aims to support patients experiencing a financial crisis by giving emergency grants to those most in need.

These grants will be available to patients experiencing financial hardship for whatever reason.

You can apply by downloading and completing our short application form here

<https://www.heartlandscf.org/news/help-with-the-rising-cost-of-living>

Once you have completed the form with as much information as possible, send it to our CF Social Workers, Jacqui Wainwright or Kaywane Wickham by email

✉ cfsocialworkers.email@uhb.nhs.uk (preferable) or by post addressed to

✉ **CF Social Worker, Ward 26, Heartlands Hospital, Bordesley Green East, Birmingham Heartlands Hospital, Birmingham B9 5SS**

If you require any more information, please contact CF Social Workers, Jacqui Wainwright or Kaywane Wickham on ☎ **0121 424 2998** or by email ✉ cfsocialworkers.email@uhb.nhs.uk

CFHealthHub

Are you interested in joining over 170 of the adults with CF at Heartlands by signing up to CFHealthHub, a personalised app to monitor your health trends? The CFHealthHub app is free to download and the content will be individualised for you.

CFHealthHub allows you to input your weight and spirometry measurements and presents them in simple, easy-to-

understand graphs. It also allows you track your nebuliser use, if you wish, through the brand new eTrack device.

If you would like to know more, please do not hesitate to get in touch with Jocelyn Choyce through email

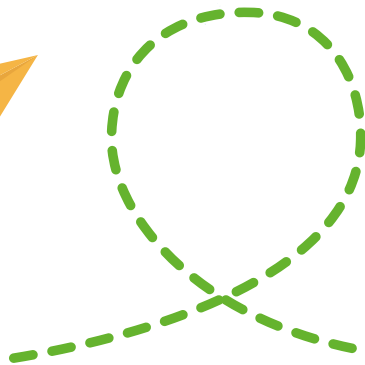
✉ jocelyn.choyce@uhb.nhs.uk

or by phone:

☎ **07928 655952**

☎ **0121 424 3775**

If you are already signed up to CFHealthHub, please make sure your white hub is left plugged in and turned on at all times (even if you are not taking your nebulisers) to allow any data to be transferred to your app. This will also mean your data can play a valuable role in helping us understand the role of nebulisers in those using highly effective modulators, such as Kaftrio.



Travel Letters

The secretaries/admin team require a minimum of two weeks' notice to create travel letters, unless there are exceptional circumstances. If you need a travel letter, please email one of the secretaries:

✉ robbi-leigh.lennon@uhb.nhs.uk

✉ patricia.bayliss@uhb.nhs.uk or

✉ hosanna.hippolyte@uhb.nhs.uk

with a list of the medications and devices that you will be taking with you on the

flight, as well as your destination and the date you are travelling. The travel letter can then be created and emailed over to you.

Eating well on a budget!

With the cost of living crisis and Christmas approaching quickly, we are aware that money for food may be tighter. Therefore, we would like to provide you with our top tips for saving some money on food over this Christmas period!

1) Plan your meals – make the most of all of your ingredients to prevent food waste and use leftovers!

2) Scale back Christmas – Don't buy food to excess, think how much you need to feed just the people you have

3) Consider how you are cooking foods – consider bulk cooking and try to cook multiple items if you are heating up the oven. Be aware that microwaves and slow cookers are cheaper to run

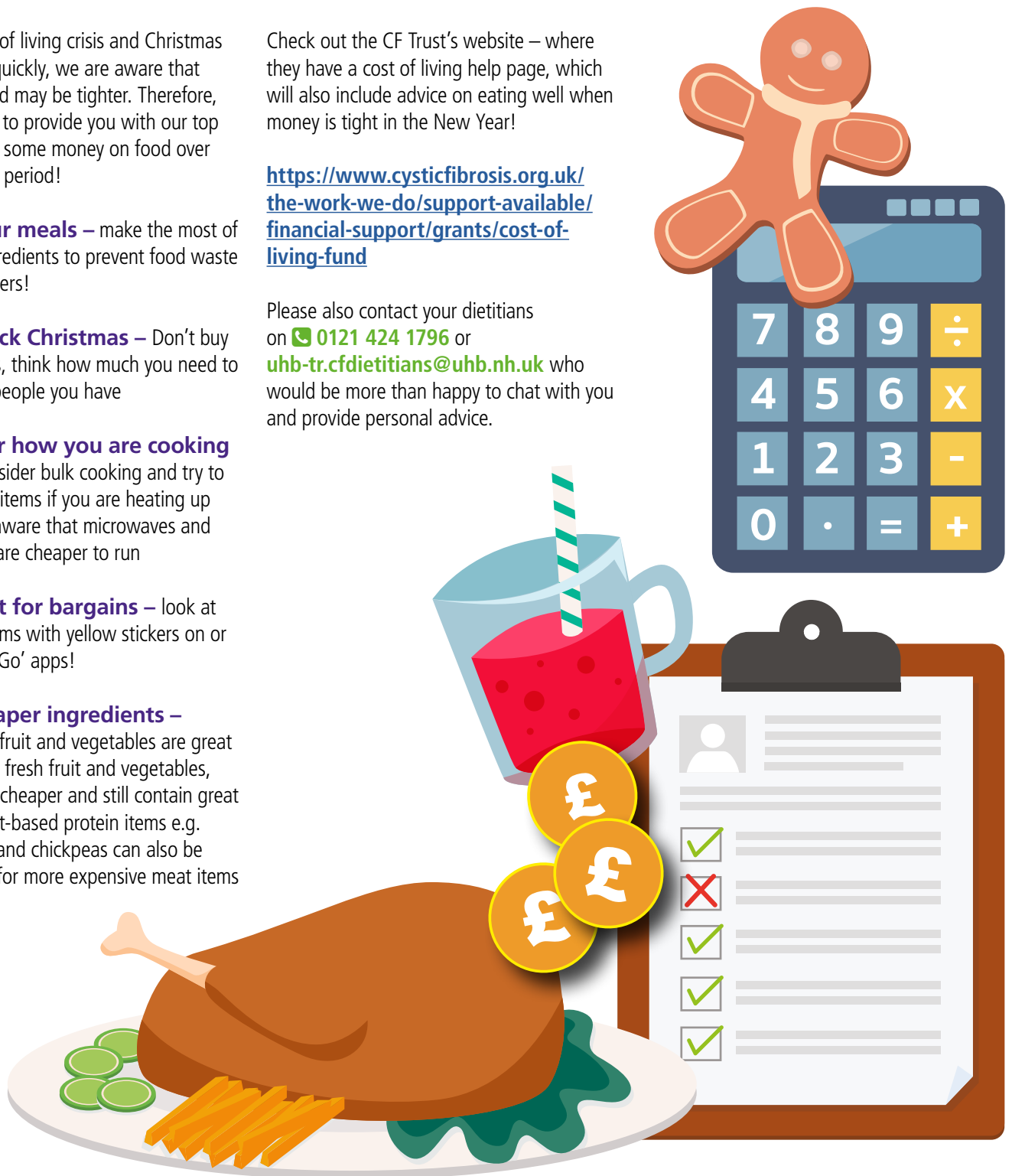
4) Look out for bargains – look at discounted items with yellow stickers on or 'Too Good to Go' apps!

5) Use cheaper ingredients – tinned/frozen fruit and vegetables are great alternatives to fresh fruit and vegetables, and are often cheaper and still contain great nutrition. Plant-based protein items e.g. beans, lentils and chickpeas can also be swapped out for more expensive meat items

Check out the CF Trust's website – where they have a cost of living help page, which will also include advice on eating well when money is tight in the New Year!

<https://www.cysticfibrosis.org.uk/the-work-we-do/support-available/financial-support/grants/cost-of-living-fund>

Please also contact your dietitians on [0121 424 1796](tel:01214241796) or uhb-tr.cfdietitians@uhb.nh.uk who would be more than happy to chat with you and provide personal advice.



Over the Christmas period, a normal CF service will run, with the exception of weekends and bank holidays. If you are unwell over the weekends and bank holidays during the Christmas period, you will need to contact Ward 26 and speak to the nurse in charge: [0121 424 0226](tel:01214240226). For more information visit www.heartlandscf.org