



West Midlands Adult Cystic Fibrosis Centre Newsletter

www.heartlandscf.org Autumn/Winter 2025

Welcome to our Autumn/Winter newsletter. We have lots of news for you, including an update on the latest information about Alyftrek, the latest triple modulator therapy to become available, and information on a change to how we will measure your lung function.

Team wise, we said goodbye and good luck to Kaywane Wickham, social worker, who sadly left the centre for a new job elsewhere. Nicky Hanlon, physiotherapist, also started her maternity leave at the end of October, and we wished her well for baby No. 3 – we look forward to seeing her again soon.

Alyftrek – the low down

What is it?

Alyftrek is designed to increase the amount of CFTR protein that your body can use. It also improves the flow of salt and water between cells. Like Kaftrio, it can improve sweat chloride levels, lung function and other symptoms of CF.

This is the next triple modulator, replacing Kaftrio and Kalydeco. It is now available for us to prescribe and we will be discussing it with you at your upcoming clinic visits over the next few months. It is suitable for everyone already on Kaftrio/Kalydeco.

How is it different to Kaftrio and Kaydeco ?

It contains a different combination of drugs;
Kaftrio – Elexacafotr/Tezacaftor/ Ivacaftor
Alyftrek – Vanzacaftor/ Tezacaftor/Deutivacaftor
Kalydeco – Ivacaftor

Alyftrek only needs to be taken once a day (two capsules once a day).

It can be taken at anytime during the day with a fat containing food. It should however be taken at the same time everyday.

Why the change?

Some people have not tolerated Kaftrio due to side effects or found it to be not very effective. Also it may have some additional health benefits and it only needs to be taken once a day.

Is it any better?

In research trials, Alyftrek was equivalent to Kaftrio, but more people with CF had a normal sweat chloride on Alyftrek than with Kaftrio. This means that Alyftrek is better at increasing CFTR function than Kaftrio in some people, which may have longterm health benefits.

Can I wait to start or switch to Alyftrek?

Yes, we would prefer you to change over when your supply of Kaftrio/Kaydeco runs out.

Can I switch back to Kaftrio if I don't like Alyftrek?

Yes you can.

Will my bloods need to be monitored?

Yes, you will need to have three monthly blood tests for the first 12 months of taking Alyftrek. This may need to continue or be more frequent if your liver function tests are abnormal.

Liver ultrasound and fibroscans

You doctor may refer you for a liver ultrasound scan or fibroscan if you have abnormal liver function test results. It is important to attend these appointments as failure to do so may suspend your prescription and supply of Kaftrio/Kalydeco/Alyftrek.

These scans are important for monitoring your response to these medications. There are limited appointment slots, therefore we would appreciate if you could attend the appointment time you are given or contact the radiology service to rearrange.

Dare we mention Christmas!

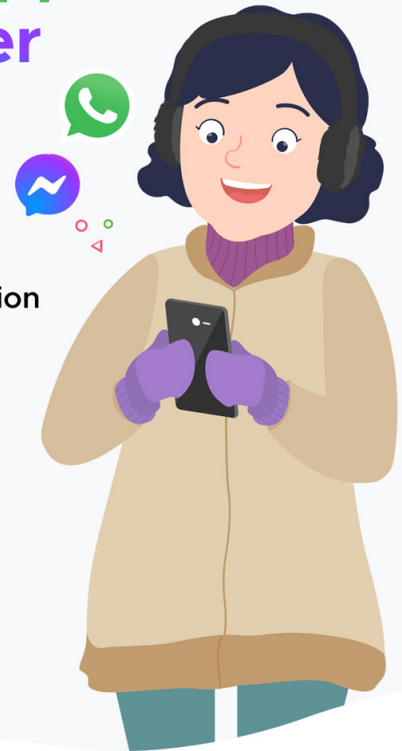
It's just around the corner and we know that many of you will be thinking about sending Christmas cards to family and friends. Why not send an ecard and donate the money you would normally spend on postage to Heartlands CF Centre Charity? Christmas cards can be sent by email, text message or WhatsApp. The process is quick and easy and our charity is registered with **DontSendMeACard.com**.

You can access our ecard page and donate **here**.



Send WhatsApp and Messenger eCards this Christmas

- Donate the cost of cards
- Get x100 eCards per donation
- Share to WhatsApp
- Share to Messenger
- Send by email
- Include your own photo



DontSendMeACard.com

Update on the more life with CF study

Thank you to everyone who has participated and been involved in this research study. Watch this short video that summarises the results of this study so far and hear from **Carly** our lead research partner.

We are now seeking people with CF and overweight or obesity to help us to design a CF specific weight management programme.

There are a number of paid involvement opportunities to find out more please email/text/phone Jo Barrett 'CFR Dietitian' on **07867 143787** or email **Joanne.barrett2@nhs.net**

Hope to hear from you,
Jo



FUNDED BY
NIHR | National Institute for Health and Care Research

WE NEED YOU

TO HELP US DESIGN A WEIGHT MANAGEMENT PROGRAMME
FOR PEOPLE WITH CF
BY PEOPLE WITH CF

Watch our video blogs to find out more - scan the QR code

JOIN OUR TEAM

Flexible
Paid Involvement Opportunity

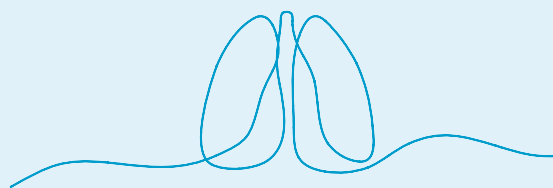
Interested? contact Jo Barrett CF Dietitian and Researcher
joanne.barrett2@nhs.net
07867 143787

Changes to how we check your lungs at the West Midlands Adult CF Centre

Starting: **1 December 2025**

We want to tell you about a big change happening about how we measure how well your

lungs are working. This change will help us give everyone the fairest and best care. Find out more **here**.



Physiotherapy

Just a reminder to collect your hospital supplied medicines when you come for your clinic appointment as we are no longer able to deliver these to you. You can call or text the CF Physiotherapy Team before your appointment for nebulised medicines on **07772 137 613**.

If you are collecting outside of a clinic appointment Heartlands pharmacy is open Monday to Friday 08:30–18:00.

You can also collect from the hospital discharge pharmacy (opposite Marks and Spencers) Saturday and Sunday 10:30–16:30. If you wish to check a prescription is ready for you to collect you can call **0121 424 0118**.

Your privacy is important to us

At the West Midlands Adult CF Centre, your privacy is our priority. We are legally required to protect your personal health information and cannot share it without your permission.

The safest way to manage your care and keep your information safe is for you to contact the CF team directly. We know managing a long-term condition like cystic fibrosis can be challenging, and you may want support from friends or family. However, we must have your consent before we can discuss any part of your care with them.

When you visit the clinic over the next few months, we will discuss and record your information-sharing preferences. If these preferences ever change, please inform a team member so we can keep your records current. Thank you for helping us maintain your privacy.



Diabetes news

The drug manufacturer Novo Nordisk has announced it will withdraw Levemir insulin in all forms by the end of 2026. **Here**, we look at what this means for people with diabetes who are affected, and what happens next. Our CF diabetes nurse will discuss

this with you at your next review, alternatively you can contact your GP who will switch you over to an alternative insulin. Don't worry, you have plenty of time... there is still 12 months until it will be withdrawn completely.

Social work team updates

We said goodbye and good luck to Kaywane in September after five years' service and wish him all the best for the future in his new job.

Struggling with your utility bills? Choosing between heating or eating? The CF Trust are offering grants of £225 to protect the health of those in most need

this winter. The winter support is focused on low incomes and only one application per household.

For more info see the **CF Trust website** or contact Jacqui Wainwright, CF Social Worker on **07740066704** or **jacqui.wainwright@uhb.nhs.uk** for more information.

Pancreatic Enzyme Therapy

(Creon 10 000, Creon 25 000 Nutrizym 22)

Community pharmacies have the same access to supplies of pancreatic enzymes (Creon 10,000, Creon 25 000 or Nutrizym 22) as the hospital pharmacy. Therefore, we are only able to supply these from the hospital pharmacy if you have requested a prescription from your GP and your community pharmacy is unable to fulfil this.

If you are still struggling to obtain a supply of pancreatic enzymes (Creon 10,000, Creon 25 000 or Nutrizym 22), please contact us. Further information is on our **website**.