

# CF NEWSLETTER

## THE EDINBURGH ADULT CYSTIC FIBROSIS SERVICE

### APPOINTMENTS, APPOINTMENTS!

The Scottish Adult Cystic Fibrosis Service at the Western General Hospital now has over 200 patients so fitting everyone in for appointments is a challenge and we need your help in ensuring you are all seen appropriately.

#### Clinics

During November, December & January 25 patients did not attend their clinic appointment without letting us know. 18 appointments were also unable to be used due to late /same day cancellations. This resulted in 43 lost clinic appointments!

Please can you call or text us on (0131) 537 1762/ 07770326301/ 07770326302 if you are unable to attend your appointment as soon as possible so we can refill it. Clinics are run on microbiology status, therefore it is important you come to the clinic you have been given. If you miss an appointment we may not be able to offer an appointment for up to 8 weeks.

There is opportunity to see all members of the multidisciplinary team at clinic and it is important you have a specialised review from doctor, nurse, physiotherapist, dietician, pharmacist and psychologist, as needed.

#### Ward Attender Appointments

During November, December & January we reviewed 241 patients on the ward with 26 patients not attending their appointments or cancelling on the day.

During this time we had 32 ward admissions and 8 day cases so we are definitely getting very busy over the winter period. Your help in coming to appointments as arranged is appreciated. We do realise there are times you are busy too and cannot make your appointment so letting us know as soon as possible will help to run your service more efficiently.

If you require to be seen outwith clinic appointments please call or text us on (0131) 537 1762 / 07770326301/ 07770326302 to arrange an appointment. We will aim to see you promptly, but this is not guaranteed to be the same day you call. Appointments are prioritised and length of appointment, doctor availability, room availability and microbiological status influence when appointments can be fitted in. Please help us by attending ward appointments as arranged and letting us know if you cannot make appointment or are running late. If you are originally booked for a short appointment such as a blood test and are unwell and need a doctor review which takes longer please let us know in advance so we can adjust the diary.

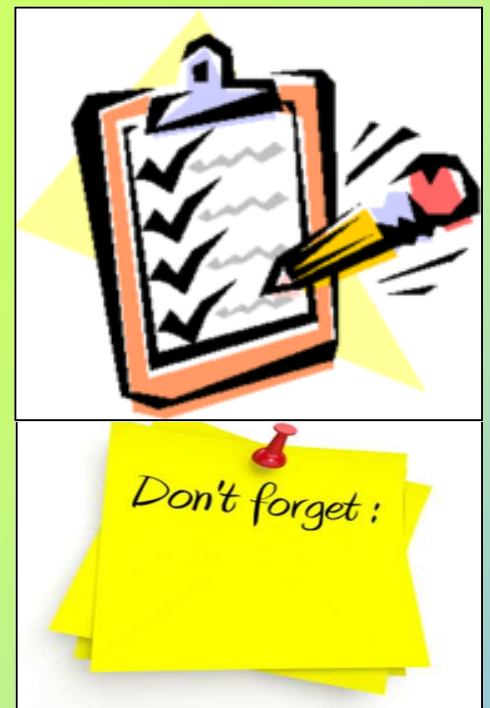
**Future Plans-** We are looking to increase our outpatient clinics so we can see more patients in clinic rather than on the ward. We are hopeful this may be achieved soon.

*Julie Robertson, CF Nurse Specialist*



Welcome to the fifth issue of our CF Newsletter.

Our aim is to update patients on all CF service changes, news, research and publications.



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## INTRODUCING OUR NEW CF TEAM MEMBERS

### Ruth Moss

CF Research Nurse

#### Contact Details:

**Tel:** 0131 537 3787

**Internal Ext:** 33787

**Mobile:** 07976 977118

**Email:** ruth.moss@nhs.net

**CF Office:** 0131 537 1762

Ruth Moss is a Senior Research Nurse and joined the CF Team in 2017, supported by the Cystic Fibrosis Trust. She has had a varied career as a nurse, specialising in critical care before moving into respiratory nursing and then respiratory research. Previously, she has worked in Ninewells Hospital, Dundee and for Edinburgh and Dundee Universities. She is always happy to be contacted about the research trials taking place and works Tuesdays, Wednesdays and Thursdays.



### Corina Mason

CFHealthHub Researcher

#### Contact Details:

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**Internal Ext:** 33366

**Email:** corina.mason@nhs.net

**CF Office:** 0131 537 1762

Corina has recently joined the team from NHS Grampian. She has a background in health psychology and has just completed her training in Aberdeen. Her work involved supporting children and young adults with chronic health conditions to self manage medication and treatment regimens. She is looking forward to meeting you all and starting the new and exciting CF HealthHub project!



## THE CF RESEARCH TEAM

The research team is made up of CF doctors and a trial coordinator/senior research nurse:

**Dr Robert Gray**

**Dr Alastair Innes**

**Dr Crichton Ramsay**

**Dr Helen Rodgers**

**Dr Antonia Tasiou**

**Ms Ruth Moss**

**Corina Mason (HealthHub)**

But the whole CF team of nurses, physiotherapists, pharmacists and dietitians all support the research process.

Plus NHS Lothian have a dedicated facility for doing clinical trials-

The Wellcome Trust Clinical Research Facility. So participants are always well supported.

Do not be surprised if you are approached in clinic and asked if you would like to take part in CF research. Please let us know if you do not want to be approached and we will update your records.



**The Wellcome Trust  
Clinical Research  
Facility (WTCRF),  
Western General  
Hospital, Edinburgh**

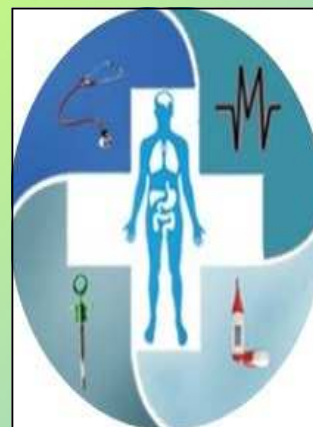
**Thinking of taking part?**

**Please find below some useful websites.**

<https://www.nhs.uk/conditions/clinical-trials/#what-happens-in-a-clinical-trial>

<http://www.healthtalk.org/peoples-experiences/medical-research/clinical-trials/topics>

<http://www.invo.org.uk/resource-centre/jargon-buster>



# CYSTIC FIBROSIS RESEARCH IS HAPPENING!

## DO YOU WANT TO TAKE PART?

### THE TRIALS

In 2017, the Cystic Fibrosis Trust chose a network of CF centres, to lead in the delivery of clinical trials. NHS Lothian is now one of those centres!

The Cystic Fibrosis Trust's aim is that every person in the UK with CF who is eligible and who wants to participate in a clinical trial can take part, regardless of where they live or the geographical location of their CF care centre. We have made good progress in NHS Lothian already. We have 2 clinical trials that are currently recruiting participants and 2 more that are due to begin later in the year. There is a new dedicated trial co-ordinator and research nurse who works to get new trials into NHS Lothian and help patients to access the trials.

#### **HOPE-1 Study: Hydration for Optimal Pulmonary Effectiveness**

A Randomized, Double-blind, Placebo-controlled Phase II Study to Evaluate the Efficacy and Safety of SPX-101 Inhalation Solution in Subjects With Cystic Fibrosis

Put simply, this study looks at whether an inhalation solution, SPX-101 helps mucous clearance in the lungs. More information can be found at:

[https://www.cysticfibrosis.org.uk/get-involved/trial-stracker/2017/09/99066?cp\\_icl=true#](https://www.cysticfibrosis.org.uk/get-involved/trial-stracker/2017/09/99066?cp_icl=true#)

#### **A Study of the Dosing, Efficacy, and Safety of Oral Cysteamine in Adult Patients With Cystic Fibrosis Exacerbations**

Put simply, this study investigates the use of cysteamine in the treatment of adults with Cystic Fibrosis who are experiencing an exacerbation of CF-associated lung disease. More information can be found at:

<https://www.cysticfibrosis.org.uk/get-involved/trial-stracker/2017/08/101870?ctap-term=cysteamine&orderby=smallcreateddate>

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## INNOVATIVE CFHEALTHHUB TRIAL GOES LIVE IN EDINBURGH

The CFHealthHub trial is part of a wider NIHR Programme (ACtiF) grant awarded in 2015. Research has found that a number of people with CF have difficulties with taking their nebulised therapies, which can unfortunately lead to more infections and less good health outcomes. This innovative and exciting research project, developed in Sheffield, aims to support individuals with CF to manage the nebuliser treatment, through working with a dedicated member of staff.

This project has already been successfully implemented in two CF centres (Nottingham and Southampton), and is now running in 19 CF centres across the UK, including here in Edinburgh. The aim is to recruit 556 individuals with CF, making this the biggest study conducted on CF in the UK! Edinburgh is one of the centres taking part, with Dr Helen Rodgers leading the study. Corina Mason is our local researcher, who can provide further information about the study and will begin speaking to individuals about this project at the end of this month.

For any queries locally please contact Corina on Tel: (0131) 537 3366, Helen via the CF Office Tel: (0131) 537 1762 or you can contact the Project Manager for the study-ChinMaguire, e-mail- [c.maguire@sheffield.ac.uk](mailto:c.maguire@sheffield.ac.uk). For more information about the project please visit our website: <https://www.sheffield.ac.uk/scharr/sections/dts/ctru/cfhealthhub>

*Helen Rodgers, CF Director & Corina Mason, CF HealthHub Researcher*



## PATIENT SURVEY FEEDBACK-INPATIENTS

You will hopefully recall from the last CF Newsletter that we had just started a new Patient Satisfaction Survey on Ward 54 to find out what people with CF thought about the ward round during their hospital admissions. We were especially keen to know what was considered to be helpful and/or unhelpful about the ward round so that we could make improvements to this, if needed.

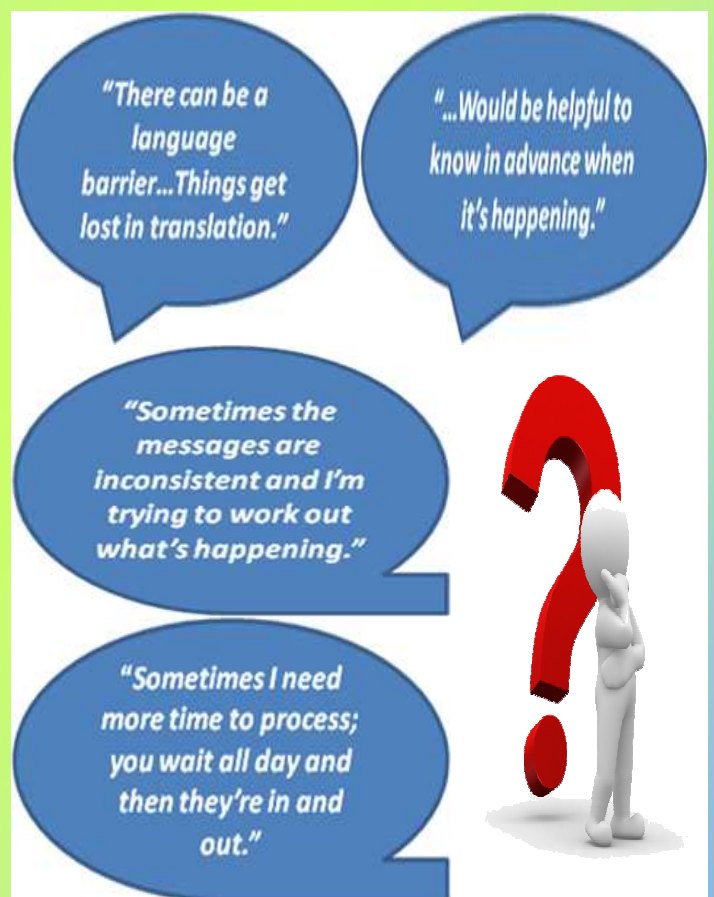
During their hospital stay, patients with CF were approached by our researcher (Dr Kath MacDonald, Senior Lecturer in Nursing) and invited to complete the anonymous survey. We had responses from 23 people in total and combined all these responses, before analysis.

Overall, the majority of in-patients surveyed appeared happy with the ward round process, as shown in Table A below.

Table A	Statement	% Strongly agree or agree (N=23)
	The place where the ward round happens (private room) is suitable.	100
	During the ward round, I am treated with dignity and respect.	95.65
	During the ward round, I am given enough time to discuss the things that are important to me.	91.30
	During the ward round, I feel listened to.	69.57
	During the ward round, any questions that I have are answered in a way that I can understand.	91.30
	During the ward round, I feel involved in decisions about my treatment.	78.26

However, further responses from patients, examples of which are below, revealed anxieties about the ward round process:

- Some people with CF mentioned feeling rushed and unprepared for the ward round;
- Several individuals felt that they did not have time to process or to respond to what they were being told; and
- A few people spoke of being put off by the use of jargon and inconsistent messages from the CF Team members visiting their bedside.



As hoped, we presented the survey feedback by poster at the European CF Conference in Seville, Spain in June 2017. We also shared the results with the CF Team at our Away Day in August 2017 to ensure that patients' comments were heard.

The ward round is such a vital part of the in-patient experience and we are very keen to consider how we can help patients to better prepare for and manage this process. We therefore plan to continue to gather more patient perspectives over the coming months. We also intend to gather staff perspectives and together discuss ways to achieve a truly satisfying experience for all involved in the ward round process.

Many thanks to all the people with CF who kindly gave their time to complete the survey whilst unwell on the ward.

Your feedback is very much appreciated and crucial in helping us to improve the work that we do.

*Dr. Audrey Matthews, Lead Clinical Psychologist &*

*Dr. Kath MacDonald, Senior Lecturer in Nursing, Queen Margaret University*

## MENTAL HEALTH - USEFUL APPS

People are increasingly using apps in all areas of their lives, and mental health is no exception. Below we've listed some apps that people might find helpful. These can be used on their own or as part of therapy.

### Stress and Anxiety Companion

This app is designed to help with management of stress and anxiety, using principles from Cognitive Behavioural Therapy (CBT). It includes relaxation exercises and games to help calm the mind. It also helps you to challenge unhelpful thoughts. It's available for free on the App Store.



### Catch It

This app is designed to help you manage feelings of anxiety and low mood, by looking at problems in different ways and challenging unhelpful thoughts. It's free on the App Store and Google Play.

### Stop, Breathe and Think

This app offers lots of free mindfulness practices. There are some available to purchase. It also allows you to 'check in' mentally, physically and emotionally, and it will suggest an exercise for you based on your ratings. It's available on the App Store and Google Play.

If you start using an app and don't find it helpful, or you notice that your problems are worsening, stop using it. If you think that you need extra help and support, please contact your GP or the CF Clinical Psychology team.

*Lauren McAllister, CF Psychologist*

### Headspace

The Headspace app contains a range of meditation and mindfulness practices. Please note, it offers a free 10 day trial period but charges for content after this. It's available on the App Store and Google Play.

### Fear Tools

This app uses CBT principles to help people experiencing difficulties with anxiety, including phobias. The tools include thought diaries to assist with reframing unhelpful thoughts, relaxation and breathing exercises, and behavioural techniques to overcome anxiety. It's free on the App Store and Google Play.

### Mood Tools

This app uses CBT principles to help people manage low mood. It includes tools to identify and challenge unhelpful thinking patterns, and suggestions for activity to help improve mood. It's available on the App Store and Google Play.

### Well Mind

Well Mind is an NHS mental health and well being app designed to help with stress, anxiety and depression. It includes advice and tools to improve mental health, as well as links to online self-help resources. It's free on the App Store and Google Play.

## CYSTIC FIBROSIS: A POCKET GUIDE

**Cystic Fibrosis: A Pocket Guide** is an excellent interactive and educational app developed by the CF Nurses in the Dundee service.

Download it for free to your device via either the Google Play store or iTunes to explore more about how Cystic Fibrosis affects the body.

## NUTTY ABOUT NUTS!

### Nutty facts – Did you know...

- Nuts are actually a type of fruit and mostly grow on trees. Unlike most other fruit, however, nuts aren't sweet and are high in fat.
- There are lots of different types of nuts – almonds, brazil nuts, cashews, hazelnuts, macadamia nuts, peanuts, pecans, pine nuts, pistachios and walnuts.
- A 28g (1oz) serving or small handful of nuts provides 160-200 calories.
- Watch your serving size and nuts can actually help you to lose weight.
- Just 1-2 Brazil nuts per day will provide you with the recommended amount of selenium.
- Walnuts are a great source of Omega 3 fatty acids if you don't like oily fish or are vegetarian.
- Nuts will keep in a sealed container at room temperature for up to 3 months or in a fridge for up to 6 months.

### Reasons to go nutty about nuts...

**Nuts provide the following top 8 health benefits and can be a NUTritious addition to your diet whether you are trying to gain weight, maintain a healthy weight or lose weight.**

#### 1. Highly nutritious

Nuts are high in fat (pecans and macadamias contain the most) low carbs and a great source of several nutrients, including vitamin E, magnesium and selenium. Ask your dietitian if unsure how many Creon you need per serving.

#### 2. Antioxidant powerhouse!

Nuts contain antioxidants called polyphenols, which may prevent cells from damage.

#### 3. Aid weight loss

Nuts have been shown to promote weight loss if eaten in moderation as part of a healthy diet. They may help you feel fuller and reduce appetite for less nutritious snacks. Several studies have shown that the body doesn't absorb all of the calories in nuts.

#### 4. Lower cholesterol and triglycerides

May help lower total and LDL ('bad') cholesterol and triglycerides while boosting levels of HDL ('good') cholesterol.

#### 5. Beneficial for Diabetes and metabolic syndrome

Eating nuts can improve blood sugar, blood pressure and other health markers in people with Diabetes and metabolic syndrome.

#### 6. Reduce inflammation

May reduce inflammation, especially in people with diabetes, kidney disease and other serious health conditions.

#### 7. High in fibre

Many nuts are high in fibre, which can reduce disease risk and improve gut health. Almonds and pistachios contain the most fibre. 28g serving of almonds provides the same amount of fibre supplied by a medium orange or banana.

#### 8. Reduce risk of heart attack and stroke

Nuts have several benefits for heart health including raising HDL ('good') cholesterol and improving artery function.

### ENJOY:

In a crunchy granola- Mix nuts with oats, sunflower oil and honey and bake. Serve with fruit and yoghurt or ice cream.

With roasted vegetables – Roast carrots, beetroot, and parsnips with nuts, thyme and olive oil. Roast broccoli with chopped garlic, chilli flakes, cashew nuts and soya sauce.

Toasted and sprinkled on salads.

As an ideal snack between meals.

An ice cream sundae- Try your favourite ice cream topped with pecans toasted in butter and soft brown sugar served with chocolate or caramel sauce.



Nuts are delicious, versatile and widely available. They can be enjoyed whole, as nut butters and sprinkled on food. They are highly nutritious, super tasty and eating them on a regular basis can be a very enjoyable way to improve your health!

*Marie & Lianne,  
CF Dietitians*

## URINARY INCONTINENCE IN PEOPLE WITH CYSTIC FIBROSIS

Many people with cystic fibrosis (CF) have episodes of urinary incontinence. This varies in severity from leaking urine or bowels, to difficulty controlling wind and urgently needing to pass urine. This mostly affects women with CF but can also affect men too.

In CF the pelvic floor can become weak as a result of:

- repeated coughing and continual straining to empty bowels when constipated
- an imbalance between breathing, postural and pelvic floor muscles
- other general factors including pregnancy and child birth, obesity, and a lack of general fitness.

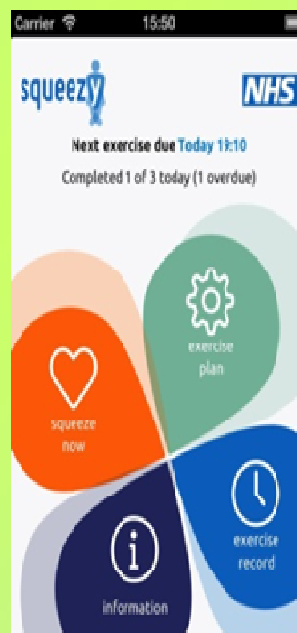
The pelvic floor consists of layers of muscles and tissue, and extends from the tail bone (at the back of the body) to the pubic bone (at the front of the body). The pelvic floor muscles support the bladder and bowel. The urethra, vagina and rectum pass through the pelvic floor.

Research shows that pelvic floor exercises are effective in improving pelvic control endurance and reducing leakage.

### So how do you contract your pelvic floor? – A quick lesson...

- Lift your pelvic floor by tightening the muscles around your back passage and front at the same time. Imagine you are stopping the passage of wind and urine.
- Try not to squeeze your buttocks or tighten your thighs or stomach. Do not hold your breath.
- Try to practise doing 10 slow tightening over 5 seconds, and 10 quick contractions- see the resources for more detail.
- Practise the 'knack'- contracting your pelvic floor muscles to brace before you cough, sneeze, huff or lift something.

*Nicola & Carolyn, CF Physiotherapists*



## RESOURCES

### CF Trust Leaflet

Informative leaflet expanding on the points we have made.

To find out more visit <https://www.cysticfibrosis.org.uk/life-with-cystic-fibrosis/cystic-fibrosis-care/physiotherapy/physiotherapy-faqs#aboutincontinence>

### Squeezzy App

A NHS supported app, specially designed to help people remember to do their pelvic floor muscle exercises. This contains very useful information and guides to exercises and the 'knack'.

To find out more visit: [www.squeezzyapp.co.uk](http://www.squeezzyapp.co.uk)

## ANNUAL REVIEW TESTS

We have spaces for glucose tests, exercise tests and ultrasounds on your day of clinic but these are very limited. If you have been given one of these appointments please let us know as soon as possible if you cannot attend. Unfortunately when we book a bone scan we have no influence on getting this on the day of your clinic and we now have a waiting list for this test so if you have been given an appointment please do your best to attend.

If unable to attend please call the medical physics department (0131 537 2155) as soon as possible so this can be rearranged for you.

Coming to appointments as arranged is essential and we do realise there are times you are busy too and cannot make your appointment so letting us know as soon as possible will help run your service more efficiently.





The Butterfly Trust provides a variety of support services in the community for people affected by Cystic Fibrosis.

They offer support for the following:

- ◇ **Information and advice**
- ◇ **Benefits support (DLA / PIP)**
- ◇ **Housing applications**
- ◇ **Employment issues**
- ◇ **Access to financial support**
- ◇ **Free massage therapy**
- ◇ **Transport**
- ◇ **Other specialist services**

**Contact Us**

109/3 Swanston Road  
Edinburgh  
EH10 7DS

**Tel:** (0131) 445 5590

**E-mail:** [info@butterflytrust.org.uk](mailto:info@butterflytrust.org.uk)

**Or Visit**

[www.butterflytrust.org.uk](http://www.butterflytrust.org.uk)  
[www.facebook.com/butterflytrust](http://www.facebook.com/butterflytrust)  
[www.justgiving.com/butterflytrust](http://www.justgiving.com/butterflytrust)

**Latest Tweets**

Tweets by [@butterflytrust1](https://twitter.com/butterflytrust1)

**THE CYSTIC FIBROSIS TEAM**

**CF Office:** (0131) 537 1762

**Out-of-Hours: Ward 54:** (0131) 537 1788

**CF Consultants**

Dr Helen Rodgers Secretary: (0131) 537 2348  
Dr Robert Gray Secretary: (0131) 537 2348  
Dr Alastair Innes Secretary: (0131) 537 1783  
Dr Crichton Ramsay Secretary: (0131) 537 1781

**CF Specialty Doctor**

Dr Antonia Tasiou CF Office: (0131) 537 1812

**CF Nurses**

Catriona McMullan CF Office: (0131) 537 1762  
Lynne McIntosh CF Mobiles: 07770 326301/  
Julie Robertson 07770 326302

**CF HealthHub Researcher**

Corina Mason (0131) 537 3366

**CF Research Nurse**

Ruth Moss (0131) 537 3787  
Mobile: 07976 977118

**CF Psychologists**

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Dr Lauren McAllister

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Diane Fanning Respiratory Office: (0131) 537 1781



If you would like to contribute to the next issue of our Cystic Fibrosis newsletter please contact us in the CF Office on:  
**Tel-** (0131) 537 1762  
**Or e-mail-** [Lothian.CFteam@nhs.net](mailto:Lothian.CFteam@nhs.net)