

CF NEWSLETTER

THE EDINBURGH ADULT CYSTIC FIBROSIS SERVICE

MANAGING APPOINTMENTS

Your Service is growing!

The Scottish Adult Cystic Fibrosis Service at the Western General Hospital now has over 200 patients. The service was set up in 1992 with less than 50 patients so we certainly have grown over the years! This is great, but fitting everyone in for appointments is a challenge and we need your help in ensuring you are all seen appropriately.

CF Clinics

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.

During November, December & January 30 patients did not attend their clinic appointment without letting us know. 27 appointments were unable to be used due to late or same day cancellations. This resulted in 57 lost clinic appointments!

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

Ward Attender Appointments

If you require to be seen out with 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. Ward attender appointments are prioritised by length of appointment required, doctor availability, room availability and microbiological status which influence appointment time. Please help us by attending ward appointments at time arranged and letting us know if you cannot make the 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 your appointment.

During November, December & January we reviewed 251 patients on the ward with 17 patients not attending their appointment or cancelling on the day.

During this time we had 38 ward admissions and 19 day case patients so we are definitely getting very busy. 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.

Welcome to the fourth issue of our CF Newsletter.

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



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THE CYSTIC FIBROSIS TEAM

CF Team from left to right:

Dr Crichton Ramsay (Consultant), Julie Robertson (Nurse), Lynne McIntosh (Nurse), Dr Helen Rodgers (CF Director), Dr Robert Gray (Consultant), Marie Richardson (Dietitian), Dr Antonia Tasiou (Specialty Doctor), Diane Fanning (Secretary), Dr Alastair Innes (Consultant), Audrey Matthews (Psychologist), Caroline Aitken-Arbuckle (Physiotherapist) & Dawn Wilson (Data Manager).



Team members not present--: Catriona McMullan (Nurse), Nicola Duncan & Sarah Ridley (Physiotherapists), Douglas McCabe (Pharmacist), Lauren McAllister (Psychologist) & Emma Wilkinson (Dietitian)

CYSTIC FIBROSIS TRUST CLINICAL TRIALS ACCELERATOR CENTRE- SCOTTISH NETWORK

We are delighted to announce that the Edinburgh Adult CF service has been successful in our application to join the Cystic Fibrosis Clinical Trial Accelerator Platform. This is a new flagship programme funded by the Cystic Fibrosis Trust.

Edinburgh and Glasgow are one of 8 lead Trials Accelerator centres to be funded with a clinical trials coordinator by the Cystic Fibrosis Trust. The combined UK centres will provide improved access to clinical trials for over 6,000 people; more than half of the UK population of people with cystic fibrosis.

The Edinburgh Adult service will receive funding from the Trust for a dedicated Cystic Fibrosis Trial Coordinator, who will oversee the day-to-day running of CF clinical trials.

Clinical research study information will be available at clinic in the near future.

Trials Accelerator Patient Advocate

The CF Trust are forming a group of Peer Advocates, who would be willing to offer support and guidance to their regional CF Community, sharing their own experiences of trial participation and promoting the value of research. If you are interested in finding out more about this role please contact us on the following e-mail:- Lothian.CFTeam@nhs.net



INTRODUCTION TO NEW CF TEAM MEMBERS

Dr Robert Gray

Honorary Consultant
Respiratory Physician



I started my research career with Professor Andy Greening around 12 years ago as part of the UK Gene Therapy Consortium, funded by the CF Trust. At that time we discovered a new way of monitoring CF lung disease using a blood test for a protein called calprotectin, which is produced by white blood cells in the body. I then had further research training at Medical Research Council / University of Edinburgh Centre for Inflammation Research (CIR), to learn further skills in scientific research and this led to the award of a Wellcome Trust Fellowship to investigate what calprotectin does in CF, while allowing me to start my work as a CF Consultant. Because of this funding I was able to go to The University of Iowa, USA to work with the CF research group for 20 months and this has now allowed me to establish my own research group at Edinburgh University. Presently we have 3 other members of the team (1 postdoctoral scientist, 1 specialty registrar conducting a PhD project and a visiting Student from Europe). Later in the year we have a further PhD student joining the team.

Lung damage in CF is caused by an over-exaggerated response to infection in the body (inflammation), leading to a loss of lung function over time. We want to understand why this happens in CF, how calprotectin is involved, and how we can intervene (with drugs and other treatments) to stop lung damage. Treatments that target inflammation will help all patients, regardless of their CF genotype and may be an important addition to drugs such as CFTR correctors and potentiators in the future. Our present studies are focussed on understanding how white blood cells in CF contribute to lung inflammation and also how the cells lining the lung may produce factors such as calprotectin that contribute to lung damage.

Carolyn Aitken-Arbuckle

CF Physiotherapist



Carolyn previously worked at NHS Forth Valley for 5 years dealing with patients with a range of respiratory conditions.

She started working with the CF team in August 2016.

Carolyn will be working on the ward, at clinics and taking more of a focus on exercise and activity.

CLINICAL FELLOWSHIP

Towards the end of last year I was awarded an NRS/Universities Senior Clinical Fellowship, which funds on-going work in the lab to investigate calprotectin and inflammation whilst also allowing me to continue work as a Consultant in the CF team. Edinburgh has a great history of CF research, particularly involving patients, and we hope to continue that tradition with the help of our patients and the clinical team. We are happy to let anyone know about our research and can provide information about our specific research studies on request.

Dr Crichton Ramsay

Consultant Respiratory
Physician



Dr. Crichton Ramsay joined the Cystic Fibrosis team in Edinburgh in the Spring of 2016. He graduated in Edinburgh subsequently did his training in cystic fibrosis and respiratory medicine in Edinburgh and London. He previously worked at the Norfolk & Norwich University Hospital where he was joint clinical lead for their cystic fibrosis centre. He was a consultant in Norwich for 17 years before returning to Edinburgh.

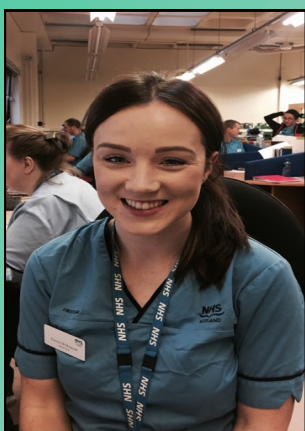
INTRODUCTION TO NEW CF TEAM MEMBERS

Dr Lauren McAllister
CF Clinical Psychologist



I trained at the University of Glasgow and did a specialist placement in chronic pain, which I thoroughly enjoyed. I am about to rejoin the chronic pain service in Glasgow. I'm delighted that I will also be spending half my week in Edinburgh, having been offered a fixed term post with the Cystic Fibrosis team. I look forward to meeting you and working with you. Having lived and worked in the West of Scotland for my whole life, it will also be nice to get to know the east coast a little too!

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



Emma Wilkinson
CF Dietitian

Emma joined the CF team in September of last year to cover for a period of maternity leave. She has been working in general dietetics for over 6 years – covering areas such as surgical, gastroenterology, intensive care, diabetes, community enteral feeding and weight management. She also works part-time covering neurology and intensive care wards in the Western General – hence why you may only catch her with the CF team on certain days! Emma is particularly interested in enteral feeding & diabetes; combining the two within CF.

PATIENT SECTION

IV HELP SHEET

Here are some helpful suggestions for when starting home IV antibiotics. (From a patient's perspective!)

Added Bonus: You will impress the CF Nurses!

Check what supplies are needed and how much (if any) you already have. Some examples are:-

- ◆ Syringes
- ◆ Needles
- ◆ Sharps bin
- ◆ Epipen
- ◆ Sterile wipes

Ensure expiry dates are valid.

If using public transport make sure you have suitable and practical carrier bags, which ideally are waterproof too. Durable and spacious bags assure that supplies are secure whilst also being able to hold those bulky items.

I hope this helps!

TOP TIP

Make a note of your findings– don't just try and remember them!



EXERCISE AND CF

2017 New Year resolution..... Must exercise!

Exercise is a great way to keep you as healthy as possible. This is something we are trying to encourage more and more, as lots of research has been done recently to show how beneficial it is for people with CF. The newest member of the physiotherapy team, Carolyn, has taken on the role of promoting exercise and hopes to increase the awareness and understanding of just how good exercise is for you. Exercise information leaflets are in the pipeline – watch this space!

Bike Test

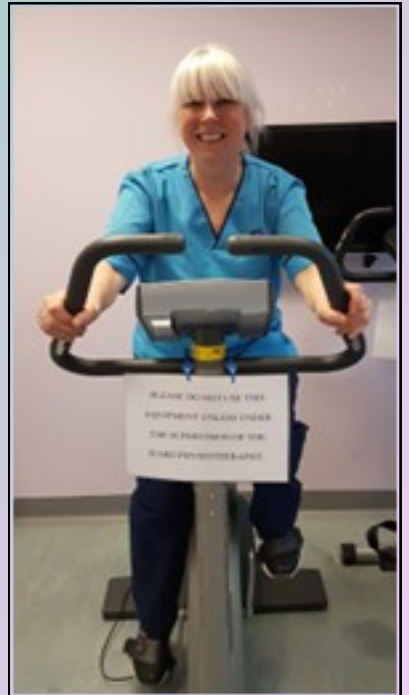
The aim of the bike test is to assess your fitness annually.

By the end of the test you should feel that you could not have done anymore. We would not expect you to exercise to this level other than during the bike test.

While it is not everyone's favourite activity, it does tell us a lot of valuable information:

- The trend of your general fitness over years
- How well your lungs work and use oxygen
- How well your heart responds to exercise

From this information we can advise you on an exercise program specifically for you.



So why exercise?

- To help maintain your lung function.
- To help clear your lungs. When you breathe faster and deeper, this can move sputum. Always do a huff +/- cough after exercise to clear any sputum.
- To help improve bone strength. For those who have thinned bones, weight bearing exercise can be beneficial.
- For those who have diabetes and use insulin, it can help reduce your need for insulin.
- To help regain your normal level of activity quicker, after an exacerbation.

The physiotherapy team will continue to review your exercise/activity level at clinic or during a hospital admission, and can help you to develop an appropriate exercise program. If you think you would benefit from this support or have any questions, please speak to your physiotherapist at your next clinic appointment.

New Year Resolution Action Plan

- Pick an exercise/activity that you enjoy and will fit into daily life.
- Pick an exercise buddy and/or tell people about your plan.
- Decide how regularly, how long, and how hard you should exercise. It's always best to build up gradually.
- Record your exercise/activity in a diary, calendar or phone app so you can see your progress.
- If you have any concerns about any aspect of exercising contact the CF Physiotherapy Team.



PATIENT SURVEY- INPATIENTS

We wanted to let you know about a new Patient Satisfaction Survey that we have just started on Ward 54. We are seeking to find out what people with CF think about the ward round during their stay. The ward round involves a Consultant Respiratory Physician and others members of the CF Team visiting inpatients at their bedside twice weekly to discuss things like your progress, treatment updates, discharge plans. We are especially keen to know what you find helpful and/or unhelpful about this during your stay on the ward so that we can make improvements, if needed. All responses to this survey will be completely anonymous. We do not need to gather any personal data about you for this project.



This project has been approved by the South East Scotland Research Ethics Service, NHS Lothian and is being undertaken by Dr. Audrey Matthews, Lead Clinical Psychologist, CF Team and Dr. Kath MacDonald, Senior Lecturer, Nursing, Queen Margaret University

Given that Kath is not part of the CF Team and is not known to most patients, she will distribute the survey for us. This will hopefully prevent patients from feeling pressurised to participate and/or feeling unable to be completely honest regarding their views.

Kath will approach you if you happen to be an in patient on Ward 54 in the next 3-4 months to gather as many inpatients' views as possible. She hopes to visit every week or two. She will explain the project and ask if you are willing to complete a short questionnaire on your experiences of the ward round. You are under no obligation to participate and you should only be approached once during your stay. If you agree Kath will leave the survey with you and collect it again at the end of the day. If you need assistance to complete the survey, Kath will be happy to help. When the survey is completed, she will ask if you have anything additional to bring up that was not covered in the survey and make a note of any issues raised.

Audrey and Kath will analyse the responses together. It is hoped to present the anonymous findings in the CF Newsletter, at any relevant CF forums or meetings (e.g. CF Study Days locally and nationally), and at the European CF Society Conference, Seville in June 2017.

The views of outpatients who have previously been admitted to the ward are not being sought at present - only those of current inpatients - but we will let you know if anything changes!

If you have any comments or questions, please do not hesitate to get in touch with Audrey or Kath via the CF Office – (0131) 5371762.

INPATIENT MULTIDISCIPLINARY CARE

We know that many patients can experience difficult symptoms when in hospital. For example- pain, shortness of breath, sickness and anxiety.

It is normal for us to seek advice and involvement from Specialist teams from within the hospital. For example - palliative care and pain teams. These specialist teams have a wealth of knowledge and experience in controlling difficult symptoms.

Many patients worry about involvement of other teams, however these are very experienced professionals who can support patients and their family. They also work very closely with the CF Team to help and advise with the management of symptoms.

If you have any worries about your health or specific symptoms please do not hesitate to talk with any member of the CF Team.

PREGNANCY

We have had quite a few mums who have given birth in the last year, so congratulations to all of them! We are always so happy when things go to plan and we can help you fulfil your dreams and ambitions. Pregnancy in CF can be managed successfully but there are a few risks involved which we can discuss with you in advance. We can also provide advice to those couples who are thinking about having a baby but are unsure of the risks, pre-natal screening or what is usually involved in infertility services. Please let us know if you are planning to have a family in the future, and this includes the boys too!

The whole team are interested in helping mums have an event free pregnancy; this includes keeping an eye on your lungs more often than usual. We have access to a high risk clinic where you can be seen by a team experienced in managing complex pregnancies. They normally wish to see mums 2-4 weekly throughout their pregnancy. You will also get advice from the physiotherapist on airway clearance, dietitian on maintaining your nutrition and pharmacist on medication in pregnancy and breastfeeding. Please remember that some medications can not be taken during pregnancy and many medicines have little or no information, especially if they are new. It takes time to build up experience on new medicines and in these cases it is often an individual decision about whether to continue taking it or not. We are more than happy to discuss the information we have at clinic, just let us know.

Thinking of starting a family? ...

We have a supply of booklets from the CF Trust offering advice on decision making, advice for women, advice for men, IVF and other options.

Please let us know if you would like a copy.

It is very important for women planning a pregnancy to look after themselves as much as possible so you are as well prepared as possible. It is also important to keep this up for the years after birth. This will include taking all your medication as prescribed, doing your airway clearance, exercise and sticking to your nutritional plan or monitoring blood sugars and adjusting insulin if this applies to you.

Please remember we like to check carefully that all your medication is safe to take before you get pregnant. It is important to use contraception to avoid getting pregnant when you are on long-term medication. Please do not stop any medications yourself if you do become pregnant, as it is also important that you keep your lungs as healthy as possible before and during pregnancy. If you think you might be pregnant please contact the CF service as soon as you can to discuss. You also may not be able to take your usual antibiotics if you have an exacerbation but we will check which antibiotics are best for you at the time.

If you want to read more about contraception, fertility or medicines in pregnancy, then these websites are a good place to start:

<http://www.fpa.org.uk/>

<https://www.cysticfibrosis.org.uk/life-with-cystic-fibrosis/fertility>

<http://www.medicinesinpregnancy.org/Medicine--pregnancy/>

CF WEBSITE- NOW LIVE

We have created a website for the Edinburgh Adult Cystic Fibrosis service.

Visit our new website at:

<http://www.nhslothian.scot.nhs.uk/Services/A-Z/CysticFibrosisAdultService/Pages/default.aspx>

Our website contains information on the following:-

- Information and leaflets on the CF Service
- Inpatient /Outpatient/ Admissions information
- Transition/ New patients information
- Annual reviews
- What to do in an emergency
- Protocols/ policies and other resources
- The CF Team
- CF research & latest developments

We will be updating our website soon.



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

They provide advice on the following:

- ◇ **Information and advice**
- ◇ **Benefits and DLA**
- ◇ **Housing**
- ◇ **Employment**
- ◇ **Access to financial support**
- ◇ **Other specialist services**

Website- www.butterflytrust.org.uk

E-mail – info@butterflytrust.org.uk

THE CYSTIC FIBROSIS TEAM

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