



# Adult Cystic Fibrosis Centre Newsletter

Sheffield Teaching Hospitals NHS Foundation Trust  
June 2017



Welcome to our annual newsletter. If you have any ideas that you would like to see included please let us know. We hope you find this helpful & we would value your feedback. The CF Team



## Outpatient Nursing News

Over the last year you will have seen some changes in the outpatient nursing team. Sadly Perveen Ali left us to join the TB service. We welcomed Paul Ratcliff from COPD & Davod Tamin moved from the CF ward.

Congratulations to both Kate and Shirley who completed their nurse prescribing course. Kate and Davod are now studying towards their nurse practitioner qualification.

**Don't forget** we are easily contactable between 7am–6pm via the CF outpatient nurse mobile—see below. You can leave non-urgent messages (voicemail or text). If this is out of hours we will get back to you the next working day. For urgent out of hours inquires please contact the CF ward. We also continue to offer a **home visiting service** when available. This is to provide support where appropriate. Please ask us if you want to know more about any of the services we offer.



Your centre in Sheffield is running the National self-management programme which has attracted around £2.6 million from the National Institute of Health Research & around £6 million from NHS England. The programme is led from the Sheffield CF unit & involves collaboration with 8 universities around the UK. The programme has worked with people with CF to develop a platform called

CFHealthHub that feeds back information from chipped nebulisers about how much treatment is taken to mobile phones and tablets. Taking treatment day in day out is really hard & the programme is designed to help people form habits that should make treatment easier. From the 1<sup>st</sup> of April Sheffield, Nottingham and Southampton started to work together to try to understand how we can redesign the organisation of care to make it easier for people with CF to self-manage. The idea is that tricks and tips about what works in terms of organising the team to better support patients & also what works for patients can be shared amongst the 3 teams in Sheffield, Nottingham & Southampton. We hope this will help us to get better at supporting people with CF to live as normal a life as possible. We would like to thank the very many Sheffield people with CF who have given so much of their time to make the work possible.

## Useful Contacts

**CF outpatient nurses mobile:** 07500572535,

Can be used for text or calls but not for emergencies

**Specialist nursing team office:** 01142266281

Option 1- Change appointment

Option 2- Order prescription

Option 3- Unwell or needing advice

If not urgent please leave a message.

**Boots pharmacy:** 01142714366

**To change/cancel clinic appointments please call Shona:** 01142269808

### Out of hours:

**CF ward:** 01142266580

If an emergency please attend your local A&E Department. Tell them you have CF and ask them to contact us.



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way





## Message from Dr Edenborough

We are thrilled to welcome Dr Rachael Curley, our previous CF Fellow & then Research Fellow as the new CF consultant. She will work 2 months in CF and 2 months in Respiratory Medicine. Frank will step down off the ward during Rachael's 2 months in CF & concentrate on out patient work. Martin will continue to do 2 clinics a week, the rest of the time being involved in research. Many of you will have met Rachael already and so know she will be an excellent addition to our team.



### Charitable donations:

A warm THANK YOU to the many of you, & your families & friends who continue to raise money for the ward & the special services it can provide. We expect to have a full time dietitian funded for another year & possibly in the long term to complete Ellie's work. We need to keep up the WiFi, maintain computers/laptops, replace bedding, Z beds, & other consumables & are looking to improve care in people's homes perhaps by having our own car funded by the Charity. If you would like to help, please get in touch with the charity on 0114 2267351

### Nearly 20% of clinic appointments are missed:

As clinic is getting bigger, we are struggling to fit in annual reviews & are finding it more difficult to find clinic slots when patients want them. At the same time we book clinics & find that many slots are wasted by people not turning up & not telling us. Some people don't even come when we have rung them to confirm they are coming! The problem is getting worse with nearly 2 in 10 slots wasted. Please can we ask you to plan carefully attendance at clinics and do all you can to come & if you can't give us plenty of notice. We will NOT be seeing people out of clinic unless its an emergency as we do not have the staff, so if you miss a clinic there could be a delay until the next one. Thank you!

## Social Work News

Most of our patients are going through a change in benefits as DLA is phased out, & DWP customers are 'invited' to claim PIP instead. Many patients who were in receipt of DLA, have been turned down for PIP. Some of these have been supported to ask for a 'Mandatory Reconsideration' & have then had the decision overturned. Others have still been turned down at the Reconsideration stage & are waiting for a date for a Tribunal, having put in a request to appeal. The CF social workers are very busy supporting these activities, but please don't be put off from asking for support. If the PIP form is completed with all the necessary information, it can make the process of reconsideration & appeal much easier, so we would rather be there to support you at the beginning of the process. A well presented form can save time later on, & we are happy to help. Once you have done the initial telephone application, & received your PIP form,

**please contact us on (01142715214)** to make an appointment for help filling it in. Don't leave it till the last minute!



## Dietetic News

You may have see some new faces in the dietetic team. Unfortunately we said goodbye to Ellie & Felicia last year. Ellie has gone to the Children's team & Felicia has started a new rotation in renal & intensive care Good luck & thank you to both!

We have welcomed Racquel & Beth. Both are experienced dietitians & are really keen to work with you & learn more about CF. Sarah & Ailsa will continue their posts working in CF.

**Home support:** We now have the opportunity to offer more dietetic support in the community. We are able to visit you to monitor weight, & support you at home. If you are struggling to gain or maintain a healthy weight & feel that you would benefit from Sarah or Ailsa visiting you please let us know.

**Contact us on 0114 2714162.**



## Nursing & Ward News

We had a particularly busy winter which you will no doubt be aware of if you have been waiting for admission. You can help by accepting a bed when it is available on the day we call. Please try to arrive at the agreed time or you may lose your bed.

A brief reminder of some of the **ward rules** that are in place for your benefit & safety:

- Visiting times on the ward 11:00 -21:00
- On leaving the ward please ensure you sign out (book at nurses station) & inform a member of nursing staff
- Return to the ward no later than 23:00 hours unless by prior agreement & on return ensure you sign back in & inform staff
- Food provided by the hospital & ward is only for in-patients not visitors
- Please abide by the cross infection guidance - no meeting in corridors or anywhere on site, keep room doors closed, do not share personal items
- On the day of admission please bring medication, nebulisers, NIV with you plus relevant chargers as we do not keep spares
- Overnight leave is by agreement with the medical team
- Having a relative stay overnight is by agreement with the senior sister
- Unacceptable behaviour will not be tolerated & you may be asked to leave this includes: Violence or aggression toward staff either physical or verbal, non adherence to the rules of the ward/treatment, use of illicit substances/alcohol

**Staff changes:** We have recently been joined by staff nurses Kirsty & Sarah, as well as support worker Emma. Unfortunately Kara left us to explore new pastures.

**Congratulations to:** Harriet who became Mrs Newman-Turner, Kara who became Mrs Wilson-Parker, & Sean who married Sophie. Rebecca gave birth to baby Oliver last year & has now returned.

**Fundraising:** Sue, Marina & Marie completed the 10k walk for wards raising £350. Role on next year girls same again?!



## CF Diabetes

There are new blood glucose (BG) meters available that are linked to an APP where you get a visible record of your BG readings on your phone or tablet. You are able to see graphs and identify BG patterns. This may make it easier for you to manage your diabetes.

Please contact the CF Nurses if you are interested.

Please don't forget to bring your BG meters to clinic so we can download the results for you



## Research News

Hui is researching on the behaviour & habit of using nebulisers, & his research relies on data from the UK CF registry, data from Martin's pilot trial & from data from Sheffield. He has now completed the data collection he needs to do, & he would like to thank everyone that has participated in his studies. Hui needs to analyse all the data & write up his report. He will hopefully finish his work by 2018.

This year at **annual review** we will be passing you your CF registry number along with your NHS number, as the CF Registry are asking you to complete an **online quality of life survey** at home.

We are also looking to see if we can tailor your clinic appointment, by asking a few questions when we contact you to attend clinic, via call, text or email.



## Physiotherapy News

**Staffing news:** Congratulations to Charlotte Clarke (physiotherapy senior assistant) and Charlotte Carolan (CF clinical specialist PT) who have both just had their babies (photo of Charlotte Carolan's new arrival & son Finley). Thank you to Grace Manderson who has been working as a senior physiotherapist on the CF unit for the last year. She has recently rotate back to respiratory medicine & has been replaced by Rachel Szczepanski who has worked on the unit before & will have met many of you in the past. For those whom didn't know, Ian Hardman our assistant physiotherapist left the team to pursue his travelling ambitions & is currently roaming around Australia. We now have Beth Oldfield whom will be working on the ward to support patients with undertaking exercise during their admission. We would also like to welcome a new senior physiotherapist who joined us in February. Her name is Sophie Cooke and she will be a static member of the team supporting patients both on the ward & in clinic.



**Nebuliser equipment:** Can we remind all patients who are on an ineb nebuliser to bring them with them to clinic appointments & for hospital admissions. This allows us to make sure your nebuliser is working correctly for you & helps us to support you in doing your treatments. For those of you on an ETrack (the form of EFlow that can show you your data) please remember to make sure your **hub is plugged in** & your **device does transfer data**. The hub should flash when a data transfer is taking place following treatment. If you have any problems with any of your devices please feel free to contact the physiotherapy team via the clinic number.

**Non-invasive ventilation:** For all those on a non-invasive ventilation device, please can you ensure that the machine is **serviced yearly**. You should receive an appointment letter from the pulmonary function unit at the northern general hospital for this to be done. If you are unsure, please contact physiotherapy via the CF clinic number. Also, please always bring your non-invasive ventilation machine and accessories when you are coming to hospital for an admission.



## Charity News

Our fantastic supporter and CF patient Gemma Louise Kelly has faced her fears and jumped 15,000ft out of a plane to raise money to support the Adult Cystic Fibrosis Centre



If you would like to keep up to date with charity news and how we are supporting patients with Cystic Fibrosis, you

can sign up to receive our newsletter by emailing: [Charity@shct.nhs.uk](mailto:Charity@shct.nhs.uk)



## Psychology News

Rachel Attfield (Senior Clinical Psychologist) & Ben Davis (Senior Assistant Psychologist) are continuing to offer support to patients and close family members. If you would like to speak to one of us please just ring.

We now have a new direct phone line so you can get straight through to psychology. You can ring us on **0114 2269796**. This phone has it's own answerphone that only psychology can access (so please don't leave urgent medical issues on there!). Rachel works Tuesday-Thursday so if you ring on other days—please be patient whilst we get back to you!

## Pharmacy News

When being admitted to hospital, please bring all your usual medicines in with you. This will help us check what medicines you are on. It will also make it easier for you to use your own medicines in hospital.

If you want to you can ask about giving your own medicines when admitted to hospital. This can help you keep your normal routine and take things in a way that suits you!

