



Adult Cystic Fibrosis Centre Newsletter

Northern General Hospital,
Sheffield Teaching Hospitals NHS Foundation Trust
2018



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

Nursing News

There have been some changes in the outpatient nursing team. Davod Tamin completed his Nurse Practitioner course and now has a job in the community which he is enjoying. Kate Foulstone got married in the summer and is now Kate Pearman. She also had baby Megan in June and is currently on maternity leave until next Summer. Welcome to Suzanne (Sue) Young who has joined Shirley Murray, Paul Ratcliff and Michelle Lowther.



The ward staff have asked if you are coming for an admission could you please turn up at a reasonable hour, and bring all necessary equipment for your care, including any medication.

Clinic Appointments

For all clinic appointments please could you ring the appointment clerk on **0114 2269808** if you need to change your clinic appointment. The nurses no longer book appointments. You can leave a message and your call will be returned. We would be grateful if you could give us as much warning as possible if you cancel an appointment. We can then use this appointment for another person. We continue to offer Home visits where appropriate. **Please ask us if you need any further information.**

If you are attending clinic and want to bring a sputum please refrigerate - **Samples over 24hrs will not be accepted.**

Annual reviews: Please ring Jo on 0114 2715283 if you need to change your appointment.

Useful Contacts

Specialist Nurses (Outpatients): 07500572535 **Not for emergencies.**

Can be used for text or calls between the hours of 8.00am-5.00pm.

Boots pharmacy: 01142714366

Out of hours

CF Ward: 01142266580

IF AN EMERGENCY PLEASE ATTEND YOUR LOCAL A&E DEPARTMENT.



Physiotherapy News

In the last 6 months we have seen Charlotte and Charlotte both come back from maternity leave. Both little ones are almost 18 months now, here's a snap shot....

Both Charlottes are enjoying their time being back and are working to help people with their nebulisers. This may include giving out new equipment, introducing patients to CFHealthhub and helping people to take their treatments. As part of this service the 'Charlottes' (as the



team like to call them) are also offering telephone support to patients who might like to talk through their nebulisers and routine. This can be very helpful to many patients to help them to increase the amount of treatment they do. To accommodate those who have work or school Responsibilities,

Charlotte Clarke's little boy Harry **Charlotte Carolan's little girl Arabella Rose**

Charlotte Carolan has extended her working hours and offers evening support. So far the uptake has been fantastic and feedback from patients suggests that it is a very helpful service. If any patients would like to access this service then please feel free to talk to any team member during your appointment and we will arrange this support for you.

If you are due to be admitted could you please remember to bring all your physiotherapy equipment. This may include nebulisers, non-invasive ventilation machine and airway clearance devices such as flutter, acapella or PEP.

Dietetic News

We have had a rotation of some of the dietitians and welcome Christian to the team. Some of you may also remember Felicia, who worked in CF a short while ago. Well Felicia has re-joined the team for a couple of days a week as well. This means that Racquel and Beth have now rotated into other areas but remain at NGH.

Sarah and Ailsa have been developing an app (with lots of technical help!!!) and are planning to test it early next year once they have ethical approval for a research study. The app is designed to help people with CF to monitor their calorie intake and weight, alongside dietetic support. The plan is that it will eventually sit within the CFHealthHub as a nutrition section.

You may have discussed the ward catering systems with Beth and Racquel as they have been working to improve them. We are now about to launch a new menu card for the ward so that food choices available are clear and may tempt you whilst you are staying on the ward with us!



Psychology News

Psychological Support: Living with CF can be demanding and bring about a range of emotions, such as low mood, anxiety and worrying about the impact of your health on relationships, work and study. Decisions about transplant and end-of-life care can also be challenging.

Psychological support is available here for our CF patients who feel they need it. Dr Rachel Attfield (Senior Clinical Psychologist), and Rebecca Mitten (Counsellor) are usually here on these days:

- Rachel: Tuesday -Thursday
- Rebecca: Monday and Friday
- We have a direct phone no: 0114 226 9796, and if we don't answer please leave a message and we will get back to you as soon as we can. You can also ask any member of the CF team to refer you to us.
- We are also now offering a small support service for close family members.

Social worker News

Dorothy Langman & Amy Johnson are your two Specialist CF Social Workers. We can be reached on Tel: 0114 2715214 (Direct Line with Message Facility). We work: Dorothy Mon (08.00-16.30), Tues (08.00-12.30) Weds (08.00-13.30)

Amy Weds (12.00-15.30), Thurs (08.00-15.30) Fri (08.00-15.30)

You can email us: Dorothy.Langman@sth.nhs.uk
Amy.Johnson@sth.nhs.uk

We are here to assist & support you with all benefit issues, including Universal Credit Applications, encompassing ESA, Employment Support Allowance & JSA Job Seekers Allowance. Universal Credit is a payment to help with your living costs. It's paid monthly. You may be able to get it if you're on a low income or out of work.



Welcome new team members left to right: Linsey and Misbah Pharmacy, Amy Social work, Deborah Ward clerk, Karen House keeper.

Pharmacy News

You may notice on the wards we have had a change of pharmacists. Tim Gleeson has moved on to a new job within the hospital and we would like to thank him for his many years with the team. Linsey Abbott has started with us in September and will work primarily on the CF ward. Misbah Tahir has also started as the regular pharmacist on B2 and will also cover the CF ward. Lara and Amanda will continue as before on the CF ward. The pharmacy team will help support the unit with medicine advice and you in managing your medicines.

In the New Year we are looking at different ways of organising the team to increase the number of people we manage to see face to face at their annual review appointment. It would be helpful if you could bring a list of your medicines with you and details of the doses you take to your annual review appointment. This is to make sure our records are up to date and answer any queries you may have. If we do not manage to see you then please leave the list of your medicines for us with the CF nurses.

Charity News

This year the staff from the CF Ward managed to raise money for the ward by holding a cake sale and being part of 'Walk for Wards.' With this money and other generous donations we will be removing the desktop and laptop computers from patients rooms and buying some up to date laptops, and refurbishing some of the rooms decor. We would still urge you to bring in your own tablets or laptops to use if you are admitted.



Research News



Sheffield is leading a National Programme to develop CFHealthHub which provides information to people with CF about how much treatment they have taken. So far over 80% of adult CF Units in the UK are using CFHealthHub. The aim is that people with CF can be supported to develop habits of treatment.

Habits are a great way to stay well because once formed habits are automatic and use up less will power than behaviours that depend on us remembering to take treatment. The CFHealthHub programme includes a large randomised trial that has recruited over 600 patients and the results of this trial should be available about 12 months from now. Sheffield, Southampton and Nottingham are part of a learning health system where CFHealthHub provides information to understand how well teams are succeeding in supporting people with CF to take preventative treatment. The learning health system is a unique development in Cystic Fibrosis care in which team members from the 3 centres get together to learn from each other how to make care better. The next meeting is in Oxford in November.

We welcome back Hui and congratulate him on the successful completion of his PhD. He will be joining us again to do more research as a CF Trust Clinical Fellow and will be supporting clinics and the ward until August. Vic also continues in her role as a Clinical Fellow. She is conducting research involving Hyperpolarised MRI of the lung in CF and will hopefully be recruiting soon.

