



## Changes to Homecare Service



From April/May 2017, Baxter will take over the tender for Home intravenous therapy from Lloyds Pharmacy Clinical Homecare (previously BUPA). They will supply antibiotics, ancillary items and medical equipment direct to patient's homes. We will provide more information about this before the transition process happens.

Lloyds Pharmacy Clinical homecare will continue supplying the high cost nebulised medicines (e.g. Pulmozyme, Promixin, colobreathe, cayston, manitol, Bramitob, TOBI) and Kalydeco.

## Ready, Steady... Go!



Some of you will have noticed we are working on additions to our established transition program to make the move from Paediatric to Adult care as smooth as possible.

These changes include appointment time dedicated to talking through the process away from clinical decisions, more written information within your own transition pack and a personal plan for yourselves and the team to work on together to best prepare you for transition.

We want to hear your views as Young People and Parents to help ensure our service meets your needs – those of you who have helped me already thank you!

Any queries/comments to Dr Rachel Elderkin, or you can let one of the CF team know when you are next in clinic.

## A research update from Dr Withers



The Exeter CF team have in recent years successfully entered a number of adults and children into trials of novel treatments.

We are currently planning to be involved in several further trials of new drugs which will run in 2017 and 2018. All of these trials are targeted at certain genes, they all exclude certain patients based on lung function and bugs in the sputum and some are only for adult (18+) patients.

The team will offer patients a chance to enter any trial for which they are eligible, although numbers entering into trials is capped. Please feel free to ask the doctor or nurse about taking part in research trials when you next come to clinic.

## Feedback from our physio team



Jayne Trott has just returned from an Associated of Chartered Physiotherapists (ACPCF) study weekend. She wanted to feed back some interesting information:

1. New "Squeezy" Apps for pelvic floor strengthening in CF are now available. These apps have been endorsed by the ACPCF and the cost is £2.99.
2. Pamela Scarborough has developed a social fitness platform for CF.

Various videos for CF are available, including MMA, HITS and Yoga through Pactster at <https://pactster.com>. Videos vary from 10 minutes to 1 hour and up to 4 people can work out together through the site. This has been supported by the CF Trust and patients can have a 2 week free trial. If you are interested, we will have some flyers in clinic and we can give you information to extend your free trial.

## With summer just around the corner...



In hot and humid weather those with CF will lose salt in their sweat and they are at risk of dehydration. This can cause tiredness, muscle aches and pains. It is important to ensure an adequate intake of salt and fluids:

Babies: Breast milk and formula milk are both good sources of fluid, salts and minerals. Offering additional frequent small feeds will help keep your baby's fluid levels topped up.

Children: encourage frequent drinks, note avoid too much coca cola as this contains caffeine. Ice creams, ice lollies, frappes all add to fluid intake. Children may need reminding to drink with excitement of the holiday. Crisps, salty snacks and adding additional salt to food at table will all boost intake.

If appropriate, salt supplements can be prescribed. Please ask your CF team if these are necessary.



## Go Henry!

In the summer I was nominated by the rugby club I play for and my school to attend some trials to see if I could get a place in the Devon Developing Player Programme run by the county and Exeter chiefs. I was successful and then went on to play in a county match against Cornwall.

We were told just before the game that the Exeter Chiefs elite academy coaches would be there, watching us play and choosing a few for their academy.

Luckily everything came together on the day and I had the match of my life and they spotted me!

Now I'm lucky enough to be in the Exeter Chiefs U16 academy. It's a challenge juggling everything with my school and club rugby, studying for my GCSEs as I'm in year 11 and my other hobbies but if you have a passion you need to give it 100%. CF shouldn't have to stand in your way. Rugby has the added bonus of keeping me well and going in partnership with my diet, physio, fitness and medicines really well.

It's the biggest encouragement to never miss a nebuliser that I could have - knowing that so far they're keeping me well and allowing me to strive for the top in a sport I love.

## A word from Sally - our new CF co-ordinator!

I have worked for the RDE for nine years in various administrative roles within surgery and I felt that I wanted a more regular patient contact role working within a small designated team.

I have found CF a very challenging yet interesting speciality in which to utilise my skills and I am pleased to have been given this opportunity to find out more about the service.

## ...and goodbye to Shelley

Dear CF patients,

I am sad to inform you that I left the post of CF Psychologist at the end of January 2017.

Working alongside you was an incredibly rewarding experience and I have grown a great deal of admiration for the way that people cope in the face of CF and all the challenges that it brings to people's lives.

A new psychologist will be appointed in due course, and patients will continue to be able to seek this type of support from within the CF team.

## Parent's Support Group

Date of next meeting Wednesday 10th May 2017, 7.30 pm, Women's health building, seminar room 1 - Please book your place on 07876 560 546.

On 8th February the lovely Pete, adult patient with CF, came to talk to the parents who attended. It was a small group of 12 which made it nice and easy for people to ask questions and for it to feel more like a chat. The feedback we have had has been very positive with many parents expressing their gratitude to Pete for his time, honesty and reassuring manner.

One parent wrote:

"It was such a valuable experience for us, to see and hear in person how someone 'deals' with living with CF was really encouraging. He really helped us see our best and that being there for our son is good enough."

Another said:

"It was really good to see a 30 year old person with CF looking so fit and healthy and getting on with life."

It would be really good to see more of you at your support group, if you would like to speak to any parents that regularly attend in order to get an idea of what goes on at the evenings, and what they get out of attending, please let us know. Also let us know any suggestions you may have about subjects you would like covered.

These evenings are for you so tell us how you want them to run. At the next meeting we will talk about future events and how we continue.

We can also go through the Information for Schools leaflet and template Healthcare plan from Exeter CF centre and also the CF trust versions. But most of all you can chat, drink tea and eat cake!!

We look forward to seeing all of you and gladly welcome any newcomers.

Your CF Team