

## Lynne, our specialist dietician says -



Lynne Cairns

The recent CF patient survey that was sent out by the CF Trust showed that people who filled in the survey were happy with the dietetic care they get. It is clear from the responses

that communication between staff and patients is very important to you therefore I will make sure I explain things clearly and would encourage you to ask me if you feel you are unsure about any part of your dietetic care.

Your answers to the survey show that the majority of you think the quality of the food while you are inpatients is reasonable but the quantity of food is poor. We are looking to get ward staff to offer second helpings as well as making sure you are aware of snacks that are available. A positive comment received showed you like being able to use the voucher from the ward to get meals from the staff canteen and we will aim to continue this. In the longer term we hope the changes in the catering department will help improve both meals and snacks as a much wider a-la-carte menu will be offered which will include a wide range of snacks that can be ordered and stored in your room fridge until you are ready to eat them.

## Clinical Psychology in the York Adult CF Unit

Hello again. By now I have met many of you who attend the York Adult CF Unit, either through the Team's annual assessments, occasionally in clinic or in providing a service to individuals. I have been (and will be) sending out appointments for people who are undergoing their annual assessment. It's up to you if you would like to take the opportunity to meet with me (if you've not already done so) and / or discuss through any issues that we could help with as a Team. If you don't want to attend the appointment then I can send out a brief questionnaire for you to complete as an alternative. This information is helpful to the Team as a whole and ensures we provide the best possible service we can.

I will also be conducting a survey of the transition process from paediatric units to the York Adult CF Unit. If you are about to transition to the adult unit or have recently done so, my colleagues may be contacting you to see if you would like to take part in a brief interview. You do not need to take part but it would be helpful in shaping up a more robust and smoother transition for all patients with CF. If you have any questions regarding this or any other issues then you can contact me via the Unit's email address or on 01904 725353.

Best wishes and merry Christmas. Caroline (Caroline Harris, Clinical Psychologist)



Caroline Harris

## Working together for our future

8th November 2013

### Working together with others

The CF team recently attended the 'Working together for our future' conference run by the Hull & East Yorkshire Hospitals NHS Trust and York Teaching Hospital NHS Foundation Trust. This was to look at ways that services at York can work more closely with services at Hull. We submitted a joint poster between York and Hull adult CF units looking at how we can work together to strengthen the care that we offer to people in North and East Yorkshire and are pleased to say that this won an award at the conference. We will let you know as we continue to develop ways of working together.



## Merry Christmas!

It's the end of another year and as all the television programmes start looking back on how things went in 2013, we thought we would do the same! Being a smaller CF unit, we are always striving to do the best we can on an individual basis for everyone accessing care here at York, and we always want to know if there is anything we can do better. So we've decided to focus this newsletter on some of the ways we've been monitoring the service this year, and feedback to you how we've been doing.

We've had feedback from the CF Trust, the specialised commissioning group (the NHS body responsible for funding the service) and yourselves, in the patient satisfaction questionnaire. Thank you to everyone who sent a questionnaire back; it's been really helpful to know what you think, and where we need to make improvements.

Happy New Year!



# News

from the York Adult Cystic Fibrosis Unit

No.6 Winter 2013



Tracey Daniels

## Patient survey - physio feedback

I'd like to thank everyone who filled in a survey form. Understanding what you think is good and bad about the CF service that you get helps us to work out what we should focus on

and gives us some great ideas about how to change things. Please don't wait for the next survey to let us know what you think, contact us anytime to tell us what you think your care should look like.

I will be working with the rest of the CF team on things that the survey highlighted which affect overall care like communication and education. I will also be looking at some physio specific things that were raised:

- Access to exercise on the ward - you felt that this was quite good however we'd like to make this even better so will be looking at new exercise equipment that can be used in your room.
- Access to exercise at home - you felt that it would be good to get more support with keeping fit outside of the hospital situation. We are looking at strengthening our links with community exercise schemes such as the HEAL scheme in York and the fitness trainers scheme in Scarborough. We are also now offering an annual posture/musculoskeletal/continence check with specialist physios. You will be asked whether this is something that you would like or you can contact us to refer you at any time.
- Physiotherapist knowledge - although most people felt that this was very good or good, we'd like to improve on this. You can help with this so if you feel that a physio doesn't understand your needs or gives you advice that isn't correct, please let one of the CF team know. We're a fairly hardy bunch so will be happy to get feedback about this and it will help us to give you the care that you want.

Tracey

To see the full survey results, go to [www.cfyork.org.uk](http://www.cfyork.org.uk) and click on the left hand news bar story 'Tell us how we're doing' or ask any of the CF team for a paper copy.



Dr Rebecca Thomas

Our most important source of feedback is always the people living with CF who access care here in York, and so the feedback from the satisfaction questionnaire that went out this year is always the most important to us. 42% of people responded, and there was some really positive feedback, including:

"They are open to new approaches and will listen to what the patient thinks."

"Because you get to know the staff well, you feel more relaxed and with friends."

"Same staff at every appointment makes you comfortable"

"Friendly capable staff"

"Always there to help even with non CF-related issues"

"You're local I don't have to travel very far to clinic can be contacted with ease."

"they keep you informed of treatment and care".

"Always there to help even with non CF-related issues"

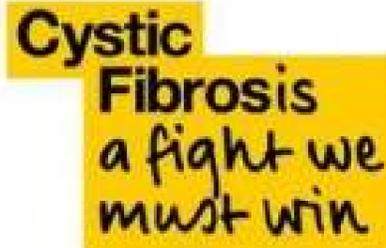
But you also let us know about things we could do better. You highlighted nursing care and education on the ward, and Andrew will update you on his plans to address this. You wanted "better communication what medication a CF patients takes from verbal to writing", and we've developed the new take home sheets from clinic in addition to your copy of the letter to the GP so you get an immediate record of any changes made.

You also highlighted communication and education, and Caroline is planning a review of the transition process, as well as parent and relative educational meetings to share advice and experiences. You raised how important sharing experiences is, with this comment among others: "Meeting others with CF (which will never happen) to find out how they deal with CF". We would highly recommend the patient forum on the CF Trust website ([www.cysticfibrosis.org.uk](http://www.cysticfibrosis.org.uk)) and are happy to put you in touch

with patient representatives and other people who have gone through similar experiences to talk on the telephone or email.

The CF team were on the whole praised on several occasions and this was also reflected in the patients perceived level of the care provided; in particular 100% of patients reported the services provided by the dietician as being 'very good'. The CF consultant, nurse and physiotherapist were also rated highly. We are always looking for ways to improve the care we offer. We encourage you to let us know of any issues or ideas that you have to improve the service here at York. There is no need to wait for the next patient survey.

Full feedback on the survey will be available on the website [www.cfyork.org.uk](http://www.cfyork.org.uk)



Andrew Booth

## Feedback from Andrew, our CF nurse specialist:

Feedback from the satisfaction survey did highlight some issues over ward staff knowledge levels. We ensure that the core CF team maintain their skills and knowledge by attending CF conferences, being members of specialist CF groups and by spending time at specialist CF units. Regarding the ward staff issues, an education programme was previously running but this was held briefly because of changes in the CF team and trust policy on study leave. We are aiming to address the ward staff issues with a combination of reinstating face to face teaching, joint treatments (eg specialist nurse seeing you alongside the ward nurse) and reference documents available on the ward. We have met with the ward sister to discuss how this may happen and are carrying out a training needs survey of staff. We encourage you to let us know at the time if you experience a lack of knowledge or skill from a member of staff. It is easier for us to correct any problem if we know at the time it has happened.

With regards to communication with the team, there was an indication that patients preferred a variation and selection of communication with most happy to utilise all methods, but with traditional formats such as letter or telephone marginally favoured. One suggestion on how to improve communication included an idea for a text alert system to remind patients of their appointments; this was mentioned in two separate patient responses. Andrew is looking into this and we should have a text alert system up and running next year!

We're also working hard to make the annual review process a lot smoother. With so many different tests and investigations, it's sometimes challenging to have them all done at one time. Some patients have commented that, because of the amount of time the annual review takes, they would rather have it split over two or more days. We'd be happy to hear your thoughts on how you would like your annual review to be conducted.



As a specialised service, care for people living with cystic fibrosis is funded in a different way to care provided for people with other medical conditions accessing NHS care. We are monitored by one of the 'National Specialised Commissioning Groups' (NSCG) against a number of outcomes, including percentage of patients admitted to a single room and number of routine appointments in clinic where a physiotherapist and dietician were present. You can see from the table that we hit 100% in all outcomes and we hope to keep this up for 2014!