

# CFNews

from the Papworth Adult Cystic Fibrosis Centre

No.7 December 2010

Welcome to the winter newsletter!



## Approval for the New Papworth Hospital

We are delighted to inform you that approval has been given for Papworth Hospital to move to a state-of-the-art facility on the Cambridge Biomedical Campus.

The new hospital should open at the end of 2015 and the move should be particularly beneficial to the CF service as we will have

much better access to specialists in diabetes, liver disease, gastroenterology, surgery and obstetrics.

We also anticipate that access by car and public transport will be much easier than at Papworth Everard with the road improvements that have already

been put in place. We will provide regular updates about the move to Cambridge on our new website at [www.papworthhospital.nhs.uk](http://www.papworthhospital.nhs.uk) In addition you can access our CF website at [www.papworthhospital.nhs.uk/ccli](http://www.papworthhospital.nhs.uk/ccli)

**Charles Haworth, Helen Barker, Dennis Wat and Andres Floto**

**Inside this issue: Page 2**

- Hypoglycaemia
- Erectile Dysfunction
- Annual Reviews

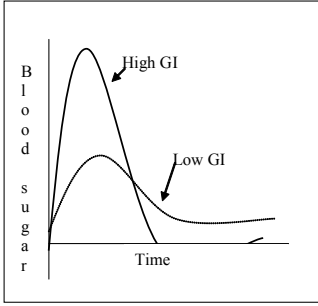
**Page 3**

- Exercise
- Medication Supply

**Page 4**

- Benefits Update
- CF Research Update
- CF Refit
- The Ward Update

# Hypoglycaemia - low blood sugar



In our patient group we are seeing more people experiencing symptoms of low blood sugars which can include feeling faint or dizzy and the need to eat something fast. These symptoms may be caused by insulin being released a little late by your pancreas and hence the insulin bringing your blood sugar down too low.

A way of trying to minimise these unpleasant symptoms is to eat regularly and to eat foods with a low glycaemic index.

## What is Glycaemic Index?

Glycaemic index (GI) is a measure of how quickly a carbohydrate-containing food or drink is absorbed by the body. If a carbohydrate food is broken down and absorbed into your blood stream quickly it has a high GI. If it happens slowly it has a low GI.

## How do I use the GI?

The GI tells you how quickly a food raises your blood sugar when eaten on its own. In practice, most of us usually eat combinations of food such as bread and butter, pasta and sauce, pizza and burgers. **The addition of foods high in fat, protein or which contain whole grains and are high in fibre slow down the absorption of carbohydrate.** You can combine foods to lower the GI: eg. jacket potato is high GI, baked beans are low GI and cheese does not have carbohydrate but is high in fat; thus combining these foods lowers the overall GI of the potato.

**Some examples of foods with low GI include:** multi-grain bread, oats, porridge, pasta, apples, oranges, beans and lentils, milk and yoghurt.

**Examples of foods with high GI include:** white bread, cornflakes, Cheerios, rice, potatoes, sugary drinks eg. coke, Fanta.

**Examples of low GI meal combinations include:** stir-fry with noodles, sponge cake and custard, spaghetti bolognese, Ryvita and cheese, waffles and ice cream, Lucozade with a sandwich made with multi-grain/granary bread, macaroni cheese, meat with vegetables and Basmati rice.

Helen Watson, Lucy Mead and Penny Walker

## Erectile Dysfunction (ED)

ED is the inability to achieve and maintain an erection adequate for intercourse to the mutual satisfaction of the man and his partner. It has an important negative impact on self-confidence, interpersonal relationships and male quality of life. The prevalence of ED increases with age and with increasing life expectancy in CF, ED is possible in this population but its prevalence is not known.

We performed a confidential postal survey looking at the prevalence of ED in our male CF population over 20 years of age using a validated questionnaire at the end of 2009.

In total, we sent out 109 questionnaires and there were 32 responses (29%). ED was reported by nine patients (28%); seven of them had mild symptoms and two patients reported severe ED. Twenty-three patients reported no ED.

This survey showed that ED is prevalent in the male CF cohort. However, the low response rate may have underestimated its true prevalence. While psychological issues may contribute to ED, it may also be related to a number of other factors including chronic infection, diabetes, medication side-effects, hormonal imbalance and increasing age. A more detailed survey is currently underway and by finding out the underlying cause, appropriate treatment can be offered. We shall report the findings of this survey in future.

*If you would like to discuss this issue further, please feel free to discuss with the CF nurse specialists.*

**Dr Dennis Wat**  
Consultant Physician

## Annual Reviews

We would like to stress how important the Annual Review process is in terms of planning your medical care.

Although the Annual Review involves a significant time commitment for you and the CF team, both we and the Cystic Fibrosis Trust consider it an essential process for the provision of top quality care.

During the first visit, you meet various members of the CF multidisciplinary team including a specialist nurse, physiotherapist, dietician, social worker and pharmacist, as well as having a number of tests (lung function, blood tests, chest X-ray and liver ultrasound).

The CF consultants then collate the information and write a report outlining treatment recommendations for the year ahead and these are discussed with you at your Annual Review follow-up visit six weeks later. This visit also provides an opportunity for you to discuss any aspect of your care and to have big conversations such as - "I want to start a family" or "I have been feeling a bit low recently" or "I'm not sure what this treatment is for" or "Do I need a transplant?"

For those of you that have given consent, we also anonymously submit your Annual Review Data to the CF Trust Patient Registry. This allows us to compare outcomes at Papworth with other CF Centres, which is an important quality control check. Furthermore, the CF Trust Patient Registry Data is also likely to be used by the Department of Health to work out the funding for each CF Centre on a year-by-year basis in the future.

It is therefore essential that we provide accurate information (completely anonymously) on everyone we see to allow us to provide you with the best care possible.

If you have any questions about the Annual Review process. Please ring the CF Specialist Nurses on 01480 830541 bleep 980 or ring Sandra Snelling, the Annual Review Administrator on 01480 364292.

**Charles Haworth, Helen Barker, Dennis Wat and Andres Floto**

# Exercise

Exercise is something you always hear the physiotherapists recommending to people with CF, but you may have wondered why. In fact it is something every adult (even those without CF) should do for the following health reasons:

## *Regular exercise*

- improves cardiorespiratory fitness
- improves muscle strength, body flexibility and coordination
- improves wellbeing/morale
- exercise releases hormones called endorphins that give rise to the feelings of 'exercise highs'. It will also reduce feelings of stress, anxiety and depression
- helps to maintain healthy bones and prevent osteoporosis

## *The additional benefits, for someone with CF includes:*

- enhanced sputum clearance (but does not replace airway clearance sessions)
- decreased feelings of breathlessness

## **So how much exercise should you do?**

The Department of Health (2004) recommends that "all adults should aim to take 30 minutes of at least moderate intensity physical activity on at least five days a week". Although there are no specific recommendations for those with CF, The CF Trust (2002) advises that the general recommendations for the normal population should be used (as above).

## **What does moderate intensity mean?**

Someone doing moderate intensity exercise should feel:

- an increase in breathing rate
- an increase in heart rate, to the level where the pulse can be felt, and
- a feeling of increased warmth, possibly accompanied by sweating on hot or humid days
- a bout of moderate intensity activity can be continued for many minutes, and does not cause exhaustion or extreme fatigue when continued for an extended period

## **Where do you start with exercise?**

At least 30 mins of exercise is a lot to start with if you don't regularly work out and are not used to it. Fortunately it can be broken down into smaller sections, (eg. 3 lots of 10 minutes) and it is suggested that if you are very unfit starting with up to 20 minutes of light intensity exercise may be better, but the aim is always to keep slowly increasing your levels of exercise.

## **What exercise should I do?**

Always pick something you enjoy, as you will be far more likely to continue it. Try and involve family or friends as it is more fun to exercise with others. Remember to vary what you do so that you don't get bored.

As many of you know we now have Nintendo Wii and Wii Fits on the CF

Unit. These are more active computer games that can work on flexibility, muscle strength, aerobic fitness and balance - all good components of any exercise programme. These can be a good way of starting and building up on your exercise levels, especially if you are recovering from a chest infection.

The ward physiotherapists will be able to help you set up and start using the Wiis. Remember though, it is still possible to injure yourself using these games if you are not careful - still try and do a bit of a warm up and cool down before starting/finishing using the Wii. Always use the remote strap around your wrist and hold onto the remote unit, leave plenty of space around you to allow for arm or leg movements and do not spend too long in one go using the Wii.

Finally, although these computer games are fun, they are not a replacement for other active exercises as they do not reach the same intensities of exercise (there have been studies that show this!).

**If you have any questions about exercise please ask any of the physiotherapists when you see them on the ward or in clinic.**

*Good luck!*

**Helen Brown**  
Physiotherapist Team Leader

# Medication Supply

From time to time, due to the vagaries of the supply chain (for example, due to shortages of raw materials, companies/products being taken over, local distributors having low stocks etc.) you may occasionally experience difficulties in obtaining some of your regular medication. The most recent issues have arisen with Vitamin K (Menadiol and Phytomenadione), Amikacin and Fosfomycin.

We are now obtaining Phytomenadione by importing a product licensed in the European Union. We are importing Amikacin from the United States and are working on importing an alternative brand of Fosfomycin.

In order to protect yourselves as much as possible from any issues with supply, I would urge you all to ensure you have a 'month-in-hand' of all your regular medicines and, if at all possible, find a pharmacy where you can build a good relationship with the staff so they will assist you when issues arise.

If supply issues are occurring regularly, please let myself or Alyson Winter know, either via the team in outpatients,

the specialist nurses or when you see us on the ward, armed with details of your community pharmacy so we can contact them and try to help resolve any issues that may have arisen. Equally, if you are on medication that is not on your GP repeat list and you need us to liaise with them to ensure this occurs, please let us know.

It is part of Government advice to hospitals that we should only supply outpatient prescriptions for use in immediate need, or where the medication is particularly specialised, so the bulk of your medications should be prescribed by your GP.

Every now and then community pharmacies have trouble obtaining TOBI<sup>®</sup> nebulas. This is because local distributors only keep small stocks of TOBI<sup>®</sup> because it is expensive. If your local community pharmacy is struggling to obtain TOBI<sup>®</sup> through their usual supplier, please ask them to contact Novartis on 01276 692255.

**Clare Cox**  
Pharmacist

## Benefits Update

Since the recent election there has been a lot of discussion about changes to the benefit system. Below is a brief outline of two of the proposed changes.

### Incapacity Benefit and Income Support

These were replaced for new claims by the Employment Support Allowance (ESA) in October 2008. The new benefit has a different test of whether a person can receive a 'sickness benefit'. The Government has announced that it intends to transfer people who are on Income Support and Incapacity Benefit over to the new Employment and Support Allowance test of 'sickness' to see if they can move over onto the new benefit. This will take place between April 2011 and 2014. People who transfer over to ESA will not lose out at the point of transfer. Currently the Government is testing the changeover in two areas before making these changes across the rest of the country.

### Universal Credit

Changes to simplify the benefits system have been proposed in a Government White Paper. This sets out the Government's plans to introduce a universal credit which will replace 'means tested' benefits like Income Support and Housing Benefit. The aim of this proposed change is to support people back into work and to end the situation where people are better off on benefits. If the ideas set out in the White Paper are accepted by Parliament and become law then the changes are planned to come into force in 2013.

**Anyone who is concerned about any of these proposed changes should talk to the social work team, Penny, Karen and Steve. The team can be contacted on 01480 364631 or 01480 364279**

**Penny Martin**  
Social Worker

## CF Research Update

Jane and Judy would like to thank all of you who have consented to allow your sputum and blood samples to be stored in the Papworth Hospital Tissue Bank. So far we have obtained consent from over 180 patients and will continue to ask for consents in clinics and on the wards for the next couple of months. Watch out for us!

Also, we are tremendously grateful to everyone who has participated in the various research projects we have done this year, particularly the inhaled Heparin, nebulised Aztreonam and the Xolair studies. All these projects play a key role in developing and improving medicines for CF and we would be unable to do this work without your vital support.

We continue to recruit to the Ghrelin study, the main aims of which are to find out if Ghrelin improves appetite and reduces lung inflammation in CF. Again a huge thank you to all those who have agreed to take part.

**If you are interested in receiving further information please contact Jane Elliott or Judy Ryan on 01480 364495 or 01480 364116.**

### Research & Database Team



## Lung Function Refurb

The Lung Function department was refurbished earlier in the year and we now have hand-held spirometers in each clinic room. This will reduce the risk of cross-infection of bugs and we hope that it is more dignified and user-friendly system. Comments are always welcome, good or bad!

As some of you may be aware, we have recently introduced new criteria for exercise testing at annual review. We now only recommend shuttle walk tests for people with lung function (FEV1) below 70%, as exercise capacity and oxygen saturations are unlikely to be affected above this figure. This will shorten the length of the annual review day for a significant number of people, which we are sure will be a popular move!

**Andy Stubbington**  
Senior Clinical Physiologist

## The Ward Update

**Hello and Merry Christmas from all on the CF unit!**

We would like to pass on our thanks to everyone who has made donations to the ward in the past year. It has enabled us to purchase new TVs, DVD players, Wii Fits and furniture for the CF rooms. We have also been able to buy a 'fold-out bed' for visitors to use.

We are also truly grateful for the generous support that we have received from John Lewis.

Over the past three months, funding has been agreed to open the additional two beds on the CF unit. At the moment we are busy recruiting new staff and are waiting for new equipment to arrive.

Nurses Lyndsay Dodds and Laura Tidnam have started on the ward and we have also employed Nicola Wills who will be a Health Care Support Worker.

**Have a very merry Christmas and a very happy New Year!**

**Caroline Weldon**  
Sister - CF Ward

***Please send us your own ideas and suggestions to:***

Dr Helen Watson  
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### Disclaimer

We encourage readers to discuss their health care with their doctors.

This newsletter is intended to provide information on CF and not to provide medical advice on personal matters, which should be obtained directly from a physician.

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