

# Gartnavel CF Newsletter



The above logo was thoughtfully designed by Karly Burns. The concept combines three different ideas, the Rose represents the commonly know term 'sixty five roses' (sounds like Cystic Fibrosis), a thistle to represent Scotland and you may notice that the Ribbon spells out CF. This was specially designed to be the Gartnavel CF logo and so you may see it about.

2010

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2nd Edition

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Hello! Welcome to the second edition of the Gartnaveil Newsletter. The newsletter is a relatively new concept and we are trying to make gradual changes to it, including increasing patient input and format changes. We are keen for input from patients and I would be delighted to have your thoughts on how to improve the newsletter. If you feel you could contribute to the newsletter, maybe you've had a big fundraiser, had a unique experience, or maybe you just have some good practical advice for other CF people that you think might be useful, please contact me at [andersjgibson@gmail.com](mailto:andersjgibson@gmail.com). I would really appreciate your help and input.

I would like to thank all the contributors to this newsletter, without your input this newsletter wouldn't get anywhere. I'd also like to thank all the people that emailed about the previous newsletter, your support is greatly appreciated.

The newsletter is online at <http://www.cftrust.org.uk/aboutcf/cfcare/centrenewsletter/> (Anders Gibson)

## **New Staff and the future**

Over the years, the treatments for Cystic Fibrosis have been getting better and better. Thankfully that means our patients are living longer and having healthier lives. Because of this success, we now have the biggest unit in Scotland and we are continuing to grow. We expect to have 250 patients in the near future and have estimated that our numbers will grow to 300 by the year 2014.

You will have noticed the increase in staff and a lot of new faces working in the CF team. We understand that new faces, brings some worries for patients, but the new members of the team look forward to getting to know you, and obviously hope that we will be able to contribute to keeping you well! There are now 3 Consultants, 1 associate specialist, 4 nurse specialists, 3 senior physiotherapists, 2 dieticians, a pharmacist, one secretary and a data manager in the team. As the number of patients continue to grow, the team will also need to expand.

The number of outpatient clinics has increased, and the biggest strain at the moment is on the number of beds which are required when people need to stay as an inpatient. We are currently planning how we will expand these over the next few years, but don't have any solutions agreed as yet. Certainly we know that the CF unit will be staying in the same wards for the next five years and so have been doing some work on the wards to try to make any overnight stays as pleasant as possible. (Gordon MacGregor)



A holiday can be a fun filled, as well as a therapeutic experience. As your CF-carers we would like help your holiday go smoothly. With CF there are some important points to consider when booking your trip away.

# H

**Hot climates:** Extra precautions are necessary in hot climates. Various antibiotics including ones that you may take regularly can cause photosensitivity i.e. make you burn more easily in the sun so be generous with the sun block and keep your body covered.

# O

You will be more prone to dehydration, so drink plenty of water and take extra salt. Watch your intake of beverages such as tea, coffee and alcohol! Salt tablets can be bought over- the- counter or prescribed by your doctor. If you have a history of developing bowel blockage, you will have to be extra careful too.

# I

**Medication & equipment:** It is often difficult and costly to obtain medication in another country, so ensure that you have sufficient supplies to last throughout your holiday. While packing divide drugs between hand (cabin) and hold (check-in) baggage. Some drugs (e.g. Insulin) are affected by extreme cold and should not be transported in the hold. Take a list of medication especially if involving use of sharps; this may be required by airlines/customs authorities at security checks. Consider the need for a standby course of antibiotics; again discuss this with your doctor in advance.

# i

If you are using needles and syringes, ensure that they can be disposed of safely in sharps bins. Compressors will need adaptors and sterilising tablets will be required for nebulisers. Portable equipment can be run off batteries but these will need recharging.

# d

**Holiday Insurance:** Please check that the medical cover being offered is appropriate and covers all eventualities. The CF team may be able to recommend some “CF friendly” insurance companies.

# a

**Fitness and other aspects:** There is a lot of preparation involved, so check with your CF doctor that you are fit to travel before making plans, particularly if you are setting off on a long break to some exotic destination!

# y

Oxygen may be required in-flight for some patients. Again discuss this in advance with your CF doctor.

It is a good idea to take a letter containing a summary of your condition, just in case there are problems, as not all foreign medical centres will be familiar with CF. You can obtain this letter from the CF team, but do give us notice as we receive over a hundred such requests each year.

Happy holiday!

(Dr Siram)

Last year I decided to travel to Sweden. My brother lives there with his wife and my niece. It was my first journey in a year or so, as I had been having problems with lungs bleeds. On planning this trip I was advised by the CF team to have a 'fitness to fly' test. This test assess whether or not you need oxygen to fly, and if so, to what degree. So the test was arranged and off to Stobhill I went to find out if I would need oxygen for my trip. As it turned out I did require oxygen for my flight, but only at a rate of 2 litres.

After discovering I needed oxygen to fly, I then had to investigate the arrangements the airline had for those that needed oxygen. Because I was flying from Scotland to Gothenburg, there was only one airline I could use, Ryanair. After some research I discovered that Ryanair were going to charge £100 for use of oxygen on their plane. Having done some politics and being reasonably aware of disability issues, I believed this constituted as disability discrimination and could well be against the Disability Discrimination Act (DDA). I was now a man on a mission and I soon found this,

*'Under the DDA, it is against the law for service providers to treat disabled people less favourably than other people for a reason related to their disability. Service providers have to make 'reasonable adjustments' to the way they deliver their services so that disabled people can use them.'*

My next step was to write to a couple of MSP's I knew, and to contact various bodies including the CF Trust and the British Lung Foundation (BLF). I soon discovered that the BLF were running a campaign on this very issue and were assessing all the airline companies in the UK to find out their attitude to providing oxygen to those who need it. I also then went to the papers and got my story into the Daily Record. My story even went global as a journalist from Sweden called me and put my story into 'The Expressen' (Biggest Swedish paper, bit like the Sun).

I had created a bit of noise, but due to a loop hole in the system that airports and airlines operate out with the jurisdiction of the state, the DDA was not enforceable. And so my dispute continues, and I continue to pay, although many other airlines have since changed their position due to the BLF campaign. (Anders Gibson)

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# F u n d r a i s i n g



Back in March 2008 I had a brainwave and decided that our wards needed better televisions and that I was going to raise the money for them. My ingenious plan was to have one big night and raise as much cash as possible. I work at a Musical Theatre School so decided to use the students to put on a Cabaret Show. We worked on the show for a month with only one or two rehearsals a week. I begged people for decent raffle prizes and borrowed a sound system. Costumes and Props for the show were also borrowed from all over and finally when the night came we had a show!

The lights were down low and onto the stage came one of the older students singing Fields of Gold, there was silence in the room everyone focussed on the singing, this continued through the ballads section only to break when that same first singer entered the stage again for the Musical Section singing "Somebody to Love" from We Will Rock You. The school did songs from various Musical including Wicked, Les Miserable and Hairspray, dancing and singing their way through them all like true professionals. The final section of the show was a mix of different popular culture songs and everyone was dancing on their seats.

I put my Gran on raffle selling duty, no one can sell a raffle like Anna Banana! There was various prizes including, designer sunglasses, ceramic hair straighteners, £100 bottle of Whiskey etc. All the prizes were donated by friends and family, or begged for from companies by the same friends and family. In all the night raised £2672.00 The TV's are now installed in both wards.

(Victoria Glen)

We have been lucky to receive money from a number of patients who have contributed money to our "CF patient fund". With this money we have bought 23 new TVs, with integrated Freeview and DVDs, as well as DVDs to watch, plus Playstation 3's and WII's for each ward. We know its not just about taking peoples minds off being in hospital that helps and so we are working on improving things like signs for privacy, better curtains, comfier seating and improved exercise equipment. We even have plans to tackle the seagulls – not promising anything here though!! Thanks to donations of money, we now have fridges for all the side rooms.

If you have any requests or suggestions, or if you know anyone who is thinking of raising some money for the unit, then feel free to discuss this with Lisa Morrison, Iona Paterson or Gordon MacGregor. Any cheques can be made payable to the "West of Scotland CF patient fund". (Iona Paterson)

# CF and Relationships



CF and Relationships is a booklet designed for people with CF and for their partners . It has been written by myself (Jacqueline) and a fellow CF patient, Emily Thackray. We realised through discussion with friends and comments left on the CF Trust forums, that there were a few issues relating to relationships which seemed common amongst people with CF. We wanted to design a booklet which could cover these topics – but did not want to give advice on subjects that can never have a perfect answer. We therefore decided to design this booklet based on the experiences people with CF and their partners so that we could illustrate how others have coped in similar situations and what their experiences have been.

We collected information mainly through the CF Trust forums by emailing questionnaires to around 60 people with CF and their partners. We also had an anonymous online survey to collect some general statistics about how common some of the problems are which we have included in the booklet.

The booklet covers many topics – from starting a relationship, moving in together and life after transplant, to the more taboo topics of sex, contraception and fertility. Many of the issues covered may not apply to you, and may never apply to you – but hopefully there is something for everyone and at the very least it might help you feel less alone. (Jacqueline Didsbury)



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At the Butterfly Trust we know that having Cystic Fibrosis can restrict your life choices and we want to help.

Some people are having difficulties in their workplace and don't know their rights, want to be independent but struggle to find a suitable property, need to increase their income but don't know what help they're entitled to or need a break but cannot afford a holiday. We have helped people with CF with a variety of issues and ways, including, finance, employment and housing.

We have helped people acquire their own house and purchase the things they need to live independently. So if you have been on the housing list for ages with no progress or if you want some support to help you settle or cope independently we may be able to help.

If you are struggling with the rising cost of everyday living expenses and can't see a way to improve your situation then give us a call. We will discuss your circumstances in confidence and advise you of any way you can increase your income or find funding for something you need and cannot afford.

We have lots of requests for help with employment issues. In many cases we have helped people to negotiate adjustments in their workplace, which has allowed them to stay in work. In a couple of cases they have retrained for a different job with the same employer. So if you are having difficulties in work do give us a call before making any life changing decisions.

Some of you may be applying for Employment Support Allowance this year. This new benefit is designed to get people into work and many people with CF have been turned down. The questions need careful consideration and appeals can be complicated and prolonged. So do ask us for advice and support before submitting your application form.

Our aim is to offer a resource that frees up your time and energy, increases your choices and where possible maximises your income. Our services now include massage therapy when you are in hospital.

We work closely with the health care professionals who provide your specialist medical care to provide the best possible support. Contact us on 0131 445 5590 or alternatively email us at [info@butterflytrust.org.uk](mailto:info@butterflytrust.org.uk).

(Helen McFarlane)



supporting people  
with cystic fibrosis  
in scotland

# Research - Can you help?

## Research - Can you help?

At Gartnavel we are trying to expand the amount of research we do. We hope that our research will lead to improvements in the treatment of Cystic Fibrosis. For this we rely on the goodwill of our patients to agree to help with research. We are currently doing the following research and also plan to expand into other areas too, and we would be grateful if you would consider helping us. If you are interested, you are welcome to discuss this with Dr Bicknell or Dr MacGregor.

Examination of "Exhaled Breath Condensate" for chemicals which may protect you from infection. This is simple and completely painless test and only takes five to ten minutes. We are asking patients to breath into a machine which cools and freezes their breath and we will then analyse the breath in the laboratory. We are wondering if there is a lack of fatty chemicals which protect you from infection in Cystic Fibrosis patients and want to measure these chemicals to test this theory. Also, if you are needing to have a bronchoscopy, we may ask you if you would like to give us some samples for this research purpose too, as we are doing a similar study with these samples.

If we find these chemicals to be low in CF, then it may well lead to the development of a new treatment, which, we hope would help you fight infection. It is hoped that the new treatment would be taken by nebuliser, and may also help clear the mucus from your chest. In the near future, we plan to develop a study using these chemicals and are working with a Scottish biomedical company towards this.

We are working with Hannah Bayes and Professor Tom Evans at Glasgow University to research a protein in Cystic Fibrosis which is involved in how your lungs react to infection. If you have to have a bronchoscopy done, we may ask you if you would like to donate some samples from your lungs to help with this project. Most people with Cystic Fibrosis do not need bronchoscopies, but you can still help with this research by donating samples of blood or sputum.

It is hoped that as we learn more about this subject, we will contribute to the future development of treatments to help. If you have any questions or are interesting in helping with our studies, please discuss this with Dr Bicknell or MacGregor at your next visit.

(Dr MacGregor)



# Ask the Team

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As some of you may remember from the previous newsletter, there was a section called 'Ask the team', well it's back for this edition and but this time we have answers. It's been a while since the last newsletter, so many of you will probably have forgotten what question was asked, here is a reminder, 'On a recent admission I noticed alterations had been made to the in-patient menus, what are these changes? Why have they been made? Will they affect the CF in-patient meal orders?'

Diane the dietician has been kind enough to give a response.

There are a range of standards designed to ensure that there is high quality nutritional care for patients. These standards incorporate a requirement to develop a menu cycle that meet the needs of individual patient groups via nutritionally analysed, well balanced recipes and menu choice.

A new 3-week patient menu cycle has been developed by the NHSGG&C in association with dieticians. Trials of this new patient menu have been ongoing since November 2007 in Gartnavel General, with menu revisions as a consequence of patient & staff feedback throughout the trial.

On the new patient menu cards new dietary codes have been applied to many of the dishes. All the dishes on the menu have been nutritionally analysed and where they have met nationally agreed criteria they have been coded as below:

V – suitable for vegetarians, Apple Symbol – These dishes have controlled amounts of fat and sugar for anyone wanting to lose weight, Strong man - These dishes contain more energy (calories).

The main change to the CF meal ordering is that there is no longer a staff menu to offer alternative choices, as the staff menu now includes the same choices from the new standard menu.

There is now a 'Lite Bites' menu which you can choose from, plus the additional choices are still available such as sandwiches, biscuits and cheese, scones, pancakes, build up soups, tinned soups, baked beans, macaroni cheese, fried fish, chicken or cold meat, omelette, scrambled egg, baked potatoes, chips, pizza and burgers. Also, puddings such as ice cream and jelly, tinned fruit, yoghurt, creamed rice and custard are available if requested on the menu card. On admission you can ask the nursing staff for this list to give you a guide of extras.

(Diane Jamison)

# Ask The Mac Gregor Nurses News

Once again we have a question for the team.

**Are there any plans to increase the number of side rooms available to CF patients?**

We fully realise the difficulties with number of side rooms and would like to take this opportunity to apologise for any inconvenience that has been caused. The CF unit continues to grow and therefore we have been in discussion with management with regard to the current difficulties and planning for the future. We are working on plans for a new improved unit. These plans are in draft form and no funding has been identified, but once everyone agrees a suitable plan we will be pushing this forward.

People have asked if we will be moving to the new Southern General when this is built. We have been told by management that the plan is for us to stay at Gartnavel - hopefully in a redeveloped unit with more suitable facilities. We agree with this as we have more control over the beds at Gartnavel and this means that there would be less competition for beds from people with other illnesses. We have already had some new side rooms built in ward 7C and are very pleased with the results, and hope that any new facilities would be of a similarly high standard. (Gordon MacGregor)



All answers have be kindly provided by the CF team.

## NEWS FROM THE NURSES

**New CF Nurse** - As many of you will know Gillian McMillan started as CF Nurse specialist in March 2009. Liz Thomson has recently taken up post as the fourth CF Nurse Specialist in the unit. Those of you who have been attending the unit for a long time may remember Liz as a staff nurse in the respiratory wards.

**Outpatient Clinics** - An additional CF clinic has now been running for some time on a Thursday morning. As far as possible the CF nurses will try and accommodate your preferences taking into account your microbiological status. All annual reviews will still be done on a Tuesday. As we have more annual reviews to do, can we remind all of you that if you receive an annual review appointment that is unsuitable, please let us know as soon as possible so that we can reappoint someone else and give you an alternative appointment if possible.

**Holiday Insurance** - Many of you will be enjoying holidays abroad this year. It is very important that you have holiday insurance that covers your CF. If you are experiencing difficulties in obtaining appropriate insurance cover please contact us on 0141 211 0051 and we will try and give you some guidance on obtaining this. You can contact us Monday – Friday 0815hrs – 1615hrs. (Susan Hempsey, Jane Young, Gillian McMillan & Liz Thomson)

