

SPRING 2005

Future Force

MAGAZINE OF THE CYSTIC FIBROSIS ASSOCIATION OF IRELAND

Pregnancy & CF..

The magazine by adults with cf for adults with cf

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elcome readers, to the bustling spring 2005 edition of Future Force. As always, your views & opinions are most welcome, so keep them coming in. In fact, we loved some of your comments so much we just had to print them - see inside.

It's great to see the smoking ban working so well. It survived the winter & is here to stay, a big breath of relief !

Congratulations to Helen Whitty in CF House. Helen was recently appointed as the new Services Coordinator in CFAI. So anything you need, don't be shy, contact Helen - you can even call her on the new CFAI Lo-call number (1890-311-211) for the price of a local call from anywhere in Ireland. We also welcome Orla Moore as the "new kid" in accounts. You can get to know all about Orla in our CF House office profile.

I "crashed" the launch of the Pollack Report in February to get my hands on the Minister for Health... but she wasn't there. This very important report condemns the level of treatment & services in Ireland. It is a wake-up call to the government, but we need to "put 'em under pressure" - so don't you dare let your local politicians escape lightly - tell them exactly "What Ails Ye!". Lets hope we all get a result!

What have you been doing to promote awareness of CF in your area? - tell us all about it. We've one kitty inside who's been doing his bit.

Welcome! Eleanor Walsh to the FF team. Thanks for all your input into this issue - its great to have you on the team!

Learn all about Buteyko! What do you mean "whats that"? Its an alternative breathing technique [Bhew-tae-ko] of course! But we'll let Michael tell you all about it. Do remember to consult your doctor about any changes to your normal routine.

Shona gets energised! Congratulations Shona, FF wish you the best of luck, we heard you've finally submitted your thesis & oh yeah, congrat's on the transplant aswell!

Caroline recounts her pregnancy days & what it's like being a Mammy with CF; and Brigid anne meets Bubbles!

That's just a taster - there's more... much more! You'll just have to carry on reading to find out.

Tell us your stories, share your concerns & send us plenty more articles - please? pretty please - don't make us beg...!

SEND ALL LETTERS/ARTICLES TO

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E-INTERVIEW WITH ORLA MOORE

Accounts Administrator in CF House !



In this issue Patricia Duffy gets to know Orla Moore.

FF: Can you tell us a bit about yourself and where you're from?

Orla: I'm originally from Cliffoey in north Co. Sligo. I finished college in 2003, having obtained a Business Studies degree and after some travelling I moved to Dublin in September of last year.

FF: How long are you working with the CF Association?

Orla: I started work for the CF Association in mid October 2004.

FF: What does your job entail?

Orla: Primarily, I am responsible for maintaining the accounts of the Association. I am also co-ordinating this years walk to Boston/

Cape Cod but there are always ad-hoc tasks that keep me busy!

FF: What do you like most about your work in CF House?

Orla: It can be very diverse but always interesting. My colleagues are very professional, committed people and are a pleasure to work with. Also, I have really enjoyed getting to know the members of the Association & being of assistance to the best of my ability to date.

FF: Do you think the CFAI Website and specifically the Community Forum works well as a medium for anyone to share experiences and ideas?

Orla: In the past, I've found the CFAI website to be very informative and user friendly. I think the community forum is a terrific way of expressing views and opinions - it really is a most effective means of communicating with others on line and I'm sure it offers a means of valuable emotional support to PWCF, their families and friends.

FF: Do your friends know anything about CF?

Orla: Until I started working for CFAI, very few of my friends knew little if anything about the CF condition. However, I have since briefed them on the facts of CF and they are now much better informed.

FF: Are you optimistic that the recent Pollack report will achieve any improvement to services and treatment for people with CF?

Orla: I believe that the launch of Dr. Pollock's report has been a huge success & has been met with great enthusiasm. Yes, I am optimistic that the report will act as a catalyst in improving the physical conditions in hospitals where CF patients are treated and the level of service provided. However, I believe that this will be a challenging process. It is vital that the momentum continues from all parties involved and that continuous pressure is applied to the government to deliver on its promises.

Quick Fire Questions....

FF:: What's the last album you bought/received?

Orla :: Fleetwood Mac

FF:: Best Concert /live act you've seen?

Orla :: U2 at Slane

FF:: Least favourite Celebrity?

Orla :: Dr. Phil

FF:: Most recent book you've read?

Orla :: The Da Vinci Code

FF:: Favourite Sport/Team?

Orla :: Irish Rugby team

Join the growing community on the CFAI website message board. Go to www.cfireland.ie & click on "Community Forum". You never know who you might meet... !

CFAI have introduced a Lo-call number for people contacting head office.

The Lo-call number is **1890-311-211**

People who call this number will be charged at the rate of a local call from anywhere in the Republic.

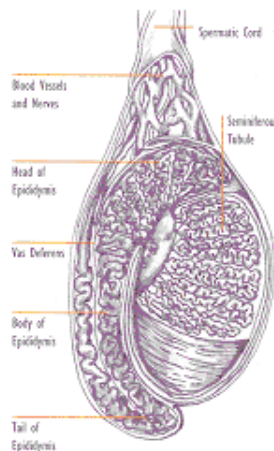


MALE INFERTILITY

Catherine Carroll, CF Nurse Specialist
St Vincent's University Hospital, Dublin

Infertility affects virtually all men with cystic fibrosis. The majority of research states that 98 - 99% are infertile (Kotloff et al 1992, McCallum et al 2000). It is important to distinguish between absence of spermatozoa (sterility) and infertility. In cystic fibrosis males, generally the testes are normal and active spermatogenesis occurs. This means that sperm is made in the testes.

The reason for infertility in the majority of cases is due to the congenital bilateral absence of the vas deferens. The vas deferens is a tube through which sperm travel from the testis to the ejaculatory duct. There is sometimes a misconception that infertility means impotence; however, infertility does not affect sexual behaviour.



Because a small percentage of men with cystic fibrosis are fertile, it is advised that all men undergo semen analysis to confirm their infertility. This is a simple procedure, which involves the patient producing a sample of semen. This is then analysed in the laboratory to determine if sperm is present or not.

Patients are advised not to use this infertility as a form of contraception. They are advised to use condoms and practice safe sex.

Males who are confirmed infertile and wish to have children have many options including:

1. Adoption
2. Attend a sperm donor clinic
3. ICSI

A procedure known as **ICSI** is available in the **HARI Unit** in the **Rotunda Hospital**. ICSI – (Intracytoplasmic sperm injection) is a method of assisted conception. A single sperm is injected directly into the egg (ovum) in the laboratory. Aspiration of sperm from the testis is carried out prior to this procedure. Procedures are available to extract sperm directly from the epididymis (fine tubules behind the testes) by either needle aspiration or microsurgery. An ovum is removed from the female, which is then fertilised with the sperm. 48 hours later the zygote is transferred back to the womb.

This is an invasive procedure for both males and females. It involves females taking injections and nasal sprays for 6 weeks prior to ICSI to stimulate ovulation. The decision to go ahead with this form of treatment should be discussed with your Cystic Fibrosis Consultant. In addition there is a one in nineteen chance of the partner being a carrier of cystic fibrosis and if so could lead to cystic fibrosis in the child. If this situation did occur, great thought must be given before treatment is embarked on.

The first known success with ICSI was recorded in 1992 in the U.K. Rates of success vary with this procedure and are thought to be somewhere between 17 and 25 percent. It is important to remember that the success rates represent the successful birth rates. We have recently had our first success with ICSI in Ireland that we are aware of.

Another important aspect that patients must be aware of is that this treatment is not always successful. The expense of each cycle of treatment must also be taken into consideration. The cost of one cycle of ICSI is approximately 5,500 Euro. CFAI are currently looking at the area of financial support for this treatment as part of their continuously expanding adult services.

For patients who require more information in this area, please contact a member of your multi-disciplinary team. It is acknowledged that this can be a difficult subject for patients to discuss.

Nip & Tuck

"Red bull may give you wings but a lung transplant is definitely the ultimate energy booster! Next week I'm going back to Newcastle for my six months post transplant bronchoscopy and I'm confident all will be well because I feel fabulous! The time has passed so fast and it has been the best six months of my life. My life has been totally transformed but don't get me wrong it was hard work, however the benefits are amazing."

Shona Stewart (Photo: Shona (right) with best friend Roslyn)



I won't bore you with my story in detail as each of us has our own. However, I will fill you in a little. Transplant first became an issue for me six years ago, but I was still too well to go on the active list, and so I put it to the back of my mind. Then about this time last year I felt I was being held back too much by the constant chest infections, hospital visits, endless medication routines and generally feeling crap, it was time to get the ball rolling. I went on the active list last June and the first few weeks of waiting were terrible. I was constantly wondering when it would all happen, a few weeks, months, years or never?? My "emergency" suitcase travelled everywhere in the boot of the car! Then after only seven and a half weeks of waiting, just when I was beginning to accept the "unknown", the phone call came. Many people have asked since how I felt when Newcastle rang, scared and elated together were definitely feelings but only for a few seconds because the adrenaline kicked in and I didn't have much time to stop and think.

I was done early the following morning on August 25th. I remember waking up and feeling for bandages and saying to myself, "Ok Shona, bandages there, go back to sleep"! Apparently I woke up a few times afterwards and told my brother we were going to go to America and that he was paying! (we had planned to go in the future if I got my transplant, but we never imagined it would be so soon!). To be honest I can remember very little of the first few days, partly due to the drugs but also because I wanted to forget. I won't lie and say it wasn't too bad because it was tough going, I knew it

would be hard but not that hard! You leave your dignity at home. I kept thinking 'just tell them you want your old lungs back and go home' and then I'd remember that there was no going back. However as time passed, things started to happen, machines and drips disappeared, I moved onto ward 27A and I started to do small things for myself. It takes great patience on everyone's behalf and you have to want to help yourself. My legs were like jelly and just starting to walk again was a challenge. Getting ready for bed, just going to the bathroom and brushing my teeth by myself after a week took an hour! But the staff were amazing and encouraged and inspired confidence in me again. I remember walking the corridors wheeling my own wheelchair for support and for when I got tired, it seemed like I would never be home again. In spite of a few little hick-ups, flights home were soon being arranged. I was home after 5 weeks. I was very nervous leaving the hospital setting and travelling home, "what if???" was constantly playing on my mind. From the moment I got home and had a good few sleeps in my own bed, the improvements were incredible. Every day I was noticing new things I could do differently, little things like blow out candles, sneeze and yawn. (I'm still amazed at how much air comes out). I was going to say cough but I don't cough anymore!

After 27 years habits are hard to break. I have had to learn to trust my body and my new health, for the past six months my mind kept on thinking my body was still sick. Even after 6 months I still go to get my inhaler going out, get Dnase out of the fridge and almost sit up

in bed to turn over, expecting to drag a bipap and oxygen with me! However, physio is one habit easily broken and forgotten! I now have 3 extra hours a day to enjoy life. I go walking every day with my new puppy and even run some of the way (I had never run before). I can head up to the big smoke for nights out again without bringing oxygen. My friends have commented that I don't ask them to slow down when walking and they can't find me in the shops, the cough was a dead give away!

Last month I had a "lung warming" party to celebrate my new life. All my relations and friends came and we celebrated all weekend, I had the time of my life! They say that it takes six months to a year to get back on top form.....I feel so good now that I can't imagine in eight to twelve months how it will be. I have great plans starting as soon as my six month bronc. is over, many places to go and people to meet!

So anyone heading down or considering the transplant route, I'd definitely recommend it! If you would like to contact me you are more than welcome to do so through future force or by e-mail, shobee2000@hotmail.com. My biggest recommendation to you would be stay active as much as possible. It was of great benefit to me that I was swimming a few lengths 3 times a week leading up to my transplant. I found it hard enough and I was relatively fit and had a put up a bit of weight, I can't imagine how hard it must have been for my friends who have gone through it and were almost bed bound for months beforehand. You must also want it, and want it for yourself. You need to be prepared to put in the effort and help yourself, as there is only so much the doctors, nurses and physio can do for you. When the going gets tough, just remember that if you put in the effort and with a bit of luck and gods blessing you too can have the life you have always longed for!!!!

(For those of you who know me, the never-ending thesis was submitted Christmas week !).



MY OWNER HAS CF



Joe, a parent from Co. Kerry, recently brought some CF Awareness Bracelets from the U.S. In the interest of doing some market research I brought one home with me. Kevin (my cat!) took a fancy to it instead and now every cat on the block knows that Kevin's owner has CF ! Thanks Kevin, for doing your bit to spread awareness about CF...

(ps CFAI are introducing their very own bracelets soon)

CFAI Medical Identification Card

WHAT IS A MEDICAL IDENTIFICATION CARD?

A Medical Identification Card is a means by which a person with CF can provide pertinent medical information to medical providers and other relevant groups.

WHY HAVE A MEDICAL IDENTIFICATION CARD?

Several of our members have reported difficulties when trying to use facilities such as lifts or disabled parking spaces. With no visible proof of a medical condition they have been verbally abused and refused use of services.

All medical entities, that is, doctors, hospitals and ambulance services require information regarding a person's health status to provide the best possible care. These cards have been designed to address the most important medical issues needed in an emergency. All the information is in one place.

HOW DO I APPLY FOR THE CARD?

CFAI will send out an application form to all members of the Association, or you can contact CF House directly. Parents can apply on behalf of children under 16. The application form will ask for the information to be included on the card. A signature strip will be included. You must provide a passport-sized photo. The cards will be laminated & the size of a credit card. Only people with CF are entitled to apply for and/or be a holder of these cards.

WHAT INFORMATION WILL IT HOLD?

Some of the information that can be found on the card includes personal information, emergency contacts, primary care physician, hospital, medical condition/s and allergies. The card will have your photograph. Each card is customised to a person's specific medical situation. You decide what information you wish to disclose.

WHO WILL RECOGNISE THE CARD?

CFAI are currently compiling a list of relevant groups/bodies to approach. They will get in touch with each of them and explain why the card is necessary and ask that it be recognised in cases where it is needed. For example, the Garda Síochána.

SAMPLE FRONT

MEDICAL IDENTIFICATION CARD

The Cystic Fibrosis Association of Ireland
Cystic Fibrosis Association of Ireland
01-4962433 www.cfaireland.ie

Name: _____ DOB: _____
Address: _____
Tel (Home) _____ (Work) _____
Doctor _____ Tel _____
Hospital _____ Tel _____

SAMPLE BACK

Medical condition: Cystic Fibrosis

Other conditions: _____

Allergies: _____

Other information: _____

In case of emergency please contact: _____
Tel _____

Signature: _____ Date: _____

INFORMATION

Grants for employers to retain employees with disabilities

The Employment Retention Grant Scheme is a scheme in Ireland that aims to assist employers to retain employees who acquire an illness or impairment that affects their ability to carry out their job. In a changing employment climate in Ireland, experienced, capable staff are a precious commodity and the onset, (or progression of) a condition or disability does not always immediately throw up issues of retention for employers.

The scheme aims to maintain your employability by providing funding to:

Retrain you so that you can take up another position within the company

Identify accommodation and/or training to enable you to remain in your current position.

Grant aid scheme for employers with disabled staff

FÁS operates the Employment Support Scheme, a scheme that offers financial support for employers that employ certain people with disabilities. Sometimes the nature of a disability can restrict an employee's productivity in comparison with other staff, irrespective of his or her ability to do a job. In situations where this restriction results in a loss of productivity of 20-50% for the employer, the Employment Support Scheme allows the employer make up the shortfall through grant assistance.

It is illegal in Ireland to discriminate against any employee on the basis of disability and this right is set down in legislation (Employment Equality Act 1998, and the Equal Status Act, 2000).

More information available at

http://www.oasis.gov.ie/employment/employment_and_disability/

We Get Letters..



Here's just a small number of the comments you've sent us about the last few issues of Future Force. Positive feedback is always great to get! Any & all comments help us to continuously improve the magazine for your reading pleasure so please keep them coming!

"I read Future Force last night in bed and it's great! I sobbed reading Fiona O'Sullivan's letter, I'm just a sucker where babies are concerned!!! Prof's piece on the clinical trial and Catherine Mc Keown's piece on depression were super." (Summer '03)

"The magazine had a great article on a teenager from Clare which was amazing, this is the first time I had seen a healthy "older" person with CF. I hope that doesn't sound as bad as it reads. Stories like this help to show that it is most definitely not all doom and gloom, which is what we are coming out of from the initial diagnosis. We had barely heard of this illness before, it sounds like that is a recurring theme with CF." (Summer '03)

"Just a quick one to say well done on the magazine. It was very good and there was a lot in it. Congrats again." (Spring '04)

"Continue good work with mag.." (Autumn '03)



Ciaran & Brendan



Kieran & Triska



Deirdre & Declan



Antony & Carol



*CF Adabt Group Christmas
Limerick Strand*



Fran & Caroline



Michelle & Deirdre



s Party, December 2004.
Hotel, Limerick.



Mike & Diarmuid



Derek & Noel



Rory & Decorations!



Jean & Fran



Triska & Rory



Deirdre & Derek

Butyeko Breathing is the art of breathing less and living a better quality of life. My introduction to this revolutionary approach to aerosol inhalation and exhalation has seen drastic changes occur over the last three months. The last few months my approach to conventional medicine changed and with it my exploration of complimentary practices has increased.

Groundhog day(s):

Twenty-five years of conventional schooling of physiotherapy and never any real relief attained. The application of this physical therapy was a continuous cycle. When I say that I mean that the process of perpetual clearance is a losing battle, as the more I coughed the more congested I got. This, allied to the CF drug programme lead to great annoyance. Conventional medicine's drug approach to treating Cystic Fibrosis was that I was always dependent on the drug without ever really seeing any improvement in my over all state of physical well-being. Conventional medicine is palliative, not curative.

The road less travelled...

I reached my nadir with conventional medicines last summer after an elongated, endurance-testing period in hospital. The daily fruitless frustrations of the CF medical team's clandestine secrecy wrenched out my belief in the approach to healing. While I have always been open to alternative assistance to maintaining good health, the episode of the hospital soured my palate and pushed me literally to explore new avenues.

Buteyko breathing is a non-invasive, effective, self-empowering tool. Since beginning this breathing voyage my life has seen me break the strangle-hold of medical routine. My journey has not been all plain sailing. Teaching my body to breathe properly has at times been like a ship without a rudder. The biochemical feedback loop is one of patience.

The first couple of weeks were amazing. The bountiful benefits that beset me were untold and only the beginning of the reward for those willing to see out the two year trek. My energy levels soared stratospherically (one day managing to play 25 holes of golf and not bat a breath or a bead of perspiration to playing competitive tennis and finishing stronger and feeling better than my supposedly more healthy opponents, etc.), my quality of sleep improved (sleeping better and waking up more refreshed) to my general well-being (no longer feeling nauseous when doing my aerosol exercises, fewer headaches from cacophony of coughing etc..).

Though I'm still in the embryonic stages of developing this technique, the benefits of the last three months and the thoughts of the future benefits of Buteyko has given me more hope and belief that this debilitating, genetic disease affecting over 900 plus families in Ireland can be assuaged and alleviated through this self empowering breathing exercise.

Always consult your doctor before making changes to your treatment.

FF contacted Patrick McKeown, Asthma Care Ireland, to find out more.

Patrick tells us *"To date most research of Buteyko breathing has been focused on the treatment of asthma. This has taken place primarily in Australia and New Zealand. Regarding CF - I am not aware of any research to date. So far anecdotal evidence of improvement to quality of life has been observed. I have worked with many persons with a variety of respiratory condidions; asthma, emphysema, bronchiectasis, pulmonary fibrosis, bronchitis, etc. The results have been very significant resulting in improved quality of life and less need for medication."*

Patrick feels that research is certainly required in the area of CF and he is offering 10 people with CF the opportunity to complete his Buteyko breathing course at a special rate. If interested, please contact Patrick at Asthma Care Ireland, freefone: 1800 931 935 (info@asthmacare.ie) & mention this article, or contact Future Force.

*Breathe
less and live
longer:
My experiences with
Buteyko Breathing
and Cystic Fibrosis*

By Michael Morrison

PERSONAL PROFILE

NAME: *Brigid anne Nee*FROM: *Galway*

AGE: 22



Hello Future Force,

I have always had it in mind to write to you guys, but I never knew what to write about :

My name is Brigid anne Nee (aka Brigie @home) I live in Connemara, Co Galway. I will be turning 22yrs on Sunday 13th February, I'm so looking forward to heading out with my mates and having a proper celebration probably wouldn't be as good as my 21st now though.

I am currently studying to become a Beauty Therapist, I'm doing it part-time Mondays 9am-5pm and Tuesday evening 6pm -9pm. After completing this course I'll be a qualified I.T.E.C & C.I.B.T.A.C Therapist. I love this course it has taken me a while to figure out what exactly what I wanted to do, I did my Leaving Cert back in 2000, God I feel ancient (",) Maybe after spending sometime in beauty therapy I might go on to do make-up artistry - meet & greet the rich and famous. The principal in the beauty collage is genuinely a lovely person who totally understands the situation with CF. Exams are now creeping up on me so it won't be long until we have our Easter mocks.

Turning 21 last year was a moving and cheerful event. I got such a great surprise (everyone's dream) - it was my sister Maureen and my Mom's idea.

We had a wee get-together in Peacockes Hotel -

family/friends, my cuzys from the USA & my aunty & uncle from England also came. They tried to keep it a surprise but I found out two weeks before my b/day they were coming over.

I guess I wasn't as good at finding things out as I thought I was! After the gorgeous dinner was eaten and the b/day cake candles blown out and pressys opened I was guided to the starlight room at Peacockes by a gang of family and friends, a million things going through my mind, one in particular was a surprise 21st party I would have killed them if it was! So off we went. As we came to the entrance door to the S/light room Maureen & her husband Kevin handed me a tiny box with a bow on it. She looked at me and said I'll have the rest of your present tomorrow, so I thought nothing of it and kept the box in my hand as we walked in - to my surprise there it was flashing her booty off in the middle of the dance floor, that's when things started to go slow-mo. Then I opened the box and there was the key to the car - my car (",)

It's a memory that will be with me for a lifetime. I was so gob-smacked I couldn't speak until ages after. Yea, like every other sad loony in the world I've given her a name - Bubbles - a red 98 Mitsubishi Colt.

Nothing will top the memory I have of my 21st, maybe my wedding day when I find my prince charming and he sweeps me of my feet. (Maybe someday!!)

If I had one wish that could come true that would be the obvious to find a 'cure' for CF.

I cherish the life I have been given, maybe it's not perfect - but who's is! I have enjoyed getting to know the special people in my life and those I will meet in the future. Just one other little thing to add before I sign off, life is precious no one knows what's in store so take the time to say I Love You to those you love and sorry if you've fallen out..

I'm not here to preach it's just my 2cents!

I hope you are all in good health and that 2005 is a healthy and happy one and that I haven't bored the socks off you!

Luv B
22yrs PWCF

Q & A



Hi, my name is Caroline; I'm a CF adult from Tuam, Co Galway. FF have asked me to answer some questions about my experiences during pregnancy, which you can read about below. I hope the info is of some interest to some of you. In the picture with me are my husband Francis and our two wonderful kids, Jamie who is six and Anna who is three. Our life is pretty busy with our two kids growing up very fast. I try to get to the gym five times a week as I find this is very good for getting up the gunk we all carry around with us. Both our families live close by so Sunday mornings (or afternoon if we have been out on Sat night) we usually cycle (weather permitting) to both sets of grandparents and aunts and uncles.

WAS PREGNANCY A BIG DECISION FOR YOU WHEN TAKING INTO ACCOUNT YOUR CF?

For me the decision wasn't a huge one, I was fit enough, good body weight, and it was something I always wanted.

HOW WAS YOUR HEALTH - HOW DID YOU FEEL DURING YOUR PREGNANCIES?

Both pregnancies were at a completely different time of year; having my babies was definitely an issue for me. Jamie was born in May and Anna in January. Also I was four years older having Anna and starting to have difficulties with my sinus. I did cough more which caused more vomiting than I think would have normally affected me. Physio was harder towards the end of pregnancy, the upward pressure also made my lungs feel like they would explode.

DID YOU HAVE TO TAKE EXTRA CARE OF YOURSELF?

Yes, I minded myself; I didn't go out as much as smoking was still an issue wherever you went. My family did whatever was needed to help. During my first pregnancy it was easier to mind myself as it was me and bump, we went to bed if tired etc... But with

my second pregnancy I also had to mind Jamie (bump one) so our families really came up trumps bringing Jamie to play school, taking him at night so we could not only rest but also continue life as a couple meeting friends etc.

HOW INVOLVED WAS YOUR CF TEAM - OR WHO PRIMARILY MANAGED YOUR CARE?

I attend Castlebar CF clinic and decided to have both my kids there, at the time of Jamie's birth we didn't have a full CF team, but the nurses and doctors on both paed's and maternity wards were fabulous, communication between both doctors made me feel very secure and comfortable. Second time round was even better from writing my script for folic acid to delivery. Even to present day they have taken care of me and my kids with advice and medical treatment. I have to say a big thank you to all the doctors, especially Dr. Michael O'Neill, the CF nurses Ann & Maura, the staff nurses, physio's & catering staff (Joyce!) & the porters; you are all fabulous and are greatly appreciated by me and anyone I know that attends Castlebar.

WHAT KIND OF COMPLICATIONS DID YOUR CF TEAM DISCUSS WITH YOU?

My main recollection of this discussion was being

told that my treatment and my health had to be taken into consideration first with the pregnancy taking second place. It sounds very straight forward, but when you are carrying a baby you tend to think more about what is happening to it then to yourself.

DID YOU CHANGE OR STOP ANY OF YOUR MAINTENANCE MEDICATION? COULD YOU TAKE ANTIBIOTICS DURING YOUR PREGNANCY?

I had selective IV's before both pregnancies to clear me out. I'm very lucky, as both times I got pregnant straight away with out any difficulties. My meds before and during both pregnancies were nebulised ventalin, pulmocort and colomycin. At the end of both pregnancies roughly at seventh - eighth month I had iv's again to help me reach the end and to have normal deliveries. I had Fortrum and Tobramycin with Jamie but we decided to only have Fortrum with Anna. Both kids are perfectly healthy. I was induced at 38 weeks with both kids.

WHAT ABOUT EXERCISE – WHAT KINDS OF EXERCISE WERE RECOMMENDED – WHAT DID YOU ENJOY DOING?

I thought I was pretty active but compared to now I was quite lazy. I swam a lot and continued until a couple of days before deliveries. Being in the water also made it easier for me to breathe.

DID YOUR LUNG FUNCTION CHANGE DURING PREGNANCY?

First time round there wasn't a lung function machine available. But second time, I went from 80% before pregnancy, slipping slightly as the pregnancy progressed and I got larger. Two weeks after Anna was born my lung functions had dropped to 46%. I lay on the treatment table in Castlebar breast feeding Anna for the last time as a doctor put a long line in my left arm, that was probably the moment when I realised I wouldn't and couldn't physically do this again (family complete). The year after Anna's birth I needed four sets of IV's, it was a hard slog. I sometimes felt I was taking two steps forward and three backwards.

DID YOU CHANGE YOUR DIET IN ANY WAY?

No I have always had a good healthy diet, with weight on my side.

HAD YOU ANY WEIRD OR WONDERFUL CRAVINGS?

I love pickles and marzipan but never had them together until pregnant with Jamie.

HOW DID YOU COPE WITH A NEWBORN - DID DAD ROLL UP HIS SLEEVES?

It was a big shock having this little bundle to mind and protect, but now I have a bigger reason to keep myself healthy and control my CF. Franny (dad) did more than roll up his sleeves and is still doing it; our kids didn't inherit my sleeping gene and still get up at night. They always ask for daddy as they know mammy needs extra sleep.

WAS YOUR APPROACH DIFFERENT THE 2ND TIME?

No, both times it was discussed with medical team and well planned. It was harder second time round, as it was double the work and I was in poorer health after.

DO YOUR CHILDREN KNOW MAMMY HAS CF?

They both know mammy gets sick more often then their friend's mummies. Jamie is starting to ask more questions, he can get upset if I'm going to hospital but at the moment he can be distracted. They both like to feel involved with my meds and often fight over who is going to get them out of the fridge. They also know mammy doesn't get out of the chair once I've started doing my neb (if I got up once I'd be up a 100 times).

WHAT RECOMMENDATIONS WOULD YOU HAVE FOR ANY PWCF THINKING OF HAVING A BABY?

If you are considering having kids think very carefully about your own quality of life and the quality of your life you can offer the baby. I couldn't rear my two beautiful kids without the support of my husband, my family and my in-laws; they all play a very important roll in our lives. Make yourself as healthy as possible, eat well, exercise, and do all medications needed to get you to that place. Talk to your CF team, take all their advice on board before making a decision.

Thanks Caroline, for answering so many personal questions. I'm sure it will be thought provoking and inspirational for our readers.

Test your knowledge of CF !!

- | | True | False |
|--|--------------------------|--------------------------|
| 1. CF is an inherited disease | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. Pulmozyme is an antibiotic | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Dehydration can cause MIE | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. If your weight is ideal, you don't need supplements | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. Good nutrition is not an important part of treatment | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. Regular exercise helps maintain healthy lungs | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. A port-a-cath delivers antibiotics into your system | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. Vitamin deficiency is common in people with CF | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. Physiotherapy clears the airways & helps prevent lung infection | <input type="checkbox"/> | <input type="checkbox"/> |
| 10. Enzymes are only taken once a day | <input type="checkbox"/> | <input type="checkbox"/> |

Towards a Better Service




An independent review of cystic fibrosis services in Ireland carried out by Dr R. M. Pollock was launched on Monday, 7th February, 2005 in Dublin. Pictured at the launch are: Carl Rainey (Chairperson CFAI), Dr R.M. Pollock, Dr Charles Gallagher (CF consultant St Vincent's) & Godfrey Fletcher (Interim CEO CFAI)

PROBLEMS AND SOLUTIONS 2005 Association of Ireland

Julie Wray (Citizens Information Centre) would like to hear from any person with CF who has been able to secure a mortgage in Ireland.

You can contact Julie at:

Julie Wray
 Information Officer
 Crumlin Citizens Information Centre
 146 Sundrive Road
 Crumlin
 Dublin 12
 Tel (01) 4546070/80
 Email: crumlin.cic@comhairle.ie
 Fax (01) 4731 749

Quieter times have arrived with the development of the silent nebuliser. These nebulisers have been on the market for some time now.

I first came across "eflow" at last year's conference in Birmingham and I was impressed by what I saw.

Pari, who specialise in nebulisers have introduced a new electronic nebuliser, the eflow, and it was cleared for market by the Food and Drug Administration on May 5th 2004. Described as a small aerosol delivery device, the eflow takes liquid medication and generates dense aerosol that can be inhaled into the lungs.



THE SOUND OF SILENCE

Olivia Coen

The eflow is designed to fit the needs of respiratory patients with COPD, Asthma and Cystic Fibrosis. Compared to current nebulisers it shortens typical nebulisation times and improves medication delivery. Treatment times can be reduced from 10 to 15 minutes to as low as 3 to 5 minutes, depending on volumes.

Schill medizintechnik are another supplier of silent nebulisers. Already on the market, these devices were successfully introduced in the UK in 1998 and are used by many NHS hospitals. The "Top" and "Profi" are breath activated silent devices. A fine aerosol mist is generated which is small enough to reach into airways and penetrate alveoli. Likewise they are also small and lightweight. Both can be powered by mains, rechargeable battery or car cigarette lighter.

The main attraction for me is the fact that they are silent - no more funny looks when staying in hostels and B & Bs. Being lightweight they sound perfect for travelling.

Since clinical programmes have just begun with eflow it may be some time before it reaches the Irish market. But it would be great to say goodbye to those big noisy bricks that are the CR60's and embrace a quieter life.

www.nutritionexplorations.org/kids/nutrition-pyramid.asp

WEB WATCH

This website is user friendly for children, to help them learn all about the different food groups. It shows the food pyramid and gives examples of the nutrients in each and explains their importance in the diet. It also contains some games and fun snack recipes for children to try out!!!

<http://www.wecare4lungs.com/cfe.htm>

Ever worried about your children doing too much exercise? This easy to use website deals with cystic fibrosis and exercise. It also deals with exercise induced asthma. It gives you the benefits of exercise for children with cf, tells you how to get them started on an exercise program. It also has a section on FAQ to put your mind at rest!!!

http://kidshealth.org/kid/health_problems/heart/cystic_fibrosis_p2.html

This is an excellent website for children. It deals with a number of health problems including cystic fibrosis. It explains the symptoms and treatment of cf easily. It also deals with other issues including dealing with feelings, growing up, my body and bullying in school. There is a glossary of medical terms and a section with recipes, from pizza to pancakes, for children with different illnesses including cystic fibrosis, which are easy for children to make!!!

The Comfort Zone..

Name & address supplied

CF affects us all in a multitude of ways - we are all very much aware how it affects us physically - but are we all aware how much it affects us emotionally?

Maybe we just don't realise how much it does affect us emotionally because we are all individuals and behaviours can be attributed to our unique personalities. However our personalities are moulded by our experiences and CF definitely has moulded my personality. Have you ever thought about yourself? How you behave in different environments? How much your CF influences your behaviour? Well, I have thought about this and I have placed everything into zones of comfort.

I mainly have physical and social comfort zones. I can be myself within my comfort zones - at ease, not compromised, not apologetic and not embarrassed. My physical comfort zones can be the most bizarre places - places where others would definitely not feel so comfortable - such as walking down an empty street in the rain! My social comfort zone is influenced partly by my physical surroundings and partly by the people I am surrounded by.

So when am I at ease? Well, when I can be myself and have CF in harmony! This must sound terrible but it's true. I wonder am I the only one who feels like this or do we all feel this way? At home I can cough - I can clear my chest, I can do my rebuliser and my physiotherapy, pop my pills, use the bathroom 5 times a day if I need to - it doesn't bother me - it doesn't bother anyone else at home. Try using the bathroom 5 times a day at work and see how paranoid you feel! Try having a coughing fit in the canteen in work or in a crowded restaurant and see how comfortable you feel! No - at home the problems aren't problem's - they're just things you get on with. At home no one stares at me like I'm a health hazard when I cough my lungs up! That all rapidly changes when I step outside the front door. Suddenly I'm in public - that awful place. I cough and twenty people turn and stare. You take enzymes in a restaurant and there's always one wannabe narcotics detective staring you down. This is not my comfort zone. I never feel more uncomfortable than when in a crowded shopping centre or restaurant or cinema. And then there's pubs - the places I dreaded for years. Thankfully the smoke has almost disappeared - once you make it past the army of fumers guarding every establishment with a wall of smoke!

So I'm out for a night with some good friends - that's fine. My good friends know me - all about me - there's no off-limit conversations. Start introducing a few loose acquaintances - work colleagues, friends of friends and the fun really starts. One recommended game to play is 'Does he know that I know that he knows I have CF?' Some conversation openers to avoid in these circumstances include:

- 'You'd never guess who I saw at outpatients?'*
- 'You have got to see this awesome bruise on my wrist?'*
- 'I love day time TV - there was this brilliant case on Judge Judy...'*



Another no-no is going to concerts or matches with some loose acquaintances. As they storm up flights of steps or race past hoards of concert goers they leave you gasping for breath as you get to play catch up 'you lazy git'.

The most ironic of all places certainly not within my comfort zone is hospital! Yes indeed - sharing a 6 bed ward where five lucky sods enjoy an audience with me - unplugged and personal - as I perform a few chest clearance numbers I composed myself. Many fortunate visitors, cleaners and attendants also get a free pass!

The more I think about day-to-day events the more I notice the lengths I go to, to avoid leaving my comfort zones. I much prefer me in my comfort zones. If you meet me outside my comfort zone - be prepared - you are the public - you are my enemy!

TOP OF THE COUGHS!

20

19

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17

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4

3

2

1

TITLE

ARTIST

Breathe

Blue Cantrell feat Sean Paul

Breathe Again

Toni Braxton

Heart and Lung

Sean Lennon

My Iron Lung

Radiohead

The Cough Song

Bob Dylan

Wind of Change

Scorpions

Wind Beneath my Wings

Bette Midler

The Reflux

Frankie goes to Hollywood

Walking with Mr Wheeze

Madness

The Hospital Song

10cc/ Ben folds 5

The Drugs Don't Work

The Verve

Bad Medicine

Bon Jovi

I've Still Got My Health

Bette Midler

The Bug

Dire Straits

Put The Needle On It

Danni Minogue

Sick and Tired

Anastasia

Doctor Doctor

Thompson Twins

Drip Drip Drip

Chumbawumba

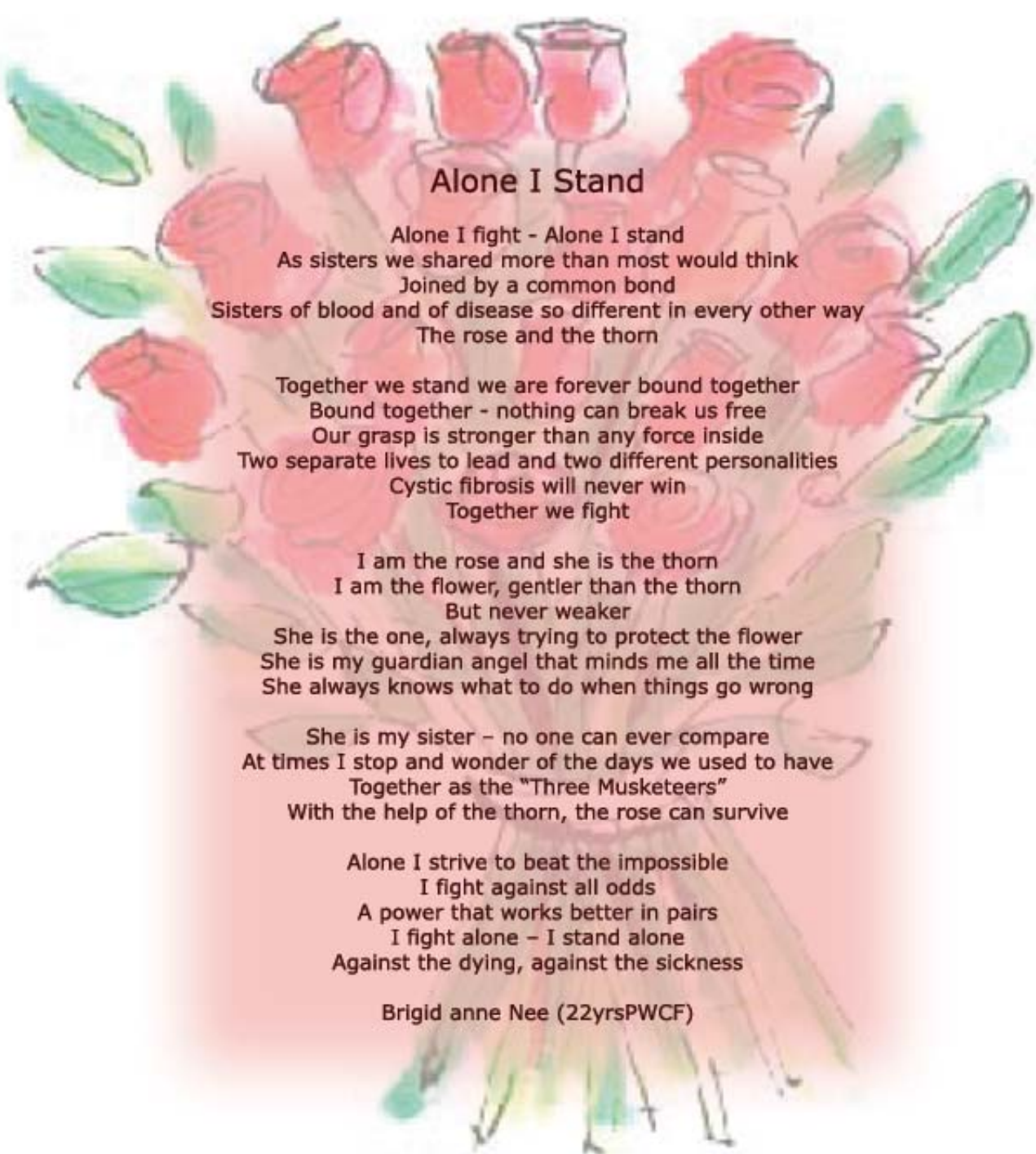
Eat Some More

Alice Cooper

The Weight

Aretha Franklin





Alone I Stand

Alone I fight - Alone I stand
As sisters we shared more than most would think
Joined by a common bond
Sisters of blood and of disease so different in every other way
The rose and the thorn

Together we stand we are forever bound together
Bound together - nothing can break us free
Our grasp is stronger than any force inside
Two separate lives to lead and two different personalities
Cystic fibrosis will never win
Together we fight

I am the rose and she is the thorn
I am the flower, gentler than the thorn
But never weaker
She is the one, always trying to protect the flower
She is my guardian angel that minds me all the time
She always knows what to do when things go wrong

She is my sister - no one can ever compare
At times I stop and wonder of the days we used to have
Together as the "Three Musketeers"
With the help of the thorn, the rose can survive

Alone I strive to beat the impossible
I fight against all odds
A power that works better in pairs
I fight alone - I stand alone
Against the dying, against the sickness

Brigid anne Nee (22yrsPWCF)

QUIZ ANSWERS

1. True

The defective gene must be inherited from both parents

2. False

Pulmozyme helps to breakdown the sputum and make it easier to cough up

3. True

If you don't drink enough water, especially if in a hot climate, this can bring on a blockage

4. False

Malabsorption of fat in CF results in malabsorption of fat soluble vitamins, therefore, vitamin supplements may be needed

5. False

Good nutrition is a very important part of treatment. It helps to keep a healthy body weight and also help fight infections

6. True

Exercise helps keep you fit and also helps your muscles and lung function

7. True

This is a device which is usually inserted into the chest, to deliver antibiotics when your veins in your arms are no longer usable

8. True

The fat soluble vitamins are lost due to malabsorption of fat as the fat stores these vitamins (A,D,E & K)

9. True

Regular physiotherapy helps to keep airways clear and this helps prevent chest infections occurring

10. False

These must be taken every time you eat a meal. The amount needed will vary depending on fat content of the meal