

♥ BACKUP BACKUP BACKUP ♥

THE NEWSLETTER OF ST.GEORGE'S ICD PATIENT SUPPORT GROUP

FUTURE DATES

Meetings of BackUp

ANNUAL GENERAL MEETING

The big event of the year will be taking place on Saturday 2nd October

Starting at 10.30 am a packed programme includes

Professor John Camm
talking on the subject of
Arrhythmias

Venu:
Post Graduate Centre

BACKUP FUNDS & DONATIONS

We reported in May that our funds during the previous year had grown to an amazing £5068.42. An enormous amount of our income comes from professional report fees for the DVLA generously waived by the medics at St.George's.

We spend probably less than 5% of it on photocopying and stationery for the newsletter and almost none of it on catering for our meetings – the ICD manufacturers, CPI Guidant and Medtronic have always been very generous in supporting these.

Please do continue to give your annual donations.

These are traditionally around £10 each. Send them to Sue Jones at the Pacing Clinic.

FROM YOUR EDITOR

On a recent trip to our local chemist I was impressed to discover that I could have my blood pressure checked. Availing myself of the service, I didn't have to use one of those machines you sometimes see in stations and airports, but rather put myself in the capably trained hands of our usual, friendly pharmacy assistant. More impressive still, she could have checked me over for diabetes if I'd had the time. Wonderful! No holding on the phone, trekking down to the GP's surgery, queueing and all the other hurdle-jumping I seem to do to get some medical attention locally – just pop in to the chemist, have a friendly chat and get simple service.

Fortunately, I don't have to go all that often, but I've generally found it easier to get an appointment to be seen at the Pacing Clinic than I do at my GP's. Whilst that doesn't say much about the GP's practice, it says a hell of a lot about the quality and commitment of the Pacing Clinic and the staff supporting it. Although it can sometimes be difficult to get through on the phone I've never found myself facing long waits for attention and I've always found staff considerate and informative. That's not merely reassuring, it makes a difference. More and more research is underlining how important back up is for patients with long-term conditions. It's great that St.George's has lead the way in providing the kind of support exemplified in the Pacing Clinic's service and in our BackUp support group. Would that more hospitals nationwide were recognising the value of this kind of support to patient well-being.

MAKING CONTACT WITH NEW ICD PATIENTS

When you first become an ICD patient, as we all know, it's a blur, and although some people get the chance to plan for it, it usually happens pretty unexpectedly. To help in the early stages after a new patient goes home, Sue Jones has agreed to work with us to establish BackUp Volunteer Phone Contacts. These are fellow-patients, members of BackUp, who will call every new patient at home within a month of them having their implant. Contact details are kept confidential, so the patient doesn't have to be concerned about further contact from the volunteer if he or she doesn't want it. The idea is to offer a bit of mutual support during a new experience, as well as to explain what BackUp is there for. Our volunteers are selected with care and are trained to make the contacts sensitively and discreetly.

You don't have to be new to make contact with fellow patients, or

LIVING WITH IT

Every patient to have an ICD implanted at St. George's, automatically becomes a member of the BackUp support group - wherever they come from and, frankly, whether they like it or not. Just as important, partners and close family also acquire the privilege of membership.

Pete Amiss is a partner to one of our newer members and offers these thoughts on living with an ICD

In September 1994 my wife Tina had some kind of cardiac episode. One minute we were watching TV the next she was on the floor not breathing. After the drama of giving CPR to someone you love and not having a clue what is wrong or what caused her to collapse begins the long and often frustrating process of finding a correct diagnosis. The medication saga comes later.

Eight years after the first episode came another. This time it was decided after a very short period of time to fit an ICD. Although the staff at St. Georges are fantastic especially Sue Jones, who I cannot praise highly enough, I did feel I was out of the loop a bit.

And it wasn't until I got my head around what it does and how it works etc., that I began to feel a little more comfortable with the idea.

The shock and realization that your loved one has a life threatening condition doesn't sink in for quite a while. You get so wrapped up in going to appointments and adjusting your working week around those appointments.

It started to sink in for me a few months later when I was finally getting around to reading some of the literature provided by the Cardiomyopathy Association.

I found it very hard to put myself in her position. On the outside they are the same person but they are also very different. You think to yourself "come on snap out of

"It!" "Pull your self together" Like you can have some kind of influence over it.

The beginning is particularly tough. The medication, the tiredness, not driving and the feeling of isolation [that you are the only two people dealing with this] all take its toll on you.

While the medication is being adjusted the function of the affected person is affected, sometimes quite dramatically. Some drugs just don't agree. Meanwhile you think, "What are these doctors doing? Surely they must know what drugs to use and in what doses." But it seems everyone is different.

The general tiredness is a huge factor. The children just don't understand it. They don't understand that Mummy is dead on her feet and just doesn't want to play.

Because they are so tired you are trying to pick up

some of the slack, to help keep the home running, as well as still doing all the stuff you did before.

On top of all this the partner is still extremely concerned about the long and short-term health issues. Is the medication working? Do you have all the facts? Is anyone trying to shield you from something they don't think you should know?

You are trying to stay strong and be the person they can rely on, the one they can lean on. But you get tired. The physical side of the relationship suffers. This can lead to difficulties in the relationship.

Add to all these things the issue of not being able to drive. You have to organize the school run gymnastics, football, Brownies and swimming lessons, shopping at a large supermarket. Trying to fit all this in around a full time job. Your own hobbies and pastimes suffer. Going to the gym, playing football or rugby takes second place to accommodate everyone else. It's not easy.

Then what about you?

Your partner isn't that interested in partying late into the night anymore. Drinking and medication just don't mix. So even when you do get to go out together they can't drive, they can't drink and they get tired very quickly. Frustrating or what!

Very few people ask you how you are coping with it all. I bet most partners would say "Oh, I'm OK"

But are they really OK?

I hope my relating my experiences will help others to come to terms with living with Cardiomyopathy and having an ICD fitted.

Pete Amiss

WANTED - COMMITTEE MEMBERS

It's about time us old stagers got shown a thing or two! We need to strengthen the committee team 'cos the job's getting bigger and we want to increase the amount of support you get out there.

First off, we need a **second editor** for the newsletter - needs to be someone who knows a bit about computers, though we'll give a bit of training. Gud spulling isn ot eessunshull.

Second, we would like a **general committee member**, to help us generate ideas and do some of the go-foring.

Third, we'd love **another partner member** to increase the focus on partner's support.

The committee meets with Sue at St. George's about once every two months and otherwise makes contact on the phone or by email. It's a rewarding activity and not too onerous.

If you'd like to know more, please get in touch with Sue Jones at the Pacing Clinic on 020 8725 1372.

EXERCISE AFTER YOUR IMPLANT

(from our newest committee member, Tina Amiss)

Professor Patrick Doherty gave an excellent talk on exercise at Back-Up's AGM in September last year, one we thought well worth reporting on in this year's first issue.

Patrick is a chartered physiotherapist who works extensively with ICD patients. His talk was on exercise post ICD.

Following ICD implantation anxiety, depression and a fear of exercise is not uncommon. With regard to exercise the common fear is that of the ICD delivering a shock during exercise. He talked about structured exercise versus physical activity. Increasing fitness does not have to mean donning a pair of trainers and shelling out on an expensive gym membership. Whatever form of exercise that the individual takes up it is important that it is enjoyable (and therefore sustainable) and fits into the individual's lifestyle. Don't make it your life at the expense of other things eg remaining sociable. Taking up a form of exercise that the individual is used to is helpful as it decreases anxiety. For these reasons walking may be the exercise of choice. However, it may be aerobic exercise of any type eg cycling, stepper, swimming etc. Exercise should be progressive ie start with a little, that is easily manageable, and gradually build up over time. How hard to exercise, for how long, and how often to exercise is important. With regard to how hard (ie intensity) it is better to listen to our own bodies and how we feel rather than rely on science eg heart rate monitors. How we feel is gauged by rating our perceived exertion on a scale of 0-10, where 0= no effort and 10=maximum effort.(5=moderate effort). Aim for roughly 5-7 out of 10 (ie not maximum exertion). Other guides to intensity include an increase in heart rate, slight shortness of breath (whilst still being able to talk), and sweating. These are all NORMAL responses to exercise.

How long - the aim is to gradually increase to 30 minutes.

How often - build up to 4 times per week.

A warm-up and cool-down period is VERY IMPORTANT pre and post exercise. This is because the heart is more vulnerable to arrhythmias at the beginning and end of exercise. A warm-up and cool-down allows for a graduated increase and decrease in heart rate during exercise. A warm-up of 3 minutes and a cool-down of 3-5 minutes is recommended. If these simple guidelines are followed then exercise is safe, and the likelihood of a shock from the ICD, during or after exercise, is no greater than it would be at any other time.

The ability to exercise can be increased by 50% in 6-8 weeks, providing that the exercise is kept up. However, stop exercising and two thirds of fitness will be lost in 4 weeks! It is therefore important that exercise is ongoing. As well as an increase in the ability to exercise and do more on a day-to-day basis, an increase in general well-being and self-esteem, and a decrease in anxiety and depression are common with exercise. On a personal note, not only do I feel much better in myself when I exercise but I also feel much more positive about living with an ICD.

It is worth remembering that other medical conditions can and do co-exist. Therefore it is always advisable to check with your cardiologist prior to taking up a new exercise regime.

Happy exercising!

Tina Amiss

Committee Who's Who

Tina Amiss, fitness instructor, whose qualifications for membership are well-documented in her story described by her husband in the newsletter 0208 900 0684

Martin Byne, a solicitor living near Bath, long-standing ICD pioneer and our most intrepid traveller, can be contacted at work on 0117 973 1019 and email byne2001@yahoo.com

Stephanie Cruickshank, leading light in sister group for Hypertrophic Cardiomyopathy, is on 020 8668 6673 (home), 020 8725 5914 (work) and email scruickshank@hotmail.com

Derek Jones, our new treasurer, lives in Surrey and has a wealth of experience in managing financial affairs.

Sue Jones, favourite ICD Co-ordinator, is on 020 8725 1372 and sue.jones@stgeorges.nhs.uk

Simon Noble, your editor, can be contacted on 01932 349727 or almost anytime on 07766-237312 and email simon@sinclair-noble.co.uk

John Pohorely, nurse and patient, based in Camberley and our latest recruit 01483 898436

Louise Power, chair and committee secretary, tireless and ever-patient supporter lives in North London and can be contacted on 020 8889 0789

BackData

want a copy?
ring Simon on
07766 237312

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