

Welcome to our Spring Newsletter



News from the Chair—Linda Reid

Welcome everyone to our Spring Newsletter! I hope this newsletter finds you doing well?

I know that will feel like a contradiction with all the wet and windy weather we have been having and I really hope none of you have been too badly affected by it all. I did grab the opportunity to take a walk at Chippenham park (see photos) on one of the nice days to later discover there were other members there that day too – such a shame we missed each other!



July is drawing nearer by the day and we are in full swing organising this year’s evening event – it will be held on Thursday 3rd July at the Education Centre, West Suffolk Hospital from 17.30 – 21.00 approx. This year’s focus is on Self-Managing your Pain – Want to know more? We have Pete Moore an internationally renowned speaker and chronic pain sufferer, talking on Self Management. He is the author of the Pain Toolkit, and will be giving an overview of self management and how it can help you live better day to day. Along with other experienced speakers, including Carole Baker giving us some helpful ways to stretch and exercise even in chairs! We will have stalls from: Mindfulness, Suffolk Wellbeing, Occupational Therapists, Psychotherapists, Yoga, Thai Chi, to name a few, so you can talk informally about how their services could benefit you, if what they offer is appropriate for you and hopefully be signposted to a helpful organisation who could help you with your condition. As well as plenty of time to enjoy some light refreshments so you can catch up with each other and new members. The event is open to members, non members, friends/family and carers. Cost is only £1 per person which is payable on the night. To book your place please call -01284 712970. It is sure to be a fun, informal and informative evening. I look forward to seeing you there!

As each New Year starts we reflect on the previous year and obviously look to the year ahead. To help us ensure we are offering you what you expect from the group, you will find a questionnaire attached to your reminder email – we really appreciate your feedback and the time taken to fill it in. We want to plan ahead as closely to your needs as possible. We really expanded our horizons last year: Facebook, new website, evening event, coffee mornings, tree festivals to name a few, so hopefully with your continued support can do the same for 2014! Don’t forget to step forward if you have any skills you feel could be of benefit to the group, volunteers always welcome!

We have the 2 new exciting opportunities open to us firstly private Yoga class at the Self Centre personally designed to suit our needs; we need to have at least 10 people interested to be able to move forward with this. So please see inside for more details. Also the possibility of a crafting group, run once a month so we can enjoy whichever craft they enjoy; knitting, sewing, crochet, beading etc. (need to bring own materials etc.) or learn something new, within a friendly, informal, safe environment, make friends and craft and chat those hours away. Studies have shown great benefits for those who knit and live in pain; reduction in pain and stress levels to name a few. If you have an interest in this please let us know.

If you enjoy our online community on Facebook, why not join us on Twitter too! A useful guide to joining and using twitter is on page 2.

At our next meeting we will be joined by members of the Clinical Commissioning Group, so please come along and find out how they support those living in pain and get to pose questions to those who help structure our health services. They want your feedback!

Thank you for Lorraine and Cheryl’s hard work and dedication to the group, I very much appreciate all that you do and could not do it without you.

A huge thank you to everyone who supported us in 2013.

Here’s to a successful and enjoyable 2014!



Run for Patients by Patients

C.P.S.G. Library of Books

We are in the process of building up a small lending library of helpful books to loan out to members, which will be displayed on the resource table at meetings. Any funds raised from lending these books will go towards new ones.

For those of you who missed the last meeting, please take a look at the read well on prescription site <http://readingagency.org.uk/news/blog/announcing-the-reading-well-books-on-prescription-scheme.html> or talk to your GP about it, as it is now possible for your GPs to prescribe you a book to help you learn more about your condition or related conditions such as anxiety.

The book on the list relating to Chronic Pain is titled 'Overcoming Chronic Pain' A self-help guide using Cognitive Behavioural Techniques and is co-written by one of the authors of the Pain Toolkit Dr Frances Cole so I am sure it will be well worth a read.



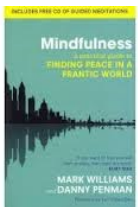
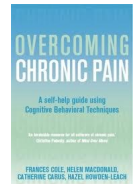
The Empowered Pain Patient—How Validated Pain Management Can Work For You
by Dr Kim Kristiansen, M.D.

Mindfulness: A practical guide to Finding Peace in a Frantic World
by Prof Mark Williams and Dr Danny Penman.

If you are interested in borrowing one of these, we ask for a small donation of £1.00. Please let us know and we will bring the book to the next meeting/coffee morning or arrange a drop off.

If you have read a book or know of one that may be useful to the group please come forward with your suggestion for consideration.

**THE
READING
AGENCY**



Yoga



Carole Baker has offered the group Yoga for Pain Management Specific looking at breathing and relaxation as well as gentle stretches and mobility poses together with some strength work.

Price: £70 for 1 hour £80 for 1 hour 30 minutes with 10% off these prices, to be paid up front. A minimum of 8 weeks for a class up to 20 people. The price rate per person is dependant on how many people sign up i.e. 10 people per hour = £7/£8.

Day: Monday or Thursday afternoon. A booking form will be provided for completion.

If anyone is interested in taking this opportunity forward/would like a form please contact Lorraine on 01284 701652.



Join us on Twitter

Fellow members! As you might have heard our group has launched itself on the social media site Twitter. Twitter offers a fantastic opportunity to spread the word of our fantastic patient led support group to literally anyone in world who is interested! It is also a great way for our group to keep in touch with the subjects that interest and benefit us.

As a member if you wish to follow us on Twitter you will need to set up your own personal Twitter account. To set up this account you will need to have internet access and an email account. If you log on to the Twitter homepage www.twitter.com you will see the option to 'Sign up to twitter'. Follow the steps that they provide and you will soon have an account! To see our updates make sure you follow us at **pain_support13**

For more detailed instructions and advice on how to use Twitter please use the link below.

<https://support.twitter.com/articles/215585-getting-started-with-twitter>



Please also feel free to ask James any questions at our group meetings.



*Self Managing your Pain
Want to know more....?
3rd July 2014*

Come along and enjoy an evening learning :-

- ◆ **W**hat is Self Management and how it could help your pain?
- ◆ **H**ow better sleep pattern and exercise could help pain levels
- ◆ **L**isten to our highly experienced speakers:-
Pete Moore, Sleep Expert (TBC), Carole Baker
- ◆ **T**alk informally to our stall holders from many relevant disciplines

Everyone Welcome - those in pain, their carers, family and friends

Stalls from Physiotherapist, Occupation Therapy, Suffolk Well being, Mindfulness, Acupuncture, Reflexology, Yoga, Herbalist, Massage Therapy

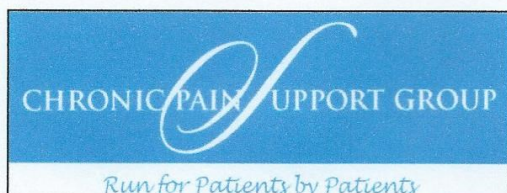
Event Details:

Location—Education Centre
West Suffolk Hospital
Hardwick Lane
Bury St Edmunds
Suffolk IP33 2QZ

Evening starts 17.30 till approx 21.00
Speakers start **18.45**

Light refreshments available and raffle
Parking—pay and display
£1 fee on door

To book your place(s) call - 01284 712970



West Suffolk **NHS**
NHS Foundation Trust

The above subject to change

My Fibromyalgia and Me by Debby Sinclair

My name is Debby Sinclair I'm 52 years young and have been married to my wonderful husband Jim for nearly 36 years, who without a doubt has been my rock since my condition became chronic 19 years ago. This article is my story, some of the terms I use are not widely used by the medical profession just terms used by some of the fibromyalgia community, such as fibro, it's much less of a mouthful than Fibromyalgia sufferer.

I was diagnosed with severe Fibromyalgia in September 95; it was the day my world changed for ever. I had collapsed at work back in June 95 after spending months just stuck in a cycle of sleep, work, sleep, work, taking caffeine tablets to try and stay awake. It didn't work just gave me chest wall pain that got so bad I thought I was having a heart attack. At one point I later found out a lot of fibros have caffeine sensitivity and my friend found me sound asleep on the loo. I had been missing over an hour, I was mortified. About 3 weeks later in the June I collapsed at work not realising it would be my last day there. I thought I must be suffering a hormone imbalance due to the hysterectomy I had in the November of 94 but blood tests said not.

I was tested for Lupus, MS, Rheumatoid Arthritis you name it I was tested for it, finally I was sent to see a Consultant Rheumatologist at Walnut Tree Hospital Sudbury, Suffolk. She spent over 2 hours poking and prodding me, I was in agony by the time I was wheeled out to the waiting room. I was totally wheelchair dependent at that point, a while later the nurse who had been all smiles and chirpy earlier was wiping her eyes. I asked if she was ok at which point she gently put her arms round me and sobbed "I'm fine". At that point I knew I was in trouble and asked for my hubby to come in with me. The Rheumatologist words to me were "what you have won't kill you but I am sorry to say it is an extremely painful condition called Fibromyalgia Syndrome". Fibro what? I asked. I've never heard of it, we had so many questions our heads were spinning. She said fibro meaning fibrous and myalgia meaning pain. She explained that although it was lumped within the Arthritis-group of conditions it wasn't actually Arthritis because the joints weren't involved.

At that point my hubby asked her how long would it be before I was on my feet again. Her reply was she won't. He said "what do you mean? she just wants to get on with life, start walking the dogs again, driving again, go to work". The doctor said "if she has a pension then I think she should apply for it, I would back her all the way if she did". I was totally devastated she gave me a copy of the only fibro booklet that was available at the time and gave me the number of fibromyalgia UK. I was put on amitriptyline 10 mg and a painkiller that I can't remember the name of now. I've had so many different ones over the years. She said she would write to my GP and explain that it would be a good idea to take the booklet along as many GPs hadn't heard of Fibromyalgia. She was right, he hadn't.

I count myself lucky at the time I was diagnosed I had the most amazing GP from Siam Surgery, Sudbury, Suffolk. He hadn't heard of Fibromyalgia and he told me if you have a computer you find out everything you can. I'll find out everything I can and we will put our heads together and see what we can come up with, we will learn about this condition together and that's exactly what we did. We later put a cognitive therapy program together that helped me but nothing that we tried would improve my sleep pattern and, believe me I've tried pretty much everything over the years so now I sleep when my brain and body allow, people think (and believe me I've heard it countless times over the years) how can you say you have Chronic Fatigue but say you can't sleep that's just stupid. My answer these days is I know ridiculous isn't it, when you've worked it out come and explain it to me because I would love to know the answer, at which point they usually can't get away fast enough.

I have learnt over the years don't assume that when someone asks you how you've been or ask what's wrong with you that they genuinely want to know. You tend to develop a sixth sense about those who are just being polite or are just dying to give you their opinion on your condition based on a five line article in some woman's magazine or are out to sell you the next miracle cure. As negative as that all sounds there are a lot of genuine people out there that do care but struggle to understand, they are the people I'm happy to sit down with and take the time to get to know and explain as best I can what living with this condition is like.



Debby's article cont'd

Back in 95 when I had my follow-up appointment with the Consultant Rheumatologist she told me that it was her belief, after reading my medical history, that I was actually brought into this world with Fibromyalgia. I was a transverse breech double forceps delivery home birth. My Dad said I was black and blue for a month after I was born. She believed the shock to my system during the birth triggered the fibromyalgia. A lot of things fell into place after that appointment I can tell you!

I am doing my article in segments so I will tell you about how things, even my early memories, began to make sense.

It is my belief and that of many other Fibros that there are 3 stages to this condition. Stage 1 mild, Stage 2 Intermittent, Stage 3 Chronic. There isn't any time frame; some become chronic earlier than others, some never do become Chronic but those that do will tell you it is a very disabling condition that you wouldn't wish on your worst enemy.

Until next time I wish you all well, may your pain stay at bay and the rain stay away.



Crafting Group

The group has been approached by a pain nurse from WSH who is really enthusiastic about setting up a craft group and who will come along periodically to assist/teach people to knit and support us initially. Two members of the group have kindly agreed to take the lead with this group. Come along, make friends and chat the time away in a friendly environment.

Using your hands has proven statistical data to help with Psycho-social side of life and wellbeing. This is created by creating something, finding it easier to talk when distracted as well as reducing pain, in a safe/confidential/non- medical threatening environment/circle of trust. It doesn't have to be knitting but any craft that involves using hands and large amount of concentration/distraction.

Considered venue—All Saints Church Hall, Park Road, Bury St Edmunds. Time period—2 hours once a fortnight. Day of the week— Monday/Tuesday. Suggested Time— 6-8pm. Members to decide on day and agree timings.

Free parking- Automatic entry doors—Use of kitchen for refreshments—Disabled toilet—Use of electrical sockets—On a bus route—Fee per session £2.00 towards hall hire and refreshments—Members to provide all own materials and equipment. Members attending covered by group constitution and insurance—Funds raised go towards the group—link to WSH.

Booking Information for Self-Management Event on 3rd July 2014—see poster on page 3

Booking line number—01284 712970 open from 1st March—27th June

By ringing this number you will be able to secure a place at this event. Tina is manning this phone line and will ask you to confirm the following details:-

Name

How many people coming?

Contact details: phone/mobile/email

Entry Fee is £1.00 on the door

Is a mobility space required?

Parking is pay & display

Where are you from: CPSG/NHS/Other—please state

How did you hear about this event?



Run for Patients by Patients

Accounts for 2013

INCOME

Raffle	£206.00
Sales	£190.30
Donations	£355.02
Misc.	£39.22
Fund Raising	£746.74
Sad Lamp Hire	£10.00

TOTAL: £1547.28

EXPENDITURE

Printing	£159.92
Postage	£193.10
Stationary	£6.39
Misc.	£209.65
Insurance	£120.10

TOTAL: £689.16



CASH IN HAND: £3998.58



Funs taken in January 2014

Raffle: £20.00 Coffee: £10.80 Sales: Foyer and meeting = £57.40 Donation: £1.80 Sad Lamp Hire: £5.00
Risby Indoor Sale: January £24.10



For Sale—BACK FRIEND



'The BackFriend' from ME Design Ltd Colour: dark red Condition: as new never been used

Price: a donation to the group funds. RRP: £61.50 + postage

Designed to provide optimal lumbar and thoracic support to prevent back pain and lower back pain.

Designed from expert knowledge with the anatomical, orthopaedic and ergonomic aspects of pain free seating firmly in mind. And it is recommended by physicians and surgeons both in the UK and abroad.

Portable—fits into any seat/chair in the office, the car, the train or the plane. Not recommended for scooters or wheelchairs.

Hand grip for easy carrying—Robust lightweight construction—Firmly padded in fire resistant material with polyether foam padding—Easy to adjust hinges—Maximum anatomical support in spinal area—Brings you support and comfort.

Please contact Lorraine if you wish to purchase or speak to Linda on the benefits of having one if you experience back problems.



Upcoming Fund Raising Events

**WALKING WITH THE WOUNDED CRAFT FAIR—Sunday 25th May 2014 in Bury St Edmunds Cornhill Walk
10am—4pm**



C.P.S.G. are having a stall at this event for one day selling handmade crafts and homemade produce. If you would like to donate to the stall/make something or volunteer to help please contact Lorraine. Please come along and support us, we would love to see you. All funds raised go towards the group.

The summer event—Party in the Park, Sudbury in July. Look out for the details in the next edition or on Facebook/website.

A **big thank you** to all of you for your support and contributions to the raffle.

Please send your articles and suggestions to the contact details below.

You can find the in-depth articles on our website www.chronicpainsupportgroup.co.uk

Bringing People Together



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Next meeting 21 March
West Suffolk Hospital