

CHRONIC PAIN SUPPORT GROUP

Issue 5

Run for Patients by Patients

Spring 2012

Welcome to our Spring Newsletter

News from the Chair – Lynda Sebbage



Well, here we are in a new year and as I write, I can feel my bones complaining about the cold! I expect all of us feel that much worse this time of year – lack of sun and lack of warmth, but we shouldn't complain really for when the warmer weather arrives we will be thinking how hot it is and phew, couldn't we do with some cooler weather!

Recently I was asked to go along to Ipswich hospital's pain clinic to give them a talk about our support group. The small group there is finding it hard to attract members for one reason or another and so were very interested to hear how successful our group is. We have shared a lot of ideas between us and hopefully, where possible, we will work together; for instance, if patients living nearer to Ipswich prefer to attend their group we will make that suggestion (and vice versa). I have extended an open invitation to them to attend any one of our meetings should they wish to come along.



Special Lamp!

Some people are affected by the lack of sunlight at this time of the year and I count myself as one of them. Depression is a side affect of pain but made worse when it is dull and dreary outside – my spirits certainly lift when it is brighter and sunnier. Ipswich hospital recommended me to use a 'Sad Lamp' – odd name you may say but SAD actually means **S**easonal **A**ffective **D**isorder. If you are affected by this you may find you lack energy, you are lethargic, depressed and prefer to withdraw into a 'shell'. 'Winter blues' are quite common place, affecting more women than men. Using a 'Sad Lamp' helps to replace the bright light that is missing at this time of the year and researchers have proved that the lack of solar ultra violet rays to some people has an effect on their brain chemistry causing these low moods. Apparently, just by sitting in front of the lamp for up to 30 minutes a day can make all the difference. We have purchased a very good quality lamp on behalf of our group using some of the funds we were provided with last year which were given to us on the proviso that we used it for the benefit of all our members. We felt this was an excellent and practical way in which we can help our members who may suffer from depression. The lamp is available for loan to our members and if it proves popular, we may decide to purchase another so there is ample opportunity for all who need to use one. In return, we would like to ask for £5 hire fee to go towards the cost. Please let us know if this is of interest to you and if there are any other ideas for items you feel will be useful for the group that we can purchase, then please do let us know. Your ideas are valuable and most welcome.



This year

On another positive note, we are delighted that we have booked speakers for the whole of 2012. In fact we have more speakers than meetings so do keep an eye open for extra fill in dates that may be arranged. The web site is regularly updated if you are able to access this easily enough, otherwise, don't worry as Linda will write to you if not!


Questionnaire

We have some interesting ideas for this coming year but as a group we can only be as effective as member input allows. We have decided to put together a questionnaire which is enclosed and from this you will see that we are asking for your thoughts about how our group has been run since its inception two years ago. Important to look back to see how we have progressed and areas where you think we can make improvements. Without wanting to sound as if we are moaning, our committee works really hard to make this group successful but sometimes we feel rather despondent when we see so few people turn up at the meetings and when we rarely receive any input. We, too, are severely affected by chronic pain and it is indeed, quite a challenge to keep the group running when each day feels so hard to cope with – but we will if you want us to!! So do please help us to help each other – it is amazing how, by being together, our spirits can be greatly improved; just being amongst other people with similar problems makes us feel we are not alone! (Moan over!!)

We do hope you will join us during this year at our meetings and please do find the time to complete and return the questionnaire! And please remember: your ideas and suggestions are much appreciated! Thank you.

Bringing People Together



Supported by
West Suffolk Hospital 
NHS Trust

Direct Payments and Suffolk Independent Living

What are Direct Payments?

If you have an assessment from Suffolk County Council and they decide you need support you will be offered either money to arrange and buy your own support (Direct Payments) or a service arranged by Suffolk County Council. People who receive Direct Payments take responsibility for choosing and providing their own support services.

Why choose a Direct Payment?

Direct Payments can enable you to live independently. Independent living is about having choice, control and responsibility over your life, it is about getting the most out of all areas of life. Choosing direct payments means you take both control and responsibility for your support arrangements. This gives you more freedom to meet your assessed needs in the way that is best for you. Some people use direct payments to employ personal assistants or care workers. You can choose who works for you and when the work is done.

An example of a Direct Payment is –

Alice needs support to get out of bed in the morning and ready for the day ahead. The agency arranged by Suffolk County Council can only come at 8 o'clock but Alice would prefer to get up later. Alice uses direct payments to employ someone to come at a time that suits her and fits in with her life.

What can a Direct Payment be used for?

A Direct payment has to be used to meet your individual assessed need so this could be care in your home, supported or daytime activities, short breaks or respite care or buying a piece of equipment. You can't use a Direct Payments to pay for a service from Suffolk County Council or buying long term residential care.

What support is available?

Taking responsibility for managing your own services can seem a little daunting, but you're not on your own. Suffolk Independent Living (SIL) is the advice and support service for Direct Payment recipients in Suffolk. A SIL adviser can visit you in your own home or other suitable location or can provide advice over the telephone or by email.

SIL can support you:

- to arrange care or support for yourself
- to arrange care or support for your disabled child
- to find personal assistants or care workers
- to keep records/to be a good employer



Daniel Lummis

SIL also runs other services you can access for support with your direct payments. These are:

- A payroll service that can work out the money you need to pay your workers
- A supported accounts service that can hold the money in a bank account on your behalf

How do I get more information?

For more information on direct payments please contact SIL on 01473 603 876 and one of our advisers will be happy to talk to you or visit our website www.ncodp.org.uk/suffolk-independent-living.

How do I get direct payments?

If you have not yet had an assessment from Suffolk County Council (ACS or CYP) you can contact Customer First on: **0808 800 4005**

If you have had an assessment and would like to consider direct payments further, you can speak to your social worker or care assessor. You can also contact SIL and one of our advisers will be happy to give you more advice and to support you to set up your direct payments.



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



Lorraine Ayling

Tel: 01284 701652

Email: lorraine@aylingonline.com

Next meeting 23/3/12

West Suffolk Hospital



www.paintoolkit.org

Free
Pain/Self
Care Toolkit

Pain & Self Care Toolkit workshops

Interactive half-day workshop for people who live with pain and long-term health conditions

Workshop overview

Activity 1

Introductions and challenges experienced living with pain and long-term health conditions

Activity 2

Overcoming day to day problems living with pain and long-term health conditions

Activity 3

Benefits of Self-Management

Activity 4

Understanding the tools in the Pain & Self Care toolkit

Activity 5

Using the tools in the Pain & Self Care Toolkit

Activity 6

How to work effectively with your doctor and health care professionals

Activity 7

Managing your medicines effectively

Activity 8

Setting realistic goals, action planning and problem solving setbacks

The Pain & Self Care Toolkit workshops are for people who live with pain and long-term health conditions. They are low-cost, simple, effective and ideal for people who need extra support or while they are waiting to see a health care specialist or for another medical intervention. They have been developed to help to increase their awareness of 'active' self-management.

The workshops main aim is for participants to feel confident in using the Pain & Self Care Toolkit tools which have proved to be so useful to patients not only here in the UK, EU and overseas.

The activities covered in the workshop are to stimulate ideas of promoting self-management so that with new tools and some gentle encouragement all who take part are more active self-managers.

The Pain & Self Care Toolkit workshops are led by experienced Pain & Self Care Toolkit Trainers who live with long-term health conditions, but are good self-managers of them.

The workshop is delivered in a relaxed environment using methods and processes common to self-management, incorporating time for questions and discussion.

"We have been using the Toolkit booklet for about a year and it helps to illustrate key pain self-management strategies used on our three week residential programme. The format is clear, eye catching and easy to read. The booklet provides a welcome addition to materials used on our programme. I thank Pete and all those involved for producing such a useful resource".
Consultant Lead Health Psychologist London

"I frequently offer the toolkit to patients with chronic symptoms as part of developing self-management strategies. Feedback from patients is always very positive and they find it helpful in managing their day to day symptoms. I find it to be a very valuable 'tool' in my practice".
GP Essex

For more information regarding the Pain & Toolkit workshops, contact Pete Moore at pete.moore@paintoolkit.org

Please see overleaf for date on this free Linda Reid's workshop:-



Dr Louise Jaynes



Consultant in Anaesthesia and Pain management

A very big thank you to Dr Louise Jaynes from the Pain Clinic, for taking the time out, to come and give a presentation to the group on 11th November 2011.

Dr Jaynes's presentation took you on a journey down many pathways from the Fundamentals of managing chronic pain, the complex psychosocial influences and the issues compounding it to a diagnosis, treatment, therapies available and medications. A whole package of strategies to help the patient to be able to continue on their journey empowering them to be more in control and not the pain.

Each pathway offered many opportunities for group involvement and feedback.



YOGA WITH CAROLE BAKER

Carole is happy to put on a free yoga class at the Self Centre and has set aside Thursday afternoon 15th March 2012 from 3-4pm, just for the group. If anyone is interested in this session and would like to have a go, please speak to Lorraine.



Free Workshop—an update from Linda Reid

Thank you everyone who has shown an interest in the **Free 1/2 Day Interactive Pain Tool Kit Workshop** we have been kindly invited to participate in by Pete Moore, for people living with pain and long term health conditions. I know it will be a really practical and informative session to give you confidence in using the pain toolkit. Along with promoting awareness of being an active self manager, in a relaxed and friendly environment. There will also be time to ask questions and have helpful discussions with Pete whose an expert in Pain Management. I just wanted to keep you informed that we are looking at a date in June/July so it can be held at the Education Centre, within West Suffolk Hospital. So will keep you posted...



Up to date Treasurer's Report

INCOME		EXPENDITURE	
Raffles	£203.00	Postage	£163.96
Donations	£60.10	Printing	£455.55
Fund Raising	£357.14	Stationary	£15.40
Coffee	£3.40	Equipment	£159.97
Sales	£40.00	Misc	<u>£20.79</u>
Council Budgets	£900.00		£815.67
Waitrose Sudbury	<u>£411.00</u>		
	£1974.64		

Balance: **£1158.97**



NEW MEMBERS

A very big welcome to all the new members who joined the group in 2011. Over 20 in all, bringing our total membership to over 60.

We look forward to



FUND RAISING



INDOOR TABLE TOP SALES

Do you have any unwanted items?

If you have any small items that you no longer want or need and they are suitable for sale please see Lorraine.

Since last August Lorraine has been doing indoor sales to raise funds for the group. From these sales £159.64 has been raised and from home made produce £21.00.



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