CHRONIC PAIN SUPPORT GROUP

Issue 4

Run for Patients by Patients

Winter 2011

Welcome to our Winter Newsletter

News from the Chair – Lynda Sebbage

As I write, we are busy planning our diary for the forthcoming year. Trying to book speakers is a mammoth task in itself and it is quite a tough challenge to find suitable people to come along and talk. We also know how hard it is for us, the patients, to come along too, especially given we all have varying reasons for our pain.

Thinking about who we should invite for next year made us think that we should consider some of the many support groups up and down the county. A number of them are keen to come along and talk to us (they have heard about our work and are as much interested in us as they hope we shall be interested in them!). To this end, we are meeting up and talking to their representatives and if we feel they have something of interest to us as a group then we shall, of course, book them in.

Committee changes

Natalie has undertaken this role since we started the group almost two years ago – I can't believe that it's our second birthday soon! Haven't we achieved a lot in that time? Natalie has had to step down because of her heavy work commitments and so I would like to say a big **'thank you'** to her for all her hard work and enthusiasm which has been an integral part of our group. We shall miss her although I know she will want to stay in touch and come along to our meetings when she is able to.

We are delighted to welcome Linda Reid who has kindly agreed to step into Natalie's shoes. Linda has a lot of experience in the world of pain as she is one of the tutors for the Pain Toolkit and so spends quite a lot of time running their very effective programme. Linda is passionate about the group and is keen to see it grow and develop.

Linda told me: *"I am passionate about the Chronic Pain Support Group because there is nowhere for people to turn to in between their appointments with their hospital specialist or doctors and this provides the perfect place. Often patients find it more helpful to be among others who are going through the same thing as they can share so much together. Isolation is one of the terrible aspects of those suffering from pain and the support group breaches that gap."*

We welcome Linda to our committee and look forward to working with her in the future.

Christmas meeting

We do hope that you will join us for our special Christmas meeting on 16th December at the Education Centre from 2-4pm (we decided not to proceed with a lunch at a pub) which will be a 'Bring 'n' Share' afternoon tea with a speaker—Kerry Overton from Suffolk Link. All we ask of our members is to bring along a small contribution to the buffet tea. A chance for the group to meet socially and celebrate the festive season.

Communication

We realise that some people are unable to access our emails or web site and so we will be mailing everything to you in future. If you know of anyone who would like to be added to our list then please let us know. If you can help spread the word about the CPSG to your local surgeries, physios and any other appropriate medical centre then could you do that? We will happily supply you with a small supply of leaflets, just let us know!

Your Support

Please do put the forthcoming dates in your diary and join us for our meetings – we are working hard for the benefit of all our members, patients and other people who find our group of benefit but without **YOU** it really doesn't mean much so please do support **YOUR** group!!

Bringing People Together

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West Suffolk Hospital NHS
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Suffolk independent Living by Olive Andrews

My late husband had a stroke in August 2009 and was admitted to W.S.Hospital. Prior to discharge he was assessed for care in the home. It was decided that he needed visits from Carers in the morning and at night. The carers would come for 6 weeks, (For some reason we had the carers for 10 weeks) then he would be reassessed and we would have a choice of either:-

a. Being transferred to an agency who would supply carers. Or

b. Being transferred to S.i.l.s. (Suffolk Independent Living)

I chose the latter because;-

- The carers came at 5.30 p.m. to put him to bed. He suffered from D.V.T. he could not be left in bed from 5-30 p.m. till next morning, the carers could not come later than 5.30 p.m. I had no choice but to cancel the evening carers.
- The morning carers were to come at 8 am. I found that the times varied, one carer arrived many many times at 6.15 am. (I was still in bed.) Another 11 am, On one occasion no one came or rang to say they had no carer available.

When one regular Carer finished caring for my husband, would sit down and wait until her next patient was due, some 2.-3 hours later. I found this very disruptful and stressful. I noted that the carers had insufficient time to include wash my husbands hair, to allow him to try to do things for himself, e.g. shaving, cleaning his teeth etc. They only had time to wash and dress him. The transfer to Sils made sense to me and it was simple.

My husband was assessed by a social worker and payment to cover his care would be paid every 4 weeks into a bank account to be used solely for this purpose. I was given a one off payment towards the first years cost of insurance, to cover anyone I employed to care for him. I had to keep receipts and account for the money spent each month, sent to Suffolk C.C every 3 months. Free Post envelopes, stationery etc. were provided. Sils advisors were always available for advice and the book keeping was simple. I could spend the money given for my husbands care on employing anyone suitable who did not reside at my home, that could be family, neighbours, friends. etc. I could take care of him myself and use the money for equipment that the Social Services could not supply e.g. A monkey pole, over the bed. I could save the money and use it for respite care, whenever I needed a break. I would have to inform the Suffolk C.C. why I was saving the money.

Although I have back and wrist problems, I was still able to care for my husband. The stroke affected his right side and hand. I would leave him sitting at bathroom sink to clean his teeth, comb his hair, and shave himself. When he couldn't manage he would call me and this restored his self esteem .

I bought a second hand rollater, (like a trolley with a seat) from the account. He could walk with it a few yards and sit on it to rest. This gave him the confidence to go to the gardeners club and social clubs. My twin grand daughters would take him out for 3 hours once a week, to give me a break. They would drive him to the barbers, buy him a newspaper and a coffee. I paid the girls, who were students, from the account.

Transferring to Sils, was the best option for me, If I had found that I could not cope, I could have reverted to the carers being provided by the agency. In September 2010 I rang Sils and asked for the account to be suspended as my husband was admitted to W.S.Hospital, he had been diagnosed with Leukaemia and I asked for their advice. They replied that if he was in hospital for few days, I could continue with the account. If he was in hospital over a specified number of days, he would be assessed and carers would be arranged for 6 weeks, then I would have the choice of agency carers or Sils. It would depend on if I could cope and how much care he needed. After 18 days, my husband was suddenly discharged. He arrived home at 9.p.m. No care was put in place. I informed Sils, they were very helpful and reinstated the account immediately.

Two weeks later, on a Sunday, I rang the Macmillan Team, my husband was very poorly, they arranged for the District nurse to call. She informed the Marie Curie Nurses, and the Rapid Response Team. They planned to come 2/3 times per day, for two weeks. After that carers would be provided for 6 weeks, then I would make the decision to have either the Agency Carers or Sils. Ten days later my husbands passed away very peacefully at home, with my daughter and I present. Later I balanced the accounts and sent a cheque to Suffolk C.C. for the monies that I was not entitled to. When the cheque was cleared I closed the account.

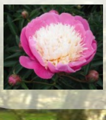
I have no regrets or complaints about the service of Sils, I would encourage anyone to try this care service.

The Marie Curie Nurses, sent information, an offer of a years free insurance on every electrical item in my home, plus cover for the central heating boiler, They included a booklet, `what to expect at the end of life.' I found this booklet very helpful, it is available on line.

* * *

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 11 Nov
West Suffolk Hospital

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16/9/11 Speaker: Truddi Dunn—Physiotherapist

Presentation—Benefits of Exercise for Chronic Back Pain

This is a specialised physio service provided to people with musculoskeletal conditions.

Aim— (1) The provision of assessment, treatment, advice and education for all patients referred with musculoskeletal conditions dependant upon clinical need with the ultimate aim for the patient to achieve, promote and maintain maximum independence and quality of life. (2) To reduce numbers of patients requiring secondary care intervention.

Scope— To cater for people with musculoskeletal conditions suitable for physio treatment including neck, back and peripheral limb problems. The service is available to all Suffolk PCT registered patients. Routine service within 13 weeks and urgent service within 5 working days. Prioritisation of referral based information by GP or referring professional.

Truddi delivered a comprehensive presentation allowing for group interaction, questions and answers. Truddi explained how the benefits of the exercise course began and with a step by step approach talked us through the vicious circle created from the onset of problems to the Toblerone Graph. She highlighted the benefits if exercise/no exercise and finished off with the good news stemming from it.

BENEFITS:

OF EXERCISE—Releases endorphins, improves circulation, function and stamina, increases energy, keeps bones strong, reduces risk of heart attack and stroke, stimulates bodies own pain killers, good for heart, lungs, coordination and balance, , improves mobility e.g. joints, ligaments, muscle strength and tendons, immune system, reduces pain-closes pain gates.

NO EXERCISE—Stiffness, muscle wastage and strength, digestive efficiency, cardiovascular capacity, reduces bone density, tissues vulnerable to injury, reduces coordination, balance, self-image and confidence, less able to cope, lowers mood and brings on depression, increases pain levels, creates fear and avoid movement.

GOOD NEWS: Deconditioning is reversible, fit tissue bodies are less prone to injury and pain, activity soon improves tissue

* * *

Read all About us!

The attached article (written by Lynda Sebbage) is featured in the British Pain Society's Autumn edition of Pain News. P44/45

Www.britishpainsociety.org

An accolade for the group.

Change of Day

To accommodate the speaker, the meeting in May is now being held on a Monday, 21/5/12.

(room 4b)

For all those who suffer with Fibromyalgia please give the speaker your support.

Contact Details

If your details change, for any reason, please let us know so that we can update our records.

* * *

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