

KEEPING PACE

JULY 2005

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SOUTHAMPTON CHRONIC PAIN SUPPORT GROUP

Welcome to our second newsletter. We got lots of positive feedback from our first one and so we hope you enjoy reading this one just as much.

As a group we have decided to keep the newsletter full of local information relevant to our members and to try to produce it quarterly, so feel free to contribute with articles or news as we are always interested to hear from you.

Our monthly Support Group continues to be well attended with about 20-25 people, and at each meeting there are always new faces.

We must continue to distribute the posters to get even more people interested in our group and spread the word around.

As you are aware we are the Southampton Branch of **Action on Pain** and Ian Semmons, Chairman of Action on Pain, came along to our June meeting and said "On a national basis the charity has been very busy with nine branches now established and others in the pipeline. "Painline" our dedicated telephone helpline has now

taken its 20000th call, which represents a considerable milestone. We have launched three new information booklets and have another in the planning stage. Over 40000 booklets have been distributed with an increasing number of pain clinics now using them. Action on Pain has also worked with AGE Concern to produce a new book "Taking Control of Your Pain" which will be a valuable asset to people affected by pain.

We have been lobbying hard with a "hard-hitting" letter to Tony Blair when he had his recent back problem. Helen Rogerson, one of our Trustees, has had two meetings with Patricia Hewitt, the new Health Secretary, raising her awareness of pain issues.

On the international scene I sit on the steering committee of the Neuropathic Pain Network which is bringing folks together from across the world to raise the profile of neuropathic pain. To share the levels of expertise which the patients and professionals bring to the group is a wonderful

experience which can only lead to helping so many more people.

Our Development Worker in the North-East has been a great success raising awareness of the work of the charity as well as attracting more people to the branch meetings. It is our hope that we will be able to replicate this role in Yorkshire to cover the branches there as well as helping with the two new ones planned in that area. As always funding is an issue, however we remain positive about securing it.

It is good to see that Southampton Branch is running so well in such a short time. I would like to thank all of you that have put in so much effort to make this happen."

QUOTES:

"Life isn't all you want but it's all you've got so stick a geranium in your hat and be happy"
~ Barbara Johnson

"This life is lived with a moan. We enter in another's pain and leave it in our own"
~ Anon

"So many people spend their health gaining wealth, and then have to spend their wealth to regain their health". ~A.J. Reb Materi, *Our Family*

"Part of the secret of success in life is to eat what you like and let the food fight it out inside".
~ Mark Twain

APRIL SESSION

The speaker at the April session was Kate Langridge, a physiotherapist from the Pain Clinic. She led a discussion about the importance of breaking the pain/decreased activity cycle. She explained how if someone stops exercising because of pain this can lead to stiffness in the muscles. The blood supply slows down and the bones get weaker. The range of movement is then decreased and even limited motion becomes painful because of the weaker and shortened muscles. This can cause tiredness, irritability, frustration, decreased confidence and feelings of worthlessness. Sound familiar?

The resulting frustration can then lead to the tendency to overdo things which, of course, causes pain. So, physios like Kate encourage gentle, paced exercise to keep the muscles toned and in shape. There then followed a lively discussion about all the coping strategies that the group members used to prevent this cycle such as relaxation, meditation, doing things within their own limitations and how the situation can slowly improve with pain appearing to be less than it used to be.

“Chipping away at change does just as well as doing it all at once”.



MAY SESSION



Royal Pharmaceutical Society of Great Britain

For the May session we were fortunate to get Jennifer Ndichu, one of our local pharmacists, to speak. We were very grateful to her for fitting us in during her lunch break.

She gave an overview of the sorts of medication used in the treatment of chronic pain. We learnt a useful fact that most chemists offer a service to patients in the form of making individually tailored blister packs for people on regular medication. This would be particularly helpful for those who have trouble remembering to take their medication regularly, for those who have complicated medication regimes and for those who find opening lots of different packets and bottles difficult.

If any of these describe you then why not talk to your local pharmacist.

JUNE SESSION



One of our recent members volunteered to take the June meeting.

Her name is Joan Bamford and she is a Bowen Practitioner. She gave us a fascinating introduction to this hands-on technique which aims to relieve pain with a series of gentle, precise moves on specific muscles, tendons and nerves.

The Bowen Technique is a non-invasive, holistic therapy consisting of a sequence of gentle moves over muscles and soft tissue, interspersed with periods of rest. Practitioners are constantly surprised at the effectiveness of the therapy.

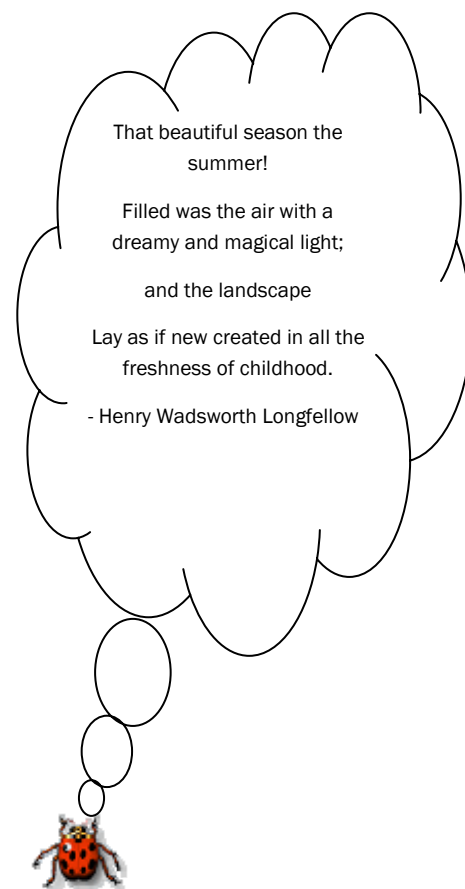
She explained how the technique is thought to correct imbalances between the muscles and brain. She then demonstrated the technique on two volunteers: one with neck pain and the other with painful knees. We will have to wait until our next meeting to hear how they got on.

We must at this point thank “The Doc” NRW for her wonderful note taking during the meetings, or as she puts it “her ramblings”

Ground Rules:

As the support group seemed to be doing so well and numbers steadily growing (we have a data base of at least 40 members to date) Norma and Joan (sort of founder members but generally the two found in the kitchen making drinks and washing up—PS any help gratefully received, hint hint!) wondered whether it was time to set some ground rules. The idea was that these should help everyone within the group to feel relaxed and able to participate freely. We spent just 10 minutes discussing this at the June meeting as we reckoned that these ground rules will need to be revisited and developed as the group grows and membership alters. The intention is to return to them at the beginning of each meeting to decide if we still agree with them or want to change them and to let any new members who have come along on the day know what the group is all about. Here are the thoughts so far:

Promote positive side of living; Accept ups and downs; Accepting all age groups
Knowing each others names; Respecting each others views; Involvement;
Making the branch work—working for each other; Confidentiality within group;
Equal opportunities; Sensitivities.



That beautiful season the
summer!

Filled was the air with a
dreamy and magical light;

and the landscape

Lay as if new created in all the
freshness of childhood.

- Henry Wadsworth Longfellow



The world is a rose;
smell it and pass it to
your friends.

- Persian Proverb

The word "member" is used quite frequently in the newsletter and during the meetings, NRW/JA thought that it was about time to explain what is meant by the term.

A member is anyone who turns up to the meeting, whether they have chronic pain or are carers/friends of someone who does. If they give their name and address to us to be included in our mailings then we assume that they wish to be members.

There is no membership fee but we are always grateful for any contributions, however small as we know a lot of people are receiving benefits, towards expenses such as tea, coffee, newsletter printing and posting costs. A money box for donations is brought to each meeting.

The issue of funding was also discussed at the end of the last meeting and there were some general ideas about approaching local businesses for sponsorship. There was interest expressed about arranging social events such as picnics that could include partners and children. There was also a request for some evening meetings and an offer of a free venue to hold them in.

If anyone has any more thoughts about any of these issues, please let us know or tell us at the next meeting.

Recommendation from a member:~

We all need comfort while we sleep;

I recommend the Sissel Orthopedic Pillow, original. This pillow was developed in the University Clinic Hospital, Lund, Sweden. The Patented design counters uneven pressure of the vertebrae whilst slightly extending and so relaxing the neck. It lends support to the spine whilst being soft enough to accommodate the shoulder and allow any sleeping position. Each Sissel Pillow comes complete with a tailored pillow case made from 100% cotton, easily removable for washing. The moulded foam pillow should be hand washed in lukewarm water. The product has been allergy tested and is guaranteed for two years.

Sissel's address is:~
Unit 10 Moderna Business Park
Mytholmroyd
Halifax
West Yorkshire
HX7 5RH

You will need to be measured up and assessed by a qualified practitioner, I recommend Barbara Deacon,

The Grove,
22 Grosvenor Road
Portsmouth
SO17 1RT

Tel: 023 80582 245
Fax: 023 80571 888



Since Iris is the Greek Goddess for the Messenger of Love, her sacred flower is considered the symbol of communication and messages. Greek men would often plant an Iris on the graves of their beloved women as a tribute to the goddess Iris, whose duty it was to take the souls of women to the Elysian fields.

-Hana No Monogatari: The Stories of Flowers

Note:

John, one of our regular attenders, is doing some work on doctor/patient consultations and what can be done to make sure that the patients get what they want out of it. Some copies of his work to date are available at the meetings.

IN PRAISE OF THE PAIN MANAGEMENT COURSE

Mrs. J HorrocksJessie writes:~

As a chronic pain sufferer (severe bilateral sciatica flaring up over a period of some 25 years) who had tried everything, on October 2002 I was finally given the opportunity to attend a Pain Management Course organized by Southampton NHS Primary Care Trust.

This course offered 13 twice-weekly sessions of 3 hours each over 6^{1/2} weeks, followed by a review after 9 months.

All aspects of chronic pain were examined and discussed and an array of coping strategies explained with input by a team of experts including consultants in Pain Management and Clinical Psychology, a Pharmacist, a Physiotherapist and an Occupational Therapist. We were each allotted a keyworker to whom we could turn if we wished to have help with any individual problem.

The initial session filled me with gloom as we were told that chronic pain is now being classed as an illness in itself, that it is somehow a malfunctioning of the nervous system and that there is NO CURE.

Fortunately we were at that point asked to fill in a form identifying a situation that led to a change in how we were feeling. We were then to identify what we were feeling at the time and then the thoughts we had

at the time that led to these feelings. I had no hesitation in writing about the gloom I felt on receiving their daunting news and saying what a bad thing it is to destroy a person's hopes! A very understanding psychologist reassured me at length and wrote me a page explaining that there was indeed still hope and detailing some of the ways that we could seek to minimize our pain by pacing ourselves in our physical activity and, by changing our attitude towards the pain, arrive at finding it more bearable and even forget about it for varying lengths of time. Hope returned and I decided to persevere.

It was a great relief to know that our pain was recognized as not 'all in the mind' and although the sessions lasted 3 hours we were not expected to remain sitting or standing, but were encouraged to change position as required and even lie down if that was what relieved the pain.

Another plus factor was being in a group all of whom had the same problem of unremitting pain although for differing reasons. This very quickly brought about a bond between the members of the group, which in itself is healing.

For me it was necessary to unlearn the 'rules' I had been trying to obey. I had been programmed into believing that I

had to lie flat day and night after day and night, for 6 months at a time, with no exercise, physiotherapy or massage, only painkillers and antidepressants. I had been told that if I got up and walked I was harming my back and making my pain last longer. It went against me that I am a conscientious and persevering person!

By the end of the course I was feeling much more confident in my ability to cope with the pain, I had 'permission' to move and walk in moderation and the deep fear of the pain and especially of the immobility was assuaged. I have been able to achieve much more in terms of travel and social outings and do not feel so apologetic if I need to take a rest.

All but one of our group of 8 felt benefit from this course and all agreed that had it been of only a weekend's duration it would have had little impact. The 'drip factor' of twice weekly for 6 weeks was necessary for life changes to be possible.

I would recommend this type of course for all those in pain who have 'tried everything' and are still suffering and I do hope that the NHS will feel encouraged to continue and proliferate such worth-while programmes.

Comments on this are welcome from other members of the group:

We are on the Web

www.action-on-pain.co.uk

Action on
pain!

20 Necton Road
Little Dunham
Norfolk
PE32 2DN
Tel/Fax: 01760 725993

NEXT INFORMAL TALK ON 21ST JULY 2005

Phoebe Ross who is a local aromatherapist with many strings to her bow; For example—RGN, Aromatherapy, Yoga Instructor, and that's to name just a few.

Date for Next Meeting

Thursday 21 July 2005

Time

1 - 3 pm

Venue

St. Andrews United Reformed Church

ACTION ON PAIN'S PHONE LINE

The dedicated telephone help-line, manned by people with chronic pain, provides expert advice and support based around their own experience.

Confidential and informal, **Pain Line** has gained a reputation for providing a quality service to their callers.

Call on: **0845 6031593**

(lo-call rate)

As the call staff are all volunteers there may be times when the line is not manned, Please leave a message and they will get back to you.

The **Pain Line** is open from 0900 hrs to 2100 hrs Monday to Friday

Answer phone out of hours.

N.B. The **Pain Line** staff are not qualified to give medical advice, however the advice given is based around their day-to-day living with chronic pain.

BACK PAGE LAUGHTER

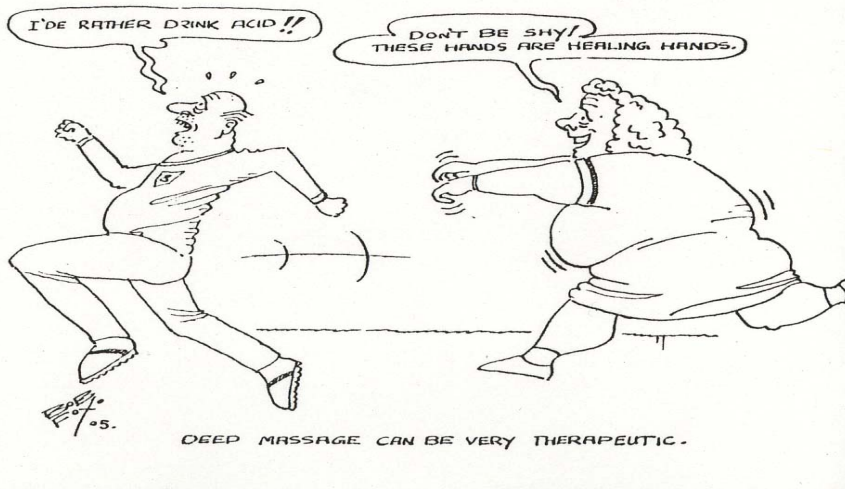


I don't exercise at all. If God had wanted me to touch my toes he would have put them up higher on my body.

A guy walks into work, and both of his ears are all bandaged up. The boss says, "What happened to your ears?" He says, "Yesterday I was ironing a shirt when the phone rang and shhh! I accidentally answered the iron." The boss says, "Well, that explains one ear, but what happened to your other ear?" He says, "Well, jeez, I had to call the doctor!"

A man walks into a doctor's office. He has a cucumber up his nose, a carrot in his left ear and a banana in his right ear.

"What's the matter with me?" he asks the doctor.
The doctor replies, "You're not eating properly."



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