



February 2011

THE DERBY FIBRO

**N
e
w
s
l
e
t
t
e
r**

Fibromyalgia Pain at Night
10 Tips for Better Sleep

ADVANCES IN CHRONIC PAIN
MANAGEMENT CONFERENCE
ASHFORD INTERNATIONAL HOTEL,
ASHFORD, KENT
OCTOBER 2010

Disability Living Allowance –
Reform

Happy
Valentines
Day

Message from the Chairperson

Hi Fibro friends,

Well we are into February already, I'll be glad when the spring and summer arrives so we get some sunshine. It's been a difficult winter this year, it maybe due to the winter months and the SAD syndrome. Some people use light boxes and it sometimes helps.

I wonder how many of us suffer the same and if it's linked with the FMS? Anyway, we have a busy year to look forward to, with the awareness day coming up on May 12th, and as it's on the group meeting day we can incorporate it with the awareness coffee morning.

I have arranged for a coffee morning at the Cathedral coffee shop on Iron Gate. For Thursday 12th May. We will be holding tombola and a raffle, (this is to raise some funds for the running of the support group). And; possibly a visit from the Mayor of Derby.

We will be keeping our eyes on the news and passing on any information regarding the changes in benefits for those who it affects. But if anyone has anything they want to know just ask and we can look into it.

Best wishes

Jackie x

Meeting Dates 2011

THERE ARE NO MEETINGS IN AUGUST

Thursday

March 10th

April 14th

May 12th

June 9th

July 14th

August..No meeting..

September 8th

October 13th

November 10th

December 8th

10.30am – 12.30pm

Saturday

February 26th

March 26th

April 23rd

May 28th

June 25th

July 23rd

August..No meeting..

September 24th

October 29th

November TBC

December 17th

2.00pm – 4.00pm

Admission

£2.50

Free Car Park at Back of Church

Off Melbourne Street

Enter gate on the right after the last
terraced house

Contact Jackie on:

0845 345 2319 or Text: 07973285571

Email: derby.fibro@btinternet.com

Website: www.derbyfibro.co.uk

45 Magellan Way, Derby, DE24 1AD

Forthcoming Church Events

SPEAKERS			Regular Events	
February			Open Circle Every 2 nd and 4 th Thursday Of Each Month 7.30pm No Admission After 7.35pm	Healing Services Thursdays 2.00pm – 4.00pm
Sun 13 th	6.15pm	Darren Brittain		
Mon 14 th	2.30pm	Tim Smith		
Sun 20 th	6.15pm	Richard Press		
Mon 21 st	2.30pm	Lisa Bonito-Day		
Sun 27 th	6.15pm	Anne Kelly		
Mon 28 th	2.30pm	Pam Franklin		
March				
Sun 6 th	6.15pm	Nicky Gunn		
Mon 7 th	2.30pm	Ted Lawrence		
Sun 13 th	6.15pm	Emily Baker		
Mon 14 th	2.30pm	Sue Presley		

SPECIAL EVENTS

Saturday 12th March

Private Readings £12 and Healing Free Will Offerings

10.00am – 3.00pm

For More Information

18 Charnwood Street, Derby. DE1 2GU.
 Tel: **01332 386 204.**
www.snu-emdc.org.uk/charnwood

Fibromyalgia Pain at Night

10 Tips for Better Sleep

By Jeanie Lerche Davis

Reviewed by Brunilda Nazario, MD

Do you toss and turn at night because of fibromyalgia pain or discomfort?

"People with fibromyalgia tend to have very disturbed sleep," says Doris Cope, MD, director of Pain Management at the University of Pittsburgh School of Medicine. "Even if they sleep 10 hours a night, they still feel fatigued, don't feel rested."

Research shows that with fibromyalgia, there is an automatic arousal in the brain during sleep. Frequent disruptions prevent the important restorative processes from occurring. Growth hormone is mostly produced during sleep. Without restorative sleep and the surge of growth hormone, muscles may not heal and neurotransmitters (like the mood chemical serotonin) are not replenished. The lack of a good night's sleep makes people with fibromyalgia wake up feeling tired and fatigued.

The result: The body can't recuperate from the day's stresses -- all of which overwhelms the system, creating a great sensitivity to pain. Widespread pain, sleep problems, anxiety, depression, fatigue, and memory difficulties are all symptoms of fibromyalgia.

Insomnia takes many forms -- trouble falling asleep, waking up often during the night, having trouble going back to sleep, and waking up too early in the morning. Smoothing out those sleep problems -- and helping people get the deep sleep their bodies need -- helps fibromyalgia pain improve significantly, research shows. Medications can help enhance sleep and relieve pain. But doctors also advocate lifestyle changes to help sleep come naturally.

Tips to Get Better Sleep With Fibromyalgia

Creating a comfort zone at home is key to better sleep, whether you have fibromyalgia or not. It's all about easing into bedtime feeling relaxed -- and staying relaxed so you sleep through the night.

These 10 tips can help people sleep better:

- Enjoy a soothing (warm) bath in the evening.
- Brush your body with a loofah or long-handled brush in the bath.
- Ease painful tender points with a self-massage device (like a tennis ball).
- Do yoga and stretching exercises to relax.
- Listen to calming music.
- Meditate to tame intrusive thoughts and tension.
- Sleep in a darkened room. Try an eye mask if necessary.
- Keep the room as quiet as possible (or use a white-noise machine).
- Make sure the room temperature is comfortable.
- Avoid foods that contain caffeine, including teas, colas, and chocolate.

Therapies to Treat Insomnia When You Have Fibromyalgia

If you're still having sleep problems, several therapies can help, including biofeedback, relaxation training, stress reduction, and cognitive therapy. A psychologist who specializes in sleep disorders can discuss these therapies with you.

The therapies help people handle stress better, which helps control fibromyalgia episodes, Cope says.

"Fibromyalgia comes and goes," she tells WebMD. "When you're stressed out, that's when it's worse." That's when you're most likely to have insomnia, too.

Medications can also help ease fibromyalgia pain at night, or directly treat insomnia. Medications to ease pain and improve sleep in those with fibromyalgia symptoms include certain types of antidepressants, anticonvulsants, prescription pain relievers, and sleep aids.

No one therapy will control fibromyalgia pain 100%, Cope adds.

"Medications help some. Exercise helps some. Stress reduction helps some. Cognitive behavior therapy helps some... If you can get restful sleep, you're going to function better when you're awake."

Reviewed on November 09, 2010

Disclaimer

The information given in this document does not necessarily imply endorsement by Fibromyalgia Association UK or Y & H FM Regional Consortium. Any information or recommendation of a medical or legal nature must always be discussed with a qualified professional. The Association or the Y & H FM regional Consortium cannot be held responsible for omissions and/or errors.

ADVANCES IN CHRONIC PAIN MANAGEMENT CONFERENCE **ASHFORD INTERNATIONAL HOTEL, ASHFORD, KENT** **OCTOBER 2010**

I was very pleased to be invited to give a talk at a Conference for Doctors and Healthcare Professionals, in the Ashford International Hotel, that was arranged by Eastern & Coastal Kent NHS Pain Team, in October. The main speaker at this event was Dr Ernest Choy, Clinical Reader in Rheumatology at Kings College Hospital in London, who is one of the UK's leading experts on Fibromyalgia. Dr Choy spoke on the 'Recent Advances in the Understanding and Treatment of Fibromyalgia', and I followed this with a talk on the 'Effects of Fibromyalgia – a Patient's Perspective'.

There were a number of other speakers at this conference: Dr Katja Wiech, Post-doctoral Research Fellow in Pain, FMRIB Centre University of Oxford, who spoke on 'Imaging of Pain'; Dr Thomas Smith, Consultant in Pain Medicine and Anesthesia, Guys and St Thomas' Hospital, London, who spoke on 'Neuropathic Pain'; Dr Neil Stanley, Manager, Clinical Research & Trials Unit, University of East Anglia, Norwich, who spoke on 'Pain and Sleep –a Different Perspective'; Dr Ahmed El Missiry, Consultant Psychiatrist, The Pagoda CMHC, Kent, who spoke on 'The Aches of the Psyche'; Professor Joanna M. Zakrzewska, Consultant/Honorary Professor, Facial Pain Lead, Eastman Dental Hospital, UCLH NHS Foundation Trust, London, who spoke on 'Why Does My Face Hurt?'; and Dr Johanna Theron, GPwSI Chronic Pain ICATS, Eastern & Coastal Kent Community Services, Kent, who spoke on 'e-Learning and Pain – 2010 and Beyond'. Unfortunately, we were not able to stay after my own talk as the whole of the time would have been too tiring but we were able to hear Dr Katja Wiech and Dr Ernest Choy speak.

We were invited to take our display board along and there were a number of other exhibitors, including pharmaceutical companies. One of these, Grunenthal, has developed an on-line interactive resource to help establish best practice in the management of pain, for healthcare providers at www.CHANGE-PAIN.co.uk. It was very interesting to speak to them and to discover that they appear to be having difficulties accessing some GP surgeries and amongst these, they mentioned some in Medway.

We met some delegates from the Medway area, including Carol and Colin Waldock, Physiotherapists from NHS Medway. Carol is the Lead on Fibromyalgia in Physiotherapy and is always keen to keep abreast of new developments in Fibromyalgia. Also there, was a Nurse from our very own Doctor's surgery. There was one GP from Medway from the Walderslade Village Surgery, an Orthopaedic Physician from the Medway Maritime Hospital, and another member of the same hospital.

The first talk given by Dr Katja Wiech on Imaging of Pain was very interesting. It was quite technical in some aspects, but the latter part of her talk was less technical and so easier to understand. She spoke about how different types of stimuli and their effect in the brain can be tracked with MRI scans. She also talked about the part played by support groups in assisting people to have a belief that there are alternative ways of looking at things rather than focussing on the pain. She explained that people who have a belief of any sort, under study conditions, appeared to cope better with pain.

Dr Choy was the next speaker and he gave an excellent presentation. He began by talking about the high percentage of people in the population who have Fibromyalgia. He said that, in some quarters, it was thought that if they were all diagnosed the result would be a heavy financial burden for the NHS. However, he said, the reality is that the money is mostly spent on testing before the diagnosis is made and there is now strong data to support the premise that, once a person is diagnosed with Fibromyalgia, the number of visits to specialist professionals decreases quite significantly. Therefore, in his opinion, an early diagnosis of the condition is a means of saving large amounts of money by the NHS, simply because the longer between the onset of symptoms and the diagnosis, the more specialist investigations take place and therefore, the cost to the NHS increases manifold.,

He, also, spoke about MRI scans and how they could show the parts of the brain that were affected by pain and how different levels of pain were recorded using stimuli during research.

He spoke about the use of Milnacipran as he felt this often helped people with Fibromyalgia as some sufferers are unable to tolerate Amitriptyline. Dr Choy also spoke about sleep studies that had been done and said that it was very clear that once the patient was into a cycle of either no sleep or interrupted sleep the pain cycle then became more severe. Part of the answer, he felt, could be in ensuring that the patients were able to have a deep sleep.

Following on from this, he talked about a drug called Sodium Oxybate that the patient takes when they are in bed, then sets an alarm for four hours later, wakes up, takes another dose and goes off to sleep again. Although this appears disruptive to sleep, he said, it actually isn't, because the depth of sleep attained during the four hour periods is more than sufficient to assist in breaking the cycle of pain. Unfortunately, because there are a number of issues with this drug, the Food & Drug Administration in America will not license its use, and it is not licensed in the UK.

Dr Choy spoke about his work as Chairman of the European League Against Rheumatism (EULAR) that was charged with developing guidelines for the management of Fibromyalgia. The group included rheumatologists, neurologists, physiotherapists, a patient representative and pain specialists involved in the management of Fibromyalgia. This group reviewed the evidence that treatment helps people with Fibromyalgia and came up with a 9-point recommendation that it is hoped will be implemented throughout Europe. There is a lot of evidence from high quality research that effective treatments are available for Fibromyalgia.

Dr Choy was asked about the new diagnostic criteria being developed in America. He said that it should not be used on its own. There is room for both but he didn't understand why practitioners couldn't just use the tenderpoint test as it was the easier and most effective to use. He emphasised that, at this time, the new criteria wasn't being adopted in the UK.

My own talk followed on from Dr Choy's and I had half an hour to explain how having Fibromyalgia had an effect on daily living. This talk was given again at our November meeting and will be reproduced in our February newsletter.

We have also been promised a DVD covering my talk and Dr Choy's presentation, and we hope to make copies of this to sell in due course.

Margaret Robson
Co-ordinator, Fibromyalgia Support Group (Medway)
Charity No: 1105247
www.fibrosupportmedway.uk.com

Disability Living Allowance – Reform

In the June budget, the Coalition government announced its intention to review Disability Living Allowance (DLA) by introducing an "objective medical assessment" and revised eligibility criteria. Although not made explicit, it seems clear that these revised criteria would make DLA more difficult to qualify for - since the budget costings proposed saving over £1 billion as a result of DLA reform. In December 2010 the government published its proposals for reforming DLA and is currently consulting on them. The consultation applies to Scotland, Wales and England with a deadline of 14th February. You can view the document at <http://www.dwp.gov.uk/docs/dla-reform-consultation.pdf>.

What does the consultation propose?

DLA is to be replaced by a new benefit called the personal independence payment (PIP). The new PIP will look very similar DLA in many respects:

- It will have 2 separate components – a mobility component based on a person's ability to get around and the daily living component based on their ability to carry out key activities necessary to be able to participate in daily life.
- It will not be means tested and will not depend on national insurance contributions
- It will be paid to people whether in or out of work
- There will be special rules for terminally ill
- Payment will be affected by time spent in hospital or residential care - after 28 days (84 days for children under 16 in hospital)
- It will be an extra costs benefit for disabled people to spend in the way they choose to help meet their needs
- The Motability scheme will still be supported by the PIP

How does the PIP differ from DLA?

Each component will be paid at one of two rates - however DLA care component currently has 3 rates. This raises the possibility that those who qualify for the low rate care component may not qualify for an award of the daily living component of the PIP.

Claimants (other than those with a terminal illness) will need to establish that they have met the qualifying criteria for 6 months before PIP can be paid. This is a doubling of the 3 month qualifying period currently used in DLA. This not only delays payment of DLA but also delays a parent's ability to claim Carer's Allowance, get additional disability elements paid with tax credits etc.

Under DLA claimants with certain specified conditions e.g. those who are deaf-blind automatically qualify for certain DLA components at specific rates. Under PIP no groups of claimants (other than the terminally ill) will have an automatic payment to DLA. This will reverse the recently won concession whereby those with a severe visual impairment will automatically qualify for the high rate mobility component from April 2011.

How will entitlement to the PIP be assessed?

Entitlement to the PIP will be based on an 'objective assessment' focusing on a claimant's ability to carry out a range of 'key activities necessary to everyday life'. The assessment process will include information from the claimant and health care professionals who look after them, and, in most cases, there will be a face-to-face meeting with an independent healthcare professional 'allowing an in-depth analysis of an individual's circumstances'. The assessment should consider activities related to a person's ability to get around, taking into account the successful use of mobility aids, interact with others, manage personal care and treatment needs and access food and drink.

The assessment will take into account the successful use of aids and adaptations as part of the Personal Independence Payment assessment to reflect the advances made in this area.

All awards will be periodically reviewed i.e. no more unlimited awards. There will be penalties if a claimant knowingly fails to report a change that would have resulted in a reduction in benefit. The

frequency and format of reviews will vary depending on person's individual needs, the likelihood that their condition may change and, potentially, the successful use of aids and adaptations.

The paper points out that 'people may undergo many different assessments' for disability support, such as the medical assessment used for ESA, and that it wants to explore 'whether it is possible to share information from other assessments and eliminate areas of overlap'. This raises the possibility that at least some of the PIP assessments may be modelled on current ESA tests. This would be worrying given that these ESA tests are more stringent and harder to meet than DLA tests.

The detail of the application form and assessment process is not finalised with consultation ongoing.

When will DLA be replaced by the PIP?

DLA will be replaced by PIP for new claims in April 2013. The government also proposes that during 2013/14 it will start a programme of re-assessing pre-existing DLA claimants under the new PIP rules.

Will the introduction of the PIP apply to disabled children?

The introduction of the PIP will definitely apply to people of working age; however the government are also 'considering' whether to apply the new criteria and assessments to children. A number of issues specific to children are raised in the document including:

- The differences between the needs of disabled children and adults
- Children's needs may change gradually as they approach adulthood
- Should eligibility requirements differ depending on the age of the child
- Could information from other assessments be used e.g. SEN
- Should support needs be taken into account for PIP if they are being met from public funds by another institution e.g. school.

Other issues of concern

The proposal that assessment of PIP will depend partly on the successful use of aids and adaptations may create a disincentive for families to pursue aids and adaptations as their use could impact on benefit entitlement. The current DLA rules take into account the use of certain aids and adaptations e.g. prosthetic limbs but not others e.g. wheelchairs – the government suggest that under PIP the assessment may consider "an individual's ability to get about in a wheelchair". In the government's view the current DLA test for the high rate mobility component is subjective - focusing too narrowly on an individual's ability to walk rather than their ability to get around independently.

The PIP will "prioritise support on those individuals who face the greatest day to day challenges and who are therefore likely to experience higher costs". This suggests that those who currently qualify for the lower rates of DLA may not qualify for help under PIP.

The consultation paper says that in designing the PIP the government will 'take into account' the way that DLA currently passports the claimant to other benefits in its reforms e.g. extra tax credits payments or premiums as part of means tested benefits. It is not made clear how they will be 'taken into account' but we need to do all we can to ensure that these forms of additional help with disability costs are not diluted as part of DLA reform.

The government will also consider how PIP interacts with other forms of support, for example adult social care, and explore whether it is possible to share information at the assessment stage and 'eliminate areas of overlap'. We need to guard against any suggestion that PIP be merged into wider LA social care funding i.e. that the PIP is not assumed to be available to spend on social care since claimants may currently choose to use the DLA to meet a whole range of other disability related costs.

Try These



Tuna pasta bake

Ingredients

- 200g (7oz) broccoli, cut in small florets
- 225g (8oz) rigatoni or other pasta shapes
- 2 x 300g (10½ oz) pot four-cheese pasta sauce
- 2 x 200g (7oz) cans tuna steak, drained
- 40g (1oz) fresh wholemeal breadcrumbs
- 50g (2oz) mature Cheddar cheese, grated
- Tomato salad, to serve



Method

- Preheat the oven to 190°C (374°F, gas mark 5). Boil the broccoli for 5 mins. Drain, rinse with cold water to refresh and drain again. Boil the pasta for 8 mins. Drain.
- Put the sauce in a pan. Break up the tuna and add to the sauce with the broccoli and pasta. Heat through.
- Put in an ovenproof dish. Sprinkle the breadcrumbs and the cheese on top.
- Bake for 15 mins until the topping is crisp and golden. Serve the tuna pasta bake with a fresh tomato salad.



www.asda-recipes.co.uk

Quick lemon tart

Ingredients

- 300g (10½ oz) lemon curd
- 150ml (¼ pint) double cream, whipped
- 2 lemons, zest only
- 20cm (8in) ready-made sweet pastry case






Method

1. Mix together the lemon curd with the cream and the zest of 1 lemon.
2. Spoon into the pastry case and refrigerate until ready to serve.
3. Sprinkle with the zest of the second lemon just before serving

Puzzle page

January Answer

	= 2		= 4
	= 3		= 1

6	9	7	2	5	4	1	8	3
2	3	5	9	1	8	7	4	6
4	1	8	3	6	7	9	2	5
7	8	2	6	9	5	4	3	1
9	4	6	8	3	1	2	5	7
3	5	1	4	7	2	6	9	8
1	7	3	5	2	9	8	6	4
5	2	4	1	8	6	3	7	9
8	6	9	7	4	3	5	1	2

1		2		3		4
	■		■		■	
5						
	■		■		■	
6						
	■		■		■	
7						

Across

- Perspicacious
- Inactivity
- Idiom
- Voter

Down

- Scam
- Foreword
- Adjure
- Quisling

1		2		3		4
	■		■		■	
5						
	■		■		■	
6						
	■		■		■	
7						

Across

- Evolve
- Windstorm
- One more
- Proposition

Down

- Diminish
- Wordy
- Tanned animal skin
- Computer instructions

3		9		7	2		6
	5		6				
	6		3				9
8		5	1	9		6	4
		7		2		5	9
		6	4			7	8
	9	1	7	4			
						2	
		8		6	3		1

Did you know?

Valentine's Day originates from the ancient Roman fertility festival of Lupercalia, which was celebrated on 15 February in honor of the gods Lupercus and Faunus, as well as the legendary founders of Rome, Romulus and Remus. During the festival, young men would draw the names of women from a box, and each couple would be paired until next year's celebration. Often they would fall in love and marry.

At around 270AD Rome was facing battles and civil uprising. The men were not keen to join the army. Emperor Claudius II believed that the men did not want to leave their loved ones and summarily canceled all marriages and engagements. Two priests, **Valentine** and Marius, disobeyed the decree and secretly performed marriage ceremonies. Valentine was caught on 14 February and dragged to jail. Later in the day he was clubbed to death and beheaded. It is said that, before his execution, Valentine himself had fallen in love with the jailer's daughter. He signed his final note to her, "*From your Valentine.*"



Valentine's Day

In 391AD, Emperor Theodosius I declared Christianity as the official religion of the Rome. The fertility festival was celebrated until 496AD when Pope Gelasius replaced it with a similar celebration. For patron saint of the celebration, he chose the "lovers" saint, St Valentine. He also moved the date of the celebration from the 15 February to the date of St Valentine's death, 14 February. Through the centuries, Valentines Day became to be remembered more as the festival of love instead of a religious day. In 1969 it was dropped from the Roman Catholic calendar as a designated feast day.

Cupid and Psyche

Cupid has always played a role in the celebrations of love. Those whose hearts are pierced by his arrows fall deeply in love. In Greek mythology he was known as Eros, the young son of Aphrodite, the goddess of love and beauty. To the Romans, he was Cupid, son of Venus. But where there's love, there often is jealousy. Venus was jealous of the beauty of Psyche, a mere mortal, and ordered Cupid to punish her (for being so beautiful). Instead, Cupid fell deeply in love and took her as his wife.

As a mortal Psyche was forbidden to look at him. Eventually her sisters convinced her to look at the handsome Cupid. As punishment, Venus demanded that she perform three difficult tasks, the last of which caused Psyche's death. Cupid found her lifeless on the ground and removed the eternal sleep from her body. The gods, moved by their love, then granted Psyche immortality.

The symbol of Cupid became part of Valentines Day only recently. Cupid is still around shooting his arrows. Psyche represents the struggles of the human soul.

It is said that Cupid's arrows are tipped with diamonds, lending it magic without equal.



Happy Valentine's!

Esther Howland, the woman who produced the first commercial American valentines in the 1840s, sold a then mind-boggling \$5,000 in cards her first year of business. Today, over 1 billion valentine cards are sent in the US – second in number only to Christmas cards.



The rose is the symbol of love, but the flower symbol for February actually is the violet.
A rose is the symbol for June: meaning of flowers