



# Derby Fibromyalgia Support Group

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**Welcome Back  
Hope You Enjoyed Any Holiday's You  
May Have Had**

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## **THE TRUTH ABOUT BENEFITS BOUNTY HUNTERS**

**The way forward for Fibromyalgia -  
for me at least!!**

### **Oats**

**How oats can help you in your  
daily diet!**

### **Regular items**

**Recipes, Puzzle and Did you know**

## Message from the Chairperson

Hi Fibro friends, Hope you've all had a good summer! Back to school for some of us and catch up with normal daily things, though we do need to remember to pace ourselves, especially now it's the slow run up to 'Christmas'. (sorry, I know it's a taboo word so soon!).

Its important to look after yourselves with the run up to the winter months, eat properly, to try and avoid the symptoms of chronic fatigue, though I know it can be difficult. The motivation and self management.

**Saturday 24<sup>th</sup> September, 2-4pm**, we have a chartered physiotherapist and nutritionist coming to the group for an informal chat and advice, and answer any questions.

I hope to have an informal chat and explain to Fibromyalgia sufferers how I have now had 10 years of wellness using my 'Combination Approach' after over 20 years of suffering with Fibromyalgia previously. I have now treated over 500 patients from all over the UK and beyond, many with impressive and lasting success.

From  
**Norah Wickerson.**

I hope you can all make it so we can chat about forthcoming meetings for the next year.  
We always welcome news recipes, stories, ideas for the newsletter, just let myself or Doug know.

*Jackie x*

## Meeting Dates 2010

**THERE ARE NO MEETINGS IN AUGUST**

### Thursday

14<sup>th</sup> October  
11<sup>th</sup> November  
9<sup>th</sup> December

10.15am – 12.30pm

### Saturday

25<sup>th</sup> September  
23<sup>rd</sup> October  
27<sup>th</sup> November  
18<sup>th</sup> December

2.00pm – 4.00pm

Admission  
£2.50

Free Car Park at Back of Church  
Off Melbourne Street

### Contact Details

Telephone: 0845 345 2319  
Email: [derby.fibro@btinternet.com](mailto:derby.fibro@btinternet.com)  
Address: 45 Magellan Way  
Derby  
DE24 1AD

## Forthcoming Church Events

SPEAKERS			Regular Events	
<b>September</b>			<b>Open Circle</b> Every 2 <sup>nd</sup> and 4 <sup>th</sup> Thursday Of Each Month  <b>7.30pm</b>  No Admission After 7.35pm	<b>Healing Services</b>  Thursdays  <b>2.00pm – 4.00pm</b>
DATE	TIME	SPEAKER		
Sun 12 <sup>th</sup>	6.15pm	Graham Lymer		
Mon 13 <sup>th</sup>	2.30pm	Nora Watson		
Sun 19 <sup>th</sup>	6.15pm	Cliff Wright		
Mon 20 <sup>th</sup>	2.30pm	Lucy Watts		
Sun 26 <sup>th</sup>	6.15pm	Shirley Dawsey		
Mon 27 <sup>th</sup>	2.30pm	Julie Brough		
<b>October</b>				
Sun 3 <sup>rd</sup>	6.15pm	Richard Press		
Mon 4 <sup>th</sup>	2.30pm	Lawrence Chapman		
Sun 10 <sup>th</sup>	6.15pm	Tina Staples		
Mon 11 <sup>th</sup>	2.30pm	Ken Sharpe		

### SPECIAL EVENTS

# SUPPER WITH SPIRIT

Saturday 18<sup>th</sup> September

£10, Book in advance



For More Information

18 Charnwood Street, Derby. DE1 2GU.

Tel: **01332 386 204.**

[www.snu-emdc.org.uk/charnwood](http://www.snu-emdc.org.uk/charnwood)

## THE TRUTH ABOUT BENEFITS BOUNTY HUNTERS

MPs returned to the commons today and, as a result, many of us will be bracing ourselves for the next round of misleading and vicious attacks on disabled claimants.

But, in reality, the hate campaign never really let up over the summer recess. The most distressing example was undoubtedly the threat to unleash private sector bounty hunters on incapacity benefit claimants.

So, to mark the return of the disablist parliament, Benefits and Work looks at what actually happens when government agencies work with the private sector to uncover benefits fraud.

We reveal:

- whether incapacity benefit claimants really will be investigated if they spend too much money on flat screen TVs, gardening or DIY equipment;
- whether disability living allowance claimants will be on the bounty hunters 'most-wanted' list;
- What the only type of fraud likely to be detected by bounty hunters actually is.

## THE RIGHT TO RECORD YOUR MEDICAL

Professor Malcolm Harrington, meanwhile, is carrying out the independent review which is supposed to find out the truth about whether the work capability assessment for employment and support allowance is working. In our last newsletter we asked you to contact the professor with your views and experiences.

We now understand that the professor would also like to know what changes you would make to improve the assessment process. Very high on our list would be the right to record your medical without the nonsense of having to provide a sound engineer and professional recording equipment.

So, even if you've already made a submission to the review, if you have practical suggestions for improvements, such as being able to record your medical, please email them to

[wca.evidence@dwp.gsi.gov.uk](mailto:wca.evidence@dwp.gsi.gov.uk)

not later than 10 September.

## WHERE'S THE BENEFIT?

For further reading about disability benefits issues in general, we can recommend the [Where's the Benefit blog](#), which was set up in August for the purpose of 'Campaigning against the government's distressing war on disabled benefit claimants'. There's lots of well-informed comment and news, some of it from people you will be familiar with if you are a BBC Ouch regular.

## CUTS CAMPAIGN

Meanwhile, CarerWatch are beginning a campaign to ask the Coalition to protect disability benefits before the October cuts. In preparation, they are asking disabled people and their carers to post short accounts of their own fears about benefit cuts and how it will affect them on the [CarerWatch site](#).

## MORTGAGE PAYMENT MISERY

One of the cuts planned for October will result in almost half of all claimants who receive mortgage interest payments facing a shortfall. The majority of those who will fall into arrears will be pensioners and disabled claimants. The coalition blithely claims that 'based on conversations with the Council of Mortgage lenders we would expect lenders to demonstrate forbearance in the vast majority of these cases' you can read more details in [the DWP equality impact assessment](#).

## **FORUMS RETURN**

The forums were closed for a few weeks in August due to a shortage of moderators. We reopened on 1 September with two new mods – welcome Survivor and DepressedDerek – and below are a few of the good news posts we've received since reopening.

[DLA Tribunal Result](#)

[ESA Success- thankyou!](#)

[Don't give up!](#)

[Relief - ESA into Work Related Group](#)

[ESA Appeal Success - Harrumble!](#)

[ESA Success YIPPEEEEE](#)

[IB tribunal](#)

MPs are only back for two weeks before going off on another break for their annual conference jamborees. We have no doubt that all the major parties will be using the occasion to try to outdo each other in demonstrating how tough they can be on sick and disabled claimants. Meanwhile, we'll carry on doing our best to reveal the truth behind the disablist propaganda.

This newsletter can also be read online at:

[www.benefitsandwork.co.uk/news/latest-news/1240-6-september-newsletter](http://www.benefitsandwork.co.uk/news/latest-news/1240-6-september-newsletter)

Good luck,

Steve Donnison

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## **The way forward for Fibromyalgia - for me at least!!**

I have been involved with Fibromyalgia for over 20 years since it became evident my wife Mary suffers with this painful condition, during that time I have seen her health deteriorate and me take on a more caring and supportive role, for which we were initially both ill equipped.

Mary and/or I, having been a member of several support groups both in Norfolk and the Midlands started a support web site [www.fibromyalgia-support.net](http://www.fibromyalgia-support.net) in 2006, and a year later Mary and I and another lady started the Rugby Support group, which has now grown to over 70 members.

I am the first to admit that, like many men who are husbands or partners of sufferers I did not fully appreciate the problems for Mary and others, the last few years have led me to become more interested in, and "hooked on" the FM cause at a wider national and international level.

About a month ago the development of me offering free web hosting via [www.fibromyalgia-support.com](http://www.fibromyalgia-support.com) seemed to open some more doors and opportunities for me in the world of Fibromyalgia and the last few weeks have been an interesting, challenging and frustrating time.

I have been asked by several FM organisations to be involved more with them, clearly it makes sense to have fewer, stronger organisations than more who are just duplicating or replicating established facts, this only serves to confuse the researchers (sufferers and their carers). How many times have we heard the phrase "I've been on the web and know it all"? OR "I have been on the web, now tell me more about it!!!"

Having seen the success of our own Rugby support group and the benefit to many members I am a great supporter of local support groups. BUT I also well know the trials and tribulations of starting and running one. Many have failed, others have grown to vast memberships of hundreds. We need MORE support groups, even if only a few people get together and remain a viable unit of friends they can achieve much benefit together than they ever can ALONE.

I found the discussions about me helping or joining other organisations somewhat tedious as communication was drawn out, it seems I was expected as "potential volunteer" to make all the running. I have provided a lot of output and received little practical response in return. I cannot and will not name people or organisations due to reasons of confidentiality. I genuinely responded to approaches, and welcomed the opportunity to do so, it set my "little grey cells" working at full speed.

In the end, I have decided to "do my own thing", its not easy, some may see me trying to "reinvent the wheel", and of course I, at present am a lone voice, however I take the following key views over which I have strong opinions (many shared by others I know from emails I have received);

1. The local, regional and national organisations are almost totally run by volunteers, and in the main draw from the sufferer base with a few associated partners, relatives and friends. The result is "burn out" for some, or frustration with attendance at meetings, getting the group known, running help and information lines etc. There is so much to do. Enlarging the volunteer base using OUTSIDE people, or finding funds for some permanent employed people can improve efficiency and reliability of the support network if done properly.
2. There is a big shortage of money in the system, many smaller groups have found grants but nationally big funding has proved in the main elusive. Many sufferers have little money and are often on benefits, paying even a few pounds to many seems difficult or impossible. There seems a big demand to provide a total free service with little or no income to support it. Our own support group can only get 25% of its membership to pay £5 a year - are we not doing enough to justify it, or are we failing in other ways?. Finding new sources of income is vital.
3. Some FM organisations have turned themselves into Charities, I am not convinced this in the short term is necessary or wise, especially as the conditions of the Charity Commission can be complex and time consuming. There are other options inc charitable trusts linked to other organisations. I am fortunate in having a neighbour who is a former accountant for the Charity Commission who can lead me along options and alternatives. The final option will depend on the support for my objectives and an acceptance of me as a leader.

4. Many of the key workers are doing excellent work, often to the point of exhaustion, or frustration. Each time we lose one of these their entire network collapses, unless they have a reliable understudy, relief team or replacement. With key people exiting and few replacements on offer the pressure increases with those remaining forcing further "burn outs". There is scope to double, or even treble the current number of support groups, provided there is adequate training, support, financing and vitally a spread of the work load.

So, what am I doing?

I am in the process of setting up a new web PORTAL <http://www.fibromyalgia-uk.org> and also soon a member's organisation the precise form is to be decided . This will then allow us to register with HMRC for tax purposes which will give us some of the advantages of a registered charity but easier to run and control.

The initial aim of the new organisation is to include such services as;

A) Promote awareness of Fibromyalgia to the UK population through its web site and extensive local, regional and national PR activity - it will collect and consolidate press and media contacts and establish a national media database. It will enlarge radio and TV as mediums for developing great awareness.

B) Stimulate and encourage the development of more local support groups and work to ensure the continued survival of those existing ones who have problems causing doubt as to their viability.

C) Set up a newsletter system - free to register, which is designed to recruit as many sufferers, carers and partners as possible. Details can be found on the web site inc code for support groups and web sites to assist with recruitment of members into the newsletter.

D) Work with other national FM organisations to collect, assimilate and distribute knowledge and information.

E) I will focus on the UK, and have neither the time, resources nor inclination to be involved in US or European organisations other than knowledge that comes my way in the normal day to day activities.

F) An online SUPPORT help desk for members to post questions which can be answered by a national list of volunteers through a secure online ticket system.

G) An online VOLUNTEER help desk where support groups can post requests for external volunteers and member volunteers can OFFER their services.

H) Critically much of the services will be provided only to MEMBERS in return for a modest annual subscription of £5. This may appear a harsh move, BUT this is the real world - if you want a "better" service it costs - we recently had to toss out a member from our own support group for their unreasonable demands and attitude, in the final death throws of discussions she was asked "what have YOU done for the group?, she replied "nothing and why should I." For me being a member of a support group is about helping others as much as yourself.

I welcome your responses, comments, criticisms, and anything you care to throw at me. A few volunteers will not go amiss, including anyone who is willing to take on any key roles or incorporate existing facilities into our portal site.

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<http://www.fibromyalgia-uk.org>

# Oats

## How oats can help you in your daily diet!

### Food for thought!

We know porridge is good for us, but whether you love them or loathe them, porridge oats are probably the **original "Superfood"**.

Years and years ago, before we knew that oats were low in fat, helped boost our energy, helped lower our cholesterol or that they were a great source of vitamin E B1 and B2, our ancestors were tucking into oatmeal as part of their staple diet.

Did you know nowadays, we consume a staggering 50,000 tons a year, sales of oat cereals have soared by 50 per cent.

If you are not tempted by a steaming bowl of basic porridge, try adding small amounts of a selection of the following, **figs, dates, organic apricots, ground almonds, nuts and flaxseeds**, they all give the porridge a tasty lift!

Oatibix have now come on the market these cereals are very much like Weetabix, but Oatibix contain a high amount of oat content, even lovely before bed-time, and keep those blood sugars more even throughout the night.

I would like to remind you that oats are very cheap to purchase, which does help the pocket too!

So.... when feeling hungry don't just dash for the biscuit tin, think about oats, try even **oatcakes** they are delicious too!

# Try These



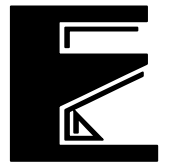
## Easy Tuna Fish Cake

### Ingredients

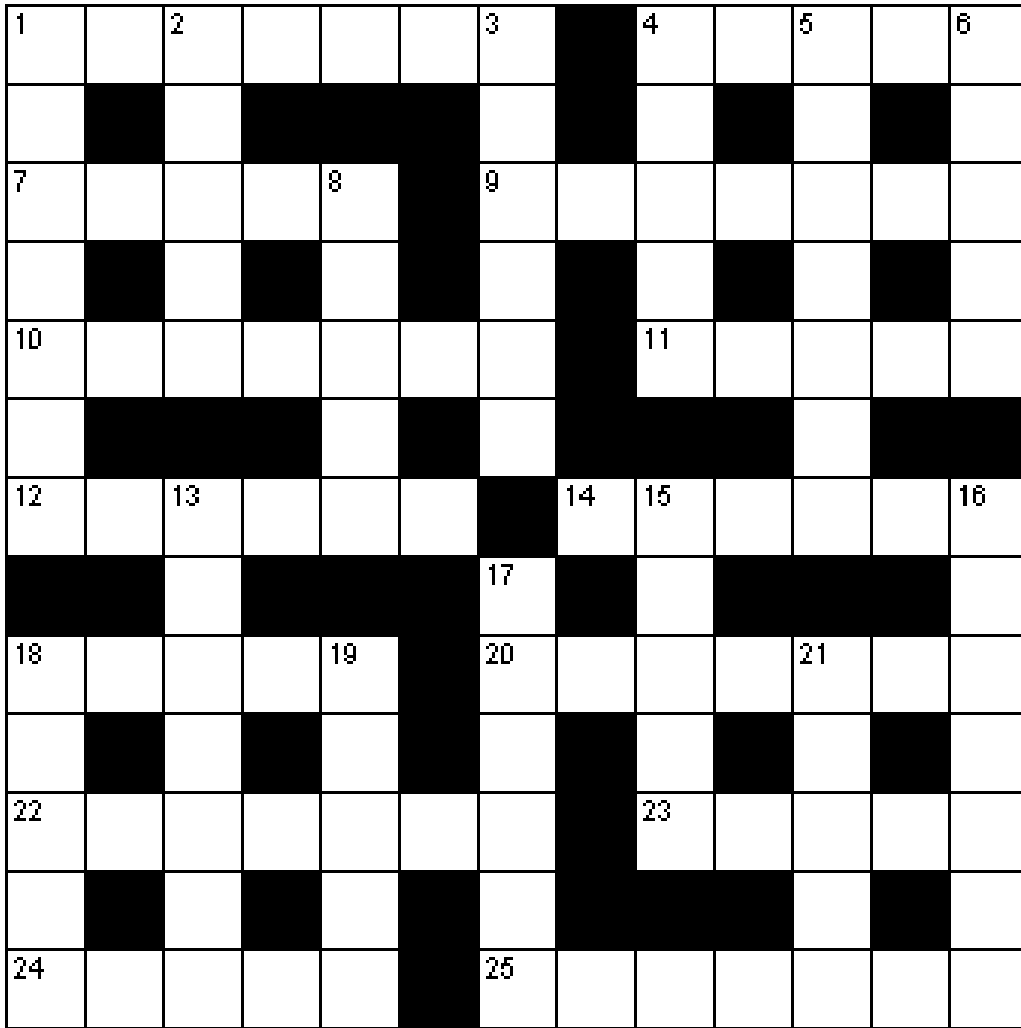
- ◆ 600g Sweet potatoes, peeled and chopped
- ◆ 300g Tuna in spring water, flaked
- ◆ 2 Spring onions
- ◆ 1 Egg
- ◆ Freshly ground black pepper
- ◆ 100g Polenta
- ◆ 3 Tbsp olive oil
- ◆ 1 Lemon, to serve

### Method

1. Cook the sweet potatoes in a pan of simmering water for 20 minutes, drain well and mash.
2. Add the tuna, spring onions and egg, season with the freshly ground black pepper and mix well. Divide the mixture into 8 equal pieces and shape into patties.
3. Put the Polenta on a plate and dip the fish cakes in it until coated on both sides.
4. Heat the oil and fry the fish cakes in each side until golden brown. Serve with lemon wedges and a tomato salad.



# Puzzle page



## Across

1. Floorshow (7)
4. Spooky (5)
7. Detection device (5)
9. Vertical (7)
10. Inactivity (7)
11. Measuring implement (5)
12. Dictator (6)
14. Ecclesiastic (6)
18. Copious (5)
20. Drawn (7)
22. Pouch worn with a kilt (7)
23. Diadem (5)
24. Admittance (5)
25. Spiny anteater (7)

## Down

1. Transported (7)
2. Emblem (5)
3. Tropical bird (6)
4. Mistake (5)
5. Dependable follower (7)
6. Go in (5)
8. Magnitude relation (5)
13. Reinforcement (7)
15. Reasoned judgment (5)
16. Musical passage (7)
17. Opportunity (6)
18. Part of a church (5)
19. Ahead of time (5)
21. Obviate (5)

## July Answer

C	O	M	M	A		S		B	L	U	R	B
L		A		B	A	L	T	I		P		A
A	G	G	R	O		E		B	L	E	A	K
N		M		D	W	E	L	L		N		E
G	R	A	P	E		K		E	I	D	E	R
	A		H						D		M	
B	I	J	O	U				P	Y	L	O	N
	T		T						L		T	
B	A	Y	O	U		S		E	L	D	E	R
O		I		S	E	W	E	R		R		U
O	M	E	G	A		E		O	D	O	U	R
T		L		G	E	L	I	D		O		A
H	E	D	G	E		L		E	X	P	E	L

## Did you know?

- Lack of water is the biggest cause of daytime fatigue. Aim to drink 1.5-2 litres of pure water each day.
- Chocolate contains health promoting flavonoids - BUT these are contained in the cocoa bean. This means that the healthiest chocolate is the 60-70+% variety such as Lindt.
- One-two tablespoons of whole golden linseeds on your breakfast each day is a great way to crack constipation.
- Drinking lemon and ginger tea each day can help reduce arthritic problems.
- Walnuts and almonds have been shown to reduce cholesterol levels (although many think that because they contain saturated fat they are likely to raise levels).

Focus on ....

### Apples

A truly health snack with many health benefits. Eating 2-3 a day can help dramatically reduce cholesterol levels. The magic ingredient is believed to be pectin (the same stuff we put in jam) that binds to the surplus cholesterol carrying it safely out of the body. (The skin is particularly high in pectin fibre, so avoid peeling your apple.)

Apples are also great for helping to stabilise mood and energy by managing to keep blood sugar levels steady. This is good news for dieters too because steady blood sugar levels dampen appetite. Include at least apple a day.

Immune boosting - those who eat more apples are less likely to suffer from colds and upper respiratory tract problems according to research.

### Vitamin & Mineral File

- We all know that calcium is important for our bones. But did you know that calcium depends on adequate Vitamin D and also the mineral magnesium? Absorption of calcium from our foods is dependent on Vitamin D, and calcium depends on magnesium to 'put it in' our bones. There are few good food sources of Vitamin D, the best being supplemented margarines and spreads. Best source anyway is the action of sunlight on the skin - 20 minutes daily throughout the summer months. Good sources of magnesium include whole grains, legumes, nuts and dark green leafy veg. 'Hard ' water also contains high concentrations of magnesium, as can mineral water.
- Pantothenic acid, Vitamin B5, is derived from Greek 'panthos' meaning 'everywhere' and is widely distributed in food stuffs. It is a key component of Coenzyme A, which is central to all energy production within the body. Adequate pantothenic acid is also important for healthy adrenals, glands that sit above our kidneys and help us resist the effects of stress. Best sources are animal foods (meat, poultry, fish, eggs and dairy), whole grains and legumes. Avoid foods containing refined grains such as white bread, as up to 75% of the vitamin is lost in the refining process (similar loss can occur during freezing and canning).
- Selenium is a great antioxidant nutrient helping us fight against degenerative disease. The recommended daily adult intake to achieve an antioxidant effect is 60-75mcg. Cancer protection, however, requires at least 200mcg. Just be careful with a nutrient like selenium though - toxic effects have been reported at fairly low levels (900mcg), although it is difficult to exceed this level through diet alone. Unless supervised, you should not exceed 400mcg from all sources. The selenium content of foods is dependent on the richness of the soil in which the food was grown. One of the best sources of selenium is Brazil nuts - their selenium content can vary from 10mcg per nut if grown in selenium-deprived soil to over 100mcg if grown in selenium-rich soil, as may be encountered in South America.

