

**ARTHRITIS**

**CHRONIC FATIGUE SYNDROME**

**ENDOMETRIOSIS**

**FIBROMYALGIA**

**IRRITABLE BOWEL SYNDROME**

**M. E.**

**SWINDON & SALISBURY FOGGY'S**

EST. 29<sup>TH</sup> JUNE 2010

DEDICATED TO RAISING AWARENESS, PROVIDING SUPPORT AND  
PROMOTING POSITIVITY



**WILTSHIRE "INVISIBLE ILLNESS" SUPPORT**

**NEWSLETTER 19**

14<sup>TH</sup> JUNE 2012

[WWW.WILTSHIRE-SUPPORT.CO.UK](http://WWW.WILTSHIRE-SUPPORT.CO.UK)

GROUP FOUNDER  
[DEB.COOKE@SWINDON-SUPPORT.CO.UK](mailto:DEB.COOKE@SWINDON-SUPPORT.CO.UK)

**0844 887 2377 BARBARA**

**0844 887 2485 ANN**

CORRESPONDENCE ADDRESS ONLY:  
112 ELBOROUGH ROAD  
SWINDON SN2 2LP

**PERIPHERAL NEUROPATHY**

**RHEUMATIC CONDITIONS**

**POLYMYALGIA RHEUMATICA & GIANT CELL ARTERITIS**

**SEASONAL AFFECTIVE DISORDER**

**TRIGEMINAL NEURALGIA**

Hi Foggy's

Sorry for a lack of newsletters of late. I've been moving for what seems like forever. I'm now in my new place, and starting to get myself organised.



Meetings have had near non-existence attendance lately. It has been suggested that this is due to:

- people are worried that they'll get coerced into helping Foggy's fundraise: No-one is asked to do anything they don't want to, and we don't expect you to !! If you do volunteer however, are you aware that it probably won't affect your benefits !!
- of course with me being pre-occupied with moving, probably has affected attendance.
- could any of you pick up someone on your way? a couple of people don't drive and new people feel more at ease if they have a friendly face to bring them.



Both our Helplines are now working. You can talk to Barbara on 0844 887 2377 and Ann on 0844 887 2485.



The website is constantly updated, don't forget to look in on it. If you're a paid member, please ask for login details for the members' area !!



**Look on UK Fibromyalgia Forum as they have interesting advice about DWP & a Solicitor you can ask questions of !!**



August meetings in Salisbury and Swindon are CANCELLED due to holidays. A lot of people are off on holidays and have children at home, so thought it wise Foggy's had a summer holiday.



Foggy's meetings are:

**Swindon afternoon:**

every first Wednesday of the month 1pm – 3pm  
Liden Community Centre, Barrington Close,  
Swindon SN3 6HF

**Salisbury evening:**

every second Friday of the month 7 – 9pm  
Bishopdown Farm, The Pavilion, Ash Crescent,  
SALISBURY SP1 3GY

**Swindon evening:**

every third Monday of the month 7 – 9pm  
Liden Community Centre, Barrington Close,  
Swindon SN3 6HF

Most meetings are on a drop-in basis, you don't need to stay the whole time and can come in late or leave early if you need to.



There are a couple more groups in Wiltshire, that aren't Foggy group's, however we aren't in competition and I'm happy to advertise them to ensure Wiltshire as a whole is covered for support:

Calne & District Helpline: Lesley 07905 123574  
meet every second Wednesday of the month

Warminster Helpline: Francis 0844 887 2346

I believe a Trowbridge group is currently being setup too. Details to follow.



Before Foggy's there was another group in Salisbury, the South Wiltshire Fibromyalgia Society. Sadly, the founder, Sue Williams, died and the group was dissolved. Before her death Sue and Pat Hurst wrote a book "Getting to Grips with Fibromyalgia, a D. I. Y. manual".

Pat used the residual funds of the group to produce a Fibromyalgia Information Pack and distributed 54 pack's including the book around Salisbury libraries, GP's and Community Health Neighbourhood team's. People in other towns of Wiltshire can request a copy via their library. There were also a number of books that the group owned and they were also donated to Wiltshire Council Library Service, again available on request, copy of list attached. The 154 page book is an interesting read !!

Having a Foggy head myself, I can't remember if Pat said we could still purchase copies of the books, I shall ask.

We have a few bagpacking dates in July and December, in Swindon. If you can't help, do you know someone who can help? We can do it in hour shifts for those willing to help.

We've had a couple of volunteers come through from the Volunteer Centre, Swindon, which is great !!

Copy of our diary of events attached. Need to do something for Fibromyalgia awareness week, any suggestions ?



I'm sorry that we had to cancel the BBQ. Lydiard, Swindon, have very kindly offered us a voucher to use next year, so we don't lose our money. I'm thinking of holding it 29/06/2013 as that will be our 3<sup>rd</sup> birthday.



Foggy's is dedicated to raising awareness, providing support and promoting positivity. With this in mind, we were pleased to have Lindsey from Fibro Action come to a couple of our meetings and she presented a program that they are rolling out to various groups called "Taking control of your Fibro". This consists of:

- Accurate & Comprehensive diagnosis
- Becoming an Expert Patient
- Accessing effective treatments

A copy of this presentation is attached. Something that's not been added, but we discussed is dealing with your doctor.

Many of us feel intimidated going to the doctor and with this in mind we discussed:

- Take someone with you to the doctor, who will speak up for you if you feel you can't.
- Your doctor is there to work for you !! Discuss with them what you want to achieve. e.g. if you wish to be referred to "Rheumatology" for example, then ask them to do so. If they refuse, ask them to write on your notes that they have refused your request and their reasons for doing so.
- Most Doctors' aren't "specialised" in any field, therefore you want to speak to someone who are more knowledgeable, don't tell them that though.

We at Foggy's advise that if you can't get the help and support you need, then change your doctor. It's very easy, just contact one you want to change to, and they do the rest.

We've tried asking people about sympathetic doctors, and get conflicting reports. Some say they have a great doctor, but someone else doesn't say the same, and this happens so much, seems pointless compiling a list. Use Fibro Action's ideas and the doctor you're registered with may improve anyway.



Reading up on symptoms and conditions from the internet can be good, but you must be honest with yourself, don't change your symptoms to fit conditions'. Also don't panic yourself into believing that you have a more serious condition. Remember a lot of the internet isn't verified !!



A test we should all be asking to be tested for is Vitamin D deficiency, it isn't something we are routinely tested for. All Fibro Foggy's go to your doctor and ask to be tested for it. Please let me know if you're refused (you probably will be, as it's not readily available). I have asked James Brown from Swindon Link about it and hopefully at our meeting with him in September he'll have an answer for us.



Take care and soft hugs

Deb x

ENCLOSED:

- South Wilts. Fibromyalgia Society book list
- Fibro Action "Taking control of your Fibromyalgia"
- Membership form
- Diary 2012 & 2013

**List of books donated by South Wilts. Fibromyalgia Society to Wiltshire Council Library Service**

<b>Title</b>	<b>Author</b>	<b>Number</b>
Fibromyalgia: Fighting back	Bev Spencer	2
The Fibromyalgia Help Book	Jenny Fransen & I. Jon Russell	1
The Fibromyalgia Hand Book	Harris Mcilwain & Debra Fulghum Bruce	1
Coping Successfully with Pain	Neville Shone	1
Fibromyalgia Supporter	Mark Pelligrino	1
Living with Fibromyalgia	Christine Craggs-Hinton	1
Fibromyalgia & Muscle Pain	Leon Chatow	1
Understanding Fibromyalgia: A guide for family & friends	Betty Dotterer & Paul Davidson	4
Good Living with Fibromyalgia	Bethany Afshar	1
Fibromyalgia - A leading expert's guide to understanding and getting relief from pain that won't go away	Don Goldenberg	1
The Pain Relief Handbook	Dr Chris Wells & Graham Nown	1
Fibromyalgia - an Essential Guide for Patients & their Families	Daniel J Wallace & Janice Brock Wallace	1
Getting to Grips with Fibromyalgia	Sue Williams & Pat Hurst	1
Living with Fibromyalgia	Edited by Thomas Romano M.D., PhD	1
Fibromyalgia Syndrome Getting Healthy	Jeanne L. Melvin MS, OTR, FAOTA	1
Treating Fibromyalgia	Bev Ediger	1
Coping with Fibromyalgia	Bev Ediger	2
Living with Fibromyalgia & Chronic Pain	Gwyneth A. Graham Camilla Lawson, RPN	2
The Art of Swimming a new direction using the Alexander Technique	Steven Shaw & Armand D'Angour	1
The Complete Illustrated Guide to Alexander Technique	Glynn Macdonald	1

## Taking Control of Your Fibro

### A presentation for people living with Fibro

The "keys" to managing Fibro are:

1. Accurate & Comprehensive diagnosis
2. Becoming an Expert Patient
3. Accessing effective treatments

## Accurate & Comprehensive Diagnosis

### Is it Fibro?

Fibro is ...	Fibro isn't ...
<ul style="list-style-type: none"> <li>• Over-stimulation of the Autonomic Nervous System.</li> <li>• Changes to the brain, spine &amp; neuroendocrine systems.</li> <li>• Symptoms of widespread pain, lack of restorative sleep, hypersensitivity, autonomic symptoms &amp; neuro/cognitive symptoms.</li> </ul>	<ul style="list-style-type: none"> <li>• Inflammatory.</li> <li>• Localised.</li> <li>• Associated with positive blood test results.</li> </ul>

### What Else Could It Be?

<ul style="list-style-type: none"> <li>• Autoimmune &amp; inflammatory conditions</li> <li>• Neurological conditions</li> <li>• Thyroid conditions</li> <li>• Spinal damage</li> </ul>	<ul style="list-style-type: none"> <li>• Vitamin or mineral deficiency</li> <li>• Chronic infections</li> <li>• Primary sleep disorder</li> <li>• Myofascial Pain Syndrome</li> </ul>
--	---

### Exactly what is causing all your symptoms?

Identify **everything** so treatments can be targeted.

### Becoming an Expert Patient

*Expert patients are patients who are expert in their own condition and how it affects them.*

How do you become an expert patient?

- Take responsibility for your health
- Educate yourself
- listen to your body
- Take charge

### Accessing effective treatments

- Medications
- Non-medication NHS therapies
- Non-medication private therapies
- Self-help

The optimum management of Fibro usually requires a multidisciplinary approach using all of these.

## Medications

- Target treatments to make them more effective.
- Deal with perpetuating factors where possible, e.g. PC3.
- Be realistic.
- Put the work in yourself.
- Educate your doctors or go elsewhere

## Non-medication NHS therapies

Get your money's worth. Go for evidence based therapies that have a good prospect of offering long-term help. E.g. Physiotherapy, Hydrotherapy, TENS, CBT, Counselling.

## Non-medication private therapies

- Go with someone who is suitably qualified, preferably with plenty of experience in treating people with Fibro.
- It may be best, especially if funds are limited, to go for therapies that have some evidence or a good level of evidence behind them as treatments for Fibro, e.g. physiotherapy, hydrotherapy, Myofascial release. A good osteopath will often offer Myofascial and visceral fascia release and they can also sometimes order private tests when needed, such as gastrointestinal tests to check for infections.
- Some people do find benefit from treatments with a poor level of evidence behind them. Many of these are relaxing, and many people with Fibro do need help with relaxing.

## Self-help

- Exercise and Physiotherapy
- Myofascial release
- Stress management
- Pacing
- Healthy diet
- Diet for food intolerances and IBS
- Supplements

## Resources

Websites	FibroAction	fibroaction.org
	<b>FibroAction.HealthUnlocked community</b> (including official FibroAction blog with articles on <i>Becoming An Expert Patient</i> and <i>Physiotherapy &amp; Fibro</i> )	fibroaction.healthunlocked.com

### NHS Choices

[www.nhs.uk](http://www.nhs.uk)

### Books for self-help that may be helpful

(Note - FibroAction does not endorse any book or product and individuals have to take full responsibility for what they read and what actions they take)

*Fibromyalgia and Muscle Pain: Your Self-treatment Guide* by Leon Chaitow  
*The Trigger Point Therapy Workbook: Your Self-Treatment for Pain Relief* by Clair Davies  
*Pain Free 1-2-3* by Jacob Teitelbaum  
*IBS: The First Year* or *'Eating for IBS* by Heather Van Vorous

---

[www.Fibro.Action.org](http://www.Fibro.Action.org)

FibroAction is a charity registered in England and Wales (registered charity number 1125957)  
FibroAction (company number 6662336) is a company registered in England and Wales  
whose registered office is at 19 Pyle Hill, Newbury RG14 7JJ.



## MEMBERSHIP APPLICATION

NAME: \_\_\_\_\_

ADDRESS: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_ POST CODE: \_\_\_\_\_

TELEPHONE NUMBER (HOME): \_\_\_\_\_ MOBILE: \_\_\_\_\_

EMAIL ADDRESS: \_\_\_\_\_

NAME REQUIRED FOR MEMBERSHIP BADGE: \_\_\_\_\_

POSTAL MEMBERSHIP: £12.00 ANNUAL FEE

WEB MEMBERSHIP: £10.00 LIFETIME FEE

PLEASE ENCLOSE CASH/CHEQUE (TO BE MADE PAYABLE TO FOGGY'S)  
THERE ARE EXTRA CHARGES FOR PRINTING LITERATURE, HOWEVER INTERNET ACCESS AND WEB MEMBERSHIP  
MAKES THEM FREE TO VIEW AND PRINT AT YOUR OWN LEISURE.

PLEASE POST FORM TO 112 ELBOROUGH ROAD, SWINDON, SN2 2LP  
(CORRESPONDENCE ADDRESS ONLY) OR BRING ALONG TO OUR NEXT MEETING

**FOR OFFICE USE ONLY:**

DOCUMENT RECEIVED:

APPROVED BY:

RENEW DATE:

VENUE	DAY	DATE		MEETING #		GUEST SPEAKER OR MORE INFO.	TIME
SWINDON	WEDNESDAY	04/07/2012		41		LOUISE VOLUNTEER CENTRE SWINDON	1pm - 3pm
SWINDON	THURSDAY	12/07/2012			FUNDRAISING	BAGPACKING - SAINSBURY'S - BRIDGEMEAD, SWINDON	5pm - 9pm
SALISBURY	FRIDAY	13/07/2012		10			7pm - 9pm
SWINDON	SATURDAY	14/07/2012			FUNDRAISING	BAGPACKING - SAINSBURY'S - BRIDGEMEAD, SWINDON	11am - 4pm
SWINDON	SUNDAY	15/07/2012			FUNDRAISING	BAGPACKING - SAINSBURY'S - BRIDGEMEAD, SWINDON	11am - 4pm
SWINDON	MONDAY	16/07/2012		42			7pm - 9pm
SWINDON	WEDNESDAY	01/08/2012				<b>NO MEETING !!</b>	
SALISBURY	FRIDAY	10/08/2012				<b>NO MEETING !!</b>	
SWINDON	MONDAY	20/08/2012				<b>NO MEETING !!</b>	
		04/09/2012	11/09/2012			AWARENESS	FIBROMYALGIA AWARENESS WEEK
		04/09/2012	11/09/2012			AWARENESS	MIGRAINE AWARENESS WEEK
SWINDON	WEDNESDAY	05/09/2012		43		JAMES BROWN SWINDON LOCAL INVOLVEMENT NETWORK (LINK)	1pm - 3pm
SALISBURY	FRIDAY	14/09/2012		11		TRISH COWIE ACTIVE HEALTH CLASSES	7pm - 9pm
SWINDON	MONDAY	17/09/2012		44			7pm - 9pm
SWINDON	WEDNESDAY	03/10/2012		45		JACKIE WRAY SWINDON MS THERAPY CENTRE	1pm - 3pm
		10/10/2012				AWARENESS	MENTAL HEALTH AWARENESS - INTERNATIONAL DAY
SALISBURY	FRIDAY	12/10/2012		12			7pm - 9pm
		12/10/2012				AWARENESS	ARTHRITIS AWARENESS - INTERNATIONAL DAY
SWINDON	MONDAY	15/10/2012		46			7pm - 9pm
SWINDON	WEDNESDAY	07/11/2012		47			1pm - 3pm
SALISBURY	FRIDAY	09/11/2012		13			7pm - 9pm
SWINDON	MONDAY	19/11/2012		48			7pm - 9pm
SWINDON	WEDNESDAY	05/12/2012		49		<b>CHRISTMAS MEETING</b>	1pm - 3pm
SWINDON	FRIDAY	07/12/2012			FUNDRAISING	<b>BAGPACKING - TESCO OCOTAL WAY, SWINDON</b>	5pm - 9 pm
SWINDON	SATURDAY	08/12/2012			FUNDRAISING	BAGPACKING - SAINSBURY'S - BRIDGEMEAD, SWINDON	11am - 4pm
SWINDON	SUNDAY	09/12/2012			FUNDRAISING	BAGPACKING - SAINSBURY'S - BRIDGEMEAD, SWINDON	11am - 4pm
SWINDON	THURSDAY	13/12/2012			FUNDRAISING	BAGPACKING - SAINSBURY'S - BRIDGEMEAD, SWINDON	5pm - 9pm
SWINDON	THURSDAY	20/12/2012			FUNDRAISING	<b>BAGPACKING - TESCO OCOTAL WAY, SWINDON</b>	5pm - 9 pm
SALISBURY	FRIDAY	14/12/2012		14		<b>CHRISTMAS MEETING</b>	7pm - 9pm
SWINDON	MONDAY	17/12/2012		50		<b>CHRISTMAS MEETING</b>	7pm - 9pm