



Fibromyalgia in Tonbridge

Support Group for West Kent

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Working with Fibromyalgia Association UK - Reg charity 1042582

NEWSLETTER - October 2013

Next meeting - Saturday October 12th

11am - 2.30pm

Tonbridge Baptist Church, Darenth Avenue, Tonbridge, Kent TN10 3HZ

Car park entrance is in Derwent Road

We will be celebrating our 5th birthday



Our Guest Speaker is Pam Wright

Pam was one of our first speakers and returns to help us celebrate! Pam, herself a fibromite, is a qualified life balance & health coach, and author of The Fibromyalgia Coach and The Ability Coach.

Copies of Pam's books will be available for purchase at the meeting

Pam also writes a regular column in The Fibromyalgia Magazine for UK Fibromyalgia.com



Christmas social on Saturday 14th December

In place of the usual December meeting with a buffet, we have decided this year that it would be more fun and less effort to go out for a Christmas meal

DETAILS TO FOLLOW SOON



- I trust this reaches you all well & having enjoyed the long & very hot glorious summer which, although unbearable at times, has all too readily faded giving us an abrupt transition into Autumn!
- Our July social event was a great success as we all basked in the summer sunshine, in a shaded area of the beautiful garden at the Fir Tree House Tearooms in Penshurst, while delighting in “afternoon tea”. Everyone who attended agreed that meeting in a relaxed & informal setting was just as supportive as formal meetings.
- Our August meeting was a very interesting and lively presentation as we welcomed Pip Salmon – Physiotherapist in Women’s Health, with Maidstone & Tunbridge Wells NHS Trust. Pip’s presentation was certainly a trip down memory lane for many of us, re-familiarising ourselves with our anatomy in diagram format. Pip gave us some very valuable information and advice on body awareness, and the things for ladies to watch out for “down below” as time progresses.
- As you will be aware from our last meeting and my subsequent contact with you, FIT has been shortlisted in the Courier Newspaper’s Heart of the Community Awards. We were featured in the September 6th edition alongside many other deserving causes. Consequently Sue, Susie and I have been invited to attend the Awards’ Presentation in mid-November at the Trinity Theatre so, it will be a nail-biting time to learn if we have been successful. Please extend our thanks to all of your families, friends & everyone else that has kindly voted for us.
- The 5th National Fibromyalgia Conference organised by Folly Pogs is being held on March 27-31st 2014. It will again be held at the Chichester Park Hotel, and a staged payments option is being offered. Further details are available on the FMAUK website: www.fmauk.org and by emailing info@follypogsfibro.org or telephoning 08433 828 829.
- Vidette Purchard our Social Events Organiser is currently looking at suitable venue offering affordable menu for our Christmas Lunch Social on Saturday December 14th Vidette will be contacting all members in due course, but please put the date in your diary now, for a fun lunchtime to take a break from your pre-Christmas planning and pacing!
- **FIBRO APPS for your smartphone:**

FMA UK FibroMapp App	£2.99 (50% goes to FMA UK)
UK FibroMapp (UK fibro.com)	£2.99
Fibro mapp-Body map apps	£2.99

As we head towards our 5th Birthday, we see how we have grown from our small beginnings in 2008, with just a handful of member volunteers meeting at the Parish Church, Tonbridge. It is heartwarming to see where we are today, with original member Sue Ryall, our Group Treasurer and myself joining in January 2009. Susie Connor joined later that year and became Newsletter Editor in 2010. Vidette & Astrid joined the Committee in 2011 & 12 respectively. Although we have seen many members come and go, we are confident that as they move forward with their lives, having received the information they require from us, they know they are assured of our continuing support if they need us. We also have a loyal core group of members who have stayed with us throughout, attending meetings and events, and giving mutual ‘fibromite’ support.

The telephone support line, for which I am responsible, receives a steady flow of enquiries, as does the group’s email address, which also includes all communications from FMA UK’s head office. As a committee we have all had to learn over time, the pitfalls and the triumphs associated with running a group - especially as we also have our health needs & families to attend to; juggling home responsibilities and FIT “behind the scenes” work, getting all to dovetail nicely is quite a challenge!

At the present time we are unfortunately nearing the last of our group funds, from all income and donations received. We cannot rely on any one source for future funding, especially as we currently have no-one willing to take on a fundraising role. As we look towards 2014, the way forward for the group may possibly be to run, at least in the immediate future, purely social meetings. This would be a coffee & chat style group on a specified day, either at TBC if funds allow for room hire, or at an agreeable venue in town or elsewhere, with other members being the regular contacts. Unless we have a volunteer from the members, or a suitable non-member steps forward in a fundraising capacity, this may be our last formal meeting. As you know our December meeting will be a social event for a Christmas lunch for all members at a venue yet to be decided. Whatever direction the group takes, we hope to find a way to continue making our library of books, CDs, DVDs, articles and leaflets available to members, as well as the telephone helpline and email support.

Earlier in the year I made you all aware of my intention to step down from my role at the end of 2013. However, I remain very committed to the cause and to you all. Therefore to see in the group’s immediate future or until such time as the funding of the group is more buoyant, I will remain in my role of Co-ordinator/Secretary, leading the committee. In June I attended the Personal Independence Payment or PIP training day run by the Benefits and Work organisation in London. PIP is replacing DLA (Disability Living Allowance). Vidette & I will be attending a Volunteer Conference later this month, and Susie & I will be attending the FMA UK annual Group Leaders’ meeting also being held in London. You can see that we are endeavouring our utmost to continue networking for the benefit of the group, gathering all the information and ideas we can to pass on to our members, supporting you & your families as well as we can, within FMA UK guidelines.

MOTABILITY SUPPORT IF YOUR CLAIM FOR “PIP” FAILS

This is a statement by Lord Sterling - Chairman, Motability Board of Governors. It describes the transitional support available to Motability customers who lose their DLA and fail to qualify for support under PIP.

Motability Scheme to provide one-off transitional support to customers who, following their initial reassessment by Government for the new PIP benefit, lose their eligibility to remain on the Motability Scheme

In April 2013, the Government introduced a new benefit - Personal Independence Payment (PIP) - which will gradually replace Disability Living Allowance (DLA) for disabled people aged between 16 and 64. Motability acknowledges that there are positive aspects of PIP compared to DLA in the longer term. However, over the last two years, the Governors of Motability have considered how PIP will affect Motability Scheme customers and, in particular, the degree to which we can assist those customers who lose their eligibility to remain on the Scheme when they are first reassessed for the new benefit.

Between October 2013 and 2018, the Department for Work and Pensions (DWP) will reassess some two million disabled people aged between 16 and 64, who currently receive DLA, for the new PIP benefit. This reassessment process will include approximately 360,000 of the 620,000 disabled people who currently lease a vehicle through the Motability Scheme. Because PIP is a new benefit with different criteria to DLA, some disabled people may not qualify for mobility support under PIP or may do so at a lower level than they had under DLA. As a consequence, they will no longer be eligible to use the Motability Scheme.

Since its inception over 35 years ago, the standard of service and support provided by the Scheme has always reflected the very special needs of our customers. Some two years ago when the Government initially proposed the adoption of PIP, we decided that we wanted to help those customers who can no longer use the Scheme to retain their mobility outside of it. Therefore, over the next five years as PIP is introduced, the Motability Scheme plans to provide a one-off transitional package of support and advice regarding alternative mobility arrangements to these former customers.

Background on Disability Living Allowance (DLA) and Motability:

Disability Living Allowance (DLA) is a Government benefit to help with the extra costs arising from disability. DLA is not means-tested or taxable, and is paid whether the disabled person is working or not. The Department for Work and Pensions (DWP) determines who is eligible for DLA, based on an application completed by a disabled person, supporting evidence provided by the applicant and, in some cases, a medical assessment carried out on behalf of DWP.

Motability was formed as an independent charity with all-party Parliamentary support in 1977. Since then, the Motability Scheme has supplied over 3.5 million vehicles to disabled people and currently has over 620,000 customers. Although we have always worked closely with DWP on issues related to the Scheme, Motability has never of course had any role in determining who should receive DLA; that is solely the responsibility of the DWP.

Once in receipt of the Higher Rate Mobility Component of DLA, a disabled person is eligible to join the Motability Scheme. It is entirely up to the recipient whether they wish to spend their allowance joining the Motability Scheme or in some other way. Approximately one third of eligible recipients choose to use their allowance to lease a vehicle through the Motability Scheme. Customers today benefit from a wide choice of manufacturers and vehicles available through the Scheme, including specialised adaptations and wheelchair accessible conversions. Through its relationships with manufacturers, dealers and other service providers, the Scheme also supports customers with a high level of personal care, expertise and service appropriate to their needs.

Once an eligible disabled person decides to join the Motability Scheme, they ask the DWP to pay the Higher Rate Mobility Component of their DLA directly to Motability Operations (who operate the Scheme under contract to Motability) irrevocably for the duration of their lease agreement. The Scheme buys over 200,000 cars each year, accounting for some 10% of the UK new car market and enabling Scheme customers to benefit both from the discounts which it can negotiate with motor manufacturers and also from the very close and helpful relationships we have with manufacturers and dealers. At the end of the lease, which is usually three years, the customer returns the car for resale by Motability Operations.

However, we cannot extend the Scheme to disabled people not in receipt of the Higher Rate Mobility Component of DLA. For more than 35 years, the availability of the mobility allowance from Government (most recently, the Higher Rate Mobility Component of DLA) has provided a sound financial basis for the Scheme and this linkage remains fundamental to the Scheme's viability.

Introduction of Personal Independence Payment (PIP):

The Motability Scheme will work with PIP in exactly the same way as it does with DLA; disabled people who receive the Enhanced Rate of the Mobility Component of PIP will be eligible to use the Motability Scheme, if they choose to do so, in the same way as people who receive the Higher Rate Mobility Component of DLA.

Today, the Motability Scheme supports over 620,000 disabled people and their families across the United Kingdom, for whom an affordable and suitable vehicle provides levels of freedom and independence that would otherwise be beyond their reach. However, PIP is a new benefit with different eligibility criteria to DLA. As the DWP reassesses current DLA recipients aged between 16 and 64 for PIP, those who are Motability Scheme customers may qualify for the Enhanced Rate of the Mobility Component of PIP, in which case they should enjoy a seamless service as they move from DLA to PIP. Some customers, however, may not qualify for mobility support under PIP or may do so at a lower level than they had under DLA and, as a consequence, they cannot continue to lease a vehicle from the Scheme. Although they had properly claimed and received DLA, these changes are the result of a new benefit being introduced by the Government with different eligibility criteria.

As a consequence, some disabled people may have enjoyed the benefits of the Motability Scheme for many years but find that they can no longer use it as they are no longer in receipt of the relevant mobility component of DLA or PIP. While we cannot replicate the benefits of the Motability Scheme for them on an on-going basis, because we have a long history of offering a unique service to disabled people, we aim to provide a one-off package of support and advice to help such customers through this difficult transition.

One-off transitional support for customers who lose eligibility to remain on the Motability Scheme:

Since 2010, Motability has maintained a close dialogue with DWP as they developed their plans for the introduction of PIP through a number of public consultations. Over the last two years, Motability has also consulted disability organisations including Disability Rights UK, Disabled Motoring UK and groups representing customers with specific impairments, as well as undertaking considerable research with our own customers, to discuss what help would be most useful for those customers who are no longer eligible to use the Scheme. We are very grateful to all of the organisations and individuals who have helped us in developing and prioritising proposals for how we support these customers.

In order to ensure that the Motability Scheme is sustainable for the long term to continue to help the disabled community for at least another 35 years, we have the responsibility to identify risks, long term as well as short term, especially in these uncertain times. Taking account of these considerations as well as of our customers' needs, Motability and Motability Operations have concluded that the following support can be provided to customers leaving the Car Scheme as a result of a PIP reassessment:

- DWP has already announced that they will allow DLA payments to continue for four weeks after they make their decision regarding PIP. In addition to this, the Scheme will allow customers to retain their vehicle for up to a further 3 weeks from the date the DLA payments end. The customer will therefore be able to retain their vehicle for close to two months after the DWP decision is made.
- Customers will need to return the car to the dealership in good condition and within the agreed timeframe in order to qualify for the following transitional support:
- For customers who entered into their first lease agreement with the Scheme before January 2013 and therefore could not have been aware of PIP and the associated risks when they joined (the vast majority of customers), we will provide transitional support of £2,000. For many customers, this will enable them to continue to have mobility by purchasing a used car.
- For customers who entered into their first lease agreement with the Scheme with an awareness of PIP being introduced and of the risk that they could lose eligibility following a future PIP reassessment i.e. after January 2013 and up to December 2013, we will nonetheless provide transitional support of £1,000.
- We will review these levels of transitional support during 2015 to take account of economic conditions and of any possible changes the Government may be making to PIP at that time.
- For customers who have made an Advance Payment (an additional upfront payment to lease a larger or more complex vehicle on the Scheme), the Scheme will continue to refund any Advance Payment on a pro-rata basis. No further costs will be applied to customers whose leases end early as a result of a PIP reassessment.
- We will work with our Scheme suppliers, including RSA and RAC, to provide general information on motoring, insurance and other motoring services outside of the Scheme. This will include information, for example, on buying a new or used car, and arranging insurance and other services such as breakdown cover. In particular, we are working with a leading UK insurance broker who will offer insurance quotes to former Scheme customers that will recognise their no-claims history on the Scheme. We are also working with manufacturers and dealers to ensure that they are aware of the issues faced by these customers and are able to discuss possible alternatives to maintain their mobility once they have left the Scheme.
- The Scheme will offer customers an opportunity to purchase their vehicle following the end of the lease. The payments that they would otherwise have received upon returning the vehicle can be directed towards the purchase price.
- We will work with customers who have wheelchair accessible vehicles on the Scheme on a case by case basis to understand and assist with their future mobility arrangements including, where appropriate, enabling them to retain their current vehicle.
- For customers with adaptations, we will help them with the costs of fitting the same adaptations to a non-Scheme vehicle.
- The Motability Scheme will also provide a package of support and advice to customers currently leasing a scooter or powered wheelchair, with the objective of allowing them to retain their current product wherever possible.

As the DWP plans to begin reassessments of existing DLA recipients in October 2013 and each reassessment will take several months to complete, we do not expect any Scheme customers to become eligible for this support until early 2014. We will monitor customers' feedback on the support and advice we provide and we may make changes to it based on experience. We will also formally review all aspects of our support package in Autumn 2015, to take account of economic circumstances and any possible changes the Government may be making to PIP at that time.

In the years to come, the Motability Scheme will receive applications from recipients of PIP as well as from recipients of DLA and we will continue to meet the needs of disabled people, as we have done since 1977.

Lord Sterling

Chairman, Motability Board of Governors

September 2013

You can find out more about PIP in our PIP guide at <http://www.disabilityrightsuk.org/personal-independence-payment-pip>
Our Motability factsheet will be updated shortly.

Source <http://www.disabilityrightsuk.org/news/2013/october/motability-support-if-you-fail-pip>

It's well known that Fibromyalgia Syndrome is associated with lack of Stage 4, also known as Delta wave, sleep. This can lead to waking up feeling just as fatigued as when we go to bed. For this reason it is important that we do all we can to help our bodies achieve as good a sleep routine as possible.

FIVE THINGS THAT STOP A GOOD NIGHT'S SLEEP

Stages of sleep

Sleep is essential to maintaining normal levels of cognitive skills such as speech, memory, and flexible thinking. Sleep plays a significant role in brain development.

Every 60-100 minutes we go through a cycle of four stages of sleep before entering dream sleep

- Stage 1 is a drowsy, relaxed state between being awake and sleeping
- Stage 2 is a period of light sleep where heart rate slows and body temperature decreases, getting ready for deep sleep
- Stage 3 and Stage 4, or deep sleep are hard to wake up from because there is the lowest amount of activity in your brain and body
- After deep sleep, we go back to Stage 2 and then enter dream sleep - also called REM (rapid eye movement) sleep

Missing out on any part of the usual sleep cycle, results in reduced quality and quantity of sleep.

1. An irregular routine

We all have a built-in body clock which tells us when we are tired, and helps synchronise thousands of cells in our body to the circadian rhythm. The main synchroniser for our body clock is light. Our eyes react to the light and dark, even when our eyelids are closed. Daylight prompts our brains to reduce the production of the sleep hormone melatonin. We become more alert, and wake up. If we sleep less, because of going to bed late or waking up early, we're unlikely to get as much deep sleep as we need, or enough of the stage that comes after it - REM (rapid eye movement) sleep, when we do most of our dreaming.

2. An uncomfortable or noisy environment

As we start to fall asleep, our muscle tone reduces and our limbs begin to relax. We may feel drowsy but our brain is still active, and any noise or discomfort can make it hard to fall asleep.

As we drift into light sleep, an area of the brain called the thalamus starts to block the flow of information from our senses to the rest of the brain, but it will still let through noises, which can wake us up. After about half an hour of light sleep, most of us enter a type of deep sleep called slow-wave sleep. The changes in the brain neurochemistry typical of deep sleep, make it harder to be woken up. But some things will always get through - such as our names being called out loudly.

3. Stimulants - coffee, alcohol, food

Caffeine is a stimulant which can stay in our system for many hours. Drinks high in caffeine make it harder to fall asleep and can result in more time in the lighter stages of sleep, with less deep sleep. This doesn't mean just coffee. Many soft drinks such as cola contain large amounts of caffeine.

Drinking **alcohol** often makes us snore more, making it harder to breathe, and so making us more restless. Although alcohol initially helps some of us fall asleep, too much of it may disrupt sleep. A lot of alcohol close to bedtime means we can go straight into deep sleep, missing out on the usual first stage of sleep. As the alcohol starts to wear off, our bodies come out of deep sleep and back into REM sleep, which is much easier to wake from. In the course of a night we usually have six to seven cycles of REM sleep, which leaves us feeling refreshed. However, a night of drinking means we'll typically have only one to two, and wake up feeling exhausted. **Eating** a large, heavy meal too close to bedtime may also interfere with sleep. Spicy or fatty foods can cause heartburn, which leads to difficulty in falling asleep and discomfort throughout the night. Foods containing a chemical called tyramine (examples include bacon, cheese, nuts and red wine) can keep us awake at night. Tyramine causes the release of noradrenaline, a brain stimulant. Carbohydrates, such as bread or pasta, have the opposite effect. They trigger the release of hormone serotonin, which makes us sleepy.

4. The wrong body temperature

Our core body temperature goes down when we sleep. It's controlled by our body clock, which starts to open up the blood vessels of the hands, face and feet to lose heat, as we approach the time we should be sleeping. If our bedrooms or duvets are too warm, our bodies can't lose heat. That can lead to restlessness and discomfort. Our core temperature should only be half a degree less than during the day. If we get too cold, we get restless.

5. A busy mind

Stress is the enemy of sleep. In bed, our mind is left free to wander, and feeling anxious about getting enough sleep will only make it worse. In these states people lose track of time. You may nod off and wake up again but it may still feel as if you are getting no sleep at all. This can result in fragmented sleep with less time spent in the deep stages of sleep. Sleep experts recommend getting up and doing an activity which distracts our mind from worry - such as a puzzle - before trying to sleep again.

Information from BBC Science Sources: Dr Chris Idzikowski, Director of the Edinburgh Sleep Centre, Professor Jim Horne, Director of the Loughborough University Sleep Research Centre, Dr Dev Banerjee, consultant sleep physician.

FEEDING THE BRAIN

With “fibrofog” often proving to be one of the most frustrating aspects of Fibromyalgia Syndrome, the following information about the effects of various nutrients on brain function, and the foods that provide them, is a useful thing to have in your armoury of self-help. To be at their most effective some nutrients need to work together. Lack of some nutrients may have a detrimental effect on brain function, mood and general ability to cope with the pressures of life with fibromyalgia. As always, eating a balanced diet is important to keeping well. These notes may help you identify deficiencies in yours.

NUTRIENTS	FOOD SOURCES	EFFECTS
Omega 3 (which the body does not produce)	Anchovy, eggs, flaxseed, herring, salmon, sardines, trout, tuna & fishoil supplements	Neuro-transmitter which aids brain processing
Omega 6 (which the body does not produce)	Brazil nuts, hempseed, pecan nuts, sesame seeds, sunflower seeds & supplements - borage oil, evening primrose & starflower oil	Neuro-transmitter which aids brain processing To be most effective Omegas 3 & 6 need vitamins A, B6, C, E & the minerals copper, magnesium*, selenium & zinc to be present.
Amino acid tyrosine	Dairy produce, eggs, meat, seafood and soy	Used to make neuro-transmitters which improve brain function
Vitamin C	Berries, broccoli, citrus fruits, peppers & tomatoes	Helps neuro-transmitters work and helps deal with stress
Zinc	Fish, nuts & seeds	Helps with concentration, immunity & stress
Complex sugars	Beans, lentils, vegetables & wholegrains	Slow, gradual release of energy over longer time period. The brain uses 20% of the body's energy.
Chromium	Multi-vitamins	Helps to maintain normal blood sugar levels

NUTRIENTS	FOOD SOURCES	EFFECTS of DEFICIENCY
Vitamin B1	Vegetables & wholegrains	Poor concentration
Vitamin B5	Vegetables & wholegrains	Poor memory & increased stress
Vitamin B6	Bananas & wholegrains	Depression, irritability, poor memory & increased stress
Vitamin B12	Dairy produce, eggs, fish, fresh fruit, meat & vegetables	Confusion & poor memory
Vitamin C	Fresh fruit & vegetables	Depression & psychosis
Magnesium	Green vegetables, nuts & seeds	Blank mind, confusion, depression, insomnia, irritability, lack of appetite, concentration & motivation
Zinc	Fish, meat, nuts & seeds	Loss of appetite & weight loss

NON-NUTRIENT	FOOD SOURCES	EFFECTS of EXCESS
Simple sugars	Dextrose, glucose, sucrose, table sugar & processed sugars found in icings, packaged biscuits & cakes, sweets, fizzy drinks & artificial sweeteners	Cause a speedy 'high', followed quickly by a drowsy 'low', leading to poor concentration, irritability & sleepiness.

*Fibromyalgia sufferers may need malic acid to aid absorption of magnesium. Combined they come in the form of magnesium malate.

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## Arthritis Support Kent

ASK meets monthly at St Philips Church, Birken Road, Tunbridge Wells TN2 3TE

ASK 2013 meetings – all are on Wednesdays, beginning at 2pm

13<sup>th</sup> November 4<sup>th</sup> December

**November** guest speaker is **CAROL BLICK** Occupational Therapist at Tonbridge Cottage Hospital. Carol will talk about Occupational Therapy, and will be showing a variety of aids and equipment available for the arthritis sufferer.

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ADVERTISEMENT

FOR SALE

ROMA VEGAS MOBILITY SCOOTER

As New
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Burgundy colour

Used twice only & in perfect working condition.
Sale forced due to unsuitability for owner.

Cost £695.00 new - will accept £450.00 ono

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Tel: 01622 873087

Fibro-fog and me.....OR.....You just gotta larf

Hubby and I went to Broadstairs today to see a relative. Steven needed LPG for the car, found a petrol station with LPG on the satnav and programmed it in as a 'way-point'. When we left the garage the satnav lady said to turn left, but then it seemed she got a bit confused, which led me to say: "How will the satnav know you've already been to the way-point?". Steven, who frankly couldn't believe his ears, said very patiently "because it's a satnav....it knows where you are." Can you believe I said anything quite that daft? Me neither, I used to be an intelligent person! I've got 10 'Os' and 2 'As' for goodness' sake. I just dissolved into laughter, a major fit of the giggles. Couldn't stop - every time I thought of it, I just started again.



The upside? Is there one? You may well ask. Yes, just think of all those jolly old endorphins flooding into my system. There's nothing like a good laugh to perk you up - whatever the cause!



Well that's the Newsletter done....

... and I have some time to relax...

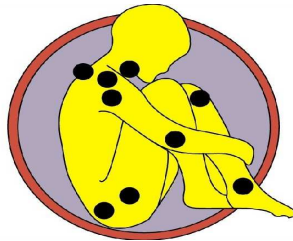
...or have I just forgotten what I should be doing next!



Fibromyalgia in Tonbridge Support Group has a library of fibromyalgia related books, DVDs, CDs and other information which may only be borrowed by our **registered members**. The items must be recorded by the "librarian" on index cards/lists provided and returned at the following meeting.

We are always grateful for donations of any relevant books, particularly those that members themselves have found helpful. They do not need to be new. Second hand is fine! If you have any queries about the library please contact Susie Connor at meetings or by email: susieconnor@live.co.uk Thank you.

The inclusion of articles, features and advertisements in this newsletter is for information only and does not necessarily infer endorsement by the Group/Association. Any advice or recommendation of a medical nature, given in this newsletter, should always be discussed with a medical professional. The Group/Association cannot be held responsible for omission and/or errors.



FIBROMYALGIA in TONBRIDGE

Working with Fibromyalgia Association UK - Registered charity number 1042582

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