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FLARE

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Beth Urmston

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INSIDE THIS MONTHS ISSUE:

Looking Back to 12 May 2017

David Tuller – PACE Trials

NEW – Nature's Healing

The magazine that has something for everyone

Aims of the Magazine

An aid to those who have been diagnosed with Fibromyalgia (FM) Chronic Fatigue Syndrome (CFS) and Myalgic Encephalopathy (ME) who need support and guidance to help them come to terms with their lifelong debilitating condition.

To help their families, friends, colleagues etc. to understand and be able to offer their own level of support.

As a tool to assist the medical profession when dealing with patients who have presented regularly over a 6 month period or more with unexplained pains which could be FM, or those who have already been diagnosed.

As an outlet for FMCFS/ME sufferers to share their experiences.

A way to raise awareness and educate the general public of the many symptoms and issues that make up these similar but different conditions.

To work toward fundraising for research, we all want the same thing:

A CURE!

PUBLISHER'S STATEMENT

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Thank You

Thank you to everyone who has contributed to this months magazine.

Contributors:

Elyse Runacre – Features Editor

Sara-Louise Williams – Graphic Design

Ailsa Bancroft – Arts & Crafts

Beverley Barnett – Copy Editor

Plus Guest contributions



To all our regular contributors, our wonderful readers and everyone who has done anything to raise awareness in whatever way they were able this month and especially to those who donated.

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Message from The Editor

Hi

Lots of people to thank this month, some are out front and you will see how much they are doing to help raise awareness, get better treatments etc. but we also have readers/members who help out behind the scenes. There are some who run local support groups in their area, those who write to MP's to try to get more parliamentary support, who deliver booklets/flyers/leaflets and those who wear purple ribbons – far too many to mention them all individually but the fibro community salutes you all for your willingness to do what you are able to help raise awareness and banish the stigma that is still pervasive in wider society.



The following are there year round, working to help others:

The magazine team – Ailsa Bancroft, Beverley Barnett, Elyse Runacre and Sara-Louise Williams.

The support group admins – Beverley Barnett, Claire Vieyra, Fiona Edmondson, Sophie Palmer, Victoria Dawson.

Juvenile group admins – Claire Vieyra and Wendy Taylor.

Fibro Flare Chesterfield – Adrienne Lakin, Leeann Lakin and Danielle Hogg.

Online Shop – Beverley Barnett.

I.T and design – Sian Phillips.

And then there are those who really help to raise awareness, especially in May.

Cath Farrer, Helen Sharpe, Janet Ward, Sarah Roberts, Jennifer Ward, Jeanette Kay, Julie Britten, Tracey Napper, The Fibro Comity Barnsley group, David Williams @Rock off Fibro

Thank you to all those who give their time to help others.

Beth X

Why Purple?

By Brandi Clevinger at Being Fibro Mom

Purple is the international colour used to represent fibromyalgia. But why? Why choose purple from the infinite possibilities of colour? Knowing the meaning of the colour purple will not only help us to understand why we use it to represent fibromyalgia, but also give us a better understanding of the illness as well.

Purple is a well-balanced composure of blue's calming properties and red's energetic properties. Colours affect people in their own ways, and purple is no exception. According to Kate Smith, writer of [Sensational Colour](#), the colour purple physically affects us by:



Uplifting;
Calming the mind and nerves.

Chakras correlate to a major nerve branching from the spinal column, and [the colours of the chakras](#) are the seven basic energy centres of the body. The purple chakra is the Crown Chakra which represents the crown of the head, the nervous system, and the brain.

Kate goes on to list all the ways purple is used around the globe, in religious aspects, political affiliations, and other interesting facts.

Courage is represented by purple in the military.

Purple is known in some cultures as faith, patience, virtue and trust.

Lavender, the plant, has aromatic calming properties as well as soothing and stress reducing qualities.

Purple and Fibromyalgia

After researching the colour purple and discovering its various meanings, I can understand why it's used to represent fibromyalgia.

Just as purple is a balance of calming blue and energetic red, fibromyalgia makes the body go through cycles of rest and unrest. One moment we are calm and relaxed, and the next moment full of energy and restlessness.

The Crown Chakra represents the crown of the head, nervous system, and brain – the places where fibromyalgia originates and affects/

Fibromyalgia is a complicated illness that leaves the affected person confused, anxious, perpetually tired, overwhelmed, consumed by pain, and never fully rested.

Once life, family, job, and day-to-day tasks are added to the illness, a person can be left feeling defeated and without hope. Courage, faith, patience, virtue, and trust are needed to keep fighting each day and manage to live life to its fullest. Hence the term, we are Fibro Strong!



You Took Up the Challenge

As you may be aware there is an international Light up the Night event each May, this year's theme was Shine a Light on Fibromyalgia and Millions Missing (ME). Last year we succeeded in getting 12 towns/cities across the UK to light up a landmark building in support of fibromyalgia/ME awareness.

Whilst there were fewer this year, those that did succeed in getting a light up event organised went along to watch their event and hopefully the light up along with so many people wearing purple/blue will have been noticed.

Just for my mate, **Wendy**.... I haven't worn purple today, so I am sharing this instead xxx AND I will keep my profile pic up in her honour xxx

<i>- Fibromyalgia - it's a pain in the well, everywhere</i>	 KEEP CALM & FIGHT FIBRO	I have FMS, what's your excuse?
fibro is not for wimps	May 12 Fibromyalgia Awareness	<i>Isn't it funny how I don't look sick & you don't look dumb?</i>
everybody hurts some of the time, fibromyalgia hurts ...		Fibromyalgia may be invisible

It is hoped that next year other local groups will take up the challenge and get a light up event organised in their area – it's not as difficult as you may think. If you do want to get involved and need help support will be given, just message Beth Urmston or put a post on the Fibro Flare Awareness Facebook group (<https://www.facebook.com/groups/fawareness/>). There are also leaflets available that you can hand out to passers-by on the day and you may even be able to get an article in your local newspaper.

Other challenges were to get as many people as possible to wear purple/blue on Friday 12th May and to help turn Facebook purple by posting as many pics/memes as possible.

Accrington



For the 4th year running, Cath Far-
rer (Trustee) organised another
country kickback event. There
were about 70 in attendance,
some who also have fibromyalgia
or know of someone diagnosed.
It's a long day, running for 12 hrs
with (almost) nonstop music pro-
vided by artists who gave their
time for free as their way of sup-
porting the fibro community, and
the hot food certainly went down
well. In total the event raised £589

– another great day and a fantastic success. The 5th annual event is already in the plan-
ning stages.

Saturday 27th May - The room is ready. Let the fun commence.

Barnsley – with thanks to Liza B and her local support group.



Fibromyalgia Awareness Event

Town Hall fountains lit up purple on the 11th May from 7 – 9 pm. We were there ready to
take photos and to start off 25th International Fibromyalgia Awareness ready for 12th May.
(Photographs courtesy of John E Kirk).

NEWSLINES Fibromyalgia Awareness

THE town hall fountains turned purple this week to mark national Fibromyalgia Awareness Week.

The council agreed to change the colour of the water feature in the Pals' Centenary Square at the request of the Barnsley and District Fibromyalgia Support Group. The group, founded by Liza Barnett-Tweedie from Athersley North, supports people who suffer from the chronic pain disorder.

Liza, of Beeston Square, said it was good to have support from the council in raising awareness and the group will be holding a coffee morning tomorrow at New Lodge Community Centre, 10am to 1pm, to spread the message further and offer support to anyone who thinks they may have the condition.

Call 07521 358 218.

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To find out more about the local support group:

Contact Tel: 07521358218

Email - barnsleyfibromyalgia@gmail.com

Facebook: https://www.facebook.com/tweetypie73?ref=br_rs

Meetings are held at Albert's Diner Albert St, Barnsley, behind Marks & Spencer's at 12:30pm each time. July and August meetings July 13th & 27th, August 10th & 24th



Blackpool – with thanks to Sarah and Lucy Roberts, Cath Farrer, Helen Sharpe and Richard
 Once again Blackpool Tower supported fibromyalgia/ME. At 9 pm the tower was lit up in purple with a blue heart. Our thanks go to Merlin Entertainments and in particular Lee We finally got confirmation the light up would take place at lunchtime on Wednesday 10th May!!! “We loved the adrenalin rush and anticipation”.

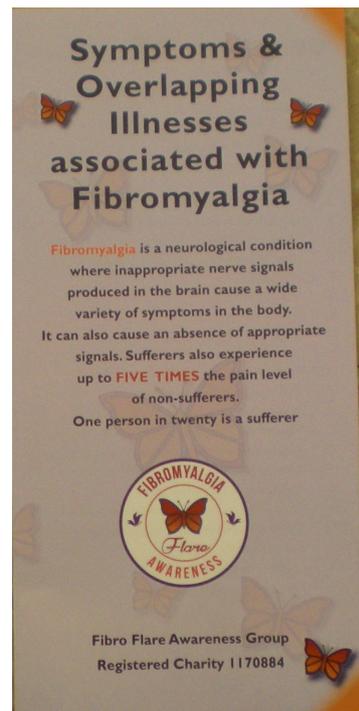
Sarah had been out and about in the weeks prior handing out leaflets

Blackpool Gazette 22.05.2017

Fibro group fights for change

The Fibro Flare Awareness Group - a charity to raise awareness into fibromyalgia - who have arranged to have the tower to be lit up. L-R Helen Sharpe, Sarah Roberts and Cath Farrer.

The Fibro Flare Awareness Group is spreading the word on a condition which leaves sufferers with chronic, widespread pain.



Blackpool Tower was lit up in purple recently to show support to sufferers of fibromyalgia, which affects an estimated one in five people.

Sarah Roberts, Blackpool and district awareness advocate for the Fibro Flare Awareness Group, has been delivering leaflets to doctors surgeries in the area to raise awareness
 Sarah, 50, from Bispham, who has suffered from the condition for 10 years, said: “I look normal. “I used to be a beautician and worked for the DWP but I have got the most chronic pain. It is so debilitating. It has affected my speech and I can only go out once a week. The people at Blackpool Tower have been fantastic at showing their support”.



Fibromyalgia can affect anyone, child or adult from any walk of life and whilst it has been recognised medically for more than 400 years much more research is needed before patients can have hope of a better future.

Earlier this month, the group was presented with a cheque for £1,200 from members of Garstang and District Ladies N.F.U Social Section. The money will be used to help the group's on-going work of raising awareness and funding research into fibromyalgia.

Beth Urmston, chairman at Fibro Flare Awareness Group, said: "We are delighted that so many people are willing to show support for the work that we do and to help us continue by fund-raising on our behalf. The Garstang and District Ladies N.F.U were extremely welcoming, we enjoyed meeting so many and being given such a fantastic opportunity to share information, although I must confess I am still somewhat gutted that I was so busy talking I missed out on the fabulous cakes that were on sale!"

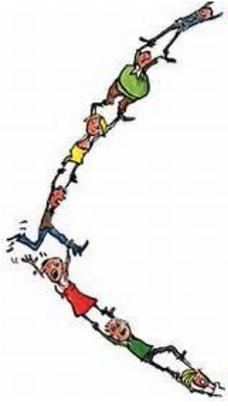
Fibromyalgia can also cause fatigue, anxiety and depression.

There is currently an online petition – www.change.org/p/uk-parliament-make-fibromyalgia-a-disability to make fibromyalgia recognised as a disability within the Equality Act 2010.

Sarah added: "There is no cure and current treatments have been shown to be only 25-30 per cent effective meaning many patients are left struggling. Many become severely disabled and need carers."

For more details contact Beth Urmston (01925) 480899 or cath.farrer@icloud.com

Stronger together

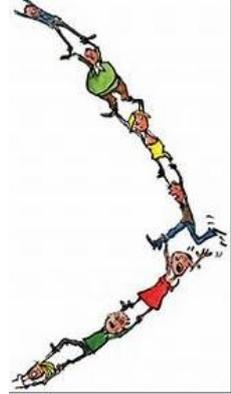


I keep looking for the answers I know that they are there
I know we must keep fighting, I know that we must share
Together we are stronger we must not give up hope
We must support each other and help each other cope

We are many, we have a voice, and one day we will be heard
Don't think you're not important as that would be absurd
You matter to each other in so many little ways
You help your fellow sufferer get through the darkest days

We must fight for what is right the recognition and the truth
One day we will have answers, one day we will have proof
So many different groups now and yet we must all speak as one
So many face book pages now have the doubters on the run

Some may not believe us still and some will still show scorn
But we are growing stronger there are more of us each dawn
It is so important the work that we all do
Your input is what's needed to get our message through



I see blogs and tweets these days and get messages from afar
Were fighting all around the world each one of you a star
Petitions to the government talking of our plight
Recruiting friends and family to aid us in our fight

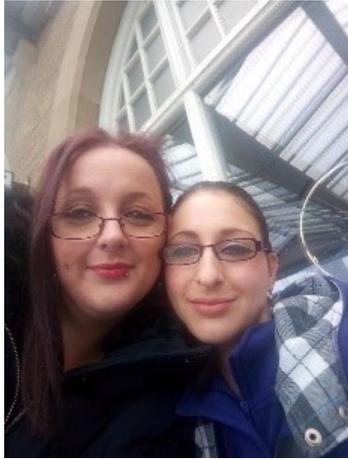
Once none of this was possible, once we were called mad
We had to suffer all alone all the hurting made us sad
Our nearest and our dearest and our doctors too
Treated us quite badly, but now we're breaking through

Each day that you are fighting just know you're not alone
There is another warrior like you in another home
They need you, and you need them, let's get the message heard
Let's all now raise awareness and rise up and spread the word

© Terry Haslett www.facebook.com/PoetrySoapbox

Chesterfield

With thanks to Adrienne and Leeann Lakin



Our first Awareness and Fundraising event, Friday 12th & Saturday 13th May 2017

St Michael's & All Angels Church, Brimington, Chesterfield, Derbyshire.

Leeann said "I thought I'd share our first ever awareness event experience with you."

Right from the get go Beth Urmston was so supportive of us. With-

out her encouragement and linguistic skills which we're sure everyone is probably used to by now (ha-ha sorry Beth!), I'm sure myself personally I wouldn't have managed to cope.

Right from the minute we decided to hold an event, we literally gave ourselves around 6 weeks to arrange everything from venue, right the way through to sponsors and stall holders! (Editor's Note: They're young, they will learn!)



At the same time Adrienne was trying to keep on top of her 2 diplomas as well as juggling making jewellery, searching for venues and sponsors. I myself took on the task of making banners, mini business cards with the petition details on, keeping up with the pages as well as jewellery.

I will admit being so passionate about making the event a success we did forget to take care of ourselves and ended up flaring right before the event!

During the planning, we had to expand the petition team, as we didn't have enough spare moments within the day to keep up with everything. So, Danielle Overend-Hogg and Faye Dempsey came on board to relieve a little bit of the pressure. The photos that are contained within this little write up are by Danielle herself, she is a lady of many talents and we've nicknamed her our fibro ninja! Faye is our twitter expert, there's days I can't keep up with her!

Anyway, on the 12th of May, I'd actually managed to convince our Reverend, Daniel Cooke to let us light up the church purple. We built the frame for the light filter and our dad bless his heart, climbed a 30ft ladder to put it up for us, there was no way we were able to.

Fast forward to the next morning and my hallway looked like a jungle. Boxes piled ready to head out to the church hall. I'd not slept the night before so I felt like a zombie by the time Danielle arrived at my home, she's one of the few people I normally listen to and she sent me for a cat nap, it's not just because she's the only black belt in her family, honest!! It's why she's nicknamed fibro ninja on the team!!!

The day went by so fast, we got to meet some of our local supporters and residents of Brimington and the kids were kept entertained by the bouncy castle and Hawks of Steele. Speaking of Hawks of Steele, Dave the head trainer has fibromyalgia himself and was such a pleasure to meet as was Kelly, they were both so passionate and patient and we cannot thank them enough!



We cannot thank enough all the stall holders and those who came along to support us.

Our very own Beth and Rachel travelled from Warrington to be with us for the day, which we shall be forever grateful for, thank you ladies, they even spent the night in Chesterfield and collected the funds we raised at the event which amounted to £200!!! We have asked that 50% will go towards fibromyalgia research and the other 50% to help raise more awareness of the condition.



It was definitely a learning curve for us – we need to give ourselves more time to plan and arrange everything. It was a whirlwind and we enjoyed every minute!

It was worth the time, effort and recovery time afterwards to see the smiles on everyone's faces and the gratitude of everybody afterwards.

We have already booked our event for next year - same place and hopefully same time. We're currently awaiting a response from the Mayor's office to see if we can light up our town hall next year and we already have interest from stall holders to return!

We look forward to our ever-growing friendships within the fibro community, for now though, we're looking forward to hopefully attending Tupton carnival on the 22nd of July to help raise awareness with our wrestling family Danielle and EBW, and finishing arranging my wedding on the 18th of August, as the saying goes, "there's no rest for the wicked".

Fibro Flare Chesterfield support group – Family/friends support group

A Facebook group has been set up to support the family and friends of fibromyalgia/ME/chronic pain conditions. Everyone needs somewhere to go and vent. Living with someone who has a long term condition is certainly not easy; our non-fibro's also need support. **Strictly no fibro patients allowed!**

If you know of anyone who may benefit please share the link below.

<https://www.facebook.com/groups/1801340096847847/?fref=mentions>

Garstang – Awareness/Fundraiser

Doris Richardson is the president of the ladies of Garstang Farmers Union social section and is also mum to our fantastic awareness advocate Sarah Roberts. Doris invited us to give a talk to the group and invitations to other local Farmer's Union ladies were extended.

On Monday 3rd April Cath Farrer, Sarah Robertson and I went along to a room of 120 people! In my pre fibro life I had been used to speaking in front of large groups but I found this totally overwhelming and really wasn't sure I would be able to hold out. Well medicated against the anxiety and the IBS I started speaking, but I could hear how shaky my voice was and stopped to take a couple of seconds to take deep breaths so I could push through. I share this information only so you may understand, I don't find this easy, I would much rather not have to put myself into this position but I know deep down, I just have to because if we want change then we have to make it happen. I had 5 minutes to try and get the point across of just how debilitating fibromyalgia is and why we are keen to raise awareness – for someone like me who likes to explain things to the #nth degree it certainly wasn't easy. Firstly I asked if anyone in the room had, or knew anyone, who had fibromyalgia, only 3 or 4 hands went up. I think by the end of the talk many more were aware. There was also a representative for Parkinson's who also gave a 5 minute talk, this was followed by sales of home-made goodies – cheese, jams/chutneys cakes (and can you believe I was so busy talking to members of the group who had come to ask questions I didn't get to buy any cake – a lesson learned). Donations from the sales on the night and the raffle were to be collected and we were invited to go along to the AGM on 1st May to be presented with a cheque.

Newcastle

In Gateshead the Millennium Bridge turned the purple and green representing both fibromyalgia and chronic fatigue. (Photograph by Margaret Riley).



It's not just groups who gather, we have some amazing individuals as well.

Facebook and Out and About

Many of our members got busy on Facebook, posting meme's and all things purple. The aim was to turn Facebook purple for the day. I think we can all add RSI to our long list of symptoms after that day – was it really only one day?!! My own timeline was certainly close at one point with only 1 in 5 posts being non-fibro related. For every post/meme/pic that was posted either by myself or another member the comment #fibromyalgia was used. It is still a very effective way of helping to raise awareness and something that each and every one of us has the ability to do (migraines and visual problems on the day allowing of course).

Those going out – appointments, shopping, lunch, and awareness events donned the fibro uniform – purple and it was good to see so many wearing purple ribbons with a butterfly attached.



Julie Britten (Trustee)

Julie always manages to plant purple pansies in her garden that are very visible throughout May and adds her purple fairy lights.



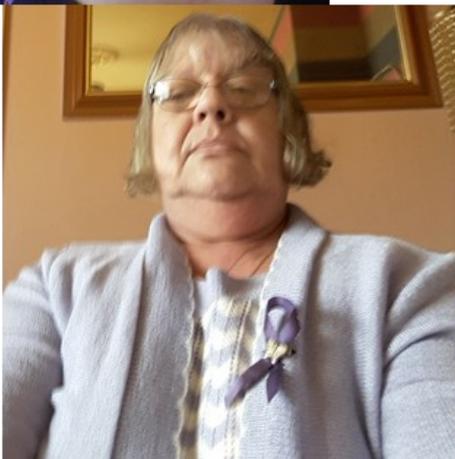
This year Julie was away in Torquay but awareness wasn't left behind. The support group she leads were out and about and managed to get stalls set up in both their local Tesco and Sainsbury's handing out leaflets, chatting to customers and fundraising. Julie meanwhile wasn't exactly slacking and the hotel she was staying at agreed to get involved and the entertainment room was lit up and decorated in purple to mark the day.



Claire Vieyra organised a raffle offering bead bracelets and angel card readings as prizes, one of which was won by Valerie Nealon in America. Thanks to all those who bought tickets and once again supported us you helped Claire make a staggering £105 for our awareness fund.



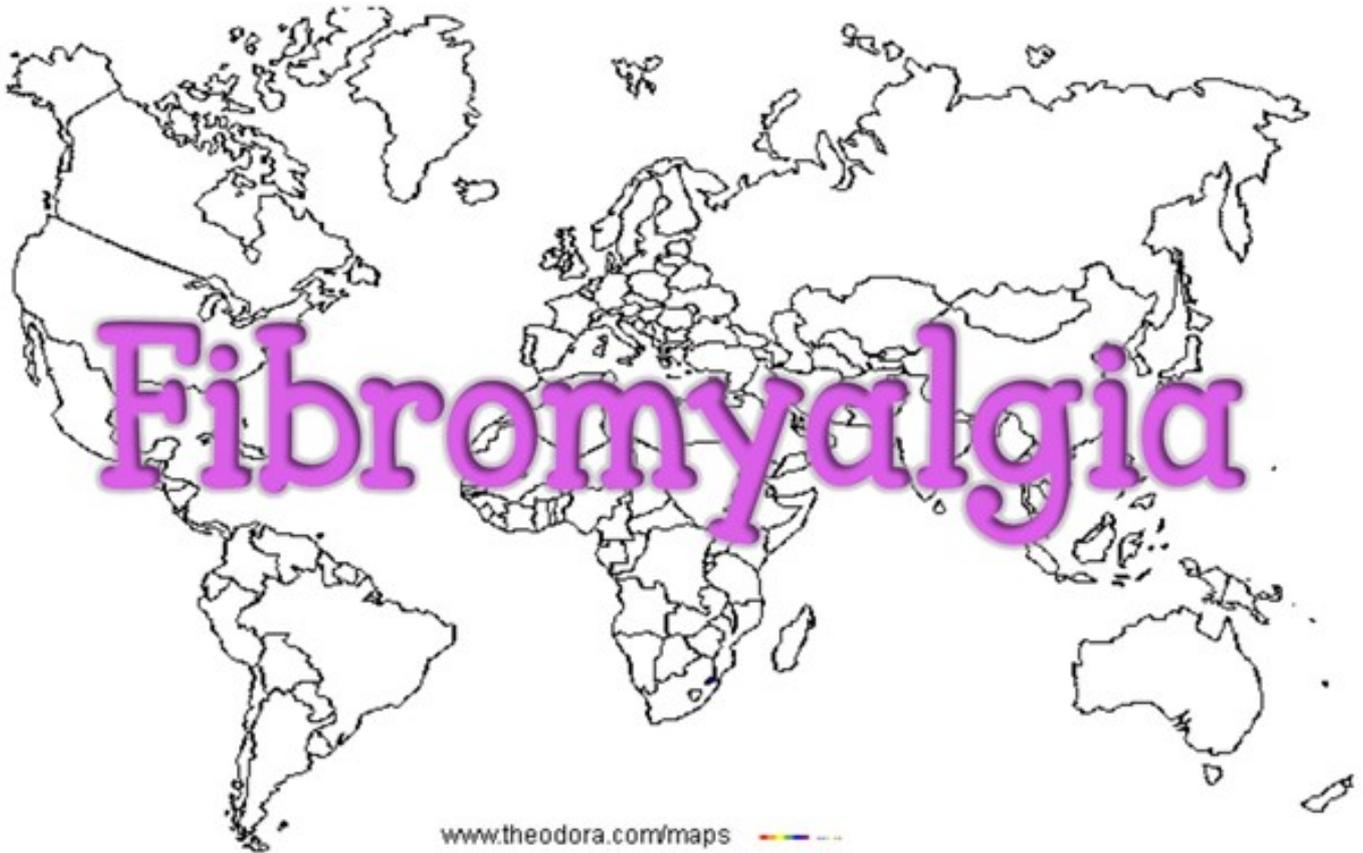




Rose Welch and Valerie Nealon
(USA)



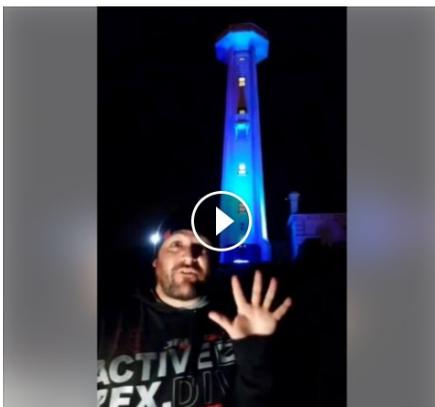
Around The World



Dubbo, NSW, Australia



South Africa – Getting Excited about M.E



Feels awesome!!

I'm feeling the love 💜 🦋 !

And I just woke up!!

We are not alone!! 🤝

We are in this fight together!

The Great Debate

By Elyse Runacre

Last Month, I asked the question....

When your DLA benefit was changed to P.I.P, did your award/money change?

For those who lost their award - Did you lose anything else (Blue Badge, Mobility car etc.?)

The result:

19 People responded as follows to the question. Thank you.

INCREASED - 8

DECREASED - 9

STAYED THE SAME - 2

Below are some of the comments we received:

“Had to take it to a tribunal, which was awful. The court upheld the DWP’S decision so I lost money, car and blue badge.”

“I was lucky. At my assessment, I had a lovely lady who knew all about fibromyalgia. She was very understanding and listened to what I had to say.”

We also asked...

When you claimed for benefits (D.L.A, P.I.P or ESA) did you have to appeal the DWP’S decision?

The results:

87 responded as follows. Thank you.

No	Yes ESA	Yes DLA	Yes PIP	Yes ESA & PIP
30	6	8	38	5

These are some of the comments that we received:

“It was a terrible experience.”

“It took quite some time to get an appeal date. However, they were really nice. I won daily living but lost mobility.”

“Had to appeal when I first claimed for DLA, but didn’t have to when benefit was changed to P.I.P.”

“I didn’t have the energy to appeal.”

“I live in Ireland and had to really fight my corner to get Invalidation Pension.”

“I think the fact that I taped my assessment helped me but it was still a horrible experience.”





Nature`s Pharmacy



Mother Nature has provided us with a whole range of plants/herbs which not only look/ taste nice, they also provide us with many ways of helping us to live a healthier life. Many plants/herbs have medicinal properties. The aim of this column is to inform you which plant/herb helps with pain/sleep or any other symptoms that we experience and to show you how to use them.

GINGER.



A flowering plant that originates from China. This wonderful plant is one of nature's stars. Loaded with powerful nutrients which has benefits for your body and brain.

Ginger can be used Dried, fresh, as an oil, juice or powdered. The unique taste and fragrance comes from its oils. Gingerol is the most important of all. This is the main bioactive compound and is responsible for much of its medicinal properties such as anti-inflammatories and antioxidants.

Medicinal uses-

- ◆ Nausea & vomiting – sea/morning sickness, post-surgery, cancer patients undergoing chemotherapy.
- ◆ Muscle pain.
- ◆ Joint pain.
- ◆ Lowers blood sugars.
- ◆ Keeps heart healthy.
- ◆ Indigestion.
- ◆ Menstrual pain.
- ◆ Lowers Cholesterol levels.
- ◆ Improves brain function – reaction times, memory.
- ◆ Relieves oxidative stress.
- ◆ Helps fight infections.

Ginger extract is being studied as an alternative treatment for several forms of cancer. 6-gingerol is found in large amount's in raw ginger. It is this which is thought to contain the anti-cancer properties. There is some limited evidence that ginger may be effective against pancreatic/breast/ovarian cancer.

Ginger recipe's.

Ginger, Peach & honey green iced tea: (vegetarian. Gluten free.)



Makes 8 – 10 cups.

TIP- freeze the ginger. Makes slicing easier and keeps longer than when placed in the fridge.

1 tsp shaved fresh ginger.

4 green tea bags.

4 large peaches.

1/3 cup honey.

8 cups of hot water.

1. Bring water to a boil and take off the heat.
2. Pit & slice the peaches. Place the slices in a pitcher.
3. Slice the ginger as thin as possible (use a potato peeler) add to the pitcher.
4. Drizzle the honey into the pitcher.
5. Tie the tea bags to the pitcher handle and place the bags into the pitcher.
6. Add the hot water. Carefully stir everything and leave for about 15 minutes.
7. Remove the tea bags and stir slowly.
8. Leave to cool to room temperature then place in fridge until ready to serve

Creamy ginger pineapple slaw. (vegetarian).



Pineapple slaw –

half head red cabbage thinly sliced,
2 red peppers thinly sliced,
half a head of green cabbage thinly sliced,
3 cups of pineapple chopped into cubes,
1 cup of cilantro roughly chopped.

Creamy ginger sauce –

1 cup of soaked cashews,
half a cup of water,
1 tablespoon plus 1 teaspoon of lime juice,
2 inches of fresh ginger,
half teaspoon of red pepper flakes,

1. place cashews in a bowl of water and leave to soak for at least 30 mins (overnight if possible)
2. drain and rinse the cashews. Place these and all the other SAUCE ingredients into a blender/food processor and blitz.
3. Into a large bowl, place the cabbage, pineapple, red peppers. Add the sauce and mix well.
4. Stir in the cilantro and serve.

Recommended –

Natural remedies by Laurel Vukovic (Amazon price £9.98)

Herbs that heal by H K Bakhru (Ebay price £ 6.09)

www.naturalremedies.org

All remedies should be used responsibly and in moderation. If you are taking any prescribed medications check with your local pharmacy that it is safe to take any extra supplements. Please always check with your Doctor before you self-medicate with any regularity.

Sources- www.authoritynutrition.com recipes from Pinterest.

By Elyse Runacre

Check out our Online Store

www.fibro-flare-shop.myshopwired.com/



Fibro Flare Magazine Shop sells many products to help raise some much needed funds for research and awareness.

Plus much more

Did You Know?

Our leaflets have been taken by The Royal Bath Hospital.

Q. Where does your money go?

A. Every item bought contributes to our awareness/research funds enabling us to do even more to help the fibromyalgia community.

Donations are always welcome and can be sent via our online shop also.

T-shirts and Hoodies can be found at: <https://teespring.com/stores/fibro-flare-clothing-store>



Various sizes and colours available.

Poem's by - Kayt Gibson

Autopsy

This isn't it.

This isn't the life I wanted, for me, for us.

The pain, the loneliness of constant pain.

The aching in my chest for a life not lived, merely survived.

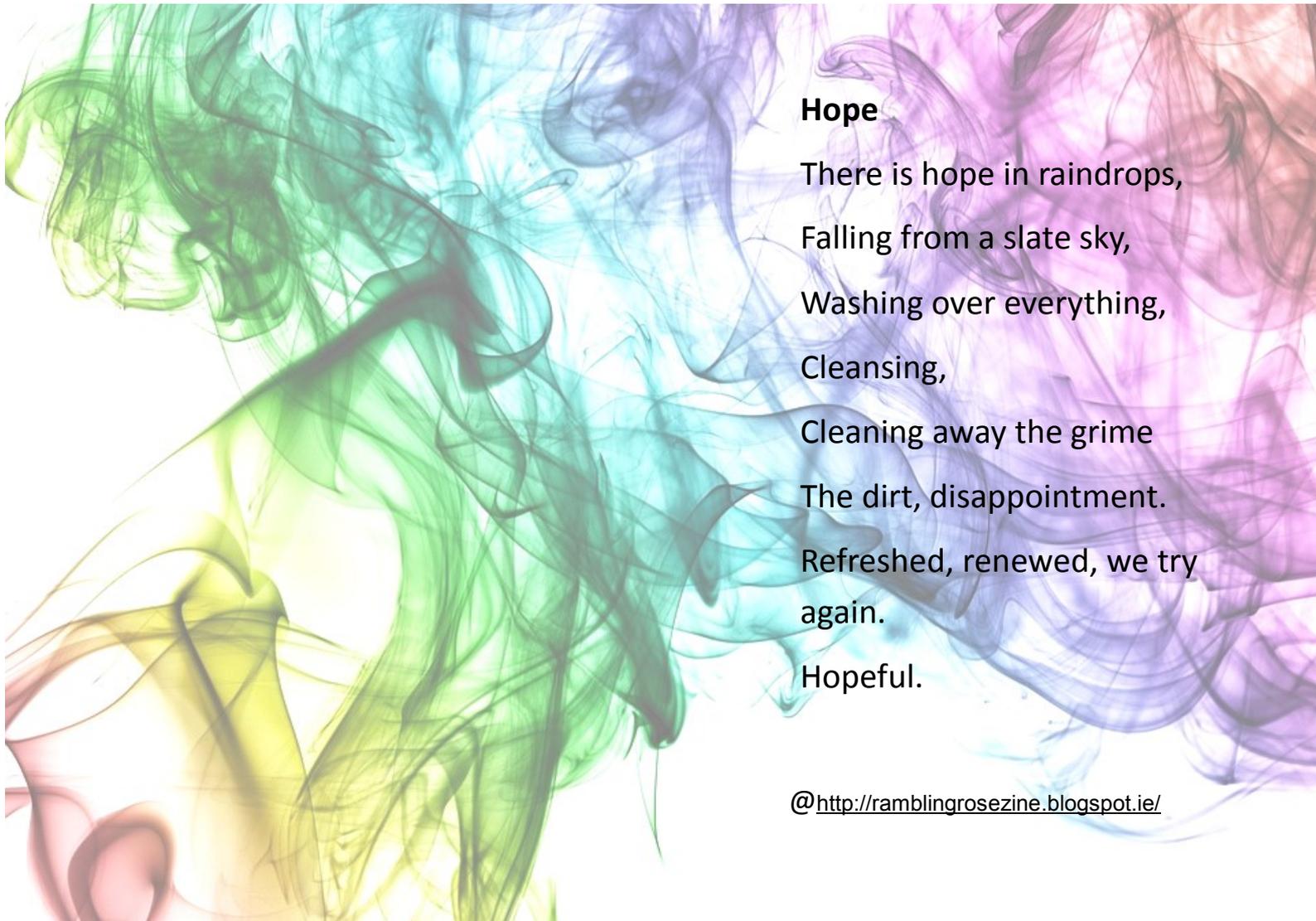
Waking each morning it starts before I can open my eyes,

Gnawing at my self-worth, my fight being drained from me.

Sometimes it's all I can do to keep breathing.

In, out.

@<http://ramblingrosezine.blogspot.ie/>



Hope

There is hope in raindrops,

Falling from a slate sky,

Washing over everything,

Cleansing,

Cleaning away the grime

The dirt, disappointment.

Refreshed, renewed, we try
again.

Hopeful.

@<http://ramblingrosezine.blogspot.ie/>

Meditation

By Elyse Runacre

Meditation has been used in Eastern cultures for several thousand years. Here in the West it is fairly new (70 years or so). There are many forms of meditation and it is practised for a variety of reasons. Some use meditation for contemplation, some for self-awareness and others for healing. In the West, it is commonly used to relieve stress. Meditation is being used as part of mindfulness/CBT programs to help people manage chronic pain.

As FM/ME/CFS patients, we all know that stress can trigger flares and make our symptoms/pain worse. This time last year, I took part in a pain management month long residential programme which is run by a London hospital. The entire programme is centred on mindfulness and meditation is a part of that. For me meditation was one of the best things about the programme and I still meditate every day. I am a self-confessed stress head, with 5 children, our many pets, voluntary work etc.; it doesn't take much to set me off. So, taking time out just for me each day is a new concept for me. But it not only helps me to relax (which in turn helps my body/muscles to relax), it also helps me manage my pain as well as other symptoms such as headaches and dizziness.

What is meditation?



It is a state of complete peace that occurs when the mind is calm and silent yet completely alert. Meditation is not easy to master, but persevere and it may turn out to be the most rewarding thing you ever do. It takes practise to achieve a peaceful state of being.

There are many books, cd`s, websites which can help you find which type of meditation is for you.

www.getthehealthyu.com

www.stopandbreathe.com

www.theconsciouslife.com

www.thequietmindsystem.com

There are also apps available for your mobile phone. I like Buddhist meditation trainer.

YouTube also has a fantastic selection of step-by-step guides.

Meditation tips for beginners-

- Establish regular practise – Realize the importance of your daily meditation and fully embrace it mentally and emotionally.
- Set aside 15 minutes every day to meditate. Be patient as meditation grows stronger with practise.
- The morning is a good time to meditate. It's easier at the beginning of the day to quiet your mind.
- If you decide to meditate in the evening, try doing it after you've had a relaxing bath.
- Find a quiet calm place to meditate. Free from distractions, drafts, bright lights etc.
- Make yourself as comfortable as possible. Fidgeting is very distracting.
- In the beginning using aids such as candles or meditative music may help establish your attention.
- Meditation is about letting go and surrendering to your inner silence.



Meet the Trustees

Chair – Beth Urmston

Sian Phillips



Julie Britten



Sara-Louise Williams



Cath Farrer



Acting Trustees – Adrienne and Leeann Lakin



We are committed to doing everything we are able to raise awareness and funds for biomedical research.

We are currently in discussion with a couple more members with a view to them joining the team. We are growing, and as we grow we will need more people on board. We will be looking for more people who have fibro but also non fibro's.

Our meetings take place via Skype as we all live in various parts of the country. Our accounts are available to anyone who would like to see them and are also submitted to the Charities Commission annually.

We still need members on board to help us achieve our aims ... help us raise more awareness, together we can make a difference.

Arts and Crafts

By Ailsa Bancroft

A paper lantern ready for a party or a picnic

Your will need:-

Yellow tissue paper

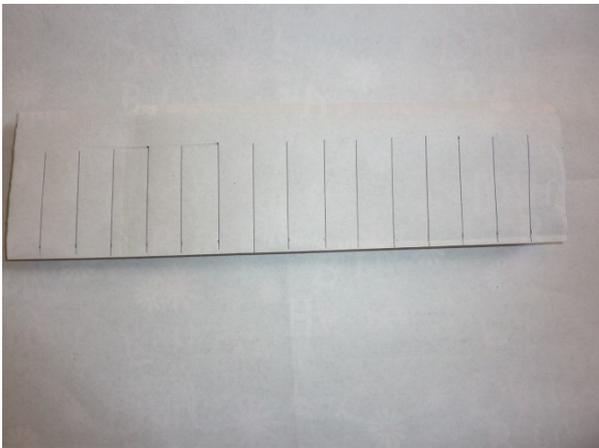
Stiff paper (I used wrapping paper)

Scissors

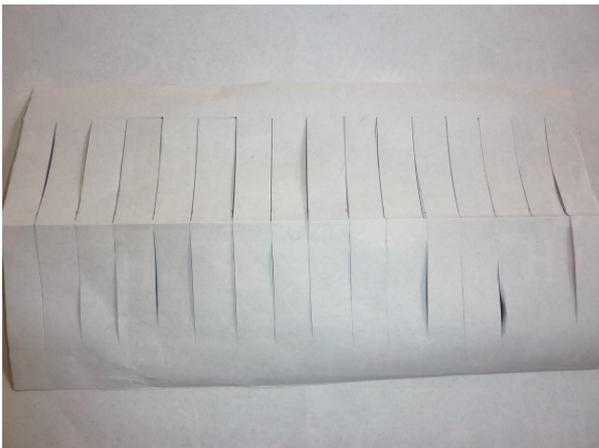
Stapler



1 Take a rectangle of stiff paper approximately 6 1/2 inch by 9 inches



2 Fold the paper in half then mark intervals of $\frac{3}{4}$ inch from the fold line leaving about 1 inch for the rims of the lantern.



3 Cut the lines

4 Turnover and fold in half again



5 Roll the paper to make a lantern shape and staple into place



6 Take a couple of pieces of yellow tissue paper approx. 13 inches by 51/4 inches and roll to make a cylinder shape then place inside the paper lantern to represent the light.



7 Staple into place

8 Cut a strip of paper for the handle and staple into place



9 Hang on some string and hang round the room or around the garden ready for a party or a picnic.

******* FOR DECORATION ONLY DO NOT ADD CANDLES *******

Invisible Disabilities

Vs The Benefit System

My experience by Hazel A'Hern

For nine years, I worked as a support worker in a homeless hostel and a resettlement worker in the community to prevent homelessness (one post doing two jobs!) 8 years into my job (which I loved) I became ill, the diagnosis – Fibromyalgia. I was left unable to work and spent the last year of my employment on sick pay until it was agreed that as I could no longer do my job, I should leave. Even though my employers didn't know anything about Fibromyalgia at that time, they were really supportive.



One aspect of my job had been to support and assist clients when they applied for all types of benefits and I regularly went on benefit training courses. But when I applied for ESA, filling in those forms for yourself it is really hard. In the end, I had to ask my sister to help. When I sent my ESA claim form back I included letters from my GP and the Rheumatologist, who had made the diagnosis. Luckily when I went to my appointment for my assessment the centre

was only 5 minutes (drive) away and my sister drove me there. Once there, the Doctor that I saw knew all about FM and was very nice and understanding.

This resulted in my claim being successful and I was put in the WRAG group for 2 years. I have continued to be put in this group every 2 years without being asked to fill out any further forms. From receiving the forms to the first payment being made, the process took about 6 weeks. I found the process stressful and it caused me so much anxiety. Nobody that is sick should have to go through these assessments. ability rate and middle rate for daily care for 2 years. The entire process took almost a year.

When it came to applying for DLA, I struggled with the forms once again. My application for DLA was turned down based on the form (you didn't have assessments then) so had to travel to attend an appeal tribunal which was awful and left me feeling totally worthless. I felt judged and looked down upon; they made me feel like a fake. I won the appeal being awarded low mobility rate and middle rate for daily care for 2 years. The entire process took almost a year.

Then when the DWP changed DLA to P.I.P and I had to reapply. This time the form was too hard and I asked my sister to complete it for me, as the questions that are asked don't fit every condition/illness. The assessment for P.I.P was done at home. The lady who came to do the assessment did not state what her job title was and I didn't ask. Straight away she said that she could see that I was in pain and anxious. She told me not to be as she had assessed people with FM before. Throughout it I felt listened to and she had a good knowledge of FM. My sister was with me and helped me to explain myself properly and when I was asked how far I could walk my sister replied that the question was difficult to answer as I can't take any pain medication. So, when I walk I'm in constant pain. The assessor stated that the question didn't fit everyone and that she would work out how to put a suitable response in her report. I got enhanced mobility and care for 6 years. This time the process took 12 weeks. Claiming P.I.P was a completely different experience from when I claimed DLA. Having my sister help me and an assessor who completely understood my condition and who didn't pre-judge or disbelieve me at any point made all the difference.

Interviewed by Elyse Runacre.



Helping Ourselves - Alternative Therapies



Members are always looking for alternatives or something to supplement their medication to alleviate the pain of fibromyalgia. Below are the more common therapies used that have been found to help some. As always some work better than others, because as we have all learned – we are all different. Most of the following are not available on the NHS and have to be paid for privately but don't be put off looking and giving consideration to any/all of these.

Magnesium

A note from Dr. Briden on Magnesium (Mg), Thyroid and Hormones:

As my patients can tell you, I prescribe magnesium for almost every hormonal condition. I prescribe it for PCOS, thyroid, adrenal fatigue, hair loss, PMS and menopausal symptoms. I love magnesium because it makes people feel better almost immediately.

What is up with this mineral? Why are we all so deficient? We're deficient because our cells dump Mg during stress. We actively push the mineral out of our bodies as a way to rev up our nervous system and cope with daily life.

A revved up nervous system is what an average modern human needs to get through an average modern day. If you work, or commute, or drink coffee, or worry, then you are deficient in magnesium. If you live the meditative life of a monk on a mountainside, then you're probably Ok.

8 ways that Magnesium Rescues your Hormonal System

1. It regulates cortisol. Magnesium calms your nervous system and prevents excessive cortisol. Your stress hormonal system (called HPA or hypothalamic-pituitary-adrenal axis) is your central hormonal system. When it is better regulated, then your other hormonal axes – thyroid and sex hormones – will function better.
2. Mag lowers blood sugar. Magnesium is so effective at sensitizing the insulin receptor that I refer to it as our 'natural metformin'. Better insulin control means fewer sugar cravings. Healthy insulin sensitivity is important for weight loss and PCOS, and it also prevents osteoporosis.
3. It supports thyroid. Magnesium is essential for the production of thyroid hormone. It is also anti-inflammatory, which helps to quiet the autoimmune inflammation that underlies most cases of thyroid disease. (Other ways to address thyroid autoimmunity include gluten-elimination and a selenium supplement.)

4. It aids sleep. As I've written here before, magnesium is the great sleep-promoter, and sleep is crucial for hormone production. Sleep is when we should have a surge in anabolic hormones like DHEA and growth hormone.

5. It fuels cellular energy. Magnesium is so intricately involved with glycolysis and the Krebs cycle (ATP energy production), that we can safely say: "There is no cellular energy without magnesium." Glandular tissue like thyroid, ovaries and testes is metabolically very active, so requires even more cellular energy and more magnesium than other tissue.

6. It makes hormones. Magnesium is involved in the manufacture of steroid hormones such as progesterone, oestrogen and testosterone. Magnesium has been shown to reduce hot flashes by 50%.

7. It activates vitamin D. Without enough magnesium, vitamin D cannot do its job. Conversely, too much vitamin D supplementation can cause magnesium deficiency.

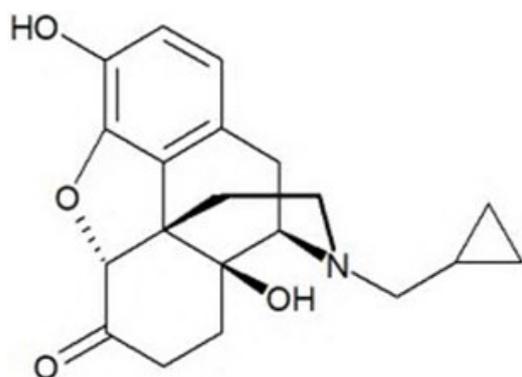
8. It is anti-aging. The mineral has been shown to prevent telomere shortening, reduce oxidative stress, and enhance the production of glutathione.

Magnesium is powerful medicine.

Mg is a big player in emergency rooms, where it treats heart arrhythmias, heart attack, migraine and the toxemia of pregnancy. But why should magnesium be restricted to acute care emergency medicine? It is time – past time – for magnesium to take up its role in treating chronic conditions.

For more information on magnesium this video link is worth a watch.

<https://www.youtube.com/watch?v=d55y4yOnn3c&t=26s>



LDN (Naltrexone in low dosage). LDN is an opiate blocker and most definitely not an opiate. It is not illegal and is a licensed medication purchased via a pharmacy. For more information check out the charity website and Facebook page. There are thousands of video testimonials and they have a weekly radio show.

Facebook: (18,000+ members) - https://www.facebook.com/groups/LDNRT/?ref=br_tf
Website: <http://www.ldnresearchtrust.org/>

CBD Oil (Cannabinoid Oil). CBD is not illegal in the UK but is in some other countries. For more information check out what the users say.

Facebook: (10,000+ members) - <https://www.facebook.com/groups/CBDusersUK/>





Hyperbaric Oxygen Therapy (HBOT) – This is proving to be extremely beneficial to some fibro patients and has good research results in many countries. It's not as expensive as you may think. For more information and to find a centre near you check out –

<https://www.hyperbaricoxygentherapy.org.uk/faq>

<https://www.hyperbaricoxygentherapy.org.uk/find-chamber>

Golden Paste (GP, made at home with organic turmeric, coconut oil and black pepper). Great for inflammation. Works for humans and animals so if you have a pet this is definitely worth looking into. For more information and user comments.



Facebook: (220,000+ members) - <https://www.facebook.com/groups/415313751866609/>



N:rem

sleep system

Thank you for becoming an N:rem Affiliate

We are thrilled to welcome you to the N:rem family as one of our Affiliates!

When one of your audience purchases an N:rem mattress with your unique voucher code you will receive £30. The customer too will receive £30 off their order.

The N:rem Affiliate Scheme will launch 8th August 2016

Add in this code at check out to get £30 off your order :



FIBROFLARE

Information on the N:rem Mattress



- 3 different densities of deep reflex foam tablets in firm, medium and soft.
- Ideal for chronic pain sufferers to provide comfort for painful areas and support where needed
- 40mm Viscoool foam comfort layer with an open pored structure to regulate body temperature
- Each reflex foam tablet is easily interchanged in the comfort of your own home

- Personally tailored options on each side of the bed allows you and your partner to have individual set ups
- 2,000 springs for added comfort and bounce
- Natural cotton cover aiding a cool night's sleep
- Both the quilted cover, viscoool layer and foam tablets can be easily removed for cleaning



[Find out more information
on the N:rem Mattress](#)

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Can Love survive Fibromyalgia/CFS/ ME?

Living with an invisible chronic condition has a major impact on not only the life of the patient, but it also impacts the lives of those we love; Partners, Children, other family members and Friends. The stress, lack of understanding and sometimes even thinking that you're "faking it" (as there is no test to prove the diagnosis) can all contribute to the breakdown of your relationship. The day-to-day chores within the home, childcare, and sometimes extra financial burden can often fall on the shoulders of your partner. You may also need your partner to help you with things such as bathing/dressing etc. This can be very awkward and time consuming for both of you. Whilst at the same time we can become frustrated with our limitations set by our conditions which can make us snappy and miserable. All of which in turn can lead to resentments for both of you.

Having watched my own personal relationships suffer (sometimes irrevocably), I wanted to know if I was alone in this emotional storm.

Deciding to start with Partners, I asked our Facebook members –

[Has your relationship ended under the pressure of your chronic condition?](#)

70 People responded to the question. (Thank you). Of those;

12 said **YES**,

43 said **NO**.

12 said – **caused problems but we worked through it.**

3 said – **it was a contributing factor to the breakdown.**

My advice (for what it's worth) is to try to remember to let your partner know that you appreciate all their help. When you're experiencing extreme pain, or feeling tired/frustrated try not to take it out on them. On your "good days" do something nice for them.

By Elyse Runacre.

Giving independence back

Pinpoint provides motorists with stress-free refuelling at the pump



Simply press the button on the Pinpoint key fob to alert filling station staff that you need assistance. A signal comes back to reassure you that someone is on their way. Stay in the driving seat while a friendly member of staff refuels your car. What could be simpler?

Endorsed by Disabled Motoring UK and attracting fantastic feedback, Pinpoint brings great service direct to your car for stress-free refuelling.



For more information check out <http://www.pinpointbycontacta.co.uk>

Living and Working With Fibromyalgia

By Liz Ashfield

I run my own company with my partner, Andy. The name of the company is our own names: "Liz Ashfield & Andy Faulkner". We are stamp dealers. Andy and I are equal partners and have been going for just over 20 years.



The numbers of hours that I work per week vary a lot so I cannot really give you a definitive answer for this one. As we live together and work together the work fits around everything else. For example, we might be out during the day but will both work all evening. Sometimes one of us is working and the other isn't.

I received my diagnosis about three years ago but have been ill for many years. I can trace fibro symptoms back as far as when I was a teenager (I am now 56).

Daily duties: dealing with admin, doing our accounts, purchasing stock, sorting stock, cataloguing stock (stamps), pricing them, doing mail order, preparing for trade fairs.

Apart from the two of us, we have another lady who helps us out at some of the bigger stamp fairs.

Fibro affects my work. In the past Andy and I used to do the fairs together. I had to stop as my feet hurt too much (the fairs require a lot of standing) and the rest of me hurts too much. As a result of this, we have had to take somebody else on to help Andy at some of the fairs.

I have to work on my own now; I get flustered if somebody else is around so I have to shut myself away. I am unable to do as much as I used to. I'm not as well organised as I used to be. I also find it difficult to talk on the telephone so Andy has to do most of the telephone answering and ringing. I have less patience now as well.

Apart from stamp fairs, we both work from home. I could not work 9-5 hours, so I do choose my own hours. I am usually better able to work in the evenings.

We only take short holidays but this is by choice. Since I have gotten worse, I find it difficult to be away from home. Three nights away is the longest that I can cope with as I find I get very homesick and miss my cats. It takes me much more effort to take a holiday than to be at home working. If we are at home we do tend to work if we are not doing anything else but we do both enjoy our work.

As stated earlier I have had to give up doing stamp fairs. In addition I try to pace myself by doing one hour's work followed by 20 minutes resting (which for me is usually watching 20 minutes of something recorded on TV). I have to write lists partly so that I remember what I have to do and partly to help me pace myself. I do need to commit everything to writing as I cannot always remember. I try and spread long jobs over a period of time, e.g. do some today, some more of it tomorrow, etc. I have to play music whilst I work or my attention will wander.

Stress - not too bad. The only points of stress are doing orders (if somebody is pestering me) = 8 or getting tax and VAT returns done (8 if I'm late, otherwise not much). Sometimes I get stressed by the amount of work that has got to be done but the actual work causes me very little stress.

Obviously my partner knows about my illness and many people whom we come into contact with know.

Some have no idea what fibro is, some understand completely. One or two annoy me by saying, "Haven't you tried..." Most of our customers know that I'm not well and will not pressure me. I can cite the difference between two wholesalers that we have bought a lot from in the past. One, John, would constantly try and push stuff onto me. On one occasion, I said that I was feeling really bad, but he said "Oh just have a look at these" despite the fact that I had a crushing migraine. The other, Paul, brings stock to me and leaves it with me for as long as I need. You can guess which one I have kicked into touch and which one I still buy from.

I could reduce my hours if I wanted to but this would mean more work for my partner. I don't like the fact that he can put more into the business than I can and I do struggle with this.

I would not want to give up work altogether as it keeps me going. I would feel a failure if I had to give up. What would I do? I also think I would resent my partner's involvement. I would never ever want to stop being self-employed. I would hate to be at somebody else's beck and call. I do not think I would be particularly employable either.

Interviewed By Elyse Runacre.



Fibromyalgia Vs Work



For many, making the decision to leave our jobs on medical grounds due to FM/ME/CFS is very difficult. It is not something any of us just do. Apart from wanting to keep our independence and a sense of worth, our finances are often the reason we keep working for as long as we do. Some of us are lucky enough to have partners that are in a position to be able to support us financially. For those who are not so fortunate benefits are a scary prospect.

The stigma of claiming benefits unavoidable. The same narrow minded people that criticise us for using a blue badge bay in a car park will always have a lot to say about us `scrounging`. No-one in their right mind would choose to live on benefits unless there was no other option. Just because our medical conditions are invisible it doesn't give anyone the right to judge.

Finding out what you are or are not able to claim is the first hurdle. The DWP website is helpful and clearly presented, but seeing ourselves as ill or disabled is often a label that we just don't want to face. There are also other places where you can receive guidance and information.

The citizen's advice bureau are located in many local libraries now. You do normally need an appointment. They can also help you to fill out the application forms. There are also groups on Facebook that can be helpful. When I was working out my notice at work I joined And they were great.

There are different types of benefits depending on your personal circumstance. Each benefit for people that are sick also have different tiers, this is determined by the severity of your symptoms.

Whilst you wait for the forms to arrive start keeping a daily diary to show how your condition/s affect daily life. Make sure to report every aspect of your day. From the second you wake to trying to sleep at night. Not just the physical but also your mental issues - how well you do or don't communicate, how easy it is or not to read a book/magazine, whether you can follow a TV programme or film etc.

This is also the time when you need to contact your G.P./specialist to request copies of notes or letters of support. They need time to deal with your request. Please also note they usually charge for this as it is not NHS work.

The application forms are long and you are given 4 weeks to complete them. Here are some tips for dealing with these forms:

- Do NOT rush or leave them until the last minute.
- Read each question properly, making sure you understand it. The form will have a help booklet sent with it. (I found the booklet more confusing than the form as I was battling fibro fog) You can ring the DWP to ask for clarification; however I have always found ringing them to be a nightmare as you are on hold for so long). Again, you can ask CAB for advice or the online support groups.
- Take your time when answering but do not feel the need to waffle on either.
- Keep your answers clear.
- Check every answer.
- Each form has a part where you can add extra information - USE IT.
- Don't just focus on the big symptoms remember the smaller ones too. It's easy to just focus on pain & fatigue. But do you have sensitivity to light/sounds/smell etc.
- Ask a family member/friend to read through what you have written. Fibro fog/sleep deprivation has major effect on how we communicate.
- Make sure that you return the form back BEFORE the deadline.

By Elyse Runacre

NB: Some council's/housing associations have financial assessors/support workers who can also assist with benefits forms. With the CAB becoming inundated it may be worth asking your council rather than attempting yourself.
If you are struggling to get help with form filling, call the DWP and ask for an extension period (usually 2 weeks).



Department
for Work &
Pensions

Help Raise M.E Awareness

Sophie Rebecca Tennent had the idea to put a video together to show how many people are supporting those with M.E (Myalgic Encephalomyelitis). Sophie asked her own and our group to help and get family, friends etc. to send her pictures. Members didn't disappoint (several reminders were needed, but that's normal ha-ha).

SO HERE IT IS!! This year's M.E awareness video.

Myalgic Encephalomyelitis affects thousands of people worldwide so I set up a campaign to get as many people as possible to join in with helping raise awareness for M.E during M.E awareness month.

This was the result to it! I am overwhelmed by how many responses I got and at how many people wanted to join in with it! (Sorry if I've missed anyone out!)

<https://www.youtube.com/watch?v=j9fxlJpL-NI&feature=share>



So please watch and share this video and if you feel like helping make a difference, please donate to my just giving page where all donations will be going towards Research trails into M.E done by the amazing charity Invest in ME.

<https://www.justgiving.com/fundraising/Sophie-Tennent4>

PACE Trial latest

Join the Millions Missing and catch up on all the latest news – believe me there's a lot of progress being made and the controversial PACE trial debacle looks set to run for some time yet. The tables are being turned!

Patients HAVE the power to take PACE down but only if we can keep [David Tuller](#) on board!

Like SO many other ME patients, I've spent yet another beautiful sunny Summer day trapped in a dark bedroom thinking of things I'd have loved to be able to do.

I've also been thinking.....it does cost a lot of money to be chronically sick but at the same time, just think of how much we save on all the things we can no longer do because of this disease. Days out shopping, nights out partying, jet setting holidays, birthday/Christmas/anniversary/wedding parties, you name it, ME stops you having it!

Please read this amazing opportunity below and dig deep peeps!

DONATIONS ARE BEING TREBLED BY [Erica Verrillo](#)!!!

URGENT UPDATE, JUNE 17: As of today, David Tuller's Crowdrise campaign stands at \$49,000. This outpouring of support has been impressive! But with less than two weeks to go, we are down to the wire if we are going to make the \$60,000 goal. (If the campaign falls short, David will lose his health insurance.)

Erica Verrillo, ProHealth's ME/CFS editor, author of Chronic Fatigue Syndrome: A Treatment Guide, and founder of the American ME and CFS Society, a new national patient non-profit, is stepping forward at this critical time. She will TRIPLE any donations made during these final days up to a total of \$5,000. How does it work? If you donate \$25, for example, she will kick in \$75. The triple matching campaign will end when a total of \$10,000 is reached. It's that simple.

NB: PayPal will convert sterling to dollars.

Donate Here <https://www.crowdrise.com/virology-blogs-trial-by-error-more-reporting-on-pace-mecfs-and-related-issues1/fundraiser/daviddtuller>

85,000 doctors in the state of New York just got a wakeup call regarding ME/CFS courtesy of the New York Department of Health. The monthly letter from Dr. Howard Zucker, NY State Health Commissioner, presented ME/CFS as a serious disease told the doctors in the state to learn about ME/CFS and consider diagnosing it when they came across patients with debilitating fatigue. This is the first state to issue a letter like this to its physicians.

We applaud the State of New York for this important action.

Read more: <http://bit.ly/2sjVwa3>



Hope 4ME & Fibromyalgia

We have some very important news to share, with permission from the Health and Social Care Board Lead Commissioner for ME and fibromyalgia, Mr Iain DeBoys.

Dr. Ian Clements, Chairperson of the Health and Social Care Board has confirmed, ALL 365 General Practitioner (GP) practises in Northern Ireland will receive new updated informative on ME and fibromyalgia, including biomedical research, confirming the very physical nature of the diseases. This decision was agreed, by DOH officials attending the Stormont conference, immediately after the speaker's presentations!

Further, more detailed information will be posted as soon as possible, when confirmed.

We expect this breakthrough to happen within a maximum of 8 weeks after further negotiations with the commissioners and Public Health Agency.

Hope 4 ME & Fibro Northern Ireland has been bringing world experts and researchers from around the world to N.I. since 2011 to educate decision makers, it has taken six years to bring us to this welcome and much needed move by the Department of Health.

We can again thank this year's speakers at our 'Seeking Solutions for ME and Fibromyalgia' conference:

Professor Mella, Linda Tannenbaum, David Tuller and Dr. W. Weir, Dr. Christine McMaster and the others before them.

Previous educational conference speakers have included Professor Mark VanNess, Dr. Derek Enlander, Dr. Judy Mikovits, Dr. Vance Spence (MERUK) Dr. Gregor Purdie and Dr. Charles Shepherd (MEA), Dr. Pamela Bell, Louise Skelly (P&CC) and Dr. Joe McVeigh, who have presented educational information and ground-breaking research to the heart of our government and healthcare decision makers in Northern Ireland.

Thanks also to Invest in ME and the Irish ME Trust who have helped and supported our efforts in bringing international experts to Northern Ireland.

A more detailed report is being compiled on the speaker's presentations at our recent 'Seeking Solutions for ME and Fibromyalgia' educational event, held in Stormont government headquarters, Belfast, 30/5/2017

There is a video of the conference, costing £10 plus £2 p&p which is available through <http://www.alphavideoireland.com/shop/conferences/seeking-solutions-for-me-fibromyalgia-conference-dvd/>



Further Good News

We are delighted our application to become associate members of EMEA has been unanimously accepted.

A great day for our members and all who have supported us since the charity was first formed in 2011.

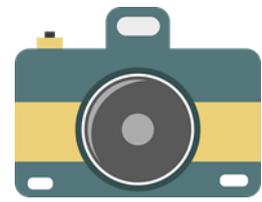
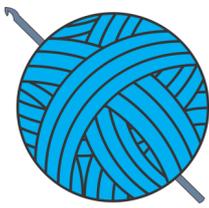
This brings EMEA's membership to 14 countries and 15 member countries, including Northern Ireland.

Thanks to Invest in ME also, for their continued help and support.



[Euro Mealliance to European ME Alliance](http://www.euro-me.org/news-Q22017-002.htm)

<http://www.euro-me.org/news-Q22017-002.htm>



CRAFTY CORNER

By **Melissa Cowx**



Even as a little girl I was into crafts. I can remember pinching my Moms scrap pieces of material to make teddy bears. Going to our local woods to collect fox skulls so that I could paint them. I choose to take Art and Textiles G.C.S.E in my teens.

However, my passion for crafts really blossomed when I was in a women`s refuge due to being a victim of domestic violence. The staff there used crafts as a therapy to help the vulnerable ladies in there. We would scrapbook and card craft. It helped me incredibly. Like opening a tube of Pringles, once you craft you just can`t stop. It goes from one craft to another.



Nowadays, I`m a self-confessed craft addict. I do my best to craft every single day, even if it`s only for 15/30 minutes it`s better than no craft at all. It`s my escape from my illness, depression and all of the other nasty little things that life throws at you.

Photography, glass painting, jewellery making, face painting, baking, crochet, drawing, colouring, paper crafts and sewing are the crafts that I currently enjoy. I don`t have a favourite, it`s more a case of whatever I`m in the mood for at that moment.



Everything around me in the world inspires me. From nature, to buildings to humans. Beautiful inspiring things are all around us. Using a variety of materials to bring my ideas to life. I buy my materials from anywhere and everywhere. I.E- Amazon, EBay, Hobbycraft etc. Things such as buttons, beads, wire, paper, card, paint wash, tape, glue the list is endless.



I did a face-painting course a few years ago. The course ran for 6 weeks. Following that I ran a face-painting business. Until Fibromyalgia raised its ugly head and said “oh no, that`s not allowed”. So, that was the end of that.

I set up my own little business selling my crafts. Unfortunately, I had to stop for a short period due to my health taking a turn for the worse. The pressure of work, being a single Mom with four children has added to my depression and illness. I prefer to craft for pleasure NOT pressure. I pick fault with everything that I craft/create.

Now that I`m crafting for pleasure it helps me in many ways. It helps to take my mind off the pain that I`m in all day, every day. I get a feeling of accomplishment, a sense of achievement. Crafting is a form of meditation and therapy and most definitely helps me. Doing a variety of crafts gives me a chance to rest – most other things drain my brain/body power. Which some days as fibromites we just don`t have. This is something that is just for me. Anything craft or art related that catches my eye, I will have a go at whether I`m good at it or not. I don`t like to follow patterns but I do use YouTube videos from time to time. Firstly, it`s free, which is always a bonus when money is tight and secondly, I find it easier than trying to follow a pattern. To make someone a gift that they love and seeing their smiles makes me

Interview by Elyse Runacre



GOING BANANAS

What do you call a man lying on your doorstep?

MATT.



Why is it so windy inside a sports arena?

All those fans.

What do you do if you see a spaceman?

Park your car.



Easy Fundraiser

Do You Shop Online?

Did you know that whenever you buy anything online - from your weekly shop to your annual holiday - you could be raising a free donation for Fibro Flare Awareness Group?

There are nearly 3,000 retailers on board ready to make a donation, including Amazon, John Lewis, Aviva, Thetrainline and Sainsbury's – it doesn't cost you a penny extra!

It's really simple, all you have to do is:

1. Join
Head to <https://www.easyfundraising.org.uk/causes/fibroflareawarenessgroup/> and sign up for free.

2. Shop
Every time you shop online, go to easyfundraising first, pick the retailer you want and start shopping.

3. Raise
After you've checked out, that retailer will make a donation to your good cause for no extra cost whatsoever!

There are no catches or hidden charges and Fibro Flare Awareness Group will be really grateful for your donations.

Thank you for your support.



Think
shopping,
think **easyfundraising**





Fibro Community

The link below is to a world map of others who have fibromyalgia. Add your name and location, find others near you. Local support can go a long way to alleviating isolation. It gives more chance of a meet up, if only occasionally and a local fibro friend who will understand.

There are several local groups listed at the back of the magazine, but there is a need for many more to be set up. If you would like to form a local support group – and this could be just for a coffee and a chat then contact Beth Urmston, fibroflaremag1@outlook.com.

It's a great way to help yourself whilst helping others and can give extra meaning to your life. Why not make a New Year's resolution to at least give it a try.

<https://www.diseasemaps.org/en/fibromyalgia/join-the-map/>

Fibromyalgia Map | Join

Map Satellite

Enter your location:

Example: **Park Ave, 10028 NY**

Find

Step 1/3: Select your location

By Beth Urmston

Making a Complaint

If you think you have been treated unfairly, or been disrespected there are a few avenues open to making a complaint. The following is taken from the NHS website:

There is a simple two-stage process for complaints about NHS services.

Your NHS complaint: what to do first

Every NHS organisation has a [complaints procedure](#). If you want to complain about an NHS service – such as a hospital, GP or dentist – ask the service for a copy of their complaints procedure, which will explain what you need to do.

You may choose to make a complaint in writing, by email or by speaking to them. If you speak to them, they may be able to resolve your concerns without you having to go through the formal complaints process.

This is called a local resolution. It aims to resolve complaints quickly, and most cases are resolved at this stage. However, if you don't feel comfortable raising your concerns directly (or your problem wasn't resolved) and you would still like to make a formal complaint, follow the [NHS complaints process](#).

You may make a complaint to either the organisation that provided your healthcare or the organisation that commissioned that NHS service. The commissioning body will be either the local [clinical commissioning group \(CCG\)](#) for hospital care, or NHS England for GP, dental, pharmacy and optical services.

Time limit for NHS complaints

You should make your complaint as soon as possible. The time limit for a complaint is normally:

- 12 months from the date the event happened, or
- 12 months from the date you first became aware of it

Patient Advice and Liaison Services (PALS)

You can get help and advice from Patient Advice and Liaison Services (PALS), whose officers are available in most hospitals. They offer confidential advice, support and information on health-related matters to patients, their families and their carers.

NHS Complaints Independent Advocacy Service

Individual local authorities have a legal duty to organise independent advocacy services to provide support for people who are making, or thinking of making, a complaint about their NHS care or treatment. Find details for [your local council](#) on the GOV.UK website

Contact your local [PALS](#), complaints manager or local authority for information about how this service is provided in your area.

Citizens Advice Bureau

You can also get advice and support from your local Citizens Advice Bureau if you want to complain about the NHS, social services or local authorities. See their website for information on [how to get advice from the Citizens Advice Bureau](#).

Other options for making a complaint

If you feel too uncomfortable to complain to the service provider directly, you can make a complaint to the commissioner of the services instead. NHS services are commissioned, planned and paid for by either NHS England or clinical commissioning groups (CCGs).

If you're unhappy with the response to your complaint after trying a local resolution, another option is to complain to the [Parliamentary and Health Service Ombudsman](#). The ombudsman carries out independent investigations into complaints about government departments, their agencies and the NHS. You can call the ombudsman's complaints helpline on 0345 015 4033 or see their website for more information about [contacting the ombudsman](#).

You can also raise your concerns by contacting regulatory bodies, such as the [Care Quality Commission](#).

For more information, see [about NHS complaints](#).

<http://www.nhs.uk/chq/pages/1084.aspx?categoryid=68>



disabledviewuk@yahoo.com

@disabledviewuk

DisabledViewUk was set up out of a group discussion between Caregiver's and Disabled People who were and still are concerned about the many systemic failings in our Society to date.

There are far too many Issues that are affecting the wellbeing of Disabled People and Caregivers, with a proper consultation in place, a lot of safeguards could be reached and established to prevent the many of the Issues being experienced currently.

3 major key factors have come to light and this was the grounds for the foundation of DisabledViewUk.

- Independent Disability Commission
- Positive Pathway Programme
- National Support group for Disabled People, Caregivers and Advocates

DisabledViewUk provides: Crisis support, member enquiry support, welfare advice support, we also contact Government departments, Agency and Charities when required. We have supported members in highlighting their cases, raising them when required too parliamentary level. To date we have had 100% positive outcome on every case we have supported.

We have consulted on Government consultation at local and national level.

As National Group DisabledViewUk is growing in membership every day.

We are speaking out against the reforms as they stand, due to the systemic, on-going and fundamental failings. We are requesting a reconsideration of policies involved.

Our main objective for 2016 is the foundation of The Independent Disability Commission, we are preparing draft document and calling for a National a consultation and discussion. We are non-political group looking to encompass the views of Disabled People, Caregivers, Charities, National Government, Local Government Bodies, all Political Parties, Employment Sectors, Health Sector, NHS, wellbeing and Social Care Agencies within the UK.

To provide a Positive National Platform in Addressing, Establishing and Supporting the Rights of Disabled People and Caregivers.

Warm Home Discount Scheme

Extra help with gas and electricity bills during the winter months for pensioners and other vulnerable people from the Warm Home Discount Scheme.

<https://www.citizensadvice.org.uk/consumer/energy-supply/help-if-you-re-older-disabled-or-on-a-low-income/warm-home-discount-scheme/>

It has been confirmed the Warm Home Discount has been extended until 2021, with a yearly review. Applications for the core group should begin in July, the broader group in October.

Also, the discount is applied to your electricity account, not gas. If you have a pre-payment meter, you will be sent a voucher to use to top up. Occasionally, the shop will put £70 on each but they aren't supposed to.

Core Group = Pensioners. They are automatically getting paid each year, they check the data with DWP. Only when they have been paid, do applications open for the broader.

Broader Group = low income, DLA, PIP, children). Broader group funding is limited so it's first come, first served - and each energy supplier will have their own criteria.

Each energy supplier has its own criteria for the broader group. Anyone needing clarification should contact their own energy (electricity) supplier.

Help for people on a low income - the Social Fund and other welfare schemes

Information on community care grants, budgeting loans and crisis loans, and maternity grants, funeral payments and cold weather payments.

<https://www.citizensadvice.org.uk/benefits/help-if-on-a-low-income/help-for-people-on-a-low-income-the-social-fund-and-other-welfare-schemes/>

Groups

Groups we are affiliated to who help and support us:

Dubbo Fibromyalgia Support Group -
<https://www.facebook.com/DubboFibromyalgiaSupportGroup/?fref=ts>

Fibro Family – You’re Not Alone –
<https://www.facebook.com/groups/1645989475667771/>

Fibro Social Club UK –
<https://www.facebook.com/groups/760266097417614/?fref=ts>

Fibro Support UK –
<https://www.facebook.com/groups/818013851580139/>

Fibromyalgia Awareness and Advocacy, Ireland -<https://www.facebook.com/groups/fmawarenessadvocacy/>

Fibromyalgia Meet Up and Support, Leicester
<https://www.facebook.com/Fibromyalgia-Meet-Ups-and-Support-Leicestershire-907503995937440/?fref=ts>

Folly Pogs Fibromyalgia Research
<http://www.fibromyaliasoutheast.org.uk/index.html>
<https://www.facebook.com/FollyPogsFibroResearchUk/?fref=ts>

Hope 4 ME and Fibro, N. Ireland –
<https://www.facebook.com/groups/newryandmourne.me.fms/>

Juvenile Fibromyalgia Group –
<https://www.facebook.com/groups/JuvenileFibromyalgiaUKSupport/>

Sophie’s ME Awareness Campaign –
<https://www.facebook.com/groups/851991271478504/>

FIBRO FLARE MEET UP GROUP
Don’t forget to check out our new group – putting you in touch with others in your area. <https://www.facebook.com/fibromeetup>

Blogs

Donna Gregory Burch - <http://fedupwithfatigue.com>

Sally K Burch - <http://sallyjustme.blogspot.co.uk>

Important Notice

By Beth Urmston

We have a bank account where you can transfer funds using online banking. This means you do not have to use PayPal and will net us more of your donations as we will not have to pay their fees.

Donate or pay for goods direct to the bank – when you pay £5 we will receive £5.

Donate or pay for goods via PayPal – when you pay £5 we receive an average of £4.63.

Our accounts are handled by Kate Lis who is a volunteer.

For bank account details please contact Beth Urmston

When making payments please add your initial and surname (e.g. B Urmston) in the reference.

NB: This only applies to UK donations and payments. Overseas members should continue to use PayPal as bank charges for transfers from overseas cost approximately £25 per transaction.

To ensure we remain safe and legal we will in future request that all PayPal payments for Goods/Services are dealt with as such.

We will have to forego approximately 5% of contributions but we hope to still be able to make the most of every penny we do receive.

If you would like more information or help when making payments please contact Beth and she will be happy to guide you through the process.

Our PayPal account is fibroflaremag1@outlook.com

Remember to use Goods/Services when making payments.

The PayPal logo is displayed in a large, blue, italicized font with a trademark symbol.



To all our regular contributors, our wonderful readers and everyone who has done anything to raise awareness in whatever way they were able this month and especially to those who donated.

Disclaimer

The information provided within the magazine is for information and should not be used as an alternative to seeking the advice of a medical professional.

In case of emergency call:

UK: 999. For out of hours advice, ring 111.

USA: 911.

EUROPE: 112. This emergency number applies to all European countries.

Links to other sites are provided for information only and do not constitute endorsements of those sites or any of the content or opinions provided therein.

The information contained within the magazine aims to be as accurate as possible at the time of publishing. The information contained herein is for support and general advice only. Readers shall not hold Fibro Flare Magazine, or any associated persons or entities, liable for any use or misuse relating to the information provided.

Readers should always consult with their medical practitioner regarding their own specific health issues.

It is assumed all contributions, articles etc for inclusion in the magazine are those of the individual contributor or do not break copyright laws. Neither Fibro Flare Magazine nor any of its associates can or will be held responsible for these items.

E&OE

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