



# Phoenix

Newsletter of The Central Lancashire ME/CFS Support Group

Patron: Doctor J Roberts

Charity no. 1106333

May 2018 issue

Inside this issue:

AGM News

Support Group and Local News	2
General information	
Local News	3
In Memoriam	
Support Group and Local News	4
National news	
Let's lighten the mood! "Alleged" humour!	5
Let's lighten the mood!	6
Recipe. Sudoku	
Meetings & Social Events / Craft News	7
Office Details Other Useful Contacts Help & Advice	8

We are very happy to report that provision of ME/CFS services as part of the 'musculo-skeletal service', assigned by the Clinical Commissioning Groups of the NHS for Preston & Chorley & South Ribble, is now definitely happening. The contract has been awarded to Lancashire Care Foundation Trust with a starting date of 1st August. At this early stage there are no exact details of how the service will work, but we are in close touch with LCFT and will keep you informed of progress as soon as possible. This is a huge step forward for the recognition of ME and its potential treatment, and by grouping "us" with rheumatology, pain management and other like conditions, we should at long last see some action on tackling the effects of 'our' illness. Watch this space!

We will still need to continue to give support to members in ALL the areas we cover and ,despite the increasing demand for our services , we will try to do this as well as we can with our limited resources. Our 3 year Lottery grant ended on the 31st March; this enabled our support workers to provide you the members with a wide range of benefits , from organising lunches to photography & craft groups, 1-2-1 support on the phone or e-mail, to providing transport to appointments/tribunals etc and much more besides. We must record our greatest appreciation and thanks to Lynn and Helen who have not only seen to all these things but have also spent many hours behind the scenes doing clerical work, networking with 'officialdom' and other charities and giving extra time to make our services as strong as possible within the financial constraints we have. Without them we would not be where we are today!

We are of course seeking to replace that funding with other grants. This is an ongoing process that takes much time to get a result, so for the next few weeks until something is found, we are entirely run by volunteers which means that we can only provide what someone is willing to help with (including searching for funds!). In this newsletter you will find tributes to Audrey Atwood, a pioneer in developing support for ME in East Lancashire ,and a shining example of what can be done. If you know of anyone who can help us in any way, especially if they DON'T have ME, please let us know. Spread the word on social media, tell your family & friends, someone will be out there who can help us to keep getting stronger, it's just a matter of letting them know !

Our AGM is on Wednesday June 13th at 1.30 p.m at Galloway's Penwortham with a minimum of 'official business!' . We have invited a representative from LCFT to talk about their proposed services, Dr Roberts our patron will hopefully be there, and there will be hand or foot massage available as well a craft table and refreshments. Please come and support us to support you.

*Kindest regards.... the Central Lancs M.E./CFS Support Group Committee*

*(Just to add a personal "editor's comment" to the above... I too have had to battle personal challenges recently, meaning that this newsletter is later... & a little shorter... than we would have hoped. Apologies for this, but can we ask again if anyone might be interested in working on the newsletter, both to help during tough times, but also, to offer different perspectives than are obtained from one contributor? I must also add my personal thanks to the support team, particularly Lynn, who has managed to get the newsletter out at the "last minute" at times, when I have been unable to "hit editorial deadlines!")*

**Disclaimer**

**The information presented in this Newsletter, particularly concerning therapies, treatments etc, are described for information only and should not be taken as a recommendation or advice. Before acting on information, please research items personally and consult with your GP or other medical professional.**



LOTTERY FUNDED

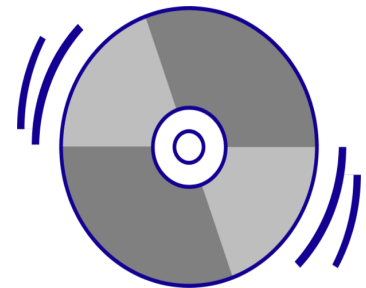
## Support Group and Local News

### Blue Badges

If you have one, remember to check for the expiry date!! Only some people get reminders to reapply (if you originally applied after Jan 2012). Aim to start about 6 weeks before expiry date. Also update your GP, OT or other health professional that you mention on the form as they may be contacted. You can either renew online, ([www.gov.uk](http://www.gov.uk)) or by telephoning Lancashire CC Blue Badge Department on 0300 1236736

### LIFELINE Talks on DVD available to borrow from the office

- Dr Roberts #1 - Pacing/Nutrition
- Dr Roberts #2 - above continued and Chemical/Environmental Influences
- Dr Roberts #3—continuation of the above 2 talks
- Gail Sumner #1 - Nutrition/Digestion
- Gail Sumner #2 – Latest research for Perrin Technique and other physiological factors
- Gail Sumner #3 – A new angle – Pyroluria
- Intro to Perrin Technique - Rob Goodman Edwards
- Joan Short - Life Coach/Intro Mindfulness/Relaxation
- Homeopathy - Christine Kirk
- Intro to Gentle Yoga – Jayne Morrissey
- METRIC project update (2014)
- Claire Gee—personal recovery/intro to GUPTA
- Helen Duxbury—Medical Herbalist



### CDs/DVDs/ Lifeline etc - reminder!

Please note... CDs/DVDs obtained from the office (or directly from Helen and Lynn) should be **returned** for others to borrow. The handouts that accompany the DVDs are yours to keep.

We do understand that due to health fluctuations, you may need to have them for a good while. If so, don't worry... contact us and we can make arrangements to get them back to the office.

### Carers' Contacts

<b>Carers Lancashire:</b>	<b>0345 6887113</b>	Ring the central number and you will be put through to the Carers' organisation covering <b>your area</b> .
<b>Blackpool Carers' Centre:</b>	<b>01253 393748</b>	<a href="mailto:info@blackpoolcarerscentre.co.uk">info@blackpoolcarerscentre.co.uk</a>
<b>Blackburn with Darwen:</b>	<b>01254 688440</b>	<a href="http://www.bwdcarers.org.uk">www.bwdcarers.org.uk</a>

### Donate your used stamps

Used stamps are still being collected to raise funds for the group. If you want to help, please cut out any stamps from envelopes received in the post & pass them on to the office.

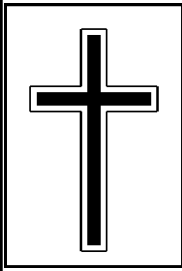
**NB: The stamps should be carefully clipped, leaving plenty of room [5 – 10mm] around the stamp. This will increase the value of the stamps to the charity.**

### Accessing a GP out of hours

NHS 111 now manages GP out of hours calls for patients.

If you think you need to see a GP out of hours, call 111 and a trained advisor will be able to direct you to the most appropriate service for your need.

## In Memoriam - Audrey Atwood - Tributes



Audrey Atwood, who sadly passed away on April 6<sup>th</sup> age 88, was an inspiration for sufferers of M.E. The help group she co-founded in Blackburn in 1989, part of Central Lancs ME/CFS Support Group since 2009, was hugely successful and many people will remember her fondly for her energy and drive in promoting ME as a serious condition, finding help for those who were suffering, and being such a supportive 'rock' to lean on. She did all this despite having ME herself and having a job and a family to see to.



Even though she had retired from 'active duty' for several years, up to just recently she was still interested in the charity's progress and the huge steps forward we have made, and still hope to make. She was always encouraging to me as Chairman, a good listener and a lovely lady. She will be sorely missed.

Our thoughts and condolences go to her husband David, sons Paul & Graham, and all her grandchildren  
Colin Briggs

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Audrey was one of the most supportive stalwarts of the local ME/CFS community. She developed ME/CFS at a time when very little was known about this very debilitating illness. During the 1980s there was no support available for people who developed ME/CFS and Audrey, a very organised person, set up a small support group for people, initially with eight founder members. At first, she did everything herself, including writing short newsletters and liaising with local General Medical Practitioners.

As more members joined the group, a Committee was formed under Audrey's guidance and the group became known as the East Lancashire ME/CFS Support Group with meetings held at Wilpshire Methodist Church Hall. Throughout Audrey's many years as Chair of the group she was very ably supported by her husband David. The group gradually grew from the initial 8 members to 150 members. Audrey was instrumental in setting up links with local Health Services and later with the local ME/CFS NHS Service, with the support of the Committee and volunteers.

Thanks to Audrey's vision and commitment, hundreds of local people with ME/CFS have been given help & hope and have learnt to accept and manage their condition better. So many members have said what a relief it was to meet other people with ME/CFS who understood what they were experiencing, and one member said she felt Audrey and the Group had saved her life.

Audrey will be sadly missed by us all. May she rest in peace.

Jeanette Birch,

Former Chair, East Lancashire ME/CFS Support Group.

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Audrey was an inspiring lady who suffered with ME from over 30 years ago when little was known about this devastating illness. She stayed at the helm of the East Lancs Support Group from 1989 to 2004. Meetings at Wilpshire were always packed and some wonderful speakers were found.

People came from all over to seek her help; if she wasn't able to provide it herself, she would point them in the right direction to get what they needed. She made many contacts regarding ME in many areas.

Most days and evenings she was available for people, always with the total support of her husband David; her phone never stopped ringing but she would answer even though she was unwell herself. I should know because I was one of those people she helped!

Thankyou Audrey for touching our lives.

Pat Hardaker

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I had known Audrey through Wilpshire Methodist Church for some years when in 2005, aged 16, my son was diagnosed with ME. Audrey persuaded me to join the support group and gave many useful tips on how to cope with this debilitating condition. Eventually I joined the committee for the E. Lancs Support Group and, now that is part of C.Lancs, we still attend as many meetings and lunches as possible where we find friendship & support. We would not be where we are without Audrey.

Ruth Fowler



## Support Group and Local News (continued)

Gail Sumner, the Perrin Treatment practitioner for the southern part of our area, came to our Bamber Bridge evening meeting on March 7th to update us on the recent clinical trial. The results were published in the BMJ (British Medical Journal), a summary follows. The next phase is to undertake a larger trial starting next year & preparations are well under way for this. Gail also introduced her colleagues Silvene and Suzane, Perrin practitioners who are able to offer home visits.

'Can physical assessment techniques aid diagnosis in people with chronic fatigue syndrome/myalgic encephalomyelitis?' BMJ Open Nov 2017



The latest research funded by FORME (Fund for Osteopathic Research for ME) was conducted by the University of Lancashire in conjunction with three NHS Trusts examining the accuracy of a physical technique for the diagnosis of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis.

At present, within the NHS the standard way of diagnosing is one of exclusion. In other words a patient will only be diagnosed as suffering from CFS/ME when all other possible diagnostic tests have proved negative. This means that for many patients the diagnosis of CFS/ME can be a very lengthy process. The research project evaluated the validity of the use of the major diagnostic principles behind the Perrin Technique. The Perrin Technique™ is based on the theory that CFS/ME is a disorder of the lymphatic drainage system. This disorder can be caused by different many factors including: allergies, stress and infections, which can lead to a build-up of toxins in the fluid around the brain and spinal cord.

The physical diagnostic process used in The Perrin Technique™ centres around the presence of five physical symptoms: postural defects, tender points around the spine, chest and lymph nodes, skin rashes or eruptions and abnormal breast tenderness and varicosities. The study, published in the BMJ Open on 14 November 2017 has demonstrated that a simple physical examination centred around these five symptoms is quicker and more accurate at aiding the diagnosis of CFS/ME than current methods.

(edited from FORME website)

### Did you know? Water, water, everywhere

You are what you drink. These body parts are (i.e... % water content):

Brain 75%... Heart 75%... Lungs 86%... Liver 96%  
Kidneys 83%.... Muscle 75%.... Blood 83%

Your body..... is 2/3 water by weight. We must replace 2.5 litres of water every day.

Water acts as a medium for chemical reactions in the body. It carries nutrients and oxygen to the cells through the blood. It helps to regulate our body temperature, and lubricates our joints. This is particularly important if you're arthritic, have chronic health problems with your muscle or bone structure or are athletically active. It also helps to maintain good skin and muscle tone, and better complexion.

It's important to recognise that there is a difference between water and other beverages (e.g...soft drinks, tea, coffee, beer, fruit juices). While these drinks contain some water they also contain substances that are unhealthy and actually accelerate your body's fluid loss, There is no substitute for drinking pure water.

### (Brief!) Summary of National News

If you have access to the M.E. Association website, there are a few stories worth reading.

**BBC Newsbeat Documentary – "M.E. And Me"**, available on BBC iPlayer from 6.00am on 8th May. There are some sad, but interesting cases covered.

**A version of Bob Dylan's "Blowin' in the Wind"**, with alternative lyrics, performed by M.E. patients and their carers from around the world, can be heard on the MEA website (I personally found it a little difficult to hear)... See MEA - 30th April news.

**MEA Press Release: People with M.E. 'measurably more disabled' than people with Multiple Sclerosis according to a new scientific study (see 16th March).**

**MEA Press Release: Reanalysis of the PACE trial finds impressive claims are 'not statistically reliable'.** Many will not be surprised to hear that further analysis of the PACE trial, is causing the original results to be doubted (see 21st March)

**Young woman dies aged 21 after an agonising six-year fight with M.E.** The very sad story of Merryn Crofts from Rochdale (see 2nd April)



## Let's lighten the mood

### All the answers (allegedly!) have Lancashire associations.

1. A Lancashire hill writer led astray. (6)
2. A Lancashire girl we hear expresses grief (4)
3. Seedy cakes from a Lancashire village. (9)
4. Historic Lancashire actress who plays cricket. (6,5)
5. Cereal for this Lancashire village. (6)
6. Island benefactor for Preston. (6)
7. Tell all after a sticky beginning in this village. (8)
8. Drink in a Leyland Pub. (3)
9. Damaging a delightful Lancashire village. (8)
10. Catch this Fylde hamlet. (4)
11. Sing about a good man in this village. (7)
12. Le Bois in Preston. (10)
13. Stephen in 'Hard Times'. (9)
14. Strong scented river in Lancashire (6)
15. The object of Washington's axe in Blackburn (6,4)

**Answers.** *editors's note: I assume these clues to be mildly "cryptic" in nature, which as someone who dislikes such clues (or just can't "do them!"), means that I'm trusting the sender of this item that they really do make sense!*

1. Pendle 2. Alas 3. Goosnargh 4. Gracie Fields 5. Barley 6. Harris 7. Tarleton 8. Ale 9. Chipping 10. Copp 11. Croston 12. Frenchwood 13. Blackpool 14. Yarrow 15. Cherry Tree



Yes officer, I did see the 'speed limit' sign, I just didn't see you.



### Aphorisms

1. The nicest thing about the future is that it always starts tomorrow.
2. Money will buy a fine dog but only kindness will make him wag his tail.
3. If you don't have a sense of humour you probably don't have any sense at all.
4. Seat belts are not as confining as wheelchairs.
5. A good time to keep your mouth shut is when you're in deep water.
6. How come it takes so little time for a child who is afraid of the dark to become a teenager who wants to stay out all night?
7. Business conferences are important because they demonstrate how many people a company can operate without.
8. Why is it that at school reunions you feel younger than everyone else looks?
9. Stroke a cat and you will have a permanent job.
10. No one has more driving ambition than the teenage boy who wants to buy a car.
11. There are no new sins; the old ones just get more publicity.
12. There are worse things than getting a call for a wrong number at 4 a.m.; for example, it could be the right number.
13. No one ever says "It's only a game" when their team is winning.
14. Be careful about reading the fine print, there's no way you're going to like it.
15. The trouble with bucket seats is that not everybody has the same size bucket.
16. In about 40 years, we'll have thousands of old ladies running around with tattoos.
17. After 60 if you don't wake up aching in every joint, you're probably dead.
18. Money can't buy happiness but it's more comfortable to cry in a Jaguar than in a Fiat.
18. Always be yourself because the people that matter don't mind and the ones that mind don't matter.
19. Life isn't tied with a bow but it's still a gift.
20. "Politicians and nappies should be changed often and for the same reason"

(Thanks to Helen for sending these in)

## Recipe - Twice Baked Potatoes (maybe not ideal for everyone, but easy!)

(Preparation time - 15 mins. Cooking time - 1 hour 15 mins)

### Ingredients

- 4 baked potatoes (and filling)

### Filling

- |  |   |
|--|---|
| <ul style="list-style-type: none"> <li>• 25g (1oz) butter</li> <li>• 1 Green pepper (seeded &amp; diced)</li> <li>• 175g (6oz) button mushrooms (sliced)</li> <li>• 1 tablespoon wholegrain mustard</li> <li>• black pepper</li> </ul> | <ul style="list-style-type: none"> <li>• 1 onion (peeled &amp; chopped)</li> <li>• 4 rashers reduced salt bacon</li> <li>• 225g (8oz) reduced fat cheddar cheese (grated)</li> <li>• 2 tablespoons low fat natural yoghurt</li> </ul> |
|--|---|



1. Preheat oven to 220°C/gas 7. Wash potatoes, prick with a fork. Bake for 1 hour
2. Meanwhile, gently melt butter in large frying pan. Add onion, green pepper, and bacon. Cook for 3-4 minutes, or until vegetables are just tender. Remove from the heat.
3. Cut potatoes in half. Scoop out flesh into a large bowl. Mash with a fork. Add mushroom mixture, half the cheese, the mustard, yoghurt and black pepper. Mix thoroughly.
4. Spoon mixture back into skins. Place onto a baking sheet. Sprinkle remaining cheese over.
5. Return potatoes to the oven. Bake for 20 minutes, or until filling is heated through and cheese is golden. Serve immediately.

(Prepare ahead - Spoon filling into potato skins and cool completely after step 4. Cover and keep in fridge for up to a day. Continue from step 5)

*[Recipe courtesy of "Delicious Meals Made Easy". This recipe has the advantage of being a "mix & match" type meal. For example, the meat used can be swapped, or indeed removed, and the meal can be served on its own, or with salad etc]*

## Sudoku

**Difficulty: medium**

Complete the grid so that every row, every column and every 3x3 box contains the numbers 1-9

	<b>3</b>	<b>5</b>	<b>7</b>					
		<b>9</b>		<b>6</b>				<b>3</b>
	<b>4</b>					<b>7</b>		
	<b>2</b>						<b>7</b>	
		<b>8</b>			<b>4</b>			
<b>5</b>				<b>2</b>		<b>4</b>		
				<b>5</b>	<b>7</b>		<b>2</b>	
<b>2</b>	<b>6</b>						<b>9</b>	<b>5</b>
			<b>9</b>			<b>1</b>		

## Open Meetings and Social Lunches 2018

Updates and reminders will be emailed to those who have provided email addresses. Details of amendments can also be found on the website, or by contacting the office on 01772 751 254

### Craft Group Last Wed of the month: 2 - 3.45pm

The Roccoco Coffee Lounge, Chapel Brow, Leyland. PR25 3NH

NOTE: **NO** craft meeting at the end of May

Will re-commence **27th June**

**ALL  
ARE  
WELCOME**

### Focus on ME Photography Society:

**Tues** Jun 5th, The Field Fare, near Chorley Tesco, **1.30-3.30pm** July 3rd, Aug 7th TBA (contact the office for details). An opportunity to catch up and chat with other members, expand your photography skills and share your photos. Each month there is a theme and you bring the printed image to the meeting for discussion.

## Preston Area Meetings

### Chair/Floor-based Yoga/Relaxation: 2.15—3.15pm - cost £5

LOCATION - Bamber Bridge Methodist church room (upstairs - lift in lobby), Corner Wesley St/ Station Rd, Bamber Bridge. PR5 6ED (PLEASE CHECK WITH THE OFFICE)

### Thurs May 10th - ME Awareness Week - Open Day!

COME for info, meet people who understand, hand/foot massage, craft (more detail/enquiries office 01772 751254)

1.30-4.30pm Galloway's, Howick Park Ave, Penwortham PR1 0LS

**Wed May 16th** Lunch/'coffee' 12.30pm The Yew Tree (opposite Capitol Centre) PR5 4AU

**Wed June 13th** **\*\*Annual AGM\*\*** 1.30pm-3.30pm at Galloways (inc Q & A with Dr Roberts)

**Wed June 20th** Lunch/'coffee' 12.30pm The field Fare, near Chorley Tesco

## East Lancs - Lunch & Meetings

**\*\*Wed Jun 6th & Wed Jul 4th** - please check with office for venue(s)



### St Annes - Afternoon Tea/Coffee

First Thursday of the month - 2pm-4pm

Jun 07th, July 05th, Aug 02nd

**Glendower Hotel**, North Promenade FY8 2NQ



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Please call the office if you would like a lift to any of the events - 01772 751254

## Useful Contacts



Registered Charity -  
No 1106333  
Patron: Doctor J Roberts

### Central Lancashire ME/CFS Support Group

Howick House  
Howick Park Avenue  
Penwortham  
Preston. PR1 0LS

Tel: 01772 751254

Web: [www.clancsme.org.uk](http://www.clancsme.org.uk)

Email: [info@clancsme.org.uk](mailto:info@clancsme.org.uk)

**Facebook:** To request to join the closed Facebook group, go to Facebook page, Central Lancs ME/CFS Support Group, and click on About on right side of screen, you will then see the request line under the map.

#### Support Workers:

Helen Crossan [helen@clancsme.org.uk](mailto:helen@clancsme.org.uk)

Lynn Green [info@clancsme.org.uk](mailto:info@clancsme.org.uk)

#### Committee Members:

Colin Briggs

Simon Bennett

Shelley Burrows

Harriet Fairhurst

Kath Grannell

Paul Leeming

Keith McNicholas

Robin Crossan

Andy Bristow

#### Newsletter:

Keith McNicholas [keith@clancsme.org.uk](mailto:keith@clancsme.org.uk)

#### Counselling Service:

Keith McNicholas (contact Lynn or email the office for initial appointment)

#### Volunteers:

Dave Berry

Tracey Cooke

Rob Edwards

Phil Green

Pat & Albert Hardaker

Viv Henderson

Anj Rathod

Brenda Wilson

## Help and Advice



For all areas call: 03442451294  
**Except** Blackburn: 03442451293  
Burnley: 01282 450535  
Blackpool: 01253 308400  
National Advice: 03444 111 444

**Welfare Rights:** 0300 123 6739 for all Lancashire  
**Except:** Blackburn with Darwen: 01254 583350  
Burnley/Nelson: 01282 470570  
Blackpool: 01253 477488

**Blue Badges:** 0300 123 6736  
Social Services Care Assessment 0300 123 6701

**DWP Benefits - DLA:** (born before 09/04/48) 0345 605 6055  
(born 09/04/48 onwards) 0345 712 3456

**New PIP claims** 0800 917 2222

**ESA** (old incapacity benefit) 0800 055 6688

#### Disability Equality North West (formally known as DISC):

Preston (Mon-Thur 9.30-3pm) 01772 558863

#### Disability First (Advocacy across Lancashire)

Blackpool 01253 476450

#### Shop Mobility:

Preston 01772 204667 Chorley/South Ribble: 01257 280888

Burnley: 01282 450684 Blackpool: 01253 476451

**PALS** (Patient Advice/Complaint & Liaison Service) 0800 032 2424

**Samaritans National:** 08457 909090

**Preston:** 01772 822022 **Chorley:** 01257 266881

**Blackburn:** 01254 662424 **Blackpool:** 01253 622218

**Burnley/Nelson:** 01282 694929

#### Useful Websites:

<a href="http://www.actionforme.org.uk">www.actionforme.org.uk</a>	Action for ME
<a href="http://www.meassociation.org.uk">www.meassociation.org.uk</a>	The ME Association
<a href="http://www.tymestrust.org">www.tymestrust.org</a>	Young ME Sufferers Trust
<a href="http://www.ayme.org.uk">www.ayme.org.uk</a>	Young people with ME
<a href="http://www.investinme.org">www.investinme.org</a>	Invest in ME
<a href="http://www.mereseach.org.uk">www.mereseach.org.uk</a>	Research & scientific info
<a href="http://www.forme-cfs.co.uk">www.forme-cfs.co.uk</a>	Research for Osteopathic Treatment for ME (Perrin)
<a href="http://www.drmyhill.co.uk">www.drmyhill.co.uk</a>	GP - specialising in ME
<a href="http://www.benefitsandwork.co.uk">www.benefitsandwork.co.uk</a>	Benefits advice/forms etc
<a href="http://www.turn2us.org.uk">www.turn2us.org.uk</a>	Benefits advice
<a href="http://www.mentalhealth.org/relax/sleep">www.mentalhealth.org/relax/sleep</a>	Podcasts-short and long