



Phoenix

Newsletter of The Central Lancashire ME/CFS Support Group

Patron: Doctor J Roberts

Charity no. 1106333

September 2018 issue

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Our AGM was held on the 13th June 2018 at Galloway's Society for the Blind, Howick House, Penwortham, Preston.

The meeting was very well attended by members of the group along with invited guests including our Patron, Dr Janet Roberts, and Kevin O'Hara and Dominic Bray from Lancashire Care Foundation Trust (LCFT)

After welcoming everybody, Colin Briggs our Chairman spoke about how well the group had been doing over the last year, particularly our ever-popular lunch, tea and coffee meetings across many of the areas we cover and our continued activities with yoga, Facebook, craft and photography groups. He thanked all who had been involved in the successful running of the Group to date, all the volunteers who have supported us with special mention for our support workers Lynn and Helen who have continued to work in their own time after their salaries ended on 31st March along with the Lottery funding.

We have applied for short-term 6 months-funding from the Lottery and since the AGM, we have heard that we have achieved this from Awards for All, so we are able to continue until the end of January 2019, although in a reduced capacity. It is our intention to carry on seeking more permanent funding whilst appealing once again for volunteers who are able to help as, without such people, we will not be able to continue to function.

The membership has remained steady compared with the last year.

Colin said that after being Chairman for 9 years he was now stepping down and by great good fortune, committee member Robin Crossan, recently retired from a senior position at British Aerospace, said he was willing to stand. Unfortunately Robin was attending a family funeral in Canada so couldn't be present, but the vote for him was unanimously carried in his absence.

Colin then introduced the other 6 committee members willing to stand again and welcomed new member Angena Rathod who has been a volunteer with us for a number of years.

Prior to "handing over", Colin received a gift of a shredder in appreciation for the work he has done & said that he was very touched by this gesture, along with the help & appreciation people have shown him over the years

Kevin & Dominic then said a few words about LCFT's intentions for the M.E. services in Greater Preston, Chorley & South Ribble and following this, everyone then enjoyed refreshments.

Helen

("Editor's personal comment"... having agreed to continue as both committee member & newsletter editor, other commitments mean I need to ask if anyone might be interested in helping to compile the newsletter? Don't worry... It's straight forward once you get the hang of it and it would also be good to offer a different perspective than is obtained from one contributor. Please contact the office for further information. Many thanks... Keith)

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

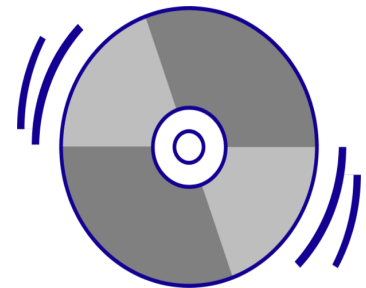
Support Group and Local News

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) 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

Carers Lancashire:	0345 6887113	Ring the central number and you will be put through to the Carers' organisation covering your area .
Blackpool Carers' Centre:	01253 393748	info@blackpoolcarerscentre.co.uk
Blackburn with Darwen:	01254 688440	www.bwdcarers.org.uk

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.

Support Group and Local News

Lottery update & thanks

As mentioned on the first page, we wish to add another quick "Thank you" to the National Lottery... but just as importantly, to all the people who **play** the Lottery. I'm sure that most of us will have heard our Olympic athletes offering their thanks for the N.L. funding sport etc... but it is also charities such as ours, who have relied on the help of Lottery funding over recent years.

In addition to this... have any of you any good news stories about the Lottery, or indeed, other uplifting stories or experiences? If so, do please let us know (anonymously if it relates to winning money!).

Allergies... What's in that Fragrance?!

When you see 'perfume' listed on the ingredients of skin care products, it represents a combination of compounds which all make up the scent of the product. It isn't possible to tell what all of these compounds are if just the term 'perfume' is used so it is hard to narrow down what exactly you are allergic to. In fact fragrances are contained in many things we use, from tissues and bin-bags to moisturiser and perfume.

It is claimed that 30% of the public report adverse health effects from being exposed to "scents". A typical cosmetic can contain between 50 and 100 fragrances often to mask the smell of the basic product. Synthetic and natural fragrances can cause a range of symptoms from migraines and rashes to difficulty concentrating, breathing problems and even seizures and collapse. Reactions can be immediate or delayed by hours or days. Reactions occur from inhalation and skin contact, and chemicals can be absorbed into the blood through the skin.

Children in particular tend to be more sensitive to fragrances. Aftershave is the most common trigger for men, possibly because the skin gets damaged during shaving increasing the chances of absorbing the chemicals (WEN). Up to 72% of asthmatics are affected by fragrance (Mintel) as well as many people who have M.E. or are undergoing chemotherapy. Those who suffer from Multiple Chemical Sensitivity (MCS) can even have severe reactions to very small traces of fragrances in products that other people use.

(For any members who have suffered similar allergic reactions to scents, the full article might prove to be an interesting read, along with providing incite as to how to avoid such dangers. It can be found at: <https://www.mcs-aware.org/general-articles/183-fragrances>)

National News - M.E. Association

ME Association Letter in The Times re: PACE trial and the need for good-quality research

Dear Sir....Professor Fiona Watt (letter, Aug 27), the executive chairwoman of the Medical Research Council, defends the much-criticised Pace trial that continues to dominate medical treatment for patients with ME/chronic fatigue syndrome.

She is confusing well-founded constructive criticism from clinicians, researchers and people with ME/CFS about the Pace trial with hostility to the research community.

We all want to see good-quality research that will improve our understanding of the underlying cause of ME/CFS along with robust clinical trials that will objectively assess the safety and efficacy of potential treatments.

However, in my experience the Pace trial did not do this. Consequently the 250,000 people with this devastating chronic illness continue to have inappropriate management of their condition and suffer the inevitable consequences.

Neil Riley, Chairman, ME Association.

(Editor's note: as ever, the people who make flawed assumptions are generally too proud to admit this and will often vigorously defend their position. However, pressure to at least discuss things rationally is growing and several MPs have now added their names to the demand to look at the Pace trial. This story, with updates in their news section, can be read on the M.E. Association website at: <https://www.meassociation.org.uk/2018/08/me-association-letter-in-the-times-re-pace-trial-and-need-for-good-quality-research-31-august-2018/>)

National News - M.E. Association news/website

Suicide Prevention Week: Suicide shouldn't be the solution for M.E.

The 16th September will be a tough day. My son James will be running in memory of his late father, and my late husband, Alan Cumming, who took his own life on 30th October 2005. He hanged himself while I was out. I found him. Thank goodness it was neither of our two sons.

Alan wasn't the first person with M.E. to take his own life. Nor will he be the last. I understand why he did it – he simply couldn't see any other way out. The pain, misery, inability to function, sleeplessness, anxiety, frustration and destitution all got too much.... and he simply felt that we'd be better off without him.

I've spoken to many people with M.E. (and their carers) about suicide since. There are so many people who have considered ending it all, because they can see no other way out of the hell that they are living.

I'm not saying they are all wrong. But so many articles have been written about the people who commit suicide, rather than the people they left behind. I felt I needed to try to redress the balance.

I believe that Alan was wrong: we weren't better off without him... not his family...or anyone who knew him.

The full story can be read at: <https://www.meassociation.org.uk/2018/09/suicide-prevention-week-suicide-shouldnt-be-the-solution-for-m-e-13-september-2018/>

(Editor's note: anyone who knows me knows my passion about M.E. rights and for mental health issues, so I felt the need to say that... if any of you, or anyone you know, ever feels so desperate as to consider life not worth living, whether because of M.E. or anything else... seek help/advice. Our group has a wealth of M.E. related information but also offers counselling as a service to members. Remember also to consult your GP if able. Above all...NEVER feel guilty about asking for help/support!)

Flu vaccination and M.E. (2018-19) by Dr Charles Shepherd

The M.E. Association's excellent adviser, Dr Charles Shepherd, has constructed a rather lengthy "for and against" argument, as regards having the flu vaccination. It is far too long to include it all here, but the website offers a free download that anyone can print off. In summary, it really is down to the individual... some of us swear by the vaccine... others are equally against it.

We would urge anyone thinking of receiving the vaccine for the first time, to read Dr Shepherd's article, along of course, with liaising with their GP. One noteworthy point, is that Dr Shepherd does state that people with M.E. should be included as vulnerable, so able to access free flu vaccination. If your GP has not included you, it may be worth politely referring them to the article.

Full story at: <https://www.meassociation.org.uk/2018/09/the-flu-and-m-e-all-you-need-to-know-about-the-2018-19-flu-vaccine-12-september-2018/>

NHS to update classification system to reflect that M.E. is neurological disease

It was confirmed by DX Revision Watch, that the recording of M.E./CFS as previous examples of a 'multisystem disorder' will now be replaced in SNOMED CT by the more appropriate, 'disorder of the nervous system'.

This follows the welcome efforts of advocate Suzy Chapman, who writes the authoritative blog, DX Revision Watch, and Sonya Chowdhury, on behalf of Forward ME and Action for M.E.

SNOMED CT is a comprehensive electronic clinical classification system used by the NHS, that records known diagnoses and symptoms with the aim of making clinical information consistent across healthcare settings.

In some respects it would seem to be more relevant to UK residents than the World Health Organisation international classification system, as electronic NHS patient records should be updated to reflect the change.

While chronic fatigue syndrome unfortunately remains the parent term in this clinical vocabulary, M.E. is recognised as a synonym along with other recognised terms. The change will take place in the UK in October, and, as SNOMED CT is also used internationally, it will also be reflected in the United States, Canada, New Zealand, Australia and other European countries.

It is too soon to say what practical effect, if any, this might have on patient relations and treatment within the NHS, but it at least means that ME/CFS will now be listed under a more appropriate heading.

Full story at: <https://www.meassociation.org.uk/2018/08/nhs-to-update-classification-system-to-reflect-that-m-e-is-neurological-disease-06-august-2018/>

Let's lighten the mood (or possibly not!)

I have noticed that in recent times, "litter" has changed. I can remember when we used to moan about cola cans, or old crisp packets being thrown on the ground, but take a look at these items that I spotted within the last few weeks, just left on streets, car parks, or next to roads.



What a lovely scene to the left... set off perfectly by the microwave oven... thrown under a bush! What the heck?!!

And to the right, why take your old hi-fi or TV unit to the tip, when you can use it to enhance nature? The aesthetics might have been slightly better if placed slightly further to the right, but maybe the space next to it, is for the lamp the vandal is bringing next week?!! But seriously... what goes on in the minds of some people?



The cartoon to the left (by "Nige") shows something that has blighted many places for as long as I can remember... shopping trolleys being abandoned, often miles from any store! "Nige" may have exaggerated it slightly, but it can seem this bad at times!

As for the photo to the right, I accept that I shouldn't give credit for vandalism, but I can't help but have a little bit of admiration for original humour!



(The Return of) Awful Joke Corner

Old people say, "There's no place like home"... But when you put them in one!!!

I knew a guy who claimed he was the best farmer in Britain. He was a man outstanding in his own field.

I've decided to sell my Hoover... well it was just collecting dust

I heard a rumour that Cadbury is bringing out an oriental chocolate bar. It could be a Chinese Wispa.

I watched a documentary about what keeps a ship from falling apart. it was riveting.

I asked a guy if there was a B & Q in Preston. He said, "No...can't you spell?! It's P-r-e-s-t-o-n"

I finally tried a drive-thru McDonalds, but it was more expensive than I thought... once I'd hired the car.

I wonder how many chameleons managed to sneak onto Noah's ark?

What's the difference between a hippo and a zippo?
One's really heavy, & the other's a little lighter!

I used to recycle old shoes. It was soul destroying.

The Confusing English Language

I take it you already know
Of tough and bough and cough and dough?
Others may stumble, but not you,
On hiccough, thorough, lough and through?
Well done! And now you wish, perhaps,
To learn of less familiar traps?
Beware of heard, a dreadful word
That looks like beard and sounds like bird,
And dead: it's said like bed, not bead -
For goodness sake don't call it deed!
Watch out for meat and great and threat
(They rhyme with suite and straight and debt).

A moth is not a moth in mother,
Nor both in bother, broth in brother,
And here is not a match for there
Nor dear and fear for bear and pear,
And then there's dose and rose and lose -
Just look them up - and goose and choose,
And cork and work and card and ward,
And font and front and word and sword,
And do and go and thwart and cart -
Come, come, I've hardly made a start!
A dreadful language? Man alive!
I'd mastered it when I was five!

(Attributed to Poet T.S. Watt, 1954)

Recipe - Citrus chicken

A zesty citrus dish. Try serving with brown rice and some green beans. Serves: 2 Time to make: 45 mins
(Allergy advice This recipe contains wheat - gluten)

Ingredients

- 1 tsp sunflower oil
- 1 chicken breast
- ½ red pepper, sliced
- 1 carrot, peeled and sliced
- 1-2 medium potatoes, cubed
- black pepper, freshly ground
- ½ onion, finely chopped
- 1 dessert spoon wholemeal flour
- juice of 1 orange, or 75ml unsweetened orange juice plus 25ml water
- chopped parsley (optional)
- 130g brown rice, uncooked

Method

1. Heat the oil in a pan and brown the onion over a low heat for 2 to 3 minutes.
2. Cut the chicken breast into large pieces and coat each piece in the flour. Then add the chicken to the pan and brown for 2 minutes, stirring all the time to make sure it doesn't stick.
3. Once the chicken is cooked, add the other ingredients. Then bring it to the boil, turn the heat down and simmer over a low heat for about 20 minutes, until the vegetables are soft and the chicken is thoroughly cooked.
4. Meanwhile, cook the rice according to packet instructions.

Each serving contains:

ENERGY	FAT	SATURATES	SUGARS	SALT
2881KJ	10.5g	2.0g	10.7g	0.2g
684kcal	LOW	LOW	LOW	LOW
34%	15%	10%	12%	3%



(Thanks to the NHS "Live Well: Eat Well" website for this)

Sudoku

Difficulty: medium

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

			3	6			8	
								5
7	2	5						
	3	6						
				7		1	4	
				3		8		
8							9	
1					8	2		
			9		4		3	

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

Wed Oct 31st ... & Wed Nov 28th

**ALL
ARE
WELCOME**

Focus on ME Photography Society:

Tues Oct 2nd, The Yew Tree (opposite Capitol Centre) PR5 4AU, **12.30pm**

Nov 6th 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

Tues Oct 16th Lunch/'coffee' 12.00pm The Ley Inn, Back Lane, Clayton-le-Woods PR6 7EU

Wed Nov 14th Lunch/'coffee' 12.30pm The Yew Tree (opposite Capitol Centre) PR5 4AU

Wed Dec 12th Christmas Lunch—contact office

East Lancs - Lunch & Meetings

Wed Oct 10th - Scarlett Tea Room, Accrington Rd, Burnley BB11 5ET

Wed Nov 07th - Simply Classic Bistro, Shuttleworth Mead Business Park, (nr jnc 8 M65)
Padiham BB12 7NG

Wed Dec 7th Christmas Lunch—contact office

St Annes - Afternoon Tea/Coffee

First Thursday of the month - 2pm-4pm

Oct 04th, Nov 01st

Glendower Hotel, North Promenade FY8 2NQ

Dec 06th Christmas Lunch-TBA (contact office)



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

Email: 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

Lynn Green info@clancsme.org.uk

Committee Members:

Robin Crossan

Colin Briggs

Andy Bristow

Shelley Burrows

Harriet Fairhurst

Kath Grannell

Paul Leeming

Keith McNicholas

Anj Rathod

Newsletter:

Keith McNicholas keith@clancsme.org.uk

Counselling Service:

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

Volunteers:

Dave Berry

Tracey & Christine Cooke

Rob Edwards

Phil Green

Pat & Albert Hardaker

Viv Henderson

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:

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