

Worcestershire ME Support Group - Annual General Meeting 2014

Letter and report to the group from Ian, 29th September 2014

Dear All,

My thanks to all who have helped to run the group for another year, and our thanks to all who have been involved in any way helping at any time, whether it was answering phone calls, emails, sending info, newsletters, dealing with membership or accounts, updating our website, booking rooms, running meetings, bringing display boards and information, making the tea or washing up the cups. Thank you.

Without your help the group cannot continue, but it always has and probably will continue to do so. However it has been getting more difficult as those most involved have done it for a long time and all are getting older. Some have improved and need to get back to normal life, some need to take more time out to unload and recover, either generally or from a 'temporary dip'. The problem always has been that those involved have ME/CFS/FM or are carers of same. This is also the group's strength, as they know from personal experience what it is like. They know most, if not all the symptoms and can empathise with contacts by telephone or at meetings.

This I think is the main need supplied by our group: talking to new contacts. Their relief is visible and audible, when they find out, often for the first time, that all their symptoms are 'normal' and part of their condition. This despite previous visits to GPs, hospitals and specialists, who often apparently still do not either recognise the conditions or are loath to give a diagnosis, or accept symptoms and suggest possible helpful advice. To my knowledge this is still happening after 25 years. Until this changes we are still needed, but how best to respond?

We have tried this year to encourage more to come to meetings, but not with any great success. Jackie Elston started Redditch monthly meetings for 5 months, but stopped as so few attended. We paid room hire and Jackie gave her time and precious energy. Could more be done by telephone, email, plus all modern texting, twittering, etc?

Meetings could be done more cheaply and less formal at free venues such as cafes or garden centres, preferably after lunch time clatter and chatter has finished. Drinks will have to be bought, but food or a meal becomes available. Will this encourage more contacts or put people off? Those that I have spoken to agree it's worth trying regular new venues, similar to our lunch time meetings. Group contacts do not have to do this, it is only a suggestion. There are sufficient funds to continue hiring rooms for now.

Recently a few people have offered to help with the running of the group, thank you and 'yes please'. We do need all the help we can get as sharing out the work will make things easier. If one person is unwell, another may be o.k. to put the kettle on and welcome new contacts to a meeting. Having a back up makes the job easy, and with ME we keep everything as easy as possible anyway. We have been doing it long enough to make it so.

None of us want to see the group diminish, but we do need more help to continue.

I am very relieved that we now have regular newsletters and our thanks go to Esther (who only volunteered as Editor). The job of filling envelopes, stamping, labelling and posting could be done by another person. Anyone?

Our members' contact list (confidential) for those wishing to telephone/email others needs to be updated, so that people can feel less cut off and have a network of friends who understand them. At our meetings I suggest the swapping of telephone numbers, etc.

There is still very little help from the NHS, who do not seem to want contact with us. See separate report. It has been reported to me recently by some of our new contacts that Dr Mirella Ling at Kidderminster Hospital has been very thorough and helpful for sufferers in getting a diagnosis.

Our ME Awareness Day in May could have been more successful. Plenty of people came during the morning, but no one after lunch, probably because of some sport on television. We have had that clash of interest happen before. To be avoided for future events. Those who did come, wanted exactly what we offer at our normal meetings. Ask questions, take away information and literature, speak to other sufferers to compare symptoms for confirmation and reassurance that they are 'normal'. We do need more helpers to set up at the start of events and cope with the initial surge of visitors. Interestingly, no one had the time or energy to stay and watch the intended DVD show of talks by specialists that was the main attraction so we did not show them.

More help is needed to run the group and meetings and particularly for the secretarial work. My thanks especially to Jill Pigott for continuing covering secretarial work this last year, having previously stood down, likewise Phil Moss for continuing to run Pershore, can anyone take over? People do need to feel able to step down without fear that it will cause failure if they do.

To sum up: another busy year for the few stalwarts who run our group. Demand will always be variable, but there are always people in need of our help. Thanks to all, I won't list names, they are in our paperwork.

Ian Logan, Chairman