**LONG TERM CONDITIONS COMMUNITY (LTCC)**

(Formerly “Hull & East Yorkshire ME & CFS Self Help Group”)

**MARCH 2025**

Hello everyone. Greetings from LTCC.

The LTCC is a support group for anyone with chronic health conditions living in Hull, the East Riding and surrounding areas. Fatigue and pain are common and these are likely to be accompanied by other symptoms. Conditions may include Addison’s Disease, Andersen Disease, Coeliac Disease, Diabetes, Dysautonomia, Fibromyalgia, FND, Gilbert’s Syndrome, Long Covid, Lupus, Lyme Disease, ME/CFS, Post-viral Conditions, Polyneuropathy, POTS, Respiratory Conditions, Thyroid Malfunction. (Please note, this list is not definitive and exclusive; there are numerous health conditions that are long term and a complication is that some can be experienced in combination. The list is based on conditions that have come to the group’s notice since its formation. We anticipate that it will grow!)

**MEETINGS:**

**Face-to-face meeting, Beverley Library, Mon 3 March**

Attendance: Chris, David, Elaine, Joyce, Julie, Tanya (Apologies: Gemma)

The five regular attendees were pleased to be able to meet and greet newcomer Joyce. We started out by very briefly saying a little bit about our own experiences and the group, all mixed in with a little catch-up on things both medical and social.

Conversation was quite broad and informal, the following being noted…

* **Joyce** has experienced fatigue as a main symptom, for some time, though it seems, at least partly, to have built up following having cancer and treatment for it. She hasn’t been referred to the chronic fatigue clinic as yet. Interestingly, she has been receiving counselling sessions with The Red Cross (something new to us) who told her about the existence of our group – so “The Word” is spreading!
* **Dr Myhill’s theories and diet and supplement regimes** were revisited, particularly with reference to mitochondrial function, mainly for Joyce’s benefit as she hadn’t previously come across Dr Myhill. Chris briefly outlined his personal experience of this, including the “Paleo” diet’s comparison with what most of us eat in the 21st century. Dr Myhill describes herself as a “naturopath” and she has written numerous books, one of which is ten years old now, but its title sums up much of what she believes in achieving a naturally healthy lifestyle The title is “Sustainable Medicine,” but it’s actually the sub-tiltle, “Whistle-blowing on 21st Century medical practice,” that packs the punch as she addresses the principle causes of the current epidemic of chronic diseases in The Western World and outlines, in a unique, no-nonsense way, how to explain, prevent, diagnose and treat those conditions for which conventional medicine currently only provides an ever-increasing amount of potentially dangerous medicines to offer. More often than not, what the pharmaceutical industry provides does no more than treat the symptoms rather than “get to the root cause.”
* **Muscle wastage** is something that is difficult to avoid for most people with long term conditions which generally ease people, through presence of pain and lack of energy, into a more sedentary life-style.
* **Getting a good night’s sleep** should be a priority for us all to try to achieve however our condition dictates against this ideal.
* **MRI Scans.** Most of those present have at least some experience of these and generally report negatively – the general discomfort and claustrophobic sensation of being in the machine, the noisy and sometimes long treatment – up to and even more than an hour some have experienced. There have often been very long waits to receive an appointment, though some hospital sites now have “open” MRI facilities improving that situation for some people.
* **Tinnitus.** This is has been experienced by most of those present. It can have many causes including exposure to loud noises, ear infections and some medications. Interestingly, these tend to coincide with hearing loss though the two aren’t directly connected. It can be experienced in both ears or in just right or left. Interestingly, all those present who reported it have left-sided tinnitus. There is no known cure for tinnitus, but there are ways to reduce symptoms. Common approaches include the use of sound therapy devices including hearing aids, behaviour therapies and medications.
* **Public transport difficulties.** Delays and cancellations are a nuisance and can be particularly energy-sapping for those with long-term health issues. David, who travels by train a lot, including his monthly visit, from his Bridlington home, to our Beverley meeting, experiences both delays and cancellations on a regular basis – it sometimes feels like it’s the norm. Not so much delays/cancellations, but Joyce is finding she has to commit a full day just to do the Beverley meetings such is the irregularity of the local bus services from and to relatively nearby Cottingham.
* **Household chores** can be draining but with a little thoughtful planning can be an aspect of your life in which good old **Pacing** can easily be applied, eg why does the ironing all need doing in one go? Dishwashers can replace a good deal of tedious work as can a cleaner if that’s a financial possibility. On the other hand, don’t let us lose sight of the need to reduce muscle wastage!

**“Teams” meeting, Wed 19 March, 6.30 pm start**

This meeting was unfortunately cancelled because of technical problems – no fault of ours – “Teams” was “down!” Bizarrely, Julie was able to get on and chat to herself for a minute or so before the novelty wore off. How could that work when even the host was unable to gain access?! The wonders of technology!

Apologies for this month’s issue being a bit late – distractions caused by holidays and other chunks of life getting in the way.

You will notice that you are not receiving this via the “MailChimp” system which we had switched to about 18 months ago. The anticipated benefits of MailChimp have failed to live up to expectations and, rather than helping, it was hindering getting the job done. So it’s back to a good old-fashioned email direct from our email address. Hope you receive it ok.

Another reminder that this newsletter is “yours,” in the same way as any other involvement with the group. Much of the contents tends to focus on what has been discussed at face-to-face and online meetings. Occasionally here is other “news” adding a bit more variety. If anyone comes across any other item they may consider appropriate, or might like to express an opinion, please don’t hesitate to get in touch with us.

**THE STRUCTURE OF OUR GROUP AND GROUP MEMBERSHIP**

This is a reminder for all existing members and for those of you who have been involved with the group for some time, but for relative newcomers it may well be new…

Our group is made up of “Contacts” and “Members.”

A **“Contact”** is anyone who has had any contact with the group, ie. an initial enquiry, an exchange of emails, a visit to our website or Facebook page, attended a meeting. Note particularly that **you don’t have to me a “member” to attend our meetings.** They are open to all.

A **“Member”** is anyone who sufficiently values the group and what it is trying to achieve that they are willing to make a small monetary contribution towards it expenses. It also allows them to be involved in the direction the group is taking, any new initiatives, etc. Membership gives you a sense of ownership and allows you to vote on matters that are relevant at the time.

**Paying for Membership**

Membership payment works on the basis of the Tax Year and stands at £10 for the year. Those of you who are already members, whenever you joined, if you wish to remain a member, are due to renew with £10 in April (hence the timing of this memo).

It is, of course, highly likely that people will wish to join at different points throughout the year. To cater for this we have a “staggered system,” as follows…

Join April, May, or June….. pay £10.00

Join July August or Sept……pay £7.50

Join Oct., Nov. or Dec……….pay £5,00

Join Jan., Feb. or March……pay £2.50

Our preferred method of payment is for you to pay by direct transfer into our account, the details of which are…

Account Name: HeyMe/CFSGroup Cic

Sort Code: 08 92 99

Account Number: 67253094

If you apply in this way, please let us know, by email, that you have done so, then we can put it on record and email you a receipt. Alternatively, the second best option is for you to pay by cash at a meeting; again, you will be given a receipt.

It is worth pointing out that membership subscriptions are our only regular source of income.

If anyone comes up with good ideas for raising money for funds, or has had past experience of such, it would be good to hear from you.

As I sit here typing, the sun on my back through a south-facing window, let us hope that Spring is really upon us and there’s no sting in the tail, wishing March to go out like a lamb as opposed to a lion to quote the old adage. Along with that, the best of health to you. Find what works for you and stick at it!

Our best wishes to you all,

**Chris**

**Tanya**

**Julie**

**David**