

YORK & DISTRICT

ME

SUPPORT GROUP

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M.E. SUPPORT GROUP
SUPPORTING PEOPLE WITH ME/CFS IN SELBY,

HELPLINE

Sandra
Tel 01347 810841
1.00 - 2.30
Monday - Thursday

e-mail enquiries@yorkmesupport.org.uk

www.yorkmesupport.org.uk

NEWSLETTER MAY 2007

ME Group Meetings

Wednesday, 2 May 2 – 3.30 pm

Social Meeting

Wednesday, 6 June 2 – 3.30 pm

Talk on Homeopathy and Kinesiology by a local practitioner Dinna Ferrer starting at 2.30.

The Group's Annual General Meeting will be held on the 4th July at 2 pm, at the beginning of the regular meeting.

Fundraiser

**Saturday 7th July at Dean's Garden Centre, Stockton on Forest, York.
Help is needed to shake collection tins. Please contact Sandra.**

Check website for further meeting details or phone 01347 810841

All meetings are held at the Holmefield Centre, Peel Close, Heslington.

A Perspective on ME/CFS as Chronic Stress

In February's newsletter Richard wrote an article concerning approaches that concentrate on the hypothalamic pituitary adrenal axis. We had one response that pointed out that not everyone is helped by talking therapies such as Reverse Therapy, and queried how this type of therapy can help a physical problem. It is important when assessing any treatment to remember that ME/CFS is NOT a true diagnosis but a group of symptoms, which conventional medicine does not understand, thus it is called a 'syndrome'.

It is most likely that ME/CFS has many causes/triggers but what all sufferers have in common is their symptoms which are those of CHRONIC STRESS. To the body stress is anything that causes an elevation in the stress hormones, it can be physical or psychological/emotional and the body's response is the same.

The body system that deals with stress is the Hypothalamus-Pituitary-Adrenal axis (HPA axis). This has been observed to be dysfunctional in ME/CFS. The end organs that suffer are the adrenal glands and this is variously referred to as adrenal fatigue/adrenal insufficiency/low adrenal reserve. The thyroid gland may also be involved.

The distinction between the body and mind that is often made is a false one. While physical stressors may be outside of our knowledge or control e.g. infections, chronic or undiagnosed illness, it may be in our power to deal with psychological/emotional stressors. This is what the talking therapies have honed in on.

These therapies, including Reverse Therapy / The Lightning Process / Alex Howard's Approach, recognize the connection between mind and body and realise that some people may contribute to the stress that makes them ill by the way they respond to what life throws at them. These therapies attempt to help people to retrain their responses to various aspects of life, so that where their previous responses signalled to their body 'stress' now the retrained responses does not alert it and the stress response is not set off and so the total stress on the adrenals is lessened.

For more information on the Lightning Process see the article below and:

www.mickeltherapy.com

www.sleepydust.net

www.alexhoward.me.uk

None of these therapies would claim that they can cure serious adrenal or thyroid problems which some ME/CFS sufferers may have as a result of chronic stress.

Another approach is that of Dr Barry Peatfield. ME/CFS involves problems in the HPA axis and the symptoms are those of adrenal and thyroid dysfunction. This is overlooked by the NHS due to a poor general understanding of the subject and a heavy reliance on blood tests, (which are not reliable!) for diagnosis. This leads to the NHS doctors telling you that there is nothing wrong in this area when there is! There are private tests available for thyroid and adrenal function using saliva or urine which give more reliable information.

He finds that many with ME/CFS report a history of glandular fever. This virus can cause the thyroid to fail. If Dr Peatfield judged this to be your problem he would advise supporting your ailing thyroid/adrenals with the relevant hormones. He has over 20 years experience in this field.

See: 'Your Thyroid and How to keep it Healthy. The Great Thyroid Scandal and How to Survive it.' Dr Barry Durrant-Peatfield.

This is obtainable from book shops or www.amazon.co.uk

Sandra

We would welcome your views on this article

So What is C.B.T. Anyway?

In the last newsletter we included a statement by ME charities on the draft National Institution of Clinical Excellence (NICE) Guidelines on the treatment of ME/CFS. One of the criticisms of these guidelines was their recommendation of the “blanket use” of Cognitive Behaviour Therapy CBT as the treatment of first choice for ME sufferers. This is a recommendation that most ME victims would feel does not get to the heart of the problem of ME, and skews it's treatment towards dealing with it as a psychological problem.

These NICE guidelines on ME come hot on the heels of previous NICE recommendations of CBT as the first choice treatment for anxiety, depression, eating disorders, obsessive compulsive disorder, post traumatic stress disorder and even schizophrenia, all of which, of course, really are psychological problems. This approach is itself controversial, but pushing the use of CBT into the area of ME/CFS is particularly contentious.

In the background to all this is the government drive to get people off incapacity benefit. Government advisor, economist Professor Richard Layard believes that with 16 meetings with a cognitive behaviour therapist (costing £750), half of the people with depression and anxiety can be cured. With one million people on incapacity benefit due to mental illness, this is an economically attractive proposition.

The big attraction to the government of CBT is the fact that it is time limited, problem oriented and it's outcomes measurable. CBT is short and cheap; a quick fix, in other words – if it works.

As it's name implies, it is aimed at altering both negative thoughts, and the behaviour patterns to which they give rise. Imagine the case of someone suffering from depression. They decide they feel so low that they cannot work. They ring in sick, and then remain at home brooding on this new failure and feeling more useless than ever – a classic vicious circle. CBT would seek to challenge their negative thoughts, which prevent them from going to work to help them see that their negative predictions of what would happen if they went to work are due to their disturbed state of mind. It is an approach based on altering behaviour and thought in the here and now, rather than dwelling on possible past influences on behaviour.

The depressed person referred to would be required to do homework too – to go away and practice replacing negative with positive thoughts, and eventually, also, to go out more and face situations with which they had felt unable to cope.

This approach may be all very well for depression, but seeking to apply it to ME/CFS is surely going too far. ME is not a result of negative beliefs. Let us be clear, the belief that ME sufferers hold that they have a physical illness is correct, and not a false belief. The NICE guidelines seem to exemplify a “psychiatric” view of ME. But how does this view explain the fact that so many previously healthy people should decide to drastically limit their lives by maintaining a supposedly illusory illness?

Does this mean that CBT should have no role in the treatment of ME? Well, first of all, it looks like it is going to have a role whether we like it or not. Secondly psychological factors do play a role in ME – they do in any disease it depends on what CBT is attempting with ME patients.

CBT may well be a cure for certain psychological conditions. It is hard to see how it can cure ME. However if it can help sufferers manage and perhaps extend their daily exertion it may have a benefit, and this may, in turn, assist with their general level of optimism and mental well being. But it still seems like tinkering at the edges of the problem of ME/CFS, and shows that the physiological basis of ME is still being neglected.

Brian Elmer

The Lightning Process

The Lightning Process is a new training programme that, for people with CFS/ME, aims to bring about changes in the hormonal system to promote recovery. It came to prominence recently following an article in the Daily Mail by Esther Rantzen who described how her daughter Emily recovered from ME using the process. Esther describes this process, derived from Neuro Linguistic Programming, Hypnotherapy, Life Coaching and Osteopathy as follows:

“It is based on the theory that ME is an illness that affects the body’s capacity to deal with adrenaline. This is the hormone the body releases when stressed – in people with ME the levels are abnormal, and they need to “train” their brain to normalise the body’s response. This stops the stress response, and in theory creates new connections in the brain.

The first step is to tackle the thoughts that trigger the stress reaction – halfway through a negative thought they have to tell themselves to stop. This stops the stress response, and in theory creates new connections in the brain, stimulating the production of endorphins – feel-good brain chemicals.!

The Lightning Process website (see below) contains further information, details of practitioners and stories of people who like Emily have responded well to this approach. It includes a quite detailed application form and information, which may help to determine whether this approach is one that might help.

It also details the schedule of treatment. Appointments are usually on 3 consecutive days. The first and second days are usually 2-3 hours long in a small group of around 3 people, and day three 1 hour, one to one. This is usually followed by one or two 20 – 30 minute phone calls to support you in applying the process when you return home. On day one participants learn the process, and start to use it immediately. The other sessions are for fine-tuning.

As the approach is new there isn’t a lot of other info out there yet and current evaluation using scientific protocols is still to be completed. (I have put websites I have found below). It is expensive at around £560 for a treatment, £50 to £100 for follow up support. I know of people who have done well, but am also aware that it doesn’t help everyone. There are many different types of approach and different techniques work for different people, so as always it is important to investigate an approach well before deciding if it is suitable for you. The March ‘Action for ME’ Magazine, surveyed 19 ME sufferers who had tried ‘Lightning Therapy’, 8 improved, 8 did not and 3 had mixed results. If you would like a copy of this article, please contact Jenny on 01904 655911.

Jenny

Websites: www.lightningprocess.com (includes links to practitioner websites)
www.meassociation.org.uk (includes Esther’s Daily Mail article of February 2007).

Various views on www.mecfsparents.org.uk www.25megroup.org

www.mariannegutierrez.co.uk

Try also forums on websites such as <http://www.brainfog.org> and www.co-cure.org

ME Awareness Week May 2007-04-05

Preparations for this year's ME Awareness week are now well underway. This includes Action for ME's campaign, which this year focuses on men, who sometimes have more difficulty getting an official diagnosis of M.E. and can face specific issues in relation to health and identity. There is a peoples day event in central London, on May 10th, lobbying parliament and Downing street. (For further events see the newly designed ME association website on www.meassociation.org.uk).

Also Children and young person's ME consultant, Dr Nigel Speight is going on a 1007-mile West Coast Cycle challenge during ME Awareness Week, beginning on 10th May to raise money for Association of Young People with ME and ME North East and would really welcome your support. Details at:

<http://www.justgiving.com/nigelspeight>

Display

The group is organising a display on ME/CFS in the main corridor of York District Hospital for two weeks from 30 April 2007.

Grants

The group has received cheques from the Purey Cust Trust for £278 and from the Norman Collinson Trust for £300 to cover the costs of the newsletter. We thank both Trusts for their support (and Jenny Gilmore too for applying on the group's behalf.)

THE DEADLINE FOR CONTRIBUTIONS TO OUR SUMMER NEWSLETTER IS 31 JULY 2007

Please send articles for inclusion to Brian Elmer, 101 Bellhouse Way, YORK YO24 3LW

Disclaimer: The inclusion of information of any kind in this document does not imply a recommendation of guarantee of accuracy, nor any views or comments necessarily those of the group.

F R I E N D S H I P N E T W O R K



Members of the network should have an updated contact list with this newsletter. If you don't then do let me know. The network is going well and we have many members across our area.

If you would like to join please send me a stamped addressed envelope

For details of the Group's Friendship Network contact

Sandra Tomlinson on 01347 810841

Talk by Azizah Clayton

For those unable to attend this meeting in March we do have notes on what was said, which are available from Sandra Tomlinson.

For those of you on line:-

If you have a Blue Badge, or care for someone who does, there is a new service where, typing in the postcode, or the name of a city shows:-

Blue Badge parking bays in 64 towns and cities across the UK

Address, number of spaces and any applicable restrictions and exceptions

Red route parking bays in London

Accessible petrol stations in the UK and their service facilities

http://www.direct.gov.uk/en/DisabledPeople/MotoringAndTransport/DG_10038295

The on line Citizens Advice Bureau (CAB) service that provide independent advice on your rights – Practical, reliable, up-to-date information on a wide range of topics, including Benefits, housing, employment and debt, consumer and legal issues. Details of reliable sources of advice if you need more help, including your local CAB. There are also useful factsheets to print off. www.adviceguide.org.uk

Good value Vegepa, which includes a donation of 50p per pot to ME research is available for ME Scheme via <http://www.thevegepaformescheme.com>. Vegepa is a patented formula of long-chain fatty acids, combining EPA (eicosapentaenoic acid) from marine fish oil and 100 mg organic virgin evening primrose oil (EPO). Intake of EPA-rich supplements – like Vegepa – have been show studies to be effective in treating symptoms of Chronic Fatigue Syndrome/ME in some individuals.

Clearing NHS debt – petitions for you to sign

The Evening Press has been voicing concern about local NHS service cuts due to the millions of pounds of debt in the newly formed Primary Care Trust for North Yorkshire. The government has written off some debt, but there may still be significant impact on services. There is a petition on the Prime Minister's website about fully writing off this debt <http://petitions.pm.gov.uk/NHSdebt/>.

There is also one from the Liberal Democrats at <http://www.madeleinekirk.org.uk>

CAN WE SEND YOUR NEWSLETTER BY E-MAIL?

If so, please let me have your e-mail address

Sending the Newsletter in this way will cost us nothing, helping the group enormously.

**THIS DOCUMENT IS AVAILABLE IN
LARGE PRINT**