

SUPPORTING EVIDENCE FOR GMC COMPLAINT AGAINST DR. ESTHER CRAWLEY

Dr. Crawley's failure to adequately assess risk associated with the intervention and failure to disclose risks to SMILE study participants – patient reports of the Lightning Process

Most of the following accounts were posted on internet websites and would therefore have been available to Dr. Crawley as anecdotal evidence of the potential risks to patients participating in the SMILE study. By contrast, the newly-diagnosed participants and their legal guardians could not be expected to be aware of the availability of or to research for themselves such information and would have no reason not to doubt their trust in the specialist NHS doctor, who is both diagnosing them and leading the research, to protect their safety and well-being.

There are anecdotal reports of success of the LP also to be found on the internet (many such reports are found to be posted on the internet by LP vendors themselves) but this is not relevant to the matter of professional assessment and disclosure of risks to study participants.

Also to be noted is the high rate of misdiagnosis of CFS/ME in patients, found in studies at Newcastle and Dundee Universities – 40-44% of patients with a CFS/ME diagnosis were found to have other, potentially treatable, conditions. It is also likely that some people undertaking the LP may have self-diagnosed; in the absence of diagnostic tests, believe they have CFS/ME when they do not. It also seems fairly common that people claim to have been cured by the LP and go on to become LP practitioners themselves; hence why the LP is often referred to as a form of pyramid-selling practice.

You may note from the following accounts the common theme of people reporting a temporary “high” following the course, followed by a relapse of varying severity.

Whilst anecdotal, accounts such as those that follow, when taken together, show to any reasonable person that there are potential risks of harm from the LP and that the risk for an individual patient could be high. It has been reported that some of these accounts have been posted on the message boards of AYME – the charity to which Dr. Crawley is medical advisor and which supports the SMILE study. Adverse events following the LP have certainly been reported to other ME/CFS patient organisations so it is inconceivable that Dr. Crawley would have been unaware of such risks when she stated in the study protocol that she did not believe there to be risks from participating in the study.

Conclusion

That Dr. Crawley failed to adequately assess and disclose the risks to study participants in the face of such anecdotal evidence and the absence of any relevant scientific data calls her fitness to practice into question.

PATIENT REPORTS OF THE LIGHTNING PROCESS

“Jan 2009 For some people, LP made them cope better, but they still had symptoms. However, they are telling the media that they are cured. For others, it worked for a while and then they suddenly collapsed. I have had crying ME patients on the telephone telling me how they have not recovered or have been made worse and believe that it is their own fault for not recovering. This in spite of totally believing that LP would cure them. They have tried so hard - for months, and followed all the instructions from their "trainers". They also believe that they must be the only ones who have not recovered, and therefore do not dare to tell anybody or to talk to anybody. They are simply not allowed to tell the truth.” Ellen Vivian Piro, Secretary, Norwegian ME Association.

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“Lightning Process unsuccessful experience

Just thought you may be interested in our experience of the Lightning Process just in case you are considering it.

My daughter (14 years) has and I was with her during it, so have first hand experience. We
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just want to give people a few points about the this that they may not be aware of, things I wish I had been aware of before embarking on this. Incidentally my daughter has felt no benefit from LP.

I think there are some misleading aspects on the Lightning Process website. We experienced no Osteopathy and the 'self hypnosis' is more like a relaxation session I have encountered after a yoga class.

In my opinion we had a particularly negative experience with the trainer we saw
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On the first day, the trainer made my daughter stand up to learn the process, which was a very difficult as my daughter currently suffers from severe leg weakness. The trainer ignored the fact that my daughter's legs were giving way while she was trying to learn the process. My daughter's confidence in the trainer took a severe blow.

On the second day my daughter insisted on sitting down to learn the process. The trainer reluctantly let her, but was not happy and said that she would have to start to challenge her beliefs. We were there to challenge our beliefs; I would not have paid many hundreds of pounds if we were not prepared to do this. On this occasion, the trainer missed out some of the process, and spent longer teaching the other girls who had no problem standing up.

Following completion of the process, I wrote to our practitioner raising my concerns because when we tried to ask questions during the sessions we were immediately told to stop. She replied with a letter, which in my opinion was insulting with grossly incorrect accusations. She also avoided answering many of my important questions. If the training doesn't work, you are told it is your fault – you have not done 'the work', they take no blame whatsoever.

We went to the LP with full believe and high hopes. Our trainer accused my daughter of not doing the process properly, and that she didn't want to get better. How dare she say that of course she wants to get better and she has worked so hard trying to get this to work! **She also said that 'it worked for everyone else'** - I would love to know if this really is the case! My daughter was in hospital 2 months ago, which is when a relapse took place. Our trainer shunned this information, as irrelevant. In my opinion the process is nothing radical and very expensive for something that may not work.

I am pleased for those who have had success with this, and would not belittle them in any way. I believe that the LP may have some success for some people, however, it is not a miracle cure for everyone and i just wanted to point that out. I would love to hear if anyone else has had less than satisfactory experiences like ours.

I would be happy to provide any further details that you may like. I really feel very strongly that people should be aware of more information before doing the Lightning Process. The trainers are making a massive amount of money from this scheme.

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they have had so many people contacting them for this apparent cure, which I can assure you it is not.” <http://www.healthboards.com/boards/showthread.php?t=486103>

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I have been advised that the person who posted the following may be prepared to comment further

privately. This account and others on forums for young people with ME contradict the statements made in the letter of support provided to the REC by the CEO of AYME and by Dr. Crawley.

“I'm a member of a charity that supports younger people with ME (8-26), we have our own forums and sometimes people say they've done LP. They get better for around two months or so, then completely crash. I've seen one girl go from moderately ill to severely affected where she's now stuck in a wheelchair. One of the key symptoms of ME is post exertional malaise; LP essentially tells you to forget about that and just keep pushing yourself. Another good friend tried LP out of desperation and was a psychological wreck for a good two months after. Whenever she failed she was told she was not doing it right, they were constantly reinforcing to her that ME isn't real and that she was 'doing' ME etc. I'm completely baffled how this has gone past the ethics committee. Not sure what else to write other than that Phil Parker is a vulturous bastard. I believe he threatened to sue the charity I am part of once because a member published some badly written literature on LP that she had scanned after doing LP herself. Such a nice fellow he is.” (Posted on Bad Science)

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“Sorry to hear you had such a bad time with/after the LP course. My experience with the course was a nightmare. In my case as I relapsed badly after day one and couldn't complete the training (my fault for not getting better then, obviously...). I have pushed myself very hard with graded activity and stuff though in the past and paid for it, so I really sympathise.

Best wishes,

Amy” mail@amyshapiro.plus.com

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“I found the whole thing very distressing, i told myself it was working but it certainly didnt and I relapsed also. Let me know what you would like to do and id be more than happy to help.

You can contact me via phone, my number is 07926358235 or my email address, robgiillard22@yahoo.co.uk i very rarely check my email so phone would be best. Robyn Holland”

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“My name is Helen Perks and I received your email address from Beth Guest reference the LP. I will be most happy to help you out regarding any research information you need to inform the public that the LP does not work if you have ME but in my mind only if you have been in the habit of being ill. I attended the LP programme at the same time as Beth and I became very ill afterwards through following their instructions. My contact details are: Tel: 004951516098302 Mob:004915225953613 and obviously you will have my email address helenbperks@aol.com. I currently live in Germany as my husband is in the armed forces, however I will be in the UK from January 11 for three months. I hope I can help. Kind regards Helen Perks”

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“As ME sufferer, and failed LP student, it is my personal belief that the LP cannot cure ME. In fact I think it could be a diagnostic criterion.

I did the LP because I have a completely open mind about my illness and its aetiology. I actually thought it might have been caused through my psychology. I know I have suffered from stress and depression in the past, so it is feasible. I also know that I have physical symptoms, feeling ill daily for 20 years, frequent infections which are hard to shift. So, I'm sure I have organic disease, but I'm not sure what makes/made me susceptible to it.

I also know that I am very strong. I continued to work for many years in a senior management position with a large company (Thorn EMI. a fantastic employer) with my ME, and have continued to remain as fit and active as possible (I do 10% of what I used to do, so now my physical activity level is about average - I hope that doesn't sound conceited, it's just meant to be factual).

I do not see any way that the LP can cure my illness, just as I would not expect it to cure cancer, AIDS or MS (although Phil Parker is trying with the latter - he knows he's on safe ground as it's often as difficult to diagnose as MS).

I could go on, but what I would like to guard you against is the provider of the LP. Everything they do is suspect. Phil Parker dabbles in the occult. He is not a scientist or a trained physician. He is a quack. He employs aggressive marketing techniques (like nice ladies on the phone). He makes a lot of money, as do his disciples/pyramid sellers. All the best, Steve sjfenney@onetel.net 01409240008”

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The Lightning Process Didn't Work For me 89 By sallycats

Shedding light on the lightning Process

“PHIL PARKER’S LIGHTNING PROCESS DIDN’T WORK FOR ME.

The Lightning Process is the latest 'miracle' cure for M.E and Chronic Fatige. It is shrouded in mystery because they **drill it into participants that if they tell anyone about it it won't work.** It has worked for some people but not for others. It is based on affirmations and counteracting negative thoughts if you are already familiar with such things it will not be anything new for you. **I paid £550 to go on the course because I couldn't find out what it was really about.** This is why I have written this.

There were four of us on the course. The morning of the first day was spent ‘proving’ mind over matter by showing us DVD’s interspersed with talks from the tutor, a stout woman in her late fifties, telling us about people who had being wrongly diagnosed with cancer and then died anyway.

‘That’s how powerful your mind is,’ she trilled and didn’t cite the many cases of people wrongly diagnosed with cancer who gave away all their money only to find themselves still alive and then sue the NHS - as was on the radio recently. We were shown optical illusions, pictures where one way it looks like an old woman, one way a young one and another one of an elephant with varying numbers of legs depending on how you looked at it. She kept pointing to her large sofas and telling us stories about people who had lain there unable to move at the start of the course and were walking again by the third day and then back at work/school by the following Monday (the course was mid week). I liked this bit. Before the course I could already walk, I could even work part time, but I still slept afternoons, travel exhausted me and nights out left me sleepless and overwrought. If others went from nothing to being able to work in four days I was sure to get well. I believed it could work. **My basic attitude was I have paid £550 for this (borrowed money as I am on benefits) I am going to do what they say.**

The first thing was to take responsibility for our illness. I had to stop saying I had M.E. Instead I have to say I am ‘doing M.E’, I wasn’t tired, I was ‘doing tired and doing muscle aches’. The implication being if I am doing it I can stop doing it. I wasn’t sure what I thought about this, but it didn’t matter because I didn’t get to put it into practice much on the course as you are not encouraged to talk about how you are. This was because we are going to concentrate on the positive which at the time seemed fair enough. The facilitator was telling us more and more stories about the people she had cured. One of them even phoned up while we were having lunch and the phone was passed round the table so we could all talk to her. By that time I was up really up for it, we all were, whatever the process was, I was going to do it with all my heart.

In the afternoon session we were told that the reason we had M.E is that we have negative thoughts. Every time we have them our adrenal glands give us ‘a squirt of adrenaline’ this builds up and stops your body functioning properly.

The Lightening Process would stop this happening. This was a miracle. The five hundred and fifty pound wonder.

The tutor stood up. 'To stop this you have to get up and say 'Stop' make a physical movement, step back or cross your wrists in a pushing away movement.' And she did the movement for us. Then she showed us how to go through an affirmation/self-coaching process, which I think is copy righted so I'll paraphrase. You ask yourself if you want to choose happiness. Which you obviously do and then you say how fantastic you are to have stopped the negativity thought. You ask yourself what you really want, then you answer yourself, and again ask yourself how you are going to get there. The answer of course is to keep doing the process, getting rid of those negative thoughts. Then you tell yourself how great you are again and maybe have a bit of a hug with yourself, then..... no nothing, that's it.

Kerching. Five hundred and Fifty pounds please.

I was a bit perturbed at this point because I have been doing affirmations and therapy for many years so I am not blighted by the kind of negativity that can be emotionally crippling, and when I first discovered that it was wonderful. **But I discovered it in a book that cost £3.50 now I it seemed I had paid £550 for the same lesson.**

However the mere fact I had paid so much money meant I was going to do exactly as they told me, it had worked for others and it could work for me. We were told to do The Process thirty times that evening. I went back to my guest house and did as I was told. I spoke to my loved ones but when they asked how it went I was reluctant to talk about it. **The tutor said that if we tell people about the process if won't work. That's right, to talk about the process means it can't work for you. She also told had told us no matter how she feels she tells everyone she 'feels fabulous'.** I wasn't quite ready to tell people I felt fabulous but equally I didn't tell anyone how much the first day had tired me because that is a negative thought and that must be countered, so I did my thirty processes, went for a walk and then to bed.

The second day when I turned up there was three big posters saying, 'DON'T TALK ABOUT HOW YOU ARE UNTIL THE SESSION STARTS'. **I soon realised once it did start that is so the tutor can control everything.** She didn't ask me if I felt better she asked what I did the night before, I said, 'I did the Process and I went for a walk' she said, 'Sally, went for a walk, hooray' like it was a victory for the Lightning process but as I said my M.E is moderate and I go for a walk everyday, but no-one would have known.

As the day went on I was getting more and more tired. By mid-afternoon I was slumped in my seat watching yet another video about how the brain makes us over-produce adrenalin and how The Process can stop it. But I had been doing the process and it hadn't stopped it. All the tutor's happy chat about even more people she had cured were starting to sound stale.

I was not the only one who looked knackered. **One of the blokes started asking questions about why he doesn't feel what they say on the DVD.**

'It's a three day process' she snaps and makes him do the Process.

Any awkward question for the rest of the session was answered with 'It's a three day process,' or anything even more awkward she says we can ask in the individual sessions we are having the next day.

If anyone says anything she thinks is negative we are interrupted and corrected.

At one point she left the room. It felt very naughty but I whispered to one of the woman sitting next to me 'how are you, is this working for you?'. She was reluctant to answer, to say anything but that she was doing well would be to go against the process because that is a negative thought. It was pointless asking really.

Still I wanted it to work, but I was starting to worry about the fact that I was not only not feeling any better the effort of doing the course, not getting my normal rest was making me feel worse.

But these were negative thoughts. I started to ruthlessly suppress them like I had been shown.

Yes by that evening I was doing the Lightning Process to counteract my thoughts about the Lightning Process itself.

The next day I still felt no different. I went and had my one to one session and when I told her that she said I was being negative (of course) and that I must keep doing the process at home and it would work. But on the course I was told that the reason it was called 'lightning process' was that because it worked liked lightning (they even produced diagram with a graphic of some lightning in case we didn't get it. I got the concept, it just wasn't happening.) **From all the literature I was sent prior to parting with borrowed money to go on the course, were testimonials saying how fast it had worked. No body said it didn't work on the course but it did later.** Also I realised when you fill in the form you have to say whether you question things, this is because they don't want anyone on the course who does. They need to control everything. You are not allowed to talk about how you are because that is being negative. In the session anything I even hinted to this effect was countered with that I was being negative. So we moved on to what else she could do for me. I said one of my biggest problems was being exhausted but unable to sleep. So we did a visualisation that involved a pressure point on my hand and she said whenever I couldn't sleep I could just rub that point.

'There you are you are cured,' she said so happily that I could see in her mind where no negative thoughts ever creep, I was. She was clearly thrilled with herself. I wanted to believe her and tried it for the next few nights, of course to no avail.

The lightning process is supposed to be NLP and osteopathy. I could see no osteopathy, the only movement on the course I attended was the stop movement and the pressure point on my hand I mentioned above. The woman who ran the process had been cured herself so maybe they have got something. I didn't disbelieve her, she had a large house with a spare flat that she no longer needed to rent out due to how much she was making from peddling the lightning process to desperate people like me.

To give her her due she did drive me to and from the station and after the course offered to work with me for free on the phone. So I accepted that but found out that working with me involved her telling me to keep working the process because it worked and arguing with my objections saying I hadn't given it time and that I was being negative.

She kept saying 'keep doing it cos it works,' and had nothing to say when I said I had kept 'doing it'. She said I had given up so soon. **I was told it had a 93 % success rate.** On my course of four it seemed to work for one person and had an impact on another, but for two of us it failed completely.

Phil Parker who invented this process charges £1000 for his three day courses and has over 20 people per course. He should put some of that money into doing a proper clinical trial. It must be easy to wire people up to see if they get a squirt of adrenaline when they have negative thoughts. Maybe that does happen for some people but not all. Some people do get cured but not me.

I wished they asked on the application form if I was plagued with negative thoughts and whether I had worked with affirmations before I could have told them No, and Yes. Then they would have known their process was nothing new for me." sallyholloway@boltblue.com
<http://hubpages.com/hub/The-Lightning-Process-Didnt-Work-For-me>

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“I had an acute onset and went from a hardworking person to bedbound overnight.

In a desperate attempt to recover I decided to try LP after reading stories of severely affected M.E. patients who had recovered. It all sounded so convincing and after a phone consultation with a LP coach I felt very positive I was doing the right thing. I borrowed the money from my parents, £880.00 as I had long lost my job, and went for it.

There were 3 other m.e. patients at the same course **none of these people nor myself recovered.** The course was over 3 days from 10am-2pm with a break at lunchtime for tea and biscuits. We were told not to discuss the content of the course with each other during the breaks. We learned the 'affirmation' and stood on the floor on paper circles with key words written on them.

Here is the big secret of what we had to say while standing on paper circles -

WHEN YOU FEEL A SYMPTOM

SHOUT- STOP! (stand on the paper STOP)

SAY- I HAVE A CHOICE (stand on the paper CHOICE)

SAY- YOU CAN CHOOSE THE PIT OR THE LIFE YOU LOVE (you then stand on the LIFE YOU LOVE circle)

SAY- I CHOOSE THE LIFE I LOVE

SAY- WELL DONE, YOU ARE A FANTASTIC GENIUS, YOU ARE ON TRACK! I AM WITH YOU EVERY STEP OF THE

WAY (you are being your own coach here)

ASK YOURSELF - WHAT DO I WANT?

ANSWER YOURSELF- I WANT ENERGY AND HAPPYNESS LIKE (you say something that means energy etc. to you)

ASK YOURSELF- HOW WILL I GET THIS?

TELL YOURSELF- BY STOPPING EVERY NEGATIVE THOUGHT

EVERY NEGATIVE EMOTION

AND DOING THE LIGHTNING PROCESS.

There are a few more short affirmations and that's it you are cured of M.E.

We all DID leave on the third day full of hope and newly found confidence and told that no-matter how we felt in the future ALWAYS SAY WERE WERE CURED OR THE PROCESS WILL NOT WORK !!!! These coaches are very good at their job but I can assure you they can not cure you of M.E. Think about it PAPER CIRCLES AND AFFIRMATIONS.

The four of us all were 'high' for a few weeks or months and did indeed do more than usual but sadly **all relapsed**" <http://forums.aboutmecfs.org/showthread.php?4687-Article-An-MD-on-the-Lightning-Process/page18>

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"I can only voice my personal experiences of LP, but I am also in contact with another 5 M.E.'ers who have done LP and all have **relapsed BADLY**

I was walking wounded before I did the course (could walk about half an hour a day before getting too tired/painful, or drive a similar amount of time) and after two weeks of applying LP to the letter all I was doing was managing to do less and less every day yet still pushing myself on with the LP. It ended up with the biggest relapse I've had since becoming ill (13 years ago), I've now been housebound for about 5 months and in a hell of a lot of pain, experiencing many symptoms I thought I'd seen the back of. I urge anyone considering doing this to be extremely cautious, I wasn't, I believed it all and went flat out for success, I wouldn't touch this with a barge pole or recommend it to anyone I know. The claims made for it are all spurious, there is no proof it can reduce stress levels (adrenaline rushes) and even if there was proof some M.E.'ers have low cortisol/adrenal levels so you shouldn't treat everyone the same. The suggestion of improving Lymph flow or any use of osteopathy or hypnosis is hilarious, none of them feature, it basically IS positive thinking and visualisation. This may be fine for healthy people wanting to sort out their phobias and confidence

issues which is what NLP was designed for (life coaching) but it is positively dangerous to use it's techniques where many physical tests (Adrenal function/R-naseL/mitochondrial efficiency and many others in my case) show that this issue is PHYSICAL in nature and you can't think your way out of it.

I lost a lot of money and what little health I had for believing some pseudo scientific nonsense designed to make money from the desperate. How handy that if it doesn't work then the blame can be passed on to you, if it's so simple (and it is) then no one should fail!? Of course the negative experiences will never appear on the testimonials page on the LP website, it hardly encourages further business. PLEASE BE CAREFUL, this technique DOES NOT work for everyone.

However I must say, if it worked for you then I'm really pleased that you're out of the hell that you were living before it but it's wrong to assume it works for everybody no matter what. Good luck to you all T66” <http://www.healthboards.com/boards/showthread.php?t=523715>

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“Warning: long post.

I was an inpatient at the CFS unit at Queen's Hospital, Romford a few years ago. The unit is run by Prof Leslie Findley. Prof Findley is a consultant neurologist, who has been known in recent years as someone who has taken a keen interest in the Lightning Process and has recommended it to many of his patients.

I spent six months in hospital working extremely hard on rehabilitation approaches (ie graded activity). I was then moved to a private nursing home, funded by my PCT, which was where Prof Findley was siphoning off patients to do the Lightning Process (I guess it wasn't possible to get it funded in the NHS and done in the hospital setting). I had a LOT of pressure put on me to try the LP, and was pretty much coerced into spending £975 of my own money (despite being an NHS patient) on having Prof Findley's LP "therapist" (not a health professional of any kind) do the LP with me at my bedside (I was largely bed bound at this point, and still am). **The LP didn't work for me and in fact caused a bad relapse** as, despite being told over and over at the CFS Unit to keep activity levels consistent and not make sudden increases, the hours of "therapy" went way over what my established baseline of activity was at that time.

When I decided to quit the LP, the trainer called Phil Parker who sent me a message saying that i clearly didn't want to get well, and subjecting me to horrible emotional blackmail bordering on abuse. They were saying this to a patient who had just enthusiastically complied 100% with the NICE guideline-consistent rehabilitation approaches used at Queen's Hospital, for 6 months of intensive therapy and hard work, and had continued to comply and basically work extremely hard with therapists at the nursing home for several more months.

I notice that Prof Findley now has his own version of therapy, called Neuro Behavioural Training, which sounds suspiciously like the Lightning Process.

Needless to say, I feel sickened by the Lightning Process and the fact that some in the NHS seem to be encouraging its use. It's pseudo-scientific nonsense distributed through a kind of pyramid sales system. And it actually does some patients harm, never mind robbing them of what little money they have.

Finally, I would like to add one point about the whole debate over treatment approaches for ME/CFS. It seems that many people with ME/CFS refuse to try any behavioural management approach, feeling that it labels them as having a mental illness which they feel they don't have. But when ME/CFS sufferers argue that they want to see something other than these approaches on offer, they have been accused, sometimes on this forum, of maligning the mentally ill, being in denial and so on. I would just like to point out that, as someone who's been severely ill for many years, my only hope and objective is to get better and get my life back. I have, and continue to try behavioural approaches to managing my illness and increasing my functioning, but sadly this has only been of

limited benefit. I am better able to manage some of my symptoms (largely through finally getting more appropriate medication) now, but my level of functioning is not improving. I would be overjoyed to have a more treatable condition, whether that was a mental health condition or not. So for me, when I complain about the over-emphasis on GET and CBT in the NHS, the only reason for that complaint is that I want to get well. And if GET and CBT haven't worked for me, I'm obviously going to want other options to be investigated. I don't often see this argument articulated - it comes out more as "how dare you suggest we're mentally ill/our illness isn't real". But for me, it's not about that fruitless mental v physical debate at all, and I expect others share my view. A great many ME/CFS patients have openly and willingly tried GET and CBT - we're not all refusenik extremists - but have had little or no benefit from it."

<http://www.badscience.net/forum/viewtopic.php?f=3&t=15791&start=1825>

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"Lightning process for ME didn't work for me By jfeesey

FURTHER to the letter from Dr John Greensmith (January 8, 2008), I would like to recount my somewhat less-than-miraculous experience of doing the lightning process.

I attended the three-day seminar at Hallsannery, Bideford, in May last year and spent five hours a day listening and concentrating intently with an open mind and religiously putting into practice all that I had been taught.

At the conclusion of the seminar my ME symptoms were neither miraculously cured nor inherently worse — just the same.

As part of the process I received a phone call two weeks later to check on my progress since the seminar.

I told my instructor that, despite practising the process regularly, my symptoms had remained the same.

He then said that I had obviously not followed the process properly, otherwise it would have worked.

There was a dogged refusal to accept that it might be possible for the lightning process not to work even if practised religiously.

I pointed out that to have an unbiased study you have to accommodate both sides i.e. those it has worked for and those it has not, but he then said that those it had not worked for were usually reluctant to come forward.

This struck me as odd so I said that I would willingly publicise that it had not worked for me but he told me that if I did that he would simply tell people that I hadn't done what I had been asked to do.

He concluded by saying that **"we're not really interested in those it hasn't worked for anyway"**.

Furthermore, he made claims to me that the lightning process was **able to cure conditions such as cancer** if practised properly.

I feel that people should be aware that the 96% success rate that they claim is only their alleged personal figure and not the national statistic; indeed the jury is still out on the national success rate, there are no official figures as yet.

What I find disturbing about the lightning process is that not only does it extract large sums of money from vulnerable and often desperate people, but the instructors' attempt to silence anybody who has not found the process beneficial.

C PUDDIFOOT, Bideford." <http://www.thisisnorthdevon.co.uk/news/Lightning-process-didn-t-work/article-613394-detail/article.html>

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LP DOESN'T WORK

<http://web.me.com/johnsayer23/LP/Home.html>

This web page has been created as a place for people to record, in the public interest, their misgivings about LP and/or its failure to 'cure' them.

Contributions should be e-mailed to: john23@sayer.abel.co.uk

Disclaimer: while authorship will not necessarily be disclosed on this page, it is assumed that accounts sent here are honest and sincere and responsibility for their contents remains with their originators.

(Most recent contribution at top.)

“The Lightning Process did not work for me. I did the training with Phil Parker himself in Crouch End, London, in November 2006. Not only did it not cure me of my CFS/ME, but it actually initiated a relapse and left me much more ill than I had been prior to starting it. This relapse lasted at least a year and a half, and I have no way of knowing what permanent damage doing the LP may have done to my body and health.

The Lightning Process is billed as a training programme, although the website does not tell you anything about the content of the course. You have to actually undertake the course in order to find out what is involved. You are also instructed not to talk about it afterwards with anyone, including fellow sufferers. My training took place in 3 hour sessions over 3 consecutive days in London, along with 4 other ME sufferers, and cost £560. There was a CD to buy for £20 at the end of the course and follow up phone calls cost £50.

It is a psychological technique. Like Reverse and Mickel Therapies, the LP website is careful to say that ME/CFS is a physical illness, thus ensuring that sufferers will pay attention, but it does not say that the technique is entirely psychological. They provide an explanation about the adrenaline cycle making you ill but it does not appear to be backed up by any actual scientific evidence relating it to ME/CFS.

I completely believed in the LP philosophy at the time I did it and was committed to doing the Process. I did experience some difference in myself in the 5 weeks after doing the training. I wouldn't say I felt better but I was doing much more than usual (as it turned out, far too much) and my sleep quality was improved during that time. But I became very ill again, literally overnight, and I was left feeling much worse than I had been prior to starting the Process. I tried hard but no amount of doing the Process was able to reverse the relapse.

The website says LP was developed using techniques from Neuro Linguistic Programming, osteopathy, self hypnosis and life coaching. However, there is no osteopathic element involved at all. My interpretation of it is as a Mind over Matter technique, akin to the 'psyching up' process that I usually have to do in order to achieve short-term goals, such as going out to the shop or an appointment, or even just getting out of bed in the morning. However the LP encourages you to employ that technique all the time. I know it can work in the short-term but it is not sustainable for any length of time.

LP claims to decrease the excessive adrenaline levels which are causing one to feel ill. However, the effect of the training was to 'psyche me up', virtually constantly for 5 weeks, until my body could obviously sustain it no longer and I crashed overnight into a relapse. I was 'buzzing' during those five weeks; my adrenaline levels must have been dramatically elevated not reduced.

During the three sessions I was encouraged and persuaded to believe that there was nothing actually wrong with me and that I could 'coach' myself back to health. Phil told us that we were not really ill but had got trapped into a cycle of thinking and believing that we are ill which sustains itself. ie. if you concentrate on your symptoms all the time, then you're going to keep having them. You are

instructed to stop thinking about your symptoms and to get on with "living the life you love". I was to think of myself as healthy and behave as if I was healthy, ignoring the symptoms and "getting on with it". I trusted in this advice and followed it completely, and as it turned out, to my severe detriment. My relapse was obviously caused by drastically overdoing it physically in the following five weeks.

As an example, on the first day, after our 3 hour morning session, Phil asked the five of us what we were going to do that afternoon. Predictably we all answered that we would be resting up in preparation for the next day's session. He said that was very dull considering there was so much to do in London. As a result, I changed my plan of spending the remainder of the day in my hotel resting and instead visited a tourist site in the afternoon. He asked us next day what we had done and, as I had been most ambitious in what I did, I was singled out and praised. One of the others had gone for a long walk and he was also commended for that. No account was taken of actually how fit or well enough we were to do these things

Phil told us our symptoms were not evidence of anything sinister, could be ignored and that we would not damage ourselves by following the technique. I was prepared to believe him because, mainly due to the inadequacy of diagnosis, treatment and care afforded to CFS/ME by the NHS, I did not have any evidence to the contrary. However, I have since had various tests done privately which show bacterial and parasitical infection in my blood, malfunctioning and deterioration at a cellular level, low cortisol levels, vitamin deficiencies and heavy metal toxicity - not exactly evidence of nothing being wrong with me physically. No amount of positive thinking and ignoring symptoms is going to wish away parasites, bacteria, vitamin deficiencies or mercury poisoning. It is ludicrous and highly irresponsible to suggest that it would.

Myself and the four others in my group were not asked anything about our medical history, the severity of our ME or of any other complications or additional illnesses which we might have had. There was no account taken of us as individuals and although some of us were obviously more ill than others, the same advice was issued to us all. It is shocking that anyone can be so irresponsible in giving blanket advice to people, of whom he obviously knows nothing concerning the severity and details of their illnesses.

A mind over matter technique cannot possibly be claimed as an overnight cure for a physical illness such as ME, with its varying and as yet, mainly unknown, causes, and diverse and frequently severe symptoms. If it was as simple as thinking ourselves better, none of us would be in the state we are now. How often have you, especially when first ill, kept on as normal, saying to yourself "there's nothing wrong with me really, I just need to try harder" when, of course, you are actually seriously ill and incapable of the efforts you are trying to make. LP tries to utilise those mistaken beliefs to persuade you to pretend that you are well when, of course, you are not.

I find the "living the life you love" concept extremely patronising. The only reason the vast majority of us aren't currently "living a life we love" is because we have been cruelly stricken down by a hideous disease over which we, through absolutely no fault of our own, have no control. I can assure Phil that without ME in my life, I wouldn't be having any trouble at all in "living a life I loved" – and without any assistance required from him.

There are a lot of positive testimonials on the website. I have not studied them all but a lot of them have been written soon after completing the training, usually within several months. I must admit that I too would have written a glowing testimonial during the five weeks after because I was still 'geed up' by the process. Also, because the process instructs you to only concentrate on the positive, it is a very convenient method of filtering out any negative and adverse comments. For instance, Phil asked us to email him a few weeks after our training with a progress report but he specifically told us to only mention the positive things that had happened to us and not to mention any negative feelings, symptoms or experiences we'd had, obviously with the laudable aim of concentrating our minds on the positive. It also has the convenient benefit of providing purely positive testimonials for the LP §

The majority of comments written about LP on the web are overwhelmingly positive, which I find surprising and suspicious. I do not believe that I am the only person that it hasn't worked for. I did find several forums that were discussing it, with both negative and positive comments on it; however, all these discussions had been closed down, which I find curious. Part of the training programme was telling you that if it didn't work, then it was entirely your fault for not doing the process properly or for not really wanting to get well (!!) and I think I may have been influenced in that respect into thinking it was somehow my fault that it hadn't worked. I was severely disappointed that the Lightning Process hadn't worked for me, and when I realised it had actually harmed my health as well, then I did actually try to forget about it for a while whilst I tried to regain a tolerable level of health again. It has taken a considerable length of time for me to realise that in no way was I to blame for the fact that the LP didn't cure me and in fact made me more ill. I suspect there may be many others like me, who are unable to admit that it didn't work for them, either because they are too ill, too embarrassed or still brainwashed into believing that it's their fault that it didn't work.

I did believe the LP could work for me at the time I did it but I am now very angry about the mistreatment I received and the resulting harm it did to my already impaired health. I have now just about got over the resulting relapse but it was another wasted one and a half years and I do not know what long-term damage it has done to my system. Doing the Lightning Process was an extremely expensive mistake for me, both financially and health-wise. The Lightning Process is dangerous and exploitative, targeting ill and desperate people who will naturally believe and do anything in order to try to get better. I am ashamed of my own gullibility but I was effectively brainwashed by Phil Parker and his Lightning Process.”

I think people should know just what LP is.

“I am almost ashamed to say that I tried LP last year. After ten years of this dreadful illness I think my reasoning has become unreliable as I am so desperate to get better and get my life back to normal.

The great publicity given to LP as a cure for M.E. is hard to ignore and as you read the 'recovery' stories the thought of good health overcomes any misgivings you might have about this mysterious 'cure'. The fact that there is NO diagnostic test for neurological M.E. leaves one with the question of exactly who does have M.E. rather than chronic fatigue or depression. This miracle cure claims to cure a disease of which medical research has not yet found the cause (impossible).

The course consisted of three days from 10am until 2pm with a half-hour break for tea and biscuits (no lunch). The cost was £880.00 - plus two nights in a nearby hotel (as the coach advises to stay away from home and look on this as a life-changing holiday).

There were four people on the course, so that's £3520.00 for the coach for just over ten hours work. Not bad wages! The coach was very friendly, caring and convincing he could teach us how to recover. He told us he had recovered from M.E. after seven years and been in a wheelchair at one stage. Another lady who was learning to become a coach was taking notes and observing everything. She too told us she had had M.E. but was now recovered by the process.

We were not allowed to discuss the process with other sufferers but just to do it and recover. We were told to cut off all contact with other M.E. sufferers and when asked about LP to say we were cured. We were told to ignore symptoms and keep saying we were cured regardless. I know this sounds crazy but the coach was excellent at his job of VERY high-pitched sales and the people he was selling to were very desperate to get better. The product he was selling us was positive thinking; nothing more, nothing less.

The Lightning Process is:

Believe the Lightning Process will cure you.

Tell everyone you are cured.

Stand on paper circles with some key words written on them.

Learn to say a rhyme when you feel symptoms, no matter where you are, and as many times as it takes to make the symptoms just go away!

Speak in positive words and think with positive thoughts only.

Shout "Stop!" at every symptom.

You are responsible and choose to have M.E. - you must choose a life you love.

If the process is not working, you are not doing it right.

That's it, believe it or not. Sounds stupid, I know, but these are highly-trained life coaches and after handing over £880.00 we all tried really hard to give it our best shot. Not one of the four sufferers recovered and from talking to them I realised they were extremely sick, desperate people who, like myself, would do anything to get better.

It's sad that we have to revert to every charlatan who looks you straight in the eye and says they can cure you. Cure you of what? So we are back to the same scenario.

Until there is a diagnostic test for neurological M.E. no one can cure us. You cannot treat a disease until you know the cause.

Many people self diagnose M.E. Many doctors diagnose M.E. but the average GP has no training in the illness. Many people suffer from depression and would probably benefit from LP but I can assure you no one can cure neurological M.E. yet.

I hope my story helps others save their £880.00. Just send it to "ME Research UK", as with enough funds they will find the cause - and indeed cure - for neurological M.E."

"I recently attended an ME Support Group, along with 8 other poor souls, and was "Processed by Lightning".

Have you ever invited an Everest Double Glazing Salesman or an Amdega Conservatory "Consultant" into your home and after 10 minutes regretted that mad impulse? I have, and with the Lightning Process, it was a case of déjà vu.

A "40 minute talk" by Emma, our Lightning Process Consultant, turned into a two hour "Death by Power-Point" seminar. I learnt all about how Emma, when younger, had phobias, post-traumatic stress; anxiety, depression and then got a "virus" on an exotic island (as one does). The "virus settled" but she did not get better until she met Phil Parker and after Day One of the Lightning Process, she was better. Ah, bless.

We learnt all about the strenuous training the "Consultants" undertake. Emma explained that it takes 12 months. Someone asked if that was full time. Oh, well "no, it wasn't". You just attend at weekends -10 weekends - one each month-then you have an exam! So it takes 20 days at The European College of Holistic Medicine, Crouch End to be trained - not 12 months!

The Power Point Presentation goes on-and on - and on -(copyright "Phil Parker Lightning Process. TM"). We are told the "Myths of ME" - "that people with ME have relapses". I pointed out that it was not a myth. Well it is, according to the Lightning Process.

The Presentation states that it is perfectly possible to successfully and rapidly recover from ME. "What diagnostic criteria do you use?" I asked. "Oh," said Emma," that's a very detailed question we can't go into now but ME, Post Viral Fatigue, Chronic Fatigue and Fybromyalgia are all similar conditions". We were told that people who had been ill for 3 months up to 40 years have been cured; that there are now 120 Consultants in this country and that dear Phil has been in the USA spreading the gospel. I guess they will love him there, and in Crouch End of course.

And the way the Lightning Process works? Illnesses can be cured by changing your thoughts. By turning all those negative thoughts into positive ones, you break the "Adrenaline Loop" and build

up the immune system which makes you all better. Sounds simple, or simplistic? Examine the detail. Is there conclusive evidence that your immune system is underactive and requires building up? Is there conclusive evidence that positive thinking can cure physiological disease? If the reason you are not recovering from ME is a continuous high level of adrenaline, do practitioners measure this before you start the course and after you finished it? The answer to all three of those questions is "No". Conclusive evidence in the diagnosis and causation of ME is not yet here.

If you do the course and do not get better, remember it is not the fault of the Lightning Process, it is you. You're just not applying the training that you received and need to work harder! Do you get your money back? Ah, well no - you just have to keep on trying.

Emma, our Consultant, does not, of course, do this training for the money. Oh, heavens no! She told us she does not need the money. So I asked her if she would be willing to offer free training courses? "I'm afraid not," she said. "If we offered it for free, anyone, just anyone, could come along who had not invested their whole self into wanting to learn the Process and to doing the retraining of themselves." You see, by investing your £700 you have invested "your whole self" and if you do not pay the fee then you are not really serious about getting better. Still, you can pay by instalments and you will be pleased to know that all classes of society attend.

Will the Lightning Process help you? Well that's where we come to the devil and the detail. The Lightning Process makes no mention of sub-groups, that's detail. Yet most doctors treat the terms "ME" and "CFS" as incorporating a huge range of symptoms and causes. You may be tired from a persistent viral infection; tired through stress, anxiety or depression; recovered from the original virus that first laid you low but needing help finding your way back into the "well-world". You may feel "not too bad" one day and "totally exhausted" the next. Where do you fit in? I don't have an answer. Even you may or may not know. But if you are to be cured by the Lightning Process or the other neuro-linguistic processes around, it is essential that you do your homework. Ask questions, query statements, treat anecdotal evidence and personal testimonials with great caution. It's the devil and the details again.

If you do decide that the cause of your ME-type exhaustion lies outside the psychological sphere, what then? Can the Lightning Process cure ME as originally described by Melvin Ramsay? Having heard how it is supposed to work, I do not believe it can.

I came away from that seminar feeling ill at ease. Let no one be unaware of the way that the Lightning Process is sold. It is a slick Power-Point sales pitch, backed up by pseudo-medical half-truths, delivered to vulnerable people who are desperate to be well. Where were the caveats to its claims? I heard none but with the "Devil in the Detail" there were not likely to be."

(Please note that the name of the Consultant given above has been changed to protect her identity)

"I did the course in 2007; it lasted three days, two in a group with four others and one 1-2-1 session with a trainer. The first day was four hours of intensive concentration with only a short break. We were taught the main coaching technique and asked to do something outside our normal comfort zone after the class, something we'd love to do but hadn't because of illness.

I love walking (or used to!) so I chose to walk home from the course venue, which was at least twice as far as I'd normally be able to walk. I knew this would be a challenge, but my trainer was encouraging - she thought it perfectly reasonable. But by that evening I was shocked to find I was much iller than I'd been for ages - all the old burning, inflammatory symptoms returned with a vengeance. This was despite using the LP technique as instructed, repeatedly all the way home on the walk, and afterwards.

I had thought that I might relapse after doing LP and was determined to avoid that happening to me. But I never thought that I would get iller before I even finished the course! My 'faith' in the process was not at all enhanced as a result. However the worsened symptoms had more or less gone by the next day so, with my sister's persuasion, I decided to carry on with the course, despite having

serious doubts at this point. Without my sister's encouragement (she was just eager for me to find something that helped), I'm sure I would have given up.

But I hung in there and I feel I got some benefits from LP. I did like the emphasis on having 'a life you love' and still remind myself of that. I made a very good decision because of that focus and felt my quality of life improved as a result. But that said, despite using LP consistently for some months I never reached what they call 'automatic' (when they say you no longer need the techniques because you can do what you want when you want). And long-term I experienced no physical improvement to speak of.

One of the most disabling of my symptoms, and the one I was most keen to be rid of, is the urgent need I have to crash out during the day, usually in the afternoons. Going without this rest/sleep almost invariably results in me feeling very ill. LP did nothing whatsoever for this symptom, and had no effect on my poor cognitive processing (another key facet of my illness).

'Belief' seems an important part of LP, and I've since discovered that hypnotic techniques are used in the training, so I wonder if those who recover are more responsive to this. I also doubt whether if those who do recover (and there's no doubt in my mind that some do, as I know a few of them) have exactly the same illness as those who don't.

LP is horrendously expensive and the price has at least doubled since I did the course two years ago. But if it really works, then of course most of us would leap at it. What we need to know is why it helps some people and not others, and how to tell if someone is amongst the constituency which will benefit, or not. I expect eventually sub-types work will show who it works for and why. Unfortunately at present the LP people will only spout that those who do not recover are not doing the process correctly, which is offensive and absurd given that it seems to 'work' for some straight away, before they had much chance to practise the technique. I've also heard it suggested that it makes a difference which trainer you have, with some more experienced than others. My trainer was [-], so certainly in my case, poor training can't be at fault."

<http://web.me.com/johnsayer23/LP/Home.html>

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The following discussion shows the evolution of a person doing the LP – from initial excitement to the post course high to being terrified it is their fault it did not work:

“March 20th, 2010 10:37 AM #1

coxy

My son & i are giving the lightning process a go on this week

Hi everyone,

I've decided (even though i'm having an XMRV test soon in uk) that we are going to give the LP a go.

My mind was swung after talking to one of the lovely phone line people at the Tymes trust (charity for children with ME/CFS). The trust obviously do not recommend this therapy or many others , so it was purely the phone lady who got my interest. Her son recovered after doing the process 4.5 yrs ago when he was 11 yrs even though he had had a postive endoscopy prior to the LP with dr chia.

It was her son who wanted to try the process because his friend who was wheelchair bound had done it and recovered (she relapsed 7 mths later though). His mum has no idea to this day how it worked, she sat in on the whole process. She does however know of people it's worked for and people it hasn't. She strongly believes that the people who relapse quickly is due to doing far to much far to quickly though as her son's friend did! Her son didn't do any sport at school at all for about 8mths afterwards to allow his muscles and stamina to build up. After that he had no problems at all. He was affected very badly with ME/CFS originally.

I do know other people it has worked for so i think it is worth a go for both of us. My daughter however (15yrs) is not willing to come along with us, as she doesn't have any belief in it whatsoever.

The trainer who i've chosen lives very locally to us and is one of the original trainers so is very experienced. She NEVER does group sessions, and strongly believes in doing patients individually or in pairs such as me & my son. She has stated that all cases of ME/CFS are different, so group sessions are not appropriate.

Watch this space. I'm remaining upbeat about it and very open minded. Maybe we will be in the subset that it helps. I'm not expecting miracles, and would be happy even it improved us 10% before our holiday.

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March 20th, 2010 03:33 PM #4

coxy

thankyou so much for those positive responses, i thought i might get blasted for it!!!

I'm actually getting really nervous now for some reason, but trying to remain positive. i do have doubts as to if my 12 yr old son will be able to commit himself to it, we'll have to wait and see, i think he thinks it's going to be some kind of miracle.

To be honest whatever happens, we can afford it luckily, and it's the never knowing if we didn't try it that started to get to me. My theory is maybe the LP helps some subsets of the illness, but like i was told on the phone, none of us know what subset we are in. At least in the future better or not at least i can tell doctors i've tried it. With 3 of us ill & a 5yr old showing worrying symptoms i've got to try something, yes i'm desperate, yes it's expensive, but the cost is split between 2 therapists for 3 days, so i guess they arn't going to be millionaires!!!

It was the fact that the tymes trust phone councillor actually told me her son had tested positive for a virus in his stomach by dr chia that really swung it for me. He then went on to do the LP and has been able to control his symptoms and lead a normal life. His mum still worries about him over doing it all the time! So far so good for 4.5yrs, whatever happens in the future he's had that time which must be invaluble especially at that young age.

.....
March 20th, 2010 09:53 PM #9

fingers

Location

SW Endland

How many people who claimed to have recovered via the LP, eventually relapse? Is this in the stats?

Sorry, my earlier post was not direct enough. **STAY AWAY FROM THIS SHIT UNLESS YOU THINK YOU HAVE PSYCHOLOGICAL PROBLEMS THAT YOU THINK CAN BE HELPED BY JINGOISM, THE OCCULT, QUACKERY ETC.**

If this is the world you live in, go ahead.

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March 21st, 2010 02:46 PM #12

coxy

fingers i could of done without that thankyou very much!!!

Sorry it didn't work for you, but there are possibly 7 different subsets of this illness (i think dr kerr has proved that?), so maybe the reason it works or helps some patients and doesn't for others is

something to do with that.

If it doesn't help us i will still be on this forum and have ticked another useless treatment off.

I don't think it's helpful to any of us when someone completely rights this off just because it didn't work for them.

It seems to me that anyone who dares say it's cured them on any forum get's told they didn't have ME in the first place then, & we all tend to believe that.

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March 21st, 2010 03:14 PM #14

coxy

girlinthesnow, i feel exactly like you, and my 15yr old with me/cfs isn't helping with her negativity about the whole thing, but i'm going to try and distance myself from being skeptical, god knows how though!!

The boy who has recovered i was telling everyone about had a food phobia due to sickness with his ME/CFS in his early couple of years & only ate 5 foods, he was completely cured of that aswell. i know it sounds unbelievable, it does to me, but the tymes trust lady had no reason to tell me her story, the tymes trust are COMPLETELY against promoting it in anyway. She is not the first person in my life to have done the LP, and all of them have been made better so there MUST be something in it.

Perhaps if i tell my story after trying it, people will trust me enough to believe the results. I have never been able to trust anyone who has talked about it on a forum, as yiou never know if they have a vested interest in it. I think the whole thing has been blown out of all proportion. I think it's unfair for anyone to be negative about anything to do with ME/CFS unless they have tried it, which in most cases they haven't.

Obviously fingers has tried it and it failed so he feels very passionate about it. To be honest even if it fails for us i wouldn't tell other people not to try it, as i have evidence of it being successful for some.

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March 24th, 2010 08:56 AM #44

coxy

update on lightning process after day 1

hi, I thought i'd update you so far.

It was harder than i thought and a lot of info to take in for my very foggy brain! i did keep mentioning i couldn't take in what she was saying, but she assured me that my unconscious brain was taking in all the info.

My 12 yr old has found it very difficult to understand as i knew he would. The trainer did simplify it for him and there was only me & my son doing it on our own (she never does group sessions).

Last night i felt really upbeat when i got home. i did something different as she suggested, and did the 3 min jog on the wii fit without a problem! i thought of Frank Lampard (chelsea football player) running around on a football pitch while i was doing it, which was the player my son chose as his energy person.

There was quite a lot about links with family members that have unconciuously (sorry my spelling hasn't improved) been negative in the past/or still ongoing which i found difficult to believe. Also a lot of trying to change the language we all use to a more positive form, which i thought i already did, but apparently not!!

I don't think so far anything remarkable has happened, certainly not to my son. I have been able to fight a lot of the symptoms when they come, which is a bonus. I'm wondering if good old adrenaline is working over time at the moment though. My head is still as foggy, which is my main symptom always.

I will keep trying to do the process though to see if what she claims is true. It's all about the unconscious mind which we have no control over, causing us to keep our illness and symptoms going, it's not our fault at all, but apparently they have ways to retrain the brain and remove our symptoms.

Day 2 starts at 10am until 3pm. i have a feeling we'e going to get told off more today for any negative action or thought. Still remaining positive as it's all working with the unknown to me, and i can't really comment on something i don't understand if it has been successful for some.

I'll keep you updated. By the way, i haven't once been told to keep anything secret (as i had heard in the past), or not to talk about it. i was only told not to talk about any of my symptoms at home last night, which we rarely do anyway.

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March 24th, 2010 06:30 PM #48

coxy

2ND DAY OF LIGHTNING PROCESS.

hi everyone an update as promised. We arrived back at the venue 10am this morning. I had taken a phone call just before we left from an exam officer to sort out my daughter with ME's GCSE's that she's taking at home. All the same awful brain fog came back while i was on the phone, memory issues etc, so by the time we got to our trainer i was suffering again badly!!

We both walked in looking awful (i was aware of that) as she pointed out later in the day. I had got quite dispondent about the whole thing and started questioning an awful lot. she was quick to point out a lot of my negative language and wrote all the words i tended to use up on her wipe board. I honestly didn't see anything wrong in my language and both myself and my son got really confused about trying to change our language. Apparently the whole world, schools etc use negative language. We were not allowed to use the word HARD, DIFFICULT etc, instead use softer words like CHALLENGING instead. Instead of saying I'VE GOT to go in the shower, say I CHOOSE to go in the shower. Unless we were prepared to change our thoughts on language we wouldn't succeed with the process.

I still struggle with this, (STRUGGLE is another negative word!), but i listened and apparently subconsiously i would of taken it onboard.

Anyway since leaving her house we have felt a whole lot better. My son has done nearly 1 hour on the wii fit and been out playing with friends until 6.30pm nearly 3 hours!! I feel a million times happier and more relaxed. My head still feels quite heavy but i'm working on it. So far definately so good

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March 25th, 2010 09:02 AM #52

coxy

DAY 3 AS I WOKE UP!

Hi, i went to bed last night for the first time like a normal person, not dressed in socks, pj's, jumper, 2 duvets and a thick dressing gown on top of me(as you can probably tell from that i suffered badly with feeling very cold). My feet were warm, even hot in bed, i couldn't fail to notice this. I did the process a few times (it's very very easy) during the evening when i felt the noise getting to me a bit. I was symptom free all evening (pretty much). I woke up again today very early, about 5.30am. I

felt fine. I got ready to get up and feel my stiff ankles, which were still there along with aching muscles in my legs from the little jogging session i did on the Wii fit after day 1 (perfectly normal to feel muscle stiffness after exercise though).

Both of us have a lot colour in our cheeks this morning.

One thing i noticed this morning was that the key board on my lap top feels completely different when i'm typing, i CAN FEEL MY FINGERS!! The skin on them doesn't dent inwards anymore, there is blood flowing around them and they are very warm. I'm typing so much faster aswell.

I'm really pleased and if i don't improve anymore than this i would be happy, but i actually think i will get stronger. I'm actually shaking while typing this as it's really exciting.

So far i can't say anything negative about doing this training programme other than i found it extremely boring at times, it's difficult to remain concentrated on it with a foggy brain, but i was told all the info would be going in and it obviously did. I don't feel completely normal as i did pre ME yet, i still feel at bit glazed eyes head

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March 25th, 2010 02:42 PM #58

coxy

FINISHED THE LP DAY 3.

As promised as you are the most important people to let know of what the results are SO FAR....

I think these are the most helpful posts to us all in whatever we try, we need as much info and help we can get.

Firstly my trainer informed us today when i questioned as to why they were doing a trial on children before adults, that they are in fact trialing on adults aswell, sorry not sure where but some of you maybe able to enquire direct from phil parker.

As i said in my early morning post today. I felt very good this morning & noticed some obvious changes in my temperature, numbness and overall happiness (although i thought i was acting reasonably happy before).

We arrived and the trainer mentioned straight away that our colour was much better today, which it was. Although the colour drained from my sons cheeks quite quickly as she put on her day 3 slides to watch, so boring, but obviously necessary to the whole process. I was completely honest in everything i said, she didn't always like me questioning anything but i was determined to get my points answered. I told her i felt better but obviously it was early days and i needed to be doing the process for a lot longer before i could be sure

i will keep in touch and have a better idea after 2 weeks holiday in florida, we are going on sunday. I will still be taking the XMRV UK test aswell. At the moment though if you asked me if you should give it a go i would say yes.

March 25th, 2010 05:18 PM #61

coxy

I'm not going to be drawn into any arguments on this one. I'm just letting you know (the one's that are still open minded enough to want to listen) in a honest way how a 43yr old mother and her 12 yr old son have gone through this process and it has made a difference worth more than £700 in my book or even 7 x that amount. Yes we are lucky enough to be able to afford it. In 6 mths time i may be saying different, i don't know yet. Or maybe i should disappear like other people that have had a positive experience with this and leave you all to listen to the people it hasn't worked for. In my book i would prefer to hear from the people amongst us it has made a difference for, i'm not into listening and wallowing in failed attempts at whatever treatment people have tried. I've always been

interested in trying things that have helped some of us.

Don't let the negative people on this forum or any other forum put you off trying this, it's worth it even if i only get a few months good health, which i'm certainly not hoping that's the case.

i won't be posting again now as i can sense certain people are ready for a fight, and that's not going to help me at this stage. The one's amongst you that have shown interest and would like to give me a personal post, i'm willing to answer any questions you may have.

As for the query about how i could suddenly get warmer, it's all down to the fight or flight response to pain with symptoms. Our body is permantly out of balance. As soon as you get the training on how to calm down and fight the symptoms when they come i.e try to stop them before they start, your body will start to rebalance itself, and digestion, temperature, etc etc will all start to improve.

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April 13th, 2010 04:44 PM #87

coxy

update on lightning process 2.5 weeks on

hI everyone,

I thought it may be of interest to some of you as to how myself and my son are doing since returning from our holiday.

Sadly the LP hasn't helped my son at all. I don't think he got to grips with understanding what he was supposed to be doing anyway which certainly didn't help. He infact ended up needing a wheelchair by day 4 of the holiday, we were doing all the disney theme parks though so it did involve a lot of walking, but he has never needed a chair before. He suffered very badly with his legs on holiday and was tearful on a lot of occasions. He also got a lot of blisters on the soles of his feet which has never occured before, maybe natures way of stopping him walking. We are due to spend another couple of hours follow up with our trainer next monday so i will see what she says about the situation.

As far as i'm concerned, i was doing fine until about day 10 of the holiday, i then suffered very badly with my legs and ankles, very stiff, they seemed to be worse if i rested, i really struggled to get going again. My head is still reasonably clear though, much better than it was before the process.

I feel very tired at the moment and my hands seemed to have died again which is really worrying me as that was one of my first symptoms when i first got ill, when i say died i mean i can squish all my fingers in and they don't spring back, as though the blood has gone from my hands.

Having said all that i'm still a lot better than before the process so i'm still pleased.

I'll keep you posted.

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April 14th, 2010 05:12 PM #99

coxy

Thanks for all your comments.

I've been wondering as to why others haven't decided to give feedback after doing the LP? I certainly didn't have my brain taken away by the process, i remembered all of the poor people left behind on the forums that need to get as much info as possible from any treatment that is tried. I wasn't told by my trainer to keep away from forums or keep anything a secret (i had heard rumours to this affect before i tried the process). I don't feel i'm doing myself any negative type of damage by talking about it, i would probably be told i was if it fails i suppose.

I can't believe that any past ME'er who has been cured by it, was that sure their cure would last, and deliberately stayed away from forums. I have no idea what's going to happen to me next and nor would they know! All of us know we can go through periods of remission if we are lucky, only for it all to come flooding back again, i've fallen for getting my hopes up about my 15yr old daughter to often in the past, only to get deflated again.

At the moment i'm feeling really nervous about going back to the trainer, i scared to death that she's going to tell my son off for not trying hard enough or something. I feel that i would lose my temper if she suggested that! I'm almost tempted not to take him at all. What do you think, especially those amongst you who have been through it?

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April 15th, 2010 12:29 PM #106

flex

Location

London area

Coxy,

as you have asked for feedback I am going to be frank with you. I feel it is down to us to filter out information as patients and particularly parents. You can take my opinion and the counter opinions you may come across and do what you want with them.

After reading the review of your attendance of the LP course and the fact that your son had to use a wheelchair for the first time ever I was further amazed by this quote:

"At the moment i'm feeling really nervous about going back to the trainer, i scared to death that she's going to tell my son off for not trying hard enough or something. I feel that i would lose my temper if she suggested that! I'm almost tempted not to take him at all."

Before reading this closing statement I thought you would have cut all links with this crazy woman. If one of my children was ever in that position I would not need to consider whether I should further expose my child to such potentially damaging nonsense in both a physical and emotional sense.

I have had a feeling of "the emperors new clothes" about this thread from the beginning with people, who I guess rightfully so, allowed and supported you to make up your own mind about this course. Many others may have not expressed their true sentiment, giving you a slightly flawed sense of overall support. You may not have "had your brain taken away by this course" as you stated but people like this trainer are born manipulators. It is more a case of trying to break down your own competent thinking brain by force or by design to trick or coerce you into submission for their own purpose. This women has no real interest in your families physical improvement. Neither is she qualified, informed enough or capable enough to do so. How could she be if all the best well meaning doctors and scientists in the world are still struggling with such matters.

If any person put my child in a wheelchair and then had the front to suggest that it was "his fault" somehow for not being a good little student they would not live to tell the tale.

Please forgive the blunt nature of my reply but it seems right that you should hear what I believe to be the majority, probably silent, opinion considering you have expressly asked for comments.

If this woman does appear on this thread I will verbally slaughter her with the truth.

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April 16th, 2010 01:45 PM #131

coxy

Update 3 weeks on

hi, everyone,

Things are not going in the right direction i'm afraid.

Strangely i seem to have taken on a new set of ME symptoms that i didn't suffer from before. Gone are the headaches and extreme brain fog, only to be replaced by an inability to sleep until at least 1am, digestive problems including very noisy tummy, sharp pains in tummy when i try to sleep on either side in bed, backache & a wired feeling most of the day until about 6pm when i suffer extreme tiredness. The tingling in my feet has returned when i stand up first thing in the morning, so has the watery eyes first thing in the morning.

Has this happened to any other LP tryers after a short amount of time?

I have emailed my trainer to ask if i can communicate with her via email instead of seeing her again on monday, not heard back yet. I've chickened out, and my son doesn't want to go back.”

<http://forums.aboutmecfs.org/showthread.php?3827-My-son-amp-i-are-giving-the-lightning-process-a-go-on-this-week/page10&highlight=lightning+process+didn%27t+work>
