Guildford ME/CFS Support Group
(& West Surrey)

Newsletter

June 2016

Future dates

Open to all members and carers.

25th July 2016 (Monday) 11.15am The Seahorse
The Street, Shalford, Guildford, GU4 8BU
www.theseahorseguildford.co.uk

22nd August 2016 (Monday) 7.30pm The White Lyon and Dragon
Perry Hill, Worplesdon, Guildford, GU3 3RE
www.whitelyonanddragon.com
(not far along from the Worplesdon Hotel)

15th September 2016 (September) 11.15am The Seahorse
The Street, Shalford, Guildford, GU4 8BU
www.theseahorseguildford.co.uk

Invest in ME conference – biomarkers

Source: www.thecanary.co/2016/06/08/people-mecfs-long-told-head-scientists-disagree

A hot topic at the 2016 Invest in ME conference was the search for reliable biomarkers to diagnose ME/CFS which can also aid understanding the mechanisms behind the disease.

A biomarker is something that can be measured reliably in the body to determine if someone is ill with a particular disease, or recovering due to treatment. For example high levels of glucose in the blood is a biomarker for diabetes. Currently there are no biomarkers available clinically to diagnose ME/CFS, diagnosis relies on a set of symptoms which are also common in other illnesses.

More promising data from Norwegian Rituximab trial
Rituximab is a monoclonal antibody that was originally developed to treat cancer, but has recently shown efficacy in treating ME/CFS in a Norwegian clinical trial. It is regarded by many in ME/CFS community as the most promising candidate to become a clinically approved drug treatment for the illness.

Professor Carmen Sheibenbogen, from Charite University Medicine Berlin, presented evidence of auto antibodies to adrenergic and muscarinic receptors being significantly elevated in ME/CFS patients compared to controls. The study published in ‘Brain, Behaviour and Immunity’, composed of a group of ME/CFS patients and controls from Germany, but also included analysis done on blood serum samples from the Norwegian Rituximab clinical trial.

The Norwegian patients’ levels of the same auto antibodies were high prior to treatment with rituximab, the levels then decreased after treatment in patients who showed recovery from their ME/CFS symptoms. The key finding however was that patients who did not respond to rituximab treatment did not show any decrease in levels of auto antibodies; indicating the auto antibodies are involved in causing ME/CFS.

Sheibenbogen states in the paper that the adrenergic and muscarinic receptors are “potential biomarkers” for response to rituximab therapy. She goes on to say:

> “It is conceivable that various symptoms of CFS including cognitive deficits, autonomic dysregulation and immune activation could be partly mediated by auto antibodies against these receptors in a subset of patients.”

The microbiome’s role in ME/CFS

The microbiome refers to the collection of bacteria, viruses, and parasites that share our body space. A large proportion of the microbiome is found in the gut, and it is increasingly being linked to involvement in a wide range of diseases including ME/CFS.

Data from an attempt to identify biomarkers by analysing bacterial DNA from the gut microbiome of ME/CFS patients was presented by Prof. Maureen Hanson, of Cornell University. The study showed a lower diversity of bacterial species present in the gut of ME/CFS patients compare to controls. This lower diversity of gut bacteria is also found in Crohn’s disease and ulcerative colitis, both of which are caused by a malfunctioning immune system.

The study failed to produce reliable biomarkers as the data produced and model used in the study was only 53% successful in identifying the results of patients suffering from ME/CFS compared to controls. This may change soon as Hanson tantalised the conference with news of an as yet unpublished study, using microbiome metabolites as biomarkers, that has achieved 100% accuracy in diagnosing ME/CFS.

Initial results from a study aiming to identify biomarkers by identifying variations in bacteriophage present in people with ME/CFS was presented. Bacteriophage are viruses that attack bacteria, and every bacteria has a specific phage that attacks it, or as Professor Tom Wileman from Norwich University described it:

> “Big fleas have little fleas upon their backs to bite them, and little fleas have lesser fleas, and so ad infinitum.”

Gibson was full of praise for the Norwich study and described Wileman as a ”star”. He explained his desire for greater collaboration between scientists in the ME/CFS field, and revealed plans for:

> “a great big complex in Norwich, a centre for ME, the first in the country. Our team [football] may be going down into the bottom division but we want science to go up.”

Big data approach to understanding ME/CFS

Big data is the way Professor Ron Davis is trying to solve the conundrum of ME/CFS, and he has compelling motivation make progress fast. His son Whitney Defoe has severe ME/CFS, which means he is bed bound and being fed through a tube, barely able to tolerate sounds, light or being touched. Davis gave a moving description of how his son had slipped further into the clutches of ME/CFS, and described him as being “missing for 5 years”.

The strategy followed by Davis differs from others in the field as he is not following a working theory as to how ME/CFS is caused, and then trying to prove that theory through his experiments. The big data approach involves collecting blood, sweat, saliva and fecal samples from people who are severely ill with ME/CFS, and then running pretty much every test known to man on them.

This produces huge amounts of data on each subject, which can be then compared to data collected from healthy people. Any differences between the two groups could be a biomarker worthy of further research.

This approach is not cheap, the cost for each person included in the study is $ 70,000 (£48,200). Davis initially had trouble raising funds from the usual funding bodies, so he had to collect funds privately. The pilot study consisted of three severely ill ME/CFS patients (one being his son) and 43 healthy controls, and collected data on metabolites only. He has since begun a study with 20 ME/CFS patients and 10 healthy controls, which will collect the full set of data (including genetic and proteomic data) which will amount to billions of data points.

Davis pointed out the importance of understanding the mechanism behind ME/CFS in his talk and said:

> “it [ME/CFS] could be fairly easy to fix, we just need to know what to do”

Initial unpublished results presented during the conference suggested three possible biomarkers in severe ME/CFS:

- Biotin a.k.a vitamin B7 – deficiency in biotin was found. It is normally manufactured by the human body or provided as a metabolite by bacteria in our gut.
- Tryptophan – deficiency in tryptophan was found. This is an essential amino acid which the body cannot make. The deficiency was possibly caused by too much of a particular enzyme being present, which breaks down tryptophan.
- Tetrahydrobiopterin a.k.a. BH4 – deficiency in BH4 was found. It is used in the synthesis of neurotransmitters serotonin and melatonin.

The results obtained also showed deficiencies, in the severley ill patients, of the citric acid cycle, which is one of the major pathways for energy production in the body. Davis is hopeful that some of the findings, once verified, will be useful in people less severely ill with ME/CFS. The current set of data, which will eventually be made publicly available, Davis hopes will enable easier funding for the next steps of his, and others, research into ME/CFS.

More complete overviews of the conference are at the following links:

www.investinme.eu/Documents/IIMEC11/IIMEC11%20Conference%20Report.pdf

http://phoenixrising.me/archives/28153

A link to an overview of a study published 23rd June in the journal Microbiome:

www.sciencedaily.com/releases/2016/06/160627160939.htm

#MillionsMissing: a day of global protest

Source: www.prohealth.com/me-cfs/library/showarticle.cfm?libid=28988

By Erica Verrillo   June 2016

On 25th May 2016 protesters all around the globe gathered to demand greater recognition and research funding for ME/CFS. Simultaneous protests were held in: Melbourne, Australia; London, England; Belfast, Ireland; Ottawa, Canada; and in Boston, Washington, DC, Seattle, San Francisco, Dallas, Raleigh, Atlanta and Philadelphia in the U.S. It was the largest protest ever held for this disease, involving thousands of participants worldwide.

The Millions Missing protest was organized by MEAction and coordinated by a group of dedicated advocates in order to highlight the long neglect of patients with ME and CFS. Millions missing represents the missing millions of dollars of research funding that should have been spent to find a cause and a cure. Millions missing also represents the millions of people who are missing their careers, their families, their friends, and their lives due to the ravages of a disease that can disable a sufferer for decades.

In most of these demonstrations, a display of shoes, sometimes in the hundreds, was laid out to symbolize missing patients who, due to illness, could not protest in person. Virtual demonstrations – pictures of shoes placed in driveways, on doorsteps, and on walkways accompanied by personal notes– were held in tandem. The virtual protest generated over 10,000 tweets with the hashtag #MillionsMissing as well as thousands of posts on Facebook.

In the U.S. organizers took advantage of this event to schedule meetings with HHS officials as well as their representatives. Jennifer Brea, founder of #MEAction, met with Senator Cory Booker's staff (Dem NJ), and patient advocate Sonya Heller Iray met with Senator John McCain (Rep AZ) and his staff for an hour.

In London, demonstrators held a silent protest at the Department of Health. Many stretched duct tape across their mouths to symbolize government neglect of ME/CFS patients. Ollie Cornes, a former software engineer, said, “The treatments the NHS provides are so ineffective as to be a waste of time and can be very harmful, which is why we are protesting at the Deptartment of Health.” Like so many other patients, Cornes was unable to attend the demonstration in person. He was represented by a pair of red baseball shoes.

To view photos from the #MillionsMissing protests around the world follow this link:

https://meaction.smugmug.com/Millions-Missing

The #MillionsMissing protest list of demands can be found at this link:

http://millionsmissing.meaction.net/protest-demands

For #MillionsMissing in the news follow this link:

www.meaction.net/2016/05/30/millionsmissing-in-the-news

Bioflow – magnetic therapy wristband

Primary source: www.ecomagnets.com/bioflow.htm
Partial source: www.amazon.co.uk

Our March 2014 newsletter, page 5, details the benefits of PEMT (Pulsed Electronic Magnetic Therapy) including increased cellular energy.

Bioflow magnetic therapy wristbands (hereafter "bioflow") are magnetic bracelets which endeavour to provide some level of PEMT benefits. According to the ecomagnets website (see primary source above) "The patented multidirectional 'Central Reverse Polarity' (CRP) magnet technology provides bi-polar magnetic fields which mimic the pulsed effect and alternating poles of the electromagnetic equipment used in hospitals."

> Although advertisement of bioflow state that they mimic the effects of Pulsed magnetic therapy I've been unable to find the associated studies to back up that claim. However, the following study does show promise. http://pivotalhealth.co.uk/bioflow-arthritis-study.html
>
> Newsletter Editor

Magnotherapy has been used for centuries by humans and animals to aid healing, alleviate pain, improve circulation and help with many other conditions including arthritis, sports injuries, poor circulation, high blood pressure, skin complaints, fatigue syndrome and general aches and pains.

Bioflow products are credited as a Class 1 medical device in the United Kingdom and contain only the highest quality neodymium magnets - the strongest type of permanent magnet known. Please note: Bioflow products should not be worn by anyone fitted with a heart pacemaker or other implant that could be affected by a strong magnetic field.

The sports version (as pictured above) of Bioflow is available on amazon from between £18 - £22 dependant on size and colour chosen.

Living with purpose

Source: www.prohealth.com/me-cfs/library/showarticle.cfm?libid=29034
By Julie Holliday

In the goal setting part of my coaching work, I ask my clients to imagine what life would be like if good illness management had helped you to reach a level of being 80% better – a life where the illness still has to be considered and worked with, but where you're mostly in control and feeling relatively well. The strongest theme that comes up is being able to have a sense of usefulness and purpose.

Early man's purpose was very simple: survival. Each individual, family group or tribe would be fully responsible for meeting all of life's needs. But in today's society it's no longer a case of 'if you don't hunt and gather you don't eat.' Our life is supported by each of us taking up roles that contribute to society as a whole. Without individuals having a strong desire to contribute in their own unique and individual way, there is no way our society could function so effectively as a collection of such highly specialised roles. I believe that we have evolved to have a natural desire to live with purpose and that sense is most fully met either through working or bringing up a family. Then chronic illness comes along and wipes away our ability to be useful in those ways.

I like to look at purpose as something that changes over our lifetime. We have a different purpose as children, adolescents, young adults, parents, workers and when we are retired. I don't believe that everything in life is predestined to lead us towards a particular purpose; instead I believe that we can choose our purposefulness and change it as often as we want to. For me though there are two purposes that stay pretty constant throughout our lifespans. The first is to learn and to grow, the second to love and to be loved. As working-age adults we often tend to forget the value in these things when we're so programmed to contribute to a specialised role that will support the productivity of society. However they are enormously important. How could anybody in society be happy if there was no love? How could anything ever be created or achieved if we were unable to learn?

Feeling useful and having a sense of purpose isn't just about our ability to take a productive role in society, it also depends on how much value we place on things. We place a high value on allowing children to have a childhood; however as a chronically ill person we tend not to place a very high value on allowing ourselves the freedom we need to be as well as possible. We tend to value other people's productivity far more highly.

I believe my purpose in life is to be as happy and healthy as possible so that I'm able to share whatever joy and gifts I can with others. My purpose is to learn and to grow and be a part of other people's learning and growth. I chose to value all the little ways I can do this just as highly as when I worked a 60-hour week looking after children with emotional and behavioural difficulties.

So my number one purpose is to learn how to be as happy and healthy as possible; to look after myself, become an expert in illness management and to make myself as well as possible. (I choose that purpose because the medics aren't yet very good at doing it for me!) I also choose to learn how to by happy despite my limited energy, because I can contribute to the happiness of those around me better when I am happy.

Having a chronic illness doesn't prevent me from loving or being loved (even if it restricts the way I can do those things.) I can still choose to wish others happiness, joy and laughter. I can still lovingly listen and share the happiness of those I care about. I can listen and support even if I have to choose and restrict the time I make myself available for such things. When I was too poorly to do much else, I would cultivate that love by bringing somebody to mind and then visualising them having fun and laughing. I would go through all my friends and family one by one, and then aim to send that love to people I didn't know, expanding to cover everyone in the world. My purpose then was to contribute to the amount of love that there was in the world, even if I couldn't do so actively.

Before I was well enough to play a part in the workforce I started contributing by planning and cooking the household meals. One of the ways I found to value that highly was to recognise what a high proportion of my disposable energy I was devoting to my contribution! And it removed the stress from another member of my family who was perfectly happy to chop and wash up but found thinking about what to eat a burden.

Now I'm well enough to share my gifts (working from home part time), much of which relate to what I have learned through overcoming my challenges. But we don't have to wait until we are well enough to work to have a sense of purpose; we just have to place a high enough value on the purpose that is in the things that we are able to do!

Ketamine – future pain and depression relief?

Source: www.healthrising.org/forums/threads/fibromyalgia-doctor-touts-ketamine-for-pain-and-depression.4063

By Cort Johnson   April 2016

Health Rising has done several reports on how surprisingly effective Ketamine can be with pain and depression. The drug has a couple of strikes against it for sure: it's an anaesthesia drug which can produce hallucinations in high doses and has been used as a date rape drug.

Ketamine has also, though, been successful in the difficult to treat chronic regional pain syndrome (CRPS). It achieved remission in about half the patients in a small CRPS trial. It works so quickly in depression that it may become the first anti-suicide drug. For some people who had about reached the end of their rope, ketamine has proved to be a life-saver.

Pain

Stephanie had severe degenerative disc disease, fibromyalgia, ME/CFS and depression. As a young woman she had the spine of an 80-year old. She had undergone multiple surgeries and had tried almost everything without success, yet ketamine infusions sent her from an 8/9 on the pain scale to a 2/3.

Recently ‘Fibromyalgia News Today’ reported on another woman who was bedridden with severe fibromyalgia whose pain virtually disappeared while using ketamine.

> “I was suffering from widespread chronic pain and fatigue for 25 years, and after a very long time, I was diagnosed with fibromyalgia in 2007. During this time, I was bedridden and did not have a functional life. My pain was managed with medication, but this did not help my condition.
>
> Finally, in 2014, I began intravenous ketamine treatment at the Florida Spine Institute with Dr. Hanna in Clearwater, Florida.
>
> This treatment has virtually eliminated my fibromyalgia pain and need for pain medication. It has given me back a quality of life and increased energy to do things I hadn’t done in years.”

In April, Dr. Ginerva Liptan, author and FM patient, touted ketamine's effects on The National Pain Report. Liptan first found out about ketamine when several of her patients experienced significant pain relief for weeks after undergoing surgery. When she looked further, she found they had all received ketamine IVs.

She suggested that ketamine may be causing the "massively over-stimulated" NMDA receptors in FM to "cool down" or reset for weeks at a time.

Depression...plus

Ketamine can also be very effective at treating depression. The really intriguing thing about the ketamine depression studies thus far is that they tend to focus on the most difficult patients of all: people with treatment-resistant depression.

Thomas Insell, former director of the National Institute of Mental Health (NIMH) at the NIH, felt ketamine might be the biggest breakthrough in depression ever:

> “Recent data suggest that ketamine, given intravenously, might be the most important breakthrough in antidepressant treatment in decades.”

A nasal ketamine spray for depression, became, in fact, the first drug outside of cancer or an epidemic to be awarded a "breakthrough therapy" designation by the FDA. One case study referred to a man whose inconsolable grief was rapidly ameliorated by ketamine. The young man was so grief-stricken by the death of his wife that he was referred to the hospital. He had refused food, spoke in a tiny voice and broke out in crying spells. The doctors described him as having catatonic symptoms.

Upon receiving ketamine the patient briefly hallucinated but after that began to: communicate; was cheerful; and started taking food orally. Three months later he was continuing to do well.

Dozens of studies are currently exploring ketamine's effectiveness in depression. Just this week a study found that ketamine rapidly improved fatigue in depression as well.

Several academic centres (Yale University, University of California at San Diego, the Mayo Clinic, Cleveland Clinic) are now offering ketamine for severe depression.

Other studies are exploring ketamine's use in neuropathic pain, autism, post-cancer pain, migraine and others. One interesting study is determining whether ketamine IVs can reduce cancer fatigue.

Anti-inflammatory

Neither fibromyalgia nor ME/CFS, of course, is depression, but antidepressants are not simply antidepressants anymore; they're also pain drugs or even microglial inhibitors. Similarly, depression is not simply "depression" anymore. Immune activation or inflammation probably contributes to or even causes about thirty percent of the depression found.

The fact that people using interferon who suffer from similar symptoms and brain abnormalities as ME/CFS patients suggests that the depression found in ME/CFS could very well result from immune activation.

Ketamine, it turns out, also appears to be an anti-inflammatory. It was recently found to reduce the levels of inflammation following hypoxia (low oxygen levels) - a condition of great interest in ME/CFS and FM. Could ketamine relieve the inflammation associated with low oxygen levels (and the fatigue, pain and mood issues) in ME/CFS and/or FM?

The point is that fatigue, pain and depression can probably be produced in many ways and any drug that powerfully affects pain or depression in another disease might be able to affect fatigue as well. We can't judge a drug by its name anymore.

The future

Ketamine is not easy to find, it is expensive and is not covered by insurance if you have FM or ME/CFS, but it is becoming more available. In North America, one Portland provider charges $3,800 for six infusions over twelve days. The effects last anywhere from two to twelve weeks.

Ketamine's possibilities for ME/CFS and FM surely lie in future drugs that do not require infusions and have few side effects. Drug manufacturers realise that the potential for a blockbuster drug is present. Thus far, they've found three molecular targets to aim future ketamine-derived drugs at. At least one ketamine derivative is reportedly in clinical trials for depression now.

Time will tell, but the future of this anaesthesia drug / antidepressant / pain reliever / anti-inflammatory looks to be bright.

15 tips from 15 years sick

Source: www.psychologytoday.com/blog/turning-straw-gold/201605/15-tips-15-years-sick
Posted May 20, 2016 By Toni Bernhard J.D.

When I began to write for Psychology Today over five years ago, one of the first articles I posted was called "10 Tips from 10 Years Sick." It's five years later. A lot has happened in my life, but there's been one constant: chronic illness (including chronic pain). And so, because 10 + 5 = 15, it's time for "15 Tips from 15 Years Sick."

1. Keep a "Try Mind."

It's not your fault that you're sick or in pain. It's not your fault that you can't do all the things you used to do. It's not your fault that you can't pitch in and help at family gatherings the way you'd like. You're trying the best you can.

And so, my first tip is to keep a "Try Mind." This is a teaching from Korean Zen master Ko Bong (1890-1962). Some days I feel so sick or in pain that all I can do is try: try to get my teeth brushed; try to find something to eat; try not complain to others; try to find some joy. And when my trying falls apart, I know I can try again; that provides solace and gives me hope.

2. Remember that the future is a mystery

Since becoming chronically ill, I've had to be particularly mindful of when worrying has taken hold in my mind. Of course, it makes sense to plan for various contingencies. But having done that, try not to worry about what might or might not happen. The future is unpredictable. You don't control it. Worrying about it only makes you miserable in the present, and the present moment is the only place you are alive right now.

3. Recognize that life's other challenges don't disappear just because you're struggling with your health

When I became chronically ill, I developed a plan: I'd accommodate my illness by living a quiet, hassle-free life. But John Lennon was right. Life is what happens while you're busy making other plans.

Here's an example from last year. Within the space of a two hours, I was faced with these unexpected challenges: our electrical system developed a short and we had no light in our windowless bathroom; our microwave broke; the fence that separates our house from the park next door developed a hole so big that it no longer kept our dog in or other people out.
In the words of one of my first Buddhist teachers, Joseph Goldstein: "If it's not one thing, it's something else." That may sound like a negative comment but, oddly enough, accepting the truth of his words has helped me roll with life's punches. I'm more at peace now that I don't expect a hassle-free life.

4. Give up your notions of how things should be

Before I became chronically ill, I was quite opinionated, especially about myself: "I should always sound smart"; "I should exercise"; "I should always make sure the house is clean and neat." Trust me on this one: Shoulds and shouldn'ts are the enemy of chronic illness. Just do the best you can and be nice to yourself.

5. Get outside if you can

It's amazing how the outdoors can change your outlook. When I'm in a blue mood, it helps to go outside, even if it's only to sit in my backyard for ten or fifteen minutes. If you don't have a backyard, try a front porch or a short walk up and down the block.

Even if the weather isn't ideal, changing your surroundings in this way can change your mood. I find that going outside for a bit often gives me an idea for something enjoyable to do when I get back inside. Sometimes I have to force myself to go outside—funky moods can make me not want to move—but it's always worth it.

6. Don’t contend with your body

For many years, I’ve been practicing what I call “non-contention” in regard to other people (at times more successfully than at other times!). One day, it occurred to me that I could benefit from practicing this in regard to my own chronically ill body, instead of always fighting against what it’s telling me to do. And so, I suggest that if your body is telling you to stop visiting, find a way to stop visiting. If it's telling you that a slow walk around the neighbourhood would feel good, take that walk.

7. Go prepared to the doctor’s office

Even if you were prepared, you might still be disappointed with how the appointment went, but at least that disappointment won’t be because you forgot to raise a crucial issue or ask an important question. I make a list. I suggest you do, too. I wrote a piece about being prepared called “Don’t Be Intimidated in the Doctor’s Office: Six Strategies.” It might be helpful.

www.psychologytoday.com/blog/turning-straw-gold/201307/don-t-be-intimidated-in-the-doctor-s-office-six-strategies

8. Be highly selective about what you watch on TV and where you surf on the web

In last year’s piece, I wrote about an incident that I think it bears repeating. One day, I was feeling particularly sick physically and, as a result, vulnerable, emotionally. I turned on the television for some comfort viewing. On came a channel that was covering the 70th anniversary of the liberation of Auschwitz. There I was, face-to-face, with images of horrific cruelty.

I closed my eyes for a few moments of remembrance and said to myself, “We must never forget.” And then I changed the channel. I found a tennis match that was underway at the Australian Open and lay back to rest as I listened to the familiar voices of the commentators (I’m a tennis fan and so the commentators are like old friends). In my view, censoring what I watched on television in this fashion was the compassionate way to take care of myself.

I recommend that you take the same care in deciding where to surf on the web. Bottom line: You be the compassionate judge of what to expose yourself to.

9. Be highly selective about what treatments you try

If you’re like me, you receive a lot of suggestions about treatments to address your particular health struggles. People are well-intentioned but it can get overwhelming. What works for one person may not work for another. In addition, alternative treatments tend to be expensive and are rarely covered by insurance. I used to jump at every suggested treatment. Now I’m highly selective.

10. Cut friends and family some slack when they don’t say or do what you want them to

Let’s face it. Most of our “wants/don’t wants” (as I like to call them) go unfulfilled in life. That includes our desire for the people we’re close-to, to always say and do the right thing in regards to our health. Instead of focusing on what they don’t get right, I suggest you be thankful that at least they’re present for you and at least they’re trying.

It helps to recognize that some people are natural caregivers and some are not. In addition, this culture does a poor job of preparing people for this role, even though millions find themselves unexpectedly having to help care for a relative or a friend.

Remember that people’s abilities or lack thereof to be good caregivers is not about you; it reflects their own life history and perhaps their own fears about illness. I used to get upset when people didn’t behave the way I thought they should. (There’s that should from #4 again.) Then I realized that getting upset about it only made me feel worse.

I feel better emotionally when I graciously accept whatever support is offered and let the rest go, including my views about how people should act and including my disappointments. It’s not always easy, but I’m working on it.

11. Don’t forget that your healthy loved-ones have problems too
This is related to #10. It’s easy for us to get wrapped up in our health struggles and to assume that those who are healthy are carefree and happy. Of course, that’s not the case. In fact, some of them may be suffering mentally more than we are physically. Don’t forget to ask how your family and friends are doing. Not only will it bring you closer to them, it will give you welcome relief from always focusing on the state of your health.

12. Recognize that spontaneity may not be possible anymore and compensate for it by planning ahead
It exacerbates my symptoms when I find myself stuck in a situation because I didn't plan ahead. As a result, I try to plan ahead for everything now. No, it's not fun, but it can keep my symptoms from flaring: I take a pillow for my back because I may be stuck at the doctor's office for a long time; I clean the kitchen over four days, dividing up the tasks into chunks of time that my body can handle; I give a friend a set time to end our visit so it doesn't go on longer than I can handle. Yes, I've lost a lot of spontaneity in my life, but it's a necessary "side-effect" of being sick and in pain.

13. A good deep breath can clear away stress, making it possible to start the day anew
Sometimes we get on automatic pilot and don’t realize that we’ve tensed up all over—in both our minds and our bodies. It’s a mindfulness practice to train yourself to become aware of when this has happened and to be able to say “stop,” and then take a deep breath, relax your body, and bring yourself into the present moment. Then you can start the day anew.

14. When thinking about your chronic illness, avoid asking “Why?” or “Why me?”
In my experience, asking “Why” or “Why me?” is not only unconstructive - it’s anxiety producing. The answer to these questions would only be helpful to me if I thought the answer would shed light on a cause I could do something about. The most compassionate thing I can do for myself is to look upon my medical challenges as simply what happened to this body along the path of life.

Everyone may not agree with the opinion I’m about to express, but I include it in case it’s comforting to you. (If it’s not, ignore it.) I don’t believe that everything in life happens for a reason, in the sense that life’s challenges and obstacles are “a test” to see if we can better ourselves in some way. I believe that illness and pain happen because we’re in bodies and sometimes they get sick and sometimes they hurt.

Everyone suffers from medical problems at some time in his or her life. In my view, I got sick because it’s one of the risks of being alive. It’s one of the risks of this mysterious, unpredictable, and wondrous life I find myself in. I don’t believe that illness and pain are cryptic messages that I’m supposed to decipher so that I can learn some cosmic or moral lesson.
And finally, an oldie but goodie:

15. When all else fails, go to bed
This was a tip I added last year, but I think it’s going to have a very long shelf life. It was great advice when it was first given to me almost fourteen years ago by Bruce Campbell of the CFS/FM Self-Help program, and its great advice on this very day.

Thank you for reading my work. I’m the author of three books:
How to Live Well with Chronic Pain and Illness: A Mindful Guide (2015)
How to Wake Up: A Buddhist-Inspired Guide to Navigating Joy and Sorrow (2013)
How to Be Sick: A Buddhist-Inspired Guide for the Chronically Ill and their Caregivers (2010)

All of my books are available in audio format from Amazon, audible.com, and iTunes.
Visit www.tonibernhard.com for more information.