NATIONAL ME/FM ACTION NETWORK
SINCE 1993

Quest
Newsletter

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Contents

Part 1 of this newsletter is about coping with ME/FM. Someone thanked us for raising the issue of mental health in our last newsletter so Lydia pursued that issue some more. Someone asked us about how people cope with feeling overheated and we turned to our Facebook followers for advice. Someone asked us about service dogs so we did some research and asked a few people. Someone pointed us to a new "ME/CFS Crash Survival Manual" which we thought had valuable advice on coping with health crashes. We found a short article on how to explain your illness to friends and family which we also thought would be useful.

In March, when the pandemic seemed to be retreating, we asked our on-line members to send in their reflections on the pandemic. The replies we received are discussed in Part 2 of this newsletter.

In part 3 of this newsletter, we mention some news items from across the country.

Coping

Mental Health Impacts of Chronic Illness

by Lydia Neilson

We who have Myalgic Encephalomyelitis and/or Fibromyalgia are reluctant to talk about how they affect our mental health. Because it has taken so long for ME and FM to be accepted as genuine illnesses, we are afraid that mentioning anything about how they affect us mentally and emotionally will set us back to being considered as having a mental health disorder.

Our QUEST, Winter 2022 newsletter prompted a letter from a ME/FM community member expressing appreciation that the National ME/FM Action Network

Lydia Neilson

opened the door to this not talked-about subject. I therefore decided to explore what we can learn about the mental health aspects of chronic illnesses in general and to reflect on how it applies to ME/FM.

Information on Mental Health impacts

One of the first articles I came across was published in 2000 and is entitled Emotional dimensions of chronic disease. This study states that the emotional dimensions of a chronic illness are frequently overlooked when medical care is considered. The study further points out that doctors are not well-equipped or trained for the challenges of understanding the psychological, social and cultural dimension of illness and health. It points out the importance of medical professionals being trained on the important role of relationships and outside activities on a patient's overall health.

This study highlights how chronic conditions force patients to adjust their aspirations, lifestyle and employment. Many patients grieve before adjusting to a different way of life. The limitations imposed by the chronic illness may cause distress. Some people develop depression or anxiety. This can cause confusion in diagnosis and treatment of the chronic illness. The study found that development of depression in a chronic medical condition is directly linked to adverse physical outcomes and substantial increases in disability.

One of the important messages stressed in this study is the key role the clinician has in bringing realistic hope and support to the patients and their families.

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1070773/

A website by the Cleveland Clinic points out that a chronic illness has disease-specific symptoms which may be invisible but form part of the patients' days. These symptoms might require the patient to do certain things to take care of oneself. Keeping up with one's health management, they point out, can cause stress. Another important message on the Cleveland Clinic website is that chronic illness or the medications may alter one's physical appearance such that people don't feel good about themselves. If people can still work, chronic illness may influence changes to their work environment. If they are unable to work, they may have to deal with financial difficulties, all of which affects their mental health.

https://my.clevelandclinic.org/health/articles/4062-chronic-illness

A WebMD website points out that it's not hard to see the cause and effect relationship between chronic illness and depression since chronic illness may cause a range of life changes and limit independence and mobility. It may be impossible to do things that are enjoyable. Chronic illness can impact one's self-confidence and hope for the future. This website also states that the more severe the illness is and the level of life disruption it causes, the more it affects mental health and causes more isolation. Learning as much as one can about one's condition gives one power and a sense of independence and control.

https://www.webmd.com/depression/guide/chronic-illnesses-depression

The American Psychological Association (APA) points out that being diagnosed with a chronic illness can cause a roller coaster of emotions as one tries to digest the news of one's illness. It states the best way to cope is facing your diagnosis head on. In a study of women with breast cancer, those who felt resigned to their fate did not adjust as well even three years later as women who dealt with their diagnosis. Another study pointed out that people who used active coping strategies such as developing plans of action or seeking social support fared better when contacted two years later than those who denied or avoided their diagnosis.

APA suggests that a good way of actively facing your illness is to write down all your questions to take to your physician and to discuss what specific steps you can take to optimize your health. Accurate knowledge helps empowerment.

APA also acknowledges that illness exacts a toll on the entire family and may cause couples to experience strain in their relationships. When a partner is also the caregiver, it is important he or she has time to care for himself or herself. Setting short-term goals can help one get through each day.

https://www.apa.org/topics/chronic-illness/coping-diagnosis

The website Healthline points out that if you have a chronic illness you may need to:

- cope with pain or discomfort from your symptoms
- take steps to manage your condition and practice self-care
- adjust to new limitations that your condition puts on your life
- manage increased financial pressures
- cope with feelings of frustration, confusion, or isolation

https://www.healthline.com/health/depression/chronic-illness

Pacing Your Mental and Physical Energy

It is much easier to pace your physical energy as you know what happens when you do too much. You will crash and PEM (post-exertional malaise) will set in. This can set your health back for days, weeks or longer.

You also spend mental energy which is more difficult to be aware of. This is particularly important if you must go out. You need to preserve as much physical and mental energy as you can to cope with what you need to do. For instance, if you are able to go to a store, then have someone else drive you as the mental energy you need to spend on being alert in traffic, the noise etc. will already rob you of some of your energy before you even get to the store. Your goal is to shop, so anything mentally and/or physically you can avoid is helpful in coping when you get there.

One of the warnings you may notice is that you will get anxious which means you have already done too much. Your best option is to stop in a quiet place until the feelings pass without panicking. Going to the store when it's least busy is helpful.

The Trauma of Developing a Chronic Illness

Author Karandeep Kaur, in an article on TheMighty.com website, highlights that when people speak about trauma, they presume that the trauma is caused by a single terrible event such as an accident or incident. They tend to forget that trauma can be caused by loss – loss of a loved one, loss of home or possessions, or loss of one's health through chronic illness. There is an emotional aftermath of trauma for years to come when someone has a chronic illness.

The author relates that ME changed her entire life. She went from being an active 12 year old to someone who spent most of her day in bed. She was suddenly a different person. As she points out, many people with a chronic illness are left to deal with the impact on their own without help from health care providers. She emphasizes that it's time that health care providers recognize chronic illness as a potentially traumatizing event and give people the help they deserve.

https://themighty.com/2022/02/the-trauma-of-being-diagnosed-with-a-chronic-illness

People Telling You to 'Try Yoga'

Amy Denton-Luke has a chronic illness. She relates, in an article published on TheMighty.com, that people she meets in her daily life tell her that they know people who have the same illness and that they got cured by trying yoga. Amy points out it is insulting to suggest that you aren't trying to do everything in your power to get better!

Amy talks about some of the strangest comments she received was someone got cured by celery juice, or wonder if she's drinking enough water and the dreaded 'try yoga'. She notes that these insensitive comments from well-meaning people who want to help don't consider their unsolicited medical advice may be inappropriate and unwanted.

Amy shares 3 reasons why people with chronic illnesses don't appreciate advice to try yoga or other non-medical suggestions:

They've heard it all before from family, friends, acquaintances and even strangers on the internet;

Outsiders don't know what you are dealing with - your symptoms, diagnoses and particular illness(es); and

Yoga is not a cure. Although Amy practices yoga about 3 times a week, she is still ill, still in pain and still has mental health issues.

The bottom line is that outsiders should resist the urge to offer unsolicited and oversimplified medical advice for chronic and incurable medical conditions. Saying that others' debilitating health issues can be fixed by 'just trying yoga' is dismissive, and insulting. What an ill person is looking for is acknowledgement, compassion and support. But people with ME/FM will receive advice like this, so it is important to recognize and handle this situation.

https://themighty.com/2022/03/stop-telling-people-chronic-illness-disability-try-yoga

Some Days Surviving is All that You Can Do

There are days when surviving demands so much of your energy that you feel disappointed in yourself and wish you were more productive and able to focus on other aspects of your life. That is the time you need to recognize that surviving is your victory for that day.

There are moments you're fighting for your life where you believe you can't go on but you do. That is a victory. You used all your strength to get through those moments and that is your victory.

There are times when you think the world will be better off without you and you can't deal anymore with the trials thrown at you. You wonder how can you possibly deal with your illness for the rest of your life when you can't manage one day? Remember that you have managed to survive similar days that put you at your lowest and that is your victory.

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Feeling Overheated?

Someone called and asked what she could do when she body felt overheated because of ME/FM. (Other causes for her overheating had been ruled out.) The standard ME/FM resources identify overheating as a symptom, but they did not provide much in the way of advice on what to do about it. So we turned to our Facebook followers for advice. Here are replies we received.

*

I don't overheat but my friend with MS does. She uses an AC unit in her room. I also know that wearing light clothes is helpful. I know that for women who get menopause they use these ice pack buddies they put on their chest, so something like that may also be helpful. But the only thing I know for sure that helps my friend is her cooling unit and a fan that she sits in front of.

*

I place a cold bottle of water from the fridge against my wrists and my neck. If I'm really struggling after exertion, I pour cold water over my head to help shock my system back to some kind of normal. This also helps after experiencing a 'crash'. A fan always helps during the summer and when it's humid.

*

Managing my POTS (a type of orthostatic intolerance) and pacing stopped my sudden extreme overheating and sweating. It took years mind.

*

I use a remote controlled fan. I can turn it on or off as needed. When I'm really hot I use peppermint oil on the back of my neck.

*

For me, B12 injections every other day have helped with my temperature control.

*

I carry a Cool n Soothe migraine patch in my bag and put it on the back of my neck. I also have a fan in every bag. But the best tip I can offer is to run your wrists under the cold tap. The inside of your wrist is one of the places where the blood vessels are closest to the surface, so cooling there for a minute will cool all your blood as it passes through that point. Works like a charm, and can be done anywhere with a tap/faucet!

*

I dress in layers and try to cool my forehead, hands and feet and just remain very still until it passes. I wish I knew a way to deal with the root cause of the issue.

*

I have heart failure as well as FM (and a few other illnesses) and I find when the heart failure is active I overheat much more easily. Anyway I dress in layers so I can take off something. At home, I have fans strategically placed around the house. Thankfully I live alone so my thermostat is set low and on the rare occasions that I'm cold I bump up the temperature. I also drink cold drinks with ice and quite often I'm sucking on ice cubes too. In hot weather I have kept witch hazel in the fridge and used it to wipe my face and neck. Cold or cool showers or a bath help too although I tend not to need those until summer. Finally in winter, I have been known stand by my open front door to get a quick blast of cold air.

*

I take towel-wrapped ice packs (2 or more) in an insulated lunch bag whenever I leave the house, and keep 3 or more with me in bed to see me through the night; I also have a fan directed at me in my bedroom. (If I get cold, I just cover myself in my blankets, or use my electric heating pad. I should also clarify that fortunately, we have central air conditioning; when we didn't, I used a window AC unit as well as a fan.) I also take at least one drink thermos everywhere I go (it fits in the insulated lunch bag), and two thermoses to last me overnight; in the summer months, it's easy to add ice to those drinks. And I use the type of thermoses with inbuilt straws, so it's easier to drink them lying down. In the summer, I also keep a folding paper fan in my purse, to easily create a breeze. I dress in layers; the base layer always has loose necks, and almost never has sleeves. I usually tie my hair back/up to keep it off my neck, except on special occasions. When it's particularly hot, I also keep a water mister with me, to spray myself and cool via evaporation.

*

Search "ice vest". I had a homemade one to use while fishing or gardening. I got it off Etsy. (Lost it somewhere, would love to get one of the "professional" ones as I think they'd stay cool longer than just a double layer of material like mine was.)

*

Overheating has been a major issue for me to the point where I have fainted on a few occasions, so I have become extra sensitive to the early signs. I start to feel a bit dizzy, nauseous and hopefully before I get too sweaty I start taking layers off. If I am at home I sit down and rest, feet up, cold drink with ice, and an ice pack that I lay on my head. When out I always have a cold drink with ice. In the summer I use these cooling bandannas that have water beads in them, you soak them in cold water for 15 mins and then tie around your neck. I have a few colours. They look cute and keep me cool. I got them from a local crafter but she sells on Etsy. I keep the heat low at home, my poor family bundles up, and we had to install air conditioning. We did use a portable one first and that worked too. Warm short showers only with the window wide open and fan on.

*

I make sure to have 2 litres of water a day, with at least one litre within the first hour of waking up, and the rest regardless of exertion levels and use the dry cycle on the AC rather than cooling. I also have Botox for hyperhidrosis (excessive sweating) and wear natural or breathable fibres. I use bamboo sheets and mostly loose clothing.

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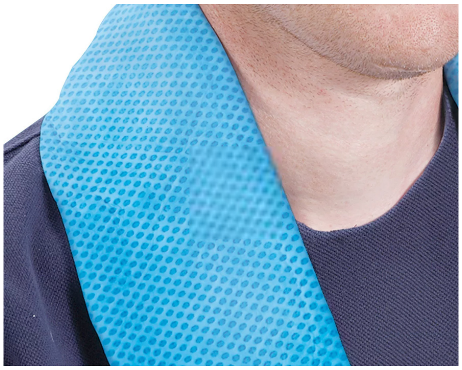


Definitely an issue. I prefer a cooler environment and like keeping the thermostat lower. I have used ice packs in the past for break thru or in an emergency. Now I also have a cooling scarf from Lee Valley (it kinda feels like a suede material when dry) which all I have to do is wet down and wring it and it stays cool for hours! I normally wrap it around my necks but sometimes need more and will wrap it around my head and eyes (sometimes my wrists). I also have a "spa eye mask" which is full of those little microbeads. I normally keep mine in the fridge so it's a bit more flexible that the freezer and wear it (also great for headaches of any kind!!). Fans are helpful, as are no socks! I tend to wear sandals year round, but do have a pair of winter boots from Manitobah Mukluks that you are supposed to wear barefoot, and the inside is designed to prevent overheating (I'm mixing up the words there, but it really works!!). Cold showers are also helpful, as are layers. Before the cooling neck wrap, I also made up a spray bottle with water and a few drops of peppermint essential oil that I could spray on my chest or back of neck to help too.

Cold drinks are great too, I keep a jug of water in the fridge that I can easily grab to fill my water bottle, and also to fill my hot water bottle, which is actually my COLD water bottle. Sooooo helpful during the summer especially! Fill it with the cold fridge water, place near the foot of the bed and bam! Works like a charm!

*

An iced drink can help. Putting your feet in a bowl of cool water or wrists in sink of cool water.

*

For the night time I purchased a cooling blanket, it helps a bit!

*

Fans, cooling socks and cool flannels in extreme hot spells.

*

An ice pack wrapped in a soft bamboo hand towel under my head and also often ice packs covered in soft bamboo pillow slips around my head as well help me a lot.

When I have to go out to appointments I take ice packs wrapped in cloth and frozen water bottles to help cool me. Often placing the ice packs between me and the seat help a lot.

Natural fibre clothes esp bamboo. Natural fibre bedding eg cotton, bamboo. Never polyester

Air conditioning with dehumidifier

Lots of cold water stored in fridge and or freezer. Double wall insulated stainless steel containers for cold drinks help a lot.

*

During the summer time, especially when it is hot and humid, I go into the shower and start out with a warm shower then slowly bring down the temperature to tepid until I start to feel better. When I need to, I put a stool in the bathtub to sit down as standing too long can bring on other problems.

Service Dogs

Somebody from Ontario asked us about service dogs and, in particular, the possibility of a service dog for someone with ME/FM. We decided to investigate. Here is a summary of what we found.

Service dogs are legally recognized in the human rights - disability law area. In the US, a service dog is an animal that is trained to do tasks for an individual with a disability. Service dogs were first used to guide people with visual impairments but in recent years there has been recognition that service dogs can help people with other types of disability. When they are providing support, service dogs are legally allowed to go to many places that ordinary pet dogs are not allowed to go. In the US, emotional support dogs are less trained and they are allowed to go fewer places. Canada, like the US, is trying to sort out the role of service dogs for people with disabilities. The law in Canada is less developed.

For people thinking about getting a service dog, there are several key questions. What do you want the dog to do for you? What training is required to make this happen? Do you want to take the dog to places where dogs are not usually permitted? Do you have the energy and the resources to take care of a dog?

*

Most of the information we found comes from the US, so let's start there.

The ADA (Americans with Disabilities Act) defines a service animal as "a dog that is individually trained to do work or perform tasks for an individual with a disability."

Wikipedia describes different types of service animals.

- A guide animal is an animal specifically trained to assist visually impaired persons to navigate in public. These animals may be trained to open doors, recognize traffic signals, guide their owners safely across public streets, and navigate through crowds of people.
- A mobility animal may perform similar services for a person with physical disabilities, as well as assisting with balance or falling issues.
- Hearing animals are trained to assist hearing-impaired or deaf persons. These animals may be trained to respond to doorbells or a ringing phone or to tug their owners toward a person who is speaking to them.
- Psychiatric animals can be trained to provide deep-pressure therapy by lying on top of a person who may be suffering from PTSD flashbacks, overstimulation, or acute anxiety.
- Autism animals have been recently introduced to recognize and respond to the needs of people with autism spectrum disorder; some persons with ASD state that they are more comfortable interacting with animals than with human caregivers due to issues regarding eye contact, touch, and socialization.
- Medical emergency animals can assist in medical emergency and perform such services as clearing an area in the event of a grand mal seizure, fetching medication or other necessary items, alerting others in the event of a medical episode; some may even be trained to call emergency services through use of a telephone with specially designed oversized buttons. Service animals may also be trained to alert persons to the presence of an allergen.

The ADA essentially says that anywhere a member of the public can go, the service dog can go as well, as long as it is serving the disabled person and is under control. This allows service dogs to go into facilities like restaurants and stores where pets are normally excluded. It doesn't allow a service dog to go into a restaurant kitchen because this is not a public area.

Emotional support dogs provide "important companionship and emotional support for owners". This is not a task that would qualify a dog as a service dog under the ADA. In the US, it is illegal to bring a dog to non-pet friendly places simply because it provides companionship or emotional support.

Emotional support dogs are recognized in the US for some purposes. In particular, people with psychiatric disabilities may be allowed to have an emotional support dog in federal housing and in some travel situations. The handler must meet the federal definition of disabled, and the emotional support dog must help alleviate the symptoms or effects of the disability. Often, the individual will need to present a letter from their certified healthcare provider, stating that the emotional support dog is imperative to their mental health and there aren't any alternative treatments.

Therapy dogs have a different role. They interact with a range of people, often in settings like schools, seniors homes or libraries. They would be allowed into the particular setting, but would not have special access to other settings that are generally off-limits to dogs.

Overall, it is recognized that a dog can be useful to a person with disabilities. It is also recognized that society doesn't want dogs to be allowed to go everywhere. There seem to be two levels of exception to the no-dog rules – narrow exceptions in places like stores and restaurants and slightly broader exceptions in places like pet-free apartments and airplanes.

*

The Bateman Horne Center is a ME/FM specialty clinic in Salt Lake City. It invited a dog trainer to give a presentation on service dogs for people with ME/FM. The presenter focused on the mobility function, suggesting that the dog could help with tasks like picking up items from the floor, bracing handlers, helping handlers in and out of chairs and vehicles, opening doors, turning lights on and off, fetching caregivers or medical professionals, and navigating crowded spaces. The presenter noted that there can be secondary benefits from having a service dog, such as companionship, better sleep, better socialization, and more routine. The video also pointed out that dogs can be a lot of work. That work can be reduced by selecting a quieter breed and selecting a dog past the puppy stage. The video is on-line and is well worth watching. *https://batemanhornecenter.org/service-animals-mobility-support/*

*

Stepping back, one can see some biases the US approach. It focuses on doing tasks while downplaying the secondary benefits. For instance, having a dog could increase an individual's confidence in going out in public and hence increase the individual's participation in society. The

US approach focuses on selected impairments (seeing, hearing, mobility etc) and the list is not fully inclusive. And it requires the dog to be trained, which could translate into cost.

*

The legislation in Ontario is spotty. There is mention of dogs in the Human Rights Act. The customer services regulations of the Accessibility for Ontarians with Disabilities Act, says that providers must ensure that a person is permitted to enter the premises with his/her service dog unless excluded by law, and must make alternate provisions in those circumstances. This regulation applies to people and businesses that provide goods and services to the public. As examples, think of restaurants, stores and taxis. *https://www.ontario.ca/laws/regulation/070429#BK3* The Ontario government website says that people can take service dogs on public transit. Note that air travel is covered by federal legislation.

How does an dog qualify as a service animal in Ontario? Here is the relevant section of the customer service standard:

For the purposes of this section, an animal is a service animal for a person with a disability,

(a) if it is readily apparent that the animal is used by the person for reasons relating to his or her disability; or

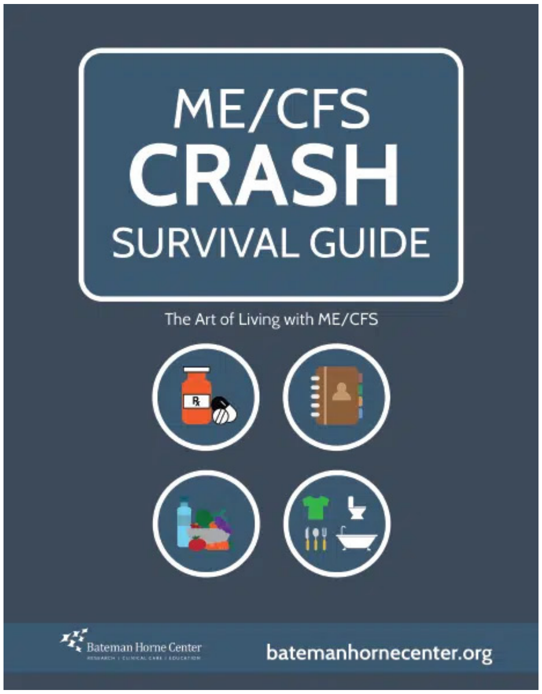
(b) if the person provides a letter from a physician or nurse confirming that the person requires the animal for reasons relating to the disability.

Thus, unlike the US, Ontario has no requirement that the animal receive special training and there is no distinction made between service animals and emotional support animals. But Ontario still requires a person to justify the use of the animal on the basis of disability which likely means convincing a physician or nurse (or possibly another health care professional) to provide a letter.

How could a person with ME/FM convince a health care provider to provide such a letter? You would have to convince the health provider that having a dog would keep you safer, help you with tasks, and allow you to do things that you would not be able to do without the dog. You would want to convince the health provider that you could manage the dog – it wouldn't use up too much of your energy. Convincing a health provider would be difficult for someone with ME/FM, but it is not impossible.

The topic of service dogs is still developing. If anyone has any experience or thoughts, we would like to hear from you.

ME/CFS Crash Survival Guide



ME/CFS
CRASH
SURVIVAL GUIDE

The Art of Living with ME/CFS

Bateman Horne Center
RESEARCH | CLINICAL CARE | EDUCATION

batemanhornecenter.org

The Bateman Horn Center, a ME/FM specialty clinic, has put together a "ME/CFS Crash Survival Guide". This document recognizes that health crashes happen to people with ME. The document explains post exertional malaise which can lead to crashes. It then advises people on:

- how to reduce the likelihood of crashes,
- how to prepare in case of a crash, and
- how to cope in the midst of a crash.

There is a lot of useful ideas and checklists in this document. The document would be very useful to anyone with ME/FM, but we would especially like to draw it to the attention of people with more severe ME/FM and to the attention of caregivers.

You can download the document here.
https://batemanhornecenter.org/education/mecfs-guidebook/

We consider this document extremely important, so if you don't have access to a computer and printer, let us know and we will send you a copy.

Conversations About Chronic Illness

Karandeep Kaur

4 Steps to Having Open Conversations With Loved Ones About Your Chronic Illness

Living with a chronic illness means adapting all areas of your life to fit around it. It might mean changing the way you work or how much time you spend with loved ones. This can cause conflict with the people in our lives, as they don't fully comprehend the impact of our illness. To help with this, we might decide to have an open conversation with our family and friends, to help them understand why we are putting certain things in place or what our lives may look like in the future now that we have a chronic illness to manage.

If you've been in this position before, you will know the issues that can arise when having these conversations, particularly with the closest people in our lives. These conversations may become heated and emotional as many delicate points can be brought up and discussed in a new way. Over the years, I have had many of these conversations and most of them did not go smoothly. After having a lot of these strained discussions, I decided I needed a plan to help me get through them and ensure the conversation was beneficial for both myself and the people I was speaking with. And so, I created my step-by-step guide to having an honest conversation with family and friends about my chronic illness.

Step 1: Decide exactly what aspect of your chronic illness you want to talk about.

A lot of the times I started a conversation about my illness with my family and friends, I would find myself easily getting distracted and drifting into other subjects. It would only be after the conversation was over that I would realize I didn't talk about the one thing I needed to. Now when I know I need to have a conversation with someone about something in particular, I bring it up at the beginning, telling them I want to talk to them about this specific thing. This helps us both to stay on topic and allows me to speak about the things I want to.

Step 2: Plan an appropriate time and place to have the conversation.

Looking back on some of the discussions I have had that quickly turned into arguments, I can identify times when I brought up a subject in the wrong place. I've found that conversations I know are going to be very emotional or difficult should be had in a private place where all people involved feel comfortable. You can't expect someone to react to something calmly if they are already in an environment they feel uneasy in. For conversations I want to feel lighter and less intense, I find going for a walk together can make it easier to talk about things. This is because you're not facing each other and you're partially focused on another activity. Some of the deepest conversations I've ever had have occurred on a walk or in the car.

Step 3: Acknowledge that some things may be difficult for the other person to hear.

When we live with a chronic illness, we can spend so much time focusing on how we are affected by it, we can forget our loved ones have been affected by it too. When I first started my blog and showed the posts to my family, I was surprised by their reactions. I remember my parents telling me that they found it difficult to read about the ways this illness has changed my life and the range of symptoms I have to deal with on a regular basis. To me, this information wasn't emotional at all because it was something I was used to but to them, it was a stark reminder of the difficulties their daughter has to face. I try to remind myself people react in different ways to the same scenario depending on the context behind it. This helps me be more accepting of reactions towards what I am saying and being open to their point of view.

Step 4: Know when to let it go.

Sometimes you can try all you can to make someone comprehend what you're going through and they just don't get it. This might be because it is too hard for them to understand or they don't want to understand. In either case, it's important to know when to let the subject go and to accept that their opinion might not match your own.

This step has saved me a lot of energy and for someone living with CFS/ME, that is very important to me.

By using these simple guides, I have been able to have much more productive and honest conversations with the people in my life and consequently, have greatly improved my relationships with them. After 10 years living with chronic illness, I know the relationships we have are incredibly important, and meaningful conversations are the best way to nourish them.

https://themighty.com/2021/10/tips-open-conversations-cfs-chronic-illness/

Reflections on the pandemic

In March, we sent around a request to people to reflect on their experiences with the pandemic. We did not receive many responses, leading us to believe that people are generally tired of the pandemic or they don't believe that it is ending.

We received three replies that look back over the time very thoughtfully, and we did receive replies pointing out four particular issues that have arisen. We feature the four particular issues first and the general reflections after that. If you have other thoughts, please don't hesitate to send them for our next newsletter.

Long Covid: The writer noted how much long-Covid symptoms are like those of Fibromyalgia and hoped that this will bring about more research on the cause and cure of both conditions.

Vaccines: The writer noted that many families have split because of differing views of vaccines.

Health care: The writer noted that she had not seen her doctor in 2 years and a call last summer was not returned. Other people have told us that their health care providers have retired so they have to find new help. This ties in with the advice we gave in to last newsletter – take good care of yourself because the health care system is fragile at the moment, but don't hesitate to ask for help if you need help.

Income support: The writer noted that there a been a single $500 special payment to people with disabilities in the last two years. The writer noted how her food costs were rising and one of her ongoing payments had increased by $500 per year. She concluded that the Federal Government has not given people with disabilities the true supportive help to survive in Canada.

***Reflection 1*:**

Surviving Covid

My husband and I are elderly, retired and living comfortably in our own home in a large town miles from a city.

For these reasons we have not experienced loss of work or income; problems of child-care; or constant exposure to others on city transport or in crowded housing.

He has no auto-immune problems; but years ago, I developed disabling MCS, ME/FM due to workplace exposures, and remain severely immune compromised.

All aspects of dealing with Covid, or becoming hospitalized, are frightening to me, as I always face medical disbelief of the above diagnoses; and do not do well in a hospital environment.

For these reasons, and because Covid is fatal for many elders; we decided to take the vaccine, despite its unknown side effects in my case. Fortunately, I had a mild reaction, and my husband had none.

We adapted to pandemic restrictions; ordering and picking up groceries; or making brief forays once a week; and ordering goods on line. Our theatre tickets expired and our social life has almost ceased.

We enjoy occasional take-out meals to support local restaurants.

Personal visits with friends and family are few, and everyone is tested in advance. This isolation is the most difficult to bear, as birthdays, Christmas and other occasions slip by. Saddest is the death of friends without the comfort of traditional funeral services.

We have changed and adapted to new methods of communication. My husband and I meet with our various groups on Zoom; our family communicates on Telegram daily, from Toronto to Saskatchewan to Australia; and emails are frequent. We read more books; do crosswords; and play board games in the evenings.

With Covid becoming endemic rather than epidemic; we now look forward to seeing friends and family in person this summer.

I believe that it is significant that symptoms of "Covid long-haulers" appear very similar to those of MCS, ME/FM. I experienced years ago. At that time, the multi-systemic physical symptoms were treated in isolation; and disabling brain and central nervous symptoms were dismissed as psychological".

I hope "real science" will at last deal objectively with what appears to be the disabling effects of viral illnesses, and that meaningful research will occur.

Covid has also revealed the disgusting state of "elder care" in our country. I hope this results in positive action in that sector also.

Reflection 2:

Compared to many, especially in my age group (I am 82) I have been lucky to avoid getting Covid - well, lucky and extremely careful to get 3 doses of vaccine as soon as I could, use masks, disinfectants, social distancing, etc.

In general, the pandemic has caused some regression in the progress I've made to manage my ME/FM over the 30 years since I was diagnosed. At the time of diagnosis, ME/FM was so acute I was mostly bedridden for three years. With expert care, I gradually returned to what could be called 80% of health and have remained more or less that way until the pandemic.

The number one symptom that has worsened is so-called brain fog which crept up on me gradually but seemed to take a bit of a leap about May of 2021. I have strategies for remembering but have to use more of them, more often. As a writer, my writing has suffered in quantity and quality.

For me, there is a link between my lifestyle practices and the severity of ME/FM (diet, exercise, etc). It is much easier to manage my health issues with social supports than without them. There is a lot of maintenance involved in managing my ME/FM. Also, the expert care I received in the States does not exist here. Many of the relevant ME/FM treatments that were covered by my insurance in the States are not covered here and I can't afford them, such as physical therapy, psychotherapy, chiropractic, nutrition, etc. The ignorance of some doctors toward ME/FM is appalling. Their reactions when I state that I have ME/FM range from ridicule, calling it the disease that nobody knows about and does not exist, to stating "that is not my area" and refusing to discuss it, to changing the subject. Few of them show any interest in learning about it. I hope that the National ME/FM Action Network can somehow change this dismal situation.

The biggest impact for me has been the isolation. I returned to Canada five years ago after living in the States for 50 years. My efforts to build a social network here have been very hampered by Covid and the illnesses and deaths among my family and friends. My social contact is mainly through phone and email with my American friends. I'm grateful for any and all family and friends that are available in any way, but it's not a satisfactory situation. I'm good at living alone but this is not the best way to live at any time, never mind during the pandemic which is very scary.

I've also been impacted with worsening FM. Typically, my nerve and muscle pain was chronic but intermittent and not incapacitating. Since the pandemic, pain has become constant and sometimes prevents normal activity altogether. As mentioned, I can't afford many of the treatments to help FM. I was fortunate to get a referral to a physiatrist who in turn referred me to a pain clinic which did treat some nerve pain successfully.

It is some relief that Ontario's Covid restrictions are relaxing now, but worrying that the mutations continue, so the future is uncertain. Managing that uncertainty, along with managing ME/FM and my financial limitations as well as the natural evolution of aging is a huge challenge. Some days I'm productive, other days I'm just a couch potato with no ambition and very little activity, which is not a good way to live.

Reflection 3

The pandemic- never thought I would be living through a pandemic, let alone that it would last more than two years.

I tried to think what effect, if any it has had on my life. Would my life be different if there was no pandemic?

Maybe, not sure. I am blessed to live on PEI. We were sheltered for so long from the high case counts of Covid-19. It felt like we were living in a special bubble protected from the deadly disease. The Island's insular nature was a safe haven and we were so fortunate compared to the rest of Canada and the world. However, the closure and shutdowns of so many stores, restaurants, gyms, entertainment venues, etc., did have an impact on one's mental and emotional health. While I may not have wanted to do many of the things that were closed, it was the fact that one could not do them - that life had become so much more restrictive and small.

If I have one regret, it is losing the freedom to travel. Even visits to family in another province were either prevented completely at times, or when possible, done with a sense of dread and fear - fear of catching or spreading the illness. It is time with my family, especially my children and my grandchildren that I will never get back.

Living with a chronic illness (Chronic Fatigue Syndrome) has imposed its own set of restrictions over the years on my daily life. There is so much I would love to do but cannot. Unlike many with this illness, I have been fortunate to be able to do many things just not to the extent or frequency I would like. However, these past two years with the imposed Covid-19 restrictions, has left me feeling a bag of mixed emotions, including angry and frustrated that I have lost two years of where my health has been relatively stable and would have allowed me the option to travel abroad. My husband and I are avid travellers and love to spend the winters in a warm climate where I experience fewer CFS crashes. This past winter has seen a sharp decline in my health to the point I have not been able to have more than two good days in a row. As a senior, I realize that aging and the threat of other health issues arising will begin to limit my opportunity to enjoy major holiday trips. You know what they say, "get while the going is good" !

All of that said, the pandemic has also instilled in me a deeper sense of compassion for others and an appreciation of how fortunate I am. It has given us all time to appreciate the importance of in-person contact, the power of a hug, and the value of even the smallest acts of kindness. I feel truly blessed to have the support and love of my husband, my family and friends, and if heaven forbid, I can no longer travel, I have the bounty of wonderful memories of my many travels.

To better days ahead filled with health and wellness for all!

News Items

Quebec Report on MCS

The organization in Quebec responsible for providing guidance to Quebec doctors is l'institut national de santé publique du Québec, (the Quebec National Institute for Public Health).

Some years ago, the INSPQ was asked to prepare a report on Multiple Chemical Sensitivities. It published the report last summer. The report compares MCS to "chronic fatigue syndrome, post-traumatic stress disorder, electromagnetic hypersensitivity, fibromyalgia, depression, somatization disorder, phobias and panic disorder". The report says that what "all of these disorders have in common is the presence of chronic anxiety".

The National ME/FM Action Network has written to the Minister of Health of Quebec pointing out the recent work, notably the reports from the IOM (US), Euromene (Europe), NICE (UK) and the Ontario Task Force have all agreed that ME is a biomedical illness, not a psychiatric one. Therefore INSPQ should withdraw the report and rethink how it is approaching ME, FM and MCS.

You can find our letter under news items on the home page of our website.

Upcoming Ontario Election

The next Ontario election is scheduled for June 2, 2022. For people living in Ontario, there are two issues you may wish to raise with your candidates.

The first is requesting action on the Ontario Task Force Report on Environmental Health. The report was submitted in December 2018. A consultant was subsequently hired to suggest an implementation plan. His report went to the Minister of Health some months ago. We would like to see the plan implemented.

The second is requesting that the new government ensure that students in Ontario have access to special education when they cannot cope with full-time schooling. This has been a gap in the system for decades affecting young people with ME and/or FM. It is all the more important with the arrival of long-Covid cases. A recent study has suggested that a quarter of young people have ongoing symptoms following Covid and many of them could require school accommodations!

Upcoming Conferences

We have received the following notices about two upcoming conferences.

The Fibromyalgia conference takes place on line. It starts at 9am European time, which is 3 am in Ottawa/Toronto/Montreal. Fortunately, the sessions are recorded and can be watched later. Regular registration is 180 Euros (about $250 Canadian) if purchased by April 30 and 250 Euros (about $350 Canadian) after that.

Further details about the ME conference are not available at this time.

Let us know if you are interested in attending either upcoming conference.

Fibromyalgia 2022

It is with great pleasure that we invite you to attend The 4th International Virtual Congress on Controversies in Fibromyalgia (Fibromyalgia2022) which will take place 25-26 May 2022.

Even as our understanding regarding the pathogenesis and neuroscience underlying fibromyalgia and chronic pain rapidly expand and proliferate in recent years, heated controversies remain regarding many aspects of fibromyalgia, regarding its place in medicine and society and regarding the best ways to alleviate suffering.

Fibromyalgia2022 will again expose and shed constructive light on some of these more central controversies, honoring diversity of opinion as well as attempting to forge understanding and a basis for collaboration down the road.

The Congress will welcome researchers, clinicians, Fibromyalgia specialists, pain specialists, treatment experts, rehabilitation & occupational health specialists and other professionals.

The congress will focus on the following key areas:

- Neuro-biological Underpinnings of Fibromyalgia and Centralized Pain
- Classification, Diagnosis, Epidemiology and the Evolving Concept of Fibromyalgia
- Genetics, Pharmacogenentics, and Epigenetics
- Treatment of Fibromyalgia
- Complex CNS
- “Transparent Pain”: How Society Deals with Fibromyalgia

We look forward to meeting you online at Fibromyalgia 2022.

IACFS/ME Conference

International Association for

IACFS/ME

Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis

Mark your calendars to join us July 27 – 30, 2022 for our International Scientific Conference to be held at Stony Brook University in Stony Brook, New York, USA. This will be IACFS/ME’s 15th Scientific Conference!

We anticipate an exciting, informative program including:

- Research presentations
- Clinical workshops
- Poster sessions
- Patient and advocates lecture series

We expect the meeting will run from approximately 9 AM to 5 PM July 27-29 and 9 AM to 3 PM July 30. A conference program will be posted on our website by early June.

The conference will focus on the biomedical, public health, and behavioral aspects of ME/CFS and associated comorbidities. A portion of the meeting will also be devoted to COVID-19 and its relevance to ME/CFS research and clinical care.

FUNCTIONAL CAPACITY SCALE:

The Functional Capacity Scale incorporates energy rating, symptom severity, and activity level. The description after each scale number should help you to rate your functional capacity at the beginning and end of each day.

0. No energy, severe symptoms including very poor concentration; bed ridden all day; cannot do self-care (e.g. need bed bath to be given).
1. Severe symptoms at rest, including very poor concentration; in bed most of the day; need assistance with self-care activities (bathing).
2. Severe symptoms at rest, including poor concentration; frequent rests or naps; need some assistance with limited self-care activities (can wash face at the sink) and need rest afterwards for severe post exertional fatigue.
3. Moderate symptoms at rest, including poor concentration; need frequent rests or naps; can do independent self-care (can wash standing at the sink for a few minutes) but have severe post exertion fatigue and need rest.
4. Moderate symptoms at rest, including some difficulty concentrating; need frequent rests throughout the day; can do independent self-care (can take a shower) and limited activities of daily living (e.g. light housework, laundry); can walk for a few minutes per day.
5. Mild symptoms at rest with fairly good concentration for short periods (15 minutes); need a.m. and p.m. rest; can do independent self-care and moderate activities of daily living, but have slight post exertion fatigue; can walk 10-20 minutes per day.
6. Mild or no symptoms at rest with fairly good concentration for up to 45 minutes; cannot multitask; need afternoon rest; can do most activities of daily living except vacuuming; can walk 20-30 minutes per day; can do volunteer work – maximum total time 4 hours per week, with flexible hours.
7. Mild or no symptoms at rest with good concentration for up to ½ day; can do more intense activities of daily living (e.g. grocery shopping, vacuuming), but may get post exertion fatigue if ‘overdo’; can walk 30 minutes per day; can work limited hours, less than 25 hours per week; no or minimal social life.
8. Mild intermittent symptoms with good concentration; can do full self-care, work 40 hours per week, enjoy a social life, do moderate vigorous exercise three times per week.
9. No symptoms; very good concentration; full work and social life; can do vigorous exercise three to five times a week.
10. No symptoms; excellent concentration; over achiever (sometimes may require less sleep than average person).

NUMBER OF USABLE HOURS / DAY = Number of hours NOT asleep or resting/meditating with eyes closed.

ICanCME Research Network

From time to time, the Research Network runs competitions for grants to researchers and for grants to students. If you or anyone you know might be interested, keep an eye on the Research Network website icancme.ca under the tabs Research and ACADEME.

Functional Capacity Scale

The Functional Capacity Scale (page 14) is a very useful tool for coping. Figure out your level based on how much your body is letting you do. Accept the fact that that is your level for now. Be very proud of what you accomplish at your level.

http://mefmaction.com

http://www.facebook.com/MEFMActionNetwork

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