NATIONAL ME/FM ACTION NETWORK
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Newsletter

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Introduction

This newsletter starts with a study published in February 2023 by a team from Montreal led by Dr Alain Moreau. The study describes a test that can distinguish ME, FM, and ME+FM from healthy controls. The Fibromyalgia Society of Quebec hosted a webinar (in French) on this topic.

This is followed by a look at Covid and post-Covid. The key message is that Covid and post-Covid have not gone away but, to a large extent, society is acting as if they never existed.

On the research front, two planning initiatives were recently launched, one developing a research road map for ME and the other developing a research road map for post-infectious conditions.

We then talk about the Canada Disability Benefit (Bill-22), a proposal by the federal government to make payments to working-age low-income Canadians with disabilities. The bill may be approved this summer or it may not. Even if it does, there are many issues to be resolved before money is paid out.

The newsletter then turns to several segments posted on the website "The Mighty" discussing issues that people with chronic illnesses have to deal with.

Contents

Test Distinguishes ME and FM

A study was published in February 2023 by a team from Montreal led by Dr Alain Moreau. Analyzing circulating micro-RNA in blood samples, the team was able to distinguish between four groups - people with ME, people with FM, people with ME+FM, and healthy controls. Thus, this test could result in more timely and accurate diagnoses.

Evguenia Nepotchatykh

Micro-RNA affects cellular protein production and the wrong mix of micro-RNAs could lead to the wrong mix of proteins in the cells which could cause the symptoms that people with ME, FM and ME+FM experience. Understanding the cell biology could result in a better understanding of ME and FM and potentially lead to therapeutics.

The study, entitled “Circulating microRNA expression signatures accurately discriminate myalgic encephalomyelitis from fibromyalgia and comorbid conditions” was written by Evguenia Nepotchatykh, Iurie Caraus, Wesam Elremaly, Corrine Leveau, Mohamed Elbakry, Christian Godbout, Bita Rostami-Afshari, Diana Petre, Nasrin Khatami, Anita Franco and Alain Moreau. It can be found here: *https://www.nature.com/articles/s41598-023-28955-9*

Dr Alain Moreau

Dr Moreau was named honorary president of International Fibromyalgia Day (May 12) by the Quebec Fibromyalgia Society. He gave a webinar for the Society on that day. You can see that webinar (in French) on youtube at *https://www.youtube.com/watch?v=ZPfE8vMZb8Y*

Here is the Quebec Fibromyalgia Society’s media release for the webinar, along with our unofficial translation.

Le professeur Alain Moreau : président d’honneur de la Journée mondiale de la fibromyalgie 2023

11 mai 2023

La Société québécoise de la fibromyalgie (SQF) est fière d’annoncer que le chercheur Alain Moreau, PhD, agira à titre de président d’honneur de la Journée mondiale de la fibromyalgie, le 12 mai, et présentera une conférence sur sa récente découverte La signature biologique laissée dans l’organisme par la fibromyalgie.

Grâce à ses recherches, il sera possible de distinguer les biomarqueurs de cette maladie, dont le diagnostic est actuellement long et souvent difficile. Un test pour dépister la fibromyalgie pourrait ainsi voir le jour. Cette conférence gratuite, ouverte à tous et toutes, aura lieu le vendredi 12 mai, à compter de 14 h 30, en direct sur YouTube ...

Au Québec, près de 200 000 personnes souffrent de fibromyalgie. La fibromyalgie est une maladie chronique, reconnue par l’Organisation mondiale de la santé depuis 1992. Parmi les principaux symptômes se retrouvent des douleurs corporelles diffuses qui s’accompagnent de fatigue ainsi que, souvent, de troubles du sommeil, de changements cognitifs et de troubles de l’humeur. Même si cette maladie n’entraîne pas de complications graves, elle peut être très souffrante et empêcher les personnes affectées d’accomplir leurs activités quotidiennes ou leur travail. Tous les groupes d’âge peuvent être affectés, femmes, hommes et enfants, peu importe leur origine ethnique ou leur statut socio-économique.

À propos de la SQF :

La Société québécoise de la fibromyalgie (SQF) a pour mission de regrouper et de soutenir les associations régionales qui aident les personnes atteintes de fibromyalgie et leurs proches afin de mieux répondre à leurs besoins. Elle favorise le partage d’informations entre les associations en plus de faire connaître et reconnaître cette maladie. La SQF travaille à devenir l’organisme de référence en matière de fibromyalgie au Québec.

Professor Alain Moreau, Honorary President of International Fibromyalgia Day, 2023

The Quebec Fibromyalgia Society (SQF) is proud to announce that the researcher Alain Moreau, PhD, will be the honorary president of International Fibromyalgia Day, May 12, and will present a webinar on the recent discovery – the biological signature left in the body by Fibromyalgia. Thanks to his research, it will be possible to identify the biomarkers of this illness, for which diagnosis is currently long and often difficult. A test to detect Fibromyalgia could therefore be possible. This free webinar, open to all, will be held on Friday, May 12 at 2:30 pm on YouTube . ..

In Quebec, close to 200,000 people have Fibromyalgia. Fibromyagia is a chronic illness, recognized by the World Health Organization since 1992. Among the principal symptoms are diffuse body pains accompanied by fatigue. There are often sleep difficulties, cognitive problems and mood problems. Even if this illness is not generally considered grave, it can cause great suffering and can prevent people from doing daily activities and being employed. All age groups can be affected, women, men and children, regardless of their ethnic origin or socioeconomic status.

About the Quebec Fibromyalgia Society: The SQF has the mission of bringing together and supporting regional associations which support people with Fibromyalgia and those close to them in order to better meet their needs. The SQF shares information between associations and works toward the understanding and recognition of the illness. The SQF wants to be the go-to organization for information on Fibromyalgia in Quebec.

Covid and post-Covid

Is Covid still a Threat? We are hearing a lot less about Covid than we did in the earlier years of the pandemic. "Three Years Later, Covid-19 Is Still a Health Threat. Journalism Needs to Reflect That" was posted by journalist, Kendra Pierre-Louis, in April 2023 on a site for journalists.

Her message is that journalists are treating the pandemic as if Covid infections don't matter any more and it's time to move on. This, she says, shames people who remain cautious about Covid and it does not communicate the risks which still exist. There are risks to the individual (the risk of death, but also the risk of long term health issues and even the risk of not being able to earn money or carry out other activities when ill). There also risks to people they are in contact with.

The author emphasizes that Covid is more serious than the flu. The flu has seasonality but Covid is not predictable. Flu antibodies can linger for decades but Covid antibodies decline rapidly. Covid is currently causing more deaths than the flu.

She quotes an expert as saying that people are willing to take precautions if they know that Covid levels are high. Cases, the expert says, are dropping from extremely high to very high. The problem is the public sees the drop and are under the impression that the threat has dropped to a low level.

https://niemanreports.org/articles/three-years-later-covid-19-is-still-a-health-threat-journalism-needs-to-reflect-that/

In May 2023, the World Health Organization declared that the world's Covid-19 emergency is over. Canada's Minister of Health clarified that: "This is the end of an emergency. This is not the end of a threat." This caution is widely echoed. The overall message is that the threat of Covid is ongoing, but the health systems around the world are better prepared to cope with it. The message for individuals is that you are allowed to be cautious.

Is Long-Covid receiving the attention it deserves? From the start of the pandemic, the ME/FM community predicted that some people would have long-term health issues after Covid, and many of those issues would be just like ME or FM. Many people are indeed having long-term ME/FM-type health issues just as we predicted.

"Long COVID is Being Erased – Again" is the title of an article posted on The Atlantic website on April 19, 2023. The subtitle is "What was once outright denial has morphed into a subtler dismissal." The article was written by Ed Yong who has written several other amazing articles about long-Covid.

A recent US survey found about 15 million long-haulers in the US (6% of the US adult population). Of those, about 3M had mild cases. About 4M had cases that seriously limited their daily activities and the remainder were in-between. Studies suggest that some of the people affected might recover but many might not.

The issue is why, with so many people experiencing long-Covid, is it not receiving more attention. The author comes up with a number of explanations which are very familiar to the ME/FM community.

Many members of the public don't know anybody with long-Covid. That would suggest to them that long- Covid is not an issue. But there are reasons why the public might not see cases:

- the symptoms of long-Covid are not well-known or well-advertised so individuals with long-Covid may not even realize they have it
- admitting to having a life-altering condition is difficult and many individuals are in denial
- even if they accept their situation, many individuals don't want to disclose it
- many individuals with long-Covid do not have the energy to interact with others and simply drop out of sight

When it comes to the bigger picture, there are reasons long-Covid is under-recognized:

- the medical system is not good about recognizing cases
- the disability system is not good about recognizing cases
- the political system and the public want Covid and related problems to go away.

While the Atlantic article is US based, recognition of long-Covid is also a problem in Canada. A May 3, 2023 CBC website article was entitled "Lack of Ontario long COVID strategy risks care: ministry documents" and shows debate in the Ontario Ministry of Health about the needs of long-Covid patients. An April 21, 2023 Global news website article is entitled "Doctor concerned long COVID patients 'left as orphans' in B.C. after clinic closures" and describes how physical clinics for long-Covid patients are being closed although a virtual clinic is expected to continue.

What conditions should be considered post-Covid? Several recent studies have looked at databases of electronic medical records, comparing people who reported Covid infections with people who did not. The studies show increased diagnoses of a number of chronic conditions in the Covid group, suggesting that those chronic illnesses might have been triggered by Covid. Examples include rheumatoid arthritis, lupus, and diabetes. *https://www.healthrising.org/blog/2023/04/26/long-covid-faces-chronic-fatigue-syndrome-me-cfs/*

Canada funds a long-Covid research network. The Canadian Institutes of Health Research have announced funding for the "Long COVID Web: Pan-Canadian Post-COVID Condition Research Network." The network is scheduled to operate from November 1, 2022 to October 31, 2027. Here is the CIHR announcement.

COVID-19 has touched every corner of the world. As reported by the World Health Organization, more than 634 million people have been infected by the virus. For most people who are infected, symptoms of COVID-19 are short-lived but for some, symptoms remain long after infection is over. Known as post COVID-19 condition, or long COVID, more than 150 million people worldwide live with long COVID, including roughly 1.4 million Canadians.

The wide range of symptoms can include general symptoms such as tiredness; breathing and heart symptoms such as cough and chest pain; digestive problems; severe joint and muscle pain; or brain-related symptoms such as difficulty thinking or sleeping, headaches, depression or anxiety. Any of these symptoms can affect the daily lives of people with long COVID.

Without proper diagnosis and management, the effect on Canada's healthcare, financial and societal systems is profound. Likewise, some communities have been affected more than others. The negative impact on the health and social well-being of individuals, families and communities is significant and must be addressed immediately.

Founded upon the unique perspectives and knowledge of patients, Indigenous communities and researchers, Long COVID Web will create a Canada-wide research network that will

i) unravel the complicated web of long COVID disease biology and behavior;
ii) develop accurate diagnostic tools, treatments and rehabilitation; and

iii) understand and widely share how care and societal systems must adjust to improve the healthcare experience and also ensure socio-economic safety for all.

Over the next five years, Canada's leading experts and voices in long COVID will develop standardized clinical practices and treatments across the spectrum of disease. The Network findings will help influence healthcare and societal policies that will ensure the well-being and livelihood of those living with long COVID in Canada and across the world.

2022-23	*$3,000,000*
2023-24	*$5,000,000*

(The remaining funding is not shown, but is anticipated to reach $20M total over 5 years.)

Research Road Maps

I remember talking to someone who had been a navigator on a Canadian naval vessel. He commented that they always started with their destination in mind – if you don't know where you are going, you are unlikely to get there.

Up to now, research into ME and FM has been piecemeal, without broad discussion of the full map and destination. (To clarify, there is some very good research underway, but it is bottom-up, not top-down.) Change is coming. Two research mapping initiatives were recently announced, one for ME and the other for post infectious diseases.

ME Research: The National Institute of Neurological Disorders and Stroke (NINDS) is one of the institutes of the US National Institutes of Health. NINDS has appointed a working group to develop a research road map for ME research. The working group has been asked to present a draft of the research road map at a webinar in late 2023 and at a conference in December 2023. The final version is scheduled to be submitted to NINDS in February 2024.

The membership of the working group is impressive. It will be co-chaired by Dr Lucinda Bateman and Dr Maureen Hansen. Dr Alain Moreau, leader of Canada's ME research network, is one of the members.

https://www.ninds.nih.gov/about-ninds/who-we-are/advisory-council/nandsc-mecfs-research-roadmap-working-group

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Post Infection Research: The US National Academies of Sciences, Engineering, and Medicine (NASEM) is hosting a two-day workshop bringing together clinicians, researchers, and other stakeholders. The public workshop, "Toward a Common Research Agenda in Infection-Associated Chronic Illnesses: A Workshop to Examine Common, Overlapping Clinical and Biological Factors," takes place June 29-30. The planning committee for this public workshop includes ME/CFS expert clinician Dr. Peter Rowe, and microbiologist Dr. Amy Proal. Here is what the NASEM says on its website.

The current concern for "long COVID" underscores an increasing recognition of chronic illnesses that appear to arise from infectious diseases. This overlooked, growing public health problem often includes a patient history of infection by viral or bacterial pathogens followed by long-lasting and often debilitating symptoms including severe fatigue, cognitive impairment, and multi-organ dysfunction.

Examples of infection-associated chronic illnesses include:

- *Long COVID or post-acute sequelae of COVID-19: Between 10 to 30% of patients infected with SARS-CoV-2 develop chronic symptoms that lead to a diagnosis of long COVID. This estimation translates to a disease burden of between 7.7 million and 23 million patients who will be living with long COVID by February 2022.*
- *Myalgic encephalomyelitis/chronic fatigue disease (ME/CFS): ME/CFS onset is often associated with a prior, unidentified infectious episode. Approximately 1.7 to 3.3 million patients in the U.S. are diagnosed with ME/CFS and experience chronic, multi-organ symptoms.*

- *Persistent or post-treatment Lyme disease: Between 10-20% of Lyme disease patients develop persistent and debilitating symptoms after standard antibiotic treatment There are approximately 2 million patients in the U.S. living with persistent or post-treatment Lyme disease syndrome.*
- *Multiple sclerosis: A strong association of multiple sclerosis with Epstein-Barr virus infection was recently reported. In the US, more than 700,000 patients are living with multiple sclerosis.*

In addition to the debilitating physical impact on patients, chronic illnesses present broader societal impacts. For example, between 31-70% of COVID patients remain absent from work after the acute phase of the disease and long COVID may be responsible for 1.6 million fewer full-time workers in the U.S. labor market. In the United Kingdom, an estimated economic loss of 32.2 billion pounds over 10 years will be attributable to permanent injury from COVID-19 in adults, 92% of which may be due to long COVID.

Given the commonality in chronic symptoms among long COVID, persistent Lyme disease syndrome, ME/CFS, multiple sclerosis and other conditions, it is not surprising to find similarities in the leading hypotheses for the explanation of these illnesses; e.g., pathogen or antigen persistence, immune response dysregulation, altered neurologic function, and altered microbiome composition and activity. Researchers studying different infection-associated chronic illnesses face common challenges in identifying disease biomarkers and developing diagnostics and therapeutic options.

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These two Research Road Maps will be very important, but questions will arise.

What types of research are included in the Road Maps? The Government of Canada's health research investment agency, the Canadian Institutes of Health Research (CIHR) supports four categories of health research: biomedical; clinical; health systems services; and population health. It appears that the two Research Road Maps (which are US-based) will put most of the focus on the first or the first two pillars.

Are the two Research Road Maps aligned with each other? That will almost certainly happen, but it will have to be confirmed.

What conditions are considered? While ME will be considered, but will Fibromyalgia? How will the recent findings associating a range of chronic illnesses with Covid affect this work?

What role can Canada play in advancing this research and ensuring that the findings of research are applied in Canada? What are the roles of the ICanCME Research Network and the long-Covid Web research network?

What resources will be provided to carry out the research identified, both in the US and here in Canada?

Canada Disability Benefit (Bill C-22)

The federal government has proposed a new program of payments to low-income working-age persons with disabilities along the lines of the guaranteed income supplement to low-income seniors. Legislation to set up these payments passed the House of Commons and then went to the Senate. The Senate made some changes, which means it has to go back to the House of Commons. So as I write, the future of the Bill is not clear. But even if it does pass, it could take a year to sort out the details.

The National ME/FM Action Network has two major concerns. One is ensuring that the eligibility criteria are fair to people with ME, FM or both. The second is that the added income is not clawed back, leaving the recipient in the same situation as before.

Claw-backs could come in many forms. One is reduction of provincial/territorial payments. Another is reduction of long-term-disability payments. A third would be increased charges or reduction in offerings in programs like housing or health care.

Some very interesting "sunburst" infographics were put together by two economists at the University of Calgary, Lindsay Tedds and Gillian Petit. They were looking at Income and Social Supports offered in British Columbia by the federal, provincial and municipal governments. They found 177 separate programs. Programs cover children, working-aged adults and seniors. The programs deal with more than disability - eg veterans, students, low income, and immigrants.

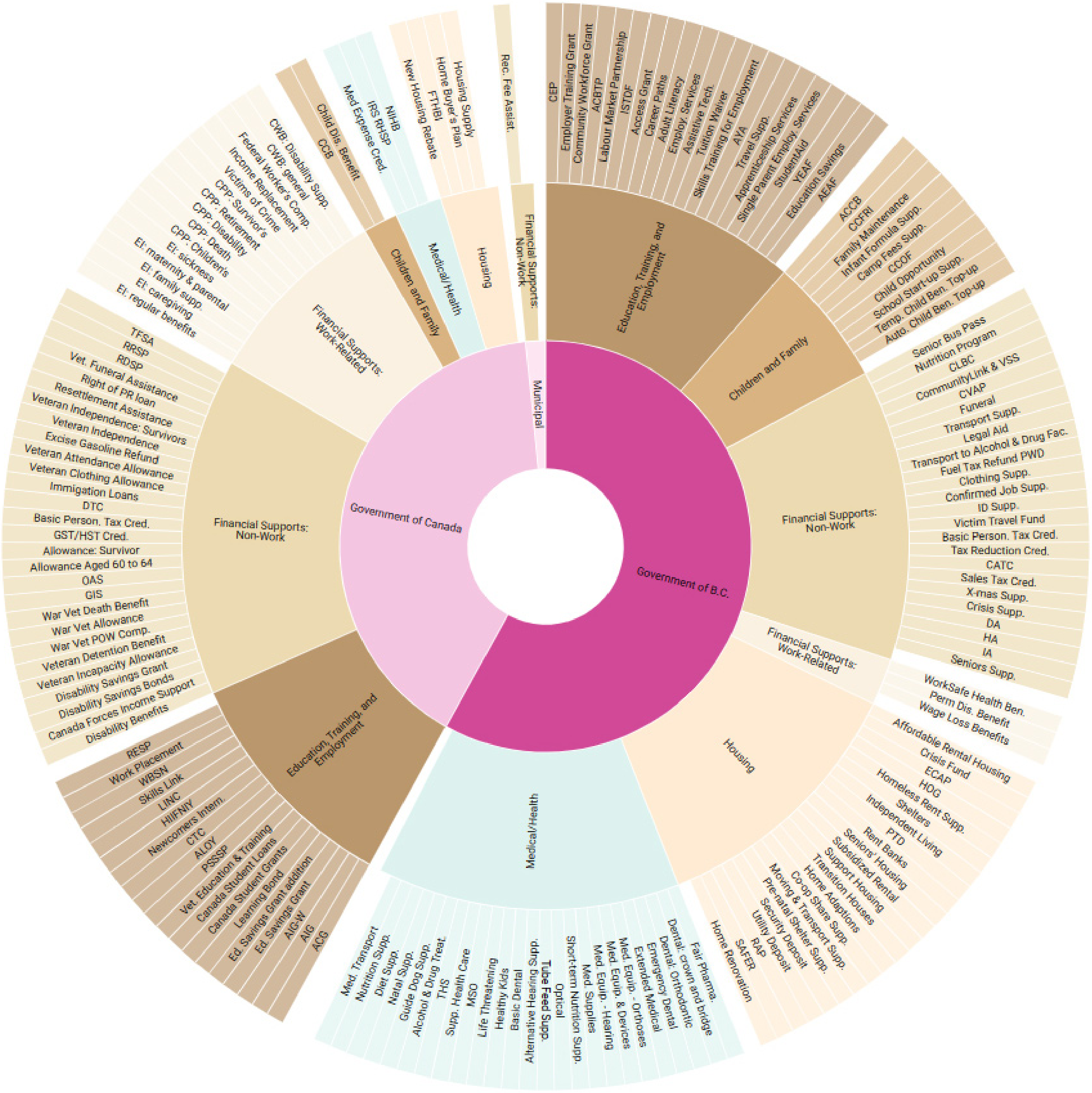
Here is one sunburst. The sunburst is seperated first by federal, BC government and municipalities, then by these categories:

- Medical, health
- Housing
- Financial supports, work-related
- Financial supports, non-work
- Children and Family
- Education, training and employment

The outside ring shows the individual programs.

Don't worry about the detail. The message is that the Canadian income and social support system has many components and that the components should be working together.

https://bcbasicincomepanel.ca/charts seventh sunburst



Patient Experiences from The Mighty

Riding the Roller Coaster of Fluctuating Disability

EmeraldMaz

https://themighty.com/topic/disability/roller-coaster-of-fluctuating-disability/

When people think about disability or chronic illness, they tend to do so in a very black and white sort of way: Either you are completely disabled, or you are not - this is your permanent status, and your disability (or lack thereof) will affect you the same way today as it will tomorrow.

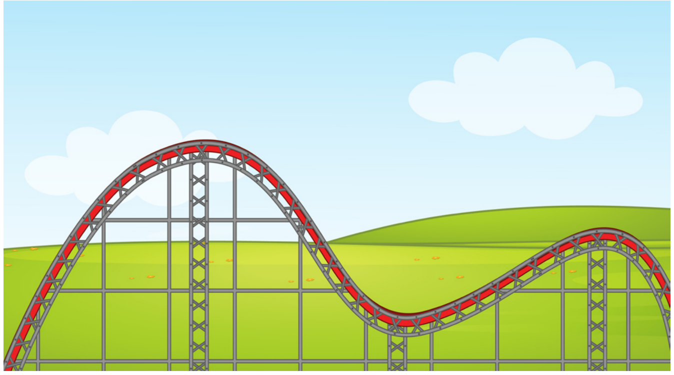
Were it only that simple.

Such black and white rigid idea that we cannot be differently affected on a daily (or weekly, or hourly) basis is, frankly, entirely asinine. Even when you're completely "healthy," your day-to-day experiences of life are never so stable and rigid. For example, it's entirely normal to maybe feel a little more tired some days, or to feel a bit more stressed. Anyone can experience these sorts of fluctuations, is it really such a foreign idea that illness and disability can fluctuate, too, and affect someone differently day to day?

There are so many ways that an illness or disability can fluctuate, so many ways that the effects of such can change. But when you do have a fluctuating illness or disability, it often comes with many of the same pitfalls of a hidden disability. Judgement from those uneducated in the realities of disability, high expectations that are realistically beyond your capabilities, assumptions from others.

There are days I will be struggling to get about with a pair of gutter crutches, and a few days later I'll be managing with one, or using only a cane. It's assumed by those who have little experience of chronic illness or disability that I must be getting "better," therefore I must be able to do more, and I will continue to get better.

So what happens when, the next day, you're back to using both crutches, or a wheelchair?



Do they understand that the day before had simply been a good day? Do they know that because of that good day, you probably overdid it by taking on more and are now suffering the consequences? Or will you be met with sideways looks and, "I thought you were getting better?"

A colleague recently said to me, "Your movement is better each time I see you."

I realized I had a choice of how to respond - I could smile, and agree, and pretend that my disability was getting better. Or I could be honest. Usually I would mask and take the first option, but that day I went with honesty, and said, "Well, on good days."

I didn't know what to expect, but I don't think it was his look of utter disappointment and a quiet, "Oh." It was as though I had let them down, that I hadn't met some sort of expectation.

There are a lot of erroneous and misguided perceptions when it comes to disabled people, and on top of that there is a role of "disabled person" to be fulfilled, which comes with certain expectations that are placed upon disabled people in order to be perceived positively and socially accepted. Disabled people are expected to 1) cope cheerfully and positively accept their role as disabled person; 2) pull ourselves together, minimizing the effect of disability on our activities and colleagues; 3) strive to improve our condition and "get well" (if you think this seems diametrically opposed to expectation 1, you're not the only one); 4) look after yourself with as little support as possible; 5) focus on recovery to return to or maintain employment.

But the nature of chronic conditions is in the name: they are chronic. They are continuous and always. Fluctuating conditions are the same - they are always present, but the severity and manifestation of them changes. This doesn't mean they've miraculously disappeared, but that they ebb and flow, ever present. There isn't "well" to get. To those without the experience or exposure to this, this is an entirely foreign concept. For them, illnesses are temporary. You get sick, or you get hurt, then you get treatment, and then you get better. The idea that there is no real getting better doesn't make sense - even when they might be aware of it cognitively, that doesn't necessarily extrapolate to truly understanding it.

"I thought you were getting better?" can hit like the pointy end of a very sharp sword sometimes. It feels accusatory. Like we're being accused of not trying hard enough, that not getting better is somehow a personal failing, or even that we're maybe just pretending that we're as bad as we are for that imaginary disabled bonus that many non-disabled people believe to exist.

Perhaps we just don't want to get better, right? But trust me, if there's better to get, we would. That's why we take advantage of whatever options are available to us. It's why we try to make the most out of the good days, sometimes even to our own detriment.

Fluctuating conditions are also shockingly unpredictable, especially at first, when you don't know what will trigger a flare or are not yet experienced enough to recognize the warning signs. One day you may feel quite carefree, you might even feel energetic, or your pain may be the lowest it's been in months — the next day you can feel like you've been hit by a truck. This unpredictability and uncertainty only adds further to the burden of disability.

Planning ahead becomes difficult, as there's little certainty that your plans will still be achievable when the time arrives. You may have to start cancelling plans, which can leave you feeling flaky and unreliable, especially when those plans were with someone that saw you on a good day recently. Your needs can change drastically day to day, or sometimes you'll have a spell of stability only to be thrown completely for a loop. It can be difficult to know what accommodations you might need, and guilt inducing to receive an accommodation that you only need sometimes (in part this is due to internalized ableism and the idea that anyone should be able to simply manage themselves regardless). It's discouraging and isolating, especially when you feel that you can't make plans simply because you do not know that you'll be able to carry them out. It all has an impact on your work life, your home life, your social life. It's really all hard enough without having to explain or justify ourselves constantly.

It's really simple, to be honest: some days are good days. And some days are not. Just like anyone else. It's just that for some of us with fluctuating conditions, the differences between those days are more marked.

7 Challenging Daily Decisions When You Live With Chronic Illness

https://themighty.com/topic/chronic-illness/challenging-daily-decisions-with-chronic-illness/

It's not a secret that people living with chronic illness face all sorts of challenges but you might be surprised by some of the decisions that spoonies wrestle with every day.

Before I was diagnosed with postural orthostatic tachycardia syndrome (POTS) - and fibromyalgia, and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) - I never really struggled with decision-making. My day job as a technical program manager means that I'm constantly making judgment calls and decisions for myself and others and that always came easily to me.

We all make thousands of microdecisions every day, and much of that likely goes completely unnoticed. When you pick up your toothbrush and dispense toothpaste on top, you're probably not really thinking about it. It's habit. You're probably thinking about that awkward thing you said five years ago that is suddenly haunting you for some reason.

What, just me? Anyway…

Until I began living with POTS, fibromyalgia, et al., I took for granted how much time and energy I truly had. I could just… do things. And unless I made a stupid decision like eating an entire bag of Lesser Evil popcorn in one sitting, I didn't really have to endure the consequences of typical daily activities.

Now that I'm living with chronic illness, I have to put serious consideration into much of what I choose to do throughout the day because it will have an immediate effect on Current Leslie, as well as risk having an impact on Future Leslie.

These are seven of the bigger decisions that I have to make every day as someone living with chronic illness.

1. Deciding if you're going to take a shower.

Right off the bat, I'm faced with one of the biggest decisions I'm going to make that day - whether or not I'm going to take a shower.

Never in my life did I think that taking a shower would actually be hard. It's an exhausting activity that usually requires me to sit or lie down for a while afterward to recover.

Yeah. Recover from taking a shower.

POTS is not a fan of standing, nor is it a fan of heat/hot water. So these days, my showers are as quick and cool as possible - which I suppose is a silver lining for our water bill and hair/skin health.

We have a small corner teak shower stool that I use most days so that I can at least sit down to help with the dizziness factor - highly recommend.

On the days that I decide I don't have the recovery time or overall energy to take a shower, I give myself a baby wipe bath (which is just wiping myself down with a bunch of baby wipes), apply dry shampoo to my hair, and throw a little cold water on my face.

2. Deciding where to spend and save your spoons.

This starts with that shower predicament - debating if I want to use some of my energy on a shower, or save it for a different activity.

In the metaphor of spoon theory where spoons represent energy and effort, you only have so many spoons per day and you have to choose where to use them.

Sometimes I feel like I can handle a shower, a walk around the block, and sitting at my desk for a full workday. On other days there's no world where I can do any of those things because I have much fewer spoons to work with.

I'm very lucky that I have a partner who lives with me that can help with things external to myself, but when it comes to the things I control about my own vessel… well, sometimes I haven't had a shower in three days because I needed my spoons to play with my neighbor's dog.

Spoon delegation isn't always about the things you have to get done on your task list. Sometimes it's about making the decision to put those spoons toward an activity you enjoy for your mental health - even if it means you're going to be a little smelly - that's what deodorant and body sprays are for!

And for the record, I will always choose to put my spoons toward playing with dogs over everything else. Always.

3. Deciding how to answer "How are you?"

You've probably seen memes with something like this before:

"Are you OK?"

"Oh god no, but for the purposes of this conversation yes, I'm fine."

It's funny because it's true. It's such a simple question, but it's so difficult to know how to answer this. It requires taking into account the audience, the timing, and how vulnerable I feel like being.

Do I lie just to get past the small talk and move on to other topics? Most of the time, yes.

Do I respond with a silly cliche like, "Livin' the dream" to avoid actually answering? Depending on the audience, I do this a lot, too.

Or is this someone who actually wants to know how I'm doing, and wants an honest answer? And do I think they have 20 minutes to hear that answer? There are a handful of people that I trust and I know fall into this category, so I know I can answer them transparently.

But at the same time… do I really want to get into it? I find more often than not I'm better off saying, "It's a rough day, but I'll get through it."

4. Deciding how to respond to "I hope you feel better soon!"

Sigh. I hate when I hear this - I really do. And I hate myself for hating it. The person saying it isn't doing anything wrong, they have the best intentions, and they're making an effort to let me know they care about my well-being.

But I'm not going to feel better (much less "soon"). This isn't a cold that's going to work its way out of my symptom and in a few days I'll be feeling in tip-top shape. This is my 24/7/365 reality.

In this reality, I might feel less terrible, which is the vein I take the sentiment in, so I just say "Thank you!" and appreciate that they care.

Though I do have one friend who also has a chronic illness and when we wrap up conversations she says, "Hope it doesn't get worse!" or "I'm gonna go scream into a pillow and take my meds — you do the same!" I appreciate that she is always a reliable source of pragmatism.

5. Deciding if you're actually able to do 'The Thing.'

"The Thing" could be anything. Maybe you'd planned on going grocery shopping. Maybe you were invited to a wedding. Whatever The Thing is, you have to put serious thought into deciding if you're actually able to do it.

We make plans with the best intentions, but when you're living with a chronic illness that can decide at any given moment to zap you of all your energy or leave you with your head in the toilet… sometimes you have to bail on those plans.

Sometimes there are alternatives, and those are the easier decisions to make. If I'd planned to go grocery shopping but have determined I won't physically be able to, I can place an (overpriced and expensive) Instacart order.

But when those plans involve other people, the stress and guilt felt by having to tell them you don't feel well enough to participate can be overwhelming.

Much of the decision-making about doing The Thing is weighing the guilt against the repercussions of too much exertion. Would I rather feel terrible about bailing, or spend the next day or two in bed with PEM recovering?

6. Deciding how much social interaction you can handle.

Even in the Before Times, my introverted self struggled with social interaction. I'm not a people person by nature, so it takes a lot out of me to be around others in general. If I knew we were going to a dinner party on Saturday, I would plan to see and speak to no one on Sunday so I could refill my introverted batteries.

And with chronic illness, it's very much the same - but even at smaller levels. Social interaction could be in person, but it could also be over Zoom, phone calls, texting, social media, or even just answering emails asynchronously.

There are days when I feel particularly lonely (loneliness is a shared theme with many chronic illness patients) and crave some social interaction, but know that I only need a little bit - so I might schedule a "phone date" with a good friend to catch up. For me it's like getting a craving for stuffed crust pizza - I just want a couple of bites to quell the craving, and then I'm good.

On other days, the thought of having an interaction with another human, synchronously or asynchronously, makes me want to cry. Mental and emotional exertion can be just as impactful as physical activities, so knowing when I can handle those types of interactions is important.

7. Deciding when to ask for help.

This one right here is personally the hardest decision I make each day: knowing when I need to ask for help.

Asking for help professionally? No problem. I refuse to waste time trying to figure something out if I know that I can get an answer from someone to speed things along, finish a task and move on to the next thing. If I don't need to reinvent the wheel and can find a more efficient solution, I'll ask for all the help I can get.

Asking for help personally? It's really difficult for me. I feel uncomfortable, embarrassed, selfish, and guilty. I'm inconveniencing someone else to assist me in doing something that a "normal" person could do on their own.

At work, I might be asking someone to take an hour to help write documentation and that doesn't bother me in the least. They're getting paid to do that.

But at home, I might be asking my husband to help drizzle dressing on my salad because my hands are too shaky and I just flung a bowl of cilantro all over myself and don't feel like coating myself with tahini, too (true story). That's going to take him less than five seconds. And he's sitting right next to me.

Yet, the guilt I feel asking for his help sometimes prevents me from doing it. This is something that I know I'm always going to have to work on.

I wouldn't say that any of this becomes easier over time, but I have learned enough about myself and my condition to make more informed decisions each day.

If there's anything consistent about chronic illness, it's that we - the patient - are always going to know ourselves the best.

17 Things I Don’t Admit on Bad Days With Chronic Fatigue

Erin Migdol

https://themighty.com/topic/chronic-illness/hidden-truths-of-what-chronic-fatigue-feels-like/

The most difficult days with chronic fatigue can also be the hardest to discuss. When one of the symptoms of your illness is chronic fatigue, you know any flare day can mean you are unable to take a shower, chat with friends or even leave your house. These physical challenges as well as their mental health effects aren’t necessarily easy to bring up in conversation, especially when others assume you’re “just tired” and will feel better after a good night’s sleep.

To shed light on the effects of chronic fatigue that aren’t often understood or discussed, we asked our Mighty community to reveal what they don’t admit on the bad days of their chronic fatigue. It’s important to note that people with many illnesses experience chronic fatigue, but it should not be confused with chronic fatigue syndrome/myalgic encephalomyelitis, a distinct diagnosis that also includes chronic fatigue as a symptom.

We’re share these answers so others dealing with chronic fatigue know they’re not alone - and so those who have never experienced chronic fatigue can begin to understand the challenges you cope with even when you “seem fine.”

Here’s what the community told us:

1. “I procrastinate showers because they’re just too much work, especially now with a central line. I don’t brush my hair between showers because it kills my arms, and my muscles get extremely fatigued and hurt. I really need help but hate asking for help and feeling like a burden.”

2. “My housework falls behind, my washing falls behind, my sorting of things and objects falls behind. I want to have a clean and tidy house but find that dumping things in piles has been the only thing I can do now. I’m constantly tired of battling a fight I don’t think I’m ever going to win.”

3. “Laying in bed, doing nothing… still equals trying. Just a little extra love and support on days like this can go a long way.”

4. “Brain fog makes me feel so out of it some days; even the simplest thing is so hard to hang onto and comprehend.”

5. “I will not admit that I’ve lost. The way I see it, if I lose a day to chronic pain, I can try again tomorrow. The chapter may be finished, but the book isn’t.”

6. “Some days it takes all day to get enough energy to shower, so around 3 p.m. I start to get terrible anxiety thinking someone will come to my door and think I’m lazy or dirty because the laundry is on the sofa, dishes in the sink and I’m unshowered and in bed in the middle of the day!”

7. “I’m in more pain than someone could even imagine. I wouldn’t wish this pain on my worst enemies. I don’t like to complain to those around me because if I did, I’d be complaining 24/7 and I don’t want to be ‘annoying’ or ‘a burden’ to anyone.”

8. “I’m on the verge of losing it at everyone because everything seems so loud, like it’s way louder than normal. And it’s so annoying it makes me angry. Like even someone drinking a drink seems like they have megaphone at their throat.”

9. “I’m exhausted. Sometimes people see it but you can’t admit it. It makes you look weak or like you’re faking it. It’s all part of the ‘invisible’ aspect of our conditions. People can’t see that we’re sick so we just ‘need a good night’s sleep.’ If only.”

10. “The ‘good days’ - now so few and far between - bring me sadness, and I’ve come to resent them. When a good day pops by, it’s hard to enjoy them, knowing it’ll soon come to pass.”

11. “Needing help to do the simplest of tasks but not wanting to admit I need that little helping hand to get through the day can make it worse as I get stressed over not asking or admitting the help would actually help me. I try to hide it all from the ones I love dearly.”

12. “I don’t admit I’m incredibly unsure of whether I can continue to hold it together - my career. It was the one thing (beyond my marriage) I wanted to keep sacred and fight for in spite of all the pain because I worked so hard to earn my degrees and license. I don't admit I'm barely limping along from one day to the next, hoping like hell I can make it from Monday to Friday each week because I'm so utterly exhausted from the pain and the painsomnia… I no longer feel that drive to be the very best at my career because of what the pain and exhaustion has taken from me."

13. "I'm often so tired that even taking a deep breath is exhausting. I will even put off going to the bathroom for as long as possible because just walking the few feet from my couch to the restroom feels like walking a mile. My whole house feels like it triples in size on my bad days and everything is so far away."

14. "Having two big days in a row wipes me out, and I need a quiet day with little interaction, which is hard for my son to understand as he just wants to talk to me."

15. "I don't admit that I'm not really strong enough to handle it all all the time like everyone around me thinks I am. It's hard to cope with the soul-crushing fatigue, but harder still [are] the expectations of those closest to us in the midst of it all. It's like taking a deep breath and sinking to the bottom of the pool just so you can actually take a break. Most don't understand. Then again admitting defeat doesn't help either. The battle is in between."

16. "I don't change out my pajamas, brush my hair, take a bath (I have a central line - no showers) and certainly don't shave! Way too much! Luckily it's still cold (enough) that I can cover my unshaved legs in pants."

17. "I don't admit that I feel lonely. CFS can be such a lonely disease because when you are sleeping constantly you are separating yourself from the rest of the world. And the pain is so segregating — you own it, no one else is sharing that pain, you are alone. It is hard to feel connected to others when you crash for days."

To Anyone Afraid to Get a Disabled Placard Because You're Worried About Judgment

https://themighty.com/topic/disability/what-to-know-about-getting-a-disability-parking-placard/

I see it almost daily. In the health communities I'm in, someone will say "I need to get a disabled placard but I'm afraid to." I see the images of awful notes left on the car of someone who uses a placard.

This needs to stop.

I too had tremendous ambivalence about asking my doctor for a disabled placard. I didn't even consider it an option until my mobility issues started in 2013. I was at the point where I had to drive between my classes and buildings on the college campus where I was teaching because I could no longer manage the walking. Anyone who has been to a college campus knows that finding a parking spot, just one spot, is worth its weight in gold. But I was having to find multiple parking spots all day while trying to get to class on time, and I would inevitably only be able to find a spot far in the back, which made my driving to get closer to the building pointless. It was becoming a daily crisis for me as I was desperately struggling to have enough energy to keep teaching and getting through the day. I could not waste all the energy I had trying to walk any distance and failing.

So I went to the doctor I trusted the most to ask him to sign the form I printed off the DMV website. Yet, I felt completely ridiculous asking for a disabled placard, no matter how desperately I needed it. I even told him how absurd it felt to ask him for it. He signed it without question. I still was not comfortable with the term "disabled" then and I was still trying to pretend I could physically do what I was no longer able to do. "Passing" as able-bodied was significantly easier than trying to live with disability (or so I thought at the time), and I was coasting on denial as long as I could. But I asked him to sign the form because I needed to be able to work. I justified it to myself by saying, "I'll only use it on the days I really need it. I won't take up a spot for someone who really needs it. I'm not technically disabled, and I don't want to endure anyone's ridicule or derision because I 'look fine.' I won't use it very often."

But I was wrong. I was and am disabled. I got the placard and ended up using it every day because it was a life saver. I wished I had gotten it sooner when I needed it, long before I finally talked to my doctor about it. I wish worrying about what others would say or the fear that someone would leave a nasty note on my car wouldn't have gotten in the way of me using an invaluable resource I needed.

There are many who are going through this right now and are debating whether they should get a placard and if they want to deal with the discrimination that can come with it. They probably read these horror stories every day and see the nasty notes people leave on someone's car because not enough people understand that most disabilities and chronic conditions are invisible.

I imagine there are a variety of reasons people leave notes on cars or make discriminatory comments to the disabled. They may believe they are standing up for those who are "actually disabled," acting as vigilante warriors protecting a "privilege" that only a select few are "entitled" to. They may believe that people are exploiting the system for personal gain or even feel envy that someone has access to a prime parking spot anyone would want. They may assume all disabilities are visible and that only individuals who require a mobility aid qualify as disabled.

When someone leaves a note on a car or makes a comment, they are making rash judgments about someone they've never even met and enacting a gross injustice on someone who faces daily obstacles already.

This needs to stop.

I count myself "lucky" because I've never had a note left on my car. I had to start using a cane right after I got my disabled placard so my disability was no longer invisible. I have gotten harsh stares or questioning glances when I have used the motorized carts at stores. The last time I drove myself to a store and used the electric cart (it's been years now since I could do this), an elderly man got angry with me because I used the last one. I needed it as much as he did. I was just trying to pick up my medications without falling or fainting in a store. Now, when I leave the house I have to use my wheelchair almost all the time.

I bring my own chair now.

When someone who doesn't "look disabled" uses a disabled placard or an electric cart, we need to remember these points:

1. Most disabilities and chronic conditions are invisible. Often, you cannot "see" kidney disease, cognitive disabilities, neurological conditions, cancer, prosthetic limbs, etc. All of these and more qualify as disabilities, and these individuals are allowed access to a disabled placard to make their lives and the world that much easier to navigate.

2. Police officers, parking attendants, etc. can ask someone to show them the permit people are required to carry when they use a placard. Other people do not need to enact their own form of vigilante justice. There is a system in place to make sure that those who use the placards are permitted to use them.

3. No one is entitled to an explanation or "proof" of someone's disability. No one is required to "prove" their disability to anyone. Believing that someone is required to explain their disability is pure ableism.

4. If someone would like to help those with disabilities, there are better ways to do this than by leaving notes on someone's car or making disdainful comments. You can support legislation that helps the disabled. We have the Americans with Disabilities Act in the U.S., but the law is not perfect. We need more laws and protection so people with disabilities can enjoy the same privileges and access those without disabilities enjoy. You can spread the word that many disabilities are invisible and learn more about why disability and illness are often considered "invisible." You can educate yourself about all that qualifies as a disability and see that one in five people in the U.S. are disabled.

5. Those with disabilities face hurdles every day the able-bodied cannot fathom. If you are concerned that the disabled are getting a "privilege" that is somehow "undeserved," you are entitled to your opinion but please don't act on it. Our society treats the disabled as a protected class and enables them tools to improve their quality of life so they can be full participants in our society. The ADA was only passed relatively recently, in 1990, and it provided legal protection from discrimination and made accessibility in public places for the disabled the law. We should celebrate the fact that those with disabilities have access to tools that improve their lives.

For any of you out there who are putting off getting the placard because you fear the ridicule or are struggling to recognize yourself as "disabled," I know what you are going through, but we must use every means available to us to help us succeed. Even if someone does leave a nasty note on your car or makes a disparaging comment to you, you can keep fighting and you can survive it. It comes from ignorance and we can only hope that someday they will understand the injustice of their act. You are making the right choice in protecting your health.

Don't let anyone diminish the choices you have to make to achieve a higher quality of life.

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