



The MEmo



Waterloo Wellington Myalgic Encephalomyelitis Association

June 2021

Brock University teaches students in the Medical Sciences program about ME!



Thank you Brock University for teaching students in the Medical Sciences program about ME!!! Ellen ran into an alumni who recognized the term "Myalgic Encephalomyelitis" and was knowledgeable about the symptoms!!! Yeah, Brock!!! With almost 700,000 Canadians (per StatsCanada) diagnosed with this debilitating illness, it's good to know that medical personnel graduating from this program will have some knowledge when encountering sufferers in their work.

Warning Signals of Post-Exertional Malaise (PEM) in ME/CFS: A Retrospective Analysis of 197 Patients

"Taking warning symptoms into consideration could alert patients to the fact that they are going beyond their energy reserves and therefore have to reduce or stop their activity level in order to avert PEM occurrence. Consequently, it seems necessary to systematically look for prodromal new or non-typical symptoms, which are different from those usually experienced by ME/CFS patients."

Read the full (free) article here:

<https://www.mdpi.com/2077-0383/10/11/2517/htm>

**MAY 12
is global M.E.
Awareness Day**

**follow
#MillionsMissing
on social media**

Follow us on:



Donations to WWMEA
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The MEmo is published
by the:

**Waterloo Wellington Myalgic
Encephalomyelitis Association,**

a Federally Registered Charitable Organization,
and is distributed free of charge to its members.

DISCLAIMER:

The MEmo is intended to provide helpful information for people with ME/CFIDS. Authors who explain treatment(s) they may be using are expressing their own ideas and/or opinions.

The Waterloo Wellington Myalgic Encephalomyelitis Association does not give medical advice or endorse specific medical products or treatments expressed in *The MEmo*, and assumes no responsibility for **any** treatment written about in *The MEmo* which may be undertaken by its readers.

Sufferers of M.E. or any other illness should consult a physician for treatment.

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Membership: \$25.00 Per year.

Subscriptions- Do you have a friend or family member who you would like to be educated about M.E.? Send them a gift subscription to the MEmo. This will help keep them up-to-date with the current information and educate more people about M.E.. The cost of \$15.00 per year covers the average cost of mailing for one year.

Please send name and address along with cheque or money order made payable to:
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Photocopying: Our thanks to:
BluMetric Environmental Inc.



Gloucester Cathedral, UK

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Casino Notabile - Mdina Local Council (Malta)



PROCLAMATION

WHEREAS, Myalgic Encephalomyelitis (ME) is a severe systemic, acquired neurological condition affecting more than 500,000 Canadians and their families;

AND WHEREAS, ME is a relapsing, debilitating illness that is still not well understood and currently has no cure or effective treatment;

AND WHEREAS, the ME Society of Edmonton is dedicated to education and advocacy to improve treatment and services for those with ME, their families and caregivers;

AND WHEREAS, the City of Edmonton supports the commitment of the ME Society of Edmonton to raise awareness about the disease;

THEREFORE I, MAYOR DON IVESON, DO HEREBY PROCLAIM MAY 12, 2021
“MYALGIC ENCEPHALOMYELITIS AWARENESS DAY” IN EDMONTON,
ALBERTA’S CAPITAL CITY.

Dated this 12th day of May, 2021



Don Iveson
Mayor of the City of Edmonton



Speaking on behalf of patients

<http://hansardindex.ontla.on.ca/hansardeissue/42-1/l262.htm>

Mme France G linas, MPP for Nickel Belt and Health critic for the NDP spoke on behalf of patients suffering from three under recognized medical conditions:

“Today is May 12. It is the International Awareness Day for myalgic encephalomyelitis, chronic fatigue syndrome, fibromyalgia, environmental sensitivity and multiple chemical sensitivities.

The Myalgic Encephalomyelitis Association of Ontario, better known as MEAO, is a registered Ontario charity which supports and represents people living with any one of these conditions. MEAO has had several awareness day events here at Queen’s Park to mark International Awareness Day. Since we are in the middle of a global pandemic, MEAO is holding an awareness webinar today to mark the day.

Since 2013, they have advocated for changes to the health care system to better support people living with these medical conditions.

In 2016, the Ministry of Health announced a Task Force on Environmental Health, which delivered its final report back in December 2018. The final report contained concrete recommendations to improve care for the patients afflicted with these medical conditions.

In early 2020, the Minister of Health mandated Public Health Ontario to prepare and submit an action plan with regard to the recommendations set out in the task force’s final report.

Here we are in May 2021, and very little has changed. So I urge the Minister of Health to publicly release the action plan, implement and fund the recommendations of the plan, make sure that care is available now, and specify the locations where the care will be available.”

AONM 2019 May Conference

Dr. Byron M. Hyde, M.D., was the keynote speaker at The Academy of Nutritional Medicine 2019 May Conference. He discussed the history of M.E., its relationship to Polio and other diseases, its prevalence and our current knowledge of the illness.

Here are his slides from the afternoon session:

<https://aonm.org/wp-content/uploads/2019/05/Dr.-Byron-Hyde-Afternoon-Session.pdf>

and a video of his presentation:

<https://youtu.be/cx5w227VHWI>

(46 min.)

Here are additional slides from the morning session:

<https://aonm.org/wp-content/uploads/2019/05/Dr.-Byron-Hyde-MorningTalk.pdf>

Dr. Hyde’s presentation was part of “**Multi-System Diseases: Improving Patients’ Lives with Proper Diagnosis and Appropriate Treatment Interventions**”

Many conditions are still not being given the urgent attention they require – either by the medical profession or by world governments.

AONM brings together several inspirational and eminent scientists whose research and work challenges the misconceptions of the status quo, putting patients’ welfare first.

Additional speakers’ slides and videos can be found here:

<https://aonm.org/2019-improving-patients-lives/>

30 Ways People Hide Their Chronic Illness

by Paige Wyant

June 27, 2017

<https://themighty.com/2017/06/hiding-chronic-illness-symptoms/>

There is absolutely no reason to be ashamed of having a chronic illness. That being said, living with a chronic condition is complex, and it can affect your life in a number of different ways. And sometimes, for better or worse, you may find yourself hiding certain aspects of your illness from those around you. Maybe you downplay your symptoms so loved ones don't worry as much, or try to appear "normal" to avoid awkward or overly personal conversations. Hiding can even become a sort of coping mechanism for dealing with flare-ups or the really tough days.

Although many of us may hide parts of our illnesses away from the world, it can mean so much when someone sees past the facade, the forced smiles, the "I'm fine!"s and asks, "How are you really?" We asked our Mighty community to share some of the ways they hide their chronic illnesses in order to shed some light on what these masks can look like. If you have a friend or loved one who is chronically ill and notice them doing some of the following, reach out a hand. They may or may not feel up to talking, but letting them know you genuinely care, will listen without judgment and want to be there for them through the ups and the downs in their life might mean a lot.

Here's what the community shared with us:

1. "I hide mine via humor. I like to make people laugh. Sometimes I can barely function, but makeup and a good sense of humor can do wonders. It's a forced way to live. It takes every ounce of whatever you've got to push through sometimes. Some people don't even know I'm about ready to break down because I try to smile and am always a joker."
2. "If I'm having a bad flare-up (adrenal insufficiency/panhypopituitarism), I tend to just stay home and avoid being in social situations where my brain fog might make things awkward for me."

3. "I go to work no matter what. I always keep a brave face even when I want to cry and scream in pain."

4. "Subtle uses of equipment, e.g. a walking stick that folds so I can use it when [I'm] most at risk and near misses of falls, and put it in my bag when doing things I'm less likely to have problems with."

5. "I hide my illness usually by trying to smile. It's hard sometimes when I'm bedridden and my 4-year-old son wants to play. He comes in bed with me and I play with his toys as I lay there with a smile. Sometimes all you can do is put on a fake smile."

6. "I take lots of medication and use caffeine to help me function whenever I leave the house. It means I can pass for normal/healthy."

7. "I force myself to be fine when I'm not. My body or my emotions might be telling me to stop doing something so I can rest, but I'll ignore it and pretend it's fine because I don't want people to see how much rest I need. I just prepare myself for the crash later on when nobody is around."

8. "I totally isolate myself. It's easier than explaining for the 100th time why I am canceling or can't keep up. I've lost pretty much all my friends because of it which really sucks, but it's hard to find someone close to my age (20) who understands."

9. "When people ask how I am, I never tell them how I really am. People don't want to know the real truth of someone who is chronically ill. When you tell the truth most people are incredibly uncomfortable and don't know what to say. I now always reply with 'good.'"

10. "I push myself to work hard (probably harder than my coworkers) just to avoid suspicion that I'm not functioning at even 70 percent."

11. "Makeup. I use it to cover bruising I get from chronic swelling. I also style my hair to cover swelling as well."

12. "I wear long sleeves and pants when weather permits. I have so many scars on my veins from the amount of blood taken, scars from cuts that couldn't heal properly and I still bruise very easily."

13. "I put on a smile and force myself through the pain. When my mask is slipping I hide somewhere until I can regain my composure. I mostly did this at work, I don't feel like I need to hide my illness at home."

14. "Walking into the bathroom when the muscle spasms and cramps get bad so no one can see it happening."

15. "I wear makeup and dress up nicely whenever I go out when I can on my good days. I don't necessarily hide my illness but I refuse to let myself look defeated from it. It can have me but it can't take the fight out of me."

16. "I overcompensate at times and chat too much, but it's because I'm scared of my illnesses showing."

17. "I have IBS (irritable bowel syndrome). Growing up I was ashamed, you know, because 'girls don't poop or fart.' I would hide my illness from past boyfriends. I would hold everything in because if I was in the bathroom too long then he'd know I was pooping and I would hold in all the gas because I wouldn't want to gross him out. This made me even more sick. I'm now engaged to a man who completely understands because his mother has Crohn's. He makes me feel comfortable in letting him know when I'm having a flare-up."

18. "[I] make up stories for my illness, like I have the flu or a cold or walked into something, when really my fibromyalgia has completely spun out [of] control."

19. "I don't let anyone too close. I don't want them to see how bad it really is."

20. "I tend to mask my pain level. I play off how bad it is sometimes too well. So well that I underestimate what my pain actually is at times. It almost becomes a game, where as long as I'm breathing it must not be all that bad. Even when it is."

21. "I take my meds in the bathroom or when I know no one else is around. If it's a bad enough day for me to need a mobility aid I don't go out. I don't gear my service dog if I don't have to. There are lots of ways to hide a bad day."

22. "I will do everything I can to keep myself busy so people don't notice. Go for walks, clean something, reorganize something, listen to music or be anti-social. I know some things could make me hurt worse, but it makes me think others won't see I'm in pain, even if I know it's noticeable."

23. "[I] make up excuses as to why I'm unwell [and] blame it on other things so I don't have to explain it's a chronic disease. I don't want to go into it with everyone."

24. "I wear baggy clothes to hide bloating from gastrointestinal disorders caused by POTS. I also wear pants to hide compression socks."

25. "I often pretend that whatever is hurting isn't. I will walk as normally as possible while having extreme leg or foot pain. I will cause myself horrible pain just to appear 'normal.'"

26. "One way I hide my illness is by smiling. Someone asks how I am doing and I tell them, 'Just trying to make every day count,' and smile. 'Are you doing alright?' 'Better than ever,' and smile. No one really questions you and tries to get more information out of you if you smile."

27. "I choose not to leave the house on my worst days, so people rarely get to see the side of me when I don't have the energy to look put together. On days where I am feeling a little more motivated, I do my make-up to hide my tired eyes and the fact that my lips are colorless from vitamin deficiency. First thing I always hear is 'You look so much better!' and my response is, 'Yeah, makeup is a miracle worker like that!'"

28. "I do not hide my illness, but I do hide how it has made me feel emotionally. I've cried a lot of tears behind closed doors. I keep the information I share basic because I do not want to be seen as an attention-seeker."

29. "I rarely tell people how I am actually feeling. In a group of people I ignore warning signs and over-extend myself to fit in."

30. "I don't hide my illness; there is no reason to. I am who I am. I never chose to be chronically ill. Hiding your illness just contributes to the stigmas surrounding invisible and chronic illness. I am a firm believer that we need to be more vocal and show our illnesses any way we can in order to humanize and normalize chronic illnesses."

“Metabolical: The Lure and the Lies of Processed Food, Nutrition, and Modern Medicine”

With Dr. Robert Lustig

[Click here to listen.](#)

[Click here to view the book.](#)

Dr. Robert Lustig explains the eight pathologies that underlie all chronic disease, documents how processed food has impacted them to ruin our health, economy, and environment over the past 50 years, and proposes an urgent manifesto and strategy to cure both us and the planet.

Metabolical weaves the interconnected strands of nutrition, health/disease, medicine, environment, and society into a completely new fabric by proving on a scientific basis a series of iconoclastic revelations, among them:

- Medicine for chronic disease treats symptoms, not the disease itself
- You can diagnose your own biochemical profile
- Chronic diseases are not "druggable," but they are "foodable"
- Processed food isn't just toxic, it's addictive
- Big Food, Big Pharma, and Big Government are on the other side

The eight pathologies are:

- glycation;
- oxidative stress;
- mitochondrial dysfunction;
- insulin resistance;
- membrane instability;
- inflammation;
- epigenetics; and
- autophagy.

“The ENERGY Formula”

With Shawn Wells

[Click here to listen.](#)

[Click here to view the book.](#)

Shawn Wells has overcome various health issues including Epstein-Barr Virus, Chronic Fatigue Syndrome, Fibromyalgia, depression, insomnia, obesity, and a pituitary tumor.

Shawn is a nutritional biochemist and a world-renowned thought-leader on mitochondrial health.

In this book, readers will discover how to utilize six critical ENERGY pillars to rebuild their own lives to rid themselves of exhaustion and, instead, power their lives with limitless potential:

- Understand how energy is created with mitochondrial health and how to get more of it
- Learn how biological shortcuts or "biohacks" can optimize longevity and quality of life
- Create measurable change in 30 short days with the help of included surveys
- Increase resilience through the science of hormesis and protect themselves from illness
- Unleash their limitless potential with chapter summaries for quick reference
- Make clear use of tools like fasting, keto, paleo, cold plunges, DNA testing, supplements and more

“Fork in the Road: A Hopeful Guide to Food Freedom”

With Dr. Jen Unwin

[Click here to listen.](#)

[Click here to view the book.](#)

Dr Jen Unwin is a Clinical Psychologist, and a lifelong carbohydrate addict. Fork in the Road guides you in a clear way through identifying if you have carbohydrate addiction, finding the motivation to change your life, understanding how to build the right daily eating plan, the strategies for long-term success, and where to go for more information and support.

In this beautifully illustrated book, Jen teams up with top clinicians in the field and with creative low-carbers who share what they have learned about freeing yourself from the emotional and physical dangers of overeating sugars, flours and processed foods.

She works with the NHS, in the United Kingdom, helping patients manage chronic illness and achieve wellbeing. She also works with her GP husband Dr. David Unwin helping patients stick to lifestyle changes.

In today's episode, Dr. Vera Tarman and Molly Painschab had the opportunity to ask Jen about her personal and professional journey.

Vera and Jen dive into the GRIN tool, which was created by Dr. Unwin, and how this can be used in the treatment of Food Addiction. Jen and Vera even do a short-role play!

Molly and Jen discuss food and where individuals with Food Addiction “go wrong”.

“Lies My Doctor Told Me Second Edition: Medical Myths That Can Harm Your Health”

With Dr. Ken Berry

[Click here to listen.](#)

[Click here to view the book.](#)

Have you been misled by doctors?

Lies My Doctor Told Me exposes the truth behind all kinds of “lies” told by well-meaning but misinformed medical practitioners.

Nutritional therapy is often overlooked in medical school, and the information provided to physicians is often outdated. However, the negative consequences on your health remain the same.

Dr. Berry will enlighten you about nutrition and life choices, their role in our health, and how to begin an educated conversation with your doctor about finding the right path for you.

This book will teach you:

- how the Food Pyramid came into existence and why it should change
- the facts about fat intake and heart health
- the truth about the effects of whole wheat on the human body
- the role of dairy in your diet
- the truth about salt
- new information about inflammation and how it should be viewed by doctors

His Youtube channel has videos about diets, intermittent fasting, thyroid health, hormone optimization, and much more.

<https://www.youtube.com/channel/UCIma2WOQs1Mz2AuOt6wRSUw>

“I'm So Effing Tired: A Proven Plan to Beat Burnout, Boost Your Energy, and Reclaim Your Life”

With Dr. Amy Shah

[Click here to listen.](#)

[Click here to view the book.](#)

Dr. Amy Shah is a double board-certified MD with an undergraduate degree with honors from Cornell in Nutrition, medical training at Albert Einstein College of Medicine, then further research and residency training at the Harvard Hospitals, and advanced training at the Columbia Presbyterian Hospital in Immunology/Allergy.

What you'll learn from this episode:

- How circadian biology is a woefully neglected component to our daily lives, but just as important to physical and mental health as nutrition and exercise.
- The benefits of what you eat and how you exercise can be optimized by choosing when you eat and exercise.
- You don't need the discipline of a monk to reap the bounties of fasting when you incorporate it into a healthy, circadian-based routine.
- Why disrupting your circadian clock can approximate the effects of a bad hangover – like brain fog and low energy.
- How technology might be utilized in the not-too-distant future to nurture the pace of your circadian rhythm rather than throw it off balance.
- And so much more!

“Your Best Health Ever!: The Cardiologist's Surprisingly Simple Guide to What Really Works”

With Dr. Bret Scher

[Click here to listen.](#)

[Click here to view the book.](#)

Dr. Bret Scher is a preventive cardiologist passionately committed to the principle that the best way to “treat” someone is to avoid the need for treatment in the first place.

Dr. Tony Hampton & Dr. Bret Scher discuss what it means to ‘live well,’ how to tailor one’s lifestyle to achieve optimal health, the strength of the evidence that shows low-carb diets are the most effective for fighting metabolic disease, the benefits of time restricted eating for weight loss goals, how to intelligently evaluate the value of a given study, the role that LDL plays in metabolic health and what its value is as a marker for metabolic health, the factor of hunger in anyone’s attempt to successfully improve their metabolic health, and the meaning of ‘functional medicine.’

Dr. Scher demystifies the important science behind healthy lifestyles. He debunks myths you’ve heard even the “experts” repeat, and exposes hidden agendas in the healthcare and food industries that can set you up for failure.

Built around the six building blocks of great health, simple weekly action plans tackle everything from eating well to overcoming sleep and stress, backed up with helpful tools like checklists, power tips, a problem-solving guide, and more.

You’ll have the confidence – and the knowledge – to start your journey to your best health ever!

“Leaky Gut, Endotoxemia, Inflammation and Microbiome Reconditioning”

With Kiran Krishnan

[Click here to listen/watch.](#)

“When things fall out of order, get to the source” says microbiologist Kiran Krishnan. He shares how a leaky gut can enforce damage to the microbiome, the toxins that can cause the damage, and how you can recondition and repair from within. Find out the foods you can add to your diet as the best probiotics that are great for microbiome support.

"Guarding and protecting the body is an understated function of the microbiome. It guards what enters our body and how our immune system responds to everything it is exposed to."

In This Episode:

- Get to know your microbiome and how it is vitally linked to all of the genetic elements and microorganisms in your body.
- Your digestive tract's role as the perfect gatekeeper to determine what gets inside our bodies and what you want it to keep out!
- How good a healthy gut looks and feels versus a dysfunctional microbiome that can lead to aggravating inflammation and a leaky gut.
- Stop endotoxemia BEFORE it begins, by learning where these toxins come from and why it's critical to remove them BEFORE they leak into your blood
- The key compound that feeds bacteria, potentially generating the root cause of many chronic illnesses when the gut becomes leaky.
- How to build a dream team of bacterial diversity and why you need to train your main players first to reinforce the 3Rs (recondition, reinforce, repair) in the gut.

“Ending Aging: The Rejuvenation Breakthroughs That Could Reverse Human Aging in Our Lifetime”

With Aubrey de Grey, PhD.

[Click here to listen.](#)

[Click here to view the book.](#)

Aubrey de Grey explains that the aging of the human body, just like the aging of man-made machines, results from an accumulation of various types of damage.

As with man-made machines, this damage can periodically be repaired, leading to indefinite extension of the machine's fully functional lifetime, just as is routinely done with classic cars.

We already know what types of damage accumulate in the human body, and we are moving rapidly toward the comprehensive development of technologies to remove that damage.

Aubrey introduces the idea of repairing the damage that aging does on the body to theoretically restore the body's biological age to maybe 30 years younger:

- why damage repair could be easier than slowing aging
- repairing structure to restore cellular level function
- 7 categories of damage that correspond to therapeutic methods of repair
- how cellular waste over the years impacts old age