

▼ n her early 20s, Melissa Geraghty finally got up the courage Lto see a second neurologist about migraine attacks that were more severe than usual after a negative experience with a first neurologist. She shared her list of physical health challenges and how she had been addressing them so the doctor could understand her health history with a view to figuring out why her migraine attacks were more intense.

"All he heard was my fibromyalgia diagnosis. He laughed and said, 'Do you want to get better? Because pain clinics are just made to keep people sick. Next time your husband gets married, he should marry someone fat and ugly as they would be too scared to be sick!'" said Geraghty.

"I left feeling devastated and furious at the same time: Here I was, finally reaching out for help, and I didn't receive any. I also couldn't believe how poorly I was treated." Much later, she was diagnosed with cluster headaches by a doctor who did listen.

Fuelled by her personal experiences with medical gaslighting and determined to make a difference for others, she became a licensed clinical health psychologist, an inaugural board member of the Coalition for Headache and Migraine Patients, and CEO of her own company called Phoenix Rising with Dr. G.

Today, Dr. Geraghty provides counselling services to patients who face medical gaslighting for chronic pain, chronic illness, depression, anxiety, and recovery from eating disorders. She also offers medical gaslighting sensitivity training for medical professionals. Dr. Geraghty's experiences are, unfortunately, all too common.

Medical professionals have long minimized, dismissed, and ignored women with health issues.

There is a plethora of examples where they have told women, "It's all in your head," "It's anxiety or depression," or "You'd feel better if you lost some weight."

Medical gaslighting is infuriating and unfair and can delay diagnosis and treatment. Here's how to spot it and what to do about it.

MEDICAL GASLIGHTING

The gaslighting concept comes from the play Gas Light by Patrick Hamilton that premiered in London in 1938. Set in 1880, it told the story of a husband who tried to convince his new wife she was insane by changing things in their house, such as dimming the gas-fuelled lights and then denying her observations of them flickering, causing her to think she'd lost her mind.

The term *medical gaslighting*, which describes manipulative behaviour by healthcare professionals, has become more prevalent over the past five years. Case in point: The Merriam-Webster Dictionary chose gaslighting as the 2022 word of the year, reflecting a rise in the use of the term to describe deliberate forms of deception and manipulation in a variety of political and personal contexts.

Medical gaslighting includes dismissive attitudes by healthcare providers that depict patients as non-credible and may lead them to doubt their own perceptions and symptoms.

said cardiologist Stacey E. Rosen, MD, Senior Vice President of Women's Health, Katz Institute for Women's Health at Northwell Health in New York. "This mistreatment may be unconscious and without malice, but it has a significant negative impact on patients' physical and mental health."

WHY MEDICAL GASLIGHTING HAPPENS

There are several reasons why women experience medical gaslighting more frequently than men:

>> MALE-FOCUSED HEALTHCARE MODEL

"For at least a century, health care has traditionally assumed that bodies and what happens to them are the same for men and women, except for the breasts and reproductive organs," said Dr. Rosen. "For example, even as recently as the early '80s, we thought heart disease affected mostly men. Only in 1985, when the cardiac death rates for women surpassed that of men, did the field recognize the critical need to focus on the role of sex differences in heart disease."

Dr. Rosen noted that differences between sexes can be traced down to our cells, according to a study by molecular geneticists at the Weizmann Institute of Science in Israel published in BMC Biology. They found that a third of 6,500 protein-coding genes express differently in men and women.



WOMEN ARE NOT JUST LITTLE MEN. PRACTICING 'BIKINI MEDICINE' MAKES NO SENSE WHEN EVERY CELL IN THE BODY HAS A SEX, A BIOLOGICAL VARIABLE THAT AFFECTS UNIQUE RISK FACTORS, DIAGNOSTIC TEST RESULTS, AND RESPONSES TO TREATMENTS.

>> UNDER-REPRESENTATION IN HEALTH RESEARCH

Lab studies have traditionally relied on male animals since they are perceived to be "more stable" for research purposes than female animals with menstrual cycles and related hormonal shifts. After the U.S. National Institutes of Health implemented a policy in 2016 that required grant recipients to include female vertebrates and cells and study sex as a biological variable in preclinical research, addressing that oversight has accelerated.

For example, researchers have discovered how differences between men and women affect risk, prevalence, and responses to treatments in several diseases, including Alzheimer's disease, cancer, and cardiovascular disease, yet more work is needed, according to Dr. Nancy J. Brown, MD, the Jean and David W. Wallace Dean of the Yale School of Medicine.

Women also continue to be under-represented in clinical trials.

Researchers from the Mary Horrigan Connors Center for Women's Health and Gender Biology and the Department of Psychiatry at Brigham and Women's Hospital in Boston recently published a study in Contemporary Clinical Trials that analyzed female participation in adult cardiovascular, cancer, and psychiatric clinical trials between 2016 and 2019.

The investigators found that the percentage of women enrolled in clinical trials fell short of the proportion of women affected by the conditions under investigation - cardiovascular disease and cancer, the leading causes of mortality among women, and psychiatric disorders, the leading cause of disability for women. They told *U.S. News & World Report* that the disparity is disturbing and a significant barrier to understanding the safety and efficacy of drugs and devices intended for both sexes.

>> DIFFERENCES IN SYMPTOMS

Women may experience symptoms differently than men, but the differences may be subtle. "Chest pain is still the most common symptom of heart attack in both sexes, but women are much more likely to have other symptoms, such as nausea, breathlessness, and back pain," said Dr. Rosen.

"Some of the symptoms and causes of stroke may also be sex-specific. Women tend to attribute their symptoms to other causes, such as not sleeping well, and have a sociological tendency to look after others first, so they are less likely to take care of themselves when symptoms of heart attack or stroke first present and are less likely to call an ambulance in a timely manner."

CONSIDER ALSO THAT MANY DISEASES AND CONDITIONS THAT DISPROPORTIONATELY AFFECT WOMEN HAVE VAGUE AND OVERLAPPING SYMPTOMS, MAKING DEFINITIVE DIAGNOSES CHALLENGING.

Dr. Rosen noted that up to 80% of patients with autoimmune disorders, including arthritis, lupus, and Sjogren's syndrome, are women, and it can take three to four years to establish a diagnosis.

"It can also be difficult to diagnose other diseases that affect women more so than men, such as chronic Lyme disease, long COVID, and certain types of migraine," Dr. Rosen said. "When symptomatology is not as well defined as other conditions, it can be a setup for medical gaslighting."

HOW TO SPOT MEDICAL GASLIGHTING

Lindsay Weitzel, PhD, is executive director of the MigraineNation Foundation, founder of the MigraineNation Facebook group, chronic daily migraine survivor, and host of the National Headache Foundation's weekly *For Heads Sake* podcast. She discussed medical gaslighting with Dr. Geraghty and shared her first experience with it in a recent episode:

As a young child, with her feet hanging off the edge of the exam table, the pediatrician said, "You're perfectly healthy. Aren't you glad?" after her blood work showed no issues. Dr. Weitzel recalled she could barely see because her head hurt so badly from a migraine. She was far from fine.

This denial of her reality is but one example of medical gaslighting. Here are some of the techniques healthcare professionals or even loved ones may use to gaslight you regarding your health issues and what they may say:

COUNTERING

"You aren't remembering that correctly; you have a bad memory";

DENIAL

"Oh, I never said that. You must have misheard";

TRIVIALIZING OR MINIMIZING YOUR SYMPTOMS

"You're overreacting; it's just a small symptom, not a big problem." Or "your lab tests are fine, so you're fine";

WITHHOLDING

"I don't know what you're talking about. That didn't happen"; and

BLOCKING OR DIVERTING

"Why are you being defensive?"

RECLAIM YOUR PATIENT POWER

Mind Over Matter® asked both experts we spoke with to recommend effective strategies for dealing with medical gaslighting. Here's how you can shift discussions with your providers back to shared decision-making:

- **BE PREPARED.** Write down your questions and concerns in advance and take a printed copy to the appointment. Consider recording the visit using a voice recorder app if you find it difficult to remember what's discussed.
- TAKE AN ADVOCATE. A friend or a loved one can youch for your atypical symptoms and help take notes during the visit.
- **CHANGE YOUR PRIMARY CARE PHYSICIAN.** You may need to speak to several providers before you find one who listens well. "Everyone should have a primary care physician they trust," said Dr. Rosen. "Don't wait to navigate the system with a stranger when you're ill. It's ideal to have a long-term relationship with a provider who knows your history and respects patient-centred conversations."
- ASK FOR A SECOND OPINION. No competent healthcare professional should feel threatened by this request. "It's ironic that women will fire a hairdresser over one bad haircut and don't think twice about looking for a different pediatrician for their child if they have concerns about the quality of care, yet they're afraid asking for a second opinion for themselves will anger a healthcare provider," said Dr. Rosen. "But what could be more important than health? Women need to advocate for themselves the same as they advocate for loved ones. If this was a referral to a specialist, you could always ask your primary care provider for another referral."
- **OBTAIN YOUR MEDICAL RECORD.** You have a legal right to access and obtain a copy of your medical record under the Health Insurance Portability and Accountability Act (HIPAA) in the United States and the Personal Information Protection and Electronic Documents Act (PIPEDA) in Canada.
- BE ASSERTIVE, NOT AGGRESSIVE. Practice calm responses in your mirror at home ahead of time, especially if you're someone who gets anxious or tends to avoid conflict. "Even if you're feeling overwhelmed and angry, use the same neutral tone you'd use to order a coffee," advised Dr. Rosen. Here are some examples of assertive statements Dr. Geraghty recommended:
 - >> "I realize you intended to make light of this matter, but what you said was hurtful." Make sure to use "and" not "but," since both points are valid.

- >> "Your perspective differs from mine. I understand what you're saying, and I'm not imagining things."
- >> "I know what's happening to my body. I live with this condition. I'm here today because I'm reaching out for help."
- ASK THE DOCTOR TO NOTE A REFUSAL FOR TESTING IN YOUR MEDICAL RECORD. Remember, though, that competent healthcare providers rely on evidence-based quidelines for diagnosing and treating diseases and conditions, and patients' requests may not align with approved protocols, advised Dr. Rosen. In these situations, she discusses why testing is not recommended and includes the decision together with the rationale in a patient's chart.
- FIND YOUR SUPPORT PEOPLE. Many health organizations have online support groups and in-person events. Collaborating with others experiencing the same health issues may help you find a better provider. Banding together can also raise awareness, lessen dismissive attitudes among healthcare providers, and may even lead to significant investments in health research.

For example, a group of long COVID survivors formed the Patient-Led Research Collaborative after connecting in the Slack group Body Politic. They conducted the first patient-reported survey on long COVID symptoms in April and May 2020 and published a report called What Does COVID-19 Recovery Actually Look Like.

Their report, based on 640 responses, was the first evidence that long COVID symptoms were not limited to respiratory issues and SARS-CoV-2 infection caused a constellation of 62 symptoms, including brain fog, trouble concentrating, memory loss, and dizziness. The report received extensive media coverage, including a September 2020 blog post by Dr. Frances Collins, MD, PhD, who was then Director of the National Institutes of Health (NIH). In February 2021, the NIH announced US\$1.15 billion in funding to study the long-term health consequences of COVID-19.

SEE A HEALTH OR PAIN PSYCHOLOGIST. Medical gaslighting itself can lead to anxiety and stress. A health or pain psychologist can support you and help you process any medical trauma you may have experienced.

Knowing how to spot medical gaslighting and how to counter it will enable you to advocate for yourself in conversations with your healthcare provider and help ensure you are receiving the best possible care.