



NOT BEING
ABLE TO
SLEEP IS NO
BADGE OF
HONOR.

Breaking the Silence on Sleep Debt

The Underserved and Overlooked Impact of Suffering with Chronic Insomnia

A Conversation with People Living with Chronic Insomnia in Canada



Mood Disorders Society of Canada
Société pour les troubles de l'humeur du Canada



Cracking open the conversation



Introduction

Elevating the Voice of People Living with Chronic Insomnia

Chronic insomnia, often dismissed and ignored, impacts the daily lives of those living with the condition and those closest to them in significant and diverse ways. This report aims to shed light on these variances, exploring how those living with chronic insomnia cope and the support systems they rely on, and their aspirations; to unearth the challenges they face but also the opportunities to realize their full potential.

By engaging directly with a small group of courageous and forthcoming individuals living with chronic insomnia we learned about their experiences. Through this report, we invite you to join us as we discover what frustrations and obstacles they face and the paths they carve through perseverance and resilience. They shared personal stories on their journey to diagnosis and how tasks can be a struggle when sleep is elusive. Initial reflections centred on how life could be so much better, describing many moments filled with discouragement and shame, leading them to wonder if they are to blame for their cyclical sleepless nights. All recounted a long and frustrating road to diagnosis and care with many speedbumps along the way.

Let's explore together what it means to live with chronic insomnia and how we can collectively contribute to a society that recognizes sleep differences, accommodates sleep divergence, strengthens a tailored path to care, and promotes sleep as an essential part of quality health.

Definition

In a recent study Dr. Charles M. Morin, published in Sleep Medicine, notes that chronic insomnia, is a condition that **affects one in six Canadians** and appears to be on the rise. Chronic Insomnia is characterized by difficulty falling or staying asleep and occurs at least three nights per week for at least three months.¹ It is categorized as a distinct sleep-wake disorder in the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5). Lack of quality sleep can negatively impact a person's quality of life, mental and physical health, and work performance. Good quality sleep can help give Canadians struggling with sleep time to recover overnight so that they wake up feeling refreshed.²



¹ Morin, Charles M., Lydi-Anne Vézina-Im, Si-Jing Chen, Hans Ivers, Colleen E. Carney, Jean-Philippe Chaput, Thien Thanh Dang-Vu, et al. 2024. "Prevalence of Insomnia and Use of Sleep Aids among Adults in Canada." Sleep Medicine 124 (December): 338–45. <https://doi.org/10.1016/j.sleep.2024.09.044>.

² Kamboj L, Ramos B, Haynes A, Sohi G, Yang H, Ling J, Barot P, Millson B, Amanullah S. A Retrospective Observational Study to Understand Medication Utilization and Lines of Treatment in Patients With Insomnia Disorder. J Clin Psychiatry. 2024 Sep 11;85(4):23m15015. doi: 10.4088/JCP.23m15015. PMID: 39265056.

10 Key Learnings

01

The brunt of chronic insomnia is substantial with **prolonged suffering** and **physical, psychological, emotional, employment and social consequences**. It affects the breadth of life's experiences and hampers individuals from realizing their full potential.

02

People living with chronic insomnia often **believe they cannot be the best versions of themselves** because they struggle to sleep and lack of sleep weighs on them heavily. This may sometimes fuel feelings of deficiency or inadequacy.

03

Chronic insomnia is underrecognized and **poor sleep is normalized** among Canadians diminishing the importance of sleeping soundly to recover and rejuvenate physically and mentally. People affected by chronic insomnia experience stigma and often suffer in silence, feeling helpless and isolated.

04

People living with chronic insomnia can **experience guilt**. They can feel sad when they realize they are not being wholly present, not being able to contribute to their full capacity or do enough to 'get better,' **they think they are letting friends and family down**.

05

It is quite common for people suffering with persistent sleeplessness to **delay seeking help, for fear of being judged** or surmising there is nothing that can be done. Sleep issues tend to "simmer" on the "back burner" particularly for **women in perimenopause and menopause** who may believe they "should be able to handle it on their own."

06

Health care professional **hesitance, dismissiveness and misinformation** about chronic insomnia recognition and management leads to delays in care for those individuals who seek treatment and support, referenced people living with chronic insomnia.

07

Though **recommended as a first-line treatment** for insomnia, patients believe few healthcare professionals inform patients about **CBT-I**.

08

There is a **fading belief** by people impacted by persistent sleeplessness **that treatments work** because of their past experiences of trying many treatment options and failing (sleep hygiene, melatonin, CBT-I, sedatives, etc.).

09

The **well-being and productivity** of people living with chronic insomnia are **significantly impacted**, impairing 'on the job' focus, cognitive function, energy, and mental health, potentially exacerbating depression, anxiety, or other mental illnesses.

10

The level of disability resulting from repeated sleepless nights is striking and costly for the **individual, workplace, and broader society**.



Approach

In a quiet Inn in southern Ontario, brave and engaged people impacted by chronic insomnia gathered to explore their journey to a better night's sleep. Eisai Limited, a human healthcare company (hhc), believes people living with chronic insomnia and their families come first, and they have a responsibility to listen to and learn from them. Together we collaboratively engaged directly with people living with insomnia to gain deeper empathy for their experiences. On November 22, 2024, members of the Eisai team had the privilege of convening a confidential conversation, both virtual and in-person with a group of six people living with chronic insomnia. Earlier an interview with another individual living with insomnia was pre-recorded providing an additional point of view. We were moved by their stories of day-to-day struggles, aspirations and resilience and will incorporate learnings from our dialogue, to ensure a breadth of perspectives inform this report, community education, public discourse, and our collective efforts.

The SECI model, developed by Ikujiro Nonaka and Hirotaka Takeuchi, is a framework for understanding and managing knowledge creation in organizations, involving four key processes: Socialization, Externalization, Combination, and Internalization. It was used to guide the engagement. Participants took part in a semi-structured roundtable dialogue, using an empathy map methodology to record observed and inferred information and draw out unexpected insights. We explored together what it means to live with chronic insomnia, the path to diagnosis, the impact of the condition and hopes for the future.

Dialogue Aims



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Insights and Themes



Chronic Insomnia Significantly Impacts Daily Life and Hinders People from Realizing Their Full Potential

More than next day fatigue, sleepiness caused by chronic insomnia impacts all aspects of daily living, reported dialogue participants. A common sentiment among respondents was how “pervasive insomnia is” experiencing daily consequences of their sleep deficit, it can be all encompassing affecting both day and night function. Negatively impacting relationships with family and friends, social outings, physical activity, mental health and work, poor sleep takes a costly toll. The Canadian Sleep Society reports chronic insomnia symptoms have significant immediate and long-term consequences affecting both our days and nights. Insomnia is responsible for exhausting symptoms such as fatigue, lower energy, lack of concentration, mood swings, increased risk of work and car accidents, as well as a long-term negative impact on health caused by sleep loss.

“Insomnia is possibly worse than when I coped with cancer, just to give you a perspective.”

“It is exhausting, everything I have to do to try to manage my insomnia.”

“Sleep issues have affected every facet of my life. Relationships, friends, relationships at work, everyday things like exercise. Exhausted most of the time I try to push myself to exercise but don’t have the energy. (I think people) perceive me as lazy in friendships and work. Fatigue causes a foggy brain, and I cannot articulate things well.”

As respondents conveyed how they first detected something ‘was wrong’, many described the countless nights lying awake, tossing, and turning and watching the clock as the minutes and hours ticked by. They described mounting fear and distress as the day wore on, several disclosing they are scared to go to bed, how the stress of their sleepless nights consumes them by day. As one participant

described, “It is a vicious cycle; poor sleep drags your life down and life drags down sleep.” Not being able to shut down their brain at night was a common complaint among participants.

“Insomnia is a loop of stress and anxiety...stress caused by anxiety over not being able to sleep.”

“I am always on the verge of tears, I feel beat up.”

“My fulltime job has become thinking about sleep.”

Feeling fatigued, anxious, and irritable can take a toll on relationships with psychosocial implications distancing spouses, children, and friends. As one contributor exclaimed, “I just say no now,” when referring to outings with friends who do not get why she does not wish to go out in the evenings or join her friends for a girls’ weekend away. Another raised a striking analogy depicting a hike with friends where she stated she was exhausted from her inability to sleep the night before - her friends acknowledged her lack of sleep and then proceeded to set a fast-paced hike that did not accommodate her lack of energy. She pondered “Would they have expected me to keep up without rest if I had a cast on my leg? Insomnia is an invisible handicap. If you let people know you only got 2.5 hours of sleep, they are usually empathetic, however, they quickly expect you to function and perform at the rate of a normal person.”

“Although my husband is very supportive... We would fight quite a bit because of work stress and tiredness; we were close to our marriage ending because I was tired all the time... we came up with a system where he asks me on a scale of 1 to 10 how much energy I have and the lower the score the more support he will give.”

“I am secretly jealous of how quickly my husband can fall asleep.”

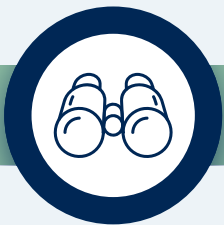


Turning our attention to what could be, for a moment participants imagined life sleeping soundly, with one respondent exclaiming, *"Could you imagine the type of person you could be if you got enough sleep?"* and another punctuating this statement with, *"If women were sleeping, we could run the world. (Referencing menopause) we're at the peak of our careers, making decent money and then many women are impacted by menopause and inability to sleep."* Envisioning the heights that could be achieved well rested, dialogue participants concur we need to do better, and we can do better to help people improve quality sleep and next day functioning.



KEY LEARNINGS

The brunt of chronic insomnia is substantial with prolonged suffering and physical, psychological, emotional, employment and social consequences. It affects the breadth of life's experiences and hampers individuals' from realizing their full potential. People who live with chronic insomnia want to live a normal life and not be *"dragged down"* by exhaustion.



UNEXPECTED INSIGHT

People living with insomnia often believe they cannot be the best versions of themselves because they struggle to sleep and lack of sleep weighs on them heavily. They may perceive themselves as deficient and others (work, friends, family) characterize them as weak, lazy, etc., only stoking internal feelings of inadequacy.



Functioning on Little Sleep Celebrated Like a Badge of Honor

We have all heard the old adage *"I can sleep when I'm dead."* This sentiment vividly symbolizes a societal norm that celebrates the ability to cope with a few hours' sleep. It is common for people who believe they operate with little sleep to wear their perceived need for little Zzzs like a badge of honor scrutinizing others that may need more as weak or lazy.

This fallacy fuels stigma and may result in people with insomnia suffering in silence. Society has normalized poor sleep and discounted the restorative power of sleep.

Among candid moments, dialogue participants shared feelings of guilt and shame for not being able to overcome their persistent sleeplessness and doing enough to improve their energy and general wellbeing. They expressed concerns that they are letting their loved ones down. They feel overwhelmed by navigating a haphazard path to sleep health distinguishing among myths, misinformation, and judgement of others. Forging ahead, pretending everything is ok while stifling a sense of helplessness, is not only tiring, but also isolating. Loneliness, sadness, and anger accompany wakeful nights, contributors explained.

"Social isolation, suffering in silence, it is truly the loneliest thing in the world."

"I have changed my world rather than conform to the world."

"I was up night, after night after night alone... I would watch Veronica Mars at 3:00 a.m."

"I just accepted my sleep issues; this is just the way it is."

The vicious cycle of sleeplessness can negatively affect both body and mind and yet studies show that few Canadians with insomnia seek medical attention, leaving them vulnerable to complications and longer-term health issues.

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"I don't mind asking for help but didn't think anybody could help."

"No one seems to want to help me, nobody offered solutions."

"My insomnia has been cyclical for 10 years."

"Sleep affects everything, I cannot lead a normal life... it is a struggle and it's annoying."



UNEXPECTED INSIGHT

People living with chronic insomnia experience guilt. They can feel sad when they realize they are not being wholly present, not being able to contribute to their full capacity or do enough to 'get better,' they think they are letting friends and family down.



KEY LEARNINGS

Chronic insomnia is underrecognized and poor sleep is normalized among Canadians diminishing the importance of sleeping soundly to recover and rejuvenate physically and mentally. People affected by chronic insomnia experience stigma and often suffer in silence, feeling helpless and isolated. They feel like they must push through sleepiness and brain fog to be able to engage in life and not be negatively judged by peers.



Delays, Disbelief and Dismissal

Social norms and beliefs that *"I have never been a good sleeper"* or *"I am wired differently"* impede people experiencing sleep disruption from seeking help. This coupled with disbelief by loved ones, *"My husband tells me it is all in my head"* and little validation by health care professionals, *"I was told to eat healthy and exercise,"* stalls clinical assessment and delays a clear diagnosis. Most participants disclosed they waited to consult a health care professional, not wanting to be judged and believing there was nothing that could be done *"It is just the way it is."* With one participant sharing, *"I took a long time before seeking help"* and another expressing, *"I had to hit rock bottom before getting help."* For some, once they decided to address their sleep issues they were met with hesitation and dismissiveness by their family doctor and/or specialist.

"My doctor rolled her eyes at me."

"I found better reception and care by doctors who treat holistically."



"I am persistent and persevered. I saw seventeen doctors over several years to treat my insomnia...I appreciated the doctors; each was great in their own way."

Surmising that a clear pathway to diagnosis is absent, most respondents did not receive a confirmatory insomnia diagnosis.

"I never received a diagnosis of insomnia from a clinician, but everyone in my life told me I was experiencing insomnia."



KEY LEARNINGS

It is quite common for people suffering with persistent sleeplessness to delay seeking help for fear of being judged or surmising there is nothing that can be done. Sleep issues tend to "simmer" on the "back burner" particularly for women in perimenopause and menopause who may believe they "should be able to handle it on their own." Studies show that few Canadians with insomnia seek medical attention promptly leaving them at risk of physical or mental health issues caused by poor quality sleep and impaired next day function.



UNEXPECTED INSIGHT

Health care professional hesitance, dismissiveness and misinformation about insomnia recognition and management leads to delays in care for those individuals who seek treatment and support reported patients. Inferring, lack of insomnia-specific expertise, patient volume and time pressures compounds assessment deferrals and unvalidated patient concerns.

For some contributors there were lengthy delays between medical referrals, noting it seemed they must pass through or 'fail' certain steps before advancing to the next, such as securing an appointment at a sleep clinic seemingly to rule out sleep apnea or restless leg syndrome. Similarly, several participants were not informed of available cognitive behavioral therapy (CBT-I) for insomnia with some stumbling across it through friends or being referred from the sleep clinic. Providing some relief, a couple of contributors found CBT-I to be beneficial and wished they had learned of its application earlier.

"I heard about CBT-I through a friend; no doctor recommended it. Through CBT-I I realized that daytime stress and anxiety about sleep caused and maintained my insomnia...worrying and stressing about sleep...I wish I knew about CBT-I 15 years ago."

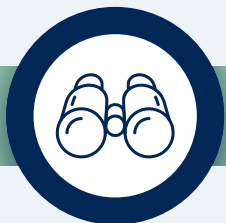
"I did an online 6-week CBT-I program to retrain my brain and had some success with it but as soon as I get stressed it stops working."

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KEY LEARNINGS

Few healthcare professionals recommend CBT-I. The quality of CBT-I differs depending on the clinician who manages it. Though recommended as a first-line treatment for insomnia, people living with insomnia believe few healthcare professionals inform patients about CBT-I.



UNEXPECTED INSIGHT

CBT-I is not a “one size fits all” treatment. Clinicians and insurance providers try to put patients in broad categories, neglecting the unique features of each patient’s experience.



Trial and Error Treatment Reinforces Helplessness

The resolve and tenacity of the dialogue participants during their path to care uncovered the prevalence of trial-and-error coping strategies and therapies present in chronic insomnia clinical practice. Those who received support and improved their sleep health shared tales of persistent cycling between and among doctors, clinics, sleep hygiene, medicines, and

cognitive behavioral therapies. This signals it is not ‘one size fits all’ or a ‘magic bullet’ that improves insomnia but rather a tailored approach to the unique needs, circadian rhythm, lifestyle, and health profile of each individual.

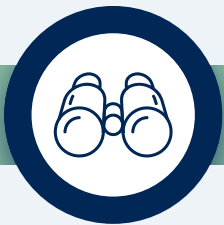
“There isn’t one thing that was going to fix my sleep, it was pieces of a puzzle, lots of little things and ditching what didn’t work.”

We were surprised by the lack of knowledge and support there seems to be in the healthcare system for insomnia and were struck by how underappreciated and underserved the needs of the people we spoke to were. It appears chronic insomnia is not considered a discrete medical concern by health care providers. Rather it is viewed as a symptom of another condition, medicine or precipitating event contributing to diminished clinical attention.

A 2018 article in *Psychiatric Practice*, ‘Review of Reconsidering Insomnia as a Disorder rather than Just a Symptom’ notes insomnia is frequently overlooked as a distinct condition instead correlated with other comorbidities (like anxiety and depression).³ This misperception leads to insomnia being treated only as a symptom of other issues, rather than as a specific condition that warrants targeted care. As a result, individuals may not receive the focused treatment they need (either as a standalone condition or a symptom within a condition), which can prolong their sleep difficulties and exacerbate overall health challenges.

Further, there is persistent hesitation among physicians and patients about the safety effects of long-term sedative-hypnotic use and fear of addiction. This is compounded by a lack of familiarity with new non-sedative sleep medicines that provide safe and effective long-term options for people experiencing chronic insomnia.

³ Benca, Ruth M., and Daniel J. Buysse. 2018. Review of Reconsidering Insomnia as a Disorder rather than Just a Symptom in *Psychiatric Practice*. Edited by Physicians Postgraduate Press, Inc. The Journal of Clinical Psychiatry. <https://www.psychiatrist.com/jcp/insomnia-in-psychiatry-not-just-a-symptom/>.



UNEXPECTED INSIGHT

There is fading belief by people impacted by persistent sleeplessness that treatments work because of their past experiences of trying many treatment options and failing (sleep hygiene, melatonin, CBT-I, sedatives, etc.).

Further, a publication in the *Harvard Business Review*, “Sleep Well, Lead Better,” states science challenges the belief that the “12-hour workday” is the key to success, concluding, high achievers perform best when they prioritize restful sleep, proving that efficiency thrives with rest, not “endless grind.”⁵

Half of the respondents we spoke to reported having to take time away from work because of their insomnia, escalating from occasional absences to sick leave, short and long-term disability.

“I am thankful for the short term and now long-term disability. My employer does not have compassion for workers.”



Overlooked and Minimized by Employers

Almost all contributors conveyed the significant impact chronic insomnia had on their jobs, describing periods of absenteeism, presenteeism, lapses in concentration and decreased productivity. Similarly, most recount little effort by employers to make accommodations, work to understand their needs or empathize with their challenges.

“My employer was not receptive or supportive...if you can’t get to work by 8:00 a.m. you are seen as lazy.”

“My employer was not tolerant or understanding of my health issues, I was hesitant to disclose sleep issues because they do not care.”

Some participants felt they would be more productive if they worked from 10:00 a.m. to 6:00 p.m., with a later start they could be more flexible with sleep strategies.

A study by Jean-Philippe Caput, the “Economic Burden of Insomnia Symptoms in Canada,” cites insomnia costs Canadians \$1.9 billion every year due to its impact on work and productivity.⁴

4 Chaput, Jean-Philippe, et al. “Economic Burden of Insomnia Symptoms in Canada.” *Sleep Health*, vol. 9, no. 2, 1 Apr. 2023, pp. 185–189, www.sciencedirect.com/science/article/abs/pii/S2352721822001784, <https://doi.org/10.1016/j.sleh.2022.09.010>. Accessed 30 Nov. 2023.

5 Barnes, Christopher M. “Sleep Well, Lead Better.” *Harvard Business Review*, 1 Sept. 2018, hbr.org/2018/09/sleep-well-lead-better.



KEY LEARNINGS

The well-being and productivity of people living with chronic insomnia are significantly impacted, impairing ‘on the job’ focus, cognitive function, energy, and mental health, potentially exacerbating depression, anxiety, or other mental illnesses.



UNEXPECTED INSIGHT

The level of disability resulting from repeated sleepless nights is striking and costly for the individual, workplace, and broader society.

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Conclusion

Navigating the Way Forward

This report, rich with insights and personal stories, offers a window into the often hidden world of those living with chronic insomnia. Our journey through these pages reveals five key takeaways that are vital for shaping a society that recognizes the importance of quality sleep and the impact persistent sleeplessness has on families, workplaces, and communities.



Acknowledge the Seriousness of Chronic Insomnia

- Chronic insomnia is substantial with prolonged suffering and physical, emotional, employment and social consequences. Poor sleep affects next day function and should be taken seriously by healthcare professionals and employers. It should be recognized as a distinct medical condition that needs to be addressed. Persistent sleep issues affect more than just a person's rest, they can raise the risk of other serious health problems, including type 2 diabetes, heart disease, dementia and mood disorders like anxiety and depression.

Break the Silence to Tackle Stigma

- Address feelings of isolation and inadequacy by meeting people living with insomnia 'where they are at' with compassion and support. Bolster awareness and acceptance of people's unique sleep needs, consequences of disrupted sleep and divergent lifestyles to make insomnia visible and relatable. Help people impacted by insomnia to reach their full potential and know they 'are enough.'

Encourage a Clear Care Pathway

- The path to insomnia detection, diagnosis and care requires perseverance and resilience. Plagued by delays and dismissal by health care professionals, people experiencing persistent sleeplessness are hesitant to seek support and often feel helpless in the face of judgement and clinical reticence. Boosting sleep training and education among primary care providers could be the first step in ensuring a capable and accessible patient referral pathway to treatment and support.

Tailor Support & Care

- A 'one size fits all' approach to relentless sleep disruption is not adequate. Considering the diverse unmet needs of people experiencing sleeplessness enables care providers, families, and peers to tailor sleep strategies, treatment and support to the unique symptoms and consequences of each individual. We call on decision-makers to ensure people experiencing chronic insomnia have evidence-informed options to treat and manage their condition.

Empower People to Seek Help

- Chronic insomnia can be lonely and dark. People living with sleeplessness need to know they are not alone, there is hope. Connecting people impacted by chronic insomnia through peer support, education and resources can lift spirits, unearth solutions, and enable a better night's sleep.

Together, we can champion policies and practices that recognize the struggles faced by people experiencing chronic insomnia. We can elevate the importance of getting good quality sleep as key to feeling energized the next day, instrumental to an individual's overall well-being and productivity. Prioritizing a good night's rest can lead to improved focus, stronger cognitive function, and better mental health. There is more we can do.

