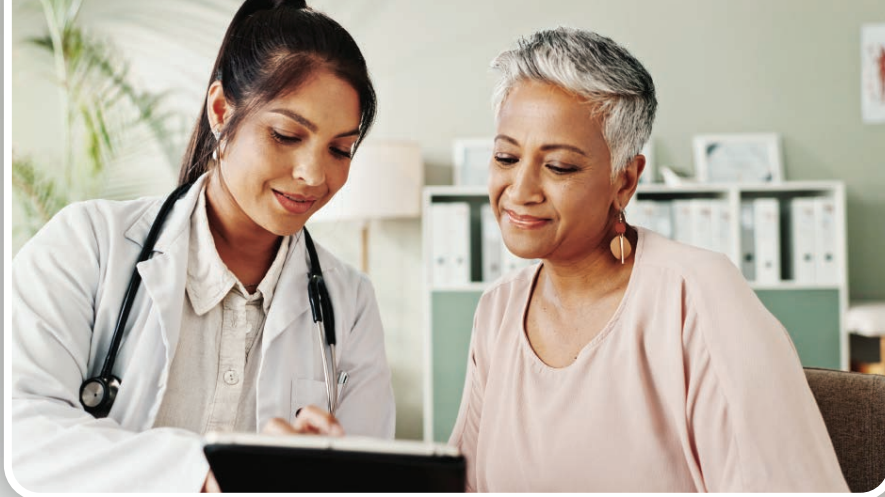


Untangling the Knot of POOR SLEEP

By Allan McCarthy

Features of good health are as varied as individual faces, but the load bearing cords of good diet, proper exercise and healthy sleep are essential for everyone. With poor sleep, doctors find many source strands pulling into a tight, difficult to unravel cluster.





Being an amputee means sleep can be even more problematic, as many common aggravating factors come with limb loss. To unwind this knot successfully, the sleepless often need to turn to more than one specialist for help.

Alarming, insomnia is quite common. “About a quarter of the population has insomnia, and in the amputee population it is higher,” tells Dr. Mark I. Boulos, Staff Neurologist at Sunnybrook Health Sciences Centre in Toronto and sleep science researcher. “Statistically, over 50% of amputees suffer from insomnia, almost double that of the general community.”

Dr. Boulos explains that insomnia in the amputee population is higher because of a number of factors, and there are specialists who can address each of these issues.

“There are some well-established therapies right now – including medications, and also something called Cognitive Behavioural Therapy for Insomnia (CBT-I),” offers Dr. Boulos. “If one became an amputee through trauma, CBT-I may be beneficial for managing some of the non-sleep issues as well... such as anxiety and depression.”

For someone who might lie in bed for a really long time and not fall asleep and makes up for it by staying in bed late, CBT-I restricts the amount of time in bed to, say seven or eight hours. Another component of CBT-I is breaking negative associations between the sleep

environment and wakefulness.

“Your bed is for sleep,” Dr. Boulos emphasizes. “It’s not for looking at the clock. It’s not for worrying. We need to basically break the cycle for someone just lying in bed. Don’t bring your work – like your laptop – into bed. That’s for a different space in the house.”

Another CBT-I component is sleep hygiene. “Create a dark, quiet environment, a good routine,” he says. “This therapy also works to change automatic unhealthy negative thoughts like repeating, ‘I can never sleep’. Therapists teach people how to relax their mind and prepare for sleep. There are some CBT-I apps available too.”

Proper rest is essential for physical and mental health, facilitating heart function, sound learning and good memory, aiding our immune system and metabolism, and more. It’s complicated with early risers,

late-night sleepers and short sleepers (possibly due to genetics) and with sleep patterns changing as we age. Yet it is vital, as sleep deprivation is linked with heart disease, stroke, anxiety, diabetes, sepsis, high blood pressure and even car accidents.

Issues that may affect an amputee’s sleep are commonplace: chronic pain, anxiety, altered body representation, depression, and Restless Legs Syndrome. Typically, the psychological and physical trauma of amputation is often linked to unsettled sleep for amputees.

Higher levels of anxiety, negative thoughts, and feelings of insecurity are widespread with amputees, which all contribute to sleeplessness. Even in the phantom limb, amputees can experience symptoms that imitate Restless Legs Syndrome, a sensation that worsens in the evening or overnight. Amputees might also have to deal with neuroplastic changes in the brain after amputation which can influence body perception and sleep patterns. Ongoing research is adding informative data about these causes and bringing new treatments.

Dr. Boulos shares that there are medications which help with insomnia as well. “Usually you will use both, CBT-I and medication. Dual Orexin Receptor Antagonist (DORA) drugs came out recently and work very well, but they can be habit forming. They help chronic insomnia by changing the

COGNITIVE BEHAVIOURAL THERAPY



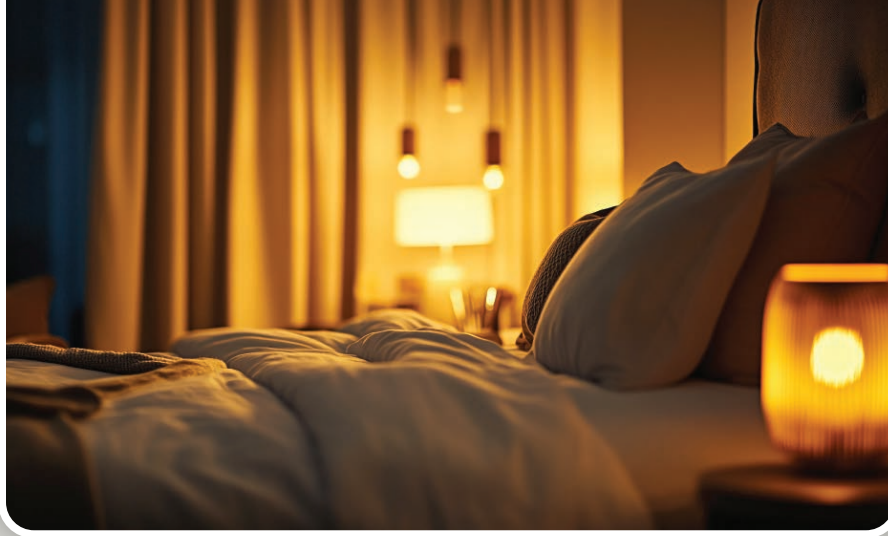
Thoughts



Feelings



Behaviours



pathways that give rise to insomnia. It works over time and can be beneficial in the long run.”

Sleep issues are unique to each individual and patients might need to see a specialist about an underlying problem as well as learning good sleeping skills.

“We always screen for everything, all disorders,” states Dr. Boulos. “If someone is just having a hard time sleeping, we refer them to a sleep specialist for a sleep study. ‘Do they have an underlying sleep problem?’ This guides their treatment, for example, chronic pain, sleep apnea, Restless Legs Syndrome or insomnia. Pain is at the forefront for many individuals, and we try to optimize pain management. Sleep apnea, a period during which breathing stops or is markedly reduced, is common. Amputation by itself does not increase sleep apnea, but comorbidities such as diabetes could increase that risk.”

Many physical problems can ruin sleep but sometimes it can be a mental health issue. “If an amputee is suffering from PTSD or nightmares,” says Dr. Boulos, “we take a look at the source. ‘What is the underlying cause of this person’s sleep disturbance?’ Because of the trauma, a psychologist might be the best route.”

Dr. Nicole Vincent is a Registered Psychologist at the Pain Management Unit of Nova Scotia Health in Halifax. “Keys to good sleep health,” she describes,

“usually involve approaches that balance three main systems: sleeping at the right time (matching our internal ‘body clock’), using enough energy and wakefulness so that there’s a need for sleep (our ‘sleep drive’), and learning ways to shift out of a high alert state (our ‘stress response’) so that the body can feel safe to rest and sleep. We have more restorative deep sleep when these three systems are working together.” Dr. Vincent adds that “Often, getting to the bottom of ongoing sleep problems will mean exploring how those three systems are being disrupted and finding ways to realign them.”

The study of sleep is both illuminating and enigmatic, as there is a mystery to it. Dr. Vincent reminds that we have to remember that sleep is a biological process. We don’t have control over whether it happens, but we can provide the right conditions to allow it to happen. “Just like our digestive system, we don’t have control over when our body chooses to metabolize food, but we wouldn’t eat rocks and expect it to work well,” she analogizes. “So, we put our efforts into providing the right conditions and let

the body do the rest (sleep or not sleep).

“Sleep problems don’t need to be a life sentence,” insists Dr. Vincent. “There are ways to get help. For example, if medication is contributing to disrupted sleep, it would be worth talking to a doctor or pharmacist about the timing of the medication or alternative options. A physiotherapist can help find safe and effective ways to move, stretch, and exercise during the day. An occupational therapist can recommend sleep positioning and bedtime equipment like body pillows or wedges to reduce posture-related pain and discomfort. If trauma or stress experiences are contributing to nighttime wakefulness, there could be a benefit in meeting with a therapist trained in trauma-focused therapy like a psychologist, counsellor, or social worker with specialized training.”

When chronic nightmares are a problem, Dr. Vincent advises finding a therapist trained in Cognitive Behavioural Therapy for Nightmares (CBT-N). If ongoing pain is disrupting sleep, it would be worth connecting with a local pain self-management service in your area or sourcing some online resources (e.g. poweroverpain.ca). “Activity Pacing” is another pain management strategy for frequent pain flare-ups or when pain intensifies when at rest.



Developing good new habits can be essential as well. Dr. Vincent can testify to the fact that amputees often report being very tired at bedtime but can't fall asleep because of busy minds or pain or both. "People with limb loss carry a high mental load just to navigate everyday life," understands Dr. Vincent. "They are faced with everyday planning and preparing, problem solving, and advocating for their needs more than the average person. This can be stressful and mentally exhausting. The brain is working hard and needs time to settle from this high alert state."

She advises that it is essential to implement a calming bedtime routine, maybe even an hour before lights out, to help reassure both body and mind that it's safe to rest. "The busy mind needs some convincing evidence that it can go on break. Routines are important, like dimming the lights, reducing sounds, brushing your teeth, reading, or some gentle stretching," she offers. She adds that "incorporating mindfulness exercises or relaxation practices, such as deep breathing, visualization or muscle relaxing, will help both the busy mind and with pain."

Yet, some sleep truths sound counter-intuitive. "Even if the night goes poorly for sleep, it's still important to stick with a regular wake-up time," counsels Dr. Vincent. "This helps keep the sleep drive and internal body clock in sync and optimizes deep restorative sleep," she explains.

But a regular wake-up time can be tricky, because our instincts tell us that we must make up for the lost sleep, to sleep in, or to nap. "This is where our instincts betray us when it comes to healthy sleep practices," she acknowledges. "The average person needs about 15 hours of wakefulness for our sleep drive to kick in. So, if we try to make up for a bad night's sleep by sleeping in later or sleeping during

the daytime, and we still aim to go to sleep at the same time that night, it's not going to work well. This is the 'feeding our digestive system rocks' analogy."

But as many amputees know, sometimes a nap is needed to make it through some days. Even so, Dr. Vincent still stresses the importance of ensuring that you build up your sleep drive and to do that, delay your regular bedtime by the amount of time that you slept during the day. "So, if I take a one-hour nap at 2:00 p.m., to build my sleep drive I need to plan to go to bed at 11:30 p.m. instead of my regular 10:30 p.m. bedtime" she illustrates.

"But watch out," she cautions. "Your internal body clock will try to convince you that you're tired enough for the regular 10:30 bedtime, but your sleep drive won't be sufficient to help you get into a deep sleep. Without the strong sleep drive, your sleep might be light, non-restorative, and easily disrupted by other stimuli like sounds, pain, hunger, or bathroom needs."

Dr. Vincent believes amputees should not get down on themselves for facing this struggle, a battle that even academics want to understand better. More research is needed on how sleep is impacted by limb loss and what might be the best treatment approaches. "It's important that people with limb loss understand that struggling with sleep doesn't mean that you've failed – it means your body has been through a lot! Sleep problems are very common with limb loss, and it will take time to adapt, but you will adapt. Offer yourself patience, support and kind words. Practicing this self-compassion can

be empowering and therapeutic. And you don't have to do this alone; there are professionals that can help."

This fight can be a marathon, not a sprint, and there are many resources to tap into to help. Dr. Vincent recommends mysleepwell.ca as a reliable online resource. Also, the poweroverpain.ca website is a fantastic free resource with live and recorded workshops from clinicians across Canada along with self-guided courses, videos, self-assessments and more.



Dr. Boulos deems that people should not be embarrassed by sleep problems. Instead, he encourages all to be proactive in seeking help. "If you're having trouble sleeping, reach out for help early on. Avoid a vicious cycle of worsening sleep. There is no shame. It might mean reaching out to more than one specialist, as the problem can be inter-connected."

The complications of sleep are a testament to the complexity and the beauty of the brain. That said, there are a lot of people who are available to help, even other amputees with similar symptoms. There is no shame in reaching out.