LIFE AFTER DIAGNOSIS

Live your best life

Improving overall health and wellbeing and how that can have a positive impact on managing Idiopathic Hypersomnia symptoms

Part Three

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This is the final part of a three part presentation and discussion on 'Improving overall health and wellbeing and how that can have a positive impact on managing Idiopathic Hypersomnia symptoms'.

In part one of our series, we delved into the important topic of self-care. We discussed what that means and how it can positively impact your wellbeing. We also explored the concept of acceptance, which can be a transformative milestone you may not even realise you need to reach. We discussed the effects of stress and effective methods for minimising its impact with practical tips on achieving that goal.

In part two of our series we explored healthy eating, including hydration and how making different choices can have a positive impact on our symptoms and our ability to manage them. Additionally, we looked at medication management and discussed ways to harness its full potential.

Our third session focuses on sleep, the important role of morning sunlight including the impact of melatonin and cortisol, the consequences of Vitamin D deficiency and also physical activity and the benefits of Mindful Movement.

Links to all 3 of the pdf's that relate to this series can be found here:
https://www.hypersomnolenceaustralia.org.au/single-post/life-after-diagnosis-live-your-best-life

DISCLAIMER - The content of this presentation and our Living with IH discussions is for information purposes only and is not a substitute for professional medical advice. Any concerns you may have about your health should be discussed with your doctor.

Improving overall health & wellbeing can have a positive impact on the severity of our symptoms and how we are able to manage them.

I started part one of this series by saying that I know making lifestyle changes isn't easy. I acknowledge that everyone is different, including the severity of our symptoms, our response to medication and the level of support we may receive. I also acknowledge that lifestyle changes can not only be difficult to initiate, they are often difficult to maintain; it can seem impossible. Even the thought of making changes can be overwhelming - I know because I spent many years thinking that way myself.

I have, through years of research, trial and error, identified some things that I know can make symptoms worse or certainly more difficult to manage. **By sharing what has proven effective for me and others, I aim to inspire hope.** I believe that, although it's not easy, it is possible to optimise the positive potential of living with Idiopathic Hypersomnia (IH).

Two important things first.

Firstly, I didn't just stumble upon the changes I have made. I've spent many years researching and learning about sleep disorders, health and wellbeing. I have listened to many people with sleep disorders and I have spoken to numerous doctors, researchers and health professionals.

But I'm not a doctor, so please speak to your doctor/s before implementing any changes to your lifestyle that will impact your health. Also, because making lifestyle changes isn't easy, you may need the assistance of a specialist therapist. If necessary, ask your doctor for a referral to one of these health care professionals.

And secondly, I am the happiest and healthiest I have ever been but I still have Idiopathic Hypersomnia (IH) with long sleep, sleep inertia and sleep drunkenness. Making lifestyle changes has not magically made my IH symptoms disappear. Research suggests IH reaches its peak in young adulthood and generally remains stable, that is, it doesn't get worse.

So, lets recap - why do people find some days, weeks or even months more difficult than others?

Aside from the people who have other medical and/or psychological conditions which can account for or contribute to their symptoms, **the most likely reason IH can appear to have worsened is because the person's ability to manage their symptoms is compromised by other external factors they are not taking into consideration.** For example, in part one we talked about the impact that chronic stress can have on us, particularly our cognitive ability. Other factors include: what we eat; our level of physical activity; sleeping patterns and hydration.

Why can Idiopathic Hypersomnia appear to have worsened?

SOME CONTRIBUTING FACTORS

- Chronic stress can have a huge impact on cognitive function
- People with chronic illness are at a greater risk of developing depression and anxiety
- Tolerance to IH medication
- Poor diet - particularly one that is high in sugar/carbohydrates
- Other medical or mental health conditions we may not be aware of or may not be taking into consideration
- Inflammation

Your ability to manage your symptoms can be compromised by other factors you may not be taking into consideration

I understand how challenging it can be to establish positive habits when your brain is in a constant fog and the urge to sleep is overpowering. Getting my brain to wake up every morning is the hardest thing I do every day. So, sustaining positive habits is definitely an ongoing process for me. I have good and bad days. In fact, some days are a total write-off for me. The key is not to give up on yourself. I acknowledge that it's okay to start fresh the next day. If you find yourself in a similar situation, be kind to yourself and allow the time you need to regroup before trying again.

Image by The Latest Kate

Lifestyle changes are behaviour modifications or habit changes that encourage positive changes in your life.

Making positive changes can create lasting effects on your personal wellbeing. The foods you eat, the amount of sleep you get and your exercise habits can all influence your weight, hormonal health, level of pain, inflammation and impact the severity of your IH symptoms and your ability to manage them.

Lifestyle changes that can help manage IH symptoms include:

- Adequate Sleep
- Healthy Eating
- Physical Activity
- Stress Management
- Hydration Habits
- Healthy Exposure to Sunlight

Adequate sleep

While it may be tempting to try to use medication to enable you to participate in life more, it's important to remember that people with IH generally do not operate very well on less sleep (less than they are used to).

You may get away with sleeping as much as an average person (7-9 hours) for a day or so; however, doing this for more than 2-3 consecutive days is likely to catch up with you and result in a 'crash'. Many people who have learnt how to best manage their IH symptoms generally still sleep excessively, they just sleep a little less excessively. Despite medication, they may still sleep 10-11 hours most nights of the week and even more on days they allow themselves to go 'med-free'. Some people will also have daytime naps too.

Prioritise sleep

Your sleep environment and routine impact your sleep health. Find a routine that works best for you, then stick to it. If naps help, schedule them into your day.

HEALTHY SLEEP PRACTICES

- **Bedroom environment:** Make sure your bedroom is quiet, dark, cool, and relaxing.
- **Wind down:** Develop a relaxing bedtime routine to signal to your body it's time to wind down.
- **Be consistent:** Go to bed and wake up at the same time each day, even on weekends.
- **Power down:** Remove electronic devices such as TVs, computers, and phones from the bedroom.
- **Light meals:** Avoid heavy meals within 2 hours of bedtime.
- **Limit stimulants:** Avoid caffeine and alcohol before bed.
- **Exercise regularly:** But avoid strenuous activity right before bed.
- **Sunlight:** Expose yourself to sunlight during the day.

Familiarise yourself with healthy sleep hygiene practices then work them into your daily routine. Understand how light, especially natural sunlight, impacts your circadian rhythm and use it to your advantage.

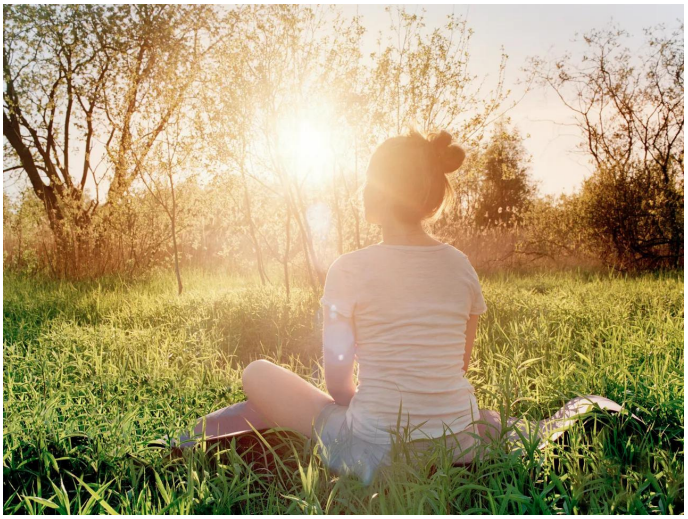
Healthy Exposure to Sunlight

Like sleep, diet and exercise, light, particularly natural sunlight, directly impacts our mood, sleep quality, ability to wake up and focus, hormone levels, immune system and ability to cope with stress.

Exposure to natural sunlight in the morning also helps regulate our circadian rhythm, often referred to as the body's internal clock. Our circadian rhythm is the body's mechanism for anticipating when to wake up and go to sleep. It also manages other biological processes like hunger and body temperature.

Morning sunlight exposure helps regulate the production of melatonin, a hormone responsible for sleepiness. Natural light exposure in the morning suppresses melatonin production, signaling to your body that it's time to wake up and be alert. Viewing sunlight within the first hours of waking (the sooner the better) also increases the release of cortisol. A morning spike in cortisol will positively influence your immune system, metabolism and ability to focus during the day and prepares the body for sleep later that night. It also boosts serotonin which contributes to feelings of wellbeing so it's a good idea to get out in the sunlight again in the early afternoon or lunchtime (this can help with the afternoon crash).

As soon as possible after you wake up in the morning go outside for 5-10 minutes. If you have time to do more that's even better. It can be a great opportunity to do some light exercise. I generally take a walk around my backyard, but some people do some yoga or stretching. If it's an overcast day, there is still enough sunlight to trigger positive effects. You'll just need to increase the time outside to at least 15-20 minutes. If it's dark when you wake up or if the weather prevents you from going outside, turn on as many bright indoor artificial lights as possible then get outside as soon as the sun is out.



You can wear your glasses or contact lens when enjoying the morning sun. However, don't wear sunglasses and blue light blockers, as they will decrease the benefits. Face the sun, but never look directly at it and blink as needed to keep your eyes hydrated and protected. Note: Looking at sunlight through windows won't work because they filter out important light waves.

As the evening approaches, follow the natural rhythm of the sun by dimming your environment. Turn off harsh overhead lights, and opt for softer lighting that lamps can provide. And, don't forget to dim your computer and phone screen as well. Apple and Android phones have night mode features you can turn on.

Sunlight is not only important for regulating our circadian rhythm. More than 1 in every 3 Australian adults has a mild, moderate or severe vitamin D deficiency. Most cases of vitamin D deficiency are due to lack of outdoor sun exposure.

Vitamin D deficiency is linked to fatigue, cognitive impairment and other symptoms including headache, musculoskeletal pain and weakness, and depression. All of these symptoms can exacerbate IH symptoms or make them more difficult to manage. Vitamin D deficiency can also affect bone growth in children and cause loss of bone density, osteoporosis, and broken bones in the older population.

Vitamin D is easy to absorb through incidental exposure to sunlight but if you sleep excessively and it takes an extended period to wake up and be functional everyday, chances are, you don't get as much exposure to sunlight as a regular person does.

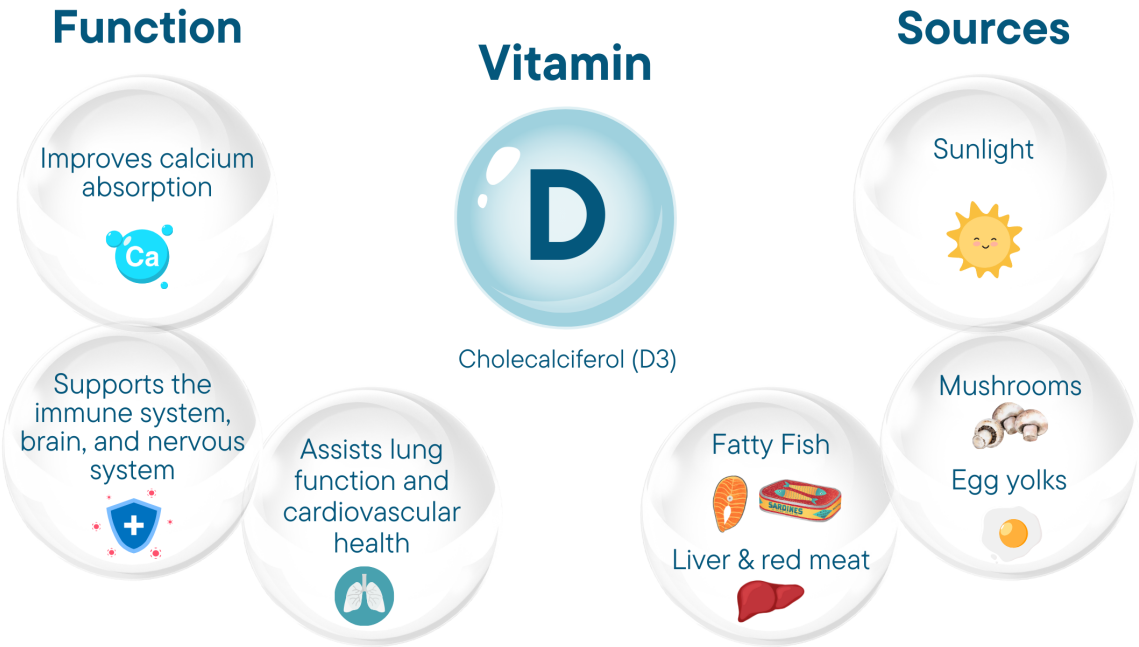
If you aim to get some direct sunlight within a few hours of waking up (the sooner the better) and again in the early afternoon or lunchtime, you will avoid the negative effects of vitamin D deficiency.

Vitamin D can be found naturally in some foods. The best food sources of vitamin D are oily fish, including salmon, mackerel, and sardines. Other sources include mushrooms (the only food source of vitamin D which is suitable for vegetarians and vegans), egg yolks, fatty fish (salmon, mackerel, and sardines), red meat, and liver. Vitamin D is added to some foods too eg: milk. *Steer clear of fortified margarine. Margarine contains seed oils - refer to part 2 for more information.*

Talk to your doctor if you are struggling to get enough vitamin D. They may suggest taking a vitamin D supplement.

Other benefits of sunlight - Hormones

Thus far, I have focused on viewing sunlight, but there is also an advantage to getting sunlight on your skin. Studies have shown that 30 minutes of afternoon sunlight on bare skin increased testosterone, estrogen, mood and libido in both men and women. For optimal exposure, consider wearing clothing that allows sunlight to reach your arms and legs. Take care in summer – don't allow the sun to burn your skin.



Physical Activity

While the suggestion that physical activity might help you may be enough to make you scream, first hear me out...

In 2016, I decided to take a look at the risks associated with prolonged time in bed (being horizontal) and excessive sleep and I was surprised at what I found. My findings revealed a clear need for more research into the causes and treatment of IH due to the profound impact of its symptoms.

Sleep is a basic human need, much like eating and drinking, and is crucial to our overall health and wellbeing. The average person will spend up to one-third of their life asleep. Research shows that people with IH sleep a lot more than that - some of them sleep twice that much.

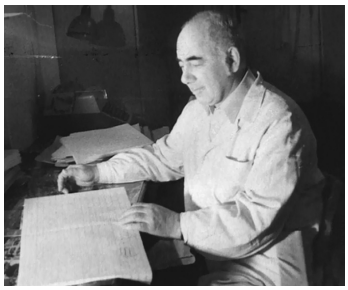
My question was, "Is sleeping more than normal good for you?" The short answer is, no. Consistently sleeping for more than nine hours a day has a negative impact on physiological, psychological and cognitive functions. We also know that long periods of bed rest (in the case of IH that would be time spent asleep and trying to wake up) also has detrimental effects on the body [1].

In Bedřich Roth's extensive studies on IH [2] he noted that some of his patients had symptoms other than excessive sleep, sleepiness and sleep drunkenness. They included increased heart rate, gastrointestinal/digestive issues, postural (orthostatic) hypotension, fainting episodes (syncope), depression, anxiety, irritability, diminished libido in men, peripheral vascular symptoms such as cold hands and feet, difficulty with body temperature and cognitive dysfunction.

More recent studies [3] show that people with idiopathic hypersomnia become tired and sleepy in both over and under stimulating conditions "*... given that the patients feel tired in the presence of over-stimulating conditions (a loud environment, strangers and flashing light), and feel sleepy in under-stimulating conditions (darkness, left alone or listening to a conversation). Basically, it appears in this study that the patients would feel all right only during holidays, in a nice landscape with sun and friends. One may wonder if they use, in this case, the motivation/mood system to stay awake rather than the usual arousal systems*".

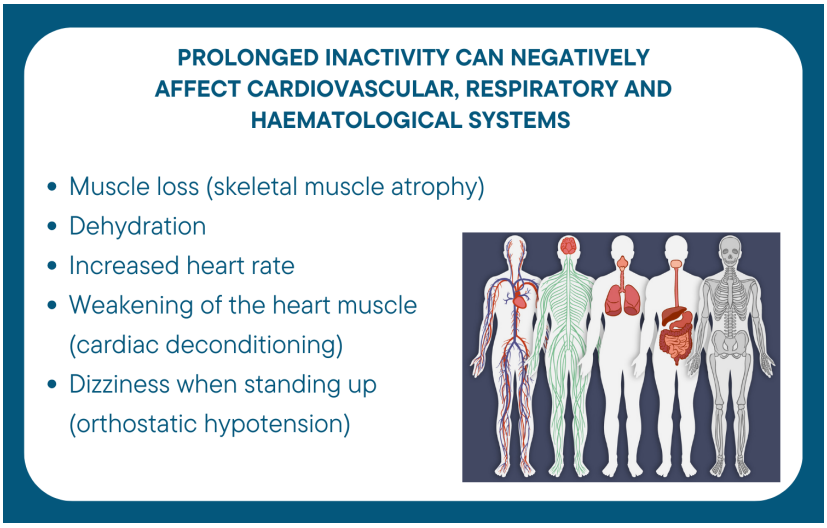
This would suggest if people with IH are constantly relying on their motivation/mood system to stay awake rather than the usual arousal systems then depression, anxiety and associated psychological difficulties including irritability, emotional and mental lability and fatigability would be an obvious consequence.

While none of the other symptoms (mentioned above) were attributed to the etiology *(the cause or origin of disease)* of IH, it was reported that they would in most cases contribute to the burden of the disease. What I found interesting is, all of those symptoms that Roth identified in his IH patients are in fact symptoms that are experienced by people who are bedridden for long periods.



Who is Bedrich Roth?
IH was identified and defined by Czech neurologist Bedrich Roth more than 60 years ago starting with his first monograph; "Narcolepsy and hypersomnia from the aspect of physiology of sleep (Narkolepsie a Hypersomnie S. Hlediska Fysiologie Spanku – 1957)". Roth's years of extensive research that led to his description of idiopathic hypersomnia as a separate disease entity was accepted and included in the first ICSD (International Classification of Sleep Disorders), the Diagnostic Classification of Sleep and Arousal Disorders in 1979. Learn more about Roth here and here.

Researchers from Swansea University wrote a very interesting three part series on the physiological and psychological effects of bedrest. The first article [1] discussed what happens to the cardiovascular, respiratory and haematological systems which includes disruption to water balance, skeletal muscle atrophy (muscle wasting), dehydration, increased heart rate, cardiac deconditioning (weakening of the heart muscles) and postural (orthostatic) hypotension.



Because the major role of the cardiovascular, respiratory and haematological systems is to deliver oxygen and nutrients to all areas of the body, the detrimental effects of bedrest have a negative impact on every organ system.

The second and third [4,5] articles explore how inactivity specifically affects the digestive, endocrine, renal, reproductive, nervous, musculoskeletal and immune systems, skin and self-perception. They also found that it can disrupt the body's circadian rhythms, leaving you more prone to illness and deprives you of sunlight exposure, which can compromise your immune system.

As well as the physiological effects the three part series also discusses the psychological effects of prolonged bedrest.

People with IH have little to no control over the amount they sleep. It is common for them to miss important family events, work opportunities, or even just simple things like being able to read a book, walk the dog or enjoy a day in the sunshine. This causes people with IH an enormous amount of distress and often causes family and friends to become resentful. The absence of physical and mental engagement may result in feelings of loneliness and isolation.

"*Several studies have reported that long periods of bedrest have negative psychological effects on individuals and their family. These include symptoms of depression, anxiety, forgetfulness and confusion. These symptoms could be partly due to the lack of personal control imposed by bedrest…*

A person's lack of control over their environment has long been linked to increased levels of stress and the release of stress hormones such as corticosteroids… It has been suggested that control, or the lack of it, directly influences health through physiological changes..

Prolonged bedrest often deprives patients of environmental and social stimulation, which may lead to increased anxiety, confusion and depression"[1]

In the research referred to above [3] it is suggested that people with IH may use "*the motivation / mood system to stay awake rather than the usual arousal systems*". If this is the case it would place an added burden on a person's already compromised stress levels and psychological wellbeing.

It is important to note that people with IH are not simply bedridden for long periods, they are actually asleep for long periods, so they are not only at risk of what happens as a result of being bedridden for long periods of time, they are also at risk of the health problems associated with actually sleeping longer than is recommended.

In a study by the University of Sydney [6,7] it was shown that sleeping for more than 9 hours puts you at a higher risk of dying young. In fact, they found that smoking, alcohol and less sleep were slightly less harmful than being physically inactive and sleeping too much. Other research [7,8] found a link between excessive sleep (more than 8- 9 hours) and a higher risk of depression, obesity, headaches, back pain, heart disease, diabetes, brain dysfunction, infertility and stroke. More research is needed as it can be difficult to pinpoint which is the cause and which is the effect with regards to excessive sleep and health problems [8, 9, 10].

So if we know that prolonged time spent in bed (horizontal and inactive) and sleeping in excess of 9 hours is dangerous, what does that mean for people with IH?

People with IH generally sleep in excess of 10 hours over a 24 hour period. While medication can help to reduce the amount they sleep, my research shows that it is often not reduced by much. Part of the reason for that is the ineffectiveness of the medications available but also because most people find that sleep restriction (eg: less than 9 hours in a 24 hour period) can make them feel worse. In fact, people with IH often report experiencing symptoms of sleep deprivation when they regularly sleep less than 9 hours so this too has obvious negative consequences. There hasn't been any research done on why this is the case but, considering what we know about prolonged bedrest and, excessive sleep we know that if people with IH don't restrict their sleep time they are at serious risk of all sorts of health issues, including an early death!

This is a pretty serious catch 22 right? Unfortunately, I don't have a perfect solution. Of all the lifestyle changes I have made, finding the right balance between enough sleep and making sure I am also vertical and physically active has been the toughest to work out. It is made more difficult by the fact that I never know how much sleep I'm going to need from one day to the next. The bottom line is, I do know being physically active is important. I acknowledge that, just like diet, being physically active won't magically cure IH. However, neglecting it can significantly impact your overall health and wellbeing. The 'Life after diagnosis' series aims to empower you to better manage IH by improving your overall wellbeing, and physical activity plays a crucial role. Let's explore options for staying active despite the challenges of living with IH.

Before I move on, these are the references for the articles that I mention in this section:

1. Effects of bedrest 1: cardiovascular, respiratory and haematological systems.
2. Bedřich Roth, His Life's Work and the 35th anniversary of the book "Narcolepsy and Hypersomnia"
3. Subjective symptoms in idiopathic hypersomnia: beyond excessive sleepiness
4. Effects of bedrest 2: gastrointestinal, endocrine, renal, reproductive and nervous systems.
5. Effects of bedrest 3: musculoskeletal and immune systems, skin and self-perception.
6. All-cause mortality effects of replacing sedentary time with physical activity and sleeping using an isotemporal substitution model: a prospective study of 201,129 mid-aged and older adults.
7. If You Sleep Too Much, You're At A Higher Risk Of Dying Young, Says Study.
8. 7 Health Risks Of Sleeping Too Much
9. Too MUCH sleep could KILL YOU: More than eight hours a night can double risk of stroke
10. Physical Side Effects of Oversleeping

Mindfulness

Before we can jump into physical activity and mindful movement, I need to start by explaining a little about what *mindfulness* is because the principles of mindful movement are the same as other mindfulness practices.

Mindfulness is a powerful human ability that allows us to be fully present in each moment. When you are being mindful you are aware of your thoughts, feelings, and bodily sensations without being reactive or overwhelmed by what's going on around you.

Think of it like this: our minds are often on autopilot, getting caught up in worries or lost in daydreams. Mindfulness is like a gentle nudge back to the present moment, allowing you to experience life more fully.

Some benefits of practicing mindfulness:

- Reduced stress and anxiety
- Improved focus and concentration
- Greater self-awareness and emotional regulation
- Enhanced creativity and problem-solving skills
- Increased feelings of well-being and happiness

Mindfulness can be practiced formally through meditation, but it can also be integrated into everyday activities.

For example, you can be mindful while:

- Eating a meal, paying attention to the taste, texture, and smell of your food.
- Taking a walk, noticing the sights, sounds, and sensations around you.
- Talking to someone, giving them your full attention and listening deeply.

Even small moments of mindfulness can have a positive impact on your overall well-being. If you're interested in learning more about mindfulness practices, I can provide some resources for you.

Mindful Movement

Mindful movement is the practice of bringing mindfulness, the awareness of the present moment, to physical activity. It's about focusing your attention on your body's sensations and movements, rather than just going through the motions or striving for a specific goal.

Mindful movement:

- **Combines mindfulness and movement:** It takes the practice of mindfulness, which focuses on the present moment and non-reactive awareness, and applies it to physical activity.
- **Focus on sensations:** Instead of getting caught up in counting reps or reaching a certain pace, mindful movement encourages you to pay attention to how your body feels as you move. You might notice the feeling of your feet on the ground, the stretch in your muscles, or the rhythm of your breath.
- **Non-judgmental awareness:** Similar to mindfulness in general, mindful movement doesn't involve judging yourself for your performance or flexibility. It's about observing your body's capabilities without criticism.
- **Applicable to many activities:** Mindful movement can be incorporated into various activities, from yoga and tai chi to walking, dancing, or even everyday tasks like gardening.

Here are some benefits of mindful movement:

- **Increased body awareness:** By paying attention to your body's sensations, you can improve your proprioception (your sense of body position and movement).
- **Stress reduction:** The focus on the present moment and non-judgmental awareness can help reduce stress and anxiety.
- **Improved focus and concentration:** Mindful movement can enhance your ability to concentrate and stay present in the moment.
- **Greater enjoyment of movement:** By focusing on the experience of movement itself, you can find more joy and satisfaction in physical activity.

If you're interested in trying mindful movement, you can start by simply bringing your awareness to your body during your next walk or workout. Pay attention to your breath, the sensations in your muscles and joints, and the feeling of your body moving through space.

I have been practicing mindful movement for longer than I knew it was a thing. Going to the gym has always required a significant effort from me, but once I'm there, I naturally and unconsciously begin focusing on my breathing. Initially, this habit developed as a coping mechanism for my poor cardio abilities (the consequences of being horizontal for so many years!). However, over time, I discovered that I truly enjoyed the sensation of being completely absorbed in the rhythm of my breath. This practice allows me to center my attention on the present moment, providing me with a meditative experience while engaging in physical activity.

Being physically active doesn't have to mean going to the gym. It doesn't even have to involve any kind of traditional 'exercise'. Being physically active simply means incorporating movement into your daily routine.

Here are some examples:

- Functional Movement: This involves activities that use your body for everyday tasks.

Consider:

  - Taking the stairs.
  - Parking further away. Add a few extra steps to your daily routine.
  - Doing yard work. Raking leaves, mowing the lawn, or gardening all get you moving.
  - Cleaning the house. Yes, I know, I too would much prefer to give in to sleep over cleaning the house however housework does count as physical activity' so I had to mention it.

'

- Active Hobbies: Pursue activities that get your body moving for enjoyment.

Explore options like:

  - Dancing. Put on some music and move your body freely!
  - Swimming. I love the feeling I get when I am in cool water; I somehow feel more awake. You don't have to actually swim laps of a pool - I would find that boring. Play with the kids or simply do light exercises. Your body weight is considerably lighter when submerged in water. This buoyancy means you do not experience the same impact on your joints or muscles as you would exercising on land so it's a great choice for people who spend a lot of their time being otherwise horizontal.
  - Fishing is another great way to be physically active while practicing mindfulness and soaking up some vitamin D.

  - Hiking or exploring nature. Enjoy the fresh air and scenic views. This is a great environment to practice mindfulness - and its an opportunity to get some healthy sunlight!

Key points when being physically active:

- Focus on Enjoyment. Choose activities you find fun and engaging. Movement shouldn't feel like a chore.
- Listen to your Body. Start slow and gradually increase intensity or duration as your fitness improves. Pay attention to your body's signals and take breaks when needed.
- Make it a Habit. Aim to incorporate some form of physical activity into most days of the week.
- Variety is Key. Try different activities to keep things interesting and target different muscle groups.

Remember, even small bursts of movement throughout the day can make a difference! By incorporating mindful movement into your daily routine, you can reap the benefits of being physically active without feeling confined to a gym or structured workout.

Conclusion - References and Resources

The aim of this 3-part series is to empower you on your journey with IH. My goal is to show how taking a holistic approach to your health, through a combination of healthy habits, emotional resilience, and a strong support system, you can navigate the challenges of your illness and thrive despite them. Remember, taking care of yourself is not a luxury, but rather the foundation for living well with a chronic condition. I encourage you to implement even one small change to your routine to make a start. You are not defined by your illness, but by your strength, resilience, and unwavering spirit.

References and resources for 'Sunlight, and the role of melatonin and cortisol' and 'Vitamin D and other benefits of sunlight'

The Healing Power of the Sun - A Comprehensive Guide to Sunlight as Medicine
By Richard Hobday
Review of The Healing Power of the Sun > https://musingmystical.com/the-healing-power-of-the-sun-by-richard-hobday/

The Sunlight Solution: Why More Sun Exposure and Vitamin D are Essential to Your Health
by Laurie Winn Carlson

The Vitamin D Solution: A 3-Step Strategy To Cure Our Most Common Health Problems
by Michale F. Holick

References and resources for 'Mindfulness and Mindful Movement' and 'Mindful Movement and Physical Activity'

Mindful - Healthy mind, Healthy life website
https://www.mindful.org/getting-started-with-mindful-movement/

Make Every Move a Meditation: Mindful Movement for Mental Health, Well-Being, and Insight
by Nita Sweeney

Links to all 3 of the pdf's that relate to this series can be found here:
https://www.hypersomnolenceaustralia.org.au/single-post/life-after-diagnosis-live-your-best-life