

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 One

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This is part one 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 want to start by saying I know it's not easy. I have been at my worse mentally and physically but I managed to turn my life around - twice. Once was a few years ago now. The first time had more to do with my mental state. I had to learn 'acceptance' and 'self care'. Things we will be talking about tonight.

My journey started many years ago when I met others with Idiopathic Hypersomnia (IH). One of the things I realised was that not everyone pushed themselves like I did. Meeting other people who were actually living with IH gave me the strength to be brave - meaning, to challenge my own expectations of myself which helped me to challenge the expectations others had of me.

SELF CARE

Practicing self-care benefits our physical, mental and emotional health and wellbeing. It supports us to foster a better relationship with ourselves and minimise stress and anxiety. It teaches us to be mindful of our own needs, to better support ourselves and others.

The second time I turned my life around was more recently and was more focused on my physical health. We will talk more about that next month.

The next slide includes some photos of me. I am ashamed of the person I became in the middle photo. I am only showing you so that you can see for yourself that I'm not perfect. I'm sincere when I say I know turning your life around isn't easy. I am not only overweight in the middle photo I was *really* unhealthy. You can see it in my face. And I mean unhealthy aside from IH, BUT my poor health was impacting the severity of my IH symptoms and the way I was able to manage them.

The first photo of me was in 2011, about a year or so before I started Hypersomnolence Australia. The second image is me in late 2019, the images on the right are me now.

Ok enough of that...

ACCEPTANCE

Acceptance is something many of us don't even realise we need to do but I can assure you until you accept your situation and live your life accordingly, the people around you will find it difficult to reach the level of acceptance you expect and need from them.



Why can Idiopathic Hypersomnia appear to have worsened?

I am going to read you some words from my 2022 Idiopathic Hypersomnia Education Day presentation because I think some of you may either relate to it now or have related to it at some stage in your journey. I also said some of this – on your behalf, in my recent symposium presentation that was attended by approx. 100 medical professionals (it was standing room only) at the Australasian Sleep Association Sleep DownUnder conference last week:

I honestly don't know how I knew what I needed to do to turn my life around but I'm guessing it came about through desperation. I had hit rock bottom. My symptoms had become so difficult to manage, I naturally assumed that my IH had gotten worse. So, I started by looking into what may have caused it to progress. Much to my surprise, I found that research suggests IH reaches its peak in young adulthood and generally remains stable, that is, it doesn't get worse.

So why was I struggling more than ever? Why did I find some days, weeks or months more difficult than others? I spoke to and read the comments of dozens of people diagnosed with IH. I spoke to doctors and other healthcare professionals, including clinicians and scientists that have studied IH for decades. What I found is that, 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 factors they're not taking into consideration. This was certainly the case for me.

Why can Idiopathic Hypersomnia appear to have worsened?

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

WE KNOW:

- CHRONIC STRESS CAN HAVE A HUGE IMPACT ON COGNITIVE FUNCTION.
- PEOPLE WITH CHRONIC ILLNESS ARE AT A GREATER RISK OF DEVELOPING DEPRESSION AND ANXIETY.

Michelle Chadwick



We know that chronic stress can have a huge impact on cognitive function. We also know that people with chronic illness are at a greater risk of developing depression and anxiety, and that this too impacts how well someone with IH manages their symptoms. But just how significant can the stress be for someone with IH?

For many people with IH, every morning is a struggle. Once they're awake, they're expected to stay awake all day, despite an overwhelming and insatiable need for sleep. And that's irrespective of how much good quality sleep they've had. There is no reprieve from the sleepiness; the challenge is never ending. But, all too often, this constant struggle is compounded by both the expectations of others and the expectations which people with IH place on themselves. Can you imagine what that would be like, day in, day out, for years and years?

Many people with IH go years without even knowing they have a neurological disorder that is responsible for what they experience. They have no "excuse" to offer those who criticise them. Then, they get diagnosed, but with a condition which is often misunderstood by even the medical profession. It isn't recognised appropriately in many parts of the world (I doubt it is recognised appropriately anywhere in the world). This diagnosis quite often ends up creating more questions than answers. The stress this can cause is enormous and quite often, but not surprisingly, it results in depression and anxiety. This stress is chronic and its effects are damaging and long lasting.

I've been living with IH for 40 years. It took over 20 years to be diagnosed - 20 long years of constant criticism and judgement from both myself and others. I wanted many things in life and I tried so hard to work toward them. Not achieving my goals wasn't something that I accepted lightly, but then I also had to face the judgement of others. On top of that were the numerous medical tests and doctor's appointments to endure, and the subsequent judgement which came from many of them too.

I have a drive and determination that I just didn't see in many of the people in my life. So why was I so hard on myself?

I don't know exactly, but I do know that there was a lot of pressure on me to be "normal". I certainly knew that being "normal" would have made my life a whole lot easier. Perhaps I subconsciously pushed myself beyond what I knew my brain and body was capable of because I was just so desperate for a "normal" life. I expected more of myself. Within a few years of my diagnosis, after spending the entire time learning about and understanding Idiopathic Hypersomnia, I finally realised that I had to accept my situation and work with it, not against it. But it was by no means an easy road to that realisation.

I'm a wife and mum of two children who were toddlers when I was diagnosed. I was working fulltime, mostly from home (due to my condition) plus I did a lot of charity work. I'm not going to lie. Externally, everything may have looked ok, but it wasn't. I was a mess. When I wasn't asleep, I was struggling to wake up and stay awake so that I could do everything that "normal" people did. I resented the pressure of this and the demands of life. It made me angry; I cried. My marriage was hanging by a thread. Hell, my sanity was hanging by a thread! And if that wasn't bad enough, my symptoms were now harder to manage than ever. I had a diagnosis and I had medication too, yet neither of them changed my situation much at all. What changed was me and, when I did, my whole world changed for the better.

There wasn't one specific thing which was my lightbulb moment for change. What I'm verbalising now didn't exist in the context of Idiopathic Hypersomnia. Back then you could Google 'Idiopathic Hypersomnia' and nothing but old research papers would come up. Back then there were no words written by other people with IH to tell me that it was ok to give in, surrender or, as I say, "accept" my situation. There was nothing which explained how chronic stress, depression and anxiety would make my symptoms more difficult to manage, but I now know they do.

Chronic Stress

- People can go undiagnosed for many years.
- They don't realise they have a neurological disorder that is responsible for what they experience.
- Then diagnosed with a condition which is often misunderstood by even the medical profession.
- Idiopathic Hypersomnia isn't recognised appropriately anywhere in the world.
- Diagnosis ends up creating more questions than answers.

Michelle Chadwick

THE STRESS THIS CAN CAUSE IS ENORMOUS AND QUITE OFTEN, BUT NOT SURPRISINGLY, IT RESULTS IN DEPRESSION AND ANXIETY.

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So, what did I do?

The first thing I did was declutter my life. The goal was to keep stress to a minimum. We all have so much more than we actually need so, I started by getting rid of a lot of stuff around my home (this is an ongoing project – my home has gotten a bit out of control again and I know its having an impact on me so I will make the time to get on top of it again).

I cleaned out my car, even my handbag... I now only carry around with me what I actually need. I cleaned out my phone and laptop too. I got rid of apps and other stuff I don't use. Now when I look at my home screen and desktop I'm not overwhelmed and distracted by a whole bunch of unnecessary stuff.

I then did little things and made them routine. I organise my morning the night before. You can do things like prepare your kids' uniforms, school bags and lunches, before you go to bed. I cook a few times a week rather than every night. I will cook extra for nights I just *can't* cook a meal. One of the best things I did for myself was to teach my children to be self sufficient at an early age. They are 18 and 19 now and they don't rely on me for anything. In fact, I haven't cooked a meal for them in a very long time, sometimes they cook for me!

I plan for things as far in advance as possible. A task that may ordinarily take one hour, may take 3 hours for a person with IH, in fact some days are a complete write off for me so I always give myself plenty of time to do simple tasks. I make a conscious effort not to take on too much too. I also make lists and set reminders. Feeling prepared reduces anxiety.

It's important to identify when you're most productive. Pay attention to when you usually get the most done, then plan your most important tasks for that part of the day. I know this can change from one day to the next – like I said, some days for me are a total write off where I literally scrap the whole day completely and start again tomorrow. So don't be hard on yourself if you too have to completely write a day off and start again tomorrow. The important thing is that you give yourself the time to re-group and then start again.

The next thing I did was remove toxic people from my life (this included family members). I was, and I still am ruthless with this. We only have one life. I will not have the limited wakefulness I have taken up by toxic people. I used to spend hours engaging with people online... now if someone online comes across as even slightly odd I either cut off communication immediately or I do not engage at all.

Stress impacts EVERYTHING

There is nothing wrong with putting yourself first. I know those of you who are mums may find the concept of that difficult but it's true, you can't pour from an empty cup. Self-care is not selfish. Self-care allows us to continue functioning and increases our ability to help care for others.

So don't feel guilty and don't apologise.

Make your life as simple and as uncomplicated as it possibly can be – you will be glad you did!

Stress impacts EVERYTHING

- Declutter your life - start with your home.
- Organise your morning the night before.
- Plan for things as far in advance as possible.
- Identify when you're most productive.
- Make lists and set reminders. Feeling prepared reduces anxiety.
- Remove toxic people. Be ruthless.
- Put yourself first - It's true, you can't pour from an empty cup.
- Self-care is not selfish. So don't feel guilty and don't apologise.

MAKE YOUR LIFE AS UNCOMPLICATED AS YOU POSSIBLY CAN

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Don't compare yourself to others

Don't compare yourself to other people with IH and definitely don't try to compare yourself to people in general.

It is important to keep in mind that due to the range of different symptoms, severity, and additional complexities including other health issues and also the different ways we each respond to medication and the various levels of support we may have it is not even possible to compare yourself to other people with IH – much less people who do not have IH.

Quiet your inner critic. Remind yourself that you are doing your best and that's all anyone can ever expect of you. Work on accepting where you are and celebrate your successes. Don't be too hard on yourself – like I said before, some days are a complete write off for me. Instead of letting this get me down I give myself what I need – which is quite often sleep! But it may also be good food, quality time with my family or just some quiet time alone away from my phone and other distractions.

Learn what your individual strengths and limitations are then adjust your expectations of yourself accordingly. It's ok to say no. Once you are aware of your limitations, be brave and clear when communicating them to others. Set boundaries and stick to them. Don't let others tell you what you can and can't do. Your time and energy are limited, so you need to be self-regarding.

And don't be too proud to ask for and accept help. Even if you don't think you need it it's a good idea to take every bit of help you can get. I said this recently to someone with IH that was contemplating motherhood but it applies to everyone. But if you are a mum or are contemplating motherhood, when we are in warrior mode as mum's generally are it's particularly difficult for us to identify when we need help – even while we are in the process of driving ourselves into the ground! If you have someone that cares about you and they want to help – let them.

Don't compare yourself to others

- Quiet your inner critic - don't be so hard on yourself.
- Work on accepting where you are and celebrate your successes.
- Learn what your individual strengths and limitations are then adjust your expectations of yourself accordingly.
- It's ok to say no. Once you are aware of your limitations, be brave and clear when communicating them to others.
- Set boundaries and stick to them. Your time and energy are limited, so you need to be self-regarding.
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YOU KNOW YOURSELF AND YOUR LIMITS BETTER THAN ANYONE ELSE

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A holistic approach to managing Idiopathic Hypersomnia is important

Taking a holistic approach to managing idiopathic hypersomnia is vital. Incorporating physical, mental, emotional, social, and spiritual components of health is essential to overall wellbeing. As I have mentioned earlier there are many things that can have an impact on the severity of our IH symptoms and our ability to manage them. If your overall health and wellbeing is compromised so too will be your ability to manage your IH symptoms. Discuss with your healthcare providers and your family the potential consequences of your diagnosis such as the need to reassess career options, adjust personal aspirations, or how you will manage the effects on existing family responsibilities. Ask your doctor to explain what a care plan is and how it can help you.

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- Discuss with your healthcare providers and your family the potential consequences of your diagnosis such as the need to reassess career options, adjust personal aspirations, or how you will manage the effects on existing family responsibilities.
- Ask your doctor to explain what a care plan is and how it can help you.

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The relief we may experience when diagnosed with Idiopathic Hypersomnia, the confirmation that we have a genuine disorder is often short-lived. If I could say only one thing to someone newly diagnosed with IH it would be; “You need to prepare yourself for this and learn how to manage your expectations”.

It is essential to recognise and acknowledge the profound impact a diagnosis of Idiopathic Hypersomnia can have on your life. For many, grieving their health after a new medical diagnosis can be an unexpected challenge. The type of grief that comes with chronic illness is complex, and the cycle can restart with each new issue that arises. Some people may not even realise they are undergoing a grieving process. If you are struggling to come to terms with this life changing diagnosis you may need the assistance of a specialist therapist. Speak to your GP.

Grief

The relief we may experience when diagnosed with Idiopathic Hypersomnia, the confirmation that we have a genuine disorder, can often be short-lived.

- It is essential to recognise and acknowledge the profound impact a diagnosis of Idiopathic Hypersomnia can have on your life.
- The type of grief that comes with chronic illness is complex, and the cycle can restart with each new issue that arises.
- For many, grieving their health after a new medical diagnosis can be an unexpected challenge.
- If you are struggling to come to terms with this life changing diagnosis you may need the assistance of a specialist therapist.

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Acceptance

I accept that miracle cures aside, genuine Idiopathic Hypersomnia is lifelong. That doesn't mean that the current treatments on offer won't help, rather that the underlying problem is not going to disappear. It is ok to mourn the loss of who we were prior to the onset of IH – in fact, it's necessary. It is ok to grieve for who or what we hoped to be but we need to accept that we will never be that person again.

Acceptance allows us to move forward and be grateful when treatments do work. It allows us to start building a life that is suited to our condition. It allows us to create our version of normal, and live a life that is free of unrealistic goals and expectations. We can replace self-criticism and struggle with revised goals and more appropriate expectations. It also frees us from the guilt and shame that so many of us feel and that alone has a huge impact on how much happier and brighter our future will be.

Worth doing, right? Absolutely. You're worth it. 

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