SLEEPY HEAD

Narcolepsy, Neuroscience and the Search for a Good Night

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Preface

This was not meant to be a self-help book. I certainly never imagined it would help me as it has done.

When I first began to think about this project, I considered writing a book solely about narcolepsy (a sleep disorder that I have lived with for more than 20 years). My agent and publisher encouraged me to go further, to cover the whole of sleep and many sleep disorders. I understood their thinking. The bigger, broader book might have bigger, broader appeal. It's probably safe to say that nobody was thinking that embarking on a more wide-ranging project would improve my own sleep. But it has – immeasurably.

By surveying a wide range of sleep pathologies, I have come to see narcolepsy in a very different light, not as an isolated sleep disorder but one with real and important connections to just about every other sleep problem out there. As I've learned about bad sleep in all its many forms, so I've come to appreciate what good sleep means and how to achieve it. This revelation, I believe, has important implications, not just for those with narcolepsy but for everyone who wants to improve their sleep.

I now have such good sleep, more often than not startled afresh by my new-found ability to function, that this project has already been worth its while. But authors write to be read and I hope that this book and its message will reach the wider

audience envisaged. In fact, this book is really for anyone who wants to know more about sleep and why it's so very important.

Before we begin, I should just acknowledge that many people with narcolepsy understandably rail against being referred to as 'narcoleptic', as if they are defined by the condition. The same goes for people with insomnia and the 'insomniac' label. I tried hard to avoid these adjectives, but I found it impossible. Forgive me. I use narcoleptic and insomniac here for their literary expediency and on the understanding that they are shorthand for the more appropriate but clunky terms 'person with narcolepsy' and 'person with insomnia' or their unutterable abbreviations pwn and pwi.

1

Bad sleep

'Sleep, those little slices of death; Oh how I loathe them.'
Edgar Allan Poe

'How is your necrophilia?'

My friend was asking after my narcolepsy, a seriously disabling neurological condition that I have lived with now for more than half my life.

'It's still an issue,' I replied. 'Thanks for asking.'

'Narcolepsy', roughly translated from ancient Greek, means 'an attack of sleep', a reference to its key symptom of excessive daytime sleepiness. But the passing resemblance of the word 'narcolepsy' to 'necrophilia' and 'nymphomania' can result in some awkward conversations. In fact, this mistake is sufficiently common for one person with narcolepsy to have worked up a couple of useful aphorisms. Necrophilia is sleeping with the dead, whereas narcolepsy is being dead asleep. Nymphomania is the urge to sleep with lots, whilst narcolepsy involves lots of sleep.

The onset of most sleep disorders is usually slow, so slow it can be difficult to notice what is happening. I was 21 and halfway through my second year at university when I experienced my first symptoms. I had always been an early riser. I loved mornings, eager for the day ahead. But gradually, over the space of several months, something began to change.

Within an hour of waking, it felt as if a smog were seeping into my brain and anaesthetising my faculties until I was left with no option but sleep. If circumstances allowed, I would give in and go back to bed, but I soon found that more sleep did nothing to refresh me. I tried to fight it instead, for a while – going to lectures, tutorials, running the college bar – but the constant struggle to prevent myself from drowning was almost worse.

I came up with little tricks that would hold off sleep for a minute or two, pinching myself, running violently on the spot, shouting at the top of my voice. Just writing about this makes me feel a little nauseous, even now. The feeling would begin to creep up on me all over again. I could battle like this for tens of minutes, convinced I was managing to take in a book, watch a film or even chat with friends, only to find I had no recollection of what had just happened. Had I been asleep, or hadn't I? The alternatives seemed to be stark: either spend all day in this zombie-state, or simply stay in bed. I began to confront the fact that I couldn't function in a meaningful way. I struggled through my degree, dribbling over lecture notes, dozing through tutorials, overdosing on caffeine to extend the fitful snatches of wakefulness I needed to make the grade.

In some lectures, I was just one of some 500 students. With tiers of desks stretching up and far away from the lecturer, I could sit near the back and put my head down without fear of being spotted. In a tutorial, however, with one professor and two students, things were not so easy. Very quickly, often within minutes, the small, sometimes windowless room and hulking radiators would conspire to bring on an attack of sleep. In order to keep up appearances, I had to keep my eyelids open. With considerable effort I found I could do this

but I know (because I've seen it in other people with narcolepsy) that there would have been no spark, no life, in my eyes.

* * *

■ *Sleep v.*
To take repose by the natural suspension of consciousness

It is perhaps understandable that sleep, as defined here by the *Oxford English Dictionary* and as most of us understand it, is a fairly vague concept. Understandable because it is so extraordinarily variable, differing wildly from one conscious species to the next.

Even within mammals – relatively recently evolved with very little variation in central sleep-regulating circuitry of the brain – there are many different takes on sleep. The giraffe, for instance, kips for no more than five hours a day. At the other end of the spectrum is the American opossum, a species that according to a student investigation at Yale University School of Medicine in the 1960s, may sleep for as much as 20 hours out of 24.

In between these extremes, there is a remarkable diversity of sleep. Most mammals are polyphasic in their sleep, drifting off repeatedly over the course of 24 hours. Dogs are the perfect exponents of this approach. Some species are biphasic, with two discrete sleeps a day. Rabbits, for instance, are most active at dawn and dusk, a crepuscular existence that carves out two clear periods for rest, one in darkness and one in daylight. Marine mammals, like dolphins and whales, boast the remarkable ability to sleep with one half of the brain at a time. Then there is also a handful of species with monophasic sleep, dividing up each day into one clear period of wakefulness and one

period of sleep. Some of these are nocturnal in their habits, like owls, some are diurnal, like people.

Humans have evolved to sleep more than a giraffe and less than an opossum. We like to sleep during the hours of darkness. We are a species that seems to need somewhere between six and eight hours of sleep in a 24-hour period. But even within a single species there is tremendous variation and sleep can vary considerably from one person to the next. Our genetics, gender, age, the seasons and our cultural traditions, not to mention the whims of everyday life, all have an effect on how we sleep.

It is only relatively recently that we have started to pay attention to this variation. For much of human history, sleep was seen as an inconvenient distraction from everything that goes on during the hours of wakefulness. 'Sleep is evidently a privation of waking,' wrote Aristotle in the fourth century BC, drawing an analogy between sickness and health, ugliness and beauty, weakness and strength. In the Old Testament, sleep is deployed as a metaphor for death so frequently it's easy to start thinking that just as wakefulness follows sleep, life might follow death and that crucifixion could be followed by resurrection. Poets too have often referred to sleep rather than death, using its reversible status to soften the dark finality that is the end of life.

Over two millennia after Aristotle, it was not uncommon to find the medical profession casting similar aspersions on sleep. 'The alternation between watchfulness and sleep … has its origin in the imperfection of our nature,' Dr Wilson Philip told the Royal Society in 1833. Sleep, if not quite 'a positive evil', is clearly a 'defect', he argued.

There are plenty of people who dismiss sleep as if it's some bothersome encumbrance. When asked how much sleep

people needed, Napoleon Bonaparte is fabled to have said: 'Six for a man, seven for a woman, eight for a fool.' Margaret Thatcher is thought to have got by nicely on only four hours a night. More recently, Donald Trump is an advocate of cutting back on kip. 'Don't sleep any more than you have to,' he wrote in his 2004 best-seller *Think Like a Billionaire*. 'I'm not a big sleeper,' he reiterated during his presidential campaign in 2016. 'I like three hours, four hours. I toss, I turn, I beep-de-beep, I want to find out what's going on.' These voices, prominent as they might be, should not be listened to. They ignore three different bodies of evidence.

First, there is the plain and simple, gut-instinctive wisdom that sleep is a force for good rather than evil. Shakespeare, for instance, had Macbeth describe sleep as 'sore labour's bath, Balm of hurt minds, great nature's second course, Chief nourisher in life's feast'. Miguel de Cervantes was similarly insightful, with Sancho Panza telling Don Quixote that sleep is 'meat for the hungry, drink for the thirsty, heat for the cold, and cold for the hot. It is the current coin that purchases all the pleasures of the world cheap, and the balance that sets the king and the shepherd, the fool and the wise man, even.' Samuel Taylor Coleridge was also upbeat in *The Rime of the Ancient Mariner*, characterising sleep as 'a gentle thing, Beloved from pole to pole!'

Then there are the data, a body of scientific observation and experiment that has been steadily growing for around a century. 'Far from being the opposite of wakefulness, sleep is in reality a complement to the waking state, the two constituting alternative phases of a cycle, the one related to the other as the trough of a wave is related to the crest,' wrote sleep science pioneer Nathaniel Kleitman in his groundbreaking book *Sleep and Wakefulness* published in 1939.

Finally, there are the stories of those who live with a sleep disorder. These are often anecdotal in nature, so don't often cut the mustard as scientific evidence and are not often heard. Yet the testimony of those with bad sleep is compelling. When sleep goes wrong, it almost always has a profound effect on our lives, eroding both mental and physical health and causing serious psychological damage. It is time to stop ignoring these first-hand accounts.

There remains plenty of debate over what is going on when we sleep and what possible function sleep might serve. Perhaps our brains spend the downtime clearing out the by-products of metabolism that accumulate during our waking, thinking hours. Maybe the brain cells are taking time out to perform some operation, like consolidating memory or expunging unwanted cognitive clutter. Sleep could simply be a cost-saving strategy, a way of passing time without expending too much energy. Alternatively, sleep could have a role in all of the above, and more.

For now it's sufficient to reiterate that sleep is the result of an evolutionary process, sleep is a widespread phenomenon and the sleep of one species is very different from the sleep of the next. Given these observations, it's safe to conclude that sleep must serve an absolutely vital function. If it doesn't, as sleep researcher Allan Rechtschaffen put it so nicely in 1971, 'then it is the biggest mistake the evolutionary process has ever made'.

* * *

The most obvious way to interfere with this evolutionary imperative is to alter the duration of sleep. As sleeping less than six hours a day is easily arranged, it is understandable that the majority of research should focus on what happens when

we don't sleep enough. This demonstrates that too little sleep is associated with a long list of undesirable health outcomes, like an increase in appetite, risk of obesity, high blood pressure, susceptibility to infection, likelihood of depression and pace of cognitive decline.

In addition to the quantity of sleep, the quality of the sleep that we get is tremendously important too. One hundred years ago, most people who'd given it a moment's thought assumed that the brain wasn't up to much during the hours of sleep. In the 1930s, scientists discovered that the electronic signals pulsing over the scalp go through a series of clear changes throughout the night. The precise order and duration of these stages can make a huge difference, so a short but well-structured sleep could leave you feeling more rested than a long but poorly structured one.

This mention of sleep structure (or 'sleep architecture' as it's known in the trade) invites a useful analogy. The perfect night's sleep is like the Taj Mahal, a construction whose beauty emerges from its carefully proportioned design and attention to detail. When the structural integrity of sleep goes awry, as occurs in most sleep disorders, it's as though the architectural plans have gone missing and the resulting edifice is simply a miscellaneous jumble of marble.

With sleep varying so wildly from person to person, from one night to the next, and its timing, duration and structure influenced by so many factors, such as late nights, alcohol, caffeine and stressful deadlines, there are plenty of everyday explanations for bad sleep. This means that it can take many months, often many years, sometimes even decades before someone with a genuine problem plucks up the confidence to take their symptoms to a doctor.

For Monsieur 'G', a 38-year-old wine-barrel retailer from

Paris, the time came on 15 February 1879. His doctor, Jean-Baptiste Édouard Gélineau, listened carefully to his patient, noting how he'd experience bouts of 'deep heaviness' and 'a heavy load on the forehead and deep in the eyes', and felt that there could be something serious going on here, a genuine sleep disorder that needed a name of its own. So Gélineau coined the term 'narcolepsy' and used a delightful Gallic turn of phrase to sum up the principle symptom of this newly described condition: 'an invincible need for sleep'.

But what did Gélineau know? He was only a provincial doctor from Rochefort and the medical elite in Paris dismissed the case out of hand. Perhaps they took one look at his patient's profession – barrel retailer – and figured that the more likely explanation for his sleepiness was inebriation. Whatever the reason for their rejection of Gélineau and patient 'G', it meant narcolepsy did not become an accepted condition until well into the twentieth century.

Even then, the experience of being bounced from one unfruitful GP appointment to the next is all too common for people with dysfunctional sleep.

* * *

Dorothy Ennis-Hand developed narcolepsy in 1953 at the age of 16 and recalls the first time she went to a doctor to get help. She'd left her home in Dublin to take up a factory job at Joseph Lucas Ltd in Birmingham, a major manufacturer of engine parts. Finding herself struggling with sleep in the drawing office, she went to a doctor, he suggested it was probably a result of anxiety and prescribed a bottle of a mysterious 'tonic' as a pick-me-up. 'It didn't help,' Dorothy tells me. A year or so later, by this time living in Ottawa, she sought

a second opinion. The Canadian doctor didn't do much better, latching on to the revelation that she'd just broken up with a boyfriend. This was probably the explanation for her sleepiness, he told her. A few years later and back in Dublin, Dorothy made yet another doctor's appointment, only to be met with more speculation. 'Sometimes newborn babies get their day and night mixed up,' he told her, implying that she must be experiencing something similar. His answer was to prescribe two drugs, one to keep Dorothy awake in the daytime and one to put her to sleep at night. Unfortunately, the sedative left her like a zombie. At work, as an orderly in the operating theatres of the Rotunda Hospital, her fellow nurses assumed she'd been drinking over the weekend. But Dorothy – a teetotaller – knew better. 'I threw all the medicine down the loo,' she says.

Several years later, after a series of bitty jobs in Dublin, Los Angeles and Liverpool, and a short-lived marriage, Dorothy found herself back in England, working full-time in the operating theatres at Manchester Infirmary and looking after her young daughter and her youngest brother. 'It was a very stressful time,' she remembers, and the sleep had become more of an issue than ever. Finally, she managed to get a diagnosis. By a stroke of good fortune, the doctor she saw had come across another case of narcolepsy and referred her to a neurologist who made the formal diagnosis. Dorothy was 33 and had lived with narcolepsy – undiagnosed – for just over 15 years.

It's easy to imagine that the repeated failings to diagnose Dorothy's narcolepsy – in Birmingham, Ottawa and Dublin – were because she was born in the 1930s and presenting symptoms to her doctors in the 1950s at a time when narcolepsy was not on the medical radar. Yet the same kind of thing was still happening decades later, in the 1980s.

Michelle Hicks was born in 1975 and was hit by narcolepsy at the unusually young age of seven. Sleeping at primary school quickly became an issue for Michelle. 'I used to go into quite deep sleeps,' she says. 'I'd just zonk out through the whole lesson.' On more than one occasion, she remembers waking up to an empty classroom. 'Everyone had gone home from school.' Her mother and sometimes her teacher would be there with her, sitting and waiting for her to come round.

Alarmed, Michelle's parents took her to the doctor and, at the age of seven, she spent a week in the Whittington Hospital in north London while they ran some tests. 'I remember them giving me blood tests every day and doing x-rays.' By the end of the week, the doctors couldn't find anything wrong with her, but they did refer her to a psychiatrist.

Michelle has the letters that the psychiatrist wrote to her GP in which he seemed more interested in the stress that she was causing her parents. He suggested the family adopt a 'bedtime ritual', getting together and teaching Michelle how to dance. 'This would have the function of bringing mother and father together more in something which they could enjoy together as a couple.' He arranged to see them all again in a month's time. 'I feel quite optimistic that I will be able to help, both with Michelle's symptoms, fears and anxieties and in relation to the parents' feelings of depression and sadness.' The dancing didn't help.

Then, in the early 1990s, when Michelle was in her late teens and had been living with undiagnosed narcolepsy for more than a decade, she was listening to a radio phone-in on Capital Gold and the listeners were sharing their stories of sleeping in unusual places. A woman called to say that her husband suffered from narcolepsy and fell asleep all over the place: while writing, in the car waiting for the traffic lights to

turn green. It was the first time Michelle had ever heard the word 'narcolepsy'. 'That's me,' she thought.

Michelle got her hands on a leaflet and her father spoke to someone at the UK Association for Narcolepsy, a charity that Dorothy Ennis-Hand had recently founded that subsequently evolved into Narcolepsy UK. Empowered with what appeared to be an accurate self-diagnosis, she went to her GP, who referred her to a neurologist, who in turn ruled out narcolepsy on the basis that the symptoms had appeared at such an early age. 'We've only seen it in adolescents,' she told Michelle. 'You're anaemic and suffer from depression and that makes you tired.' By this time, Michelle had lived with narcolepsy – undiagnosed – for most of her life and to an extent she had come to accept a life of sleep.

It took another ten years before Michelle had built up the confidence to seek another opinion. It was 2004 and she was studying for a foundation degree at Farnborough College of Technology. Her GP took Michelle's self-diagnosis seriously, referring her to a specialist at Frimley Park Hospital in Surrey, a different hospital than the one she'd visited in the 1990s. When she entered the consulting room, she was dismayed to find herself face to face with the same neurologist she'd seen a decade earlier, recently moved to Frimley Park.

'She thought there were signs of narcolepsy and sleep apnea,' remembers Michelle, but sent her to be tested for the apnea first. When the results came back negative, Michelle still had no explanation for her sleepiness and did not relish a follow-up appointment with the same doctor. Consequently, it was only in 2010, when Michelle was 35 and had battled her symptoms – alone – for almost three decades, that she finally got a proper diagnosis.