At a dinner party in the winter of 2011, a famous novelist, who's in his mid-50s and whom I'll call Paul, told me he'd used the neuroenhancer modafinil to help him get through a long, gruelling book tour. He also told me it was another novelist, of equal fame, intelligence and reputation, who had given him his first sample of the drug. Paul and I had met many times before, and he was among the few people who knew that, in 2008, I was diagnosed with multiple sclerosis. And so, when Paul had finished his bowl of soup, I mentioned Margaret Talbot's New Yorker article about neuroenhancers, and asked what he thought about them.
That's when Paul told me he'd used the drug, and changed my life. Talbot's article, like many published since the mid-1990s, turned, in part, on the fuzzy ethics of the use of neuroenhancers. These controversial drugs, strictly licensed for the treatment of narcolepsy, sleep apnoea and ADHD, have become immensely popular among users without prescription because they promote a keen sense of wakefulness and sharper cognitive focus. As is the case for many people with multiple sclerosis, the effects of weakened limbs, spasticity and fatigue had cut my working life in half. Yet not a single GP, neurologist or nurse, and none of the MS websites, had mentioned the use of neuroenhancers for the treatment of neurological fatigue. Although I knew that surgeons regularly use modafinil as a substitute for the ratty and short-lived perks of caffeine, and so, too, do hundreds of sleep-deprived domestic airline pilots, Ivy League students (both average and brilliant), many of the brightest minds in academe and hundreds of women and men in the US military, until that night, I'd never met anybody who'd used the drug – and I wanted to know as much as Paul was willing to tell me. As we drank our coffee, I asked if the drugs worked. "Sure," he said. "They worked beautifully." "Did they alter your mood," I asked, "or just pep you up? Like coffee or nicotine?" "The effect was much more than purely physical." "Did you feel euphoric?" I'd read that some users get a high from the drugs. "Not quite. But it's hard to explain." Paul smiled as though remembering something nice. "It was a long road trip and I was damned exhausted." The waiter had come to our table with the bill, and many of the guests were glum, counting out their notes and coins.
Most, except two drunk writers arguing about Iraq, had stopped talking, and that awful end-of-night mood seemed, as it so often does, to wreck all that had been good about the earlier laughter.

But Paul wasn't in a hurry to leave. Maybe he sensed the importance of our chat. Maybe he sensed that I needed to know more.

"How much did you take?" I asked.

"Only half a pill at first." He'd snapped a 200mg tablet in half, on the advice of the other writer.

"So, did you feel any major difference, besides wakefulness?"

"Yes, the change was major. Not to my psyche or personality, but it was dramatic. I went from utter fatigue to feeling like me on my best day."

"You on your best day?" I said.

He smiled again. "I was like a younger me after a very good night's sleep."

"Did you take any more?" I asked. "After the book tour?"

"A few. Now and then. When I really need them."

"Do you have any with you?"

He laughed. "Now?"

"Yes."

He didn't have any, but as we took the lift together and walked outside to catch our separate taxis to our separate hotels, he told me how easily I could find modafinil, and that he'd found his on a Canadian website.

We stood for a while in the bitter cold, the howling wind pushing paper and plastic coffee lids through the gutters.

"What about side-effects?" I asked. "Like insomnia?"

"None," he said. "But Maria, don't take them after midday."

When Paul's taxi came, we hugged and said goodbye, and I went on waving and smiling at him while he sat in the back
seat of his taxi, because I was sure that what he'd told me was about to change my life, for good and for better. The next morning, in my hotel bed, I went online and did some research. The short-term side-effects seemed to include headaches and possible nausea, but the only real long term side-effect reported in medical journals was a vague complaint made by users that they'd become monomaniacal; too fixated on work and study, at the expense of spending time with friends and family. A few users complained of insomnia and some reported that they'd given up using the drugs, even though they'd suffered no ill side-effects, because of a superstitious dread that they were "too good to be true" and that there "might be unknown side-effects in the future".

It's not known how many people are using neuroenhancers: the drug remains strictly off-licence in the UK and the US. But on 9 November 2011, the BBC's Newsnight tried to get closer to an answer by running an anonymous online questionnaire. There were 761 replies, from New Scientist readers and Newsnight viewers: 38% said they'd taken cognitive-enhancing drugs, 40% said they'd bought the drugs online, and 92% said they'd use them again. These numbers are crude and anecdotal, and that's because, as Newsnight discovered, it's nigh on impossible to find hard data.

There would be no point calling my neurologist or going to my GP; the NHS position in the UK is fixed: no prescriptions of modafinil except for conditions such as narcolepsy or sleep apnoea, not even for MS patients with fatigue. And so I stayed in that warm hotel bed, paid for another hour's worth of Wi-Fi and ordered a batch of modafinil online. If monomania was the worst side-effect, then so be it: the drugs might put me back to where I was before I became ill. I might even return to being a souped-up and tireless
worker, tapping out words for six or seven hours a day, reading until the wee hours, and rarely sleepy. I wasn't in the least bit nervous, and my expectations were realistic. These drugs don't turn dullards into super-achievers, and there's scant evidence that any IQ points are gained. Along with incontinence (of both kinds), poor motor skills, spasticity, heat-intolerance and weakness in both my right leg, right arm and hand, MS means I suffer from the pest of fatigue. But before the onset of neuronal damage and the loss of axonal potential, I was fully alive, and liked to call myself an improbable survivor. At my most narcissistic, I even bragged that I was bionic.

I grew up in a bookless house with a father and brother who have spent most of their lives in prison, psychiatric hospitals or living rough, and a mother who has spent her life slaving and scrimping to pay the bills, living a nervous and troubled life. I was the first and only person in my family to go to university and I spent two decades redesigning myself: even my voice is the product of elocution lessons.

Before MS moved in on me, I'd worked for seven years as a city lawyer, as the editor of a literary magazine and, before the age of 20, I'd also worked as a cadet journalist and as an assistant director in both film and TV. And then, after the lesions of MS, both on my spine and in my brain, I was the opposite of bionic. I needed a nap after a two-hour lecture, couldn't stand in a post office line for more than five minutes, couldn't walk more than a few hundred metres without resting and had to sneak down alleyways when my bladder opened. Worse than any of these curses, when I tried to write for more than an hour or so, my right hand curled up like a prawn cracker. I was sure my life as a novelist was dead.

In 2011, on the night of that dinner party, the idea of ever feeling like "me on my best day" seemed as unlikely as
swimming the Channel or converting to Scientology. And so there was no question: I'd try modafinil and, if it worked, I'd take my anecdotal evidence of the drug's effects to both my neurologist and GP.

In the hotel room that morning, it took less than half an hour to find more than a dozen websites selling modafinil, and I chose a site that called itself a pharmacy and that looked a little less fishy than the others. The one I chose had fewer spelling mistakes, and no photo of a fake doctor with shiny hair. I ordered two boxes of modafinil: 30 x 200mg and 30 x 100mg.

The precise mechanisms of neuroenhancers remain unknown and unclear, and most of what I'd read was cautious and circumspect, dominated by concerns about possible long-term side-effects. In newspapers and magazines, neuroenhancers are typically called "Viagra for the brain" or "mind steroids", and their use is often regarded with disdain and suspicion.

The notion shared by most journalists and commentators seems to be that the drugs work, but because they're rarely used for legitimate medical reasons, they are stained, disreputable. The fact that they are frequently used by people commonly characterised as cheaters – students who want better grades, A-type personalities and overachievers who want to get brain-hyped so that they might gain an unfair advantage – appears to be the only real reason medical professionals who treat MS patients are so silent on the subject.

I didn't care at all about the morality, or otherwise, of taking brain enhancers. If the drugs worked, I'd be able to finish my fourth novel, and I'd be able go on teaching and editing.

My supply of modafinil arrived at about 10am on a Monday morning: a small box within a larger box, both covered in thick brown masking tape, postmarked Hong Kong.
handwritten label described the contents as "Book". I put Schubert on the stereo, ate a banana and, with half a glass of milk, swallowed 100mg straight away. An hour later I was vacuuming my car and scrubbing black gunk from my oven. In the afternoon, I went to a cafe and wrote until closing time, taking just a few short breaks, every half-hour or so, to rest and massage my stiffened hand. I didn't eat all day and when I'd finished at the cafe, I went home, cleaned the toilet, then read until 2am, my brain alive and sure again. In the first weeks of using modafinil, I felt a bout of happiness, a steadily upward-moving mood; a strange and sustained euphoric effect. I doubt this heightened state was caused by the drug's pharmacological workings. It's more likely to have been brought on by pure relief, perhaps even the power of placebo. After more than two years of being made sluggish and clumsy by MS, my mind muddied and muted, I was wide awake. In the stuffy, darkened house of my head, all the windows and doors seemed to have been flung open and the air was crisp and cool. The euphoric effect faded after a month or so (no more cleaning frenzies), but the wakefulness remains both robust and reliable. I take 400mg just about every day (with no side-effects) and I'm twice as productive and considerably happier. I'm not smarter, but I have the hours I need, and loads of them.

I'm not cured of MS, of course – my right hand (and leg) still flags, still stiffens, still weakens – but the effects of modafinil have a way of sacking off the urge to quit. The mysterious workings of the drug seem, somehow, to trump or override physical weakness, and the effects allow me – compel me – to push through the pangs and the pains, and the pesky failings of my right hand. In this hard-to-describe way, modafinil has revealed something more complicated. By swarming my brain, the
drug seems to compel me to use my hand even when it hurts or twists or trembles; even when spasms and pains unnerve me, or would ordinarily make me want to take a sleeping pill, or hide in bed and turn off all the lights. I use the word "compel" when I talk about the effect of neuroenhancers, because this seems the most useful way to describe the irresistible urge to work provoked by the drug: the very state of being that I'd known all my life, before the frightening onset of MS.

My hand is still retarded by the disease, but modafinil continues to mask the worst of the emotional and psychological pains – the sulks and sadnesses – and lets me do at least twice as much as I'd done before. In my case, modafinil has shown what the science of neuroplasticity promises. If a weak or damaged limb is used in spite of its limitations, and used often, then different or new neurological pathways might be found, and the lame or weak limb has greater hope of working.

When I'd been using modafinil for a few months, I asked my GP for a prescription. He vehemently refused, and refused again a week later, even when I told him my neurologist endorsed the use of the drug to treat fatigue. And so, for six months or more, I went on ordering those expensive double-taped boxes from the Hong Kong "Book" pharmacy. Finally, my neurologist, after facing infuriating resistance from the NHS, found a way to get me a legal prescription.

In the US, modafinil has been trialled for MS patients (albeit on a small scale) and the results have been positive. Yet the drug remains off-licence, and in the UK there's still no sign of any major randomised controlled clinical trials. In August 2012, I wrote for the first time about my MS and, soon after, hundreds of emails poured in from fellow sufferers. These emails came from academics, GPs, scientists, teachers, athletes, writers, nurses and PhD
students, many of whom have been so stunted by fatigue that they've quit work (and play) altogether. There's no credible argument against the use of modafinil for fatigue in MS. The problem isn't the drug, but the curse of its image: the stigma of its "recreational" use; the idea that the benefit of cognitive endurance is inherently greedy and frivolous, in the same dirty class as steroids, Botox and Viagra. And there's the cost, perhaps the most powerful reason for the failure (or refusal) to run long-term clinical trials, and the NHS's dogged refusal to relax its position. If both efficacy and safety were proven, there would be a long line of people with MS asking their GPs for a taste of this brain pill.

As for me, I won't bother hounding doctors and neurologists, or writing agitated campaign letters to NHS bureaucrats. I'm too selfish, too preoccupied by my work. But if the status quo doesn't shift, and shift soon, let there be words, and let some of them be furious. And if Paul reads this, I hope he hears me say what I tried to say to him in the taxi on that cold night, and have been too afraid to say since: "Thank you."

- A photograph originally used in this article has been removed at the request of the writer.