

Scientists search for sleepless souls suffering lifelong insomnia

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Most people have experienced the odd sleepless night before a crucial exam, a job interview or before going on holiday, but few people get by with just a couple of hours of sleep a day, every day.

Terry McKinnes, 54, of Falkirk, is one of the unfortunate people who suffers from idiopathic insomnia who feels she has spent almost her entire life awake.

Unlike psychophysiological insomnia, which occurs in adulthood and is normally triggered by stressful life events and may resolve at some later point, idiopathic insomnia starts in childhood and never ends. Sufferers usually get by on just a few hours of [sleep](#) a night and can spend their days chronically fatigued.

In an effort to help scientists discover more about the condition, and hopefully an effective treatment, Terry is taking part in a study conducted by the University of Glasgow at its Sleep Centre in the Sackler Institute at the Southern General Hospital.

Terry, who is originally from Wandsworth in London, said: “I’ve tried everything to get a good night’s sleep: Nytol, herbal remedies, hot milk, [sleeping pills](#), lavender pillows, hypnosis, neuro-linguistic programming, counting sheep, but it just doesn’t work. I wish I could just take an anaesthetic and be out like a light. It would be fantastic.

“My first memory of insomnia was when I was two or three and had

been taken into hospital. After three days the nurses called my parents and asked them to take me home because I'd kept the whole ward awake for three nights in a row.

“But when I was young it had no effect on me at all. I didn't suffer from the [lack of sleep](#). But in the last few years I've not had as much energy as before and it's beginning to really affect me. I haven't slept for two days.

“I'm on antidepressants, as it is really getting me down now, I'm really tired and I've had laryngitis for a couple of weeks now. It's hard to deal with when I have other health problems, including asthma and problems with my sinuses.

“I've been on some really strong sleeping tablets but they just don't work. My doctor gave me 50mg of Amitriptyline. When I went back a fortnight later and told him they didn't work he doubled the dose and it still had no effect, other than making me feel miserable.

“Eventually, you just get used to a routine and you give up and think what's the point of going to the doctors? There's nothing they can do and they're busy enough as it is. You have to learn to live with it.

“I'm fortunate that I run my own business so I can go home and have a sleep whenever I want. I really feel for people that have to hold down a nine-to-five job and even when really tired have to work through until they can get home. By that time they are overtired and their brain can't turn off and it's a vicious circle.”

Terry, who runs a number of bed & breakfasts in Falkirk with her husband Colin, wasn't always worried or troubled by her insomnia.

She said: “My father was schizophrenic and so my mum and I were on our own from when I was 11. At age 15 I started work and had two or

three jobs. Sometimes we'd get into financial difficulty so I'd just get another job. It was not a problem for me.

“After I left school, I got a job in a bank during the day. When I finished there I'd go home for dinner and leave at 7.30pm to work in a pub until midnight. We'd then have a lock-in until 4am before I'd go home for some sleep then get up an hour or two later and do it all again. I could party all night on a couple of hours sleep.

“When my son was born in 1985, I got a job in the post-office where I worked night-shift so I could be with him during the day. I'd come home at 10am after going for a walk, play with my son. Then, when he went to bed at 7.30pm, I'd have two hours' sleep, before getting up at 10pm to start work.”

Only rarely does Terry get any respite from her sleeplessness, and it requires a very particular setting.

She said: “It's absolutely crazy and weird, but the only time I can get a good sleep is on water. I can doze right off in a swimming pool, I've fallen asleep on a fishing boat trip and when we went on a honeymoon cruise I slept like a log.

“I don't know what it is about the water - maybe it's relaxing or it's akin to the rocking motion of a cradle. I've even fallen asleep in the bath before. I'm actually shocked whenever I have a good sleep.”

Professor Colin Espie, of the Department of Psychological Medicine at the University of Glasgow and Director of the Glasgow Sleep Centre, who is leading the study, said: “Idiopathic insomnia is a life-long condition that has been a neglected area of research because no treatments have been found to be effective. It is thought to affect up to one per cent of the population

“Despite the differences between this type of insomnia and the adult-onset variety, patients with idiopathic insomnia are usually managed and treated by clinicians in the same way. This can mean that they are left to suffer the effects of this chronic condition throughout their lives with no effective assistance.

“This study will compare a number of psychological variables between the two types of insomnia and hopefully we will be able to suggest how possible psychological treatments could be developed and utilised in future.

“At the moment we know that cognitive behaviour therapy (CBT) works very well for psychophysiological insomnia. We are hoping that we might be able to adapt CBT in some way so that it works also for idiopathic insomnia.

“Certainly there is a need to develop appropriate treatment interventions that are tailored for use with different types of insomnia and target patients’ individual sleep difficulties. In order to achieve this we first need to develop a better understanding of how these insomnia subtypes differ.”

Terry says she has tried not to let insomnia get in the way of her life and has even taken advantage of the fact she can spend longer awake than most people, but the older she gets, the more she craves a normal sleeping pattern.

She said: “I’ve had a fantastic life in so many ways. I’ve been lucky and taken every opportunity that’s come my way, but now the insomnia is really holding me back. I’m sick of looking at my bedroom. My God, what I’d give for a good night’s sleep!”

Source: University of Glasgow

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