Wake up call: Sleep is impacted before Huntington's disease symptoms appear

For Sleep Awareness Week (March 9-15), HDBuzz is giving a wake up call to sleep disturbances in Huntington's disease. New research suggests sleep changes start early, before other symptoms appear—but there are steps you can take to catch better Z's!

By Dr Zanna Voysey | March 10, 2025 | Edited by Dr Sarah Hernandez

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After getting a poor night's sleep, anyone would agree that good sleep makes a huge difference in day-to-day life. (Just ask any student who has stayed up all night to cram for a test...or anyone with a newborn baby.) It's so critical that there's an awareness week dedicated exclusively to sleep! So during this Sleep Awareness Week, March 9th through 15th, we're sounding the alarm on sleep issues related to Huntington's disease (HD) by sharing new research that suggests sleep-related changes may be happening even earlier than we previously thought.

Your brain needs sleep!

Sleep problems are common in people with HD after they begin to experience symptoms. We know that people with HD tend to have less deep sleep and insomnia is really common - in fact, 88% of people with the HD gene report having disturbed sleep. But much less is known about whether sleep issues also occur in people with the gene for HD *before* symptoms arise.

A new study using wrist-worn motion detectors finds that sleep is disturbed in people with the gene for Huntington's disease, as much as 15 years prior to the onset of other symptoms.

Image credit: Ketut Subiyanto

This is an important area of study, because poor sleep can cause problems with thinking, memory, and mood – already common features of early HD. Plus evidence from other diseases, like Alzheimer's, has suggested that chronic poor sleep might even accelerate dementia on a biological level.

So if sleep problems were present in people with the gene for HD before other symptoms appear, it makes researchers wonder: If we could intervene and improve sleep, could it lessen thinking, movement, and mood symptoms associated with HD, and perhaps slow down disease progression?

Restless nights start up to 15 years before symptoms

A new study from Monash University in Australia, led by Emily Fitzgerald and colleagues, has recently helped to extend our understanding of how early sleep issues arise in people with the gene for HD.

They recruited a group of 48 adults without the gene for HD alongside a group of 36 people with the gene for HD who were not yet experiencing symptoms. Based on age and CAG repeat length, around a third of the people with the HD gene were predicted to be more than 15 years from developing symptoms, while two-thirds were predicted to be less than 15 years from symptom onset.

They asked study participants to wear a motion sensitive device on their wrist (a bit like a research-grade 'FitBit') continuously for two weeks to record their sleep and activity patterns.

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They found that sleep in people with the HD gene who were more than 15 years from predicted symptom onset was no different to that of people without the HD gene. However, people with the HD gene who were less than 15 years from symptom onset had markedly disturbed sleep, characterised by broken sleep and more time spent awake during the night. This wasn't just limited to the study participants who were close to symptom onset; it was even present in those 10-15 years from symptoms.

'But I carry the HD gene and I sleep fine'

Additionally, they found no relationship between the presence of these sleep problems, and what people with the HD gene reported on subjective sleep questionnaires.

This means that many people with the HD gene who are not yet experiencing other

symptoms may be unaware of or underestimate their sleep problems, or that sleep questionnaires fail to capture these sleep problems. So this area may well be a bigger problem than we currently know about.

Don’t turn out the light yet

Before we can say we’ve put sleep issues in HD to bed, it’s important to acknowledge some important caveats related to this research.

Traditional ‘sleeping pills’ are not the answer for people with the gene for Huntington’s disease who want better sleep quality.

Even though the devices used in this study are much more accurate than ‘consumer-grade’ devices like FitBits, it’s important to remember that they only record movement, so their ability to reliably distinguish wakefulness from sleep isn’t 100% accurate. It’s possible, therefore, that some of the movement they picked up was while people were asleep - like turning over in bed.

It’s also important to acknowledge that around a third of the people with the HD gene who were less than 15 years from symptom onset were taking antidepressants, which can impair sleep continuity. When the study team re-analysed the data excluding these individuals, the findings were less extreme.

A high proportion of the people with the HD gene were also women of peri-menopausal age. Women are 40% more prone to insomnia than men (wow!), and on top of that, perimenopause often causes poor sleep, so this may have influenced findings.

Nevertheless, there have been other studies directly recording sleep brainwaves of people with the HD gene who don’t yet have symptoms, including in those not taking antidepressants, that have found similar patterns – suggesting the findings from this recent paper are robust.

Tips for counting sheep

Naturally, the next question is: How could we improve sleep for people with the HD gene who don't yet have other symptoms?

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The answer is NOT to be reaching for traditional 'sleeping pills' (things like Valium, Ambien, or drowsy antihistamines), as these induce poor quality sleep, alongside lots of negative daytime side effects like hangover drowsiness, memory problems, and in some cases, dependence.

A new kind of 'sleeping pills', known as orexin antagonists, have recently been licensed and appear to induce healthy sleep with a much better side effect profile. However, they are still being studied and have not yet been directly tested in people with HD. Regardless, before any 'drug-based' treatment is considered, several other steps are recommended. Our take-homes would be:

- Take the time to **consider your lifestyle factors** and how they might be affecting your sleep quality. Things like caffeine, alcohol, nicotine, or lack of daytime activity/light exposure all adversely affect sleep quality, and can be easy to overlook. The same goes for poor 'sleep hygiene' – things like sleeping at irregular times, evening screen exposure, or working in the same space that you sleep. Organizations like Sleepstation and The Sleep Charity in the UK and the National Sleep Foundation in the US have great tips on this.
- Think about having a **discussion with your HD clinician or family doctor** as to whether you have any symptoms of common sleep disorders – things like 'restless leg syndrome' or sleep apnoea (where there are long breathing pauses in sleep). As far as we know, these aren't more common in HD, but if you did happen to have one of these coincidentally, there are many good treatments available that could improve your sleep quality. So it would be a good idea to get these addressed if they're present. Likewise, night-time urinary problems, menopausal symptoms, pain, or untreated depression can all really impair sleep – so try to get them addressed with a healthcare professional where present.
- If insomnia and broken sleep remain an issue after the above steps, consider asking your HD clinician or family doctor if they think a **referral for 'cognitive behavioural therapy for insomnia' (CBT-I)** would be appropriate. This is a highly evidence-based treatment that can really make a difference, and quite a few places now offer it through

a digital app, so no need for face-to-face appointments. For instance Sleepio offers CBT-I, which may be covered by your employer's health care plan in the US and is free through the NHS in the UK.

We still have some way to go before we fully understand the nature and repercussions of sleep problems for people with the HD gene who don't yet have other symptoms. But if we could hit the snooze button on sleep issues, it's tempting to dream that this could help keep people with HD healthier for longer. So while work remains, it's an interesting research area to shine a (night) light on.

The authors have no conflicts of interest to declare.For more information about our disclosure policy see our FAQ...

GLOSSARY

CAG repeat The stretch of DNA at the beginning of the HD gene, which contains the sequence CAG repeated many times, and is abnormally long in people who will develop HD

caffeine stimulant chemical found in tea, coffee and soft drinks like cola

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