

Opinion

Huntington's and the History of Sleep

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Long before I first heard the words Huntington's disease, I had trouble sleeping: difficulty falling asleep, problems staying asleep. Even as a kid I worried about sleep. My therapist father would comfort me, telling me not to worry; resting in bed, he would say, was almost like sleeping: not the advice sleep experts give today. He too had trouble sleeping. My sister Nancy, on the other hand, has been a gifted sleeper most her life. From the time she was little, she could fall asleep instantly at night, in the car on road trips, and on planes during long flights. Mostly she stayed awake and alert during the day.

Her sleep changed as Huntington's symptoms emerged, long before her diagnosis. She began falling asleep during the day, dozing off at meetings or in front of her computer. I attributed her daytime sleepiness to her overbooked schedule and lack of time in bed due to heavy professional and social commitments. With her diagnosis—followed several months later by the pandemic—she began staying up extremely late; she awoke more often during the night and had more difficulty returning to sleep; she slept late, sometimes past noon, though once awake, she usually remained so. No matter if her partner without Huntington's followed a regular timetable, going to bed and awakening at more or less his typical workday hour, Nancy's pattern did not adapt. Even as her Huntington's progresses, my sister remains a free spirit. With few externally-imposed commitments, she can follow her circadian rhythms wherever they take her, though not without pressures from others in the household to follow a more conventional

schedule; that includes me when I visit from across the country. I too have tried to discourage her owl-like habits, perhaps more for my benefit than hers. She and I joke that the hours when we are both awake form a narrow window of opportunity.

Since seven or eight hours of good sleep is widely acknowledged to influence the cognitive, emotional, and physical well-being of people without Huntington's, I am excited to see the increasing interest of neuroscientists and clinicians in improving the sleep of people with Huntington's. I'm encouraged by their enthusiasm for more research and clinical trials in this field. At the same time, thinking as an historian, I began this essay curious to know if current understandings of 'good' sleep have been shared throughout time and across cultures, dictated by our fundamentally similar human biology. I discovered that, as the historian Benjamin Reiss [1] put it, "what passes for 'normal' sleep today in the US and the West is, by any historical standard, quite strange" (p. 23). Another historian, Roger Ekirch [2], has found evidence that the typical pattern of sleep in the West before the modern industrial age was segmented sleep, and that "until the close of the early modern era, Western Europeans on most evenings experienced two major intervals of sleep bridged by up to an hour or more of quiet wakefulness" (p. 300). By the early nineteenth century, the industrial revolution and the invention of electricity, along with the growing pervasiveness of artificial light, helped push sleep times later and toward a more consolidated single stretch of sleep. It was not until the late nineteenth century, according to Ekirch [3], that physicians began viewing nighttime awakening as abnormal

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(pp. 183-184). Even then, as anthropologists such as Brigitte Steger and Lodewijk Brunt have proposed, differing sleep cultures—monophasic, biphasic, and polyphasic—persisted. The Japanese practice of *inemuri*, or napping in public, and the Mediterranean siesta are just two examples [4].

It is striking, then, that, neuroscientists on the one hand, and historians and anthropologists on the other, appear at times to talk about sleep across a conceptual abyss. On one side neuroscientists such as Matthew Walker [5] insist that “there is no biological rhythm—of brain activity, neurochemical activity, or metabolic activity—that would hint at a human desire to wake up for several hours in the middle of the night” (p. 70). On the other side, historians have presented credible evidence that many ordinary men and women in preindustrial Western Europe and the UK did sleep in two phases with an hour or so of wakefulness in between. (Whether this was refreshing restorative sleep, however, seems unclear; Ekirch [1] himself has speculated that common descriptions of early modern laborers as lethargic, erratic, and slothful could indicate a state of chronic fatigue (pp. 298-299)).

Of course, sleep changes in Huntington's and other neurodegenerative disorders go far beyond increased night awakenings, with evidence of inefficient as well as interrupted sleep. But I wonder if historical and

anthropological evidence about the wide variability of human sleep practices, over time and across classes and cultures, could be useful to discussions of Huntington's and sleep, at the very least by compelling us to keep questioning how we define ‘natural’ and ‘normal’ sleep. As a Huntington's disease family member, historian, and poor sleeper, I would love to see what conversations across these disciplinary borders could suggest. It does not seem farfetched to imagine that such dialogue might give rise to novel research questions and even produce innovative strategies to test in the lab and in the clinic, to benefit those living with Huntington's like my sister, and by the way, everyone else as well.

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