

# Virtual Mentor

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## CLINICAL CASE

### **Weighing the Duty to Inform a Patient of Possible Future Illness**

Commentary by Shannon Sullivan, MD

Mr. Watts went to see Dr. Pass, a specialist in sleep disorders, because of his history of violent behavior during sleep. Although Mr. Watts didn't have any complaints, his wife was extremely frightened by the episodes of shouting, kicking, and punching that would occur while her husband was sleeping, usually in the early morning hours. After conducting a thorough history and physical exam, Dr. Pass was certain that the diagnosis was idiopathic REM sleep behavior disorder. Although Mr. Watts had always been healthy, Dr. Pass had seen in the literature that, with this diagnosis, Mr. Watts—now 58 years old—had a significant chance of developing a neurodegenerative disease within the next 10-15 years. He wondered whether he should tell Mr. Watts about his risk, given that there was some chance that he would not develop neurodegenerative disease. Whether or not he developed more serious disease later, Mr. Watts, currently an active, working attorney, might experience depression and grief if he were informed of this possibility. To complicate matters even more, there was nothing Mr. Watts or Dr. Pass could do now to prevent or delay onset of the disease.

### **Commentary**

REM sleep behavior disorder (RBD) is a parasomnia that occurs during REM sleep and involves loss of normal REM-related skeletal muscle atonia. It is often associated with motor activity and the acting out of one's dreams [1]. The condition is more common in men than in women and is often characterized by violent behaviors. Those with RBD have more aggressive dreams than those without the disorder, but this tendency does not carry over into the waking hours.

It has been proposed that many patients with "idiopathic" RBD are actually exhibiting early clinical signs of an evolving neurodegenerative disorder [1]. Current data indicate that approximately two-thirds of men aged 50 and older who are diagnosed with this disorder go on to develop Parkinson's disease or a linked condition, dementia with Lewy bodies [2]. The average interval between the onset of RBD and the onset of classic Parkinson's disease is about 13 years, but the time span can vary greatly. Interventions are available to treat the symptomatic manifestations of RBD, but there is no reliable neuroprotective treatment to slow onset or to reduce the risk of Parkinson's disease. Ongoing research in this area could produce such protection within a decade.

### **Ethical Considerations**

Dr. Pass has a duty to make relevant information available to his patient [3]. This is one application of the principle of beneficence—the notion that the practitioner must act in the best interests of the patient. But this same duty to act in the patient’s best interest also invokes the principle of autonomy, which recognizes that competent individuals have a right to make their own health care decisions. Mr. Watts should be informed that his RBD places him at increased risk for being diagnosed with a neurodegenerative disease in the future because it may be important for planning and making decisions about relationships, retirement, finances, and travel. Although there is no neuroprotective treatment available now, Mr. Watts might benefit from discoveries made between the present and the onset of disease, if indeed he falls ill. Without knowledge of his increased risk, he will not be able to take advantage of new interventions should they become available. In these ways, information about his condition is likely to be relevant to Mr. Watts and should be communicated to him. Dr. Pass may also feel that withholding information about a patient’s health status is dishonest, insofar as omission of important details about his risk for disease is akin to avoiding part of the truth, as it is understood among experts in the medical community.

On the other hand, Dr. Pass must balance the duty to inform his patient with the principle of nonmaleficence, the ethics term for “first, do no harm.” One can argue that imposing on Mr. Watts the psychological burden of knowing that he is at increased risk for a neurodegenerative disease associated with dementia is not justifiable. This may be especially true if Dr. Pass has reasonable clinical suspicion that such knowledge will prompt Mr. Watts to develop depression or exacerbate other conditions, such as anxiety, that will impact his overall well-being. There is, after all, a reasonable chance (about 33 percent) that Mr. Watts will not develop neurodegenerative disease. Even if he is diagnosed in the future, the time until onset may be so long as to minimize the beneficial value of being informed now—a type of “future discounting.” If knowledge of disease risk is disclosed now, Mr. Watts will be burdened by the possibility of neurological deterioration at any time. Dr. Pass may deem these considerations, in combination with the lack of available treatment options, as insufficient justification for imposing potential emotional and psychological distress.

Dr. Pass may harm Mr. Watts to some degree either by informing him of the risk or by withholding the knowledge of future disease. Dr. Pass must weigh his duty to avoid psychologically burdening his patient unnecessarily against his duty to be truthful and forthcoming with important information and Mr. Watts’s right to know relevant medical information that may affect his future.

## References

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3. American Medical Association. Principles of medical ethics. *Code of Medical Ethics*. Chicago, IL: American Medical Association; 2008. <http://www.ama-assn.org/ama/pub/category/2512.html>. Accessed July 30, 2008.

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