



# The real malady of Marcel Proust and what it reveals about diagnostic errors in medicine



Yellowlees Douglas\*

Clinical and Translational Science Institute, University of Florida, Gainesville, FL 32611-7150, USA

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## ABSTRACT

Marcel Proust, author of *À La Recherche du Temps Perdu*, was considered a hypochondriac not only by the numerous specialists he consulted during his lifetime but also by every literary critic who ventured an opinion on his health, among them several clinicians. However, Proust's voluminous correspondence, as detailed in its attention to his every symptom as his novel, provides valuable clues to Proust's real, organic, and rare illness. Proust, in fact, was not only genuinely ill but far sicker than he even he believed, most likely suffering from the vascular subtype of Ehlers–Danlos Syndrome. Ironically, Proust's own doctors and his clinician-critics replicated the same kinds of diagnostic errors clinicians still routinely make today, shedding light on the plight of patients with rare illnesses.

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## Introduction

Literary history teems with hypochondriacs, but none as famous or prolix as Marcel Proust, who lovingly documented his every ache, fever and bout of dyspepsia in a correspondence nearly as voluminous as the pages of his novel *À La Recherche du Temps Perdu*. No commentary on Proust is complete without mention of his hypochondria, evidenced most recently in Alain de Botton's *How Proust Can Save Your Life*, [1] just as no history of famous hypochondriacs is complete without mention of Proust, who cropped up most recently in Brian Dillon's recent *Nine Hypochondriacs* [2]. The ranks of commentators on Proust's hypochondria even include several clinicians [3,4], one of whom dedicated an entire monograph to Proust's morbid preoccupation with his own ill health which, every commentator agrees, amounted to little more than relatively mild asthma exacerbated by peculiar dietary, sleep, and living habits.

This picture of Proust has only a single, but rather substantial problem, lurking in it. The same loving catalogue of aches and fevers also reveals that Proust was suffering from an organic and visceral illness. In fact, if one reads Proust's correspondence with an eye not toward branding him a self-obsessed neurasthenic but toward understanding what afflicted him, one understands that Proust was not only genuinely ill—but almost certainly more seriously ill than even he imagined himself to be.

## Hypothesis

The more one considers Proust's case, the more striking and puzzling the unanimous agreement about his hypochondria. However, the explanation for his literary critics' reactions is simple. No one who complained of ill health at such length and in such detail could be genuinely ill and still manage an output of three million published words in a career begun relatively late in life. In contrast, the response of the clinicians requires more unraveling and sheds some light on diagnostic errors in medicine—and on the fate of patients with rare, multi-systemic diseases. Proust, as a differential diagnosis of his extensively-chronicled symptoms reveals, most likely suffered from Ehlers–Danlos Syndrome, the somatic disorder that accounts comprehensively for every one of his multi-factorial and multi-systemic symptoms that so puzzled his doctors.

## Evidence

### What ailed Proust: a differential diagnosis

On one point, Proust's commentators all agree: the writer suffered from asthma, evident from his first attack at age ten. If we disregard the belief, held by clinicians in Proust's day through the fifties, that asthma resulted from a morbid craving for maternal affection [5], what is most striking about Proust's symptoms is that complaints about his breathing account for less than half his reports on his bodily afflictions. The rest concern the state of his stomach and bowels, with a small proportion dedicated to bodily aches and pains, as well as intermittent fevers departing as mysteriously as they arrive. Nor were these complaints due to either

\* Tel.: +1 (352) 273 3215.

E-mail addresses: [yellowleesdouglas@gmail.com](mailto:yellowleesdouglas@gmail.com), [yellowleesdouglas@icloud.com](mailto:yellowleesdouglas@icloud.com)

Proust's predilection for self-medicating or to the bizarre practices he adopted to avoid what he believed were triggers for his asthma. These practices included seldom venturing outdoors in daylight and remaining shut in a sealed bedroom, burning fumigation powders, lying swaddled in blankets and coats before a fire that blazed year-round. On the contrary, his complaints about his sinuses, stomach, bowels, and joints long pre-date his attempts to accommodate them, as evidenced in early letters to his mother during a period in which he was living and eating normally.

Most significantly, Proust's letters chronicle a long history of gastrointestinal complaints, including bloating, stomach pain, diarrhea and what gastroenterologists would recognize as early satiety. If he drank more than a quarter-glass of Vichy water prior to bedtime, nine or ten hours after consuming his evening meal [6], he reported feeling full. By his late twenties, Proust complained of being unable even to lie down, let alone sleep, within eight hours of eating. These same symptoms also afflicted his father's sister, Élisabeth Amiot, the model for Tante Leonie in *À La Recherche du Temps Perdu* and an invalid for much of her life [6]. While some of the digestive problems Proust describes could be caused by dyspepsia, his early satiety and feeling full for prolonged periods after eating point to a single possibility: gastroparesis or significantly delayed gastric emptying. While standards vary among gastroenterologists in classifying the length of the delays in gastroparesis, most agree that any patient with more than 10% of a meal retained after four hours exhibits some degree of gastroparesis with severe cases involving delays of anywhere from five to sixteen hours [7]. Gastroparesis results in bloating, abdominal discomfort, refractory gastroesophageal reflux or GERD, and chronic nausea with vomiting and occasional diarrhea stemming from the stomach simply dumping its contents, largely undigested, after hours of gastric inactivity [8]. In his correspondence, Proust complains of every one of these symptoms associated with gastroparesis, in addition to numerous sore throats, most likely the product of GERD. Proust's gastroparesis was also responsible for his celebrated abstemious diet, widely reported in his correspondence and confirmed by his housekeeper to have consisted during the last decades of his life of a croissant and two bowls of café au lait [9]. If Proust's gastric emptying were delayed for anything approaching the six to eight hours he reports, his gastroparesis was both severe and far from imaginary. But his gastroparesis also holds the key to what really ailed the writer, as gastroparesis can be symptomatic of serious, multi-systemic disorders.

While 8% of patients contract gastroparesis through viral infection [10], Proust, a scrupulous reporter of sniffles, aches, and bloating, never reports anything approaching the symptoms of a gastrointestinal infection. Nor does he report symptoms congruent with the other common causes of gastroparesis, which include diabetes or the use of opioids [11] like the heroin he once asked his mother to procure for him [12]. While the use of opioids can cause both gastroparesis and the constipation Proust occasionally reported, he only reported taking trional and heroin years after he first mentioned symptoms of gastroparesis [12]. Ironically, the sedatives and painkillers Proust used to dampen the discomfort caused by his gastroparesis ended up exacerbating the very symptoms he was attempting to alleviate [13]. During his last months, Proust suffered from edema and also reported results of an earlier urinalysis that found glucose in his urine, which could have resulted from diabetes. But, given Proust's complaint that he urinated very little for years [6], his symptoms are hardly congruent with the excessive thirst, frequent urination, and complications that would have accompanied diabetes, especially given a diet consisting almost solely of carbohydrates that would have exacerbated the disease.

Proust is equally unlikely to have suffered from the other diseases most likely to have caused his gastroparesis, which include

lupus and hypothyroidism, as well as infections such as tuberculosis and syphilis. Contemporaries described Proust as "wraithlike" even during the years when he was attempting to eat robust meals [12], exhibiting the pallor, loss of appetite, and weight loss consistent with tuberculosis [14]. Proust, of course, had a prolonged cough, also consistent with a diagnosis of TB. However, the writer's cough was notably non-productive, even during his final weeks, when his brother, clinician Robert Proust, was certain the writer suffered from a lung abscess [9]. Moreover, if tuberculosis were the source of Proust's cough, not asthma, giving rise to the fatigue, weight loss, and gastroparesis that afflicted Proust from his childhood onward, the disease would have progressed during the writer's adulthood, with the secondary TB lesions spreading to other parts of the body, most commonly the kidneys, lymph nodes, brain, and bones. However, Proust neither exhibited evidence of any other symptoms of TB, nor did his brother or the veritable army of other specialists he saw ever diagnose him with TB.

Proust's malaise, fatigue, and gastroparesis are also symptomatic of hypothyroid disease, which could also have caused his alternating bouts of diarrhea and constipation [10,15]. Proust's sensitivity to cold is also consistent with a diagnosis of hypothyroidism [16]. However, Proust never reports any of the other symptoms hypothyroidism would have also caused, particularly the hoarse voice and dry skin that are most commonly linked to the condition, which also tends to affect women far more commonly than men [16].

Similarly, Proust, who had his symptoms and even his urine scrutinized by clinicians throughout his life, also never exhibited signs of syphilis, which in its primary stage, would have resulted in a chancre, albeit one on the writer's penis or rectum, a place he was unlikely to have invited a clinician to inspect. Moreover, Proust, in his letter to his brother, written in his thirties, asks his brother whether he should be taking calomel and sugar or mercury enemas, ostensibly for the worms he believes are causing his asthma [12]. Mercury had been long used as a cure for syphilis, which doctors had discovered was poorly absorbed by the bowel but worked best when administered orally as mercurous chloride—known as calomel [17]. Moreover, metallic mercury was also commonly used as treatment for syphilis, administered via fumigation [17], and Proust was notorious for burning fumigation powders throughout his adult life. However, throughout the nineteenth and early twentieth century, calomel was also used widely as both a cathartic and diuretic. In addition, fumigation powders were commonly employed as treatment for asthma. Maimonides was the first to counsel patients with asthma to raise the temperatures of their sick rooms through the burning of herbs, and the practice continued into Proust's day [18]. Furthermore, by the late 1880 s, bismuth had largely replaced calomel as treatment of syphilis, with bismuth itself being replaced by the end of World War I by salvarsan [17].

If the evidence is mixed whether Proust suffered from syphilis, however, syphilis is unlikely to have caused Proust's gastroparesis, as he failed to exhibit the most common symptom of secondary or tertiary syphilis, the macular rash found on nearly 90% of syphilis patients [19], despite exhibiting the sore throat, malaise, weight loss, anorexia, and ocular complaints also common to secondary syphilis. Moreover, stomach and bowel dysfunction are symptomatic of tabes dorsalis, a development of late neurosyphilis, which is accompanied by sensory ataxia. Had Proust's neurosyphilis caused his gastroparesis, it would also have caused ataxia, first becoming evident by making Proust unsteady while walking in the dark, then developing into worsening balance and difficulty maintaining a normal gait [20]. As Proust never exhibited any difficulties with his balance or walking and confined his social calls during the latter part of his life to late-night hours, he is highly unlikely to have suffered from neurosyphilis.

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