# Tilly Rose's memoir sheds light on the struggles of chronic illness



Two years ago, Tilly Rose faced what many would consider a devastating moment in her prolonged battle with chronic illness. A hospital consultant advised her that there was nothing more to be done for her condition, merely offering “comfort care” — a term she felt inadequately described her enduring suffering of excruciating pain several times daily. Reflecting on that moment, she said, “He was, essentially, leaving me to die.”

For the past 20 years, Rose, an Oxford graduate, has experienced an extensive medical journey spanning various specialties, including respiratory, gastroenterology, urology, endocrinology, cardiology, and neurology. After enduring numerous health crises, including a burst appendix, emergency bowel resection, recurrent pneumonia, unexplained seizures, and severe nausea, Rose found herself disheartened by the implication from some medical professionals that her constant state of illness implied she somehow preferred being unwell. “Tilly, do you want to be in hospital?” was a common refrain she faced as she laid confined to a hospital bed, far from the life she once imagined.

In a bid for understanding and potential solutions, she took to Instagram under the handle @thattillyrose to summarise her intricate medical history. Within days, she received a flood of responses from other patients, academics, and health professionals, all hoping to unravel her medical mystery and potentially save her life.

Fast-forward three years, Rose has transformed her harrowing experiences into a memoir titled *Be Patient: Life, Loss and Laughter from Behind the Hospital Curtain*. Her book presents not just a medical enigma but also encapsulates her perspective on the duality of the British healthcare system, a system where she encountered both exemplary service and significant shortcomings. It distinguishes itself from Adam Kay’s bestseller *This Is Going to Hurt*, by presenting the oft-overlooked perspective of patients navigating the complexities of healthcare.

Rose hopes her insights reach influential figures in the health sector, such as Wes Streeting, the Secretary of State for Health, asserting the need for awareness regarding the conditions faced by long-term patients. She describes her prolonged illness as “the full-time job you never signed up to and you don’t get paid for,” a sentiment reflective of the challenges endured by the ten million people in Britain classified as chronically unwell.

Now residing in southwest London with her boyfriend, Finn, whom she met during her first term at university, Rose recounts her experiences with unabashed openness, referring to some hospital stays as “the sleepover from hell.” She recounts scenes of inadequate staff support, including lack of basic cleanliness in her surroundings and instances when medical professionals were overwhelmed.

She candidly illustrates her experiences, having witnessed hospital negligence, such as when emergency call bells failed and patients were left unattended. At one point, her mother, Lorraine, took matters into her own hands to assist other patients due to staff shortages, even saving a life during a critical moment when no medical assistance was forthcoming.

Rose articulates the stark reality of life as a patient, noting a disheartening decline in care she experienced over two decades. Her encounters with doctors often revealed a harsh truth about overstretched staff: “I have noticed more and more that a basic level of care has been lost,” she states, while also acknowledging moments of compassion between staff and patients, which, however, were often constrained by systemic issues.

Reflecting on her relationship with the NHS, Rose demonstrated resilience in maintaining an academic life amid her health battles. Despite numerous absences from school and university, she not only graduated but endeavoured to succeed against the odds, fuelled by her desire for a normal life.

The turning point in her medical journey came as she discovered, through suggestions garnered from her online inquiries, the possibility of vascular compressions affecting her organs. With her mother's dedicated research leading them to a world-renowned expert in Germany, Rose underwent vascular compression surgery. This procedure attributed her myriad health issues to hypermobile Ehlers-Danlos syndrome and related complications, confirming her complex medical narrative.

While Rose still maintains her health journey, she holds hopes of leading a more normal life in the future. Her story is set to become a crucial voice for others facing similar challenges. “I don’t blame anyone for not finding out what was wrong with me,” she remarks, highlighting that her experiences have underscored the importance of compassionate communication within medical interactions.

*Be Patient* is set to be published on Thursday, poised to shed light on the realities of living with chronic illnesses and the systemic hurdles faced within the healthcare system.

Source: [Noah Wire Services](https://www.noahwire.com)

## References

* <https://createhealth.com/us/tilly-rose-a-patients-story-of-resilience-red-tape-and-rethinking-rare-disease-care/> - This article highlights Tilly Rose's personal journey with chronic illness and misdiagnosis, underscoring the challenges she faced in the healthcare system and her role as a patient advocate.
* <https://thatoxfordgirl.com/post/national-tuberculosis-day-my-story> - Tilly Rose shares her story of living with undiagnosed active tuberculosis, which she eventually overcame despite healthcare system challenges, and her experiences with rare diseases are documented here.
* <https://rdpodcast4medics.buzzsprout.com/1875024/episodes/12453839-living-with-an-undiagnosed-condition-with-tilly-rose> - This podcast episode features Tilly Rose discussing her experiences with chronic illness and the process of seeking a diagnosis, reflecting on her medical journey and advocacy work.
* <https://www.instagram.com/thattillyrose/> - Tilly Rose uses her Instagram account to share her personal experiences with chronic illness and advocate for patients, offering insights into her health journey and interactions with the healthcare system.
* <https://www.thatoxfordgirl.com/> - Tilly Rose's blog provides additional context to her story, offering insights into her experiences with healthcare and her efforts to increase awareness about chronic illnesses.