# How social media helped Tilly Rose uncover her rare hEDS diagnosis after 20 years



Tilly Rose’s quest for a diagnosis has been anything but ordinary. Over the course of twenty years, she has traversed the harrowing landscape of undiagnosed illness, navigating an array of symptoms that left her repeatedly in and out of hospitals. The culmination of her struggles, chronicled in her book *Be Patient*, reflects not just a personal narrative but a testimony to the complex interactions between patients and the healthcare system, particularly regarding rare conditions like hypermobile Ehlers-Danlos syndrome (hEDS).

From the age of five, Tilly's life has been punctuated by medical emergencies and a seemingly endless search for answers. It wasn't until she reached her teenage years, following a burst appendix and an emergency bowel resection, that the severity of her condition became apparent. Despite extensive consultations and evaluations, none of the doctors could piece together the array of symptoms she experienced. This disjointed approach—doctors focusing solely on isolated parts of her body rather than the holistic picture—mirrored a common issue faced by many patients with chronic illnesses. Often, individual symptoms are treated in isolation, while the underlying causes remain elusive.

In a moment of profound despair, Tilly turned to social media during a troubling hospital stay, where she faced an unthinkable discharge into 'comfort care' without a definitive diagnosis. This choice highlights the growing trend of patients using online platforms to seek not just support, but also essential information regarding their health. Tilly's viral social media post attracted responses from medical professionals, researchers, and fellow patients, ultimately leading to the unearthing of her diagnosis. This mirrors findings from recent studies indicating that patients with hEDS frequently utilise social media platforms to connect, share experiences, and seek advice. An engaged community often rises around such conditions where information can be scarce and difficult to navigate.

Following her active engagement online, Tilly discovered that her symptoms were linked to hypermobile Ehlers-Danlos syndrome, a genetic disorder that affects the connective tissues, causing joint hypermobility and a spectrum of related complications. This diagnosis came as both a frightening revelation and a source of relief—knowing that there was a name for her suffering represented a significant turning point. As the medical community has gradually begun to understand hEDS more comprehensively, the importance of proper diagnostic protocols and patient education has come to the fore.

Healthcare professionals are urged to engage with patients regarding their social media use, as it can be a vital tool for support and education. However, such platforms can also present challenges, with misinformation potentially overwhelming accurate medical advice. It is essential for clinicians to guide patients, fostering an environment where safe and reliable information can be shared and discussed. Tilly’s experience exemplifies the potential of these digital communities; they can transform isolation and confusion into a network of understanding and collaboration.

In her journey, Tilly has demonstrated an extraordinary capacity for resilience. Her book, *Be Patient*, not only chronicles her quest for diagnosis but also reflects on the small acts of kindness that offered comfort throughout her health battles. The encouragement from fellow patients, hospital staff, and the support she found online have instilled a renewed sense of hope in her life. As she continues her advocacy, Tilly aims to raise awareness about patient care and the vital role of community in the healing process.

In a world where the label often precedes treatment in medical practice, Tilly’s narrative emphasises that understanding a patient’s condition is only the first step. True healing encompasses addressing the psychological and social dimensions of chronic illness, ensuring that patients are not merely seen as their conditions but are recognised as individuals with hopes, dreams, and identities beyond their diagnoses. As she looks to the future, Tilly embodies the resilience and optimism that many seek, paving the way for a narrative of hope for others navigating similar challenges.

With a newfound diagnosis and the tools to manage her condition, Tilly Rose exemplifies how the convergence of personal determination and community support can lead to a profound transformation. She hopes to reclaim the 'ordinary' life she has always aspired to, one supported by the knowledge and connections she has garnered along the way.

### Reference Map

1. Paragraph 1: [[1]](https://www.mirror.co.uk/news/health/doctors-couldnt-tell-what-wrong-35210419)
2. Paragraph 2: [[1]](https://www.mirror.co.uk/news/health/doctors-couldnt-tell-what-wrong-35210419)
3. Paragraph 3: [[1]](https://www.mirror.co.uk/news/health/doctors-couldnt-tell-what-wrong-35210419)
4. Paragraph 4: [[1]](https://www.mirror.co.uk/news/health/doctors-couldnt-tell-what-wrong-35210419), [[2]](https://blogs.iu.edu/bioethics/2024/07/24/social-media-use-by-patients-with-hypermobile-eds/), [[5]](https://ehlersdanlosnews.com/news/researchers-urge-doctors-talk-social-media-heds-patients/)
5. Paragraph 5: [[1]](https://www.mirror.co.uk/news/health/doctors-couldnt-tell-what-wrong-35210419), [[4]](https://pubmed.ncbi.nlm.nih.gov/38860470/), [[5]](https://ehlersdanlosnews.com/news/researchers-urge-doctors-talk-social-media-heds-patients/)
6. Paragraph 6: [[1]](https://www.mirror.co.uk/news/health/doctors-couldnt-tell-what-wrong-35210419), [[3]](https://www.chronicpainpartners.com/eds-advocates-to-follow-on-social-media/), [[2]](https://blogs.iu.edu/bioethics/2024/07/24/social-media-use-by-patients-with-hypermobile-eds/)
7. Paragraph 7: [[1]](https://www.mirror.co.uk/news/health/doctors-couldnt-tell-what-wrong-35210419)
8. Paragraph 8: [[1]](https://www.mirror.co.uk/news/health/doctors-couldnt-tell-what-wrong-35210419), [[6]](https://www.ehlers-danlos.com/may-awareness/awareness-materials/), [[7]](https://www.ehlers-danlos.com/community-voices/)

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## Bibliography

1. <https://www.mirror.co.uk/news/health/doctors-couldnt-tell-what-wrong-35210419> - Please view link - unable to able to access data
2. <https://blogs.iu.edu/bioethics/2024/07/24/social-media-use-by-patients-with-hypermobile-eds/> - This article discusses how patients with hypermobile Ehlers-Danlos syndrome (hEDS) utilize social media platforms to seek support, share experiences, and gather information. It highlights both the benefits and challenges of online engagement, emphasizing the importance of critical evaluation of information and the need for healthcare professionals to guide patients in navigating these platforms effectively.
3. <https://www.chronicpainpartners.com/eds-advocates-to-follow-on-social-media/> - This resource provides a curated list of EDS advocates active on social media, offering insights into their personal experiences, educational content, and support networks. It serves as a valuable tool for individuals seeking community and information related to EDS, showcasing diverse voices and perspectives within the EDS community.
4. <https://pubmed.ncbi.nlm.nih.gov/38860470/> - This study examines the social media usage patterns of patients diagnosed with hypermobile Ehlers-Danlos syndrome (hEDS). It identifies key themes such as connecting with others, seeking information, and the associated risks, providing evidence-based suggestions for clinicians to engage with patients regarding their online activities.
5. <https://ehlersdanlosnews.com/news/researchers-urge-doctors-talk-social-media-heds-patients/> - This article reports on research urging healthcare providers to discuss social media use with patients diagnosed with hypermobile Ehlers-Danlos syndrome (hEDS). It emphasizes the role of social media in connecting patients, sharing information, and the need for clinicians to guide patients in navigating online resources effectively.
6. <https://www.ehlers-danlos.com/may-awareness/awareness-materials/> - This page offers various materials and initiatives aimed at raising awareness for Ehlers-Danlos syndromes (EDS) and hypermobility spectrum disorders (HSD). It includes translated brochures, social media frames, and information on global awareness days, providing resources for individuals and communities to engage in awareness efforts.
7. <https://www.ehlers-danlos.com/community-voices/> - This section features personal stories and experiences from individuals living with Ehlers-Danlos syndromes (EDS) and hypermobility spectrum disorders (HSD). It includes contributions from various community members, offering diverse perspectives and insights into the challenges and triumphs of living with these conditions.