# Milly’s battle with Lyme disease highlights systemic gaps in NHS care for complex chronic conditions



Milly’s prolonged struggle with a chronic fatigue illness, initially diagnosed as ME/CFS but later identified as Lyme disease, underscores significant challenges within the NHS in diagnosing and managing such complex conditions. Her father, Patrick Barkham, recounts their exhausting and painful journey seeking answers, a story emblematic of many families grappling with persistent physical symptoms that elude straightforward medical solutions. Despite his feelings of guilt, experts affirm that the responsibility does not lie with him but rather with systemic shortcomings in care and understanding.

Chronic fatigue conditions like Milly’s often fall under the umbrella of “persistent physical symptoms,” which arise when the body’s natural defence mechanisms become dysregulated. Current evidence-based approaches emphasise the interconnectedness of brain, thoughts, feelings, and physical activity, recommending tailored rehabilitation plans built on patients understanding how their symptoms relate to the body’s danger signalling systems. Recent rigorous clinical trials in Norway, examining both post-Covid conditions and medically unexplained symptoms, have validated the efficacy of such mind-body approaches. However, it appears that in Milly’s case, the implementation was flawed, leading her to internalise guilt over symptoms that are not her fault—an emotional barrier known to impede recovery.

The complexities around treatments for chronic fatigue illnesses remain deeply contested. For example, pacing—managing energy to avoid exacerbation—is widely recommended and accepted as beneficial, while graded exercise therapy, which promotes gradual increases in physical activity, has been discredited due to evidence of harm and lack of effectiveness. This distinction is crucial yet often misunderstood, contributing to patient frustration and mistrust in medical advice. Such missteps exemplify broader dissatisfaction reported by ME/CFS patients in healthcare systems, with many feeling abandoned post-diagnosis and left with little effective support.

The debate extends into contested diagnoses such as chronic Borrelia infections in Lyme disease, where reliable links to symptoms remain elusive, and the efficacy of long-term antibiotics has yet to be convincingly demonstrated. Harvard Health highlights symptom management strategies, including stimulant medications to alleviate cognitive and fatigue symptoms, underlining the necessity for close clinical supervision and personalised treatment plans.

Adding to the clinical challenges, environmental factors increasingly come into focus. Warmer climates and ecological changes have led to expanding populations of ticks and mosquitoes in regions like the UK, raising concerns about the spread of vector-borne diseases similar to Lyme and other tropical illnesses. This emerging medical risk demands a nuanced balance between promoting biodiversity and public health vigilance, an issue that has historically received limited attention in medical research.

Amid these medical uncertainties and evolving landscapes, patient perspectives and lived experiences remain central. Stories like Milly’s highlight the urgent need for compassionate, evidence-based care that addresses both physical and psychological dimensions of chronic fatigue conditions. They also stress the importance of continued research to deepen understanding, refine diagnosis, and develop effective treatment frameworks—offering hope that recovery is achievable despite the complexities involved.

### 📌 Reference Map:

* Paragraph 1 – [[1]](https://www.theguardian.com/world/2025/oct/03/failed-by-the-nhs-on-chronic-fatigue-illness), [[2]](https://www.theguardian.com/world/2025/oct/03/failed-by-the-nhs-on-chronic-fatigue-illness)
* Paragraph 2 – [[1]](https://www.theguardian.com/world/2025/oct/03/failed-by-the-nhs-on-chronic-fatigue-illness), [[3]](https://www.sciencenorway.no/chronic-fatigue-syndrome-covid19-me/chronic-fatigue-conditions-are-not-incurable/2439883)
* Paragraph 3 – [[1]](https://www.theguardian.com/world/2025/oct/03/failed-by-the-nhs-on-chronic-fatigue-illness), [[4]](https://meassociation.org.uk/2023/11/me-cfs-research-published-24-30-october-2023/)
* Paragraph 4 – [[1]](https://www.theguardian.com/world/2025/oct/03/failed-by-the-nhs-on-chronic-fatigue-illness), [[5]](https://www.lyme.health.harvard.edu/managing-symptoms/)
* Paragraph 5 – [[1]](https://www.theguardian.com/world/2025/oct/03/failed-by-the-nhs-on-chronic-fatigue-illness)
* Paragraph 6 – [[1]](https://www.theguardian.com/world/2025/oct/03/failed-by-the-nhs-on-chronic-fatigue-illness), [[6]](https://www.ncbi.nlm.nih.gov/books/NBK613143/), [[7]](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10122830/)

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## Bibliography

1. <https://www.theguardian.com/world/2025/oct/03/failed-by-the-nhs-on-chronic-fatigue-illness> - Please view link - unable to able to access data
2. <https://www.theguardian.com/world/2025/oct/03/failed-by-the-nhs-on-chronic-fatigue-illness> - An article from The Guardian discusses the challenges faced by a patient named Milly, who was initially diagnosed with ME/CFS but later found to have Lyme disease. The piece highlights the difficulties in diagnosing and treating chronic fatigue illnesses within the NHS, emphasizing the importance of accurate diagnosis and appropriate treatment plans.
3. <https://www.sciencenorway.no/chronic-fatigue-syndrome-covid19-me/chronic-fatigue-conditions-are-not-incurable/2439883> - An opinion piece from ScienceNorway challenges the practice of prolonged rest and reduction of social and sensory stimuli as methods for managing chronic fatigue conditions. The authors advocate for raising awareness that improvement and recovery are possible for individuals living with chronic fatigue conditions, based on extensive research and clinical experience.
4. <https://meassociation.org.uk/2023/11/me-cfs-research-published-24-30-october-2023/> - A report from The ME Association summarises recent research on ME/CFS, including a study that found patients with ME/CFS in Norway experienced dissatisfaction with healthcare services, with many reporting that services had nothing to offer them after receiving their diagnosis.
5. <https://www.lyme.health.harvard.edu/managing-symptoms/> - Harvard Health discusses managing symptoms of Lyme disease, noting that stimulant medications may help with symptoms including brain fog, concentration issues, fatigue, and sleep disorders. The article advises working closely with a doctor to find the right dose and duration of treatment.
6. <https://www.ncbi.nlm.nih.gov/books/NBK613143/> - An evidence map summarising myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) research from 2018 to 2023. The map includes studies on the causes, diagnosis, assessment, and management of ME/CFS, highlighting the need for further research to inform future studies.
7. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10122830/> - A case study published in the Open Journal of Clinical and Medical Case Reports discusses a patient with long COVID who attempted self-rehabilitation. The study highlights the challenges and complexities of managing long COVID symptoms and the importance of a comprehensive treatment approach.