specialist. If there is a knowledgeable doctor in a practice, a **Limitation of Consent** form is downloadable from barrister Valerie Eliot-Smith's site. See page 6.

File Complaints and Seek Legal Advice: Patients can file formal complaints with governing bodies and involve their MP. If a doctor's neglect or disbelief leads to harm, patients or their families may consider seeking legal counsel, especially in cases of gross negligence. When all available routes have failed, it has proven necessary to use the media and employ an ME-literate solicitor.

Involve Patient Advocacy Groups: Patient organisations, such as the ME Association, and The 25% ME Group (which supports severely ill patients), can offer advocacy support, legal guidance, and resources.

Ensure Proper Documentation: Patients should meticulously document all interactions with medical professionals, including all dates, interventions suggested or denied, and any dismissive comments. This record can serve as evidence in potential legal proceedings or complaints.

Prevention of Future Deaths: Patients with ME facing medical neglect, inappropriate treatment, or denial of essential nutritional support can use Coroner Deborah Archer's 2024 Section 28 report as a compelling advocacy tool. While not mandatory, this report exerts significant legal, reputational, and regulatory pressure on healthcare providers. Patients may request urgent intervention from hospital management, escalate concerns to the Care Quality Commission (CQC), or seek legal action, if necessary.

A Coroner's Section 28 Notice—also known as a "Prevention of Future Deaths" (PFD) report—is a formal warning issued under Schedule 5, Paragraph 7 of the Coroners and Justice Act 2009 and Regulation 28 of the Coroners (Investigations) Regulations 2013.

This particular report was issued following the inquest into the death of Maeve Boothby-O'Neil, who died of starvation after her hospital refused to provide a feeding tube. In a grave misjudgement, her consultant, believed that doing so would 'medicalise' her illness.

CONCLUSION

The denial of ME as a legitimate disease by some doctors is a gross injustice, causing unnecessary suffering and contributing to premature deaths. With mounting scientific evidence, revised NICE guidelines, and legal protections like Montgomery's Law, patients and their advocates have powerful tools to fight for appropriate care. By asserting their rights, seeking legal redress, and raising awareness, ME patients can challenge medical negligence and demand the compassionate,

LINKS TO AUTHORITATIVE SOURCES

Aim your phone's camera at the QR code and click the bit.ly link to automatically visit the website on your phone.

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: the biology of a neglected disease: bit.ly/biologyofME

Cardiovascular Disturbances Strongly Interact to Severely Affect Tissue Perfusion and Mitochondrial Function in ME/CFS Evolving from the Post COVID-19 Syndrome: bit.ly/cardiomitochondrialME

NICE care recommendations for severe and very severe ME (NICE NG 206 1.17): bit.ly/NICEsevereMEcare

Barrister Valerie Eliot Smith's **Limitation of Consent** form: bit.ly/limitationofconsent

Coroner's Section 28 Notice, "Prevention of Future Deaths" bit.ly/futuredeaths

When Your Doctor Denies the Existence of ME

BY JENNY WILSON
Associate Member of Doctors with ME

Myalgic Encephalomyelitis (ME) is a devastating neuroimmune disease that can be progressive and even fatal. It severely impacts patients' lives, leaving many bedridden in darkened rooms, unable to care for themselves. Even those with mild ME experience at least 50% disability.

Patients with very severe ME experience continuous Post-Exertional Malaise (PEM) / Post-Exertional Symptom Exacerbation (PESE) and cannot tolerate additional exertion or stimulation. Forcing them to exceed their anaerobic threshold—even in minor ways—has led to cardiac arrest and death in some cases.

Despite decades of scientific research, and compelling autopsy findings, many doctors continue to deny the existence of ME, dismissing it as psychosomatic or the result of deconditioning. This disbelief leaves severely ill patients in a perilous position, deprived of adequate medical care and validation.

> "The EQ-5D-3L-based HRQoL (Health-Related Quality of Life) of ME/CFS is the lowest of all the compared conditions, such as chronic renal failure, bleeding ulcer, lung cancer, rheumatoid arthritis."
>
> —Peer-Reviewed Danish Article, 2015

When faced with this level of medical negligence, patients and their advocates must be aware of the scientific evidence supporting their condition, their

rights, and the legal avenues available to challenge such harmful interventions.

SUPPORTING ME AS A BIOLOGICAL DISEASE

ME is a complex multisystem disease. In 1969 it was recognised by the World Health Organization (WHO) as a neurological condition (ICD-10 G93.3). Biomedical research dating to the late 20th century has provided clear evidence of immune, cardiovascular, neuroinflammation, endocrine, metabolic dysfunction, and viral persistence in ME patients.

Deaths from ME: There have been confirmed deaths directly attributed to ME, particularly due to starvation when doctors fail to provide appropriate means of nutrition. Cases such as Brynmor John MP, Sophia Mirza, Emily Collingridge, Kara Jane Spencer, Merryn Crofts, Stella James, and Maeve Boothby O'Neil demonstrate the severity of the disease. Coroners confirm that ME is a prime cause of death, highlighting its potential lethality.

Autopsy Results: Autopsy findings in ME patients have revealed significant pathological abnormalities. Postmortem examinations of individuals who died with or from ME have identified active enteroviral infection, inflammation, and evidence of a degenerative process in the brain and spinal cord, including dorsal root ganglionitis. Additionally, findings such as cardiac fibrosis and kidney damage further confirm the disease's impact on both the nervous system and major organs.

Research Findings: Further studies have demonstrated low natural killer (NK) cell function, elevated cytokines, mitochondrial dysfunction, severe endothelium damage, cerebral hypoperfusion, and severe hypovolaemia in ME patients, confirming a biological basis for the disease. These findings counter the long-standing narrative that ME is merely a form of psychological distress or deconditioning.

THE ROLE OF THE WESSELY SCHOOL

The dismissal of ME as a legitimate disease can largely be traced to the influence of the Wessely School, (see Hansard 1998) a group of mostly psychiatrists who promoted the notion that ME is a psychosomatic disorder, contrary to the overwhelming evidence at the time that it was a serious biomedical disease. Their Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) approach dominated ME treatment guidelines for years, despite mounting evidence of its ineffectiveness and harm.

NICE Guidelines and Their Revision: The National Institute for Health and Care Excellence (NICE) in the UK, were influenced by the Wessely School, and in 2007, endorsed CBT and GET as treatments for ME. However, in 2021, NICE updated its guidelines, explicitly rejecting GET due to the overwhelming evidence that it causes harm, particularly in severely ill patients. The updated guidelines called for personalised, supportive care instead of psychological interventions.

Ongoing Stigmatisation: Despite the new guidelines, the legacy of the past inappropriate psychiatric involvement in the disease has left a damaging imprint, with many doctors still viewing ME as a mental health issue. This leads to gaslighting, neglect, and the refusal of appropriate care for ME patients, perpetuating and exacerbating their suffering and sometimes hastening their deaths.

Legal Protections and Patient Rights: When a doctor refuses to acknowledge ME, patients and their families can invoke legal protections. Some key legal principles and laws protect patients' rights:

- **Montgomery's Law (2015):** This landmark UK Supreme Court ruling established that doctors have a legal duty to inform patients of all material risks of proposed interventions properly. In the context of ME, this means that doctors must inform patients

of the potential harms of interventions like any form of exercise therapy, and the use of medications, anaesthetics and procedures that can worsen the disease. Failure to do so could constitute negligence.

- **Duties of a Doctor:** According to the General Medical Council (GMC), doctors must "provide a good standard of practice and care" and "take prompt action if patient safety is compromised." Refusing to recognise a legitimate disease, dismissing evidence-based care, false accusations of Fabricated or Induced Illness (FII), unnecessary Safeguarding alerts, or offering harmful interventions could breach these professional standards, giving patients grounds for complaints or legal action.
- **Gross Negligence Manslaughter:** In cases where medical neglect leads to the death of a patient, gross negligence manslaughter charges may apply. For example, if a doctor refuses to recognise ME, ignores the NICE guidelines without sound reason, withholds care such as failing to provide an appropriate system of nutrition, or recommends interventions that can potentially worsen the patient's condition, they could face serious legal consequences if they harm the patient to the degree that it causes death.

WHAT THE CARERS OF ME PATIENTS CAN DO

When a doctor denies the existence of ME, their caregivers can take several steps:

Assert Their Rights with Evidence: Patients can present evidence-based guidelines, such as the updated 2021 NICE guidelines, and research findings demonstrating the biological nature of ME. Providing printouts or links to peer-reviewed studies and reports from ME organisations can be effective in challenging misinformation.

Request a New Doctor or Specialist Referral: If a GP or specialist dismisses the diagnosis, patients can request a second opinion or referral to an ME-literate