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## The latest thinking on chronic fatigue syndrome

For decades, ME has been the subject of controversy among doctors, patients and the public. Conflicting views on the cause and treatment of this debilitating illness have been rife, with patients caught in the crossfire. Sally Turner, who spent years housebound with ME, uncovers the latest thinking on the illness.

Please note that this article has been superseded by updated guidance from the National Institute for Health and Care Excellence (NICE). The latest evidence on their recommendations can be found in our leaflet on **Chronic Fatigue Syndrome**.

[Myalgic encephalomyelitis \(ME\)](#), also referred to as chronic fatigue syndrome (CFS), is thought to affect around 250,000 people in Britain and 17 million people worldwide – children as well as adults. One [study](#), published last year, estimated that the annual economic cost of ME/CFS to the nation in relation to lost income, benefits and health costs was at least £3.3 billion, yet the illness has long been plagued by controversy.

ME involves a range of debilitating symptoms that characteristically fluctuate in severity, but is characterised by 'profound and disabling activity-induced fatigue which almost always affects both physical and mental functioning. The fatigue and other symptoms are not caused by ongoing excessive exertion and are not relieved by rest' ([The ME Association](#)).

Dr Charles Shepherd, medical adviser to the ME Association, explains: "We use ME, even though it doesn't fully describe the symptoms, because many people have chronic fatigue for different reasons, whereas ME is a specific disease process."

# Living with ME

In 1984, aged 14, I contracted what my GP referred to as a 'glandular fever-related virus'. My swollen glands and fever disappeared after a couple of weeks, but I was left with painful muscles, clouded cognitive function and crushing fatigue after minimal exertion; walking to the corner shop, sitting in a lesson at school, and even an animated chat on the phone to a friend would leave me barely able to function for hours, sometimes days at a time.

My GP said it was 'post-viral malaise' - it took a year, but eventually the symptoms subsided; I was over it, or so I thought.

Then, more than a decade later, aged 28, I was fighting off a nasty flu bug while also trying to manage an acutely stressful situation at work. Suddenly the symptoms returned, and with far greater severity.

Too ill to work, I lost my job, and then my financial independence, active social life and self-esteem. It would take me seven years to recover, and I spent most of that time more or less housebound. Today I'm able to work and exercise, but still have a flare-up of symptoms from time to time, and I get frequent viral infections which it takes a lot longer than average to recover from.

## What causes ME?

"Emerging research suggests that ME is a complex, multi-system disease that involves abnormalities in muscle, brain and immune system function," says Shepherd.

"We now think there's a genetic predisposition to developing it when the right trigger appears. There is a strong degree of consensus that infections are a major factor - vaccinations and pesticide pollution may also be triggers for some people, and undue physical or mental stress at the time of the initial infection may also play a role, but we still have disagreements about what maintains and perpetuates the illness."

During an infection, the immune system releases chemicals called cytokines which are what makes us feel 'flu-like' and under par. Research has shown that in people with ME, cytokine levels are raised, indicating an ongoing overactive immune response.

"Another finding is that some people with ME have an autoimmune component to their illness; they produce auto-antibodies which act against their own tissues," explains Shepherd. "We also know there are abnormalities in mitochondria [organelles in our cells that produce energy], and other research has demonstrated disturbances to the hypothalamus in the brain, a gland which helps control temperature regulation, appetite and sleep."

The autonomic nervous system is also involved and issues with the nerve signals that pass to the heart, bladder and bowels may cause problems.

"There's quite a lot of comorbidity going on," says Shepherd. "People with ME may report [migraine-type](#) headaches, [irritable bowel syndrome](#) (IBS), [bladder symptoms](#) and problems regulating pulse and blood pressure. All this pathology we now think is linked."

This has certainly been my experience - along with classic ME symptoms I have also been prone to low blood pressure, IBS, hyper-sensitive bladder, [vulvodynia](#) (nerve pain affecting the vulva) and autoimmune issues.

## Diagnosis

The crucial first step in management is to get a prompt and correct diagnosis, and then a referral to specialist ME services.

"Many people are going back and forth to the doctor with chronic fatigue for years," says Shepherd. "GPs should really be making a firm diagnosis in children and adolescents within three months of onset of symptoms and in adults within four months. Yet our own research showed that only about 16% of people with symptoms were being diagnosed within six months and over 50% were waiting more than a year."

Misdiagnosis is also an issue and, as there is still no simple diagnostic test to identify ME diagnosis, has to be partly based on the exclusion of other causes of chronic fatigue and similar symptoms.

"In one study of patients given a diagnosis of ME/CFS in primary care, 40% turned out to have another condition altogether," cautions Shepherd. "They'd got an autoimmune disease, heart or lung disease, muscle disease, psychiatric disease, or something else, but not what we call ME."

## Common treatments and tips

It took me months to access specialised NHS treatment, but eventually I was offered graded exercise, [cognitive behavioural therapy \(CBT\)](#), and tricyclic drugs to help with disturbed sleep and muscle pain.

### Avoiding 'boom and bust'

I soon learned the hard way that the harder you push against the symptoms, the worse they get. Energy management is crucial to making some degree of progress, but managing this at an optimal level without specialist support can be difficult.

"There's no point in going to bed and just staying there, but there's also no point in trying to exercise your way out of it," confirms Shepherd. "Activity needs to be gradually increased within your limitations and fluctuations. In the early stages, there's a tendency to get into a cycle of going back to work then going off sick again and this has a very negative impact on people's chances of making an improvement. You need specialist advice early on from a physiotherapist or an occupational therapist."

### New treatments and the current 'toolkit'

"Until we understand what's causing all these abnormalities in the immune system, brain, muscle and so on, we don't have any overall form of treatment aimed at the underlying disease process," concedes Shepherd.

"There are new treatments being looked at, including drugs which can dampen down this immune response, but they're speculative at the moment."

This leaves doctors with their existing toolkit to treat patients' individual symptoms such as muscle pain and sleep issues.

### Alternative therapies

"Some people find complementary therapies such as acupuncture useful for ME, but there's a lot of so-called miracle cures out there which are unsubstantiated, such as Reverse Therapy and Mickel Therapy," warns Shepherd. "We're very unhappy about things like the Lightning Process – I've referred several Lightning Process practitioners to the Advertising Standards Authority for making completely unsubstantiated therapeutic claims about these processes."

I spent years trying every treatment available, conventional and alternative, and I have to say (with my head below the parapet) that it was Reverse Therapy (RT) that finally worked for me. While I'm not convinced that RT has all the answers in terms of what causes and perpetuates the illness, it certainly provided me with a practical means of managing the axis between the emotional, cognitive and physiological processes that can influence symptoms.

However, I know people for whom RT hasn't worked and the frustrating truth is that as yet there is no 'magic bullet' that works for everyone with ME.

## NICE guidelines

Official advice on the diagnosis and management of ME from the National Institute for Health and Care Excellence (NICE) states that: "The physical symptoms can be as disabling as multiple sclerosis, systemic lupus erythematosus, rheumatoid arthritis, congestive heart failure and other chronic conditions."

However, the [guidelines](#) have not been updated since 2007 which has been a point of contention across the ME community.

"The ME Association has long regarded these guidelines as unfit for purpose," explains Shepherd, "as they include general recommendations on two controversial forms of therapy - graded exercise and CBT. The whole management system on which that was based was flawed."

The ME Association makes the point about CBT that: "At the one end of the spectrum, CBT is used - as it is with many other chronic medical conditions - to help people develop better ways of coping with symptoms such as fatigue, pain, or sleep disturbance, with a clear acceptance that these have a genuine physical basis ... At the other end of the spectrum, CBT is a therapy based on the idea that ME/CFS is essentially a psychological illness that may well be triggered by an infection but is then perpetuated by a vicious circle of abnormal illness beliefs and abnormal illness behaviour - both of which need to be addressed and challenged if recovery is going to occur. Not surprisingly, this is an approach that many patients find both inappropriate and offensive."

The ME Association petitioned NICE to review the guidelines and Shepherd is now a co-opted member of the guideline committee. A NICE workshop last year invited new input from all the different stakeholders on the CFS/ME guideline which is now up for review.

"The strong message from the workshop was the need to ensure the new guideline will help to improve the lives of people with this condition by properly addressing and resolving the continuing debate about the best approach to treatment," says Paul Chrisp, director of the Centre for Guidelines at NICE.

"We have therefore appointed five lay members to the guideline committee rather than the usual two. This will ensure the views and experiences of people with the condition and their carers are given a high priority when developing the individualised, patient-centred recommendations for their care."

## Where to seek help

The ME Association offers a wealth of information and expertise on all aspects of ME management, from diagnosis and treatment to practical advice on claiming welfare benefits. [Action for ME](#) is another great resource.

Back in the late 1990s, once I had gone through my savings, I had to navigate a benefits system ill-equipped to deal with this misunderstood disease. My claim went to appeal and I had to appear before a tribunal to finally access the financial support I was entitled to. During this process the advice of ME support organisations was invaluable.

I like to think that the public's perception of ME as a serious illness is improving, yet only last week when I mentioned to an acquaintance that I was writing this piece he remarked, "Oh, chronic fatigue, the lazy disease, is that still a 'thing'?" and wanted me to chuckle along with him.

ME often affects fit, ambitious young people living life to the full - the 'lazy' tag is as offensive as it is absurd. The illness has had a devastating impact on my life and it has taken a good deal of resilience to pull through.

It is my hope that in the not too distant future an effective new treatment will emerge that will work for everyone with ME and give people back their lives. And, once and for all, this much-maligned illness will be understood by all.

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