

# Patients with severe ME have little or no access to specialist treatment services

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One in three severely affected adults with ME in England have no access to local specialist services, new research has shown.

Published in the *British Medical Journal Open*, the research by the University of Southampton reveals NICE guidelines, which say severely affected patients with ME, otherwise known as [chronic fatigue syndrome](#) (CFS), should have access to specialist care, are not being met by many NHS Trusts across England.

Over a third of specialist adult ME/CFS services in the NHS provide no service to severely affected patients, and a further 12 per cent of trusts provide only minimal or occasional help to housebound patients, primarily due to lack of funding.

It is estimated that ME/CFS can affect up to 250,000 people – children as well as adults – in the UK. It leaves people with debilitating physical and [mental fatigue](#) and pain. Severely affected individuals can become housebound, wheelchair or bedbound and dependent on carers for all basic activities of [daily life](#). Around 25% are thought to have severe ME/CFS.

Researchers warn that many severely affected patients are going unnoticed and untreated.

Clare McDermott, NIHR School for Primary Care Research funded Doctoral Research Fellow at the University of Southampton, led the

study and had ME/CFS when she was younger. She comments: "People with ME should be able to seek the advice of a specialist service close to their homes. We were surprised by the lack of services and access to services that our survey revealed. Even if the local Trust provides a service, some housebound patients will never get to use it. Many, very ill patients are going without."

The research surveyed all 49 NHS specialist ME/CFS adult services in England in 2013. Of these services, one in three (33 per cent) provided no service for severely affected, housebound patients while 55 per cent of services did treat patients with severe CFS/ME and the study found that their interventions followed the NICE Guidelines. The remaining services (12 per cent) offered occasional or minimal support where funding allowed. There was one NHS unit providing specialist inpatient CFS/ME care in England.

Jenny Patterson is 20 years old and has had ME/CFS for the last 10 years. During her worst days Jenny was bedbound, only able to get up to go to the toilet and had to be cared for full-time by her mother Frances. However in the past three years she has greatly improved due to the specialist service she has had access to. Jenny still requires full-time care but she is now able to go outside for short periods of time and have visitors. She credits her recovery to the specialist care she has recently received.

Jenny comments: "My quality of life has dramatically improved from how it was three years ago. Being housebound is an awful and isolating feeling. What I am able to cope with during the day is now carefully monitored and my routines are very important to prevent a relapse.

"I have been very fortunate to receive specialist care in the past three years. My ongoing recovery and how well I am improving is down to them. Unfortunately most people with severe ME don't have any access

to specialist services, they can't get to a hospital or their Trust can't get services to them. Access to a specialist has undoubtedly changed my life; more people with this debilitating condition should have access to better care."

The Association of Young People with ME (AYME), of which Jenny is a member, is one organisation which has long-since spoken of the urgent need for [specialist care](#).

The charity's chief executive, Mary-Jane Willows, says: "We have over 3,600 members who are all young people with ME. As the paper discusses, severe ME/CFS [patients](#) present particular clinical risks. What we see at AYME is the devastation caused by this condition, to the lives of young adults, children and their families. Patients are isolated at home, missing years of education and suffering extensive pain. Life for many is a darkened room they can rarely leave, with visits lasting a few short moments as that is all their bodies can tolerate."

The Southampton team are now conducting a pilot study to evaluate a community based intervention that will aim to reach the most severely affected people with ME/CFS. This intervention has been devised through a two-year patient and public development process which involved over 40 people with ME and carers, as well as many specialist health professionals. People with first-hand experience of getting better from ME have played a central role in helping to design the study, in order to explore strategies that can reach and meet the needs of the most vulnerable housebound people. The development work and study design were presented to the All Party Parliamentary Group on ME in March 2013 and results are expected in 2016.

Provided by University of Southampton

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