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Research Article

Recent research in myalgic encephalomyelitis/chronic fatigue syndrome: an evidence map

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Plain language summary

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Plain language summary

What was the question?

Myalgic encephalomyelitis/chronic fatigue syndrome is a long-term condition with many different symptoms. People with myalgic encephalomyelitis/chronic fatigue syndrome have exhaustion, stopping them from doing activities and having a big impact on everyday life. They also have postexertional malaise, meaning they become more unwell after using even small amounts of energy. Myalgic encephalomyelitis/chronic fatigue syndrome is not well understood. The symptoms needed for a professional to tell someone that they have myalgic encephalomyelitis/chronic fatigue syndrome have changed over time. Now, people have to experience postexertional malaise to confirm myalgic encephalomyelitis/chronic fatigue syndrome, but this has not always been the case. We wanted to bring together recent research on myalgic encephalomyelitis/chronic fatigue syndrome and explore the numbers of studies and the topics that were scrutinised.

What did we do?

We searched for all the studies on myalgic encephalomyelitis/chronic fatigue syndrome that were published between January 2018 and May 2023. We brought together information about these studies. We grouped research studies based on the topics they investigated. We made an interactive map that shows all these myalgic encephalomyelitis/chronic fatigue syndrome studies. The map has filters to let people explore the studies that have only included the people with postexertional malaise.

What did we find?

Our map contains 639 studies that have studied over 600,000 people with myalgic encephalomyelitis/chronic fatigue syndrome. The main topics we looked at were:

- 'what is the cause?' (53% of studies)
- 'what is the problem?' (38% of studies)
- 'what can we do about it?' (26% of studies)
- 'diagnosis and assessment' (15% of studies).

Some studies looked at more than one topic.

Studies do not always report things clearly. Some do not explain how it was decided if someone had myalgic encephalomyelitis/chronic fatigue syndrome; 11% of studies *only* included people with postexertional malaise.

How can this help?

This map of myalgic encephalomyelitis/chronic fatigue syndrome studies can help plan future research. Knowing the numbers of studies looking at different topics can help plan what research to do next.