



Making informed decisions

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Making an informed decision

Because we don't yet understand the biology of ME, there are no targeted treatments that work for the majority of people with ME.

This differentiates ME from other conditions where better understood biomarkers can offer clearer treatment pathways and protocols.

It also means a treatment approach that one person finds effective may or may not have a different impact on someone else with the illness.

Other people may recommend a particular approach that has helped them. While this can be helpful in considering the options available to you, please remember that you should only take medical advice from an appropriately qualified healthcare professional.

To decide what symptom-management approach is right for you, you should look at the evidence, and make sure you fully understand what the treatment involves.

It's your decision, and yours alone, which treatments you try, and which you don't.

You should never be pressured into trying a treatment you feel strongly against or be dismissed for wanting to try a treatment approach that you believe might be of value to you.

We work to increase interest and investment in biomedical research, with the aim of developing more effective treatments and, one day, a cure.

To do this, we work collaboratively with people affected by ME, scientists, clinicians and industry professionals, aiming to bring more money and more people into the field.

UK Government guidelines

The [2021 NICE guideline for ME](#) and the [Scottish Good Practice Statement](#) make it clear that:

- shared decision-making between you and your healthcare professionals should take place during diagnosis and all phases of care (this means that any decision regarding treatment or care should be made in partnership with you)

- you have the right to refuse or withdraw from any treatment or care plan without this affecting other aspects of your care, or future choices about care.

Unhelpful stereotypes and myths sometimes still persist about ME, including that it is psychiatric (a mental health condition) or even psychosomatic (a physical illness caused by mental or emotional stress); that it is “yuppie flu” or burn-out, or depression.

None of these are correct.

While it’s a fact that research has found significant abnormalities in ME relating to the brain and the immune system, these are not specific enough to be used as a diagnostic test – yet.

A lack of awareness about these facts can, unfortunately, impact on the support you might receive from friends, families and even professionals.

If you feel that your care is being influenced by stereotypes or prejudices, then it is right that you should challenge this – we can support you with this.

And please remember there are many good healthcare professionals, not influenced in this way, who provide excellent support and care.

Advocating for your rights

Because of the complexity of the illness, its fluctuating nature and the wide spectrum of symptoms, different things work for different people.

Reading and reflecting on as much good-quality information as you can about the treatment you want to try, based on the best evidence available, will help you make a decision about what feels right for you.

If you have already begun a symptom-management programme and are concerned it’s not right for you, it’s never too late to discuss your concerns with the therapist working with you.

If you are finding the programme difficult or painful or are not sure about what you are being asked to do (or why), or if you feel uncomfortable for any other reason, it’s really important to [bring this up](#).

[Read about](#) communicating more effectively with your doctor or [contact our Information and Support Service](#) to talk it over with one of our friendly, experienced team.



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