



Severe and very severe ME

Updated: March 2025

Contents

Severe and very severe ME	1
Healthcare for severe and very severe ME	1
How we can help	2
Learn about severe ME podcast	3
Other support available	3

Severe and very severe ME

Around one in four people with ME can become severely affected by the condition.

They are often unable to leave the house or their bed, and accessing appropriate care and support can be a challenge.

Action for ME's 2019 Big Survey of more than 4,000 people with ME found that:

- 95% of respondents with severe ME said they had stopped or reduced household tasks
- 98% had stopped or reduced social contact
- 66% require full or part-time care
- 59% were no longer able to leave their home independently.

Severe ME has a considerable impact on the whole family. One Big Survey respondent told us:

"My youngest daughter does not know me without ME. I spend the majority of my time in my bedroom, alone. I would only see the children for one minute a day with an hour gap in between for me to rest. I spend very little time with my wife and children."

Hear from people with ME and health professionals in the [Dialogues for ME/CFS](#) film series about severe ME.

Healthcare for severe and very severe ME

The [2021 NICE guideline for ME](#) describes four levels of severity of ME and offers specific guidance for caring for people with severe or very severe ME.

This includes advice on:

- awareness of severe and very severe ME, and its impact
- assessment, and care and support, planning by an ME specialist team

- access to care and support, including hospital care
- managing ME, including energy and symptom management, and dietary strategies.

The guideline says: "Service providers should be proactive and flexible in delivering services to people with severe or very severe ME, who may have particular difficulty accessing services and articulating their needs. This could include home visits, online or phone consultations, supplying written communication, and supporting their applications for aids and appliances."

How we can help

We work collaboratively with professionals to raise awareness and increase understanding of ME, including severe ME.

If you have severe ME, we can offer information, support and signposting to services that can help you and/or your carers.

We may also be able to support you to self-advocate and access health, care and education you're entitled to.

[Contact our Information & Support Service](#)

Our Healthcare Services team includes doctors, physiotherapists, counsellors and chaplains, offering individually tailored whole-person care, with an understanding of severe ME.

[Access our Healthcare Services](#)

As a charity, we charge fees for our Healthcare Services only to cover our costs, and a bursary for up to 50% of fees may be available, depending on your financial circumstances.

If you are able to use a device to get online, even if only for a short amount of time, our free, supportive [ME Friends Online forum](#) offers friendship and understanding in a safe space.

Learn about severe ME podcast

Emily Collingridge's book [Severe ME/CFS: a guide to living](#) offers guidance on every aspect of life with severe ME.

It's aimed at families and professionals, and the author herself lived with severe ME for many years.

In her first chapter, Emily says:

"Patients with severe ME are vulnerable and in need of a great deal of practical help, emotional support and comfort from others. However, it is possible for patients to take control of their lives and the management of their condition, to achieve mental/emotional independence and to guide others in providing the personalised care that they need."

Other support available

There have been almost no biomedical research studies on severe ME, so we know very little about its biology, and what treatment or management approaches might be helpful.

The [25% ME Group](#) is there for people affected by severe ME and includes guidance on their potential care needs.

If you are unable to get to the surgery because you feel too ill to leave your home, your GP may agree to visit you at home.

It may be helpful to discuss this with your GP on the telephone or get a friend to do this for you.

Local social services/social work departments are responsible for providing home care services for people who need help with washing and dressing.

Home care may also be called home help, social care or community care.

Your GP can refer you for an assessment or you can contact your local department for an assessment yourself.



Registered office:

Action for ME
Unit 2.2 Streamline
436-441 Paintworks
Bristol, BS4 3AS




Telephone: 0117 927 9551

Info & Support: infosupport@actionforme.org.uk

Fundraising: fundraising@actionforme.org.uk

If you have found this resource useful, please consider making a donation to help us reach even more people affected by ME.

www.actionforme.org.uk/donate/

 [@actionform.e](https://www.instagram.com/actionform.e)  [@actionforme](https://www.facebook.com/actionforme)  [@actionforme](https://www.linkedin.com/company/actionforme)

Registered charity in England and Wales no. 1036419
Registered in Scotland no. SC040452
Company registered by guarantee in England no. 2906840

