

# THE 25% ME GROUP

SUPPORTING THOSE WITH SEVERE M.E

## How to Help People with Severe and Very Severe ME

Helping people with severe and very severe ME is mostly about not causing harm, whilst quietly removing risks and barriers.

People with ME, particularly severe and very severe ME, need demands on their energy reduced and the support around them increased.

### Protect From

- Overexertion
- Stimulation
- Medical harm
- Disbelief
- Unnecessary assessments
- Unnecessary travel

### Reduce

- Energy expenditure
- Demands on the person with severe or very severe ME
- Sensory stimulation

### Ensure Environment is

- Dark
- Scent free
- Quiet

### Increase Support

- Don't ask for explanations or decisions to be made swiftly
- Where possible complete tasks quietly, efficiently and with minimal input from the person with severe ME.
- Ensure suitable food and drink is provided adhering to any dietary requirements.

Make sure homecare workers are appropriately trained.

Ensure they-

- understand about post exertional malaise.
- Do not encourage activity
- Know when not to interact

## Support with

- Providing written information, summaries including around care needs and sensory requirements
- Accessing welfare benefits
- Advocating for the person. Speaking for them when they can't. (Do check the person is happy for you to do this.)

## Advocate for

- Recognition of severe and very severe ME
- Medical care at home where possible

## Do Not

- Encourage exercise
- Suggest therapy
- Assume it is psychological

## How can I support people with severe and very severe ME?

Small gestures which do not place demands on energy are often gratefully received.

You could-

- Send them a message saying you are thinking of them. Tell them it's ok if they can't reply.
- Send them a postcard.
- Offer to collect prescriptions for them.
- Offer to help with shopping or posting letters

**Believe the severity of their ME; don't ask for proof. Share accurate information; correct misinformation, educate others.**

*Advice Sheet produced by the 25% ME Group, support group for the severely affected.*

*We also have a range of resources for people with severe ME, their supporters and professionals, on our website at: [www.25megroup.org](http://www.25megroup.org)*