

Severe M.E. Awareness & Care

How do I help someone with severe M.E.?

Linda and Greg Crowhurst

First and foremost you have to remember that the person with Severe ME. does not react to the environment in the same way that you, a person without M.E., does.

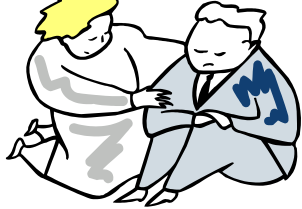
The environment is hostile and assaulting. 'Normal' things that you would not even notice or would enjoy are too much for the person with Severe M.E.

Everything you do can make that person hurt, can make the person more ill, can cause their physical health to deteriorate.

However dreadful their life is, you have to remember you can make it worse without intention.

The best thing a person with Severe M.E. can hope for is that you :

- ◆ Accept that they are extremely physically ill.
- ◆ Know that they will not react normally to any stimulus.
- ◆ Know that they may not be able to communicate their needs and wishes at any one time, or at all.
- ◆ Know that their reactions are because of illness, not necessarily how they feel about you.
- ◆ Understand the affect you have on them, because they are physically ill and extremely hypersensitive, in multiple ways.
- ◆ Minimise the impact you have by respecting what the person with Severe M.E. tells you acting accordingly. For example, if they say '*Don't wear perfume*', it is because of multiple chemical sensitivity - so please do not wear perfume.
- ◆ Do not minimise the importance of what they tell you or think they are being difficult. Realise how significant things are.
- ◆ Even if things seem bizarre and extreme to you, do what is asked of you. You can make a person dreadfully ill otherwise.

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- ◆ Understand what is physically wrong in the person; in Severe M.E. there is complex multiple system dysfunction. You need to be clear that M.E. is a Disease, not a 'fatigue' state: it is not about just being 'tired'; exercise or trying to be more active will not make it better.
 - ◆ Do not buy gifts that make you feel like you are a good person, but which are irrelevant or in denial of the person's reality. For example: don't buy toiletries and perfumes for a person with multiple chemical sensitivity; don't buy sweets, pastries, cakes, for the person who has food allergies (unless you know it will not harm them). Be aware of any sensitivities, allergies the person may have and really try to think what the person needs or likes, that will not harm them.
 - ◆ Be aware of the way noise sensitivity impacts upon a person with Severe M.E. and do not do things that will exacerbate it. It may be worse at different times of day. Understand when is the best time to try and make contact, if that contact involves noise e.g. telephone.
 - ◆ Do not turn up unannounced if they have asked you not to. Be flexible in your arrangements with the person with Severe M.E. Do not blame them or think they do not care, if they cannot keep an appointment.
 - ◆ Communicate in a way they can manage; overstimulation can lead to worsening symptoms.

Do not disregard the physical limits placed upon a person with Severe M.E. :

- ◆ If they say they can only talk for a minute, do not go beyond that limit, no matter how frustrating that might be.
- ◆ If they say "*do not ask a direct question*", find another way, because the cognitive dysfunction is complex and very real. A question could shut the person's head down completely



- ◆ If they say they can only cope with one person in the room, do not bring others with you.
- ◆ Be open and flexible.
- ◆ If they say they cannot physically do something, do not disbelieve them.

Do not assume that the medical world knows best. The current medical system is compromised by psychiatric untruth.

Do not assume that because you want to help, that you can help. Ask yourself what can you offer: how can you help, not hinder or make worse? Any interaction needs to be based on respect, honour and acceptance.

Respect the person

Honour the illness

Accept the physical reality

Combat all untruth

You need to know that there are no straightforward paths to help a person with Severe ME, no matter how much you want there to be.

You need to know that most things will not help; many may cause additional suffering. You need to know that even if you do all you can to help the person, they may still not be able to access and take advantage of what you offer.

The gap between their life and your life is vast and may be unbreachable. Isolation may be the only way a person can cope with the torments of their illness and the assaults of the physical environment.

Help them to live their life in their way and aim not to hurt them by ignorance, neglect, rejection, denial, carelessness, condescension, unawareness or over-enthusiasm and good intentions .

You need to be very careful to make sure that you do not wrongly interpret the reality of the person with Severe ME and end up blaming them, either overtly or covertly, for the situation they are in.

Do not give up hope, do not abandon them, listen and wait and love them still realising that they are horrendously physically ill; there is a great physical need for healing but the answers are not necessarily there, no matter how much you want them to be.

How can a doctor help someone with M.E.?

Dr Nigel Speight

In my view, people with M.E. will be best served by doctors who:

- understand and believe in M.E. as a genuine (if poorly understood) organic/physical illness;
- remember the principles of respect for patient autonomy and the need for informed consent;
- will act as patient advocates;
- can tolerate the severity of some cases and their own feelings of impotence when confronted with them, and not feel duty bound to 'cure' their patients somehow;
- are open to new ideas *e.g.* the possibility that some cases of apparent M.E. may in fact be Lyme Disease and may be curable by antibiotic therapy.

In terms of specialist services, M.E. sufferers deserve a medically led service, with the authority to make a definitive diagnosis of M.E. in patients referred.

Dr Speight is medical adviser to the 25% M.E. Group

Carers' Organisations

Carers UK

<http://www.carersuk.org/>
 Advice Line 0808 808 7777
 Mon-Frid 10 am - 4 pm
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Carers Trust

<http://www.carers.org/>