

The care needs of people with Severe ME



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THE EXPERIENCE OF SEVERE ME

The Care Needs of People with Severe ME

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With so much misinformation, misinterpretation and and misunderstanding about ME in the public domain, it is important that Carers and Agencies providing care are in receipt of accurate and safe information on how to provide care in the best way.

First and foremost it is essential to know that Myalgic Encephalomyelitis is a serious physical disease, with complex multi-system dysfunction.

Enormous harm can be done by someone who is not fully aware that the person with Severe ME is seriously physically ill and that they are not going to be “made well” by changing their thoughts or increasing their activity in a graded way.

When you work with someone who has Severe ME you need to be more sensitive and aware than you can possibly imagine. Harm, even death for some, may follow poor treatment, care and ignorance. The physical frailty and the high risk of deterioration, of someone with Severe/Very Severe ME, cannot be exaggerated nor adequately described. You need to take the greatest of care.

The most important aspect of caring for a person with Severe Myalgic Encephalomyelitis (ME) is the 'how' of caring; the basic core beliefs the carer has about caring and the person to be cared for. What the carer believes will subtly or overtly impact on how caring is provided and has a huge affect on the relationship, quality of care and health of the person receiving the care.

The basic principles behind Severe ME-aware care are :

1. Never define the person by their behaviour.
2. Acknowledge the serious and severe physical illness underlying the person's symptom experience.
3. Adhere to a strictly defined definition of ME (The International Consensus Criteria).
4. Honour the WHO classification of ME as a neurological disease and respond appropriately and equally as in any other recognised neurological disease.

5. Treat the person with respect on all levels; respect for the way interaction occurs, the physical and the cognitive limitations enforced on the person by their severely disabling multi-system dysfunction.
6. Honour what the person says regarding their physical and cognitive needs.
7. Listen to the person and to only interact at the correct time in the correct way. We call this the MOMENT approach, honouring the severe illness the person has whilst maximising the opportunity to engage safely in order to help, not harm them, when undertaking all care needs.
8. Understand any hypersensitivity issues (chemical, drug, touch, noise, light, movement, motion, food); never ignore, undermine, negate or belittle them, recognising the danger of the ordinary environment as real, not just perceived.
9. Understand and comprehend that the person with Severe ME is not experiencing the world the same way as a well person and cannot fit into the demands and obligations imposed on them by others, easily or at all. A flexible, knowledgeable, sensitive, compassionate, non-judgmental, person-centred not goal oriented approach at all times is critical. Being aware of the after impact of any interaction is essential; that even something once achieved cannot necessarily be achieved or tolerated again or regularly or increased.
10. Recognise the irrelevance, unhelpful and dangerous nature of a psychosocial response and interpretation of Severe ME, a physical disease. Psychiatry has no right to first hand intervention in this disease which requires a biomedical response and care pathway .

It is vital to ensure that that you never put any overt or covert pressure, demand or expectation to improve, upon the person with Severe ME, nor any underlying belief that is in opposition to the truth and severity of the disease and very real lack of valid treatment and cure.

Why a Moment by Moment approach is required

When your whole body and head is on fire with multi-level pain and you have unimaginably complex multiple system dysfunction, resulting in complicated hypersensitivities and massive indescribable cognitive disruption, blanking out your mind, with a high risk of deterioration, just by someone being in the room with you, a Moment by Moment approach is realistically the only way that you can possibly get any of even your most basic needs met and even that is incredibly difficult and painful to achieve.

If you take the first letters of the word “M.O.M.E.N.T, you could say that it means:

M aximising

O the opportunity
M to meet
E each
N need
T tenderly

We call this the MOMENT approach.

Maximising the Opportunity to Meet Need Tenderly

If you are to care for someone at this level of illness, you must learn what is tolerable to the person, when it is more tolerable, if at all and how you might safely approach the person and engage in practical care such as cooking, cleaning, washing, shopping or more intimate care such as helping the person eat, wash, dress, move, urinate or evacuate their bowels.

Every instant counts when you are caring for a person with Severe ME. Every single movement you make, every noise you make, every activity you undertake impacts them.

In order to truly interact in the right way, you need to be committed to learn more about yourself and develop real body awareness, not only when you are with the person but when you are anywhere in the home, so that you perform everything gently, carefully, with awareness of the potential impact.

You must also develop an acute awareness of sound, movement, light, chemical sensitivity, so that you can see, feel, recognise danger instantly and so help protect the person from harm and further deterioration, by reacting quickly and effectively.

You need to notice how you do things, then determine whether you can be more careful in the way that you do them in future, so that they perhaps take less time or can be done with more care to keep noise to a minimum. It might involve slowing right down and taking longer than normal, especially in first hand, direct care.

It is surprising how loud footsteps can be and how easy it is to bang a cupboard door too loudly or cut food too noisily without any awareness that it could be quieter. Obviously no noise at all is impossible to achieve; nevertheless you must grow in awareness of how every single thing you do might inadvertently cause pain and increase in symptoms.

You need to consider how you are going to avoid chemical, perfume exposure and unnecessary harm from light; this is not as easy as it sounds.

You need to be incredibly sensitive to the person when you are moving around the home, especially the room they are in and even more especially when you are close to them. The slightest quick movement or action, cough or head scratch, unnoticeable to you possibly, can cause tremendous pain and trigger other symptoms.

With Severe ME, natural responses are foreign now.

Nothing seems as it is, for the body does not respond in the normal way to the expectations of most people in the ordinary world. Here you enter a different landscape; the terrain here needs careful investigation and traversing. You may need to adjust your assumptions and presumptions.

Here :

- rest does not bring relief
- friendly chatting and conversation are often if not always intolerable
- information is not easily received, understood or remembered
- movement leads to deterioration
- touch hurts
- ordinary light is painful to agonising
- your favourite perfume or deodorant can nauseate and harm
- even quiet noise can torment and at worst paralyse
- movement can irritate and confuse, can even cause pain
- communicating need is not easy
- peaking may even be impossible
- the possibility even of simple movement may come and go or not materialise
- the way you cook things may not be appropriate, delicious -seeming food to you, is simply not what it seems and may be inedible or harmful to the person, especially if you add ingredients not tolerated or cook with the wrong method
- gifts, unless incredibly well thought through, can lead to illness deterioration
- visitors calling unannounced may be far too much to deal with
- the telephone ringing with a friendly message may be an unintentional torture

Everything is turned on its head with Severe ME, where there is not necessarily even enough energy in the body for organs to work effectively and even things kindly, yet ignorantly done, are dangerous.

The result is isolation, from normality and people, on every level. Any interaction can literally be a torment and potential for distress and deterioration.

Nothing is simple ; it is rarely obvious what to do. Follow any instructions or guidelines the person provides.

Your focus must be on the person and how they are experiencing your interaction with them. You need to be present mentally, emotionally and physically to the person. You need to be able to sense when the person cannot tolerate your contact or presence. They may not necessarily be able to tell you directly. Some people cannot speak. For others it may be

unpredictable. You must learn the subtlety of communication and develop understanding together.

With Severe ME everything is unpredictable and relentless, you simply cannot control the illness itself and neither can the person experiencing it themselves.

It is easy to get frustrated when the action you want to do, seemingly quite simple and easy for a well person, is impossible in that moment for the person with Severe ME.

It is a matter of waiting, looking, hoping for the best moments to arise before you can act. It is essential that you understand that the symptom experience is beyond the person's control or you may fall into false expectations or wrong interpretations. The relationship will deteriorate if you do not understand or at least accept their inner reality, the complex, intolerable symptoms they are experiencing, the difficulties with the environment and even with you, being near them.

There is nothing more wonderful than connecting and flowing together, especially in difficult circumstances and feeling good about yourself as a carer. If you can get it right you can bring comfort and reassurance, trust and valuing to both your lives. You can genuinely help, not inadvertently harm.

Adapted from “**Severe ME : Notes for Carers**”

by Greg Crowhurst

<http://stonebird.co.uk/Notes/index.html>

Ref : **Myalgic Encephalomyelitis: International Consensus Criteria, Journal of Internal Medicine, 20 July 2011**

<http://www.meassociation.org.uk/2011/07/myalgic-encephalomyelitis-international-consensus-criteria-journal-of-internal-medicine-20-july-2011/>

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