

# Caring for People with Severe Myalgic Encephalomyelitis: an open heart, open mind approach

## *What is Myalgic Encephalomyelitis?*

Myalgic Encephalomyelitis is a WHO classified disease with multi-system dysfunction. In its more severe forms people are completely or nearly completely incapacitated all the time or may vary in a very limited capacity. 25% of people are invisible and hidden away, house bound, bed bound or unable to access care due to severe incapacitation. This disease lasts decades and many find no relief at all, nor receive adequate care or medical support for their complex symptom experience.

## *How to care for people with Myalgic Encephalomyelitis (ME)*

For the most ill, even a very gentle, sensitive approach to caring might be difficult to tolerate, due to intense pain, the interaction of specific hypersensitivities to movement, light, noise, touch, perfume and chemicals and other severe to profound symptoms.

Your presence is of the utmost importance:

- All you say and do
- How you are feeling in yourself
- Your energy level
- What you are conveying through your posture toward the other person
- Your values and attitudes

These are all key to interacting well with anyone, but especially so with someone who is in high physical pain with a range of tormenting, unremitting, very severe symptoms.

It is important that you know how the slightest wrong movement, noise or action, on your part, may lead to even worsening levels of symptom experience and physical distress. You cannot afford to not be ultra-aware of the potential to do harm.

Every nuance, every breath, every movement counts and can bring relief or negatively impact the person.

A flexible, aware, moment by moment approach is key to successful interaction or at least as a way to try to minimise the risk of triggering deterioration and indescribable additional physical suffering.

To care for someone with Very Severe ME you need to know how to:

- Maximise the
- Opportunity to
- Meet
- Each
- Need
- Tenderly

This says it all.

We call this the “MOMENT” Approach (Crowhurst 2018)

It is up to you, the carer, to maximise the opportunity to engage safely with the person and meet their need tenderly.

1. Each MOMENT can be a moment of possibility and hope.
2. Each MOMENT can be experienced positively or negatively.
3. Each MOMENT can flow with the next one or change direction, good or bad.

Not all moments will be the same. The more extreme the symptoms the more peaceful, patient, open and aware you need to become, in order to help, not unintentionally trigger, a worsening of symptom experience. Even with the most careful attention, you cannot take away the physical suffering. The caring experience from the view of the person may never be pleasant or comfortable despite best effort. Yet the best effort must always be made.

Remember, every single thing impacts the person with ME.

*Who is this approach for?*

This approach is essential for carers, but it can also be used by anyone who needs to interact with the person, visitors, friends, social workers, healthcare professionals, family, who may need to know how to communicate, how not to wear perfume, how to be flexible about visiting times, how to not feel rejected if contact is impossible, how to be willing to try again in another moment, how extra quiet and careful you need to be, given how sudden movement or actions can hurt.

*What does the carer need to know?*

The carer needs to know that ME is a neurological disease. There is no universal treatment or cure. There is great physical suffering and isolation enforced upon the person. Your presence matters. How you approach the person, the attitudes and beliefs you hold about the illness, alongside the way you perform tasks and provide care can make a profound difference.

A good carer is :

**Compassionate**, they reach out with genuine concern and empathy for the person.

**Kind**, they naturally think of all that needs doing and they respond in the kindest way possible.

**Loving**, they have an open heart and open arms.

**Thoughtful**, they reflect on themselves, the other person and all that needs doing, they help in the best way possible.

**Loyal**, they do not give up at the first difficult hurdle, they stay the course, they remember the bigger truth of the relationship.

**Determined** to get it right, they do their best.

**Passionate**, they learn, they grow, day by day they strive to understand more of the experience of the illness.

**Committed** to the person and the relationship, the bond of connection.

**Creative**, they find new ways to connect, they try to see things in new ways, they bring



freshness of interaction and support.

**Gentle**, they do things quietly, gently, tenderly, they are incredibly aware of the enormous potential, in any moment, to trigger a worsening of symptoms, an increase of pain, an episode of paralysis, they always seek to bring comfort and goodness to the person's life.

Ref : Crowhurst G (2018) Caring For ME : a Pocket book Course For Carers, Stonebird  
<http://stonebird.co.uk/CARE/index.html>