**25% Group and Stonebird**

**How not to care for someone with Severe ME**

Response to BACME Working Group on Severe CFS/ME

Shared Clinical Practice Document Version 1

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 frailty of someone with Severe/Very Severe ME cannot be exaggerated nor adequately described. You need to take the greatest of care.

The problem with this BACME document is its underlying psychosocial values and attitudes. If you expect a person to get better, that will be your intention, that will be your goal, that is going to influence all your thoughts and actions in your caring role, especially if you set goals or limit care over time.

The care provided by someone with a biomedical understanding of Severe ME is going to be fundamentally different, however much the starting point of care might appear to be similar in this document, to the person who has a psychosocial approach to, because of the opposing underlying values and attitudes**.**

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.

Great 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, as this dangerous document from BACME suggests.

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 ICC).
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. (Crowhurst 2015)
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.

In ME when you push yourself you deteriorate, whether immediately or delayed, if you push too hard you may even enter worse illness experience than you have already experienced, beyond which you may not be able to recover from at all or only partly. The depth and level of physical and cognitive deterioration and harm that can follow is literally unimaginable before it occurs. The impact can be permanent or very long term.

There are many good observations and insights into the reality of Severe ME in this document; but its expectations of recovery that could impose unreasonable, unrealistic, even fatal demands, render it extremely dangerous.

Anyone who believes the message that people with Severe ME can do more than they physically can, by thought and activity, even if only over time, no matter how genuinely they believe it or how nice they are or how encouraging they are, can so easily do untold harm because they will exact subtleif not overt pressure, however kindly, upon the person to improve.

A carer following this guide, we fear, is unlikely to be able to separate care from treatment, to comprehend the importance of flowing with the person, just to help them cope, rather than set goals for “recovery” , however seemingly small from the well perspective nor appreciate the long term commitment just to improve quality of life and comfort rather than quality of thought and ability.

There is no place for complacency, mediocrity or carelessness in the life of someone with Severe ME. A carer’s interventions can cause serious harm to the person's health. As the PACE and FINE Trials have shown, the psychosocial approach that this guide is constructed upon, is bound to fail and not just fail but cause real harm. (Vink 2017). Itmust be

Viewed within its psychosocial context, this document cannot possibly be recommended for anyone with WHO G93.3 defined Myalgic Encephalomyelitis.

References

Crowhurst G (2016) **The MOMENT Approach** <http://stonebird.co.uk/main/index.html>

**BACME Working Group on Severe CFS/ME Shared Clinical Practice Document Version 1** (2017) http://measussex.org.uk/severely-affected-guidelines-february/

Vink M (2017) **Assessment of Individual PACE Trial Data: in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Cognitive Behavioral and Graded Exercise Therapy are Ineffective, Do Not Lead to Actual Recovery and Negative Outcomes may be Higher than Reported.** J Neurol Neurobiol 3(1): doi http://dx.doi.org/10.16966/2379-7150.136