

The Moment Approach

How to help someone with Severe ME



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The MOMENT Approach

ALL OUR EXPERIENCE, two decades of living with and caring for someone with Very Severe ME, finds expression in what we have termed the Moment approach. I first outlined the approach in a nursing article that went on to be recommended by NICE in its 2007 Guideline. (Crowhurst 2005)

MOMENT means :

Maximising the Opportunity to Meet Each Need Tenderly

This is your primary aim, because the person with Severe ME is:

- extremely hypersensitive to the environment and vulnerable to harm.
- easily drained of any energy and may experience a post- exertional reaction to any effort or interaction.
- constantly experiencing their symptoms severely to profoundly.
- not experiencing the world and the immediate environment in the same way that you are.
- seriously ill, with multi-system dysfunction, but it may not be obvious just how vulnerable to deterioration their health is from the outside.

- severely disabled, yet their disability may not be clear to someone unaware of ME and its impact, because the symptom experience is so complex and disabling itself.
- likely to react in unexpected ways to the simplest attempt to help.

The moment approach is about making a commitment to honour the person and understand their reality as much as is possible. It is to know that the way forward is not simple, obvious, easy or straightforward. It is to accept the complexity of the situation, the possible torment that a person may be experiencing, how that impacts upon the relationship and the way the person is able to communicate and connect with you or not.

The 'louder' the symptoms experienced within the body, the more the person is blocked from connecting with you and the outside world.

It is important that you understand that the person is not irritable, seemingly uncooperative, behaving oddly, flinching at your touch, from some bizarre choice or mental health reason, rather they are experiencing the environment and you and their own body in an altered state to the norm.

Everything you do and say is a potential source of harm to them. If they react badly to you, consider the possibility that each word you speak may be being experienced as a blow to the head or a knife to the guts, in terms of the pain it elicits. Each noise you are making, no matter how quietly you try to do something, may be having a similar affect. You do not experience noise or light or touch in the same way that they do, so you have to try even

harder to understand what you are or might be doing to the person inadvertently by your actions which may be unintentionally causing pain or disturbance.

If you and they can accept that you may not always get it right, but still hold firm to a greater truth, a deeper relationship of warmth and kindness and equality, then the difficult moments can be just that, nothing more. Hopefully as trust grows and understanding grows, reactivity may decrease or at least be understood.

The more severely ill and hypersensitive the person is, the greater the need to understand the risk of harm and the potential for deterioration to the person's health, even though unintended, from thoughtless carer interaction.

Partnership

Partnership requires two way connectedness, an acceptance of equality of personhood both of the carer and the person needing care. The illness can so easily get in the way of seeing this, from both sides; a determination to grow in positive regard and respect is needed, although that can be difficult given the intensity of physical suffering and the stress of the moment.

Co-operation is key to good caring. That must be mutual to avoid harm, disconnection, mistrust, and misinterpretation of events.

A partnership approach requires commitment to grow together and work out how to help, when to help and when to wait. What to do and what not

to do. When to try now and when to try later, but never to walk away and neglect or give up.

It needs input from both sides, no matter how long that takes to gain and how complicated the communication is.

Partnership is not just about care, but about a way of being with the person to enhance their life and minimise, if possible, the sense of isolation and separation they may feel due to the severity of illness.

Its aim is to find peaceful flowing moments that reach beyond or through the illness, to connect with the person and touch their lives with goodness so that your life may also be touched with goodness in return.

You appreciate who the person is. Partnership is not just one sided, but a mutually rewarding experience based on respect and relationship, where both lives are enhanced by the connection.

How to help someone with Severe ME is not necessarily obvious or apparent, it is complex, particularly because of the high risk of deterioration from seemingly small interventions. The specific experience of each person needs to be learned and understood as much as possible, because each person will be different in what they can tolerate and when and how they can be helped. You need to be able to read the signs very carefully.

Knowing how and when to engage is often unpredictable because of the illness and its impact and the post- exertional experience. In the absence

of clear signs, you have to be intuitive and empathic and always learn from every mistake you make.

It is almost impossible to comprehend the chaos the person's body is experiencing from different factors, noise, light, touch, colours, chemicals, movement, perfume as well as the illness itself, your very presence in their environment, the effort required to engage with you, all can be too much for the person to deal with, in any one moment.

The person might appear to be coping, until you try to help; just your entering into their space can tip the balance for the worse, unexpectedly and unintentionally. Nothing is simple and straight forward in Severe ME; always remember that you are entering into a world of chaos, where everything is turned upside down and not as expected, where everything in the environment, including yourself, is potentially hostile and harmful without meaning to be.

How to help the person get their needs met

There are several possible carer responses to the dilemma of how to help the person get their needs met, including :

- **Fear**, preventing you from acting and helping, leading to avoidance, inaction and neglect or even negation.
- **Ignoring the person's reality**, either by not helping them, assuming they will help themselves eventually or by just doing the care task anyway, because it needs doing, no matter what.

- **Distress**, leading to inaction, inability to cope with the person, feeling overwhelmed and incapacitated or being inadequate or over-protective.
- **The moment approach**, looking for those moments when the person can engage, if only you are centred enough, respectful, silent, attentive, compassionate, focused, knowledgeable, aware and willing to be flexible enough, patient and kind. This may require acceptance that you do not know everything and you certainly do not know best! You will be willing to be flexible and try again, you will not blame the person for their reactions to your mistakes or because they are too ill to connect with you and unable to help you to help them. You look with kindness and love upon the situation and look for new ways to connect, with awareness that great patience is required and not engaging may be more effective sometimes than overwhelming and overloading the person with your need to fix things and do things in the wrong moment for them.

Underlying the moment approach is a desire to understand and an intention to empathise with the person who has Severe ME, an intention to stand in solidarity with them, to enable and support the person, to connect with them and meet their need as well as you can.

To maximise any opportunity to help the person in a gentle and tender manner, you need to be flexible, compassionate, sensitive, personally aware and attentive, not only to your own actions and the persons need, but to the environment and the impact you are having upon the person. You also

need to be able to remain calm and respect the person's reality. This is not always a comfortable experience.

With Severe ME, it is never really possible to know from moment to moment, whether any thought, action or interaction is possible. You really do need to understand why this is so. You specifically need to understand the symptoms that the person has and how they impact and are impacted further by your presence and any attempt to engage with and help that person. This needs a balanced approach.

To maximise the opportunity to provide the best possible care, it is very useful to think holistically, from a Mind, Body, Emotion and Spirit perspective, so that you are able to interact in the best way, on all levels, with the person.

The aware carer is the best carer, so reflect on each aspect to gain a better perspective of how available you are, to fully engage in the moment.

Here are some possible questions you might ask yourself to be better prepared and more aware:

MIND :

- What am I thinking about when I approach the person with Severe/Very Severe ME?

- Am I thinking about the person and the situation or is something completely different distracting my attention?
- Can I focus solely on what I am doing ?
- Have I thought ahead about what potential issues might come up?
- Do I understand that ME is a neurological disease with multi-system physical dysfunction?
- Do I know what to do and what not to do to avoid exacerbating symptoms?
- Do I know how to help the person?
- Am I actually mentally available to interact with the person and notice all that I need to?

BODY :

- What is my intended posture? Open? Solidarity? Am I congruent with my intended posture or am I coming from a less helpful posture, such as authoritarian?
- Is my physical posture in keeping with my intention? Am I conveying kindness, warmth, integrity, awareness, sensitivity, understanding?
- Am I able to be gentle enough, when I help the person?
- Am I too tense to help the person? Do I need to take a moment to physically still myself and relax?
- Am I too tired to help sensitively and carefully?
- Am I in pain anywhere myself and is that pain distracting me?

- What sort of energy have I got? Is it likely to be helpful to the person?
- Is my energy likely to irritate or exacerbate the symptoms or drain the person?
- What do I need to do to centre myself in a peaceful place inside myself, so that I can best help the person in the least disruptive way?

EMOTION :

- What is my emotional state?
- Is it going to have a good impact upon my interaction or get in the way?
- Am I distracted by other issues?
- Am I distressed by the person's situation?
- Am I upset about anything?
- Do I feel good about myself and the care I offer?

SPIRIT :

- How do I feel about being with the person?
- Can I connect with them and meet their need?
- Do I know the best way to connect and interact with the person?
- Am I flowing with the right energy to have contact with the person?
- Have I built up enough trust with the person? How might I do this?
- Have I conveyed respect to the person?

There is a massive gap between will, hope and the person's ability to function, in Severe ME. Will power alone cannot change the person's physical reality or disease, no matter how much the person may want to do a particular thing or how much you want or need them to.

To maximise the opportunity to interact with, physically help and support the person with Severe ME, you need to take a moment-by-moment approach and be flexible. You cannot force the person and they cannot force themselves and you need to know this and fully understand it.

An holistic approach to care

In taking a holistic approach you need to take account of the person's reality. You might reflect upon their experience from a mind, body, emotion and spirit perspective, before engaging with them.

It may help for you to be consciously aware of the following:

MIND:

- There are complex cognitive difficulties which the person may be experiencing when trying to interact with you
- There is likely to be a break to all forms of communication in and out of the person.
- Thought and information processing is often severely affected, therefore the person's understanding and comprehension of what

you are trying to communicate or convey or do, may not be as straightforward, simple or as possible as you imagine it should be.

- The person may not be able to tolerate or understand any form of communication you can make in any one moment. They may also not be able to communicate with you in any predictable or expected moment.
- Cognitive dysfunction will interact in a complex way with other severe symptoms such as visual disturbance, noise sensitivity and functional incapacity (for example a lack of motor control and muscle dysfunction) to make communication a major difficulty in both an inward and outward direction.
- You have to think about how to communicate to the person in ways that they can tolerate, receive the information and understand it. You also have to think how to enable the person to communicate with you and what to do when direct communication is impossible. It cannot be forced. Being prepared in advance for a range of possibilities and reactions is always the best way to approach helping someone with severe ME. Problem solving needs creativity in our experience.
- Communication is not simple and can be frustrating and complicated to understand and may change from moment to moment.

BODY:

- The interaction of symptoms and the general level of pain and physical suffering must be understood as much as is possible.

- Every effort must be made not to hurt the person further or cause deterioration or distress.
- You have to think about what you need to physically do with the person to help them and how to do it in the most careful sensitive way possible.
- You have to understand the affect of physical contact.
- You have to understand the affect of movement on the person.
- You have to understand if the person can tolerate particular positions or not.
- You have to understand the Central Nervous System chaos and crash that over stimulation causes.
- You must allow adequate recovery time after any interaction to avoid further or more, long term deterioration.
- You need to understand the post- exertional reaction to any stimulation or activity, no matter how apparently little or ordinary it seems to you.
- You must understand that something quite small, like too much pressure on the skin, on some other apparently unrelated part of the body or exposure to even what you think is a slight noise or a small amount of light or just making a particular repeated movement in the visual field of the person, might still cause huge reactions in the persons body, such as numbness in throat, paralysis in tongue, paralysis in arms, full or partial body spasms, nausea, head pain, etc. and last for hours beyond the time you have spent with the person, making it harder to re-engage the next time you want or need to.

EMOTION :

- Emotional lability is part of ME.
- There may be physiological reasons for a person being apparently emotional, such as hormone imbalance or drugs causing heightened emotional, even suicidal states, for example steroids and some anti-depressants.
- Any negative care impact, even though unintended, is likely to cause distress and mistrust.
- It is important not to misinterpret the physical experience and any consequent distress, as the person being over emotional or unduly sad.
- Pain and careless exposure to environmental stressors will cause reasonable upset.
- The person with Very Severe ME, particularly, is likely to be extremely isolated and in need of comforting and affirming experiences.
- Make sure that you do not misinterpret the person wrongly and label someone as difficult, depressed or over emotional, for genuinely being upset with reasonable cause, because you do not understand their experience.
- If possible try to have happy moments which are uplifting.
- The symptom experience itself can be frightening.
- The lack of knowledge people, including carers and health practitioners have, can be frightening and makes the person with severe ME very vulnerable.

SPIRIT:

- The connectedness a person feels with you will be enhanced if you get the care right.
- You need to convey reassurance that you care and that you are aware, so that you can flow together in any moment.
- You need to convey kindness and genuineness.
- You need not to bring discord into the room with you on any level, whether noise, light, busyness etc. .
- You need to convey unconditional positive regard that you are there for and with the person and not only do you want to help them, but you want to help them in the right way.
- The caring you exude in your energy will touch the person and uplift them, hopefully if it is right.
- You need to not judge the person and keep trying to find the right moment to connect.
- Quiet, centred, attentiveness is most likely the posture that will aid a feeling of connection and solidarity. Even so, symptom experience can be so extreme that the person simply cannot feel any affirming experience or good feeling from the interaction, no matter how well-intentioned, because everything hurts so much or is disturbing or the impact and after reaction is so great that it causes deterioration.
- The person may need to be left alone to survive and not fit into a rigid regime or needs. Their need for space to cope may be paramount.

- If the person indicates that they cannot tolerate carer input in any one moment, this needs to be respected and then worked out with the person how to meet their needs at some other moment.

With the moment approach you need to grasp this idea that a moment in time can make all the difference to the person with Severe ME; that even when something is totally impossible in one moment, it may be achievable in the next. We daily hope for better moments.

You especially need to make sure that you are caring for the person, when they need help, not expecting them to fit in with your convenience. It does not come naturally to us to stand by and wait, to not speak, to not act, when the need is dire, yet still the right moment must be found to do no harm. This is our experience.

Often it may seem as if there is an empty space around the person, in which nothing is possible, yet if you are paying enough attention and are willing, able, gentle and patient enough, there may be a moment in which you can achieve something together.

The moment-by-moment approach often refers to what might be considered insignificant or tiny achievements, such as being able to cope with moving the bedclothes, take a sip of water, open your eyes and looking at something, being able to tolerate the help needed to get to the toilet; these can be big events in the life of the Severe ME sufferer, even though the well person might take them for granted or not realise how huge they are.

In the ordinary world, often you see something is needed, you see how to do it and you take action because it makes sense and is quite simple practically to do, but in the world of Very Severe ME particularly, nothing is obvious, nothing is simple and what appears to be simple can do a lot of harm if done without awareness, in the wrong moment and in the wrong way, without the person's co-operation and without striving for partnership and connectedness with the person.

The moment approach requires personal maturity and great commitment. You wait upon the person to indicate their ability to accept help and you watch out, with awareness and knowledge to make sure that when that moment comes, you are ready and available.

The change in the person's ability to cope in a particular moment, when it comes, may be very subtle. It may take days, weeks, months even, to achieve the simplest thing, like washing the person's hair, which you would normally take for granted in your own life. It is often a matter of finding the right moment. So many moments will be the wrong one.

It takes great alertness, sensitivity, skill and tenderness to notice and enable the person, in this moment, that has suddenly, unpredictably arrived.

This cannot be over emphasised. It is very skilled help that is required. It is paramount that the relationship the caregiver has with the person with Severe ME is hopeful, uplifting valuing and validating. The caregiver

potentially makes the difference between a totally hostile environment and a positive hopeful moment.

The role and the relationship of the Carer are key in lessening the impact of the disease upon the person's life. The caregiver becomes a link between the outside world and ME world. So it is imperative that the care giver understands as much as possible about the person's reality, so as to represent them accurately.

The moment approach is rooted in a value system that believes in the integrity and equality of person-hood of the other, alongside a deep belief in the human spirit to triumph over adversity.

Always remember that seeing the person as themselves still requires awareness that they are seriously physically ill; it can be easy to focus on the person and almost exclude their physical reality - or deny the wider reality of the illness and its impact.

To care for someone with Severe ME, you need to see the person and the illness in context, understanding how the illness, in all its severity and complexity, impacts the person's life in both the obvious and more subtle ways and then give them your very best in all that you do with and for them.

THIS IS AN EXTRACT FROM MY FORTHCOMING BOOK :

“SEVERE ME” : OUT SOON

<http://www.stonebird.co.uk/new/soon.html>