



**Very Severe ME :**  
underlying principles of Care

stonebird

# **Very Severe ME**

## underlying principles of Care

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# Very Severe ME : underlying principles of Care.

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**V**ERY SEVERE ME COMPLICATES both the understanding of care and the provision of care itself.

The sensitivity of the person's body is so acute that no one can begin to really know or imagine how bad Very Severe ME is, unless they have personal experience.

*The person's physical suffering, combined with feeling helpless to change it, can leave you feeling a whole range of feelings, not least devastation and frustration that you do not know how to make it better for the person.*

First and foremost, TO HELP THE PERSON WITH Very Severe ME, you need to be present with them, but what does that actually mean?

It is to be available physically and emotionally, to put aside your own distress, opinions and preoccupations, to really be with the person, reaching out to perceive their reality, comprehending as much as possible about what impact your presence is actually having on them.

For some, your presence alone, no matter how sensitive, gentle, kind, will be too much to bear.

If a person needs physical contact in order to access physical assistance and is also in very severe pain, or has acute hypersensitivities, then it is most likely going to hurt them in some way; most or all the time, that hurt will be way too much to bear, so you have to work very carefully with the person's consent.

This requires a sensitive agreement with the person in advance, if possible, so that you know what to do, how to communicate and approach the

person, what is needed and when to stop if pain is too great ; it is to have a plan for how to care in place, so that you can act confidently as well as tenderly and respectfully, present and conscious both of the pain of the person and the potential for symptom deterioration.

Whatever works best for the person needs to be figured out with the person, when able.

This needs to be a priority, yet the limitations and restrictions on communication imposed by the severity of illness must also be respected. It is important to establish early on exactly what symptoms are present. You need to know and understand all of the symptoms and the potential impact of both communication and care upon those symptoms, so that you can understand the impact of care upon the person and their health.

*You have to train yourself to notice things that you would not normally notice. The person with Very Severe ME is not experiencing the environment in the normal way that you are. It is hostile and assaulting to them.*

This is of the utmost importance.

The way that you experience the environment; noise, light, movement, people, chemicals, perfumes, is not the same as the person with Very Severe ME who can be harmed by the wrong thing at the wrong moment - the smallest thing can trigger a massive physical reaction.

This is not easy to understand or comprehend or witness.

It needs fast learning.

## **Posture**

It is highly inappropriate to adopt any posture that is authoritarian, cold, withdrawn, overtly or even subtly judgemental; any attitude you may have, that if only the person could “pull themselves together and snap out of it”they would get well.

You should never think that the person is “just tired all the time”. Seriously and very severely ill, they need assistance, even if you do not fully understand why.

The person may be in complex physical, not just mental or emotional distress when you help them, so you need to be fully present to them, with all the warmth, kindness and awareness you can muster.

*Often the best you can do, the only thing you can do, is to be totally present with the person, not saying or doing anything, just accepting their reality, rather than thinking you can fix it or cure it. If you can convey love and warmth through being present, then that is the greatest gift you can give.*

This is called a posture of “solidarity”: engaging with the person in their actual rather than some perceived reality, that you might wrongly envisage.

The person’s reality is highly likely to be a deconstructed, empty, distressed, tortured one, a shifting mayhem of physical agony, unimaginable pain, lost proprioception and physical feeling, an inability to move or think or feel.

Any contact at all can cause shaking spasms and a further descent into indescribable illness. If they have acute hyperesthesia it can cause massive irritation if stroked or touched lightly, even accidentally.

They may even shout or cry if touched and hurt.

The person cannot necessarily see clearly outside of the state that they are in, in order to see that you are actually being as gentle as you can be. It can be bewildering as well as agonising to feel as if the person helping you is assaulting you too.

You need to be very aware. Causing upset, even though unintentional, can have an additional negative physical impact upon the symptoms and the body, for example crying can impact on chest and diaphragm muscles, hurting eyes, exhausting energy, causing post- exertional neuroimmune response and deterioration . The extra, unexpected use of muscles can itself cause deterioration.

You have to understand the physiological implications and the sheer physical vulnerability of the people you aim to support and aid. You need to understand that a simple movement, for example, shaking a finger or scratching or making a particular irritating subtle movement or a very slight but painful noise, can trigger gut and muscle spasms, numbness paralysis, pain, overheating, hypoglycaemia, irritability, cognitive blankness and distress or a host of other symptom deterioration.

Each person is different and will experience their illness uniquely to them. The gesture you make may be tiny to you. The reaction massive. The danger to the person's health seems way out of proportion to the trigger! Yet is very real and present at all times.

*You need to learn what triggers deterioration in the person you are helping. You need to consider what it is like, as much as possible, for the person to experience your care, so that you can give it in the best possible way. Great empathy is required.*

You really do have to know ME is physically real and out of your control.

You have to be open, honest, genuine. You have to accept that the person's experience is real – it is not false or mentally controllable and any distress is valid, given the tormented reality the person lives in.

There is unimaginable physiological breakdown going on in their body. They don't need to change their thoughts, they need proper investigation and treatment, currently denied or unavailable mostly. In the meantime they need help with understanding and awareness of their reality.

Never assume that someone with Very Severe ME can cope with or understand your speech; they may be so cognitively affected that they cannot take in what you are saying, they may be so hurt by noise that your tone or loudness even when speaking quietly may be vastly too much to tolerate or they may cope for a few seconds no more. Even if they need physical help, they may not be able to tolerate anyone near them or in the room at any given time. Flexibility and patience are demanded then. You may have to wait for another moment, when you can quietly gently try again.

## ***The basis of Communication***

It is very easy to over- stimulate someone with Very Severe ME and cause a shutting down of their cognitive abilities or physical functioning. This can be frightening or confusing for the person.

Every aspect of their communication may be broken due to the severity of the disease or may shift and change so that in an instant the possibility of communication is lost. Even the tiniest bit of energy can be frittered away without awareness, in a meaningless exposure to unnecessary communication, noise, environmental stress from you.

*A “moment” approach, where you maximise the opportunity to meet the need of the person in the most tender caring, aware, present way is required.*

You need to establish what, when, how and if speech or any communication is possible for the person, whether listening to a voice is ever possible or variable for them.

You need to try and establish as safe and as clear a way as possible for two-way communication to take place. It may not be possible all or some of the time. It may not be possible for direct face to face speech. It may require lateral or creative thinking. It may not be a simple process. There may be a time delay. Nothing can be expected on demand. Very Severe ME just does not work like that.

It may be that the person cannot speak or can speak but you cannot reply because to do so would cause pain and deterioration. There are many variables.

A whisper can sound as loud as a thunder clap to the person with very severe hyperacusis, the noise can go on and on for hours or longer after exposure, still resounding inside the persons head, causing extreme pain and irritation. Anyone involved with a person with Very Severe ME needs to understand this. Noise may not just cause pain in the ears or head but impact the whole body via the vibration.

*Long after you have gone away, the person with ME will still be hurting if you got it wrong directly from something even seemingly small and insignificant.*

## **Partnership**

The person with Very Severe ME is severely ill, not just physically disabled and needs all their basic needs meeting. Partnership means to work with the person in such a way that they comprehend what, when and how you are going to help them. This can be particularly hard to establish when there are complex communication issues.

It means to work out specifically what help is required and how to do it in as non harmful a way as possible. Understanding how the person's symptoms can and might deteriorate must be worked out as quickly as possible, with the person, without forcing them beyond their capability and energy level.

It is very easy to misinterpret or not understand the person's level of physical disability, its potential variability and the impact of the illness itself upon the level of disability.

Sometimes things might be more tolerable or possible in one moment that are impossible in another. This tends to be completely unpredictable.

You want people to do what they can and to be in control of their life, but no one should be forced to do more than they are able. In Very Severe ME nothing is obvious, predictable or necessarily repeatable, so the concept of independence has to change.

*The person with very severe ME is struggling to live, it is that serious.*

You have to respect the person's rights to equality; they do not need encouraging to do more or better. They know who they are and what is happening in their body. They just cannot function. You can never predict what if anything they can do or how much more ill they will be a moment



later. You can never expect the person to do something on demand because you saw them do something or tolerate or cope with something in some other moment.

Just because something is possible in one moment does not mean it needs encouraging again in some other moment. People do not need “encouraging”; that is patronising, wrong and dangerous. Only the person knows their needs and how best they can get them met and what things they can cope with and how much, though it may not be so easy to convey this. This needs to be established so anyone involved in care knows too.

*Unfortunately the popular image is to encourage people to do more and improve; in Very Severe ME that will almost certainly lead to harm.*

With multiple symptoms all interacting together, all causing torment, torture even, high levels of staffing are likely to be required in order to provide the high quality, sensitive care that is needed. Everyone should be aware of the risks of harm and what needs doing if they have to step in to help with care. It is not necessarily obvious.

People with Very Severe ME are constantly vulnerable to inappropriate comments, misinterpretations, misrepresentation and mistreatment.

The most important thing, where care is provided by an external agency or home, is for staff to understand that the harm they can do is immense and long lasting. It is very easy to blame the person or think they are being difficult, not understanding that they simply cannot bear physical contact and may be helpless to express their need or experience in the moment. If they need help you simply must find the right moment to try and assist them in the right way.

### ***The Five Key Service Accomplishments:***

A service must aim to meet the care needs of the person with Very Severe ME, in the ways that they want them met, providing dignity and respect.

To summarise, in order to ensure that the person with Very Severe ME feels in control of their life, that they are treated with respect and equality

and that the service works in partnership with the person, an aware service will be based, from our experience, upon the following five key Service Accomplishments:

## **Acceptance & Validation**

## **Safety & Security**

## **Respect & Equality of Personhood**

## **Affirmative Healthcare**

### ***Acceptance & Validation :***

#### **Inclusion & Access**

Your approach and understanding can make such a difference. You can be a lifeline, a true support, an advocate, a help. Or you can just be another part of a tormenting hostile environment, alienating the person still further, inadvertently adding to their discomfort and neglect and isolation from the world.

You have to accept that the person is severely physically ill as well as severely physically disabled and needs your assistance.

You need to know that even if the person can appear to manage something themselves, it will not be so in every moment or in any predictable moment and even so the cost of attempting to do something may be too high in terms of the possible post- exertional reaction.

A lot of the symptom experience will not necessarily be visible or obvious to you. You need to grow in your understanding and comprehension of Very Severe ME and its impact upon the person.

## **Safety & Security :**

The experience of the world in which the person with Very Severe ME lives is not the same as your own; it takes time, effort, great compassion to enter into a genuine supportive and caring relationship.

*Their environmental hypersensitivity, physical dysfunction and their physical frailty, places people with Very Severe ME at great risk of deterioration. This is experienced in different ways for different people.*

Safety means that you understand the person's symptoms, the risk of deterioration and the potential harm that can be done through ignorance and unawareness. You have to understand that the person is physically ill.

It means that you have made the environment as safe as possible for the person, taking into account all environmental factors: noise protection, light protection, freedom from chemicals, physically appropriate bed and bedding and seating, suitable wheelchair, appropriate aids and equipment, appropriate dietary needs etc.

It means that the care provided will be of the highest calibre, sensitively aware of the physical issues involved in caring. Providing care will not be easy or straightforward. It will require problem solving and creative awareness. It requires involving the person in the decision making process, to ensure need is thoughtfully met.

Security means that you have managed to convey to the person that you are aware of them as a person with rights and needs and that you are willing to support and meet them within the bounds of possibility.

*Security means that the person feels safe in your care and respected and seen for who they are.*

## ***Respect & Equality of Personhood :***

This means seeing the person as an equal, listening, caring, responding appropriately with understanding, reflecting, being creative and imagining their life: these are all things that will help the person have a better quality of life.

It will not make them well. They will continue to be severely disabled and ill, but you will have made a difference.

When you respect the person and their illness and their physical reality you will not come from an authoritarian, over-protective or cold, judgemental posture. You will be open and compassionate and see the person wholly.

## ***Affirmative Healthcare :***

Myalgic encephalomyelitis is a WHO neurological disease with multi-system dysfunction . The person with Very severe ME is profoundly ill; there is a quantum difference in the physical experience of the person who has Very Severe, not just Severe ME.

Each person experiences their illness differently.

Health needs are so complex they are unlikely to be fully understood or treated.

There may be tests and treatments that can alleviate symptoms or help heal the body, but either because the person is too ill to tolerate investigations or any medicines or supplements or not able to afford private healthcare, those tests and treatments may be completely inaccessible.

It is essential to find a doctor who knows and understand the physical illness in ME and is willing to work with the person .

To advocate effectively for the person's health needs, you must understand how very seriously ill they are. You must know how and when it is safe communicate with them. To safely help the person get the best healthcare possible you must also understand the political and medical context that surrounds the illness. You may be in a position where you have to

communicate for the person on their behalf. Make sure you do so accurately and with the utmost integrity.

*You cannot ignore the illness when caring for a person with Very Severe ME. To do so leads to harm.*

## ***Inclusion & Access:***

Inclusion means including the person in their own life and any decisions you are making about them. It means going out of your way to respect their identity and equality in every decision made about their care and life.

It means that the truth of their illness is central in your mind when you make any decision or speak on their behalf or represent them.

It means that you remember that when you enter their room and their space you understand their complex reality and that you always treat them as a person, not an object. You include within your awareness all that you know of that person, for they are much more than a body or an illness or a need.

They are a person with hopes, dreams, losses, loves, feelings, experiences. They are greater than their illness, despite its incapacitating presence.

Inclusion is always to remember who the person is and ensure that it is not forgotten by anyone.

Access means just that. People with Very Severe ME need access to the world. You are the gateway to that world as it is unlikely that they can directly access anything without help and support.

If you are an advocate or facilitator for a person with Very Severe ME you need to protect them. You may have to speak for them at times. To enable access to safe care, services, benefits, healthcare, for a person who is completely physically cut off from the world because of severe illness, hypersensitivity, disability and complex communication difficulties, you need to be very clear that you represent the person not your own opinion, interpretation or judgment.

You need to help be a voice for them so that they do not remain isolated, invisible and neglected, not heard, seen or understood.

Inclusion means going out of your way to connect with and relate to the person where they are, not where you are.

Moments of connection will help you get to know the person more; try to reach out in a spirit of solidarity to improve their life through excellent care. You can enhance those moments in the person with Very Severe ME's life or you can negate them.

Choose solidarity as your stand.

**EXTRACT FROM “SEVERE ME” (2ND EDITION)**

By Greg Crowhurst

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