

# How to Care, really Care



for someone with Very Severe ME

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# How to care, really care, for someone with Very Severe ME

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**W**HEN YOU CARE FOR someone who has Very Severe ME you need to be more sensitive and aware than you can possibly imagine. Harm, even death, may follow poor treatment, care and ignorance. The frailty of someone with Very Severe ME cannot be exaggerated nor adequately described. You need to take great care :

## ***Be knowledgeable***

It is too easy to harm someone with Very Severe ME, even by the simplest action, wrongly timed or inappropriately carried out.

*Because of the complex multi-system dysfunction and extreme hypersensitivity that they experience, people with Severe ME do not respond in the same way as in other illnesses.*

You need to be knowledgeable about the disease process, the symptoms, as well as the impact you are likely to have upon the person.

## ***Be sensitive***

The manner in which you present yourself in the caring role, is critical to the success of the interaction. How you speak, act, move within the person's environment can harm, frighten them, lead to physical deterioration and distress, if it is not grounded in sensitivity to the vulnerability of the frail, seriously ill person in whose presence you are.

You can help or harm. There is no room for carelessness, clumsiness, impatience, inattention; the harm you can inadvertently do to a person with Very Severe ME is not just in the immediate moment; the impact may go on for days, weeks, months and can be catastrophic.

## ***Do no Harm***

You need to make sure that you are biomedically aware, that you know that ME is a serious and severe neurological disease. The person you are about to interact with needs specific, sensitive physical support and assistance.

Your main aim should be to make sure that they get the physical help they require, on their terms.

People with Very Severe ME cannot fit into a tight, institutional framework. If you expect the person to be able to do what you need them to do, you will not have grasped the fundamental principle: that you are there to do what they need doing; this is an important difference.

Utmost sensitivity is required to ensure that their needs are met in a positive fashion. Without this, your approach will be fundamentally wrong. You are unlikely to respond to the person in a safe way.

*You need to make sure that the thoughts you have are the right thoughts to have in order to engage with someone with ME. If you believe that the person just needs encouragement or can do more, if pushed, you will probably do great harm.*

## ***Be Calm***

Because they are incredibly hypersensitive, the energy you exude impacts greatly upon the person with Very Severe ME, much more than you realise.

If you suddenly walk into the room of the person with Very Severe ME, with your mind and energy in a busy state you are likely to create chaos. Even something as simple as being busy-minded, full of enthusiasm and raring to go, can be too much for the person and may cause harm.

You need to still yourself down. Be focused and aware of the person's reality: a radically different reality than the one you exist in.

Being too tired can have a devastating impact; your lack of energy can be irritating to the person. They do not need to feel their energy being drained by your presence. If you are too tired, then this is the time when

mistakes are made and carelessness happens.

## ***Be Aware***

Awareness is key. You have to be aware of what you are doing, what impact you are having, what noise you are making, for example with your clothing, your feet, your every action: these all make noise which you may not be aware of.

You have to do more than your best to limit any harm to the person.

It is essential that you care about how you are caring for people with Very Severe ME. Care, of itself, will not be enough, unless it is grounded in a true appreciation of the nightmare reality you can create by getting it wrong.

You have to take care of the fine details of caring as well as the basic care needs. It is not just what you do; it is how you do it and in which moment you do it.

*In Very Severe ME, it is the acute nature of the harm that can be done by the smallest thing, that you need to understand and really care about.*

Caring does not take place in a vacuum. If you get it wrong it is disastrous, but if you repeatedly get it wrong you damage the relationship and trust that you have with the person. There is a power issue where you hold a lot of power as a carer.

You must not take advantage of that power or misinterpret the person, because of your inadequacy at comprehending their need and how to safely meet it.

## ***Engage in Relationship***

You are engaged with an extremely ill, vulnerable person whose health can easily deteriorate and whose symptoms can rage and flare for hours, after even the gentlest contact.

At the heart of good care is awareness that it is a two-way interaction. When you offer care to a person with Very Severe ME never forget that you are engaged in a personal relationship with that person, especially if it involves intimate care.

The only way to engage positively and sensitively, is to focus on how you approach the person and connect with them, so that they feel good about your help and are not lessened or harmed by your interventions.

## ***Engage as an Equal***

Remember that you are both equal in humanity and person-hood. Never abuse your power over someone who is physically frail and dependent upon you for care.

*Never blame the person when you get it wrong.*

Go out of your way to engage, as an equal, with them, respect and validate them. With genuine empathy, compassion and care make sure that you see, really see, the person you are helping; let this inform the way you help them.

## ***Care with Dignity***

Even if the person cannot move or speak, they can still feel and are still aware of you. How you engage with them is critically important to the care experience.

Always carry out any care task with the utmost dignity and respect that it deserves. Make sure you really know what the person needs. A person receiving your care should never feel that you have undervalued or dismissed their reality. You should always respect their right to say 'no', 'not now', 'try again later', 'I am too ill right now, even though I have a need.' 'If you help me now it will make me too ill.'

This is not an excuse to neglect the person, the need is still relevant and needs to be worked out in partnership with the person. It is not necessarily

easy but it needs to be worked out together, somehow.

## ***Be Flexible***

You will find that the only way to meet the need of the person with Very Severe ME, is not to pigeon hole them into a predetermined time slot. It will not work. You have to have a flexible approach that is sensitive to how ill the person is feeling, the likely impact of your presence and involvement, as well as how much energy the person has to engage in any interaction, even one that they need.

It is also needs to take into account their extreme environmental hypersensitivity.

*You have to find the right moment to safely and appropriately engage with the person. This is not always obvious but should become apparent.*

## ***Pay Attention to Detail***

When entering into the room or the presence of a person with Very Severe ME you must pay extremely close attention to every detail of your interaction:

- The amount of pressure you place on the person's skin can hurt unimaginably.
- The movement of your hand across their skin even unintentionally can be a torment.
- The quietest whisper can sound like a shout or a thunder clap even, in terms of its impact.
- Turning on the light carelessly can cause excruciating eye and head pain and vivid after- image for many hours after you have gone away and forgotten all about your carelessness, not realising the harm you have inadvertently done.

To truly help someone with Very Severe ME you must learn about their physical hypersensitivity and how they react to a tormenting world; most likely this will be way beyond anything you have ever experienced yourself,

so great empathy and tender caring is required.

## ***Stop and Listen***

There is no place for complacency, mediocrity or carelessness in the life of someone with Very Severe ME. Your interventions can cause serious harm to the person's health. Whatever you do, right or wrong, make sure you learn what helps and what hurts.

*Make a commitment to always do better and always intend to get it right!*

Know exactly what you are doing and be prepared, even so you may not always be able to predict a bad reaction.

Stop what you are doing immediately and wait till re-engagement is possible.

If the indications are that the person is suffering, distressed and not flowing with you, never keep on doing something because you think you are right.

The person who is severely ill will always know better than you what impact you are having upon them and what they can tolerate. Always stop and listen.

Learn how to interpret their reaction and communication. Never leave the person feeling bad about themselves because you got it wrong !

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Greg Crowhurst (publication date : Autumn 2013)

