

Severe ME:

When you have to say, "Go Away"



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Severe ME: **When You Have to Say** **“Go Away”**

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When you have to say: “Go Away”

With Severe or Very Severe ME, you may at times have to say ‘*Go away, I am too ill to cope with your presence at the moment.*’ And when you have to say it, it means just that...

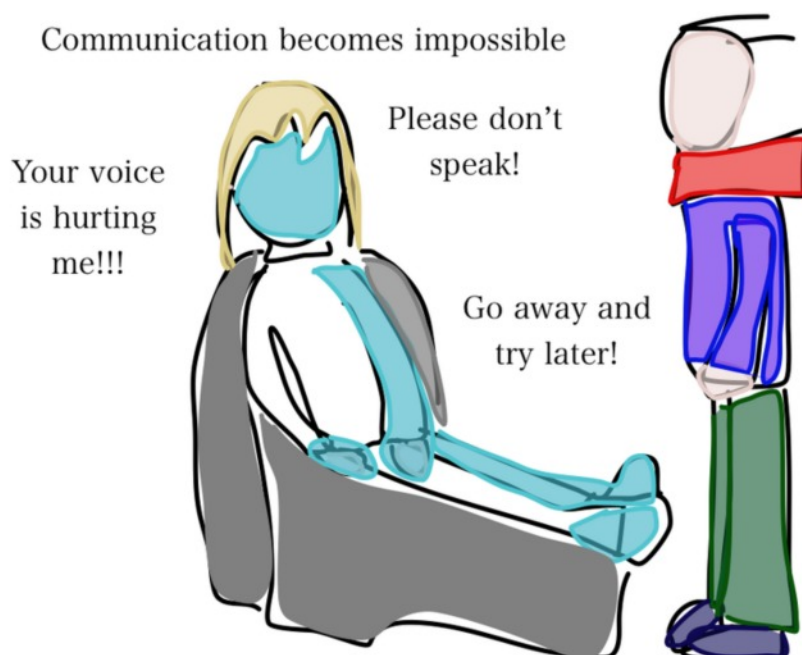
“Go away” must always be listened to and respected, however it can be very strange and difficult, even worrying, for a Carer to understand, especially if they are new to providing help and support for a person with Severe or Very Severe ME.

It may not be possible to say ‘Go away’ in a polite way or give a detailed explanation of why it is so necessary at that moment. The person needing care may be far too ill to tolerate conversation or contact, at this point. Each person will have different needs and symptom combinations that need individually to be learned by the carer and understood and recognised.

The Carer needs to learn how the particular physical and cognitive symptoms affect the person that they are supporting, so as not to unintentionally cause a worsening of experience or a long or longer-term deterioration of health.

They must learn how to safely approach and be with the person and know the best ways to help them.

It is absolutely vital that the Carer understands what might be the likely consequences and impact upon the person if they get any aspect of interaction or care wrong. It is essential to work in an aware fashion.



There are likely to be so many ways that you can trigger deterioration or symptom exacerbation if you do not understand how to be with the person and when not to be with the person and why it is necessary.

This is why it is so incredibly important that the person has a detailed care plan, not only for what needs doing, but also outlining how it must be done and when it might be tolerated best, alongside a core outline of communication issues such as the forms of communication possible, the limitations set by the illness and symptom experience, potential and actual blocks to two-way communication and comprehension and so on.

The more detail a person has, the better. If possible, the what, why, when, how of communication needs spelling out, so that the Carer does not feel helpless nor intrude on the person's space unhelpfully.

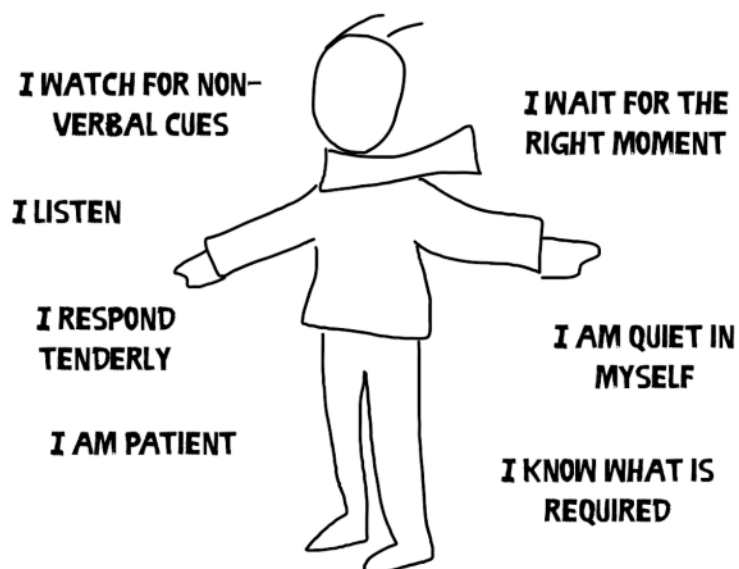
It is a very likely situation, with Severe and Very Severe ME, that sometimes the person is not going to be able to cope with interaction. The Carer is going to need to learn how to deal with this safely.

Massive flexibility must be factored in to any care plan.

If the carer has to go away and leave the room, it is very important that they know what is expected of them, what and how carefully they should or should not do anything somewhere else in the home and exactly how that should be done, so as not to cause further deterioration or difficulty for the person. It may be that nothing is tolerable and the Carer needs to wait patiently and peacefully.

The important thing is to have clear instructions that are followed to the tee.

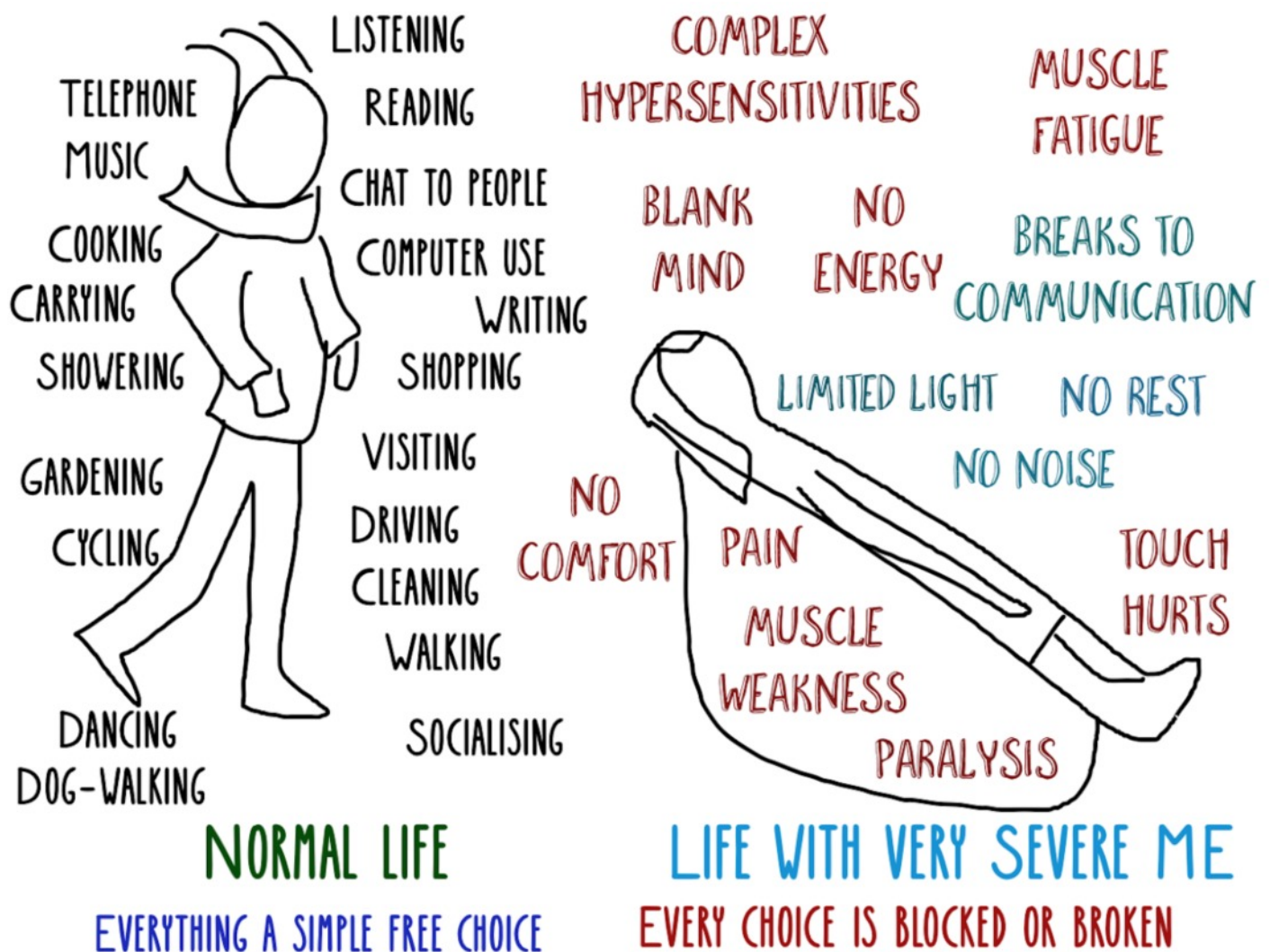
It is crucial that the Carer understands why they are being asked to go away; they should not take it personally, this cannot be emphasised enough. Feeling hurt or reacting poorly is not helpful.



They need to know if they are expected to return to help with particular care needs. There needs to be a guideline on how long to leave the person before returning, very carefully, to see if interaction is now possible, if this is wanted or needed.

If the person wants the Carer to stay but not do anything specific whilst waiting, again, clear guidance is required on where to stand or sit, how to wait in a supportive and sensitive way.

If the person is unable to speak the carer needs to be skilled in non-verbal communication. What to do and how to proceed, in these circumstances is best known in advance.



There could be many different reasons for a person's inability to tolerate your presence; a physical inability to speak; it would take too much energy for them to speak; the person's cognitive function is variably limited and impacting their ability to find the words to say; their voice is too weak; the effort of communicating will make their symptoms worse, ie pain may become intolerable, ability to think might

be lost, movement might be lost, the carer's voice might be incredibly painful and hard for the person to comprehend. There could be many other reasons.

The person with Severe ME will not be experiencing interaction in the same way as the carer, therefore it is requisite not to speak when your speech is not tolerable, not to demand information that simply cannot be given, not to try and plough on with an action, ignoring the reality of the incredibly ill person, especially if they have indicated they cannot tolerate it in that moment.

It is fundamental to understand each and every hypersensitivity that the person has, in order to ensure that if you are told to go away, that you do it in a way that does not exacerbate the situation, for example being very aware of issues that could have an impact, like how you move, walk, open or shut doors, potentially expose the person to light etc.

Try to understand how much pain the person is in or how severe other symptoms are, that the person might be experiencing and their impact upon them.

Try to recognise that anything you say may overwhelm the person, draining them of vital energy that they need to be able to cope with the rest of the day.

Try to understand that any action or interaction will have an after-impact and how any unwanted intolerable action or interaction can make that catastrophically worse.

Try to learn to empathise with the person, for if they are too ill to speak or receive physical help from you in any moment, that moment is an incredibly difficult one for them. They may feel too sick, they may be in too much pain, too weak or too sound, movement, noise or chemically sensitive to literally be able to tolerate your presence.

Highly skilled and sensitive care is required at all times. It is vital to have an emergency protocol in place so that you know what to do if there is a crisis. Never leave a person in an unsafe situation but work out respectfully how to support them.

This is an individual thing, it highlights the need for any professional, particularly, to do a detailed risk assessment on how to provide the best, most effective care support.

The language and attitude of the Assessor will hugely impact understanding and interpretation of the needs of the person and influence any approach.

People with ME need a biomedical interpretation of their disease and recognition that it is a neurological disease in order to truly understand their needs.

Be aware of any language used in reports or assessments incorporating the words, "*feels as if*", for example, "*the person feels as if their symptoms are too extreme to engage,*" rather than the more accurate phrase, "*the person's symptoms are too extreme to engage.*" Or "*the person feels as if their pain is so extreme it overwhelms them*" as opposed to "*the person's pain is extreme and overwhelming*". Or, "*the person feels as if they have been poorly treated and misinterpreted*", as opposed to, "*the person has been poorly treated and misinterpreted*".

The phrase, "***feeling as if***", is potentially a denial of the person's true reality, an implication that it is not necessarily as bad as it feels, especially if they change their thoughts and perceptions; it is a judgement about the person, whilst implying an empathy that is actually missing, whereas stating how something is, is factual and will represent the person's true experience.

Other phrases, such as, "*needs encouragement*" or "*requires reassurance*", may also indicate an underlying psychosocial approach that will risk denying the person's correct level of need for support. If you are seen as "*needing encouragement*" to do things, rather than recognise the impossibility of doing things and therefore needing full support, your needs may well be misinterpreted and misrepresented.

Any assessment needs to be agreed with, by the person being assessed, for accuracy, language and interpretation of need, though this may be difficult with severe cognitive issues and breaks in communication pathways. Any assessment must accurately reflect the person and how they must be approached safely.

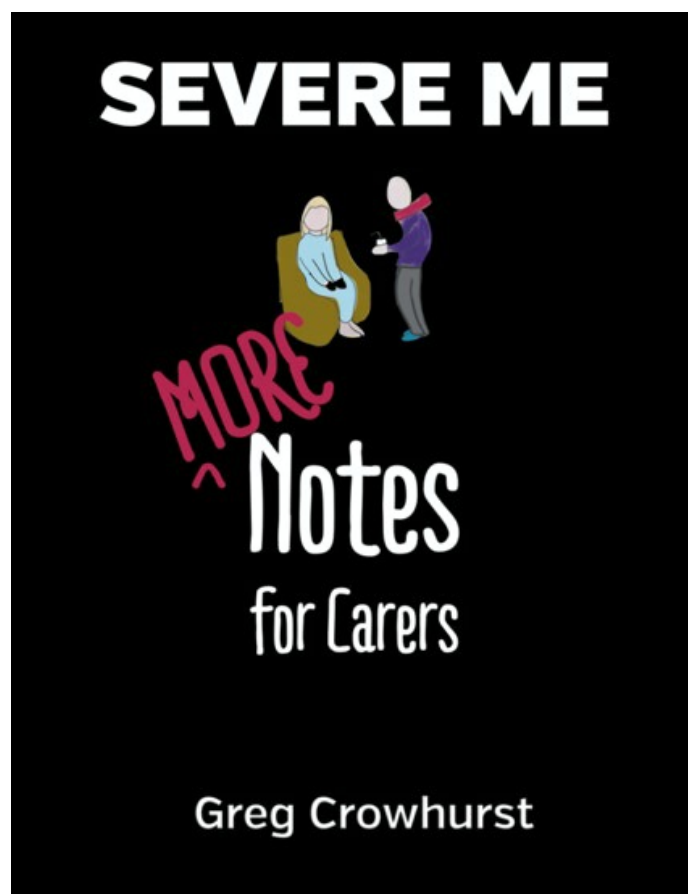
A Risk Assessment needs to reflect the very real dangers and risks to symptom exacerbation or health deterioration that interaction imposes and suggest realistic ways round this. The way a person communicates and how long it is realistic to engage with them should also be recorded. It is worth remembering that the worst case, not just the best moments of possible engagement need to be recognised, considered and recorded to ensure the reliability and usefulness of the Risk Assessment.

A good Risk Assessment protects the person and their carer and should provide detail that supports any care to be provided.

The importance of listening to the person and working in partnership to get it right for them, in the right moment for them, is absolutely paramount. Great unnecessary suffering and potentially long-term harm can sadly ensue from the ignorance and unawareness of others.

Going away when asked or indicated is an important part of respectful care for someone with Severe or Very Severe ME. It must be dealt with responsibly by both parties and not misinterpreted or misunderstood.

For much more information, please
see my new book :
"Severe ME: More Notes For Carers"



<https://stonebird.co.uk/morenotes/index.html>