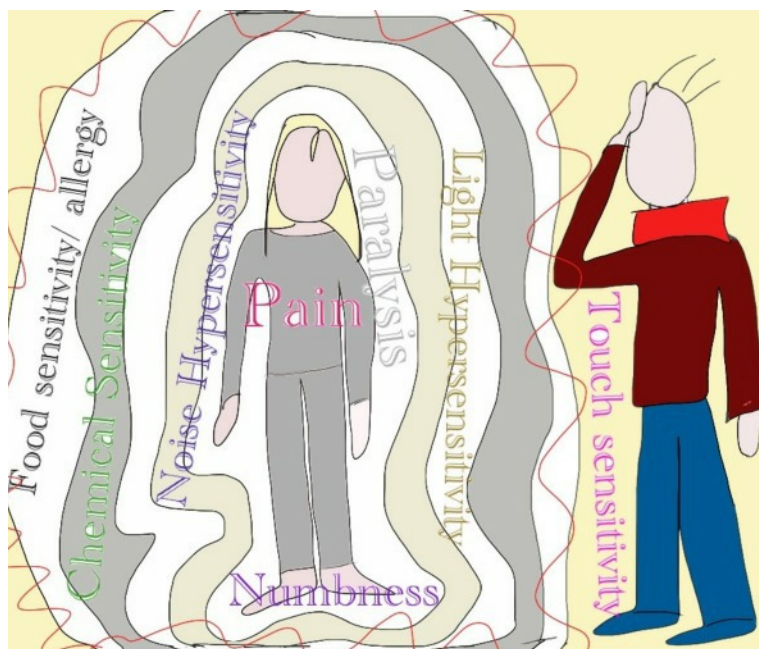


**ISSUES OF NOISE, LIGHT, TOUCH,  
CHEMICAL & MOVEMENT SENSITIVITY IN  
SEVERE/ VERY SEVERE ME THAT  
CARERS NEED TO BE AWARE OF.**



- Since 2006 -

**Stonebird**

THE EXPERIENCE OF SEVERE ME

Stonebird : the lived experience of Severe ME

# ISSUES OF NOISE, LIGHT, TOUCH, CHEMICAL & MOVEMENT SENSITIVITY IN SEVERE/ VERY SEVERE ME THAT CARERS NEED TO BE AWARE OF.

## Severe ME : 10 Carer Rules.

- 1 Don't just try to get it right. Get it right! They are not the same.
- 2 The way you do things matters, beyond imagination. Be aware.
- 3 Your reality and experience is not the same nor any way like the person you are helping. Remember this.
- 4 See the person not their reactions. Understand their reality.
- 5 Understand as much as you humanly can what the person is experiencing physically. It is complex.
- 6 Be careful in every moment. It is so easy to get things wrong.
- 7 Be ahead of the situation and think in advance of potential issues and problems you may encounter. Being consciously aware can make all the difference.
- 8 Do not demand too much. Wait and flow with the person not against them.
- 9 Think creatively about what might help the person. New perspectives may give greater insight.
- 10 Waiting and patience, care and attention are always going to take time when engaging with someone with severe ME. Let 'I am with you' be your motto.

Greg & Linda Crowhurst 2013



stonebird

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Stonebird : the lived experience of Severe ME

**Issues of Noise, Light, Touch,  
Chemical & Movement Sensitivity in  
Severe/ Very Severe ME**

## ***Introduction***

**FOR THE PERSON LIVING with Severe/ Very Severe ME the environment, moment by moment, is a torment; the person helping them can increase, unintentionally, that torment through lack of awareness and sensitivity. It can be extremely difficult for someone with Severe ME to get their needs met in a safe and caring way when their acute and profound levels of hypersensitivity are invisible.**

***These are so outside of most people's ordinary experience, that they are particularly hard to imagine.***

**IT IS ESSENTIAL THAT ANYONE CARING FOR THEM FINDS OUT WHICH SENSITIVITIES A PERSON HAS, WHAT LEVEL OF SENSITIVITY IT IS AND WHETHER IT IS VARIABLE, CONSTANT AND THEN WORK IN A WAY THAT MINIMISES THE DAILY EXPOSURE AND IMPACT.**

One very small wrong intervention on the part of a carer can have dramatic and long lasting impact, causing indescribable suffering.

It is a very serious issue, one that takes great commitment to try and comprehend.

Because communication is so complex in Very Severe ME, due to severe multisystem dysfunction, a verbal response is not always possible, or for some, never possible.

**THIS MAKES YOUR UNDERSTANDING OF THE SITUATION AS SOMEONE PROVIDING CARE, VITAL, SO THAT ONE MISTAKE DOES NOT BECOME MANY.**

### **Noise sensitivity - Hyperacusis**

EACH PERSON WILL BE hypersensitive in different ways, one person may tolerate something that would destroy another, it is very important to understand the implications of ignoring or forgetting to respect this seriously disabling and invisible symptom.

It is essential to understand that because you have helped one person with ME, every person will not be exactly the same. Never assume you know anything or everything.

Here are sixty-four things not to do around or near someone who is noise sensitive, without first checking absolutely that the person can tolerate it occasionally, at all, or with limitations.

## **Issues of Noise, Light, Touch, Chemical & Movement Sensitivity in Severe/ Very Severe ME**

Never ignore instructions.

**ALWAYS DO WHAT IS ASKED, NOTHING MORE, NOTHING LESS.**

### **Do not:**

1. shout.
2. knock.
3. bang.
4. cut things up, especially food on a plate or hard surface.
5. talk.
6. drill.
7. dig.
8. mow the lawn
9. put the washing machine on.
10. Hoover.
11. speak on the phone.
12. let anyone in the house stomp on the stairs or floor above the person. listen to music through headphones, not realising noise still leaks out and still causes harm.
13. turn the radio or tv on, even in a different part of the house.
14. boil a kettle.
15. sweep or brush the floor.
16. turn the tap on and especially leave it running.
17. scratch your head or rub your face or hands together.
18. cough.
19. sneeze or sniff.
20. laugh.
21. breathe heavily or too close.
22. shower/ run a bath/.
23. wear clothes that rustle.
24. flush the toilet.
25. run the car engine.
26. open/ shut a door.
27. forget to shut a door so it bangs.
28. open and shut a cupboard.
29. wear noisy jewellery that clangs or clanks together.
30. whistle.
31. talk or even whisper.
32. chat to a neighbour outside the window or at the door.
33. leave the window open for noise to waft in unless expressly asked to.
34. tap on a computer keyboard or tablet screen or use printer.
35. open the mail - letters and parcels.
36. do the washing up.

## **Issues of Noise, Light, Touch, Chemical & Movement Sensitivity in Severe/ Very Severe ME**

37. read a newspaper.
38. turn the page of a book.
39. put things down on noisy surfaces or on any surface noisily.
40. walk loudly in outdoor shoes.
41. turn things on and off.
42. eat.
43. pour a drink.
44. play a musical instrument.
45. have a clock that ticks.
46. wear a ticking watch.
47. talk to yourself out loud.
48. make any noise without warning.
49. clap or tap hands or feet.
50. leave mobile phone ringer on.
51. be uptight or angry or loud in your voice tone.
52. sigh, snort, snore.
53. yawn.
54. fidget.
55. clank things together.
56. write on a surface.
57. switch things on or off that make a click.
58. use your computer or tablet nearby make any noise that can be irritating or indescribably tormenting
59. prepare food.
60. cook.
61. move about the room unnecessarily or at all
62. continue to do something if it is clearly causing pain and distress.
63. make a noise repeatedly.
64. move anything without agreement.

It is only when you stop and think about all these daily ordinary things that you do without thinking, that you begin to realise what a dangerous and tormenting world the person with severe hyperacusis lives in.

They are hurt and harmed by the ordinary or even the quiet. As a result, how very hard it is to help the person and sustain contact and engage with the person without causing serious distress and harm.

How very difficult it is to offer care in an appropriate and aware manner and maintain relationships.

**EVEN IF YOU DO NOT UNDERSTAND FULLY, STILL YOU NEED TO ACCEPT AND RESPECT  
THE PERSONS REALITY OR HARM WILL FOLLOW.**

**Issues of Noise, Light, Touch,  
Chemical & Movement Sensitivity in  
Severe/ Very Severe ME**

**Noise sensitivity:** *Any noise can cause instant partial or total paralysis, or extreme body shaking then paralysis, skin goes numb, speech becomes impossible, eyes stare, guts tremor, muscles turn to jelly and collapse, pain intensifies everywhere, pain from light increases, vision is diminished, eyes stare, swallowing becomes difficult, nausea overwhelms, breathing goes shallow, hot sweats or extremities freeze, inflammation in head and neck increase, intense head pain follows, face becomes palsied, tongue goes numb, muscles throb, burn, itch, scream with pain, skin crawls with indescribable sensations, energy instantly drains away, brain fog descends further blanking out all thought; nothing is possible, contact is unbearable, communication unachievable. Noise sensitivity increases and lasts well after the noise has gone.*

Unfortunately noise sensitivity, a torment in itself, does not just stand alone, but links in with other symptoms, increasing them too. Basically any noise, even a seemingly quiet noise to you, can still be a torment and a harm leading to worsening deterioration of symptoms and illness experience..

Noise can hurt or be so painful and destructive that it can cause paralysis, muscle spasms, cognitive confusion, severely worsening cognitive dysfunction, making the experience a literal torture where even breathing or whispering will be a nightmare for the person to experience.

For the most profoundly affected, noise, even a slight noise that you might not even notice or describe as noise, or might accidentally or unintentionally make, can be so harmful that it is utterly traumatic and dangerous. It is not just the loud noise that causes problems. It may be certain sorts of noise, like voice tone, or cutlery or the slightest touch or a

## Issues of Noise, Light, Touch, Chemical & Movement Sensitivity in Severe/ Very Severe ME

It is hard to truly comprehend the impact or register even what level of noise you are making, as infinitesimally small noises can hurt and trigger a devastating response if they are the wrong sound at the wrong moment, as much as large and repeated or constant sounds can.

Exposure to noise, especially loud and continuous noise can be inexplicably painful and cause lasting damage. The life of such a person can be an ongoing noise nightmare that makes every aspect of life inaccessible or indescribably difficult to tolerate and experience.



It is not just the sound itself that can hurt and be unbearable, but in the most sensitive people, the vibration itself can cause massive physical assault and cause unbearable muscle tremor and whole body spasms and whole or partial body paralysis, numbness and loss of proprioception. It is very serious and cannot be underestimated, down played, trivialised or ignored, nor the person expected to somehow get over it or *'pull themselves together.'*

**EVERY SOUND, LOUD AND SMALL CAN FEEL AS IF THE PERSON IS BEING REPEATEDLY KICKED IN THE HEAD OR PUMMELED ALL OVER THEIR BODY OR KNIFED IN THE GUTS OR WORSE.**

Unfortunately living in the ordinary world, things make noise, even when trying to be quiet. It then becomes a complex dance between action and non-action, between leaving things however long they take or trying to figure out a way to avoid the noise or lessen its impact. For those who cannot wear ear defenders and ear plugs due to touch and pressure sensitivity, the daily living experience is particularly horrendous, especially if noise is unavoidable or noise issues ignored or forgotten or not addressed. Isolation, avoidance and protection are then essential strategies for living.

## **Issues of Noise, Light, Touch, Chemical & Movement Sensitivity in Severe/ Very Severe ME**

### **Light sensitivity - Photophobia**

**IT IS ESSENTIAL TO work out with the person how you can safely meet their need without exposing them to light.**

This is a complex issue especially for the most severely affected and the importance of understanding the implications of ignoring or forgetting to respect this seriously disabling and invisible symptom, cannot be over emphasised.

Light is so much a part of the every day that it may be hard to imagine how much extreme pain and autonomic chaos it can cause to a person with very severe or profound light sensitivity.

Light Sensitivity can trigger muscle shaking, seizures, intense head, eye and body pain, increased inflammation, nausea, vomiting, paralysis, irritability, total deterioration of other symptoms and justified distress. The after impact of unexpected exposure can last for hours, days, weeks; be indescribably damaging.

**IT IS ESSENTIAL TO UNDERSTAND THAT BECAUSE YOU HAVE HELPED ONE PERSON WITH ME, EVERY PERSON WILL NOT BE EXACTLY THE SAME. NEVER ASSUME YOU KNOW ANYTHING OR EVERYTHING.**

Here are twenty-two things not to do around or near someone who is light sensitive, without checking absolutely that the person can tolerate it occasionally, at all, or with limitations.

DO NOT:

1. switch on the light for your own need
2. change the light bulb to a different strength
3. open the curtains even a centimetre to let in light so you can see, without agreement.
4. leave the door ajar to let in light.
5. forget to have a spare pair of dark sunglasses incase they get broken.
6. switch on the TV screen unexpectedly.
7. switch on the computer screen unexpectedly.
8. have the computer screen set on anything but the lowest setting
9. strike a match.
10. flash a torch in the room and especially not at the person.



## **Issues of Noise, Light, Touch, Chemical & Movement Sensitivity in Severe/ Very Severe ME**

11. ignore the pain and distress of acute photosensitivity.
12. wear bright colours or brightly patterned clothes.
13. wear sparkly things that shimmer.
14. open the door and let in light unexpectedly.
15. forget to close the curtains fully at night, when it is dark, so that early morning light can penetrate and torment.
16. forget to check that the person has whatever eye/ body protection they need on and is able to tolerate and prepared before exposing them to any light.
17. shine a light directly at the person.
18. take photograph with flash on.
19. move a person to another room without taking precautions to
20. ensure that the person is still as light protected as possible and all issues have been thought through.
21. use a mobile phone with light screen pointed toward the person or in the room with the person.
22. let someone unaware enter the room and cause pain and physical chaos through exposing the person to light unintentionally.

**SAFETY OF THE PERSON IS IMPORTANT ALONGSIDE THE HEALTH AND SAFETY ISSUES OF THE PERSON CARING. THIS IS A DIFFICULT ISSUE TO BALANCE. EXPLORE OPTIONS THAT WILL ENABLE YOU AS A CARER TO HELP AND SUPPORT THE PERSON WHILST RESPECTING THE LIGHT SENSITIVITY ISSUE.**

If you are involved with someone, especially someone who has severe to profound light sensitivity, it is essential that you understand your impact upon the person. It is of absolute importance that you know what affect light will have on the person.

It is absolutely essential that you know how to respond appropriately if the person is unexpectedly exposed to light. It is important to stay calm, centred, focused and not panic or do something else wrong.

## Issues of Noise, Light, Touch, Chemical & Movement Sensitivity in Severe/ Very Severe ME

*Light exposure can result in: agonising eye pain, head pain, face pain, throbbing, burning, piercing pain, extreme headache, increased cognitive dysfunction, light after- image lasting long after source is gone, shaking spasms, nausea, distress, visual disturbance, weakness, paralysis, irritability.*

### Touch Sensitivity - Hyperesthesia

THE SLIGHTEST TOUCH, WRONGLY made, can cause agony and deterioration and real distress or harm and last hours, days or longer, long after the contact has passed, for the person who has Hyperesthesia and is sensitive to physical contact and pressure or movement on the skin.

Understanding the implications of ignoring or forgetting to respect this seriously disabling and potentially invisible symptom is essential.

Here are twenty nine things not to do around or near someone who is touch sensitive, without checking absolutely that the person can tolerate it occasionally, at all, or with limitations or at certain times.

***NEVER DO IT AT THE WRONG MOMENT.***

#### **DO NOT:**

1. touch a person without permission.
2. touch a person unexpectedly.
3. pat a person.
4. stroke the person.
5. move bedding without warning.
6. lean against the person.
7. put pressure on the person's body.

**Issues of Noise, Light, Touch,  
Chemical & Movement Sensitivity in  
Severe/ Very Severe ME**

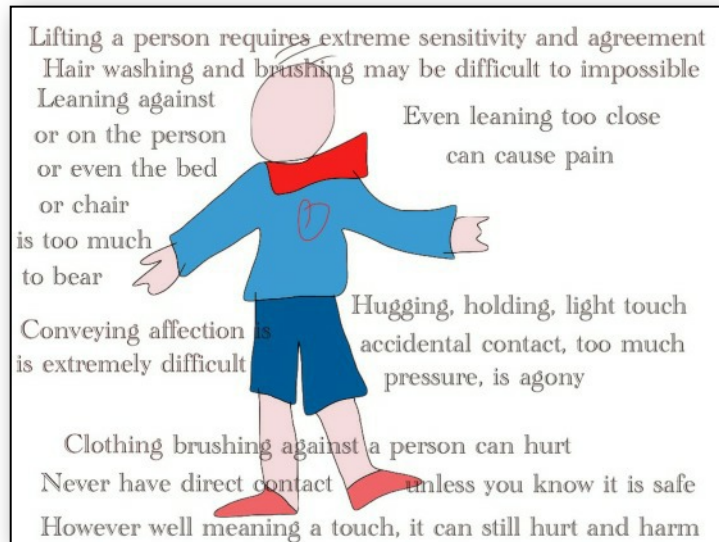
8. try to lift them without warning.
9. try to lift them without their cooperation and preparation.
10. hold them in the wrong way.
11. try to help them without awareness.
12. touch a part of the body that cannot tolerate contact.
13. leave a person in an awkward or dangerous position because you did not know how to help safely.
14. move limbs carelessly or without awareness to help with getting dressed or undressed.
15. put clothes that are too uncomfortable or tight or just not quite in the right place causing discomfort or agony.
16. move the person without consent or in away they cannot tolerate
17. do things at your pace not theirs.
18. lean on or sit on the bed to talk or help.
19. lean on or sit on the wheelchair to talk or help.
20. do anything in a different order than the person is expecting
21. brush their hair without knowing how, when and if tolerable.
22. shake hands unless you know the person can tolerate the touch and pressure.
23. hug the person.
24. kiss the person.
25. hold hands with the person unless you know it is safe and acceptable.
26. have any contact that you are uncertain is safe.
27. put a tray or other object on top of the person or on their lap or on the bed clothes even.
28. put anything on the bed either on top of them or even beside them as the sensitivity can be so subtle it will hurt without being obvious.
29. touch their face or body

## Issues of Noise, Light, Touch, Chemical & Movement Sensitivity in Severe/ Very Severe ME

It is essential that someone with extreme sensitivity is touched and helped in a gentle, compassionate, empathic and aware a way as possible, only doing things with agreement, in ways that are acceptable and tolerable.

Even so pain and hypersensitivity can be so intense and constant that pain is unavoidable even to meet the most basic minimal needs. So great care and precautions are required. Never touch anyone with Severe ME unless you know it is tolerable and the contact is wanted and the moment is right.

The more severe and extreme the symptom experience, the more profound the affect of contact, even if well-intentioned. Even if contact is tolerated in one moment or once, repeated contact may still be far too much. Never assume anything.



For the affectionate person who reaches out in compassion and kindness to convey warmth and comfort, it may not come naturally to avoid touching or hugging a person, especially if they are in discomfort or distress.

However, the natural instincts to reach out to comfort in the normal ways one would do, need to be altered in the presence of someone with touch hypersensitivity and severe pain, as the gentlest contact, meant lovingly, can still cause agony and deterioration and unbearable increase in symptoms.

Find out what, where, how and when it is safe to touch or not. This is essential to safely aid a person with Severe ME with touch/ pressure sensitivity and intense physical pain.

**ALWAYS RESPECT THEIR REALITY.**

## Issues of Noise, Light, Touch, Chemical & Movement Sensitivity in Severe/ Very Severe ME

*Touch sensitivity in Very Severe ME: causes agony on slightest contact, has unbearable indescribable impact, means pressure intensifies pain which is already intolerable, makes sitting, lying down intensely painful and impossible to rest or be comfortable, makes it difficult to tolerate physical assistance, even when needed, without causing deterioration of symptoms, can induce paralysis or shaking spasms, inflammation, nausea, blacking out, numbness, dizziness, makes it hard to find suitable clothes that do not hurt or add pressure, means the slightest accidental contact can really hurt the person and hard for the person to find suitable clothes and materials or tolerate enough bedding to keep warm.*

## Multiple Chemical sensitivity - MCS

CHEMICAL SENSITIVITY MAY BE difficult to imagine or even notice for the person who does not have it, who lives generally in the world of perfumes and chemicals, even enjoying the smells or becoming so accustomed to certain chemicals that they are simply not noticed.

However, to the person who has severe chemical sensitivity, the world is literally a poisonous place and people who wear perfumes and use perfumed products become difficult to impossible to be near.

The environment also becomes extremely dangerous, unpleasant, even a hostile experience.

Everything that touches the person needs to be chemical free.

## Issues of Noise, Light, Touch, Chemical & Movement Sensitivity in Severe/ Very Severe ME

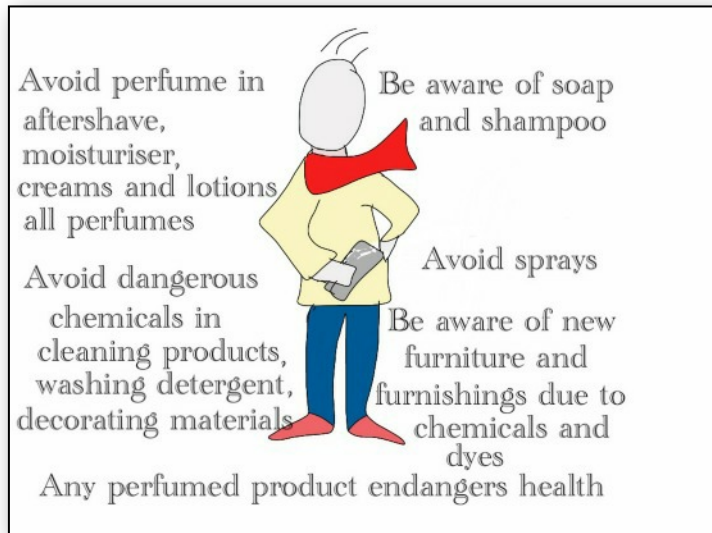
Living with Multiple Chemical Sensitivity (MCS), people become isolated and alienated from the world and people around them. They also live tormented lives and are made extremely ill by exposure to chemicals and perfumes.

Some people with Severe ME develop MCS.

Here are twenty-two things not to do around someone who experiences MCS, unless you specifically have their agreement that they can tolerate it.

### **Do not :**

1. wear perfumed products on the days you are helping and preferably never wear them, as they linger on clothing, hair etc. This includes deodorant, shampoo, aftershave, hand lotion, moisturisers as well as perfume itself.
2. wear clothes washed in perfumed detergents. The person may be able to tolerate certain products which hopefully you might choose to use your self to make life easier for you both.
3. disregard the person's perfume and chemical sensitivity.
4. use products to clean with, other than those specified as safe, by the person.
5. buy any alternative product that has dangerous chemicals or intolerable perfumes as a substitute to please yourself or because something is unavailable. Always check ingredients.
6. forget to ask the person for alternative products that they might accept, for when shopping, in case the store has run out or order things online well in advance, to ensure that there are no problems with supply, in agreement with the person.
7. leave windows open without being asked, as environmental chemicals can waft through the open window.
8. expose the person to petrol or other fumes or bonfire smoke.
9. clean without express permission, only perform cleaning tasks at the time the person can tolerate it, in the way they have asked you to do



## **Issues of Noise, Light, Touch, Chemical & Movement Sensitivity in Severe/ Very Severe ME**

10. expose the person to cleaning products that may have go onto,your skin or clothes. Make sure you wash off all odours as even if they may be acceptable at a distance, close contac may still cause reactions
11. use herbicides or pesticides in the house or garden
12. use paint that is oil based and needs chemicals to clean the brush
13. unless expressly asked to by the person.
14. use perfumed carpet cleaner.
15. ignore the importance of being aware that the smell of certain drinks and certain foods may also trigger a bad reaction.
16. sit down on any seats with perfumed products on you, as the smell may transfer and be impossible to get rid of and be dangerous or intolerable to the person. It can linger for many months.
17. enter into any uncontaminated safe room if you think you may have chemicals or perfume on you. You may need to wash or change your clothes and shoes before entering or aiding a person with MCS.
18. ignore instructions concerning food packaging when buying, storing and cooking and be aware of plastic bottles and containers. If glass only has been stipulated, then stick with it. Plastic containers, utensils etc are a danger to health with MCS.
19. give the person water that has come from a potentially unsafe source such as a plastic bottle. Establish what is safe and what is tolerated before you begin to help the person.
20. prepare food with different ingredients or unknown, untried sources, as their may be chemicals or flavourings etc that are harmful in them
21. suck strong smelling sweets such as cough sweets
22. assume that natural, perfumed products, such as lavender oil, are tolerable because they are natural or organic. Always check with the person. Perfume free can still have an intolerable odour and impact. If you have MCS and you are exposed to chemicals and perfumes you cannot tolerate, they make you instantly react and become even more ill. They may trigger headache, nausea, rash, skin irritation, vomiting, muscle weakness, paralysis, immediate and severe increase in other symptoms. It may affect your breathing.

**IT IS COMPLETELY INCAPACITATING TO BE CHEMICALLY EXPOSED. IT CAN ENDANGER YOUR HEALTH AND LEAD YOU LIVE A TORMENTED AND VERY ISOLATED LIFE.**

It is extremely important to learn how to safely engage and work with someone with severe ME and MCS. The ordinary things you take for granted will be a huge issue potentially. Carpets, bedding, new clothes,furniture, furnishings, decorating; all new products have dyes and chemicals such as fire retardants, glues etc that can cause allergy and / or sensitivity and may be intolerable and endanger health.

## Issues of Noise, Light, Touch, Chemical & Movement Sensitivity in Severe/ Very Severe ME

*Exposure to chemicals and perfume can cause: burning skin and throat pain, rashes, nausea, severe instant headache, swallowing difficulties, numb throat and tongue, muscle weakness, shaking, indescribable collapse, dizziness, intense malaise, burning eye and face pain, massive deterioration; the after-effect goes on and on, with no relief.*

### **Movement Sensitivity**

MOVEMENT CAN BE DEVASTATING to the person with this unusual sensitivity, whether this is movement past them, in front of them or physically moving the person while assisting them or even them moving themselves. It may be hard to understand or even begin to comprehend the disturbing and painful impact you can have on a person just by making a slight movement at the wrong time in the wrong way. It is especially difficult, because we do a lot of things inadvertently and without awareness, such as move our hands to express ourselves or tap a toe or finger, scratch our head, wander about looking for things etc.

All these things we need to learn to control. It does not necessarily come naturally, but the person helping someone with profound movement sensitivity needs to develop their own body awareness to a higher degree than is normal, so that they can move gracefully, peacefully and with consciousness, flowing with and rather being with the person rather than irritating them further.

Here are sixteen things not to do around or near someone who is Movement Sensitive, without checking absolutely that the person can tolerate it, whether occasionally, at all, or with limitations and how to accommodate helping them in the context of this complex Movement sensitivity, so they can still get their needs met

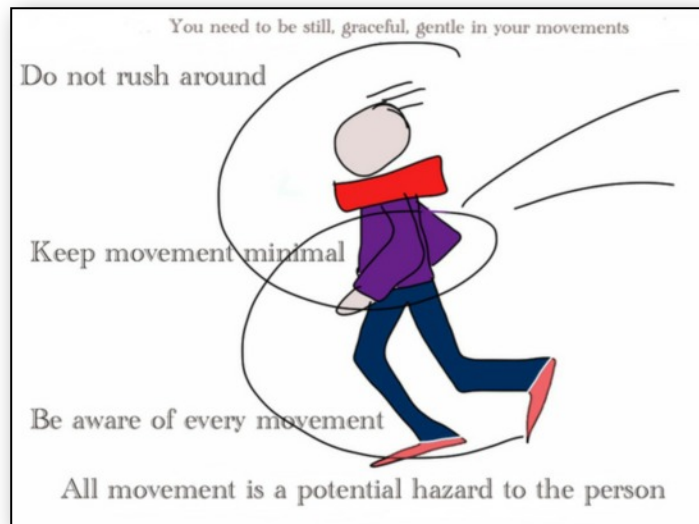
#### **Do not**

1. Make any fast movement at all that will cause irritation and deterioration of symptoms.



## Issues of Noise, Light, Touch, Chemical & Movement Sensitivity in Severe/ Very Severe ME

2. Scratch your head or body unnecessarily or if you have to then indicate this first, to minimise the impact.
3. Gesticulate in the air.
4. Tap on things.
5. Type in view of the person unless expressly asked and agreed.
6. Push the person in a wheelchair without letting them know they are about to move so they can be prepared.
7. Push the person quickly unless asked to, as speed will increase the potential disturbance to the person as things move past them.
8. Pull the person backwards especially without warning. This can have a dramatic impact on autonomic system and cause complete chaos in the head and be extremely disturbing, may cause nausea, dizziness, head pain, black out, irritation, distress, chaos in whole body, simply be intolerable and unbearable, without necessarily being able to adequately explain the experience or why it is so unbearable.
9. Move repeatedly past the person and especially not close to the person as they can actually experience the nearness as pain.
10. Move the person quickly while helping them unless this is necessary and with agreement. Movement can be painful, disorienting, disturbing, upsetting, deteriorative.
11. Walk with the person faster than they can tolerate or bear
12. Take the person into crowded places or near groups of people if the person has to go out ie to a hospital appointment. The more people, the more movement and disturbance.
13. Drive faster than the person can cope with, if they can be in a vehicle at all, be aware that speed bumps can also cause distress as motion changes.
14. Drive on busy roads or at busy times of day if avoidable as vehicles driving fast towards the car can have a frightening impact, especially large and noisy vehicles
15. Kick a ball or throw a ball or let a pet off the lead to run about back and forth in front of the person
16. Hoist a person awkwardly or too quickly or without respect for their complex physical symptoms. To use a hoist or lift someone with movement sensitivity is incredibly difficult to manage. It needs the utmost respect and care to safely engage with and move such a person. Make sure you understand how to do this properly . Make sure you stop and rest at intervals as required. Only move a person in a way that can cope with and with their cooperation.



## **Issues of Noise, Light, Touch, Chemical & Movement Sensitivity in Severe/ Very Severe ME**

It really is a matter of discussion, if possible and understanding of the affect of movement, to minimise damage and maximise support, to try and optimise the experience of interaction, not cause such negative experience unintentionally that the person has to tell you stop and go away because you have caused such deterioration and autonomic chaos and cognitive shut down that the person can no longer tolerate any help. This serves no bodies need and leaves both people feeling bad.

Obviously some movement is necessary. It is the how and when, that is important and when not to. This is possibly unpredictable and may be more a matter of stop immediately if you are asked to. It may be that familiar movements and routines will help and be better tolerated. It is unique to each person what they might tolerate or the best way to help them cope with your presence. It is also about being still in yourself and not doing extra movements that are unnecessary and risk irritation, exacerbation and deterioration. If you can learn to be present, aware and very still in yourself and graceful in your movement there is a better chance of assisting productively.

### **Conclusion**

There are no easy answers for these complex hypersensitivities. It may be trial and error. The important thing is to aim to flow and work with the person in partnership so that you do not cause further alienation and isolation for the person, or harm, nor go away feeling you are a failure or that it is impossible to help the person.

It is absolutely essential to understand all the symptoms and how they interact together to impact the person. In reality they never work in isolation. The most important thing is to respect the person and know the way the illness manifests in them. Never disregard any medical information.

**Greg & Linda Crowhurst**

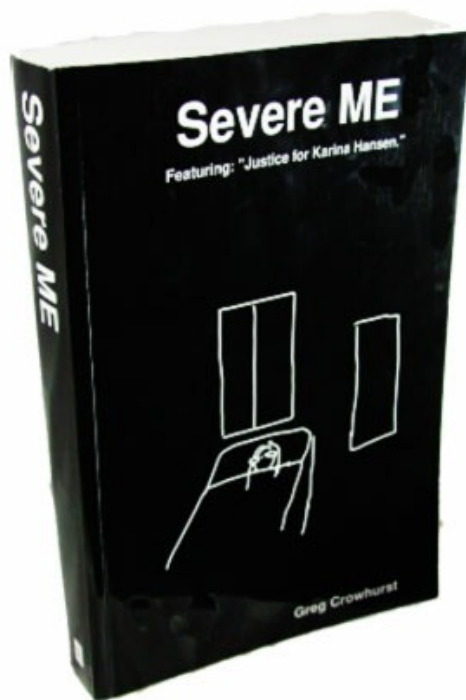
*Severe ME Understanding &  
Remembrance Day Aug 8<sup>th</sup> 2014*

**Issues of Noise, Light, Touch,  
Chemical & Movement Sensitivity in  
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**For much more information please see :**

" IT WILL HELP YOU UNDERSTAND WHAT THE PERSON WITH SEVERE ME IS GOING THROUGH, BETTER THAN ANY OTHER BOOK I KNOW OF"

Natalie Boulton maker of [Voices From the Shadows](#)



<http://www.stonebird.co.uk/severemebook/severeme.html>

**Updated and expanded, featuring the  
voices of people with Severe ME, Carers,  
Advocates and Professionals from around  
the world.**