

# Stone Bird

Supporting someone with Severe ME : Care  
Sheets.

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## Supporting someone with Severe ME : Care Sheet

**Important** : the suffering hour to hour is relentless in severe ME. Studies have shown that patients with this condition have more physical dysfunction than those with multiple sclerosis, and that in ME/CFS the degree of impairment is more extreme than in end-stage renal disease and heart disease.

Typical Severe ME Symptoms	Typical impact upon the severe ME sufferer.	Care Need	Carer Response
<b>Sleep Paralysis</b>	Will be completely unable to move. Difficulties with breathing Difficulties with speech Difficulties with swallowing	The severe ME sufferer will not be able to sit up/move/get-out of bed/feed themselves/get a drink/get dressed/talk/go to toilet/wash them self/answer the door/get the post	<ul style="list-style-type: none"> <li>• Provide physical assistance: lifting</li> <li>• Supporting (assisted walking)</li> <li>• Mobility</li> <li>• Dressing</li> <li>• Personal Care</li> <li>• Shopping</li> <li>• Cooking</li> <li>• Feeding</li> </ul> <p><b>Try and always think through what the person needs in advance.</b></p> <p>Be sensitive and aware</p>
<b>Light sensitivity</b>	Will not be able to bear bright light, maybe any light at all, even with eyes closed.	The severe ME sufferer may need to wear dark glasses, have the curtains shut, have no lights on or low lights only.	Be aware and be prepared. Work in low light situations and/or protect the person you care for from light, if the light needs to be on.
<b>Noise sensitivity</b>	Will not be able to bear loud noise, unexpected noises, banging and thudding in the room or in the environment	<p>The severe ME sufferer may not be able to cope with electrical/mechanical machines i.e. the Hoover.</p> <p>Listening to speech may be a problem.</p> <p>Loud voices/certain tones of voice may cause distress.</p> <p>Doors being shut / loud footsteps/ rustling paper/opening drawers/ cupboards etc can cause acute torment.</p>	<p>Try and develop appropriate communication system i.e. written instructions, low voice, possible sign language.</p> <p><b>Be very gentle and quiet in all movements/actions.</b></p> <p>Be aware that your noise may cause distress even if not noisy to you.</p> <p>Respond appropriately if you cause noise</p>

Typical Severe ME Symptoms	Typical impact upon the severe ME sufferer.	Care Need	Carer Response
<b>Sleep Disorder</b>	<p>The severe ME sufferer may experience real problems going off to sleep and/or problems in waking-up.</p> <p>Their normal sleep pattern may be grossly disrupted (little or no restorative sleep).</p> <p>They may experience night insomnia and sleep all day. May sleep more than normal.</p> <p>Their body-clock may be out of sync with normal rhythms.</p>	<p>May be awake at night, distressed, severe fatigue, but still unable to sleep.</p> <p>Their body functions may be altered e.g. need to urinate more alongside a severe thirst and need to drink.</p> <p>They have low blood sugar because of increased time in bed during the day.</p> <p>Increased irritability.</p>	<p>Advice on enhancing sleep possible relaxation /breathing techniques.</p> <p>Reduction of over stimulation.</p> <p>Warm bath to relax muscles.</p> <p>Drugs to aid sleep</p> <p><b>Assistance day and night to enable basic needs to be met: toilet, food, drinks etc.</b></p>
<b>Pain</b>	<p>Their whole body may be too painful to touch.</p> <p>They may experience skin itching / burning/ hypersensitivity.</p> <p>They may experience muscles throbbing/burning/screaming</p>	<p>May be continuous, may vary in degree.</p> <p>Poor response to drug treatment.</p> <p>Cannot bear to be touched.</p> <p>Difficulty in getting comfortable: seating and bed and wheelchair.</p>	<p><b>Pain awareness and extreme sensitivity.</b></p> <p>Knowing how to touch and lift carefully.</p> <p><b>Patience and time is required to 'flow' with the person.</b></p> <p>Advice on what is available to alleviate pain: aids and equipment and drugs.</p>

Typical Severe ME Symptoms	Typical impact upon the severe ME sufferer.	Care Need	Carer Response
<b>Headaches</b>	<p>They are not normal, they maybe constant or last for days, can be predominantly left-sided, may not respond to drugs.</p> <p>There may also be the experience of head-pain, as opposed to headache.</p>	<p>Scalp sore to touch.</p> <p>Eyes throbbing / burning.</p> <p>Face can hurt as well.</p> <p>May be accompanied by numbness, paralysis, swollen eyeballs, and nausea.</p> <p>May be sharp, throbbing, may be dull but no less severe.</p>	<p>Be sensitive to noise and light issues.</p> <p><b>Great awareness of the potential emotional distress of being in constant pain and the potential for the person to be irritable.</b></p> <p>Help with medication</p>
<b>Muscle Weakness/ Variability</b>	<p>The severe ME sufferer may be able to use their muscles one moment and not the next.</p>	<p>Danger of falling/stumbling.</p> <p>Affect upon the person's independence: may be not able to use hands/fingers/perform fine movements.</p> <p>May be able to walk one moment and not the next, or at all.</p> <p>May not be able to write/type/turn things on and off/cook/clean/attend to personal care/eat.</p>	<p>Mobility issues may require a wheel chair.</p> <p>May be bed bound and/or housebound?</p> <p><b>May require help with cooking, cleaning, shopping, personal care, with eating, writing, communicating, social interaction.</b></p> <p>May not be able to use stairs or unreliable use of stairs.</p> <p>Help with adaptations/aids/equipment</p>

## Supporting someone with Severe ME sufferer: basic information that carers should find-out.

Symptom	Questions/Observations	Comments
<b>Hyperacusis (Noise sensitivity)</b>	What is the patient's response to electrical equipment, noise, telephone, doorbell, washing machine, Hoover ?	<b>Noise sensitivity can be so great that even a whisper sounds like a shout; it may be painful and it may increase a whole range of symptoms.</b>
<b>Hyperesthesia (Touch Sensitivity)</b>	Does the patient flinch, become irritated and distressed ?  Is their skin hypersensitive to touch ?  They may be unable to tolerate massage, stroking, accidental contact.	The patient may find any kind of contact or movement over the skin unbearable.  May flinch, may react strongly, verbally, be very distressed by even a slight brushing.  <b>The carer has to be very careful and aware.</b>
<b>Pain</b>	Is the patient experiencing sleep difficulties because of pain ?  Do they need special aids and equipment ?  Are there analgesics that help/ease the pain ?  Is touch and lifting difficult because of pain ?	The patient with severe ME might experience muscle pain, nerve pain, skin-crawling sensations, burning, itching, throbbing pain.  <b>The person with ME might feel extremely ill at the time, on top of the other symptoms.</b>  It may help to identify some of the symptoms in order to aim for relief.
<b>Multiple chemical sensitivity</b>	Does the person feel nauseous, experience headaches, rashes or other symptoms in response to being exposed to certain chemicals, smells, perfumes, toiletries, household cleaning agents ?  Have they developed specific food sensitivities/allergies ?	<b>The carer must be aware that perfumes, deodorants, might have a deteriorative effect on the person with ME, which can be extreme and immediate.</b>  Household cleaning agents etc require careful consideration. Organic products might be less harmful.

<p><b>Orthostatic intolerance</b></p>	<p>The patient may become greatly distressed moving from lying to sitting, to standing.</p> <p>They may be unable to sit upright.</p> <p>They may experience dizziness, increased feeling of illness, panic even, if made to stand.</p>	<p>The severe ME sufferer may feel utterly ill and/or unable to stand, but may not be able to identify why.</p> <p><b>It is important for the carer to know there is a physiological reason for this.</b></p>
<p><b>Unrestorative sleep</b></p>	<p>Does the patient feel more ill and in more pain upon waking ?</p> <p>Do they feel unrefreshed and unrested ?</p> <p>Do they have difficulties going to sleep and staying asleep ?</p> <p>Do they have difficulties waking up ?</p> <p>They may need to sleep during the day ?</p> <p>Sleep may push the person into a worse state of illness and paralysis.</p>	<p>The sleep pattern in ME is altered. May be awake during the night and asleep during the day.</p> <p>They may not experience restorative sleep.</p> <p>They may have nightmares.</p> <p><b>Paralysis is a significant symptom in sleep disorder.</b></p>

## Supporting someone with severe ME : a guide to understanding the symptoms for carers :

<b>Severe ME/CFS : Experience &amp; Symptoms</b>	
<b>Patient's Experience</b>	<b>Some Possible Symptoms</b>
<b>I can't think</b>	<b>Cognitive impairments</b> (impaired attention, memory and reasoning) <b>are among the most frequently reported and least investigated components of CFS/ME.</b>
<b>I can't understand</b>	<i>Processing problems, brain fog, intermittent partial or complete memory loss, recurrent stupor or stroke-like episodes, tremors, aphasia, ataxia, discalcula, .</i>
<b>I can't cope with noise</b>	<i>Hyperacusis, loss of adaptability and worsening of symptoms with stress</i>
<b>I can't speak</b>	<i>Word , number and thought sequencing difficulties , information absorbing difficulties, difficulty with voice production, paraphasia – incorrect word selection.</i>
<b>I can't sleep</b>	<i>Reversed sleep pattern disturbance, hypersomnia, vivid &amp; disturbing dreams</i>
<b>I can't eat</b>	<i>Food intolerances, difficulty with swallowing, choking, abdominal pains, problems with diarrhoea</i>
<b>I can't sit up</b>	<i>Muscle weakness, severe pain, palindromic arthropathies.</i>
<b>I can't walk</b>	<i>Pain, muscle fatigue, paralysis, persisting dysequilibrium and ataxia, cardiac arrthmia, angina-like chest pain</i>
<b>I can't telephone</b>	<i>Noise sensitivity, no energy, muscle weakness, loss of memory, concentration, intractable pain</i>
<b>I can't write</b>	<i>Pain, weakness, numbness, parasthesia, cognitive impairment, agraphia (inability to locate the words for writing), neurological changes in motor skills (handwriting, walking gait, vision, etc</i>

<b>I can't get to the toilet</b>	<i>Muscle dysfunction and twitching, orthostatic intolerance, Extreme post-exertional muscle fatiguability, recurrent nausea and profound, incapacitating malaise. Light-headedness and/or syncope (fainting), lower than normal blood volume, hypotension, loss of thermostatic stability,</i>
<b>I can't wash myself</b>	<i>Poor coordination, pain in muscles, joints, head, back, limbs, chest and stomach</i>
<b>I can't stand up</b>	<i>Orthostatic intolerance, muscle fatigue, weakness, difficulty with breathing, sudden attacks of breathlessness, dyspnoea ; the more severely affected are unable to stand unsupported for more than a few minutes.</i>
<b>I can't cook</b>	<i>Transient paralysis, pain, brain fog, poor coordination and balance, dizziness, volitional problems and/or cognitive slowing, loss of fine motor skills.</i>
<b>I can't read</b>	<i>Dry eyes, pain, blurred and double vision, difficulty in focusing , swollen and painful eyelids, word blindness, alexia (problems with reading)</i>
<b>Colour hurts my eyes</b>	<i>Neuralgia, disorders of colour perception,</i>
<b>Touch hurts me</b>	<i>Hyperesthesia, light touch can be acutely painful</i>
<b>People's energy affects me</b>	<i>Severe lack of energy to cope, prosopagnosia - not being able to recognize faces, facial agnosia, impairment of concentration, difficulty with visual and aural comprehension, an exaggerated response to even small amounts of additional input.</i>
<b>Light hurts me</b>	<i>Photophobia, perceptual and sensory disturbances, special instability and disorientation, abnormalities of sensation.</i>
<b>Food hurts me</b>	<i>Food intolerance, IBS, problems with maldigestion or malabsorption of food, histamine intolerance, esophageal spasms , difficulty swallowing, esophageal reflux, changes in taste and smell, bloating, abdominal pain, nausea, indigestion or vomiting , intense gallbladder pain,</i>



**Supporting someone with severe ME sufferer: an ME-aware Approach for carers.**

<p><b>MIND :</b> What am I thinking about when I approach the severe ME sufferer?</p> <p>Can I focus solely about what I am doing ?</p> <p>Have I thought ahead about what potential issues might come up ?</p> <p><b>Do I understand that ME is an organic, physical disease ?</b></p>	<p><b>BODY :</b> <b>Am I able to be gentle enough , when I help the patient ?</b></p> <p>Am I too tired to help sensitively and carefully ?</p> <p>Am I in pain anywhere myself ?</p>
<p><b>SPIRIT :</b> How do I feel about being with the patient ?</p> <p>Can I connect with the patient and their need ?</p> <p><b>Am I flowing with the right energy to make contact with the person ?</b></p>	<p><b>EMOTION :</b> What is my emotional state ?</p> <p>Is it going to have a good impact upon my interaction ?</p> <p><b>Am I distracted about other issues ?</b></p>

