

# Stone Bird

A practical guide to supporting someone  
with Severe ME

by Linda & Greg Crowhurst

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# A practical guide to supporting someone with Severe ME

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# **A practical guide to supporting someone with severe ME**

## SECTION ONE :

### **YOUR VALUES & ATTITUDES**

Supporting someone with severe ME may be daunting as there are complex symptoms which may be hard to understand . We have put together this short guide to help you to raise your awareness and hopefully make a difference to your understanding , so that you are much better prepared.

There are no hard and fast rules. Each person is an individual and you will need to develop your levels of awareness in relationship with the person you are helping. It may take time to grow in understanding.

Definition of a carer:

COMPASSIONATE  
AWARE  
RESPECTFUL  
ENABLING  
RESPONSIBLE

These are the essential qualities needed when helping someone with severe ME.

#### **Compassionate**

Caring and compassion are at the heart of being a responsive carer. Just feeling sorry for the person can act as a barrier to true communication.

## **Aware**

Awareness is the key to good practice. Awareness of your self helps you to better understand what your skills and knowledge are, where you can improve and what your strong points are. Awareness of the person's needs, their symptoms and things that will help the person or aggravate the symptoms are essential to help you best assist them.

## **Respectful**

Part of respecting the person with severe ME is to accept and believe that they are ill and that they need what they need when they tell you. Because people's bodies may work differently at different times, for example, they may have greater energy at one moment than another or may be unable to move one moment then be more able the next -you have to trust them when they say they need help. This is a fundamental part of respect.

## **Enabling**

To enable is to help someone to do something they need to do in a sensitive and caring way. It means that you make a difference to their life. To enable is to truly help someone.

## **Responsible**

To be responsible is to be aware of your actions and reactions and to own them. When you help someone they are vulnerable. You need to take responsibility clearly for what you do and how you do it.

## **Attitudes**

Be aware of all your good points. Feel good about

yourself and remember why you want to be a carer. It is important to be aware of your strong points and where your skills lie. It may not always be easy, but your intention to help is important. Growing in self awareness will help you both to develop a strong relationship.

Helping someone with severe ME will probably throw up challenges to you. You may become aware of certain aspects of your personality that were not so evident till you were in a caring situation. Caring can be exhausting. It can also test your skill, knowledge and patience.

People with severe ME may have had previous bad experiences :

- *They may have been disbelieved*
- *They may have had their symptoms denied.*

The symptoms are hard to understand sometimes and it is important to know how important it is for the person to be believed, accepted, respected and to be appropriately supported : to be seen as a person within the context of severe illness and disability.

Because ME is a difficult illness to understand and requires a high degree of awareness of yourself and the person's needs, there are certain attitudes that are unacceptable and need to be guarded against, when helping someone:

- **Disbelief** is hurtful and wrong
- **Ignorance** leads to misunderstanding
- **Negativity** makes everyone feel bad
- **Unacceptance** is offensive
- **Impatience** may exacerbate symptoms
- **Judgement** leads to wrong attitude

- **Roughness** leads to pain and distress
- **Neglect** means the person is not being helped
- **Anger** leads to disconnection and upset
- **Laziness** means the help needed is not being given
- **Carelessness** can cause harm
- **Loudness** can cause pain , distress, worsening symptoms

## SECTION TWO

### **DEALING WITH SYMPTOMS**

ME is a well documented, neurological illness acknowledged by the World Health Organisation. It is not a psychiatric illness. The person you help is physically ill. Their needs may vary and their ability to communicate with you clearly may also vary.

The abilities of the person may vary throughout the day. You need to learn how the illness impacts specifically on the person you are helping. Each person may be different.

Main Symptoms you may come across:

There are 63 accounted symptoms in ME. These are some of the main ones you may encounter:

#### **Pain.**

There may be various sorts of pain and odd sensations experienced. Pain may come and go or be constant or vary in intensity. There may be no drugs available to alleviate the pain. The person you help may just have to cope with the pain ; no matter how bad.

There may be :

- burning
- throbbing
- itching ,
- muscle pain ,
- skin pain,
- joint pain,



- all over body pain.

The person in pain is very sensitive to touch and how you approach them to help may be key to success or failure; especially if they need physical assistance.

## **Head Pain**

Head pain and headaches may be extreme and long lasting. They may go on for days or weeks at a time without relief. For some people they may be permanent feature without relief. They may cause acute eye pain and may be left or right-sided. They may be completely incapacitating, making communication extremely difficult .

They may result in the person having to be incredibly still without any stimulation or noise, to try and cope with it. Decision making may be impossible at these times.

There may be no pain relief available.

## **Transient Paralysis**

You may be surprised to find that the person you are helping has various degrees of paralysis in various parts of the body at varying times of the day and night :

- Sleep, for example may lead to overall body paralysis which may last several hours or longer.
- Being in a stationary position following movement may also lead to transient paralysis.

Therefore never assume that a person can do the same thing all the time. Always ask what help they need, unless they have told you they do not want you to speak to them whilst in this state. In that case you need to communicate with the person when they

are more able to explain their needs. Or ask for written instructions as to how to help them if possible. Or ask that someone they know tells you what is needed.

Remember that a person who is paralysed may not be able to open their eyes - it does not necessarily mean they are asleep :

- They may not be able to speak or call out.
- They may have difficulties swallowing.
- They may not be able to move their arms or legs or sit up or stand up without assistance.
- Their pain may increase when in this state so do be aware .
- Mobility will be extremely difficult depending on which parts of the body are paralysed. Sometimes it may be a left-sided paralysis or more unusually a right -sided one.

### **Pins and needles**

This is not like ordinary pins and needles that you shake and it goes away :

- It may last a very long time or not go away all day or at all.
- It may come and go.
- It may be triggered by vibration ie sitting in a car.
- Their body may go 'dead 'and be extremely difficult to get sensation back into.
- They may experience pins and needles anywhere in the body and in unusual, unexpected places ie tongue, throat, ear, side of head, face, nose.
- It may be a very unpleasant and distressing experience.

## **Spasms**

These may be like fine tremors of the muscle, barely discernible, or may be whole limb or even whole body spasms. They may be quickly over or continue for several hours. They may be upsetting to observe especially when new to helping.

## **Noise Sensitivity ( Hyperacusis)**

This is a severely disabling symptom in its own right, causing acute difficulties with communication and being in the presence of other people. It makes going out into the world very challenging or even impossible

You need to be aware that things you do without thinking or noises in the outside environment may be tormenting the person. These include things like :

- rustling a paper or plastic bag
- turning the page of a magazine or newspaper
- walking in the room
- noisy feet walking up or downstairs
- banging cupboard doors or draws
- washing up
- tidying things away
- ringing bells
- sirens
- passing car engine
- running car engine
- letter box rattling
- dog barking
- doorbells or knocking at the door
- opening a tin
- opening or shutting a door
- eating a meal
- cutting something up on a plate
- telephone

- radio, television, music, singing, dancing
- a clock ticking
- speaking normally , even speaking in a whisper may be too loud.

It requires great awareness on the part of the person helping someone who suffers from noise sensitivity .

## **Light Sensitivity (Photophobia) and Visual Acuity**

The person with light sensitivity or photophobia may have it to varying degrees.

- It may be that the person needs to use dark glasses even in normal daylight.
- They may need to have the curtains pulled during the day and they may need to hide under the bed clothes if you need to put a light on in order to help them or use some form of eye mask.
- They may lie all day with their eyes covered not being able to bear any light.
- They may cope with subdued lighting at night but not cope with the main light being switched on.

Light can cause physical pain to people with this symptom. You may need to negotiate with them how best to help them, if you need a light on to see something they need. You need to work in partnership on this.

Eyesight may be affected and reading become difficult to impossible, due to the eye muscles not holding their focus. There may be double letter vision letters may appear to dance around the page. It may be difficult to follow lines or columns.

Don't just assume that reading is easy or possible.

## **Irritation**

The person with severe ME may become irritated very quickly by noise or your voice or other sources of stress, because they are over stimulated .This can happen very quickly and may not be easy to judge. You need to understand that the person is extremely hypersensitive to many stimuli and you may need to stop speaking or leave the room or wait till the person has calmed again. This is something you need to be aware of and not take personally .You need to develop awareness of things you do that might aggravate a person , so that you can try to avoid exacerbating the symptom.

## **Hypoglycaemia**

The person may have variable blood sugar level. It may be another source of irritability. You need to learn which signs indicate that the person might be hypoglycaemic and be aware of how to respond ; eating the right food for example.

## **Sleep Disturbance**

The person may have insomnia and be unable to sleep nights on end or may have an altered sleep pattern, not sleeping till the early hours of the morning and sleeping way into the afternoon. Despite difficulties getting to sleep, the person may then experience difficulty waking up. Or may keep falling back into further bouts of further sleep without being able to stay awake. They might feel like their body or mind has not woken up all day.

This could have a big impact upon when you are needed to help the person . The times people may need help, may vary considerably. The help they need may not fit into the normal pattern of everyday life. Or example

breakfast may be eaten at lunchtime. Timings may be skewed because of this.

## **Flu-Like Symptoms and General Malaise**

The person with severe ME is likely to feel ill all the time or most of the time. Never forget that even if you cannot see how a person feels, nevertheless they feel ill and it therefore will have an impact on what they can cope with and what they feel able to do.

## **Post – Exertional Fatigue**

The person may at times seem to be, extremely tired, however this is not the fatigue of ME.

ME fatigue is post-exertional , which means that any activity, mental or physical, even as slight as moving a limb, can lead to a worsening of symptoms and extreme exhaustion, that may mean muscles will not function, pain may increase dramatically and the person may feel more ill.

The post exertional fatigue may be long lasting and may not even manifest for several days to several weeks after the particular action.

This makes it very difficult to know what is impacting upon the person , it is also incredibly difficult to determine how much is too much, especially for the more severely ill.

For the very severely bed-bound person even the minimal exertion of living can be too much ; even if from an outside view, they have done little to nothing, it still may have a post-exertional affect.

It is absolutely essential to understand the level of illness and disability of the person you are trying to help so that you do not inadvertently cause the person to do more than they can manage, by, for example, asking them a question or talking too long.

Post-exertional fatigue is the hallmark of ME and is profound unimaginable fatigue which can have a physical effect and is difficult to recover from. This cannot be over-emphasised.

## **Nausea**

Nausea may be a permanent or near permanent feature and the person may also have fits of vomiting. Feeling sick will again have a huge impact on appetite, ability to cope, eating habits and generally feeling unwell.

## **Cognitive Difficulties**

The person with severe ME is likely to have cognitive difficulties. This may be variable or constant.

- It may cause problems with communication as their brain can have huge difficulties in receiving , processing and therefore understanding information.
- It may feel to the person as if their mind has shut down, they may describe this as “brain fog”. They may not be able to follow details or respond to questions. Persistence with questioning or talking may lead to aggravation and worsening of symptoms . Even if someone can cope with a short conversation, they may still be too ill later to do the same again.
- It may make reading, using the telephone, watching television, listening to the radio, having 2-way conversations, very difficult if not impossible to do.

There may be a better time of day when the symptoms ease slightly and the person can better express their needs or think more clearly.

## **Numbness**

A person with severe ME may have a numb body. This again may vary in degree or come and go.

A numb body means the person cannot feel properly. they may not be able to tell accurately the temperature of hot water or hot surfaces such as a cooker or heater. They may have less body awareness.

They may be at risk of burning themselves on i.e. a hot plate or a hot water bottle or in a bath or shower.

These are important things for you to know, so that you can help a person safely.

## **Dizziness**

A person may be dizzy at various times off day or when doing various things, such as moving from lying to sitting or sitting to standing. they may even be dizzy lying down flat.

This is important for you to know , especially if you are physically assisting someone with these actions.

Dizziness is not something obvious externally until someone stumbles or falls. Knowledge should help avoidance .



## Section Three

### **PROVIDING PRACTICAL HELP**

All that we have been advocating finds expression in our MOMENT approach :

#### **MAXIMISING OPPORTUNITY to MEET NEED TENDERLY.**

This is your primary aim, because the person with severe ME is :

- extremely hypersensitive
- easily exhausted
- constantly experiencing their symptoms,

even if they vary in degree and one seems more prominent than another, and even if not visible from the outside.

You need to be flexible, compassionate, sensitive and attentive to maximise your opportunity to help the person in a gentle and tender manner.

### **Partnership**

You need to try and work as best you can with the person. This means learning to understand what they need, when they need it and how they need it. It may not always be obvious.

You need to understand their symptoms and the impact they have on the person so that you will better understand their reaction to you :

- If you speak too loudly for example you might get an irritated response, or the person might put their head under the bed clothes because the noise has distressed, hurt or disturbed them.
- You need to be aware that moving around in proximity to the person you may well be being noisy in relation to the person, even if you are not aware of the noise yourself. Understanding the need for silence and a quiet voice may make all the difference to how you get on and how helpful you are in reality.

You therefore need to work together to build up trust and respect and a relationship that works for you both.

When helping someone with severe ME you need to be :

- prepared
- calm
- centred
- focussed on what you are doing and the person's reaction
- open to change, to stop, be more gentle, willing to try something else, or to wait for a better moment.

You need to be person-centred in all your interactions.

## **Communication**

Communication is of supreme importance when trying to help a person with severe ME. It is also something that will most likely be difficult for the person because of the range, complexity and severity of their symptoms.

- Noise sensitivity may mean that whispering is the

best level to keep your voice, though even this may be too loud at certain times of the day or night.

- Some people may have difficulties speaking at all. You will need to find out how they communicate or who communicates for them possibly.
- It may be that a person needs to leave you notes to follow as the effort of thinking and talking may be too great. This may be more difficult at certain times such as when/if paralysed, close to waking up , if the person is very sleepy. These are only examples. Each person varies.
- There may be problems holding a pen to write ,but it may be possible to type , for example.
- A person may not be able to hold the telephone or may not be able to speak on the phone. Hands free head sets are available but the person may not still be able to use a phone or may find the sound of the phone difficult to cope with or may need to use an answerphone.
- You may be required to answer the door or take messages for the person or speak for the person even at times. Only do such things with permission and try to be as clear as possible with the person of what you have done for them. always respect their communication difficulties and work with them on this.

### Planning

There are certain tasks you may be asked to perform or be involved with. Awareness and planning will help make a situation less stressful for both the person and the carer.

## **Shopping**

- Know what particular brands of food are safe to buy - a person may have food allergies or food sensitivities and be on a particular diet. Certain foods may contain things ie sugar, dairy etc. that a person with severe ME may need to avoid.

This is not just being fussy - it is essential.

- Make a shopping list at a time that the person can best tell you what they need or want. Perhaps you can make a basic list of shopping so that you don't need to keep asking , will help conserve energy and make the task easier. Try to find out alternative brands that will still be ok to substitute for the person if the regular brand is not available.

- When putting stores away be aware of all the noise issues. Try to be as quiet and sensitive as possible.

## **Cooking**

If you are asked to cook meals , again try to be aware of noise issues when chopping, moving pans around etc.

- Even if a person is up and dressed this does not mean that they are well or able. They may need just as much help as when in bed. This will take time to get used to a person and how their illness affects them.

- Never assume that someone can do something. If they ask for help they need it.

## **Cleaning**

- A Hoover may be irritating , so ask if vacuuming is essential? Are there alternative ways to clean or would these be just as irritating ie a dustpan and brush? Agree to do it when the person feels able to cope.
- When cleaning ask beforehand if the person can cope with any chemicals and make sure you have the right product that the person has informed you can be tolerated.

Only do this with agreement of the person and at a time when they will be able to tolerate the use of any products.. It could make them feel very sick.

All cleaning products need to be agreed with by the person.

Due to chemical sensitivity it may be that no standard cleaning products can be tolerated. It may be that alternatives have to be sought, with more natural ingredients.

## **Washing**

- You need to be aware that the washing machine noise may be very difficult for a person to cope with.
- Try to do the washing at a time that is convenient for the person.
- Only use washing powder , conditioner etc that the person has told you they are not allergic to. People are often chemical sensitive both to contact and to smell.

A tumble dryer may also be too noisy for a person as

may be a spin dryer.

## **Personal Care tasks**

You should have been informed what personal tasks you are expected to help with. Always try to perform them in a gentle and caring manner. Be aware that the person you are helping is not just a body, but is a person who has feelings, may feel vulnerable and dependant, may be upset and feel very ill all the time.

Always remember this when you are performing intimate tasks.

## **Bathing/showering/washing**

- Be aware that the person you help may not have normal sensation and certainly will not have normal energy or ability.

They may also be in great pain and any contact may be agony to them.

Try to help them in the way that is best for them, Listen to what they are saying or communicating to you.

Respect their need for specific help in ways that are manageable for them. Try to be flexible in your approach if possible.

Always use aids and equipment provided and carefully follow any guidelines given to you for lifting and for personal care.

***Thank you for taking the time to read this guide and for your interest in helping people with Severe ME.***

