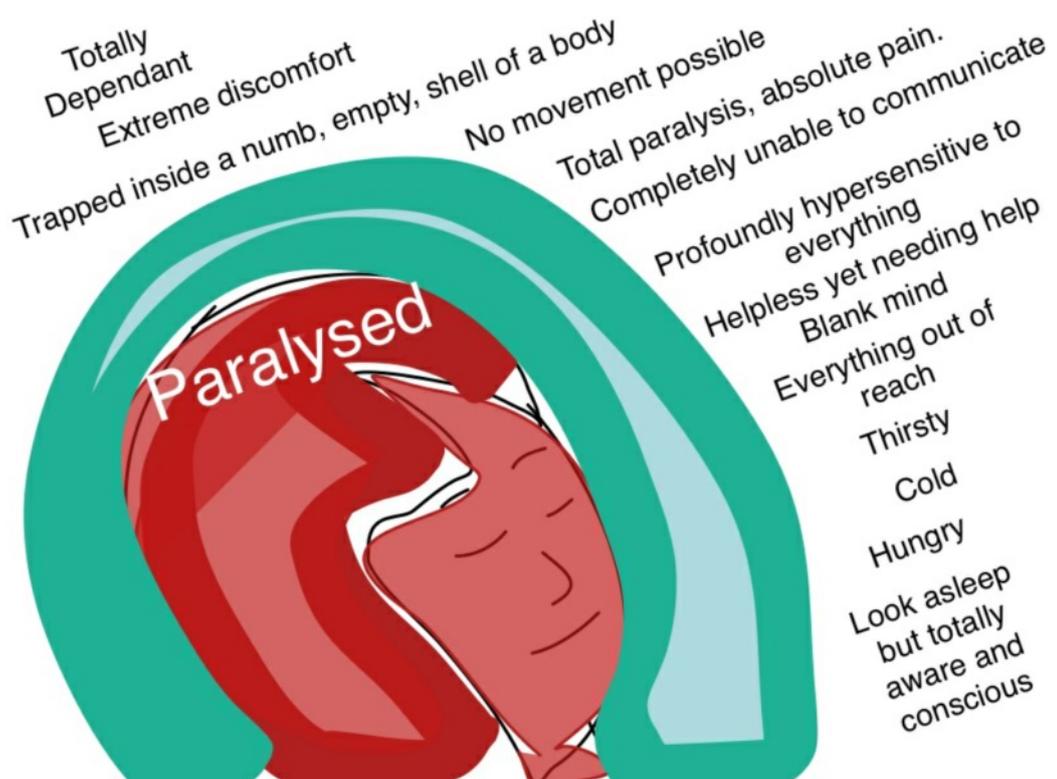


Who Cares for ME?



Greg & Linda Crowhurst

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- Since 2006 -

Stonebird

THE EXPERIENCE OF SEVERE ME

Welcome to my world
Where what is before you
Even close by you
Is out of reach
Where words disappear
From your head
And memory is turned to ice
Which slowly drips
and melts away
Where letters dance
Upon an unread page
And thought cannot be conjured
No matter how hard you try,
Where people are not just
an irritation to you
But harm you
inadvertently,
Simply by their presence

Linda Crowhurst

Who cares for ME?

A universal care approach to Myalgic Encephalomyelitis (ME)

OUR STATEMENT ON STONEBIRD that ‘*you don’t have to do anything to be of beauty and value in the world. Even if you cannot move, even if you cannot communicate, even if you cannot think, still you are precious and your presence matters*’, underpins our approach to caring:

Provide the best care possible, in the best possible way, at the best possible moment.

What is ME?

Myalgic Encephalomyelitis (ME) is a WHO classified multi-systemic neurological disease. It was originally identified as an enteroviral illness. People with Severe and Very Severe ME are so ill that most people cannot easily or safely participate in ordinary life or perform basic living tasks without help. The most severely affected are housebound, bed-bound or spend many hours if not all day, incapacitated and unable to help themselves. They may use wheelchairs part or full- time and are barely able to move.

Their lives are severely isolated.

The suffering of the most ill is often invisible and unrecognised.

There is no cure. There is no consistent or universal treatment. The pain of Severe/Very Severe ME is so extreme that drugs may not touch it, many are forced to take extremely strong drugs to gain minimal reductions in pain level. Others have no pain relief at all due to their acute drug sensitivity.

There are a range of serious physical symptoms, with underlying neuro- immune and other physiological implications.

Currently there is no biomedical pathway in the UK to help recognise, investigate and validate the most severe symptoms and extreme suffering that people endure, often for decades on end, once diagnosed.

A person with ME, with any level of illness, whether mild, moderate or severe, can always become more ill, especially if exposed to wrong treatment and inappropriate expectations and demands to do more. It is extremely easy to trigger a deterioration of symptoms.

Never ignore a person's symptoms thinking that they can just push through them.

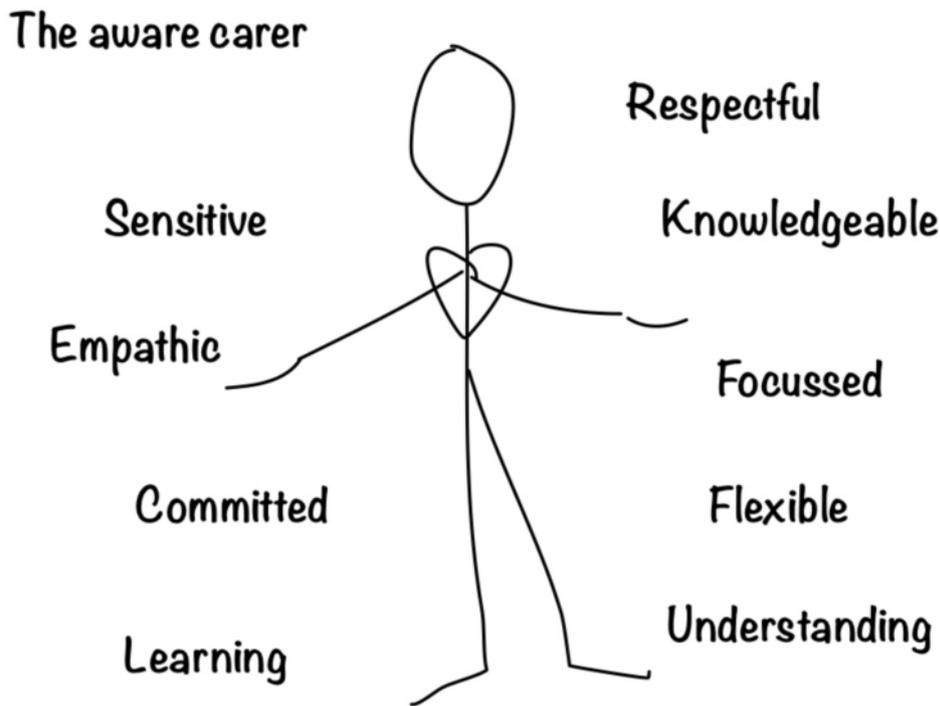
Why do people need care?

People need care because with ME any exertion can result in post-exertional deterioration. People either do not have the energy to begin with, to even perform every day tasks, let alone have a quality of life or they run out of energy trying to meet basic needs, then deteriorate and become incapacitated by debilitating, multiple symptoms, such as:

- Pain
- Muscle weakness and muscle fatigue
- Sleep difficulty
- Numbness
- Paralysis
- Muscle spasm
- Cognitive dysfunction
- Noise sensitivity (hyperacusis)
- Light sensitivity (photophobia)
- Touch sensitivity (hyperesthesia)
- Movement sensitivity
- Chemical and perfume sensitivity (Multiple Chemical Sensitivity)
- Gut issues, swallowing difficulty and gastroparesis

- Heart and blood pressure issues
- Dysautonomia

Rest brings temporary, little or no relief, depending on the severity of illness. The suffering and the consequences of over-exertion are often invisible, making it sometimes hard for people to understand why care may be needed.



People with Severe and Very Severe ME need care to survive. They may suffer intensely without relief, yet accessing that care is extremely difficult because of the nature and severity of their symptoms.

Care needs to be provided in an extraordinarily aware and sensitive fashion, understanding that any wrong move, demand or action may lead to unimaginable deterioration and long term consequences.

The ordinary things that people take for granted every day, become things that fail to get done and in the worst, most severe forms of ME, they become absolutely intolerable and incredibly difficult to manage, even with help available.

Things like getting dressed, washing your hair, cleaning your teeth, making a phone call, writing a letter, understanding a bill, dealing with problems, filing things away, chatting for even a few minutes to a friend or giving care instructions, all become a complex activity that are literally beyond possible, yet not necessarily explicable as to why they are so hard or not achievable.

Communication is a massively complex issue that people face in getting their needs met and this needs to be understood.

A flexible approach to Care.

Your presence is of the utmost importance:

- All you say and do.
- How you are feeling in yourself
- Your energy level
- What you are conveying non-verbally toward the other person
- Your values and attitudes

These are all key to interacting well with anyone, but especially so with people who are in high physical pain with a range of tormenting, unremitting, very severe symptoms.

It is important that you know how the slightest wrong movement, noise or action, on your part, may lead to even worsening levels of symptom experience and physical distress. You cannot afford to not be ultra - aware of the potential to do harm.

Every nuance, every breath, every movement counts and can bring relief or negatively impact the person.

A flexible, aware, moment by moment approach is key to successful interaction or at least as a way to try to minimise the risk of triggering deterioration and indescribable additional physical suffering.

To care for someone with Very Severe ME you need to know how to:

**Maximise the
Opportunity to
Meet
Each
Need
Tenderly**

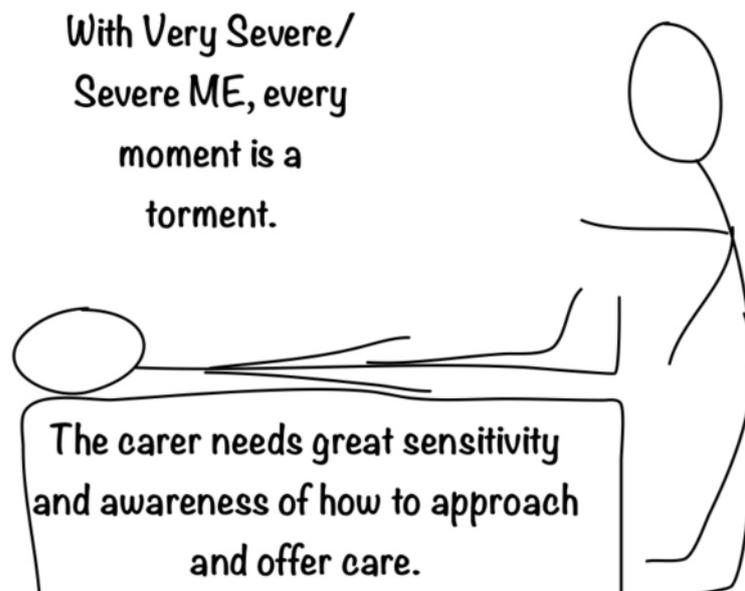
This says it all. We call it the “MOMENT Approach”.

It recognises how each moment is significant and that care may be better provided and interaction may be easier or possible, in some moments more than others.

Remember EVERY moment is a moment when the person is ill.

Some moments can feel a lot worse than others. With Severe/Very Severe ME the suffering and symptoms are continuous; there may be no moment when interaction or meeting care needs is tolerable, due to the intense unrelenting severity of symptoms.

The best moment to approach the person and help them, must be determined in partnership, together, so that you gently help, not inadvertently make things a lot worse for the person.



It is not only that you need to know about the illness and how it impacts the person you help, you need to know specifically, exactly and accurately, what needs doing to help the person and most importantly of all, you specifically need to know the 'how' of caring, which is essential to get right.

This takes:

Respect both of the person as an equal and respect for the illness itself, that ME is a neurological disease, certainly not caused by maladaptive thinking or deconditioning.
Respect what the person tells you.

Commitment to learn what is required and to get the care right.

Knowledge about the illness, the unique symptom experience of the person you care for and how you affect the person directly.

Willingness to grow and learn. It requires the highest level of comprehension, plus a willingness to understand that this is not like any other ordinary illness that you will come across.

An ability to change habits that are not appropriate or helpful. You must learn to do things specifically as required by the person, not just the way you may think they should be done. This requires enormous sensitivity, humility and willingness to change.

Awareness. Untold harm can occur if you do not notice things in the environment, especially the impact of your presence for example, how loud you are, whether you remembered not to wear perfume, whether you know that you do not just switch on lights without warning. Each person will have different issues that you will need to be acutely aware of. That awareness must be incorporated into all that you do.

Focus on every aspect of need. You cannot afford to lose focus. 100 % attention is needed, if you are to be present in the MOMENT to help in the right way.

Compassion and genuine empathy for the person's situation and their need.

Understanding. Without understanding the symptom experience and the moment by moment need, you are unlikely to be able to respond appropriately, you risk losing a moment of opportunity when you could help in the best possible way. You need to understand how you impact the person. You need to understand their symptoms and how they can be exacerbated and what that means for the person.

Flexibility. You cannot be driven by external demands. You have to be person-centred and willing to meet each need tenderly.

Tenderness. A tender, gentle approach makes such a difference to the person with ME, who lives as if in a different world to you often, whose need is great, who will appreciate beyond imagining a kind word, a tender action, a gentle approach to how you help them, in every aspect of care, whether putting groceries away or offering intimate care.

This approach is essential for carers, but it can also be used by anyone who needs to interact with the person, visitors, friends, social workers, healthcare professionals, family, who may need to know how to communicate, how important it is not to wear perfume, how to be flexible about visiting times, how to not feel rejected if contact is impossible, how to be willing to try again in another moment, how extra quiet and careful you need to be, given how sudden movement or actions can hurt.

What I need to know as a carer

- I need to know what to do.
- I need to know when and when not to do things.
- I need to know how carefully and quietly I have to perform activities and interactions.
- I need to know how to communicate with the person and how they will communicate with me; it may not always be verbal.
- I need to learn how to actively listen.
- I need to know what affects the person negatively, what endangers health.
- I need to understand the nature of the disease, especially the dangers of pushing the person beyond their limit, however small that may seem to me.
- I need to understand the risks of deterioration and how they might be triggered.
- I need to understand the best way to help the person.
- I need to know what is my responsibility as a carer and what is the responsibility of the person I care for.

- I need to know what to say and how to say it, if I am asked to advocate for the person.
- I need to know what to do in a crisis.
- I need to be able to flow with the person, providing the best care in the best moment and understanding how to act at all times in the best interest of the person.



Since 2006
Stonebird
AN ASSOCIATE OF STONEX BY

Where can I get more information on how to care and find inspiration?

Stonebird website - free care documents and information on the MOMENT APPROACH
<http://www.stonebird.co.uk>

The MOMENT APPROACH explained - free document.
<http://www.stonebird.co.uk/moment.pdf>

A practical guide to providing care for someone with Severe ME
<http://www.stonebird.co.uk/A%20Practical%20Guide.pdf>

Stonebird Care sheets
<http://www.stonebird.co.uk/Care%20Sheets.pdf>

The Care needs of people with Severe ME - a free document written for the 25% group for Severe ME day 2017
<http://www.stonebird.co.uk/careneeds.pdf>

Very Severe ME: underlying principles of care
<http://www.stonebird.co.uk/principles%20of%20care.pdf>

How to care, really care for someone with Severe ME
<http://www.stonebird.co.uk/Care.pdf>

Caring for ME book - a pocket book course for carers which highlights the MOMENT APPROACH
<http://stonebird.co.uk/CARE/index.html>

Severe ME: Notes for Carers - how to care for people with Severe/Very Severe ME
<http://stonebird.co.uk/Notes/index.html>

Issues of noise, light, touch, chemical and movement sensitivity in Severe/Very Severe ME that carers need to be aware of.
<http://www.stonebird.co.uk/hypersensitivity.pdf>

Emily Collingridge's book

<http://www.severeme.info>

Voices from the shadows film

<http://voicesfromtheshadowsfilm.co.uk>

The ME show, Gary Burgess: podcast Episode 8

<http://www.meassociation.org.uk/podcast/>

25% ME group

<https://25megroup.org>

The Grace Charity for ME

<https://www.thegracecharityforme.org/prayer/>

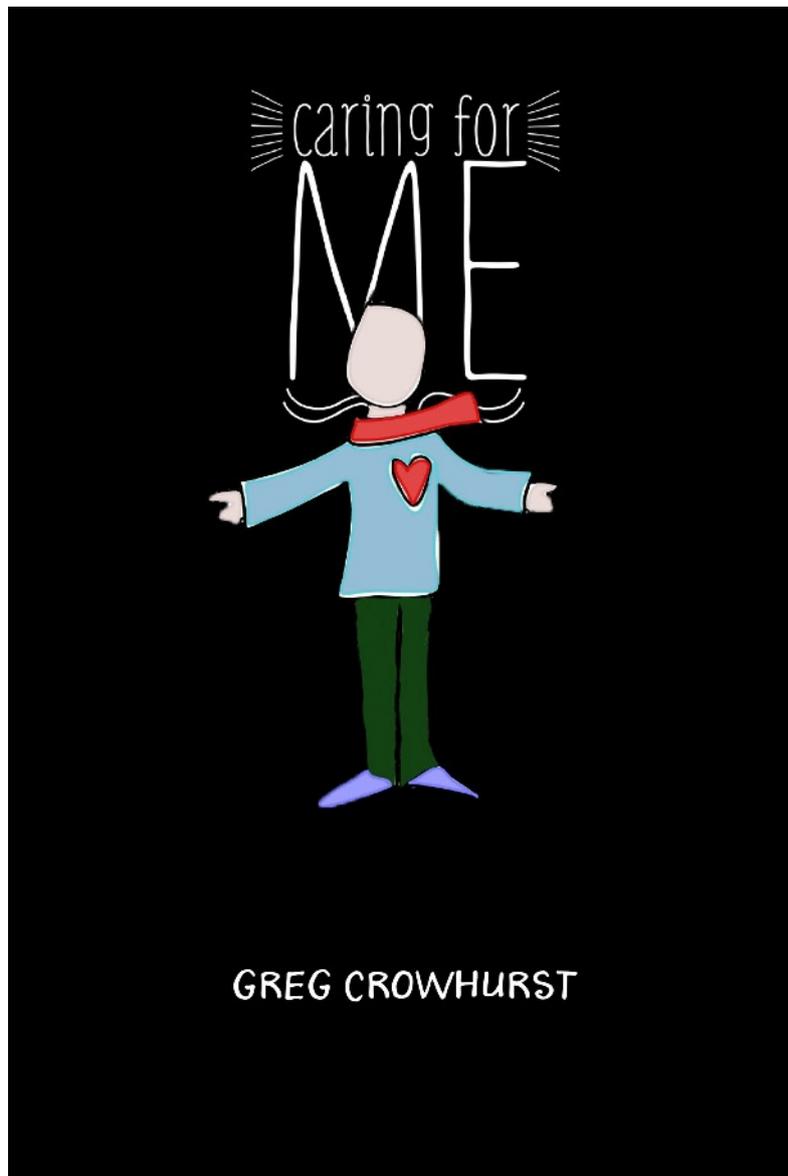
For children: The Tymes Trust

<https://www.tymestrust.org>

Caring For ME, a Pocketbook Course for Carers.

We are sure this will be a great life saver to many carers out there ...This book offers a caring and helping hand coming from a person of such experience and knowledge in the field.

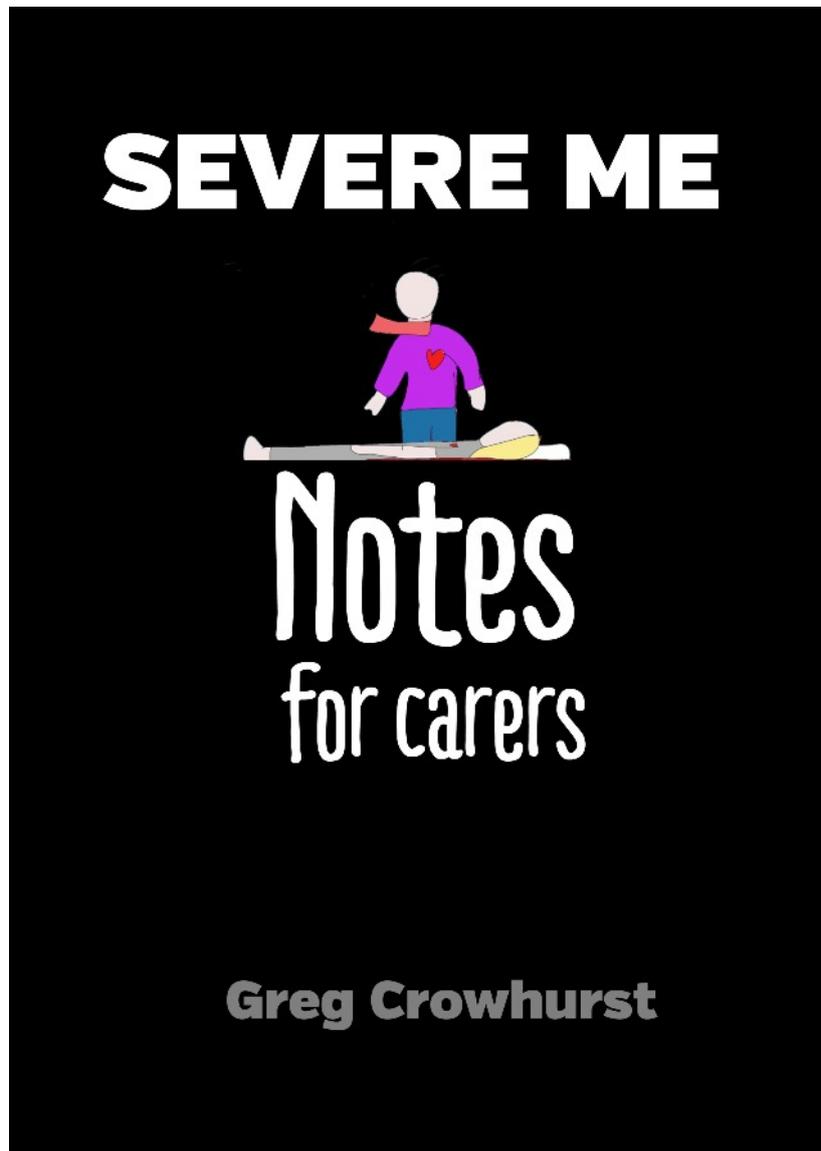
25% ME Group



<http://stonebird.co.uk/CARE/index.html>

Notes for Carers

An illustrated handbook packed full of practical tips, insights, guides and exercises.



<http://stonebird.co.uk/Notes/index.html>