

STONEBIRD, SEVERE ME, NOTES FOR AUSTRALIA, RESOURCE PACK



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Stonebird
THE EXPERIENCE OF SEVERE ME

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A Stonebird production for ME Group Australia

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SUMMARY OF THE VIDEO

Once you have a diagnosis of Very Severe ME everything becomes uncertain. You have a long list of tormenting symptoms that remove you from ordinary life as you knew it and you may have a range of negative experiences, as we did over three decades ago, leading to worse and worse illness.

This led us on a journey of advocacy to try and get a better medical service for people with a diagnosis of Severe and especially Very Severe ME. Nowadays the definition for ME is still very broad and includes a lot of people, probably with different illnesses and treatment pathways.

If you try the wrong treatment you can get even worse. Your life is fraught with difficulties decisions and you probably will not have enough support.

You may become removed from ordinary life.

If you need care from a partner, parent, friend or

formal carer they will most likely not know how to care, move, interact, communicate, in the right way to not cause extra difficulty for you.

This was our own experience. We very quickly had to make big decisions about our life. I gave up my business to care for my severely disabled wife and devoted my life to trying to help her get well.

There was considerable denial, misinterpretation and negation from the medical establishment. Both our backgrounds were in caring for severely disabled people. Our value base, then, has always been a person centred compassionate caring and respectful one.

We have worked in partnership to create a new caring approach called the MOMENT APPROACH, for when every moment of your life is a torment and anyone in your presence can unintentionally cause a deterioration further of your already intolerable symptoms, you need the most understanding person to provide for your care needs and enable you to stay connected with them.

The Moment approach is basically this:

MAXIMISING THE OPPORTUNITY TO
MEET NEED TENDERLY

How do you do this?

- By understanding the symptoms and the experience of each one and how they are impacted by your presence.
- By being flexible in the exact moment you provide help.

- By never neglecting the person, even if you have to wait to help them.
- By understanding it's a complex situation.
- By looking for solutions to difficult issues.
- By working in Partnership with the person.
- Is there anything you can change in the environment, in yourself?
- Can you do something differently?
- Are there any work arounds for intractable issues?

If you get it wrong please don't beat yourself up, but always learn from it. You are unlikely to always be perfect.

At the centre of the MOMENT approach is the value base that you are both precious and that your presence matters:

- Try again at some other moment.
- Listen, learn, grow.
- Look after yourself too as a carer.
- Be still with each other and let go of the past life you had.
- Create a life of new meaning.
- Always believe in the person you are caring for even if you cannot fully comprehend their reality.
- Try to understand, even if it is not your experience.

- If noise hurts, accept this and avoid making it, even if you cannot fully comprehend.
- If perfume triggers symptoms, respect this and help the person avoid suffering from it.
- If light hurts the person accommodate this.
- If touch is intolerable, work out together what to do when contact is necessary.
- If shock triggers worsening be very careful how you move about and interact.
- If stress makes symptoms worse and makes it harder to care, try to reduce stress, simplify life, make changes that are possible and desired.

Most of all learn if possible to flow together. A bad symptom day does not have to be the worse day if you can get the approach and the care right and more than this, be in harmony with each other, however simply that manifests in reality. Our best days are when we flow together.

The MOMENT approach can be found:

On my website **Stonebird**

<https://stonebird.co.uk/>

In my book **“Notes for Carers”** , which can be downloaded for free here:

<https://stonebird.co.uk/Notes%20For%20Carers%20Free%20Edition.pdf>In

In “More Notes for Carers” which is my most comprehensive book on caring.

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

If you want to learn more about yourself as a carer
see my pocket book course:

“Care For ME”

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

Stonebird Resources

For Nurses : <https://stonebird.co.uk/nurses.pdf>

Severe ME, Patient Surveys : <https://stonebird.co.uk/psurvey.pdf>

A Rule For An ME Advocate : <https://stonebird.co.uk/psurvey.pdf>

Moment Approach: <https://stonebird.co.uk/moment.pdf>

Straightjacked By Empty Air, a Political History of ME : <https://stonebird.co.uk/emptyair/sj.pdf>

Issues of Noise, Light, Touch, Chemical & Movement Sensitivity in

Severe/ Very Severe ME that Carers need to be aware of : <https://stonebird.co.uk/hypersensitivity.pdf>

A Human Rights Approach to ME : <https://stonebird.co.uk/Human%20Rights.pdf>

Very Severe ME, Underlying Principles Of Care : <https://stonebird.co.uk/principles%20of%20care.pdf>

Severe ME, Aware Care : <https://stonebird.co.uk/AwareCare.pdf>

Channelopathy : an important issue for those

with Myalgic Encephalomyelitis. : <https://stonebird.co.uk/channelopathy/paralysis.htm>

The Experience of Paralysis in Severe M.E. :

<https://stonebird.co.uk/experience/paralysis.html>

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An award winning Nurse, Greg has qualifications in Staff Training & Development, Experiential Learning, Counseling, Spiritual Care, Life Coaching and Web Design. He also has an MA in Moral, Spiritual and Personal Development.

