

# Keys to Better Balance

a practical body-mind approach to ME/CFS

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First, a warm *thank you* for inviting me! I have long looked forward to visiting the Dead Sea Clinic, and finally it became possible. I am grateful and happy to experience the clinic's services for chronically ill people up close, and I look forward to what the week will bring.

I have called my contribution *Keys to Better Balance* – a practical body-mind approach to ME/CFS. Although I began working with people suffering from ME by way of a research project in 2001, I consider myself primarily a practitioner. I believe in solid clinical work. When it comes to a disease like ME, where there still are more questions than answers, I have learned how useful such an approach can be. At a time when new advances in medicine and science are made every day, and theories and research results change faster than we can adapt, pragmatism – what we experience to be of help – is a lifeline for those struggling with this illness. The American ME specialist Dr. Bateman says the following about ME: 'You don't have to understand it to respect it.' I add: 'And to do something about it.' Research is necessary, and we need even more research. But we must not put off providing the best we can, while waiting for solutions to medical enigmas and discovering new drugs or treatments. I would have been more than happy to give you a practical, hands-on workshop in conjunction with this talk. Instead, I can point you towards a documentary about the first work we did involving people with ME in 2002. The film is called *Less is More* – a rehabilitation project for people with ME. Some adjustments have been made since then, but the film still provides an insight into how these exercise and coaching groups – which I now call *Keys to Better Balance for ME/CFS* – are run today, 12 years later.

I am a therapist, but I have always enjoyed teaching. Let me quote one of my own teachers: there is a lot of good therapy in good pedagogy. I also believe in groups. I have taught groups for over 30 years, as long as I have worked as a psychomotor therapist and coach. The framework for my groups or courses has differed somewhat over the years, but they have mostly consisted of the same

ingredients, that is to say: slow movement exercises like Taiji and Qigong, meditation and mindfulness, and mental techniques based on NLP and other cognitive methods. For many years, my courses were filled with musicians and singers, a group I continue to work with. But thirteen years ago, something changed. I received a call from a colleague and researcher that was to provide a new focus for my work. It is also the reason for going ahead with my forty-seventh exercise and coaching group for people with ME/CFS this autumn. Together with individual courses, weekend seminars, week-long workshops and the *ME advisory*, my individual counselling service, this amounts to many hundreds of participants and clients.

So how did I become involved with this patient group, a group and a medical field that hardly lead to glory, fame or wealth? And more importantly, why do I continue? The last question has many answers. Here is one of them: I believe in something more than just coincidence, and I think that this 'something more' has had a special mission for me.

Here is another answer: I think that every era has its disease that challenges the old paradigm. ME is such a disease. The Danish Professor Henrik Isager has called ME a lever to a more holistic view of human beings and treatments in our time. Somebody has to put their weight on this lever. I wish to be one of them.

But, as I mentioned earlier, a telephone call thirteen years ago was to spark off my work with ME patients. It was my colleague Lillian Festvåg, a physiotherapist and former employee of the research department at Sunnaas hospital, who called me. They had done research into post-polio syndrome, that is to say the late effects of poliomyelitis. Eventually they developed a course of remedial treatment after this ME-like condition had been rejected by the medical community for many years. Several of the patients the researchers at Sunnaas hospital came in contact with did not have a conclusive diagnosis of polio with paralysis, but otherwise had identical symptoms: disturbances of brainstem functions such as sleep, alertness, breathing, heart functions, blood pressure, temperature regulation and digestion. In addition there was cognitive impairment, sensory defensiveness, and especially fatigue, as well as the typical

exercise intolerance with delayed reaction, post-exertional malaise. A number of these non-paralytic polio patients (one of the many names given to ME sufferers throughout time) took part in a small pilot project. Here they trained based on optimal exercise principles using interval training on an ergometer bike. The effect was studied by measuring the physiological response throughout the six weeks of the study. The discovery that a correctly apportioned, individually tailored exercise program for a highly motivated patient does not have any effect after six weeks, and even leaves the subject in measurably poorer shape, raised some questions among the experts. If these people with ME cannot improve their health by exercising, and we know how important activity and exercise are, what do we do?

This was the question that led Lillian Festvåg to contact me. Not because I knew a lot about ME at the time, but because I have taught Taiji and Qigong since the eighties, Chinese forms of exercise based on slow, soft and meditative movements. Although this is not what a physiotherapist, an athlete or people in general would call exercise, we were to find out that it can result in astonishing and sometimes completely different results than what can be achieved with traditional exercise. To make a long story short, over a five year period we conducted two studies of slow movement exercise ad modum Qigong for people with ME.

We wanted to examine whether any form of physical activity could be tolerated by this patient population. In the first study, 14 people with ME were given easy Qigong exercises once a week for 5 months. The second study compared two groups: one that exercised for 5 months, and a control group that did not exercise at all. Both before and after the study period, all participants were given physiological tests and questionnaires to measure their health, quality of life and level of fatigue.

The project showed that slow-movement exercise ad modum Qigong can be tolerated by people with ME. The strongest indication of this was the fact that no one dropped out of any of the groups. In addition, we found both clinical and significant improvement in symptoms such as fatigue, pain, self-perceived

health, and, perhaps most interesting, increased oxygen uptake – better fitness, in other words! In the light of conventional physiology theory, it is quite remarkable that one should be able to improve one's fitness by exercising this lightly and slowly, and only once a week! For me, with 30 years of background in these forms of exercise, the results confirmed my own experiences. They were an eye opener for many professionals and opened the door for introducing slow forms of exercise like Qigong in the treatment of ME. Today, private as well as public Qigong classes are available to people with ME throughout Norway. As mentioned earlier, in the course of my career I have held nearly fifty individual courses with students attending weekly classes, with an equal number of students beginning and completing courses every semester.

What, then, is the key to success, the reason why this approach works, when many other exercise regimes and treatments do not work for these patients?

Firstly – and I consider this to be a prerequisite for any action regarding this patient group – a deep acceptance of the patients' own history and experience of being seriously and physically ill. This also means to accept that we are dealing with an actual physical illness. It does, in other words, *not* imply that we know everything there is to know about ME, because none of us do. *You don't have to understand it to respect it*, as Dr. Bateman says.

Even with my background in psychiatric and psychosomatic physiotherapy, I have never perceived ME as being 'all in the head'. From the very beginning, I have maintained that ME is a disease much like MS, arthritis, lupus, Crohn's, etc. As you may be aware, in 2009 two Norwegian cancer specialists accidentally caused a breakthrough in ME research. The cancer drug rituximab will certainly not be the final solution or cure for ME, but the findings of Dr. Fluge and Prof. Mella have led to an understanding of ME as a serious neuroinflammatory autoimmune disease. Such an understanding can in turn trigger funding for further research and treatment for an utterly neglected group of people with a serious illness.

In spite of this research and some 5,000 studies that all point in the same direction, the medical community continues to discuss whether this is a mental or a physical illness. The discussion is sure to waver back and forth for many years. That is a shame. Because the discussion shows that we continue to hang on to a dualistic understanding of disease. What's worse is that this prevents patients from getting the best help they can get. The discussion creates uncertainty. When doctors and other clinicians face uncertainty, they often feel resigned and afraid to do anything at all, even though they see their patients suffer. Many become passive because they wish to avoid looking foolish or risk their good name and reputation. Many of them also realize how time-consuming it is to fully engage in the care of these children, young people or adults. Many feel helpless. I understand them. It is difficult to face illness and suffering without being able to offer a watertight explanation, medicine or treatment.

The philosopher Inga Bolstad talks about *inntil-videre-kunnskap*, which may be translated as 'pending knowledge' or 'for-the-time-being knowledge'. It is an expression I am fond of, and I use it in my encounters with people suffering from ME. I owe them an explanation, but I could just as easily call it a working hypothesis. I cannot simply fob them off by saying that 'We know so little' or 'The experts disagree'. Instead, I offer simple explanations and hand-drawn diagrams and see how that in itself creates confidence and hope. And then there is another inexhaustible resource – it is our own humanity, our love, our values and beliefs, our total acceptance. We all have the ability to clear away prejudices and unfounded myths. And there are many of them when it comes to this disease.

The fact that ME is also called CFS, created a great deal of confusion during the eighties, and trivialized a very serious disorder. That would be like referring to tuberculosis as 'chronic cough syndrome'. It is equally useless and incorrect to call ME a lifestyle disease, a diffuse women's disease, a psychosomatic illness, a self-inflicted disease, a prolonged stress response, yuppie flu, or an illness that affects perfectionists or overachievers. Neither is ME a disease rooted in

negative thought patterns, dysfunctional family patterns, pathological behaviour, laziness or lack of motivation. No more than MS, arthritis or cancer.

When meeting a patient, it is essential to create an opening in order to be able to offer all the good tools known to us for coping and recovery. It is important to understand how vulnerable and often traumatized these people have become after encountering a society and health care system that still lacks a disease marker able to confirm their own experience of disability. Recognizing ME as a 'real' disease is to me a fundamental requirement in meeting people afflicted with ME, and absolutely necessary in order to pave the way for all possible resources, including both mind and body medicine. My rule of thumb is the following: What I say to a person with ME about the reasons for their illness and their ability to affect it, is no different than what I would say to someone with MS, arthritis or cancer.

The second key to succeeding in the treatment and training of this group is to understand a phenomenon that is entirely characteristic of ME, and that distinguishes ME from illnesses such as depression, burnout and general hypersensitivity. It is a phenomenon whose existence is agreed upon by everyone dealing with ME, no matter what other causes they may associate with ME. It is the reaction to physical activity and exercise, also called post-exertional malaise. This means that up to 72 hours after physical activity above a certain threshold, the person feels increasingly ill, developing symptoms such as exhaustion, freezing, sore throat, swollen lymph nodes, headache, pain, brain fog, disturbed sleep, muscle twitches, mental unrest, etc. The very opposite of what a healthy person or a depressed person experiences after activity. In short, it appears that the triggering factor lies in exercising above the anaerobic threshold, and this threshold has been found to be abnormally low in people with ME. If we are to succeed in reconciling exercise with ME, we have to stop thinking cardiovascular exercise. But there are ways to work around the problem: We must redefine the term exercise from meaning cardio or strength training to include the lighter and softer forms of movement like Qigong, light yoga, Feldenkrais, Mensendieck, Basic Body Awareness, light Pilates, etc. The key word is dosage, about a third of what one would think to be appropriate!

Exercises or relaxation in a lying position are a matter of course in this context, as well as the instruction to pace oneself and adjust all efforts to the stage of the illness and one's state of health on any given day.

And finally, over-eager therapists need to stop thinking 'progression'. If 'graded exercise' is taken to mean gradual and steady progression, one will quickly discover that it will not work. The key is to find a level at which the patient feels well afterwards, or recovers after no more than one day – and then *maintains* this state. As they say, don't change a winning team. These patients already have so many experiences with 'push and crash', they don't need yet another one! We see that improvement comes by itself when we maintain the same intensity, and above all when we accept that we are not talking about weeks, perhaps not even months, but years.

It is also useful to know that slow, light exercise is not the 'next best' option for those who are unable to exercise 'properly'. I have already mentioned several light and slow forms of exercise. What they have in common is that they strengthen the deep inner muscles, something that in turn seems to result in a better balance in muscle tension and breathing, the autonomic nervous system and one's emotional life. Slow movements, especially rotations and diagonal movements, stimulate the brainstem and the interbrain, and regulate neuromotor disturbances in a completely different way than hard and fast exercise. And the more meditative these exercises are, the better. The sense of presence in the movement is a key in itself. Research on mindfulness has shown that this form of focused attention and presence allows these particular structures and functions of the brain to regulate themselves. This is why I prefer Qigong to Mensendieck, although I have long experience with both methods. It may seem odd to draw on Eastern methods when there are suitable Western forms of exercise using slow movements. For me, this is about the fact that the Eastern approach maintains a meditative focus. It is also about the metaphors that are used – tranquillity, softness, and an underlying philosophy that invariably emphasizes that less is more, the path rather than the goal. These are good approaches to chronic diseases with uncertain prognoses.



That brings us to another aspect of exercise, namely the mental or cognitive factor. Besides Qigong, which combines the physical and the mental level – meditation in movement – I have added short mini-lectures to my courses. They deal with the various keys to achieving better balance, such as *inside and outside, doing and being, me and you, breathing in and breathing out, pacing and leading*. I draw illustrations and tell stories and anecdotes. In that way I appeal less to the conscious, logical and rational parts of the brain, but all the more to the subconscious, the visual and metaphoric part of the mind. All of this in order to activate the body's own healing process and strengthen the patient's hope and belief in change. These short lectures also present holistic ways of understanding illness and health, and the importance of the power of thought.

I have always believed in the power of thought. That is probably why I began to study NLP, Neuro Linguistic Programming, communicology, solution-focused brief therapy and hypnosis as early as the late eighties. Together with neuromotor stimulation by way of slow movement exercise like Taiji and Qigong, I saw change processes emerging and taking off in a completely different way than before. I have used this 'body-mind package' in both individual treatment and counselling sessions – and as the basis for all my courses and groups.

But when I suddenly found myself immersed in working with ME, often involving serious and even dramatic issues, receiving inquiries from around the country and standing alone with the responsibility for groups with very sick people, I became a bit cautious and restrained in using these very powerful tools. Indirectly, I used everything I had to offer to bring about positive attitudes, weed out negative use of language, instil and strengthen hope and belief in recovery, while at the same time encouraging patience and acceptance of what actually *is*.

I usually draw a continuum with *acceptance* at one end and *ambition to change* at the other. We move back and forth along this line. When people get an illness such as ME for which there is no cure, drug or operation, most of them begin frantically searching for precisely such a cure. Their ambition to change is great,

they start to spend money hand over fist, and eventually their energy runs out along with the belief that anything at all can help. Then comes the moment of realization. At best, acceptance of what is, but often swinging from one extreme to the other, from manic determination to resignation and depression. I observed these reactions and became careful in promising improvement and reluctant to use the tools I had previously used. It all became too severe, the patients were too weak and vulnerable. I felt that we knew too little about ME and the changes that were – or were not – possible. The tooth I had to pull wouldn't grow out again, regardless of which of my techniques and strategies I used. That much I knew. Neither would an amputated leg, or a motor neuron cell. I had to tread carefully. I could not offer easy solutions or promise infinite possibilities for change and recovery.

We can place different treatment philosophies along the same axis, between acceptance and ambition to change. I have experience with methods and techniques at the extreme end of the scale, with infinite possibilities and slogans such as 'You're a powerful genius and you can do anything!' The Western idea of rehabilitation also includes the ambition to change, brought about by pushing boundaries, fighting and overcoming illness and handicaps.

But I have a different and to my mind sturdier foothold. This is the tradition of the East. The philosophy of Zen, or mindfulness as it is called today, and the philosophy of Taiji and Qigong, telling us that 'soft overcomes hard', and whose fundamental principle is the idea of yielding. And I have a foothold in Christian beliefs and practices, where people find strength and courage to bear suffering and pain, to create meaning and accept their fate. I have come to understand that I need to be rooted at this end of the scale in my meeting with ME. That is where I feel at home as a human being and as a professional. In a soft approach, in silence and in 'not-doing', as the Chinese say. In the motto that 'less is more'. And to distinguish this approach from passivity and resignation, I like to quote Gestalt therapist Fritz Pearls: 'When you stay with what is, what is changes.'

Biomedical research is underway as I continue with what I know to be good and useful, what we have researched, and not least what I can see to do good. Under the motto *cure sometimes, treat often, comfort always*, and with the goal of providing optimal conditions for the healing process – not by *curing*, but by *caring*. By offering tools for physical and mental fitness in my groups. By meeting people where they are with their individual needs in individual counselling sessions. This may also involve cognitive techniques and hypnosis. It may entail piloting people through the system, writing proposals, taking part in meetings at the welfare office, talking to family or employer, finding therapists who have sufficient curiosity, confidence and patience to follow these patients for a better part of the way. By visiting the sickest patients at home and conducting hundreds of telephone consultations with people in great need, their families and their caregivers. I hear many sighs of relief and see many tears of joy at being met and understood, even if I do not have a solution or a cure. I meet pale and dispirited people as they arrive at my weekly training sessions, seeing the colour return to their cheeks, their conversation become more relaxed, and see those same people leave with a lighter step, with more rotation in their bodies, a fuller breath, and more hope. I see improvement, not over weeks, but over months and years. No quick fix, but slow stabilization, symptom relief and a gradual improvement in quality of life.

My approach to ME will not last forever, nor is it the only one. But these twelve years have given me experiences I could not have found in any book. And there is one more experience that gives me assurance in this uncharted landscape. As many know, I myself am one of those who became ill with ME. Probably in childhood after an attack of meningitis, later after a severe flare-up during pregnancy, and considerable external pressures. I knew none of this when I was asked to do research on ME. As I said earlier, I believe in something more than coincidence. I feel I have been given the opportunity to use my own experience with illness in my work. This experience represents my most important expertise, and is my deepest source of compassion and understanding, and something I would not wish to be without.

There is no reason to idyllize disease. But I often talk to my students and clients about the 'School of ME'. It is a school where I meet myself (me), and where I can find myself again. Where I have a chance to reach even deeper than if life had gone smoothly. It is hard work, but it can be deeply meaningful to learn to live with and hopefully get better from ME. One of the side effects is that one becomes a wiser, truer and more tolerant human being. A human being with more love for others – but above all with love of oneself.

*Merete Sparre, November 2013*