

For Nurses

An extract from
Severe ME featuring
Justice for Karina Hansen



Greg Crowhurst

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by
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Severe ME : For Nurses

THERE IS AN URGENT need to develop an appropriate biomedical model of nursing practice for people with Severe Myalgic Encephalomyelitis (ME), if practitioners are to avoid tragedies like that of Sophia Mirza, who died from ME, after suffering appalling treatment at the hands of doctors and nurses following sectioning under the Mental Health Act for two weeks in 2003.(Hooper 2006)

Crawford, Aitken and McCagh (2008) found that nurses still respond more positively to patients with Multiple Sclerosis and Rheumatoid Arthritis than patients with ME/CFS, which they are more likely to wrongly view as a psychological disorder. Nurses also report low levels of training and confidence in their skills when working with patients who have ME.

Ironically perhaps, the prevalence of ME has been show to be twice as high in nurses than in the general population suggesting that nurses might represent a high-risk group (Crawford, Aitken and McCagh 2008) for developing this disease. 1,088 out of every 100,000 nurses suffer from ME, according to Jason (1998) .

A great deal of conflicting advice still surrounds ME leaving many patients "dismissed and abandoned without support". (Hooper et al 2005).

Central to the care of people with ME and the cornerstone of any nursing model (Archibald 2000) are the beliefs and values, the experience and knowledge of the nurse.

It is imperative that nurses understand there are no known universal treatments for ME available at this time, that some of the mainstream therapies applied to ME sufferers have been unhelpful or dangerous on many occasions. It is pressing that nurses know that treatments such as Cognitive Behavioural Therapy (CBT - or Complex Incremental Pacing) and Graded Exercise Therapy (GET - or Incremental Pacing) , which unfortunately have been championed by nurses (FINE Trial), are wrongly based on patients seeing their "symptoms as temporary and reversible and not as signs of harm or evidence of fixed disease pathology (Bavinton et al 2004); you may have come across these terms in the PACE and FINE Trials .

Given that exercise worsens - or even precipitates Severe ME , there is great danger in advocating exercise per se, especially for the severely affected. Exercise-based regimes tend not to have been studied amongst those most severely affected (DH 2002). While strategies such as pacing appear to make sense, the situation especially in severe ME is much more complex and a baseline is impossible to establish.

As my wife says : " My body moves towards paralysis and increased pain the closer I get to the sleep state, even "resting" my body will move towards an inability to function : I won't be able to move my fingers, arms, walk, breathe easily, so the notion of pacing, which is based on rest, isn't adequate because rest brings dysfunction and disability closer."

The issue is not so much setting "baselines" - highly unlikely in Severe ME anyway- but of learning how to be aware of the subtlety of the illness; the key is the patient being aware, of : when they can, when then can't and when they might.

Patients need to learn how they are in any one moment so they can cope with it; they need to learn how to be accepting of themselves in whatever state of illness they are in without giving up hope that it might/will/can change, at least on a micro-level, if not in an external obvious way.

It is crucial that nurses are aware that on the 17 May 2011, the PACE trial authors admitted "The PACE trial paper refers to chronic fatigue syndrome (CFS) which is operationally defined; it does not purport to be studying CFS/ME...CFS defined simply as a principal complaint of fatigue that is disabling, having lasted six months, with no alternative medical explanation (Oxford criteria)"

As Hooper (2011) states : "This is exactly what the ME/CFS community has been saying from the outset, namely that the PACE Trial was not studying those with ME." It is the central argument of this book, that ME -the neurological disease, needs to be clearly separated from psychiatric Chronic Fatigue, in order to ensure safe and appropriate treatment of patients.

There is a very real difference between using CBT as a coping strategy, which is how it is advocated by NICE and using it to change maladaptive thinking , as might apply for mental health issues. Very real damage can be done to the patient who is severely physically disabled, by the nurse who misinterprets Severe ME as a mental health fatigue condition and then proceeds to deny that person's physical reality; this, from our experience is a very real issue and is so important because it could endanger lives.

It is only by Nurses treating each person individually, listening to what each person is saying and being well-informed about the true physical

nature of ME, that patients with Severe ME will begin to be given the respect they are due and will begin to feel safe.

It is a travesty that people with Severe ME are not currently safe, because of misrepresentation, misunderstanding and physical neglect.

As nurses we have a duty to speak up when we see wrong practice, which unfortunately abounds in ME, because of the ongoing confusion with chronic fatigue and lack of awareness of the difference.

As Consultant Paediatrician Nigel Speight explains:"In 2007, NICE Guidelines gave qualified approval to Graded Exercise Therapy (GET) and Cognitive Behaviour Therapy (CBT) due to limited evidence that they might be helpful in mild and convalescent cases.

There is no significant evidence that they help severe cases, and plenty of evidence from the patient community that over-enthusiastic forms of GET can be positively harmful." (Speight 2012)

My wife stresses :

“You probably cannot imagine what it is like to be trapped in a cycle of never ending opposites, where rest leads to increased dysfunction, where sleep leads to a complete ceasing of your body’ ability to move and an agony of increased pain. Where touch, noise, communication, even gentleness can be experienced as an assault on your physical and mental processes.”

If you want to engage with people with Severe ME then try imagining a world that responds completely the opposite way to your intention, where exercise leads to inability and increasing disability.

Nurses need to be aware that :

- ME is a serious neurological disease with multi- system dysfunction.
- ME patients are at risk of harm if you do not understand the dangers of post-exertional impact, a key feature of neurological ME.
- ME does not arise from deconditioning and wrong thought; a current misconception.
- ME is not a mental health disorder.
- There are over 4000 scientific publications on ME and significant progress has been made in the scientific understanding of the disease, particularly in the last 20 years.
- Inflammation and immune activation are involved.
- Infection is important. Illness starts with an acute, infectious-like episode in many patients.
- Neurocognitive abnormalities are prevalent. Endocrine (hormonal) abnormalities can be found. Hypothalamic-pituitary-adrenal axis dysfunction is a well-recognised feature.
- Symptoms are serious, and chronic illness is common.
- A significant number of patients (between 10% and 25%) are severely affected – housebound, bedbound or immobile – and severely overlooked.
- Genetic factors play a part, shown by family and twin studies.
- Neurological abnormalities can be detected.
- Muscle function is impaired in some patients, with abnormalities to both skeletal muscle and cardiac ‘bioenergetics’.

Severe ME

- Prevalence is high. Epidemiological studies show that ME – under its many different names, such as postviral fatigue syndrome, ME/CFS, chronic fatigue syndrome, chronic fatigue immune dysfunction syndrome etc. – affects around 200,000 people in the UK and 1 million in the USA. This makes the disease more prevalent than multiple sclerosis, systemic lupus and HIV infection.
- Exercise can harm patients with ME.
- CBT and GET are potentially dangerous for the patient with Severe ME.
- Patients with Severe ME are acutely hypersensitive to the environment, and special consideration must be given in the nursing process to accommodate their physical needs.
- Specific hypersensitivities such as chemical, light, noise, drug, touch and food sensitivities must not be ignored; to do so risks deterioration.
- There are no universal treatments for ME.
- There is no cure for ME.
- Some 25% of people with ME may be severely ill , sometimes for decades. Severely ill patients tend to have poor prognoses, whether children or adults. (Pheby and Saffron 2009)
- If you write a report about someone with ME it needs to accommodate their physical reality and experience, not your assumptions.
- You must be willing and able to be flexible in your approach and understanding of patients with ME.

- You need to understand the full range of symptoms and how they impact upon the person and how you will provide care for them.
- You need to always listen to the patient and respect their illness . To do otherwise can lead to serious harm.
- Genuine partnership is the way to safe practice, alongside up to date awareness of the physical disease.
- There are different definitions of ME. Make sure you understand the difference and the importance of knowing if a patient has ME or a mental health disorder.
- The incidence of ME is known to be rising , the prevalence of ME in the UK has been estimated to be three times higher than MS. No other disease surpasses its increase. (Hooper et al 2001)
- Patients die from Severe ME.
- Your attitude and responses can help or harm
- Do not abuse your power or position.

Integrity, wisdom and patience are required. Any improvement or response may be extremely small, almost invisible perhaps to the nurse, yet the person with Severe ME may discover significant benefit from what might seem like a small, even insignificant outcome.

New ways of enabling nurses to assist patients with ME urgently need developing .

The starting point, as this book has stressed , must be awareness that ME is a neurological disease , with multi-system dysfunction . A self-reflective, partnership-based model of practice has been outlined, in

order to begin to meet the complex needs of these grossly neglected patients.

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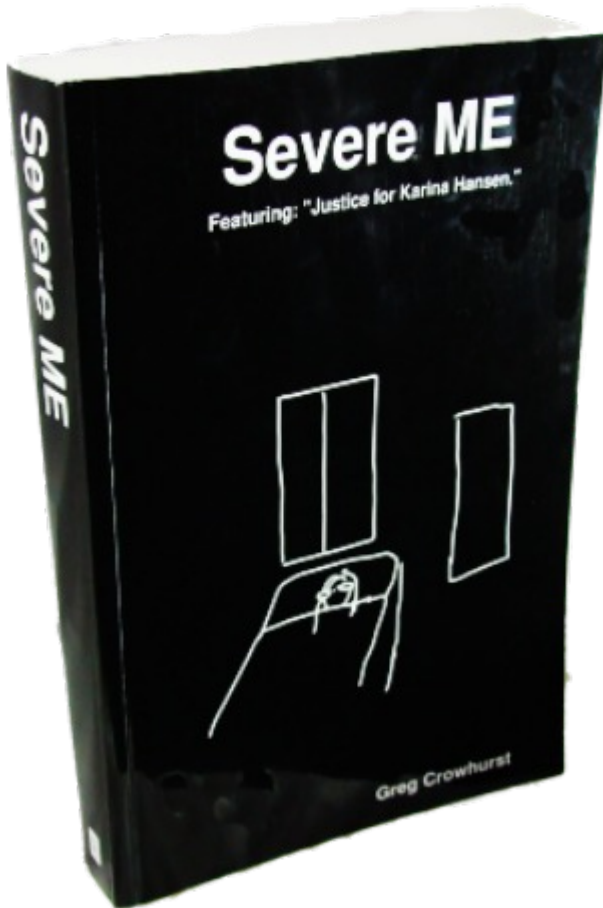
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