

Supporting people with severe myalgic encephalomyelitis

Greg Crowhurst RNMH, MA, PGDip Experiential Learning, Cert Counselling Skills, is a full-time carer and secretary of The 25% Severe ME Group, Great Walsingham, Norfolk.
Email: gregcrowhurst@yahoo.co.uk

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Summary

This article aims to raise nurses' awareness of myalgic encephalomyelitis (ME) also known as chronic fatigue syndrome (CFS). Key symptoms are presented along with possible service responses and treatment options. It emphasises that this condition is often misunderstood but that it can be serious and more research is needed to promote better understanding of the physical symptoms.

MYALGIC ENCEPHALOMYELITIS (ME), or chronic fatigue syndrome (CFS), varies widely in severity – from mild to moderate to severe. Treatment options are just as varied. There is a psychiatric lobby which, at its most extreme, denies that ME/CFS exists, while a collection of user groups and small research charities are pushing for further recognition and a cure for this condition. It is essential that nurses have an understanding of how severe the condition can be and the contribution they can make to the lives of patients and carers.

There are an estimated 62,500 people with severe ME/CFS in the UK receiving 'seriously inadequate' health care according to the Chief Medical Officer (CMO), Sir Liam Donaldson (Department of Health (DH) 2002a). Quality of life tests indicate that people with ME/CFS feel similar to patients with acquired immunodeficiency syndrome (AIDS) two months before death in their ability to do things (Munson 1995). Peterson (1995) describes ME/CFS as 'one of the most disabling diseases that I care for, far exceeding HIV except for the terminal stages' (Marshall *et al* 2001).

Twenty five per cent of the 62,500 patients with severe ME/CFS describe themselves as bedridden, and 57 per cent have been either housebound or bedridden for more than six years (ME Research Group for Education and Support (MERGE) 2002a). This illustrates that morbidity in ME/CFS can be substantial, despite the opinion of many healthcare professionals to the contrary (MERGE 2002b).

Australian researchers found that patients with this disorder experienced more dysfunction than those with multiple sclerosis (MS); that in ME/CFS the degree of impairment is more extreme than in end-stage renal disease and heart disease; and that

only in terminally ill cancer and stroke patients was the sickness impact profile greater than in ME/CFS (Marshall *et al* 2001).

Crowhurst (Crowhurst L 2004), a severe ME/CFS sufferer, describes how: 'Everyday I wake in a state of all-over paralysis unable even to move my fingers or open my eyes. Not only am I unable to move but I am in extreme pain and a state of acute hypersensitivity such that I cannot bear to be touched even lightly and even a whisper seems like a shout.'

In section G93.3 of the current International Classification of Diseases (ICD 10), the World Health Organization (WHO) classifies ME – and now CFS – as a neurological condition (WHO 2003). The CMO's report (DH 2002a) includes the definitions outlined in Box 1.

The health minister Lord Warner announced in February 2004 that ME/CFS is a neurological disorder not a psychiatric one (Burne 2004). Little research has been carried out in the UK on the physical causes of this illness. However, the National Institute for Clinical Excellence (NICE) (2004) is currently preparing guidelines for the diagnosis and management of ME/CFS.

CFS is the term used by medical staff internationally, but this can be misleading because, in the author's opinion, it does not describe the condition accurately. Shepherd (2004) questions whether anyone would take Alzheimer's disease seriously if it was renamed chronic forgetfulness syndrome and there is growing recognition that the category CFS is 'unsafe and unsatisfactory' (Abbot and Spence 2004).

Marshall *et al* (2001) state that the incidence of ME/CFS is rising. It is three times as common as MS in the UK (Anon 2003). The physical, psychological and social difficulties as well as the disability caused by severe ME/CFS are significant (DH 2002a) and yet patients, particularly children, continue to experience 'gross and barbaric abuse and persistent denigration' (Hooper 2003). Patients with Parkinson's disease, MS, epilepsy, diabetes, Graves' disease (thyrotoxicosis) were all said to have a mental disorder until medical science revealed their true aetiology (Hooper 2003).

Disbelief, especially by GPs and family members, makes it difficult for patients to access services. A report by Action for ME (AfME), one of the UK's leading campaigning charities, established in 1987 found that (AfME 2001):

Key words

- Chronic fatigue syndrome
- Long-term care
- Myalgic encephalomyelitis

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- 77 per cent of patients experienced severe pain; and more than 80 per cent had felt suicidal as a result of the illness.
- 70 per cent were either never able, or sometimes too unwell, to attend a doctor's clinic.
- 65 per cent received no advice from the GP on managing the illness.
- 80 per cent of those who were bedridden with ME reported that a request for a home visit by a doctor had been refused.
- Many people do not receive the state benefits to which they are entitled.

Aetiology and pathogenesis

The aetiology and pathogenesis of ME/CFS are not fully understood. There is, however, growing optimism that physiological abnormalities can be detected in many patients with ME (Abbot and Spence 2004). The disease is heterogeneous (composed of different elements) and it is not clear whether ME/CFS refers to a single condition or several distinct diseases that are bracketed together because of the similarity of their clinical appearance. Shepherd (2004) states that there is no satisfactory explanation as to why people with the illness continue to experience severe levels of ill health and disability.

Infection – bacterial and viral – seems to be the most common trigger of ME/CFS. Approximately two thirds of ME cases are triggered by an obvious viral infection, for example, viral meningitis, viral hepatitis or glandular fever, and less commonly by bacterial infection or caused by other organisms (AfME 2004). Abnormal activity of the anti-viral immune responses has been reported (Shepherd 2004).

ME/CFS has been noted to occur or worsen following anaesthetics (Marshall *et al* 2001). Abnormalities involving chemical transmitters in the brain, including serotonin, dopamine and acetylcholine, may explain why many ME/CFS patients are sensitive to the adverse effects of drugs that act on these chemical transmitter systems (Shepherd 2004). In rare cases, immunisations have been identified as possible triggers of the illness (AfME 2004). Muscle biopsies and magnetic resonance imaging (MRI) scans show a variety of muscle abnormalities, for example, altered metabolism and abnormal response to exercise (Abbot and Spence 2004). A high proportion of ME/CFS patients studied had measurable signs of muscle weakness in the arms and/or legs (Abbot and Spence 2004).

A major difficulty for severely ill patients is orthostatic intolerance – difficulty in remaining standing. This can trigger a cluster of symptoms such as dizziness, altered vision and nausea, which may be the result of disturbed blood flow (Spence and Stewart 2004).

Disturbances in hypothalamic function (hypocortisolaemia) have been registered in a number of studies (Bakheit *et al* 1992, Demitrack *et al* 1991,

Richardson 1995, Scott *et al* 1999) and may explain sleep difficulties and temperature control problems such as Crowhurst (Crowhurst L 2004) describes: 'I am so tired I cannot wake up properly and I fall back into two to three further bouts of sleep. Each time the pain, paralysis, numbness, prickling, itching, burning sensations worsen in my whole body. My face, eyes and scalp also burn and itch, my lips are numb, my throat and my tongue are numb, I can barely breathe if it has grasped hold of my chest muscles and diaphragm.'

ME/CFS patients seem to display an increased response to acetylcholine – a substance that causes blood vessels to dilate. Brain scans indicate a reduced blood flow (hypoperfusion) (Costa *et al* 1995, Ichise *et al* 1992, Tirelli *et al* 1998) that has not been demonstrated in any other medical condition (Abbot and Spence 2004).

There are currently no drugs available to treat the underlying disease process in patients with ME/CFS. Individual symptoms, however, may be treated using a variety of different drugs, including antiviral, immunoregulatory, metabolic, supplemental nutritional and antidepressive preparations, but none has demonstrated definite clinical benefit (Reid *et al* 2000, Werbach 2000, Whiting *et al* 2001). In an interview with AfME Dr Abhijit Chaudhuri stated: 'We all know there is no cure for ME/CFS, MS or Parkinson's disease. As physicians all we can do is try to treat the symptoms and improve quality of life with advice on lifestyle changes' (Coe 2002).

One survey shows that almost 90 per cent of CFS patients (n=90) use pain medication in pursuit of symptom relief, with vitamins and minerals constituting the second most frequently used category (Jones *et al* 2003). Few alternative and complementary therapies have been properly assessed, although acupuncture and homeopathy may have beneficial effects in some people. There is no evidence to indicate that treatments such as anti-candida programmes, involving restricted diets, probiotics and anti-fungal medication, used by many patients, are of any value in ME/CFS (Shepherd 2004).

Care and management

Action for ME states that 65 per cent of patients have received no advice from the GP on managing their illness (AfME 2001). A more recent survey found that many patients with severe ME experience poor treatment and inappropriate attitude towards their condition from various healthcare staff (The 25% Severe ME Group 2004). This is a key area for nurses to address.

The most severely affected patients experience barriers to accessing all forms of care, variable responses to treatments and under-representation in research (DH 2002a) and therefore it is not surprising that there is insufficient evidence to guide the specific management of severe ME (DH 2002a).

Box 1. Definitions of severe and very severe myalgic encephalomyelitis

Patients with severe myalgic encephalomyelitis

will be able to carry out minimal daily tasks only, face washing, cleaning teeth, have severe cognitive difficulties and be wheelchair dependent for mobility. These people are often unable to leave the house except on rare occasions with severe prolonged after-effect from effort

Patients with very severe myalgic encephalomyelitis

will be unable to mobilise or carry out any daily tasks for themselves and are in bed for the majority of the time. These people are often unable to tolerate any noise, and are generally extremely sensitive to light

(DH 2002a)

The condition is a complex one and there is an urgent need for a generic template CFS/ME care pathway (MERGE 2002c). In the meantime it is crucial to listen to and respect the patient when he or she describes his or her symptoms, even if the symptoms are not fully understood. Wall (2000) says: 'My injuries are invisible, subtle in neurones, enzymes, cytokines, the intricate inner circuitry of the body that still eludes concise theories, that require scientific minds to make a leap of faith, to become, as it were, believers.'

It is important to appreciate the scale and impact of the symptoms associated with ME/CFS. It can be very difficult for patients with ME to communicate their needs because the energy required to speak or think can precipitate a relapse and/or increase their pain or affect the ability to cope physically and emotionally. It is essential for the nurse to be aware of the importance of such information. A symptom and service response table (Table 1) provides further information (Crowhurst G 2004). It can be difficult to attend to a patient who is hypersensitive to touch, light and sound. Tenderness in all procedures and minimising stress in the relationship and environment are crucial to caring for a patient with severe ME/CFS.

Exercise-based regimens advocated for less severely affected patients tend not to have been studied among those most severely affected (DH 2002b). Graded exercise therapy (GET), cognitive behaviour therapy (CBT) and pacing – learning to successfully manage activity and rest intuitively (AfME 2004, Jackson 2002) – might help some people with ME (Mulrow *et al* 2001). However, it is misleading to consider CBT, GET or pacing as treatments – they are management or coping strategies (Jones 2004).

While strategies such as pacing appear to make sense, the situation in severe ME/CFS is complex. Crowhurst (Crowhurst L 2004) says: 'My body moves towards paralysis and increased pain the closer it gets to the sleep state, even "resting" my body will move towards an inability to function: I won't be able to move my fingers, legs, arms, walk, breathe easily, so the notion of pacing, which is based on rest, isn't adequate because rest brings dysfunction and disability closer.'

In a survey by The 25% Severe ME Group (2004) 82 per cent of patients with severe ME/CFS stated that their condition was made worse or even caused by GET. Jones (2004) warns of the danger of imposing inappropriate coping or management strategies on severely ill patients because such methods have been shown to make little or no difference, or worsen the condition dramatically and, in some cases, irreversibly.

Diagnosis

The diagnosis of ME/CFS is controversial. In 1994, the United States Centers for Disease Control and

Prevention (CDC) published a working case definition called the Fukuda criteria, which has become internationally accepted (Fukuda *et al* 1994). However, the CDC criteria were primarily intended for research purposes and not for clinical definition (Carruthers *et al* 2003). Because the CDC emphasises fatigue as the sole compulsory criterion, it has attracted criticism for allowing disparate fatigue conditions, for example, post-traumatic stress disorder, depression and conditions that improve with exercise (Spurgin 2003) to be diagnosed as CFS/ME; the CDC definition is increasingly viewed as too broad and indistinct to be useful (Carruthers *et al* 2003).

The Canadian Clinical Case Definition (Carruthers *et al* 2003) requires that a patient's condition worsens following exercise and that other symptoms are present for a diagnosis of ME or CFS to be made. These symptoms include (Carruthers *et al* 2003):

- Sleep dysfunction.
- Pain.
- Neurological manifestations, such as difficulty in processing information, disorientation and hypersensitivity to noise.
- Autonomic manifestations, such as hypotension, urinary frequency and bladder dysfunction.
- Neuroendocrine manifestations, such as sub-normal body temperature, marked weight change and worsening of symptoms with stress.
- Immune manifestations, such as recurrent flu-like symptoms, general malaise, new sensitivities to food, medications and/or chemicals.

Adoption of the Canadian Clinical Case Definition as a single, unified, physical case definition of ME/CFS that can be used clinically and for research is actively being campaigned for in the UK by The 25% Severe ME Group (Anon 2004).

Manley (2004), who has been collecting and analysing data from more than 320 people severely affected by the illness since 1994, has found that most severe ME/CFS patients have had to wait more than four years for a diagnosis. Crucially, diagnosis is the first step in actively managing the condition (DH 2002b).

Current criteria (DH 2002a) suggest that symptoms should be present for six months before a diagnosis of CFS/ME can be made, however this threshold is arbitrary and clinical diagnosis can and should be made well before this time, especially in children and young adults. If symptoms persist, a provisional diagnosis should be confirmed by six months, while the plan for managing the illness and its consequences should already be in place (DH 2002b).

Principles of care

It is acknowledged that current healthcare provision is inadequate (DH 2002a) and many patients with ME/CFS will have had negative experiences of the health service.

Table 1. Severe myalgic encephalomyelitis/chronic fatigue syndrome: key symptoms, impact and service response

Symptom	Experience	Outcome	Nurse/service response
Sleep paralysis	Completely unable to move Difficulties with breathing, speech and swallowing	The patient cannot: <ul style="list-style-type: none"> ■ Sit up ■ Move ■ Get out of bed ■ Feed his or herself ■ Get a drink ■ Talk ■ Go to the toilet ■ Wash ■ Answer the door ■ Get the post 	To provide physical assistance with: <ul style="list-style-type: none"> ■ Lifting ■ Support to move ■ Walking ■ Mobility ■ Personal care ■ Shopping ■ Cooking ■ Feeding Obtain as much information as possible about the patient before commencing care Demonstrate sensitivity and awareness
Noise sensitivity	Cannot tolerate loud noise, unexpected noises, banging and thudding in the room or in the environment	May not be able to cope with electrical or mechanical machines, for example, the vacuum cleaner Listening to speech might be a problem Loud voices – certain tones of voice might cause distress Actions such as doors being shut, loud footsteps, rustling paper and opening drawers can cause torment	Develop an appropriate communication system, for example: <ul style="list-style-type: none"> ■ Written instructions ■ Sign language Lower voice and speak softly Be gentle and quiet in all movements Be aware that your noise might cause distress, even if it does not seem unreasonable to you Respond appropriately if you cause noise, for example, stop and be prepared to back away if necessary
Light sensitivity	Cannot tolerate bright light or any light at all, even with eyes closed	Need to wear dark glasses, have curtains shut, no lights on or low lights only	Be accepting and prepared Work in low light situations and/or protect the patient from direct light if one is needed
Headaches	They may be constant or last for days, can be predominantly left-sided and may not respond to medicines. Also, patients may experience head pain, as opposed to headache	Scalp is sore to touch and eyes may be throbbing or burning. The face can hurt and may be accompanied by numbness, paralysis, swollen eyeballs and nausea Headaches or head pain may be sharp, throbbing, may be dull but no less severe	Be sensitive to noise and light issues An awareness of emotional distress or being in constant pain and the potential for the patient to be irritable is important Help administer medication if needed; be aware of any possible side effects; be able to discuss possible options
Muscle weakness and variability	Might be able to use muscles intermittently	Danger of falling or stumbling Affects the patient's independence: might not be able to use hands, fingers or perform fine movements Might be able to walk intermittently Might not be able to write, type, turn things on and off, cook, clean and attend to personal care such as eating	Mobility issues might require a wheelchair Might be bed-bound and/or housebound Might require help with cooking, cleaning, shopping, personal care, eating, writing, communicating, social interaction and sexual relationships May not be able to use stairs or may find using stairs difficult, adaptations, aids and equipment should be provided as required
Pain		Whole body might be too painful to touch Might be continuous and vary in degree Poor response to drug treatment Cannot bear to be touched Difficulty in getting comfortable when seated either in bed or wheelchair	Pain awareness and extreme sensitivity Knowing how to touch and lift carefully Patience and time are required to 'flow' with the person, avoiding any unnecessary diminishing of energy Advise on what is available to alleviate pain, including aids, equipment and medicines

(Crowhurst G 2004)

The importance of adopting a person-centred approach to patients with ME/CFS has been outlined (Crowhurst 1999, Crowhurst *et al* 1993). Nurses could use Kolb and Fry's (1975) learning cycle to underpin their practice (Figure 1). The nurse is encouraged to reflect on his or her practice, experientially and holistically, for example:

- What thoughts am I thinking about the situation I am in? (Mind)
- Is my posture relaxed and easy, or is it directive, assertive or aggressive, or potentially hostile? (Body)
- Am I feeling fearful, valuing, open, angry, distressed, helpless, centred? (Emotion)
- Am I connecting with my underlying values and

beliefs? Am I connecting with the person? Am I connecting with colleagues and other service providers? (Spirit)

The emphasis is firmly on the practitioner's own learning and growth.

Key questions for each stage:

Experience Has my intervention been positive or negative?

Reflection What did I do right or wrong?

Conceptualisation What have I learned? And what could I do differently to meet the person's need?

Action Try again, when appropriate, with insight.

Maximising opportunities to meet the individual needs of patients, whatever those needs are from moment to moment, and promoting good communication are crucial when caring for patients with ME/CFS (Table 2). The nurse can seek to improve patient care by:

Preparation Being aware of the symptoms that patients are likely to experience, so that they are prepared in advance. Knowing as much as possible about severe ME/CFS and possessing a working knowledge of the resources available, for example, benefits, advocacy, practical help and the roles of other professionals and user groups.

Developing trust Believing the person and honouring what they tell you and developing excellent listening and communication skills.

Respect Being aware of the need to respect the person's experience and the limitations imposed by the illness.

Valuing Appreciating the person through a warm person-centred approach (Rogers 1981).

Reflecting Recognising the importance of reflection for nurses on a moment to moment basis to creatively and gently meet the needs of the patient.

Figure 1. The holistic learning cycle

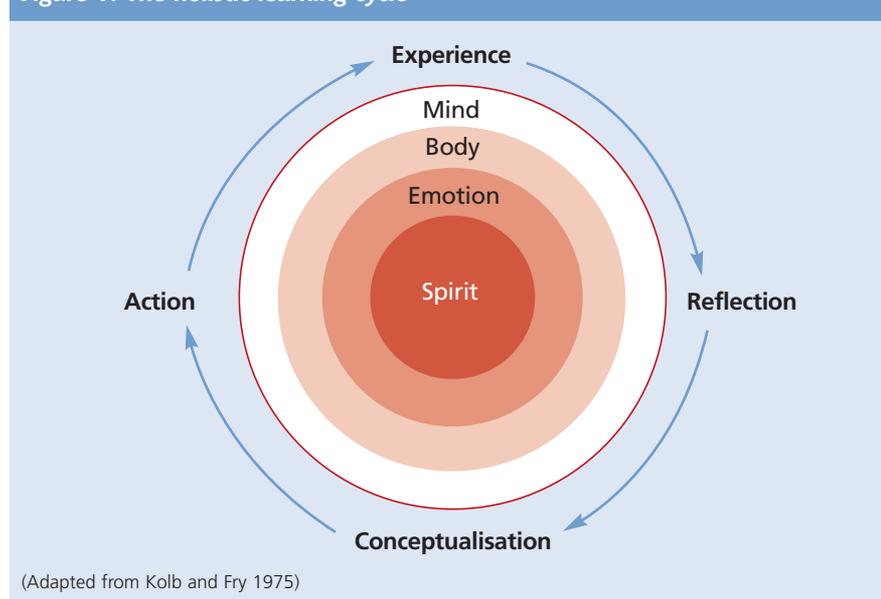


Table 2. Communication is crucial to caring for patients with myalgic encephalomyelitis/chronic fatigue syndrome

The nurse communicator	Outer barrier	Inner barrier	ME/CFS patient
How should I approach this patient?	Touch/light/sound sensitivity	Heat/cold intolerance	Either reached out to or pushed further away because of a lack of knowledge and understanding of the condition
Can the patient process information?	Numbness	Hypoglycaemia	
Do I need to keep my voice low?	Paralysis	Worsening of symptoms with stress	
Is my tone likely to irritate the patient?	Pain	Fatigue	
Does the patient or do I need to whisper?	Tingling, and pins and needles	Post-exertional malaise	Either feels valued, seen and heard, or devalued, unheard and ignored
Is it easier for the patient to have something in writing to share with me?	Inability to stand or walk or breathe	Cognitive impairment	
How long can the patient tolerate or cope with my presence?	Dizziness	Headaches and pain	
	Disorientation	Sleep disturbance	
	Sense of unreality and distortion	Digestive disturbances	
	Difficulty in waking up	Food intolerances	

Conclusion

A positive nursing approach is urgently needed in managing patients with severe ME/CFS. Although the condition can seem overwhelming, it is important to maintain an approach that does not negate the person or his or her illness experience. The focus needs to be on the practitioner's skills of sensitivity and creativity rather than making the person feel that he or she has to get well, because this is a long-term chronic condition. The rewards may seem small to the practitioner, but they could be immensely valuable to the patient.

When giving care to patients with severe ME/CFS it is important to be aware that:

- Any action the nurse takes may lead to an exacerbation of symptoms.
- The nurse should always be ready to stop any intervention at the patient's request.

- Acceptance of the patient's reality, despite its complexity, is crucial to the provision of effective care.
- External appearance is usually not a marker of symptom severity.
- It is dangerous to make judgements based on what you think you know without checking it with the patient first.
- Patients with ME/CFS may be ultrasensitive to the effects of light, noise and touch, and this should be taken into careful consideration when providing care.

It is essential to adopt a positive outlook and to work constructively and creatively with patients who have severe ME/CFS. The nurse who is willing to work in partnership and communicate sensitively with patients, developing a trusting, caring and professional relationship can make a real difference to the quality of life of these patients 

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