



Caring for seriously ill ME-patients: A small survey

By

Sidsel Elisabeth Kreyberg

Institutt for allmenn- og samfunnsmedisin, Universitetet in Oslo

(from the Journal of IiME Volume 2 Issue 1)

(Invest in ME have helped in translation of this article from Norwegian to English and have been given permission to republish the article, which first appeared in Norsk Tidsskrift for Sykepleieforskning, 2007; 9: 2, 16-26)

ABSTRACT

Caring for seriously ill ME-patients: A small survey

Norwegian medical professionals generally lack the knowledge and experience needed to diagnose and provide advice on how to manage Myalgic Encephalopathy. The subject is also absent from the education of nurses and other health workers. Experience must, for now, be accepted as key to understanding and managing this largely unexplained disorder.

Seven nursing homes here outline which extra resources would be necessary to adequately treat and care for seriously ill ME-patients, according to their experience. Apart from suggesting specialised units, the answers comprise technical adjustments to provide maximum protection from sound and light, advanced ventilation systems, flexible kitchen facilities and individually adapted dietary regimens; medical advisors; and a carefully selected and limited number of carers to look after the ME-patient around-the-clock. Stability, predictability and consistency are necessary for the patients to cope, and a small team will enable the carers to cooperate, be alert to signs of adverse reactions, and take adequate measures to prevent deterioration. Routines for debriefing staff working with patients in a permanent crisis-like condition was called for; and extra time and resources to support relatives that assist in planning and caretaking, speak on behalf of the patient, and are crucial in providing know-how - all of which necessitates increased staff in general.

Key words

English: Myalgic encephalopathy, chronic fatigue syndrome, nursing, rehabilitation, experience



Introduction

Myalgic Encephalopathy, ME, is discussed more often in the media than in professional healthcare curriculum literature. The condition is often given other names such as "Chronic Fatigue Syndrome", "fatigue syndrome" or "lack of energy", which are more or less vague definitions of various longstanding fatigue states (Lindal, Stefansson & Bergmann, 2002; Jason, Helgerson & Torres-Harding, 2003; Kennedy, Abbot & Spence, 2004).

In addition to subjective symptoms, which come and go, such as self-reported fatigue, nausea and malaise, ME is characterised by reduced stamina brought on by physical or mental activity, otherwise known as *activity intolerance* or increased fatigability (objective exhaustion). These patients are thus *exercise intolerant* (Hyde, Goldstein & Levine, 1992). In addition they are different from other "low energy" patients in that they are at times disablingly intolerant of sensory stimuli, have markedly reduced tolerance for alcohol, medicines and various food stuffs, with disturbances in autonomous, hormonal, neurological and immunological functions, disturbed body clock, and pains which are not relieved by treatment. In a fully developed illness there are symptoms from all organs and bodily systems. Symptomology is constantly changing. Lack of explanation for a cause gives rise to psychiatric interpretations. Recent studies, however, show changes in the peripheral circulation which can explain a lot of the phenomena of changing symptomology over time. (Streeten & Bell, 1998; Rowe, 2002; Peckerman, Lamanca & Dahl, 2003; Khan, Spence & Kennedy, 2003; Khan, Kennedy & Spence, 2004; Spence & Steward, 2004; Kennedy, Spence & McLaren, 2005).

Clinical presentation of ME is a condition with large disturbances in the ability to restore the physiological balance. This means *prolonged recovery time* with subjective symptoms and objective loss in physical and mental functions after activity and stimulation. It depends on the individual how much can be tolerated, and the capacity varies within the course of the illness. The capacity can also vary considerably within one day. Patients benefit from reducing activities to a level which, from experience, can be tolerated without provoking symptoms, and therefore need to be protected from stimuli that provoke symptoms. Increased recovery time makes it necessary to rest after activities and stimulation so that symptoms ease and physical and mental functioning is slowly improved. Problems with circulation make it furthermore necessary to lie down a lot; completely flat in severe cases.

ME patients need help in stabilising their condition despite the severity of the illness. When activity limitations are exceeded, there is an increase in symptom intensity, increasing deterioration and ever increasing recovery time. The illness has from experience an inherent tendency for slow improvement over months and years as long as it is not provoked. The best prognosis is for young people who are allowed to rest from the start of their illness, for grown up married or for co-habiting couples or for the ones who have marked improvement during the first 12-18 months.

The World Health Organisation classifies ME together with Post Viral fatigue Syndrome (PVFS) as a neurological illness (G93.3, ICD-10), but have not given criteria. The character of the illness is described in the literature, often in the form of symptom lists or set of criteria (Hyde, Goldstein & Levine, 1992; Kreyberg, 1999). The knowledge of the nature of the illness is spread considerably from person to person via formal or informal networks among people with personal experience, also within doctors. The illness is difficult to understand, and what one sees can be difficult to intermediate because connections between cause and effect often



are the opposite compared to what one sees in other illnesses. The limitations of the illness are seen clearer *after* activity and stimulation than beforehand, and there are no adequate concepts to describe the subjective symptoms. Those who try, will often be interpreted in the psychosomatic model of understanding, either are ill themselves or speak for the ill.

One of the reasons why ME is still considered a somatic illness is that it can develop as a direct consequence of another physical illness or trauma. It can also begin acutely after a latency period of several months or years after exposure, possibly in connection with a new unrelated illness episode. It is easiest to diagnose acute, fulminant cases and cases that occur during epidemics. In a fully developed illness the presentation is the same despite the triggering event or the way in which the illness started. ME can therefore be seen as a type of general reaction.

The pattern of increasing loss of physical and mental functioning after activity is especially noticeable with the most severe cases, whose reaction most likely shows up straight away. Upon recovery the reaction can be delayed or overruled. Even if the ill person is careful the reaction can happen after hours or days, or even after a longer period, and one has to take this experience into account.

The reaction can be abrupt, dramatic and long lasting. Activity level can therefore be increased only in small steps within periods of improvement. If there is a reaction the activity level has to be down regulated straight away. The ill person will feel *beforehand* if there generally are energy reserves and will *spontaneously* increase their activity level, expose themselves to stronger stimulus, try new food and more. So the ill person must not be encouraged or stimulated but benefits from adjustment.

Observation over time is necessary if one wishes to avoid exposing these very vulnerable patients for lengthy, painful and potentially harmful investigations which can neither confirm nor rule out the diagnosis with today's routine examinations. At best one achieves ruling out another illness which is only necessary if there is clinical suspicion (Holmes, Kaplan & Ganz, 1988). However, suspicion of another illness comes up often because of the changing symptom flora, where new symptoms show up constantly. It is therefore important that healthcare professionals and others who take care of such patients have certain knowledge of the everyday presentation of the illness. The following sums up a quick survey which was carried out in the autumn of 2006, motivated by the upcoming nursing home reform in Oslo and knowledge of the case of what is officially on offer for ME patients being taken up by parliament (Dåvøy, 2007). Many seriously ill ME patients are cared for at home by their families, often for years, without essential support, respite care or guidance. It is mainly patients themselves and their families who have the knowledge around this area and it is spread via distinct networks.

The illness presents itself more or less the same despite sex, age and over national borders, and is most easily recognised in serious cases, those in need of care. For this reason one could expect experiences in institutionalised care situations to be fairly similar, even with relatively restricted material.

A Small Survey



In all eight institutions which had been known to have taken in a severely affected ME patient, were contacted by telephone. It varied whether it was the ward nurse or someone else in the team around the patient who answered the phone. They were told about the objective, which was to obtain an enunciation from a person with "hands-on"-experience with a severely ill ME patient in an institution, with the idea of how one could give adequate services in the future for this patient group, without taking into account the existing restrictions in resources. It must be said quite explicitly that especially "grass root" experiences can be as important as recommendations and therapy suggestions from professionals who do not know what the care situation involves. It was left to the departments themselves to decide who would formulate the answers. The following questions were asked: *Which resources should you be provided with to be able to offer adequate care for a seriously ill ME patient? State reasons for your answer based on your own experience.*

Seven of the institutions gave written answers by e-mail, post or via both. The eighth considered that ME was not the reason for the patient's care need and their experiences were irrelevant for our study.

One institution asked for the question to be provided in writing but had reformulated the given problem when they gave their answer. This didn't affect the outcome and was only taken as a novelty. In three cases single statements were elaborated upon after renewed contact.

The study's starting point was five women and two men who needed care. In one case the patient lived with the parents but was cared for by permanent staff from a nearby institution. In one occasion the ill person lived in a care home connected to a nursing home. In one occasion it was a rehabilitation centre that admitted patients on a short term basis, with a clear target of improvement during the stay. In this case the place was used as a half way house because of lack of space elsewhere. In one case it was a short term department within a nursing home that ran the rehabilitation. The others were ordinary nursing homes.

Some of the institutions didn't have any previous experience of ME, whilst others had experience of several ME patients with unequal grades of severity. The extent of this experience material is not known.

The relatives were involved in to different extents in the daily care and acted partly as advisers. In a few places the staff also functioned in a supportive role for relatives.

RESULTS

The answers are concentrated especially on economical support for physical efforts, extra staff, individually adjusted eating and extra time. One wished for regular staff with a limited amount of chosen carers and guidance both before and after the stay. A few were also concerned about how one could look after relatives and carers after meetings with patients in a permanent crisis. The special problems that materialised when patients got more energy became more apparent in various degrees and are in the borderline toward rehabilitation.

Screening against sound



The fewest could look after the need for complete sound proofing. Amongst the suggestions were a private room in an area with least noise pollution, a sound proofed room, a sound proofed door and eventually one's own screened ward. In one case there was a built in sound proofed room within a supportive housing accommodation.

Common dining areas were too noisy. Even if a few could physically get to the dining area themselves, the food had to be brought to the room.

Many pointed out that the staff had to perform tasks quietly and be aware of their voice level, use of equipment such as plastic utensils, finish as quickly as possible, not talk unnecessarily, possibly use cards instead of spoken words, make sure that housekeeping tasks were done in such a way that the patient was not burdened.

Many noticed that tolerance for sound and talk improved as the condition improved and then it was mostly the ill person themselves who initiated discussion with the staff and exposed themselves to sound from the radio or sang to themselves.

Screening against light

The patient's need for complete black out could mean problems in caring. Many wished for lights that could be dimmed gradually. In one ward it was suggested, in order to avoid a gap between the window and screening, to install a roller blind inside the double glazing and additionally double curtains.

Comfort for lying down

For patients who spend most of the time in bed it was identified by one institution of the special need for a good bed/mattress.

Temperature and air quality

One place which took in several ME patients pointed out that a normal ventilation system was not good enough. The ill people had to have even temperature and could feel uncomfortable by the heat in the summer. For the consideration of both the patients and carers the need for good air circulation meant installation of an air conditioning system, especially where there was extra sound and light proofing.

Kitchen and food

Customised food was seen to some extent differently depending on the routines of the institution and reflected somewhat the knowledge of, or acknowledgment of food intolerance problems with ME. It was difficult to register if a patient deteriorated due to certain foods.

In one case a special diet was only present if there was a doctor's note. It was, however, known that many institutions avoided usual foods such as milk, sugar and flour. Even this caused extra work.

A few found it natural to work with a dietitian and adjusted the food according to the patient's wishes. Others called for a nutritionist and for a possibility to order special food.



To have enough time for feeding was, as a rule, seen as the biggest problem. It was simpler if the ill person took all food in a liquid form. The need for extra time for feeding was seen throughout as a resource problem which had to be solved by adding extra staff elsewhere.

Purely physically some pointed out the need for a private kitchen for more flexible solutions for the ill person and their families to be able to cook for themselves. The relatives could then also more easily function in a supporting role for the ill person and at the same time offload the staff.

Staff

In addition to special physical efforts, there was a need for extra human resources. There was a wish for a regular, stable staff with the fewest possible people, who could cover the ME patient's need 24 hours a day. "[...] all care such as tidying up, feeding, washing and so on takes at least three times as long as one is used to." This demands such large resources that it requires increased staff in the ward as a whole.

Among other things it was wished for a limited amount people involved with every ME patient because "it is difficult for the patient to relate to too many of the staff". Here one wished for a lot of accommodation to reduce the amount of people in the team.

A few involved also wished for everyone concerned to be able to see warning signs of deterioration and take precaution- " for example sleep, chest pain, blurred vision, runny eyes, headache, pressure on the forehead, sweaty palms, cold extremities, tingling of toes and fingers, sound of voice". The carers also had to act as the ill person's spokesperson to the outside. ME patients have to mobilize to be able to talk and cannot always talk when it suits others.

Forward planning

Prediction and the possibility of being as well prepared as possible for what is happening and when, is vastly important for the ME patient to be able to manage the daily life. Ordinary home nursing care doesn't therefore work well. To be able to take care of the patient's "physical, psychological and social needs demands a certain amount of understanding of the diagnosis (complexity of problems)", as expressed by one of the carers. For example, to understand the consequences if one arrives a few minutes late. "We set alarms and change times for other tasks so that we can be precisely with an ME patient. If we don't attend we know the consequences for the patient becoming worse and having to, for example, rest a day or two afterwards to recover." Another one explains how deterioration was triggered by the cleaning staff being five minutes late.

The two institutes which followed detailed instructions from relatives, and took patients' wishes to the point, had experienced that this worked and the ill person improved. A leading caregiver was surprised at how little extra work it took to make carers come at agreed times and do all the tasks exactly in a way the patient advised – even though the ill person could additionally call for help outside the agreed times.

Many called for information well in advance before the patient arrived to the ward, while others had had enough information from relatives. Many put weight on the usefulness of



important people in the ill person's network. Many on the other hand called for professional guidance, courses and seminars. The setting up of an ambulant specialist team was suggested, possibly regional ME wards.

Cooperation

Coaxing and stimulation can have the opposite effect of that which was intended. The ill person wants to, but can't, and becomes frustrated over coaxing – if it is not always so well meant: "It is important when advising the staff connected to the ME patient that one has to think differently compared to how one thinks with other patients in the ward, for example patients in rehabilitation, long term patients, and others.". As a consequence of improvement there is often a need for stimulation and a big need for talking. "Let the patient make contact without him being bombarded with impressions...". One can for example "respond with cards or simple nods". In other words: Let the ill person take the initiative themselves.

The staff often became tired in one way or another. It could be to do with constant arranging, the special considerations one had to take into account all the time, and to be related to the ill person's problems of accepting the diagnosis, their frustration of not being able to do as much as they wanted, set backs and so on.

It was pointed out that a care plan was important to ensure that everyone gave the same treatment. Carers who would be part of the team had to be carefully chosen:

"The medical follow up [...] is important, but the personality of the carers [...] is equally important and has to be appraised accurately. One has to have both nurses and nursing assistants in the team, but it is not necessary to have only professional staff as long as they [...] understand the illness and are willing to take on the challenge. The illness and its symptoms can seem challenging and the staff have to be well prepared and in a position to handle this in a confident way both in the presence of the patient and others. It demands confident people who can pacify and who can see the fluctuations the illness brings. It can be difficult to tackle the behavioural pattern when the care is very detailed and it is the patient who steers what shall happen and when. The negotiation of this (with the ill person, added by writer) can have negative consequences for the illness development. It is important that the staff themselves are willing to be in with the resource team because this is demanding 'one to one' care. [...]"

The staff also has the need for 'debriefing'. This is not common in a nursing home and one has to set aside a way and time for this.

The role of Relatives

ME is a long term, demanding condition which takes the relatives' time, and where all involved have to live with great uncertainty not only for the future, but for what every single effort can bring on – the daily as well as the extra ordinary ones. The risk for a relapse is always present, and poorly ME patients have very small margins. In this context the relatives were mostly seen as a resource. Often they were in a position to guide both beforehand and during the stay, and they acted in various degrees as relief persons. They were also better than the staff in registering a patient's deterioration and could act as spokespersons for the ill person. Many take on the role as the extended arm of the ill person.



The staff expressed on the other hand also a wish for enough time and resources to be able to look after the relatives better: "As it often involves young people it is important that one has also time for the family [...]. The life situation for the whole family becomes very insecure, both because at the moment there is so little knowledge of the illness itself, individually how the illness runs its course and what timescale we are dealing with."

COMMENT

The results confirm the expectation of relatively similar answers even though not everyone brought in the same points. The task opened up for suggestions and reflections, and it was varied how thoroughly reasons were given. Some opinions appeared already during the first contact and are included to complement the picture.

Everybody emphasized structure initiatives, especially in connection with screening and dining area, and professional guidance. A few also called for readiness for conflict solving and "debriefing". Several pointed out the need for specially selected staff, great flexibility and extra time because ME patients put demands on staff resources both physically and psychologically. To be able to prioritise ME patients, it was necessary to have extra staff to solve problems elsewhere in the ward. Alternatively one had to set up personal ME wards. Even though relatives were seen as a resource, a few also saw the need to be able to better look after the relatives, also family members who were not directly involved in the care.

Some of the differences in the answers are due to different prerequisites regarding the physical conditions of the institution and existing competence. Some are also due to unequal aims regarding the stay and treatment environment in general. Those who actively rehabilitated differed from the pure care wards, mainly regarding expectations of results.

Obviously frustration regarding the illness was expressed more clearly by both those among the ill and carers who aimed for advances via mobility. Even if the expectation is improvement over time with ME, the improvement is mostly very slow, with major or minor relapses when limits are exceeded or with extra strain which is outside the ill person's control, such as moving, infection or a shock of noise. An approach with preplanned aims is in contrast with the nature of the illness unless the aim is stabilisation, which can be achieved most easily by screening against sense stimulation and limiting activity to a level the ill person can tolerate without bringing on a reaction. At the same time there needs to be an activity plan within the tolerance limit. The thought process is in other words opposite of the usual rehabilitation, where active or passive mobility is guided by tolerance levels being pushed in order to get results.

With stabilisation over time the tolerance ability in different areas increases unevenly. There is being created a palpable energy reserve which can be used in *small doses* with pauses in between in such a way that there is time to register a prospective reaction. The improvement starts with a concept of finding out what the ill person can tolerate out of the different challenges, and then these are tested out carefully with gradual introduction of light and sound, new foods, elevated position and so on, and active movement of muscles and joints, preferably without weight bearing to start with. It is considerably harder to *work against* gravity than it is *with* it, a relationship that was described as early as 1934 (Gilliam, 1938). Planning and personalised exercises can be useful so that the ill person doesn't spontaneously increase physical activities too soon and too long while improving. Passivemobilisation and/or massage is validated if it increases well being. ME patients



experience well being with an activity within tolerance limits and do not need encouraging. They rather need to be told to take rest breaks *before* they reach their performance limit so that they don't push for a reaction ahead of them, with increased symptoms and lengthened recovery time as a result.

The impression was that rehabilitation institutes aimed to find an optimal balance between pushing the limits carefully and thereafter stabilising with rest, but found it difficult to calculate the length of the necessary stabilisation, or what would trigger a reaction. The result was frustration both among patients and carers when there was a relapse. It is possible that some of the pressure of expectation is created by the false impression that micro training is favourable with ME. Such an approach goes against all experience and is based on a concept of *fatigue* being caused by an underlying lack of motivation, which is postulated in the so called Oxford criteria (or similar psychosomatic interpretations) which form the basis of many of the studies concluding that GET (Graded Exercise Therapy) or CBT (Cognitive Behavioural Therapy) are good for "chronic fatigue syndrome" (Kreyberg, 2004a).

CBT and GET are activating therapies which do not take into account the ME patient's tolerance limits in any other way than that taking part is voluntary. The therapy is offered and therefore caters for the patient's experience of being ill. Such recognition gives hope after years of rejection and disbelief, which many have met within the health care system and/or family. Studies which show positive outcomes for treatment in no circumstances include the most severely affected patients who are not able to attend treatment

The principles of ME treatment are the same regardless the severity of the illness, but the ill person's performance abilities are diverse, and efforts for relief follow thereafter. One has to know the condition can go within hours or days from being self-supporting in several areas to needing fulltime care, and even someone with a high grade of autonomy can be totally exhausted during parts of the day, without an ability to have a conversation, call for help or look after oneself.

A severely affected patient is extremely vulnerable and unstable so that the smallest effort can trigger a reaction. Small details will influence the everyday life a great deal in good and bad, both for the ill person and carers. This can be both demanding and rewarding. It is a big improvement when the ill person can do something themselves, for example lift a glass up to the mouth or type in a telephone number. This saves the ill person from sensory input, which is being loaded by having a helper in the room. But the glass has to be kept at the right height, not be too heavy and so on. The care has to be creative, and carers have to learn from one another.

Rehabilitation and care go thus hand in hand, even for the very severely affected. Whether it deals with care or organising an activity by oneself, one has to be aware of the pattern of the ill person's limits which are not usual in other illnesses – and this at such a detailed level is difficult to imagine. In addition one has to be practically odour free, sound free and invisible.

The carers have to develop increased awareness in order that the patient can be saved from using energy to give instructions. They have to do their work and then leave the room because every attendance drains the mental capacity of the patient. On the other hand it can help if someone is around when there are severe and constant symptoms because it gives security and certain diversion.



It can be impossible to hold a tooth brush, fork or pen or hold a telephone conversation, yet still be possible to press an sms message with the hand resting on support. Such apparent inconsistencies in what the ill person can and can't do, show a totally characteristic pattern, but often becomes a source of conflict amongst the staff.

These conflicts have to be acknowledged early and have to be solved by someone who knows the nature of the illness.

Improvement requires more stimulation and contact and the staff becomes easily overworked when the ill person's capacity increases. The capacity to talk by oneself is greater than the capacity to take input from others or enter into discussion, which demands adaptation of concentration from outgoing to incoming. All adjustments are abnormally demanding with ME. Even though this wasn't directly formulated, this insight was expressed in different ways, also considering the difficulties with transport, change of staff and similar.

One area where the answers were somewhat different involved food and food intolerance. Food intolerance increases symptoms, and a severe patient becomes just quieter. It is obvious that one can't experiment with activities even if the rules allowed one to do so, and that the institution should be able to take this into consideration. Here the rules have to be adjusted to the nature of the illness. It is known from experience that people with ME all over the world spontaneously change to a lighter diet with lots of fruit and vegetables. Thinking of the unstable circulation that is a trademark of ME, it is maybe not unexpected as one knows that several litres of blood is redirected to the intestine after a meal, and that the composition of the diet's nutritional content can make a big difference. (Waler, Erikse & Janbu, 1990; Waler & Eriksen, 1992; Eriksen, Waler, 1994; Waler & Toska, 1999).

Those who didn't have previous experience of ME patients, wished to a greater degree for medical justification to support the care being given. A few also expressed a certain ambivalence toward relatives' strong opinions. Those who knew the patient and/or relatives beforehand, were more open for their expertise even if the illness was not medically understood. Even though performance targets were not asked for here, it was clear that systems which were outlined by patients/relatives were followed because they worked well.

There is no overview of how ME is distributed in the population. Hospital statistics can show the relative emphasis of those with the strongest resources. There can be a large hidden number among drug users, students and the young unemployed, farmers, artists, pensioners, vagrants and misdiagnosed people in locked wards in psychiatric hospitals (Kreyberg, 2004b).

This small survey shows how important experience is in the work with ME. It would be preferable to do a wider survey of the competence that exists all around the country, and build on this in order to begin to establish adequate and decentralised services for a very vulnerable and forgotten group of patients as soon as possible.

References

- Dåvøy, L. (2007). Interpellasjon i Stortinget
- Eriksen, M. & Waler, B. A. (1994). Priority of blood flow to splanchnic organs in man during pre- and post-meal exercise. *Acta Physiologica Scandinavica*, 150; 363-372.



- Gilliam, A. G. (1938). Epidemiological study of an epidemic diagnosed as poliomyelitis occurring among the staff of the Los Angeles County General Hospital during the summer of 1934. *Public Health Bulletin* No 240, April. United States Public Health Service, Washington D. C. Government Printing Office
- Holmes, G. P., Kaplan, J. E., Ganz, N. M. et al. (1988). Chronic Fatigue Syndrome: A Working Case Definition. *Annals of Internal Medicine*, 108; 387-9.
- Hyde, B. M., Goldstein, J. & Levine, P. (Ed.) (1992). *The Clinical and Scientific Basis of Myalgic Encephalomyelitis /Chronic Fatigue Syndrome*. Ottawa: The Nightingale Research Foundation.
- Jason, L. A., Helgeson, J., Torres-Harding, S. et al. (2003). Variability in Diagnostic Criteria for Chronic Fatigue Syndrome May Result in Substantial Differences in Patterns of Symptoms and Disability. *Evaluation and the Health Professions*, 26(1); 3-22.
- Kennedy, G., Abbot, N., Spence, V. et al. (2004). The specificity of the CDC-1994 criteria for chronic fatigue syndrome: comparison of health status in three groups of patients who fulfill the criteria. *Annals of Epidemiology*, Feb; 14(2); 95-100.
- Kennedy G., Spence V., McLaren, M. et al. (2005). Oxidative stress levels are raised in chronic fatigue syndrome and are associated with clinical symptoms. *Free Radical Biology and Medicine*, Sep 1; 39(5); 584-9.
- Khan, E., Kennedy, G., Spence, V. et al. (2004). Peripheral Cholinergic Function in Humans With Chronic Fatigue Syndrome, Gulf War Syndrome, and With Illness Following Organophosphate Exposure. *Clinical Science*, Feb; 106(2); 183-9
- Khan, E., Spence, V., Kennedy, G. et al. (2003). Prolonged acetylcholine-induced vasodilatation in the peripheral microcirculation of patients with chronic fatigue syndrome. *Clinical Physiology and Functional Imaging*, 23(5); 282-5.
- Kreyberg, S. (1999). *ME/CFS En innføring for foreldre og andre som arbeider med barn og unge hjemme eller i institusjon*. Stensil, Universitetet i Oslo, August 1999: Appendix. <http://www.kronisktraethedssyndrom.dk>
- Kreyberg, S. (2004a). Kronisk/postviralt utmattelsessyndrom. *Tidsskriftet for Den Norske Lægeforening*, 124; 2382-3.
- Kreyberg, S. (2004b). Pasienter ut av av ingenmannsland. *Norsk Epidemiologi*, 14(1); 79-83.
- Lindal, E., Stefansson, J. G. & Bergmann, S. (2002). The prevalence of chronic fatigue syndrome in Iceland - A national comparison by gender drawing on four different criteria. *Nordic Journal of Psychiatry*, 56(4); 273-7.
- Peckerman, A., Lamanca, J. J., Dahl, K. et al. (2003). Abnormal Impedance Cardiography Predicts Symptom Severity in Chronic Fatigue Syndrome. *The American Journal of The Medical Sciences*, 326(2); 55-60.
- Rowe, P. C. (2002). Orthostatic intolerance and chronic fatigue syndrome: New light on an old problem. *The Journal of Pediatrics*, 140(4); 387-9
- Spence, V. & Steward, J. (2004). Standing up for ME. *Biologist*, 51(2); 65-70
- Streeten, D. H. P. & Bell, D. S. (1998). Circulating Blood Volume in Chronic Fatigue Syndrome. *Journal of Chronic Fatigue Syndrome*, 4(1).



- Waaler, B. A. & Eriksen, M. (1992). Post prandial cardiovascular responses in man after ingestion of carbohydrate, protein or fat. *Acta Physiologica Scandinavica*, 146; 321-7.
- Waaler, B. A. Eriksen, M., & Janbu, T. (1990). The effect of a meal on cardiac output in man at rest and during exercise. *Acta Physiologica Scandinavica*, 140; 167-173.
- Waaler, B. A. & Toska, K. (1999). Fordøyelseskanalens store og vekslende behov for blodtilførsel. *Tidsskriftet for Den Norske Lægeforening*, 119(5); 664-6.

This document is provided for your information only and may not be construed as medical advice or instruction. No medical recommendations are given or implied. No action or inaction should be taken based solely on the contents of this information; instead, readers should consult appropriate health professionals on any matter relating to their health and well-being.

The information and opinions expressed here do not necessarily reflect the views of Invest in ME. The charity is not responsible for errors or omissions.

Please consult your own medical practitioner for the treatment of your personal symptoms.