

IS STRESS MORE THAN A MODERN BUZZ WORD?

By definition, stress represents any force, which threatens, or appears to threaten, the body's natural equilibrium. A certain amount of stress appears to be necessary, not only for keeping our stress reactions in working order, but to permit a musician, an athlete, an artist or a writer, for example, to give their best performance. Nevertheless, too much stress can work in the opposite direction and give rise to illness.

HOW MUCH STRESS IS TOO MUCH?

The human body has a natural capacity to produce glucose regulating steroids in response to stress, including cortisol (the natural form of Hydrocortisone), which organises glucose metabolism so that, in an emergency, vital supplies are redirected from less important organs to the brain. However, after the crisis has passed, there is a feedback mechanism which switches off production before the blood levels of cortisol become too high, producing serious side effects including an increase in blood pressure, suppression of the immune system and an alteration in normal glucose metabolism.

UNDER WHAT CIRCUMSTANCES CAN THIS STRESS MECHANISM FAIL?

The production of cortisol demands proper functioning and co-ordination of two important areas in the mid brain and of the small adrenal glands attached like triangular caps to both kidneys. In the mid-brain, the hypothalamus, which is responsible for homeostasis of the body by maintaining an equilibrium of its various functions and of tissue chemistry, co-ordinates production of ACTH (a hormone regulating the steroid output of the adrenal glands) with the pituitary, an endocrine gland attached to the hypothalamus and subject to its control in respect of hormone output. Damage to the hypothalamus, pituitary or adrenal glands will therefore interfere with normal stress responses.

- a) In ME where disturbance of hypothalamic/pituitary function in the brain decreases the response. This damage can clearly be demonstrated by low cortisol blood levels and by PET and SPECT scans of the mid brain ¹ showing low uptake of radioactive dye due to reduced cellular metabolism. It results in failure of transmission of the appropriate stress signal to normal adrenal glands (often referred to as depression of the HPA axis)² People with ME do not, therefore, respond normally to stress and may suffer a serious relapse in health following overwork or mental strain
- b) In depression there is a familiar tendency to over react to stress signals owing to failure of the normal switch off mechanism³. Although this may return naturally, patients with depression can suffer weeks, months or years of over reaction to stress with serious side effects including weight loss, dangerous mood swings with suicidal tendencies and retardation of activity and thought.
- c) Malignant invasion, serious infection or trauma to any part of the organs participating in the HPA axis will cause illnesses such as Cushing's syndrome or Addison's Disease which are sometimes confused with ME.

WHY IS ME SO OFTEN MISDIAGNOSED AS DEPRESSION IN MODERN MEDICAL PRACTICE?

There are two reasons for this:

- (1) The two illnesses may coincide since both are relatively common in the general population with a life long history of depression undoubtedly contract ME in addition. Under such circumstances depression must be considered the more serious of the two illnesses because

of the undoubted risk of suicide, but because of intolerance to commonly used antidepressant agents in patients with ME, treatment is a matter for experts.

- (2) Nowadays, the diagnosis of depression appears to be made entirely by the use of pre-set questionnaires (often referred to as ‘structured psychiatric instruments’) ⁴ which are not designed for use with medically ill populations and do not employ physical examinations or laboratory and other confirmatory tests, as in general medical practice. A normal physical examination and good history taking with additional confirmatory tests would readily disclose the following differences between depression and ME: (a) Fatigue – this is persistent and invariable (tired all the time) in depression compared with the highly variable course in ME (b) Distortion of the patient’s mood – in depression, this leads to persistent feelings of guilt and unrealistic morbid thoughts, including either to hyperactivity and flights of fancy or to suicidal preoccupation and torpor. Mood swings also occur in ME (especially during adolescence yet most sufferers not only retain their mental balance and sense of humour but also their intention to enjoy life and plan for the future (e) weight loss and anorexia are serious features of depression, though such patients can tolerate alcohol, while in ME, the reverse is generally true (f) the two illnesses have a different neuro-endocrine profile, especially in relation to cortisol blood levels (g) there are wide differences in motor co-ordination and exercise tolerance (h) using psychometric testing (a type of automated psychological test) there are vast differences between the two illnesses in respect of input and retrieval of memory, motor and mental speed and have often been self estimation of performance. (i) SPECT and PET scans of the brain in both illnesses compared indicating significant differences in the degree and site of metabolic under activity.

IN VIEW OF THE PHYSICAL, PSYCHOLOGICAL AND ENDOCRINE DIFFERENCES BETWEEN DEPRESSION AND ME, HOW CAN THE SAME MANAGEMENT BE EXPECTED TO SUCCEED IN BOTH?

Evidence indicates that it does not, except in one respect – since both illnesses are either precipitated (in the case of depression) or made worse (in the case of ME) by failure in the natural stress response, no therapy can be completely successful in either state without prior attention to removing the sufferer from a stressful situation. Apart from this, patients with depression differ in their response to therapy from patients with ME in the following respects:

1. Response to Exercise – whereas exercise, outdoor activity and, if possible, a full time job are undoubtedly therapeutic for patients with depression, most patients with ME already function at their energy limits, suffer distressing after effects following over exertion and (in approximately 1/3 cases) have metabolic defects of skeletal muscle⁵.
2. Response to cognitive behaviour therapy -whereas any regime which can encourage patients with depression to discard or distract their damaging unrealistic morbid thoughts is helpful, patients with ME are usually capable of greater insight and understanding about their illness. Unfortunately, ME sufferers are too often denied care in our society, so it is essential that they should remain as well informed as possible about treatment options and not ‘brainwashed’ into disbelieving their own symptoms.
3. Patients with ME are almost universally sensitive to the effects of alcohol and to other psycho active agents. Extreme caution is therefore required in the prescription of anti depressant or anti-psychotic drugs⁶. In the dosage recommended for psychiatric patents, such drugs have precipitated severe side effects (including temporal lobe epilepsy) in individual sufferers from ME.

BY WHAT MEANS CAN A YOUNG PERSON SUFFERING FROM ME AVOID UNDUE PHYSICAL OR MENTAL STRESS?

Granted that the average young person so affected is not in possession of vast wealth plus a retinue of servants, the following might be the scaffolding upon which a stress free environment could be built:

1. For the very ill – Rest and quiet are pre-requisites until the illness stabilises and all outside negotiations with school, college or work should be postponed if necessary. As a fragile yacht may tack in a stormy sea, aim only to survive one day at a time, changing course as the symptoms vary.
2. Accept from the start that the illness may be long lasting and require the adoption of a change in life style.
3. Be open to information and suggestions from those with ‘hands-on’ experience, if necessary by linking to a network of other young people.
4. Aim to set realistic targets for yourself (knowing how variable your illness can be) rather than adopting the unrealistic expectation of family members, friends or outside groups. Even the smallest achievement will then spell success and restore your self-esteem.
5. Seek to structure a stress free environment in which you can succeed. This will (of course) need delegation to family, or outside agencies of all the hassle and form filling that goes with financial and mobility support, home care and adaptations, or negotiations about home tuition, part-time school/college education/part-time employment or home working.
6. Be prepared to say ‘No!’ to unreasonable demands or interruptions when trying to rest, pursue hobbies or study. These must all be respected as vital therapeutic activities.
7. Many young people with ME especially recommended ‘furry therapy’. Pets of various species whether bearing fur, fins or feathers, yet small enough to adapt to a bedridden owner if necessary, will undoubtedly provide interest and a great deal of happiness.
8. Make sure that brief holiday breaks or treats are planned well in advance, so there is always something to look forward to. As many of these do not demand pre-payment they can be postponed rather than cancelled if you are not well enough at the time.
9. Do keep in touch with friends, peer groups and clubs if at all possible. Provided they respect the limitations of your illness, they have much to learn from you and, in this way, you can help to educate the general public as well as the medical and teaching professions about the serious problems of ME and stress.

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I LIKE WORK : IT FASCINATES ME!

In the absence of any specific medical treatment of lasting benefit that can, at present, be recommended to sufferers from ME, the main principles of management rely upon conservation of energy, reduction of stress and simplification of work. Of these, problems relating to work may well prove to be the most difficult to solve, especially in the case of young people.

Work has been defined as the application of energy to a principle and, since the most important principle of management in ME relates to conservation of energy, this valuable and scarce commodity needs to be applied sparingly and efficiently to making any job of work as simple and enjoyable as possible. Ill or well, we cannot afford to ignore work, though one's feelings towards it may be ambivalent – as concisely expressed in a book about 3 young men on a boating holiday ¹ “I like work; it fascinates me. I can sit and look at it for hours. I love keeping it by me; the idea of getting rid of it nearly breaks my heart”. I would therefore advise a young person with ME to formulate a “business plan” before embarking upon any major new activity – to include (a) the job description (b) the possible value of doing it (c) any problems likely to arise (d) practical solutions to these. Whereas the problems in (a) and (b) ought to be a matter of civil rights, as for any other disability (c) and (d) must be tailored to suit the very special difficulties encountered in this illness.

A JOB DESCRIPTION FOR ME

As for any other disability, this must be firmly based upon the art of the possible, and may range from just planning to sit up in bed or maintain independence at home to training in one of the arts or professions. Absolute pre-requisites include support from family/outside agencies as well as full information or previous experience relating to the job and the facility to negotiate flexitime. However, if you have a burning ambition and an enjoyable and easy opportunity to pursue it arises locally, do muster all available support and go for it.

WILL IT BE WORTH THE EFFORT?

Voltaire ² assures us that work banishes those three great evils; boredom, vice and poverty! Though sickness invariably accelerates the trend to poverty under current legislation, you may also lose out financially if already on benefit or if child care is required, to say nothing of deterioration in health due to travelling or over exertion. However, there is an unquantified benefit in terms of self esteem, status and social fulfilment and I would seriously recommend all ME sufferers to keep in practice and retain former skills, even if not completely fit, by making an initial effort from home or in the voluntary sector.

SPECIAL PROBLEMS RELATING TO ME AND SOME SOLUTIONS

Political and Social

The major disadvantage of this illness is not a medical one but relates to a social climate of opinion in the media and medical press, which ascribes this serious neurological disability to some type of “personality disorder” rather than to underlying organic causes, of which we now have overwhelming research evidence. While this monstrous distortion of the facts blames the patient for deliberately causing and maintaining the illness, it conveniently absolves the statutory caring agencies from caring. Patients and carers therefore must bear the heavy burden of educating these agencies (including the medical and teaching professions) while attempting to solve the problem of re-entry into education, training and work as required by government policy. Simplification of this process (if at all possible) may require contact with the following agencies. The local CAB (Citizens Advice Bureau which can supply free legal aid); GP (who is the gateway to the social services, mobility aids, including wheelchairs and disabled parking (for help with form filling and employment rights); physically handicapped associations and British Red Cross (equipment, holiday concessions, handbooks detailing local facilities for disabled people ³); Social Services (home care, and adaptations, stair lift etc); Medical charities and self help groups (guidelines for doctors and teachers⁴. general welfare advice ⁵); ME youth groups (contact with peer group, internet facilities etc ⁶); Educational Authorities (Exam concessions and modified tuition). NB. One visit to your library will provide information on all the above, apart from holding lists of agencies supplying advice on housing, marriage and personal problems and offering access to mobile libraries and talking books. Your local MP should always be kept informed of any difficulty.

Medical

Though ME is classified as a neurological illness, (with variable involvement of other body systems) it differs from similar disabilities (e.g. MS) because of the daily fluctuations in mental and physical energy, which may mislead the casual observer into mistaking it for a trivial condition. There is, however, sound evidence of fluctuations of metabolism in the brain stem, mid brain and temporal, parietal and frontal areas of the cerebral cortex ⁷ with delayed recovery following physical or mental overexertion. This leads to impairment of brain function in respect of short term memory, verbal and mathematical ability, fine motor control (e.g. of handwriting) balance, appreciation of shape and distance as well as subtle alterations vision and hearing, all of which may improve with rest and removal of stress. In addition to these “cognitive” problems, there may be generalised pain (including severe headache) persistent nausea, bowel and bladder problems and a reversal of the normal daily sleep/waking cycle, all of which may require special concessions during school, training or work. It must be emphasised that the management of this fluctuating illness, with sensitivity and full support from the onset, encourages progress towards stabilisation.

SUGGESTED MANAGEMENT TO SIMPLIFY WORK AND ENCOURAGE STABILISATION

This maybe summarised briefly according to the following stages of the illness (1) Bedridden, housebound or able only for learning or work at home (2) able for part or full time school attendance (3) able for part or full time college or work training (4) able for part or full time employment outside home.

OBJECTIVES	MAJOR PROBLEMS	POSSIBLE SOLUTION
(1) Securing as much independence in the home as possible. Obtaining educational material or aids to work from bed or home	Financial Provision of care & home conversions Boredom Isolation	State benefits & social Services, education authorities for home tuition/”Education Otherwise” Open University. Grants for equipment Computer/access to Internet. Pets, hobbies
(2) Re-integration into school on a gradual basis, without undue stress or exam pressure. Contact with peer group. Recreation	*Mobility, over exertion. Requirement for exam concessions for support & understanding from teachers.	Arrange transport, school bus pass, and wheelchair access, as required. Guidelines on ME for staff and information for pupils. Modified timetable, spacing of exams. Join social club or attend social events.
(3) Continuing education/ training after 16 years.	Financial *Mobility/over exertion Self care away from home	Contact education authority for financial support for student (and carer if required). Aim to get college place near home or accommodation on the campus. Consider open university. Register with GP.
(4) Flexitime if possible. Avoid jobs requiring routine immunisations and exposure to infection Aim at graded career Progression without exam stress.	*Mobility/over exertion. Self care away from home.	Apply for disabled parking badge. Liase with Occupational Health Service with guidelines on ME if available. Avoid using up holiday entitlement in lieu of sick leave

NB *Mobility includes access to premises, parking facilities, disabled parking badge, wheelchair or modified vehicle.

SUMMARY

I have knowingly omitted the most important job of all from this study - bringing up children. The majority of ME parents do this marvellously, but forward planning to avoid unwanted pregnancy during illness, combined with special advice on nutrition, labour and after care of the baby as well as family support in early years, is essential. In this fluctuating illness, the risk of relapse may be lifelong but most patients who are well informed and experienced in self management can derive confidence from their ability to recover from most of these set backs. During some 35 years of follow up, I **can quote** many examples of patients who have achieved high grades in the arts, entertainment and the media as well as university degrees and become writers, researchers, psychologists, accountants, computer experts, home tutors and excellent cooks! With the technology now available (if shared equitably between all disabilities) young people with ME could and should avoid the most serious disability inflicted upon them by a sadly misled and seemingly uncaring society – a potentially avoidable loss of education and training for work. Is there anyone out there prepared to fund education research?

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