

WHAT EXACTLY IS THE CHRONIC FATIGUE CONDITION CALLED ME? THREE DOCTORS GIVE THEIR OPINIONS

An illness that starts in the mind

Jane, a lawyer in her early twenties, should have had the world at her feet. But her life has been affected by such a long period of ill health that it now seems that the career she had planned may be beyond her grasp.

Sensitive, but forceful and obviously bright, it seemed hard to believe when I saw her that she had just had a year off work followed by a further six months working only part-time. Jane had ME (myalgic encephalomyelitis), a diagnosis made by her general practitioner as a result of having been told about her lassitude.

In Jane's case, her lassitude was less a weariness, more an overpowering exhaustion so that what strength she had was so readily drained that she had to lie down after an hour's shopping. Climbing the stairs was an undertaking not to be tackled too often.

Jane had been signed off work, prescribed complete rest and had

been told to leave certain items out of her diet. With the help of this regime and her doctor's encouragement, she was, 18 months later, fit to return to full-time work.

On closer questioning, it transpired that both Jane's mother and father had histories of severe depressive illness, which had responded to traditional treatment. Her sister is at present an in-patient in a psychiatric hospital. Jane herself has had two previous episodes of ill-health. In her teens when at school she had become depressed. The school doctor had treated her with anti-depressants so that, without taking time off, she was back to her old self within a few weeks. A similar episode when she was at university was dealt with equally quickly.

Can anybody really believe that Jane's illness is different now than it was previously, or that it has a different aetiology from that of the rest of her family? It is possible that her career has not so much been undermined by the strange disease ME, but by the excessive enthusiasm of her GP to diagnose it. The diagnosis is one that cannot as yet be substantiated by any objective clinical test. Such changes in the metabolism or circulation as do occur could equally well be found in other patients whose lifestyle and metabolism had been altered by depression.

The history of the discovery of ME is different from that of other diseases. The clamour for its acceptance as a distinct entity has not been from earnest scientists or



DR THOMAS STUTTAFORD

doctors who have spent years peering down microscopes, walking the wards and studying statistics as they unravel its origins and pathology.

In the case of ME, it is the patients with an intense interest and knowledge of their own symptoms, and those of their associates,

who have fought to have ME acknowledged. They have done so with no scientific foundation on which to rest this knowledge, nor the privilege of having other patients with whom their symptoms could be compared.

The patients' campaign, sometimes aggressive and strident, initially persuaded some sections of the lay press, and now some doctors, to accept that they are suffering from what is primarily a physical disease, with secondary psychiatric complications; rather than a psychiatric disease in which physical symptoms predominate.

Even before ME became a fashionable diagnosis, it was difficult for doctors to persuade patients that depressive illness is often associated with bodily symptoms.

Dr Michael Gelder writing on depression in *The Oxford Textbook of Medicine*, the standard British textbook, goes so far as to say that physical symptoms — lack of appetite, weight loss, constipation, menstrual disturbances, general feelings of ill-health and discomfort and pain in the limbs — are the most common way in which a general physician will be confronted by depression.

Dr Gelder cites two other ways in which depression appears physically. Either the low mood can make previously tolerable pains from existing physical disease intolerable, or the change in lifestyle engendered by the depression affects the patient's physical health — complete rest for months at a time is unlikely to do much for

anybody's sense of well-being.

ME sufferers often say that in 50 per cent of the cases of the disease the symptoms do not fit the classification of depression by the World Health Organisation. However, this classification includes the extraordinary proviso that the patient should admit to feeling depressed. Many patients who are depressed prefer subconsciously to attribute their problems to the worsening of any physical signs or symptoms they may have rather than to acknowledge that they have a psychiatric problem.

No doctor minds what a patient wants to call his or her disease. Most appreciate that the attribution of a label to the disease is an all-important part of the treatment. Doctors do, however, want patients to get better and are concerned when, as a result of a misdiagnosis, some people, such as Jane, are denied the treatment which could prevent many months of misery.

Don't swallow the myth

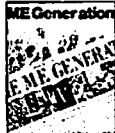
Too much ME propaganda spreads despair, argues Simon Wessely

Last week I was telephoned by the BBC programme *Points of View* for my reaction to the production of *Wide-Eyed and Legless* (BBC1, September 5), widely reported as a play about ME. I said that much as I admired the performances of Julie Walters and the peerless Jim Broadbent, the play overstepped the line between fact and propaganda. As is usual when anyone deviates from the party line on ME, I spent a sleepless night anticipating the inevitable hostile barrage of letters. I needn't have worried. *Points of View* ignored my comments, preferring instead letters

Maudsley Hospital. Epilepsy has nothing to do with ME. Viewers saw her developing progressive painful contractions leading to claw hands. These are not part of ME, unless the illness is grossly mismanaged. It is questionable whether the central character had the disease at all, whatever it may be.

Wide-Eyed and Legless is another part of the myths surrounding ME. ME is not a progressive disease of the neu-

romuscular system. The muscles themselves can function normally. There is no evidence of inflammation of the brain or spinal cord, as implied by the term encephalomy-



Child patients need sympathy

Even four-year olds can suffer this debilitating and frustrating condition

The youngest of my ME patients, Emma, was four when her parents brought her because of her profound tiredness, her unwillingness to walk anywhere and her uncharacteristic lack of enthusiasm for her much-loved nursery school. At the time the term ME had not been coined. Most of us had heard of Royal Free disease, the epidemic that hit the nurses at that hospital in 1966, and some of us had read the distressing accounts in the magazine *World Medicine* of those still not fully recovered after 20 years; but this mysterious condition seemed to have little relevance to sick children.

When I saw Emma, in 1977, we made unsuccessful efforts to try to track down a cause. Her mother reminded me that when she had been a junior nurse at my teaching hospital in 1966, she herself had been ill for nine months with an undiagnosed illness which she thought was identical to her daughter's. Eventually her parents and I decided to stop investigations, stop trying to

ted by her cat. Usually, though, tests draw a blank.

No diagnosis in paediatrics should ever be in physical terms alone. The story is incomplete without diagnoses in social, emotional and family terms. I don't see illness as either physical or psychological but always having elements of both. And, of course, any child with a debilitating chronic illness is entitled to become depressed eventually.

Some doctors make a fundamental error (not just in ME) of performing lots of investigations, finding nothing positive and then suggesting a psychiatric opinion. Nothing could be more calculated to make patients bewildered, insulted or angry. I ask parents at our second consultation if a psychiatric colleague might assess what is going on. I cannot remember a refusal and the commonest report is that I am dealing with a family without significant mental health or relationship problems.

Conflict can arise when a family that does have these disadvantages contains a child

praising the progress-
ion for the good it
will bring ME suf-
ferers.

The play, written
by Deric Longden and
Julie Walters, is a
struggle of his wife Diana
with a mysterious illness
which left her progressively
disabled and in a wheelchair.
Despite the wit of Jack
Rosenthal's script, it was a
brilliant portrayal of relentless
disability. The only question
was whether or not the central
character would die of the
disease or take her own life.
The ending, in which she was
found dead in the bath, was
ambiguous.

Without exception every
newspaper trailer for the pro-
gramme included the informa-
tion that this was a play about
ME. Several soundings it con-
cerned a "terminal" case of
ME. A high-profile screening
was arranged by the pressure
group, Action on ME. On which
the play was based said the
same. But was it?

In one scene the Julie Wal-
ters character is seen having
an epileptic convulsion while
being investigated at the



Jim Broadbent as Deric Longden and Julie Walters as his wife, Diana, in the BBC play, *Wide-Eyed and Legless*

believing you have an incur-
able progressive condition,
even when it is not, worsens
disability and prevents recov-
ery.

The real prognosis for CFS,
ME or whatever we wish to
call it, is far removed from that
visited upon Diana Longden.
Although the self-help litera-
ture often suggests that after

Moderate exercise rather than bed rest is the best treatment

two years of illness, recovery is
unlikely, this is untrue. Our
own studies at the National
Hospital for Neurology and
King's College Hospital show
that recovery can occur after
many years of illness.

It is also suggested that the
illness is untreatable, and all
that sufferers can do is wait for
a medical breakthrough. This
too is untrue. As with any
chronic disease, sensible reha-
bilitation reverts the effort.

As depression is common
affecting at least half of all
sufferers, and is the only cause
of death, there is no excuse for
doctors failing to diagnose or
treat it. This is particularly
important since studies are

emerging that suggest that
antidepressants are effective
even in sufferers who are not
depressed, perhaps because of
neurochemical overlaps be-
tween depression and ME.

Another myth about ME is
that the best treatment is rest.
In the early days, when suffer-
ers are still struggling with an
acute viral infection, this may
be true. I frequently see pa-
tients who continue to main-
tain an active, and often
overactive, lifestyle during an
episode of influenza when
most of us would have spent a
week in bed. However, in the
long-term over-exertion advice
to rest does more harm than
good. Everyday spent in bed
causes a measurable decline in
muscle structure and function,
which will be reflected in
progressive fatigue and weak-
ness. The psychological conse-
quences of prolonged bed rest,
including helplessness, fear
and depression, are equally
serious. Enthusiastic exercise
programmes may be too ambi-
tious for an exhausted suffer-
er, but slow, cautious and
predictable increases in activi-
ty are rapidly becoming the
mainstay of medical treat-
ment.

For many, however,
conventional medicine
seems to have little to
offer. Sometimes this
is because doctors find dealing
with chronic, ill-defined ill-
nesses difficult. Sometimes
sufferers reject conventional
treatments seen as psychologi-
cal. For many the only treat-
ment comes from unconven-
tional medicine. Some of these
approaches have helped pa-
tients I have seen, perhaps by
restoring faith and optimism.
But others seem to be the
cynical exploitation of the dis-
tress.

This is nothing new. Con-
trary to popular opinion, ME
is far from a new disease. Its
predecessor, neurasthenia, at-
tracted even more attention

coax her back to part-time
nursery and just wait. About
nine months after her illness
began, Emma was restored to
health over a weekend.

Nowadays I see four or five
such patients every year in my
clinic, which serves 25,000
children. They come in all
ages, shapes and sizes, in all
middle-class and working-
class families. GCSE candi-
dates and primary school
children.

They have headaches and
limb pains, sometimes stom-
ach pains and nausea; they are
easily exhausted; they can no
longer cycle and their walking
becomes slow and interrupted
because of profound fatigue.

They cannot concentrate on
school work and their sleep
pattern is disrupted but, un-
like depressives, they usually
eat well, gain weight and can
be persuaded without much
effort to smile; they register
irritation and frustration with
their illness rather than ap-
athy and resignation — at least
in the early stages.

The first time I see them I try
not to jump to what might
seem the obvious conclusion.
Some need special tests — the
child whose school perfor-
mance and personality have
changed may need a brain
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Simon Wessely is senior lecturer
in psychological medicine at
King's College Hospital.

with a chronic fatigue state. Is
there a connection or is it a
coincidence? The same might
be said when one comes across
the many families with major
allergic problems.

After rolling out danger-
ous and potentially
treatable conditions,
offer us full an explanation as I
can, provide — with a physio-
therapist colleague — a plan of
campaign consistency to keep
up physical fitness but actual-
ly to keep fit, morale, and
negotiate with teachers and
educational psychologists on
how to do their best for the sick
child.

There are fashionable me-
trics, of course. They come
and go so rapidly that it is
clear that none provides an
answer. From time to time I
have used some of them —
diets, injections of magne-
sium, or capsules of the anti-
allergic preparation cromo-
glycate; sometimes a child
seems to do well, mostly not.
I remain sceptical of the claims
made for them. Alternative
practitioners seem to do at
least as well, and no better but can
be persuaded without much
effort to smile; they register
irritation and frustration with
their illness rather than ap-
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