

Putting exercise through its paces

A new study has rekindled controversy over the treatment of chronic fatigue syndrome

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A PROMISING career as a barrister awaited Peter Evans until, at 27, he was struck down by a virus.

The incident began a 17-year period of peaks and troughs in mood, energy and general health: a pattern all too familiar to the roughly 180,000 Australians suffering from chronic fatigue syndrome, also known as myalgic encephalomyelitis.

Evans — who was previously active and healthy — has had his life upended by his illness. He has been left with repetitive bouts of poor sleep and problems with memory and concentration, in addition to the near-continuous fatigue associated with ME-CFS.

Despite a three-year period of improvement, Evans, of Brisbane, relapsed in 2004.

"Now I can only do a very small amount of part-time work," he says. Evans lives under financial constraints and has found forming long-lasting relationships nigh-on impossible. He has no children.

ME-CFS is generally defined by persistent fatigue unrelated to, but often worsened by, exertion, with other possible symptoms, for at least six months. The condition has long been controversial, in part because of disputes over whether its cause is physiological, psychological or both.

Now patients such as Evans, and the organisations that represent them, are up in arms over results from a recently published landmark trial that they say could lead to patients receiving treatments that make them worse instead of better.

Some patients fear the \$8 million PACE trial, published in British medical journal *The Lancet* earlier this year, will put pressure on sufferers to be more physically active than is good for them, possibly causing relapse.

The trial looked at 640 British

patients, who all received specialist medical care with a hospital-based specialist.

They then received one of three treatments on top of this.

The first, adaptive pacing therapy, generally preferred by ME-CFS patients groups, encourages patients to fit their activity level to their energy limits, identifying and so avoiding activities that worsen their symptoms.

The second, cognitive behavioural therapy, is based on the premise that a fear of engaging in activity, and avoidance of activity interact with physiological processes to perpetuate fatigue.

The third treatment, graded exercise therapy, helps patients to gradually rebuild their physical capability through increasing exercise.

A fourth group received only specialist medical care.

Sixty per cent of patients who had cognitive behavioural therapy or exercise therapy improved, and about one-third recovered sufficiently to lead normal lives, twice as many as in the pacing therapy group.

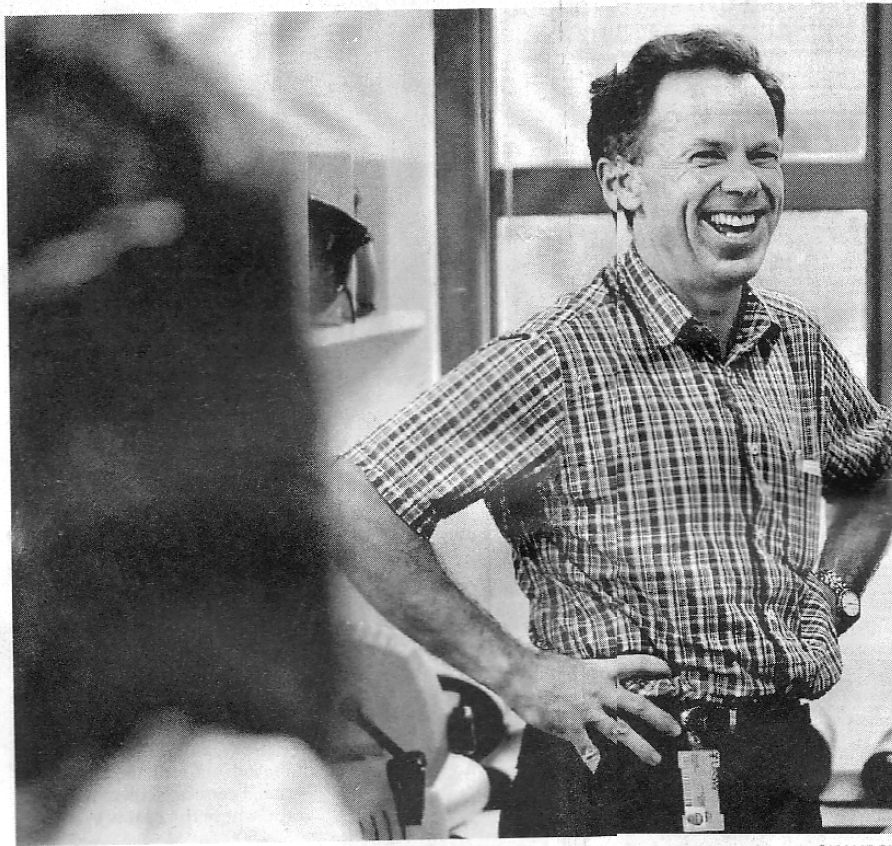
Serious adverse reactions to treatment were very low in all groups, proving, the authors say, the treatments are equally safe.

Patient groups have been mostly but not universally negative. In Britain, Action for ME disputes the findings, but the Association of Young People with ME welcomes them.

Penny Abrahams, the chief executive of ME-CFS Australia, has many criticisms of PACE.

She says the study used little-known guidelines to select patients instead of more condition-specific Canadian guidelines that exclude patients with anxiety and depression. This meant participants did not necessarily have ME-CFS.

Abrahams says the Oxford



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guidelines included patients with anxiety or depression, despite the fact both conditions can cause fatigue and are helped by exercise therapy and cognitive therapy — potentially skewing the findings in favour of these treatments.

One of the PACE authors, Michael Sharpe of the University of Edinburgh, counters that the Oxford criteria have been used frequently in treatment research, are simple and require chronic disabling fatigue as the main symptom.

Sharpe agrees that many patients in PACE were anxious or depressed, but says the study found a similar treatment response in patients who did not have

these psychiatric diagnoses.

"This suggests that the criteria used do not determine response to these treatments," he says.

Critics warn that the PACE findings cannot be applied to all patients because they excluded severely affected housebound patients, and children.

"It would be reasonable to expect that all groups within the ME-CFS population would have been included," Abrahams says.

But Andrew Lloyd, who runs the fatigue section of the Lifestyle Clinic at the University of NSW, believes that PACE is representative of at least three-quarters of ME-CFS patients in Australia, namely young or middle-aged adults

who are not housebound. Lloyd is generally positive about PACE but has reservations: the moderate benefit and the overlapping of the three therapies making it hard to conclude some are better or worse than others.

His clinic provides a 12-week individualised and mostly home-based program. A psychologist assesses fatigue, mood, sleep disturbance and pain, and an exercise physiologist does a functional assessment.

Lloyd is surprised at the negative reaction to PACE from ME-CFS Australia.

"Our clinic has been oversubscribed, so it's clear that patients are benefiting from these treatments," he says.

Lloyd believes any harm comes from patients not sticking to their agreed plan.

Abrahams and Evans disagree, and say there are countless examples of people following their plan, then crashing with even worse symptoms.

Christine Hunter of the Alison Hunter Memorial Foundation, an advocacy organisation, says PACE's findings reflect the fact it is easier to get funding for public psychiatric-based research than more expensive biomedical research.

"As a physiotherapist, I know that many people with ME could not enrol in an exercise program," Hunter says.

"PACE participants agreed they were willing to exercise, and this influences the findings."

Lloyd says the relative lack of government funding for ME-CFS stems partly from highly competitive grant tendering to the National Health and Medical Research Council.

"A lot of ME-CFS research proposals don't stand up," he says. "ME-CFS also lacks a critical mass of big-name researchers prepared to fully commit to researching it."

Future priorities have been outlined by the International ME Research Collaboration, comprising experts in neuroscience, immunology, primary care and public health.