

Consumers as leaders in choosing wisely: a case study

Graded Exercise Therapy (GET) for ME/CFS

Effective? NO

Harmful? YES

Still recommended in the US? NO

Still recommended in the UK? Maybe

Still recommended in Australia? YES



[Before and after ME/CFS](#)

When consumers face pressure to accept a treatment that is suspected of being low value and known anecdotally to cause harm, how might they engage with the scientific and clinical communities to influence change? People around the world with the disabling neuroimmune condition [ME/CFS](#) (Myalgic Encephalomyelitis, also known as Chronic Fatigue Syndrome) have done just that.

Consumers as documenters of science

What can consumers do when the science is compelling, but the clinicians, professional associations and clinical educators do not recognise or act on the science?

Australian consumer, Simone Eyssens, comprehensively documented the science and laid it out in a coherent form for use by patients, clinicians, educators and government agencies.

For an overview, read pp2-3.

[PEM-GET Primer](#)



Consumers as seekers of data

What can consumers do when the data in a highly influential journal article is clearly misleading and further errors are suspected?

- “...more than [30 requests](#) to see the data under the Freedom of Information Act and still the data was not public.”
- [On what basis](#) did the university claim the data could not be released? And on what basis was that overturned?
- What is the [impact on a consumer](#) whose illness is defined by exertion intolerance, when they persevere through court appeals to the successful data release ruling, while fighting against £250,000 of legal expenses by the university holding the data?

Consumers as peer reviewed authors

Examples of journal articles:

[Oct 2014](#) Assessment of recovery status in chronic fatigue syndrome using normative data.

[April 2016](#) The biological challenge of myalgic encephalomyelitis/chronic fatigue syndrome: a solvable problem

[Dec 2016](#) Can patients with chronic fatigue syndrome really recover after graded exercise or cognitive behavioural therapy? A critical commentary and preliminary re-analysis of the PACE trial

[March 2017](#) Do graded activity therapies cause harm in chronic fatigue syndrome?

[March 2018](#) Rethinking the treatment of chronic fatigue syndrome—a reanalysis and evaluation of findings from a recent major trial of graded exercise and CBT

[Aug 2017](#) - **Journal of Health Psychology Special issue on the PACE trial**, with several consumer authored and co-authored articles, including Australian, Susanna [Agardy](#)

Examples of letters to journals:

[May 2011](#) The PACE Trial in chronic fatigue syndrome: [Tom Kindlon](#); [Sarah Feehan](#); [John Mitchell](#); [Andrew Kewley](#)

[Dec 2015](#) Treatment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

[Jan 2015](#) Re: Tackling fears about exercise is important for ME treatment, analysis indicates

Consumers as drivers of change

- Consumers crowd-fund investigative journalist, David Tuller, to continue his [reporting](#) on PACE.
- Biomedical research is crowd-funded to create an alternative narrative to PACE, for example OMF [Big Data study](#); and patients provide their own privately funded data to studies, for example [ME/CFS Genes Study](#).
- Major petitions are delivered, including a successful UK [call for review](#) of NICE guidelines, which include GET; and an international [call for retraction](#) of claims in *Lancet* and *Psych Med*.
- #MillionsMissing [social media campaign](#), Australia 2018, targets GET.
- Media support is sought, for example SBS [The Feed](#).
- Consumers publish books, including [Through the Shadowlands](#).
- Cort Johnson's [Health Rising](#) blog explains the emerging science.
- Patient led, crowd-funded documentaries, including [Unrest](#), challenge the psychosocial view of ME/CFS.



Change: now and in the future

Major international changes to date:

- July 2016: [AHRQ downgrades evidence](#) for GET to unsupported.
- July 2017: CDC removes GET from its [recommendations](#).
- September 2017: NIH agrees to [fund](#) biomedical research that requires [PEM](#) as a prerequisite for participant cohorts.
- January 2018: NICE agrees to [review](#) its recommendations for ME/CFS, that currently include GET.

Changes currently sought in Australia:

- Updating of RACGP website information, including removal of GET recommendations and PACE materials from the [HANDI guide](#) for CFS.
- Public acknowledgement from the Chief Medical Officer that GET for ME/CFS is not supported by the evidence and is potentially harmful.
- NHMRC funding for biomedical research that leads toward effective and safe therapies for ME/CFS.
- Education for undergraduate and practicing health clinicians on ME/CFS and the implications of PEM for management of the condition.
- Updating of Centrelink and NDIA assessor reference materials to indicate that GET is not an effective treatment and therefore is not an appropriate prerequisite for ME/CFS applicants seeking services and supports.

Question: What future roles might Choosing Wisely members take in supporting consumer led investigations into disputed therapies and promulgating the consumers' findings?