

### What are GET and CBT?

- Graded exercise therapy (GET) and Cognitive behaviour therapy (CBT) are symptom management approaches recommended by the 2007 National Institute of Health and Care Excellence (NICE) guideline for M.E./CFS (undergoing extensive review, with a new guideline expected in December 2020).
- There is much debate and discussion about these approaches – and the published evidence for them – as to whether or not they work, and whether they may cause harm.
- Our response to NICE's October 2019 call for evidence made it clear that we do not support the current guideline's view that CBT and GET "are the interventions for which there is the clearest research evidence of benefit" because of the legitimate questions raised about their safety and effectiveness.

### What is M.E.?

- Myalgic Encephalomyelitis (M.E.) is a long-term, fluctuating, neurological condition affecting many body systems.
- Within the NHS, a diagnosis of chronic fatigue syndrome (CFS) or M.E./CFS is often given.
- Everyone who experiences M.E. has a different pattern of illness, and symptoms and severity can fluctuate and change over time. One in four people with M.E. are severely affected, ie. house and/or bed-bound.
- People with M.E. experience debilitating pain, fatigue and a range of other symptoms linked to post-exertional malaise.

### What did our Big Survey find?

- One in three (33%) respondents who completed our survey had tried GET in the past five years.
- More respondents (40%) had tried CBT in the past five years.
- See next page for more detailed results.

*"I did CBT and found it to be very helpful with depression and anxiety caused by M.E. Both myself and the professional I was working with agreed it would be futile to try and use it to try and deal with the physical symptoms of M.E."*  
Male, 32, Bournemouth

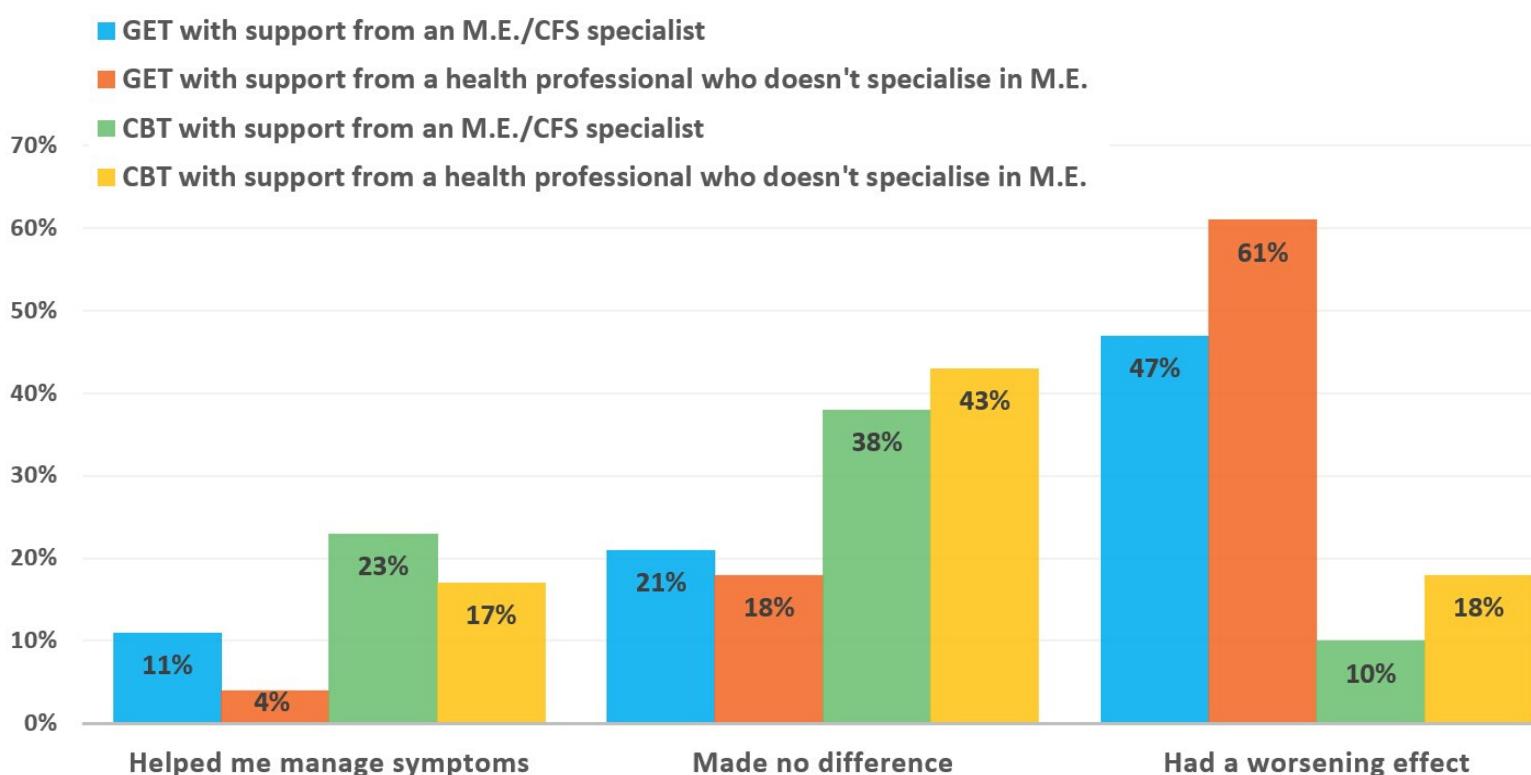
*"I did GET and after 3 months it left me severely affected, house-bound, bed-bound half the day and unable to have visitors. All my symptoms worsened and I have lots of new symptoms too."* Female, 39, Liverpool

### What is Action for M.E.'s Big Survey?

- Between May and August 2019, UK charity Action for M.E. surveyed more than 4,000 young people and adults with M.E.
- We asked about diagnosis, education and employment, health and social care, symptom management and Universal Credit.
- Nearly two thirds of respondents were 40 years or older; 5% were under 18.
- There was a ratio of one to five male to female respondents; nearly 90% had been ill for four years or more.
- 99% said they experience post-exertional malaise either always, usually or sometimes.
- 96% were White British, Irish or other. 82% of respondents were from England, 12% from Scotland, 5% from Wales and 2% from Northern Ireland.

We asked survey respondents who tried GET and CBT to select a series of statements they agreed with including:

**Who supported you to try it and what effect did it have on your symptoms?**



Even when people are supported by an M.E. specialist, only one in 10 reported that GET helped manage symptoms, while nearly half reported a worsening effect. CBT makes no difference in almost half of cases and had a worsening effect for one in five.

Our Big Survey showed that treatment outcomes are most likely to have a worsening effect:

- when people are supported by a healthcare professional who does not specialise in M.E.
- when people do not feel like an equal partner in their treatment
- for those respondents (almost one in four) who said that the professional they worked with did not understand how M.E. affects them.

**The symptom management approach that the majority of people with M.E. consistently tell us offers them the most benefit is pacing.**

Pacing is a way of carefully managing physical, mental and emotional activity and rest to avoid post-exertional malaise. Find out more at [www.actionforme.org.uk/pacing](http://www.actionforme.org.uk/pacing)

Action for M.E. takes action to end the ignorance, injustice and neglect faced by people with M.E.  
We meet need now to improve lives while taking action to secure change for the future.

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# Living with the impact of M.E.

Action for M.E.'s Big Survey: two-page explainer

## What is M.E.?

- Myalgic Encephalomyelitis (M.E.) is a long-term, fluctuating, neurological condition affecting many body systems.
- Within the NHS, it is diagnosed as chronic fatigue syndrome (CFS) or M.E./CFS.
- Everyone who experiences M.E. has a different pattern of illness, and symptoms and severity fluctuate and change over time.
- People with M.E. experience debilitating pain, fatigue and other symptoms linked to post-exertional malaise, a cardinal symptom of M.E.
- Around one in four people with M.E. are severely affected by the condition, ie. bed-and/or house-bound.

*"The hardest part is the psychological impact of knowing that no-one (family, friends & colleagues) understands what it means for me personally to live with M.E./CFS."* Mark, Brighton

*"If teachers and doctors had more knowledge on realistic life with M.E., things would be so much easier. It was heartbreaking to hear someone who is supposed to understand me the most dismiss my symptoms."*

Young person, London

*"I had to hide severity from my employer at first as it was difficult to get them to understand without having a diagnosis. It was so much easier with diagnosis as there is clarity on the condition and limitations."*

Phillip, London

*"Learning to listen to your body, to trust what it tells you and to act in a responsible way to its messages, enables more than simple activity; it allows you to feel more in control, have greater self respect and self worth."*

Julie, Worcestershire

## What did our Big Survey find?

- One in four survey (25%) respondents said they were severely affected, with 62% saying moderately affected and 13% saying mildly affected.
- Just 7% of children and young people and 16% of adults are obtaining a diagnosis within the NICE guideline timescale of three months and four months respectively. Almost one in five adults (18%) waited more than six years for a diagnosis.
- Three quarters (77%) said they are unable to work because of the impact of M.E.
- Of those respondents who said they are supported by a carer, almost all (89%) said the carer was a family member, most of whom (84%) receive no financial support at all. One in ten respondents (10%) pay privately for care.

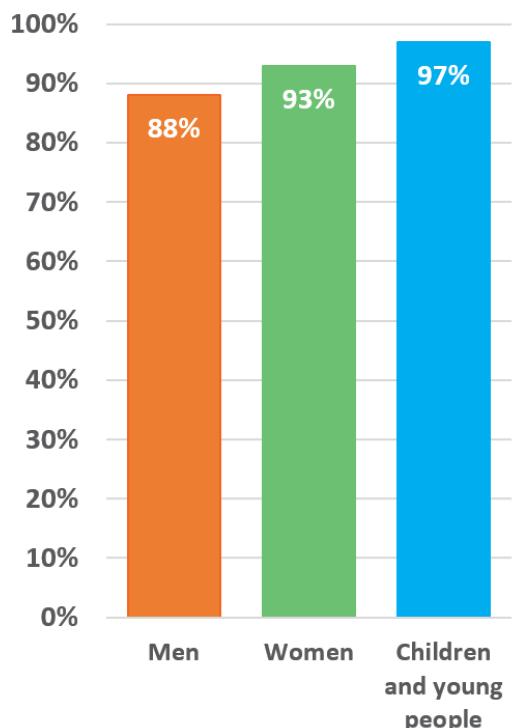
## What is Action for M.E.'s Big Survey?

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- We asked about diagnosis, education and employment, health and social care, symptom management and Universal Credit.
- Nearly two thirds of respondents were 40 years or older; 5% were under 18.
- There was a ratio of one to five male to female respondents; nearly 90% had been ill for four years or more.
- 99% said they experience post-exertional malaise either always, usually or sometimes.
- 96% were White British, Irish or other. 82% of respondents were from England, 12% from Scotland, 5% from Wales and 2% from Northern Ireland.

### We asked: what impact has M.E./CFS had on your life?



### Those who said they feel socially isolated because of their condition



### We asked: how confident are you that your GP understands M.E.?



Respondents who said they **don't** feel socially isolated were more likely to have mild (30%) or moderate (66%) M.E.

### What support is needed?

- Three in four people said that they are in need of support to access more appropriate or different health or social care services.
- Almost half need support to challenge a decision relating to welfare benefits.
- one in five need support to have their views represented to their employer to make work more accessible for them.

Action for M.E. takes action to end the ignorance, injustice and neglect faced by people with M.E.  
We meet now to improve lives while taking action to secure change for the future.

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# Pacing for people with M.E.

Action for M.E.'s Big Survey: two-page explainer

## What is pacing?

- Pacing is a self-management technique, and should not be seen as a treatment but more as a way of coping with the impact of M.E.
- For some, activity may be very minimal (especially for those who are severely affected), such as sitting up in bed, yet still have a considerable impact on energy and symptoms. This can also refer to mental and emotional activity.
- Pacing as a practice involves indentifying your activity and post-exertional malaise patterns, then modifying or reducing your activity levels in response to this.
- This is the symptom management approach that the majority of people with M.E. consistently tell us offers them the most benefit.

Find out more about pacing at  
[www.actionforme.org.uk/pacing](http://www.actionforme.org.uk/pacing)

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- People with M.E. experience debilitating pain, fatigue and a range of other symptoms linked to post-exertional malaise.

## What did our Big Survey find?

- Almost 9 in 10 (88%) respondents who completed our survey had tried pacing in the past five years.
- This is an increase from 75% in our 2014 Time to Deliver survey.
- See next page for more detailed results.

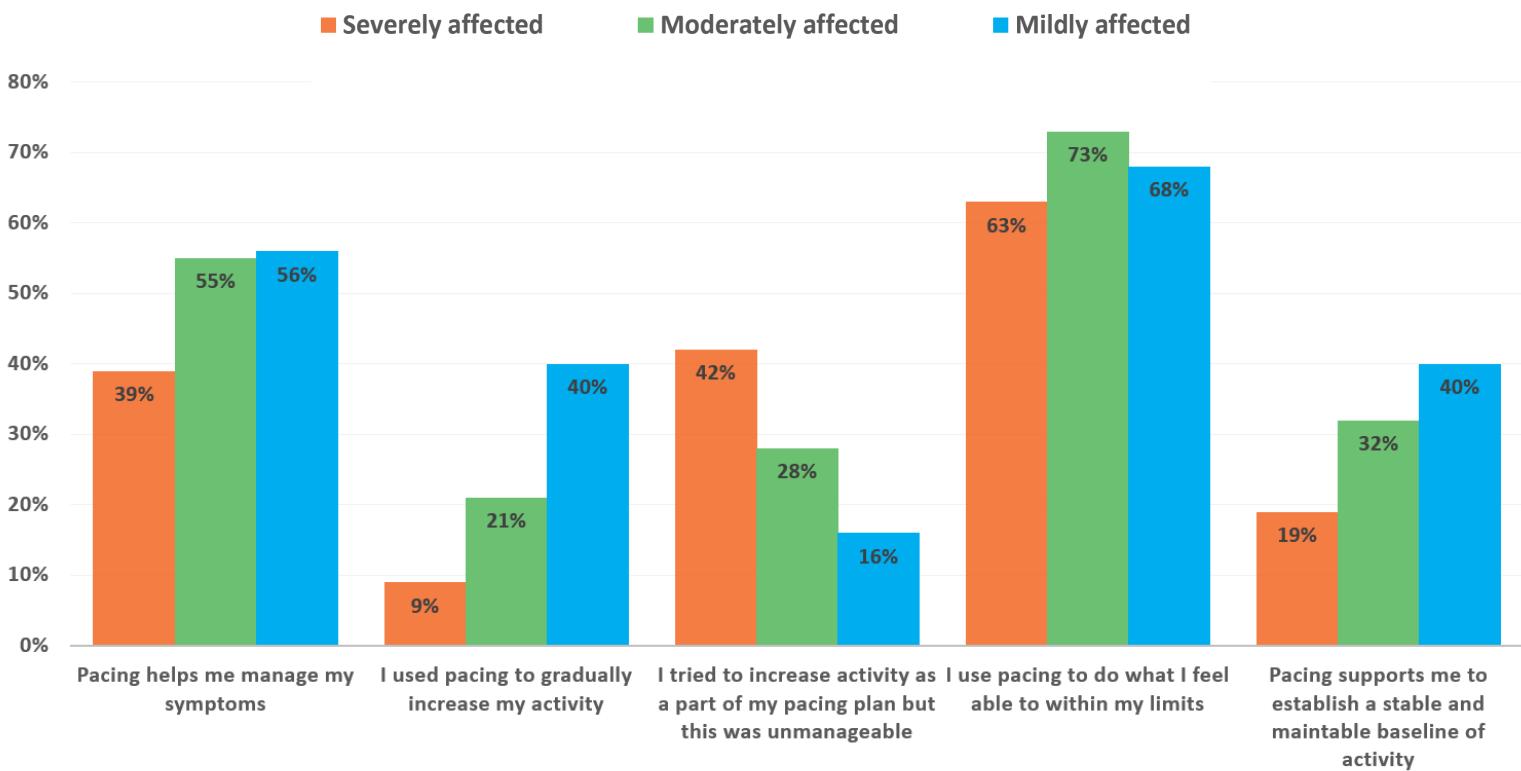
*"Pacing has become ingrained into mine and my family's lives. My wife and carers manage my activity and my wife makes plans, always considering pacing. Although I do not keep a pacing diary anymore, when I was first starting pacing, I did religiously."*

*"I tend to be the type of person who tries to do too much, so if anything, trying to pace myself has taught me how to listen better to my body and manage my own expectations of how much I can do."*

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We asked survey respondents who tried pacing to select a series of statements they agreed and have broken down the results depending on the severity of their condition.



Even when people are mildly affected, less than half are able to increase their activity through pacing. It is of most benefit to mild and moderately affected people with M.E. with the majority saying they use pacing to do what they feel able to within their limits.

Our Big Survey showed that pacing is most likely to help manage symptoms when:

- they keep a pacing diary to record information about activity levels, stressful events and symptom flare-ups (61%)
- they establish a stable and maintainable baseline of activity (81%)
- when their health professional acknowledges the reality and impact of M.E./CFS and their symptoms. (59%)

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