



# 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 identifying 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)

## 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?

- 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.

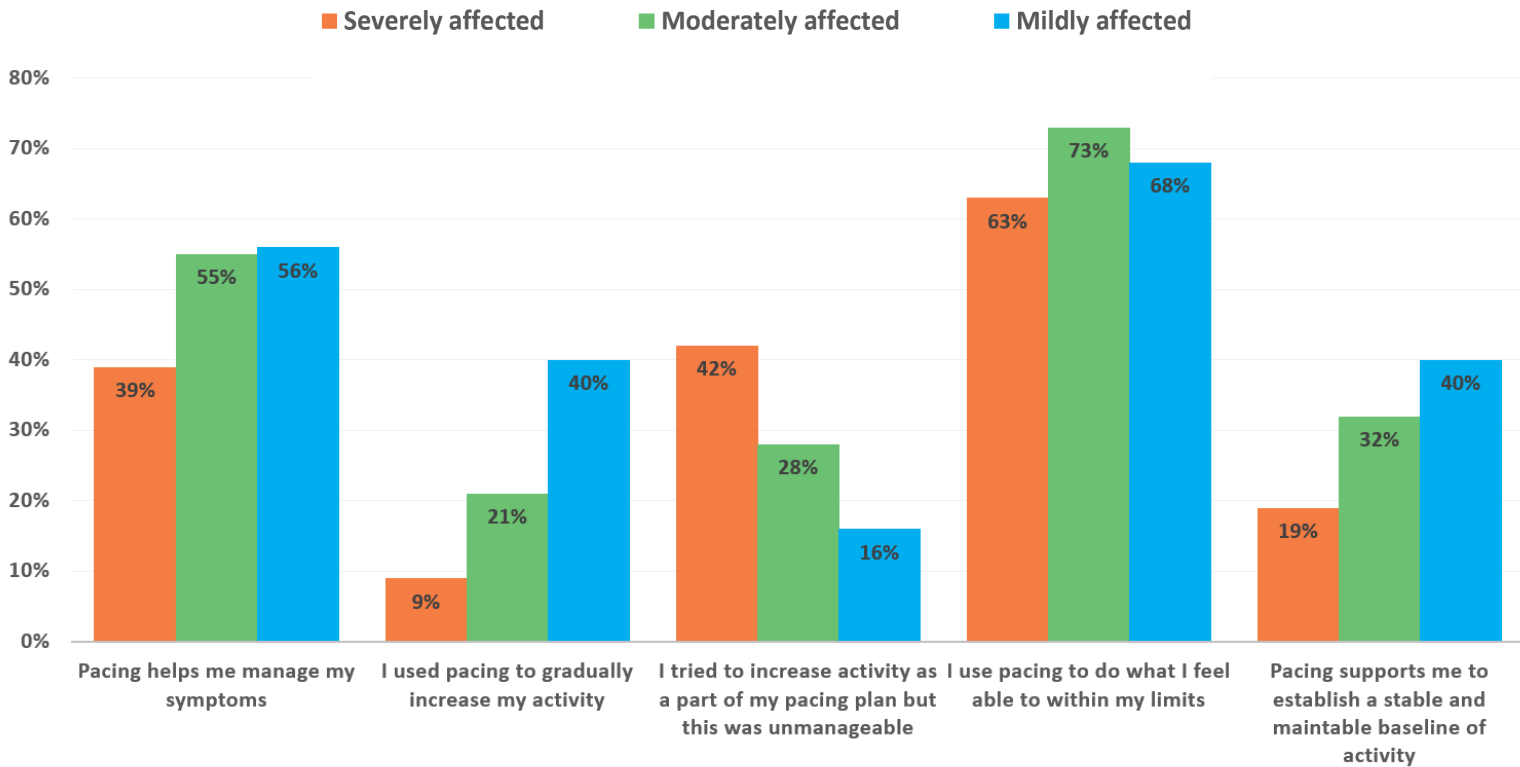
*"Pacing has become ingrained into mine and my family's lives. My wife and carers manage my activity and my wife makes plans, always considering pacing. Although I do not keep a pacing diary anymore, when I was first starting pacing, I did religiously."*

*"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."*

## 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 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%)

**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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