

# Monitoring ME

Emily Skye trialled Visible for six months. Here shares her own experience of using the health tracking app and armband.

## Speed read...

Emily outlines what Visible does in tracking activity and helping users pace effectively. She explains what she has found helpful in terms of understanding her symptoms and the benefits of being able to contribute to research. She also reflects on how it could be unhelpful, especially if you struggle with anxiety and don't have other support or some existing knowledge of pacing.

*Emily's experience and views are her own and offer a valuable first-person perspective. Please note that this does not constitute as medical advice.*

## What is Visible?

Visible combines a wearable armband heart rate monitor with a corresponding app. It requires a smartphone. Based on patient-led research, it is designed to help us with illnesses which require pacing to manage post exertional malaise (PEM)/ exacerbation of symptoms.

## What Visible does

- It uses 'PacePoints' to help us budget the energy we use throughout the day.
- It shows the impact of our activities, so we can prioritise.
- It tracks our heart rate variability (HRV), symptoms and medication to see what is making us better or worse.
- It uses breathing exercises with HRV biofeedback to drive deeper rest.

## Acknowledging the limitations

Visible only knows what we and our bodies tell it. The more information we give it, the more it can help, especially over time. However, I also found that the more I told it, the more hyper-focused I became on my illness and symptoms.

In the first two weeks of using the app, I became more ill. My anxiety was high. Seeing that anxiety reflected in my heart rate was unhelpful. It had an audible exertion alarm at that point, which was alarming.

Our cognitive and emotional

overexertion does not register as quickly. I found I could log and track this using my own judgement, but because it did not impact my heart rate to the same extent that movement might, I would not always recognise my over exertion when my numbers looked good. PEM still happens whenever it does, so this did nevertheless show up in my 'stability scores' (these show whether we are on an even keel or not).

## It seems likely to be helpful if

**You want to be able to understand your illness and your baselines and to explain this** to loved ones, health, social care and benefits providers or as part of awareness campaigning. I have used the information with preparing adjustments with dentist, communicating with ME clinic for assessment, communicating with DWP, and campaigning via my MP.

**Contributing to research is enjoyable and satisfying for you.** There is an option to make your data available to ongoing research on these illnesses. This is a big motivator for me. I had felt frustrated and helpless. This was a way to contribute.

**You are reasonably confident with using apps.** It is user-friendly and I was able to use it even when struggling to sit up and with persistent cognitive impairment.

**You are familiar with processing basic data in the form of graphs.**

Despite being severely limited in capacity for months prior to using the app, it had been possible for me to tick predesigned boxes daily and monthly and gradually make sense of trends and correlations. That was an important stepping stone for me.

**You have good supporters to help you.** Loved ones have helped me recognise this as *one* tool and not the whole picture. Because of this, together with my own professional and personal mental health knowledge, I was able to address the anxiety I was experiencing from using the app.

## It seems less likely to be helpful if

**You have significant electromagnetic sensitivity.** I noticed mild discomfort when I was more ill, but not now.

**You are in a particularly unstable or declining phase with your illness.** I had two stressful coinciding events – losing my job and an ESA application. These events led to a sharp decline from 38% functional capacity back to 28%. Seeing my decline on the app prolonged the decline.

**You are experiencing high levels of anxiety** and do not have support or strategies that help you manage this.

**You have had no specialist input** or information or practice with pacing.

**Technology is a source of stress for you.** It's not for everyone and there are other resources that can help you with pacing

## Untethering myself

I waited until I had written the main part of this review before removing the armband. It was a relief to unplug. I had arrived at techno saturation point and needed a digital detox. It had added a layer to feeling imprisoned in my home and body, on top of the existing tethers from the illness.

It is difficult to make a final judgement, as I am not the same person I was when I began using the app six months ago. It provided useful data when I needed to assess my sleep routines, leading to sleep improvements. As I am now, I feel better without the app, because I have learned to listen and respond at subtle levels.

As a research and campaign tool it is a powerful mobilising force. I may continue to engage with it as a research participant after a break and to learn from the contemporary research summaries available via the app.

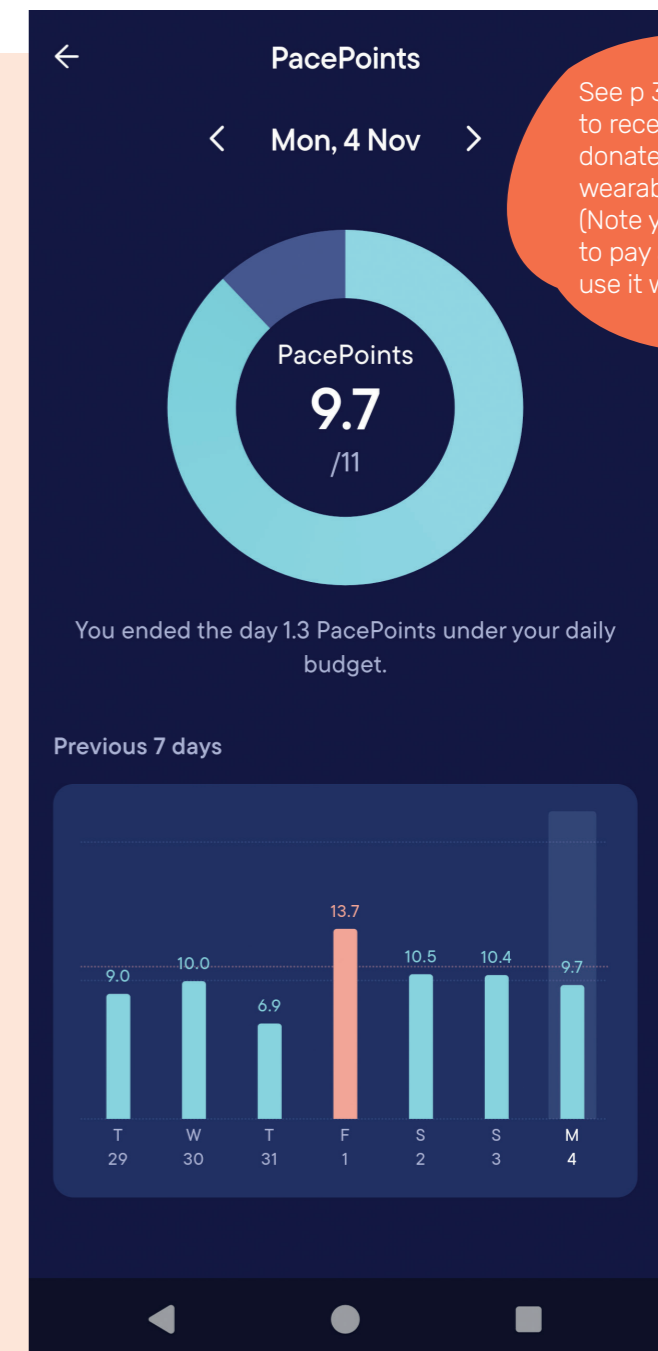
## In conclusion

Using a wearable health tracker can help to inform us about and interrupt our habits of pushing or being overly determined. However, it can exacerbate fear and sense of threat.

It can helpfully rein us in as needed. However, it can add stress (and exertion) to all activity and inhibit us unhelpfully.

It can disrupt our unhelpful habits that might hinder our effective pacing. However, it can undermine our confidence in our judgement.

It has potential to be helpful in managing this illness, improving pacing skills and where possible, improving choice and functional capacity. However, it is important to see this as just one tool and to use it in conjunction with our own judgement and experience of living with ME.



See p 37 for a chance to receive a **free**, donated Visible wearable armband. (Note you will still need to pay a subscription to use it with the app).

Visible is a health tracking mobile app and one that increasing numbers of people with ME are letting us know they are using. This 'wearable' – the name given to devices you attach to your body to gather health-related data – is one of a number available that aim to help people with energy-limiting illnesses pace more effectively. Other apps include ME/CFS Pacing, Trackuility, and The MindfulPacer from the University of Zurich.

Not everyone can afford or has capacity to use technology in this way. If these tools don't suit you, you can apply similar principles through gentle self-management. Pacing aims to balance energy and rest. It is not a treatment, but a way of coping with the impact of ME. You can find resources on our website to support you with understanding pacing and how it might help you manage your symptoms:

[www.actionforme.org.uk/managing-symptoms](http://www.actionforme.org.uk/managing-symptoms).

If you have questions about pacing, you can also get in touch with our friendly Information and Support team (see p 2).