



## Inside The Body Wilds: The Reality of Life with a Chronic Illness

At Living ME, we believe that energy is life. For those living with energy-limiting chronic illnesses, how much energy we have determines not just what we can do, but how we experience the everyday moments that make life meaningful. In the preceding Pacing 101, we explored practical strategies for conserving and managing energy. Now, we invite you to dive deeper—into the stories that bring these challenges to life in a more personal way.

In this segment, we share three powerful reflections that illuminate life inside the body of chronic illness. Una Hearne's essay, **"In the Red,"** compares the relentless drain of chronic fatigue to a phone running on low charge, offering a poignant metaphor for energy depletion. In **"Pain: An Off-Tune Orchestra,"** (Lisa, USA) we take a raw and evocative look at the physical and emotional toll chronic pain exacts. Finally, **"Drifting Away"** (Josh Bean, Canada) brings us into the profound stillness and isolation of life with severe illness, a perspective rarely shared yet deeply important.

These narratives remind us that while our illnesses may differ—whether ME/CFS, dysautonomia (POTS), fibromyalgia, MCAS, or others—the shared threads of resilience and adaptation connect us all. We hope these stories resonate with you, and we invite submissions from writers in the chronic illness community. If your experience echoes the themes in this section or offers new perspectives, we'd love to hear from you. With your input, we will continue to expand the conversation as we increase awareness.

Reach us at [LivingME@wildflowerwisdoms.com](mailto:LivingME@wildflowerwisdoms.com) with the subject line **Inside the Wilds** to share your story or connect further



## In the Red

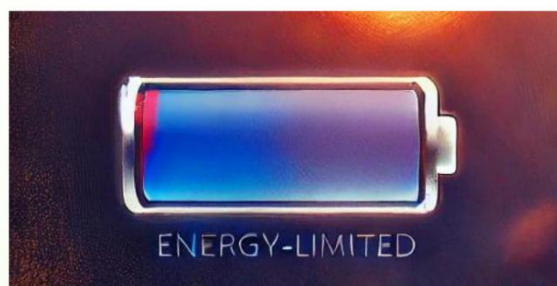


When the battery in your phone runs down you plug it in and recharge it up to 100%. Imagine your body's energy source is a battery – it runs down as you go about your day. You eat and sleep to recharge and start afresh in the morning.

Now imagine your battery is broken. It will only charge to 15% no matter how much you eat or sleep. It fluctuates unpredictably, as if it is poorly connected. This is what it's like to have ME. Unfortunately, this is only the beginning.

Imagine if you exceed your energy by even a few Joules and your battery simply will not recharge – for days, weeks or months. This is called 'crashing' in the ME world. You are incapacitated until you recover. And that only means recovering back to 15% energy.

With so little energy every drop matters. Every day is a constant calculation and re-calculation of what is possible. It is a complex calculation: taking into account how depleted you are today and what energy you will need for tomorrow and the next seven days - how much energy do you calculate you have for today? At best, it's a guess.



The daily basic activities take all of your energy – it is more of an existence than a life for the most part. Additionally, since the energy you do get to use is mostly derived from adrenalin you don't feel the pain and exhaustion until long after you stop and lie down. The ever-present risk is that you will push too far because you want to finish something or are enjoying it. For this you will pay dearly.

Your calculations must all be factored into any plans you make. If you insist on making plans with other people you will need to cancel regularly because you overestimated what you could manage, or you simply have a bad day.

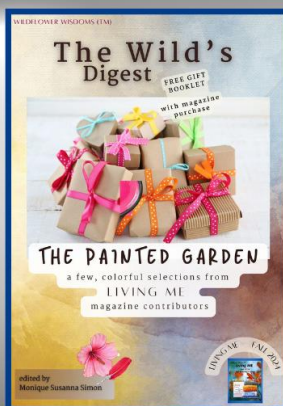


Maybe you can't imagine such a restricted life. Maybe if I make it more concrete? Do you ever have to consider how much energy it takes to brush your teeth? Have you ever skipped brushing your teeth so that you can talk to a friend on the phone for ten minutes? Have you ever been too tired to eat your dinner? When the act of raising a spoon to your lips is actually too much right now and you will have to sleep for a few hours before you are able to eat? Has this ever happened to you? Every week? Every day?

Imagine all day, every day your routine is: calculate energy, do one thing, lie down and wait to assess the current state of your energy, re-calculate, do something else or simply stay down. Every day is a practice of prioritising the essentials and accepting the frustration of not being able to do what you want. And a practice of accepting that you cannot buy another battery. This is ME life.

**Una, Ireland, 2024**

### SPOTLIGHT ON BONUS CONTENT:



*In the Red* by Una Hearne is also featured in our premiere edition of The Wild's Digest: The Painted Garden. This special booklet is a **free** bonus included with the Fall 2024 issue of Living ME.

#### Subscriber Perks:

Subscribers to a full year of Living ME receive The Painted Garden with the Full Premiere issue, as well as additional exclusive e-booklets throughout the year, available as PDFs or online flipbooks.

#### Get Your Copy:

Individual copies of The Wild's Digest: The Painted Garden are available for purchase at our online storefront: [www.wildflowerwisdoms.com](http://www.wildflowerwisdoms.com).