



Here's what it isn't
By Anne

Here's what it isn't

It isn't that I haven't tried hard enough,
It isn't that I've given up
It isn't that I've been fooled into a google diagnosis
It isn't my "unresolved childhood trauma"
It isn't my unresolved adult trauma
It isn't my normal blood count
It isn't a "journey"
It isn't waiting for a cure
It isn't coming to terms with, or rising above
It isn't a question of getting over it
It isn't the flu!
It isn't doing the same thing and expecting a different result
It isn't about writing it down and saying this is who I am in A and E
It isn't the absence of self advocacy
It isn't the excessive evidence of self advocacy
It isn't about being cared for or caring about
It isn't about unwillingness
It isn't about overidentifying with the illness
It isn't addiction, or being addicted to being sick

It isn't me!

It is M E

It is bone crushing fatigue
It is pain that makes you hold your breath
It is a body that can't do things not a spirit that won't
It is the total absence of stage four restorative sleep (try functioning on that, they use it as torture you know)

Anything I do on a given day is a miracle, but forgive me if going for a pee, or putting on a kettle isn't enough of miracle today.

The requirement and expectation of humongous resilience is exhausting

It isn't that I'm not doing it right

Not doing "sick" right

I'm either not doing enough (if you'd just get out of bed)

Or doing too much (if you'd just rest more)

Or eating the wrong thing.

It isn't that I'm not "in the moment" enough

Or that I'm too much in the moment

It isn't that I've not tried enough alternatives

Or that I've tried to many alternatives

That I don't believe in God or miracles

Or that I believe in a God too much (hang in a miracle will happen)

It isn't that I won't let it go.

It is that IT won't go

It would be easier if!

If there wasn't gaslighting

If society understood chronic illness as part of continuum of what it is to be human

For able bodied people the presence of disability is a reminder of vulnerability

disability is "other than" and not "intrinsic to" the human condition

It would be easier if....

My body would do what YOU want it to do (trust me that would be a LOT easier)

It would be easier if....

There was as much research into ME and LYME as there is into COVID

If there was a cure

Illness didn't drop into my life.

A bacteria found its way into my body and TOOK IT OVER

It was undiagnosed

It is still denied