The Art of Hurrying Up and Waiting



A cheerful grumble about calendars, quarterly reviews, and learning to exist in the in-between.

There is a particular flavour of frustration that nobody warns you about when you develop a life-changing condition.

It isn’t pain, exactly, and it isn’t boredom, though both of those can show up uninvited and help themselves to the biscuits.

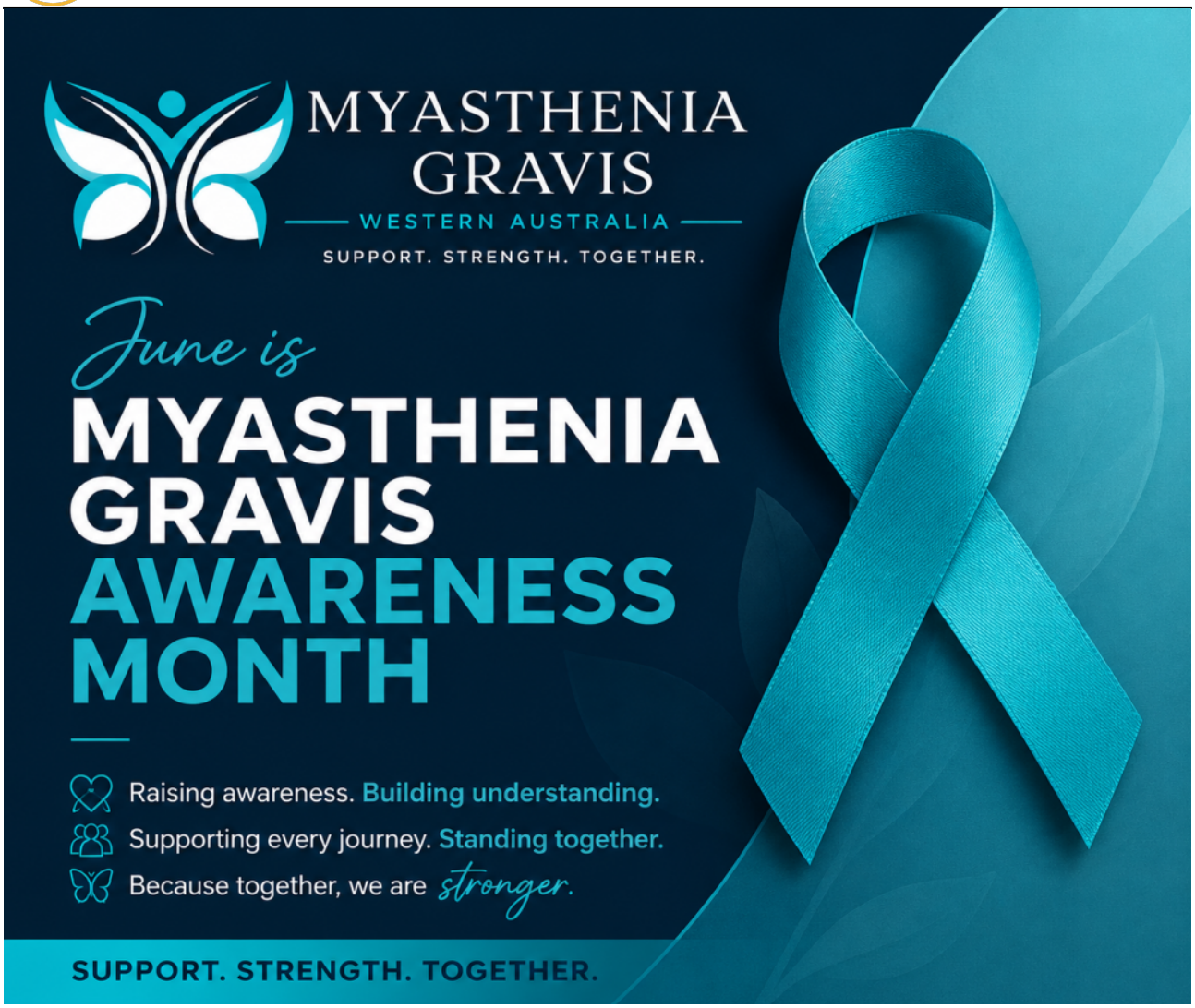
No, this one is subtler. It is the frustration of being perfectly ready to find out what comes next — and discovering that what comes next is entirely on someone else’s calendar.

Welcome, fellow patient, to the quarterly review. That magnificent, distant, slightly mythological event around which all planning must now orbit like a small bewildered moon.

“Soon,” they said. And they were right. It will be soon. Just not, bloody soon enough for any of the seventeen mildly urgent things you were hoping to sort out first.

Here is the situation: fresh out of a couple of months in hospital, navigating life with myasthenia gravis — a condition that, with characteristic flair, affects the very muscles you use to do literally everything — you find yourself in a holding pattern.

The next waypoint is the quarterly review.



Until then, making plans feels less like optimism and more like a form of performance art. “Shall we book that thing in August?” Great question.

Ask me after the review. “What are your thoughts on next month?” My thoughts are that next month is a concept I am treating with respectful caution.

The condition itself, of course, has no interest in your scheduling preferences.

June is Myasthenia Gravis Awareness Month, and when you have it, you do try and make

people aware. I guess these thoughts contribute to that.

MG operates on its own timetable, which appears to have been designed by someone who has never used a diary and finds the whole concept faintly amusing.

Some days are magnificent. Other days, your eyelids and your ambitions make a mutual agreement to take the morning off.

Remission is the goal, the hope, the north star — and it is a genuinely real and achievable thing for many people.

But remission, too, will arrive on its own terms and not a moment before.

Here, though, is where I find something unexpectedly useful in all this enforced waiting: you get very good at existing in the present tense.

Not in a smug mindfulness-retreat sort of way. More in a cheerfully pragmatic “well, I can’t plan anything so I might as well actually enjoy Tuesday” sort of way.

Tuesday, it turns out, is quite good when you stop trying to use it as a stepping stone to something else.

The people in your life who understand this — the ones who say “let me know when you know more, and we’ll sort it out then” — reveal themselves to be absolute treasures, worth keeping at all costs.

The ones who press for firm commitments and get faintly huffy about the vagueness of your schedule are, let’s say, learning opportunities in human patience management.

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Managing MG day-to-day is itself a small project in creative adaptation. It’s pacing — real pacing, the kind where you genuinely have to decide whether the activity is worth the energy it costs, like a particularly consequential game of budgeting.

It’s medication routines and watching for the signs that mean rest now, not later.

It’s accepting help, which is harder than it sounds if you’ve spent years being the capable one.

And it is, honestly, occasionally sitting with the low-level absurdity of a body that can be fine and then conspicuously not fine, sometimes between breakfast and lunch, with no obvious reason for the editorial decision.

But here’s the thing nobody tells you, and I’m telling you now: there is real life happening in the in-between. Actual life, not a waiting room version.

Books. Conversations that go sideways in delightful directions. The way light comes through a window at 4pm. The small reliable pleasure of a good cup of coffee.

The quarterly review will come.

Remission may well follow, in its own unhurried way. And in the meantime, here we are — still standing (on good days, quite literally), and very much present for whatever Tuesday has to offer.

Which is, when you think about it, not a bad place to be.