



Myasthenia Gravis Association of Queensland Inc.

MessaGes

OCTOBER
2026



Myasthenia Gravis Association of Qld Inc **IN NO WAY** endorses any products, medical procedures or medical practitioners mentioned. Articles are provided as a guide, and/or for information purposes only.

We take this opportunity to thank Queensland Health, who by the provision of a grant, make the work of the Association and the publication of this Newsletter possible, and to those who take the effort to contribute to its success.

PRESIDENT'S REPORT OCTOBER 2026

A very successful Annual General Meeting was held last month with all executive and general positions being filled. We welcome new executive members Leilani and Jeff. Also remember that, if you have a bit of spare time to give, it would be appreciated as every little bit helps. We are also looking for project managers for some smaller activities which will have a start and end date attached so people know the level of commitment required.

The next MGAQ activity to look forward to is our **Get-together on Sunday, 15 November at the Brightwater Hotel, 15 Freshwater Street, Mountain Creek on the Sunshine Coast.** We have this as our Christmas function as we have found that many people have commitments with family and friends in December.

I am pleased to report that our funding from Community Services Branch, Queensland Health has continued for the next financial year. As well as having a face-to-face meeting in September, we have provided them with a copy of our AGM booklet and Annual Operational Plan 2026-2027. Main-

taining a positive relationship with Queensland Health is a key priority for this association.

The MGAQ research ***"The Effect of Heat and Humidity on People with Myasthenia Gravis"*** is progressing very well. Andrew Hunt, the lead researcher, will give a presentation at the MAA 5th Annual Conference to be held in Brisbane on 31 October. Please take the time to look at it and make a decision about attending this event. The program involves speakers with a very high level of knowledge and understanding about MG which, I am sure, will give all attendees very relevant and useful information.

National Carers' Week was celebrated on 12th-18th October. We certainly acknowledge the wonderful work done by family and carers who provide fabulous support for us all and make living with MG more manageable. A big thank-you to our carers from all of us living with MG.

Summer seems to have come very rapidly so I hope you are all keeping well and managing to stay cool. We look forward to catching up with members at the Christmas function.

Regards, Carol

Myasthenia Gravis Association of Queensland Inc

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Vice-President: SHARIN NISHA

Secretary: JULIE VON GRUM

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Supported by

Ausenco

Active Members, **Stronger** Advocacy, **Better** Outcomes



MYASTHENIA ALLIANCE AUSTRALIA

MAA UPDATE

It has been full steam ahead over the past month progressing the Conference planning. Such events are detailed and innovative. The schedule for the day is very full with wide ranging content on offer.

Welcoming the attendees will be an absolute pleasure for your committee members. Everyone is keen to meet up with much learning and connection expected. For those where it was not possible to attend, every effort is being made to share as much information as can be made available. Some restrictions do apply.

The fourth UCB sponsored webinar is scheduled for **November 25th with Dr Marion Simpson**. Please look out for registration details and attend if possible. We are hoping to finish 2026 showing our support and appreciation for this series of invaluable webinars.

Kind regards

Susan White, MAA Chairperson

If you are not already registered with the Alliance please go to www.myastheniaalliance.org.au

Myasthenia Alliance Australia

PATIENT TOOLKIT

Trusted resources to help you understand and manage life with myasthenia gravis.

- Practical tools
- Educational resources
- Support for every step of your MG journey

All in one place, whenever you need it

Explore the Patient Toolkit today
New resources added regularly

Myasthenia Alliance Australia

Your Association is your **VOICE** with Government.

Join our webinar to discuss

Beyond the Symptoms

Supporting Psychological Wellbeing in MG

Proudly sponsored by  Inspired by patients.
Driven by science.



Wednesday 25 November | 6:30pm–7:30pm AEDT

NSW, VIC, TAS | 6:30pm–7:30pm **QLD | 5:30pm–6:30pm** **SA | 6:00pm–7:00pm**
NT | 5:00pm–6:00pm **WA | 3:30pm–4:30pm**

Myasthenia Alliance Australia (MAA) is pleased to invite you to an informative and practical webinar with Dr Marion Simpson, a neurologist and clinical researcher specialising in Neuroimmunology, Neurophysiology and Stroke Medicine.

This is the fourth webinar in the **'Your MG Journey, Supported by Shared Care'** Webinar Series, proudly sponsored by UCB.

In this session, Dr Marion Simpson will explore the psychological impact of living with MG, from navigating flares, hospitalisation and recovery to coping with symptoms others may not see.

She will share practical strategies for emotional wellbeing, discuss when and how to seek support, and highlight the value of connecting with others who understand.

REGISTER YOUR ATTENDANCE NOW

Registration: https://zoom.us/webinar/register/WN_XL90JUOHSbGx9AFneDxZ7Q



GUEST SPEAKER

Dr Marion Simpson

*Consultant Neurologist,
Austin Health, Melbourne, VIC*

Dr Marion Simpson is a Consultant Neurologist at the Austin Hospital, working across inpatient and outpatient care with a focus on Neuroimmunology, Stroke and Neurophysiology. After graduating from the University of Edinburgh in 2004 she migrated to Australia to complete specialist training in Neurology. Her particular areas of clinical expertise include Multiple Sclerosis, Myasthenia Gravis and other autoimmune neurological diseases.

AGENDA



5 minutes
Welcome



40 minutes
Beyond the Symptoms
Supporting Psychological
Wellbeing in MG



15 minutes
Q&A

For those unable to attend the live webinar, a recording will be shared via the MAA website after the session.

Need support?

If this topic is concerning for you or you need someone to talk to, please contact your healthcare professional or Lifeline on 13 11 14. For additional support visit:

rareportal.org.au/mental-health-and-wellbeing-support-for-australians-living-with-a-rare-disease

Abbreviations: AEDT, Australian Eastern Daylight Time; MAA, Myasthenia Alliance Australia; MG, Myasthenia Gravis; NT, Northern Territory; NSW, New South Wales; QLD, Queensland; SA, South Australia; TAS, Tasmania; VIC, Victoria; WA, Western Australia

Proudly sponsored by  Inspired by patients.
Driven by science.

UCB Australia Pty Ltd, ABN 48 005 799 208, Melbourne, Victoria.
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CONVERSATION CONNECTION COMPANIONSHIP

TOOWOOMBA



CAIRNS



SOUTHPORT



TOWNSVILLE

Dear Members, our November lunch will be our Christmas Lunch, you are invited to bring a gift (\$15.00-\$20.00) and we will exchange gifts.

Looking forward to your company.

Family members are welcome.

**It will be held at the Sports Club,
159 Bamford Lane, Kirwan, Townsville.**

Ph 07 4773 1223

**on Saturday, 28th November 2026
at 12 noon.**

If you can come please
RSVP Daphne Clay Mobile: 0400 778 637
Email: daphclay@gmail.com

BECOME INVOLVED - MAKE A DIFFERENCE

For membership payments and donations, the MGAQ account details are:

BSB: 124032 A/c: 10263772

Ref: YOUR NAME

Become **INVOLVED** - make a **DIFFERENCE** for yourself and others.

WHAT WORKS FOR YOU?

Share your best Tips & Tricks and a photo for making life with MG easier.
Email info@mgaq.org.au to feature your ideas in this section

TIPS & TRICKS *to better handle* MYASTHENIA GRAVIS



Practical tips
Better days
Stronger you

Carry emergency ice packs: this is mainly for summer, but if you know you are heat reactive carrying instant ice packs can be a life saver in those situations when you thought you were going somewhere with air conditioning and maybe it has failed or it is not as effective as you thought and you overheat.

ANNA



Issues and Responses are published in the What Works for You as-is without any recommendation as to their suitability or accuracy. The opinions expressed are entirely those of the contributor. Care should be taken if following advice or suggestions presented and it is strongly recommended that the advice of your GP or Specialist is taken in all cases.

Remember, we cannot offer medical advice – this can only be offered by a registered Medical Practitioner.

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SUPPORT *your Association by*
VOLUNTEERING.

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MEMBERS' FORUM

Please send in contributions to the Members' Forum – it provides an ideal opportunity for members to share their experiences or questions. It is YOUR Forum and shared experiences with fellow MG sufferers makes understanding the condition just that little bit easier. If you have a response or an issue to raise, please forward it via mail to

PO Box 16 MT GRAVATT 4122 or via email to info@mgaq.org.au

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Part 2: The Art of Hurrying Up and Waiting

by Kay and Michael on 1 June 2026

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.

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

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.

PUZZLES

Sudoku

8				3		7		
1	5			2		9	6	
7			1	9		8		
4	7	6		8	9		2	
					1		8	9
		8			2		4	
6				4	7	5	3	8
5			9		3		7	
	3	7						

Word Search - African Countries

A	C	C	M	I	T	U	O	B	I	J	D	E	I	L	G	ALGERIA
E	L	O	A	A	A	C	E	P	A	H	N	A	E	N	E	ANGOLA
N	T	O	M	P	D	H	M	U	X	R	N	S	I	A	R	BENIN
I	A	S	G	O	E	A	F	J	J	F	O	N	N	W	I	BOTSWANA
U	Y	G	A	N	R	D	G	A	J	T	E	I	V	G	T	BURKINA
G	N	S	D	O	A	O	Y	A	H	B	K	R	H	Y	R	BURUNDI
V	E	R	D	E	C	B	S	O	S	R	H	A	O	C	E	CAMEROON
B	K	G	F	N	I	O	H	A	U	C	N	A	A	W	A	CAPE
A	G	O	Y	L	F	T	Y	B	I	A	A	M	K	W	V	CHAD
A	A	J	I	P	T	S	S	Q	X	P	E	R	A	F	N	COAST
I	B	M	Y	P	T	W	Z	O	J	R	O	F	A	S	O	COMOROS
R	O	O	Q	B	X	A	G	B	O	Q	T	I	B	S	O	DJIBOUTI
E	N	O	F	X	N	N	N	O	D	Z	X	T	H	M	Z	EGYPT
G	F	B	Z	H	V	A	N	R	A	T	X	L	B	T	V	ERITREA
L	O	H	L	D	J	B	U	R	U	N	D	I	T	P	E	ETHIOPIA
A	A	I	R	E	B	I	L	Y	R	O	V	I	I	B	Y	FASO
																GABON
																GHANA
																GUINEA
																IVORY
																KENYA
																LESOTHO
																LIBERIA
																LIBYA
																MADAGASCAR
																VERDE

Bamboozable

BED	cycle cycle cycle	STAY NIGHT
$\frac{1}{1}$	i SLEPT	RACE

Word Change

cost
bowl

Answers

1	9	4	5	6	8	7	3	2
6	7	2	3	1	9	4	8	5
8	3	5	7	4	2	1	9	6
7	4	3	2	5	6	8	1	9
9	8	6	1	7	4	5	2	3
5	2	1	9	8	3	6	7	4
3	5	8	4	1	9	2	6	7
4	6	9	8	7	2	3	5	1
2	1	7	6	3	5	4	9	8

Word Change 24 answers: cost, coat, coal, cowl, bowl.
Bamboozable 23 Answers: 1. Bunk Beds; 2. Tricycle; 3. Stay overnight; 4. One on One; 5. I overslept; 6. A close race

SUPPORT your Association by **VOLUNTEERING.**

FREECALL 1800 802 568

Brisbane Anita 0414 588 312	Bundaberg Denise 0431 571 399
Gold Coast Southport Nader 0415 834 401	Mackay Kym 0410 616 165
Gold Coast Currumbin Julie 0423 766 321	Townsville Daphne 0400 778 637
Sunshine Coast Michael 0447 887 652	Cairns Donna 0414 397 462
Toowoomba John 0412 576 888	

COFFEE & CHAT ROUND-UP



- **Sunshine Coast – Peregrine Springs**
Saturday 24th October, 10.30am Peregrine Springs Golf Club,
95 Peregrine Springs Drive
- **Sunshine Coast - Wurtulla**
Monday 2nd November, 10.30am, Club Kawana, 476 Nicklin Way Wurtulla
- **Moreton Bay - Bribie Island**
Saturday 7th November, 10.30am, Bribie Island RSL Club,
99 Toorbul Street Bongaree
- **Gold Coast – Currumbin**
Saturday 7th November, 10.30am Currumbin RSL Club, 165 Durling Street
- **Brisbane - Wellington Point**
Thursday 12th November, Wellington Point Farmhouse Cafe
2/623 Main Road Wellington Point
- **Gold Coast - Southport**
Saturday 14th November, Southport Sharks Club,
Cnr Olsen and Musgrave Ave, Southport
- **Townsville**
Saturday 28th November, 12 noon Kirwan Sports Club,
159 Bamford Lane, Kirwan

WHAT'S COMING UP

What's On?	When Is It?	Where Is It?
MAA Patient Conference	Saturday, 31st October 8:30 am	Rydges South Bank, South Brisbane
MGAQ Christmas Function Sunshine Coast	Sunday, 15th November 11:30 am	Brightwater Hotel, 15 Freshwater Street, Mountain Creek