



Myasthenia Gravis Association of Queensland Inc.

Messages

DECEMBER
2025



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 DECEMBER 2025

As we near the end of the calendar year I want to take the opportunity to let our MG community know of the wonderful work that members of our management committee have undertaken this year. The ones that are directly available to all members are:

- The newsletter which contains a wealth of diverse information and activities;
- The 1800 802 568 freecall number;
- The very informative website;
- The MGAQ Facebook and Instagram;
- The wide range of written information for members and the medical profession;
- The Coffee and Chats both face to face and via Zoom;
- The regional get-togethers organised by our Regional Co-ordinators;
- The south-east Queensland functions in June, September and November;
- The Annual General Meeting and associated paperwork;

- Information about our involvement in ongoing research;
- Ongoing communication about new medications;
- Emails containing urgent information to be distributed.

The ongoing responsibilities, legislated activities and committee priorities are very necessary but also time consuming for management committee members who, like others, have good days and not-so-good days because of their MG.

THE LEVEL OF COMMITMENT BY MEMBERS OF YOUR COMMITTEE IS EXCEPTIONAL AND I AM VERY PROUD TO BE THE PRESIDENT OF A GROUP OF PEOPLE WHO ALL HAVE MYASTHENIA GRAVIS BUT ALSO WORK TIRELESSLY FOR OTHERS WHO LIVE WITH MG.

I hope that everyone has a happy and safe Christmas with family and friends. Maybe the weather will be kind to us over Summer.

Regards, Carol

Myasthenia Gravis Association of Queensland Inc

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Supported by



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Government

Ausenco

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

SOMETHING BIG IS COMING IN THE NEW YEAR!

**THE MGAQ IS
COLLABORATING WITH
QUEENSLAND UNIVERSITY
OF TECHNOLOGY (QUT)
ON A NEW RESEARCH
PROJECT EXPLORING
HEAT SENSITIVITY IN PEOPLE
WITH MYASTHENIA GRAVIS**



MYASTHENIA GRAVIS
ASSOCIATION OF QUEENSLAND INC.
(MGAQ)



**Queensland
University
of Technology**
QUT ethics approval 10508

For more information visit:

mgaq.org.au/news/something-big-coming-our-mg-community



The Oh MG art exhibit have gone to new heights with its inclusion in the Blue Care calendar for 2026. Many thanks to Kay and the ladies at Carlyle Gardens, Townsville for making this happen.

Also, big congratulations to Chloe, our MG artist, for all her dedicated work with both the display and spreading the word about MG so widely.

The heart behind the art

Townsville Crochet Group (Snowflakes - Kay Wickham) Carlyle Gardens Townsville Retirement Village

At Carlyle Gardens Townsville, creativity often begins with compassion and community spirit.

When a friend who lives with Myasthenia Gravis (a rare autoimmune condition that causes muscle weakness and fatigue asked if there was any way we could help raise awareness, our Carlyle Gardens Crochet Club was moved to take action.

Inspired by The Snowflake Project, our members lovingly handcrafted 570 crocheted snowflakes, each one is unique as the people affected by this condition.

The snowflake holds special meaning for those living with Myasthenia Gravis. It symbolises how no two cases are ever the same, earning it the nickname "the snowflake disease."

Every stitch became a message of hope, understanding, and support.

The snowflakes were later sent to Brisbane for an awareness exhibition, shining a light on this often misunderstanding illness.

Before sending them off, we gathered for a celebration morning tea - a joyful moment shared among friends, united by purpose and kindness.

Because here at Carlyle Gardens, we celebrate every moment.



Photography Christina Lowry





MYASTHENIA ALLIANCE AUSTRALIA

MAA UPDATE

As the year comes to a close many of us are wondering why we still do not have the medications recommended at the **March 2025 meeting of the PBAC**. Of all the medications recommended at that meeting only 5 have not been resolved. 4 of the 5 are for Myasthenia. We note that some patients have received treatment via early access programmes but most patients are still waiting. The MAA have continued to follow up on progress and have offered input when invited. We are hopeful that this situation will shortly be resolved. Plans are in place for more enquiry to occur in the new year should it be needed.

A sixth PBAC submission will happen by January 21st. This is an additional request from Argenx to make **Efgartigimod (Vyvgart) available in a pre-filled syringe**. The MAA support this offering and will respond accordingly.

The recording of the webinar with **Nurse Jenny Stofmeel** is now available via the MAA website. Your patience in waiting for this recording is well rewarded. Jenny presents very patient friendly and very practical content. It is very promising to see Neurological nurses becoming invested in Myasthenia care and the number of nurses made available will hopefully grow. Understanding the **vital role of nurses supporting patients with Myasthenia Gravis** is most welcome knowledge. Visit here

myastheniaalliance.org.au/nursing-excellence-vital-role-of-nurses-in-mg-care

MGVic have called for committee members and have hosted two morning teas for people to gather together. There will be more offerings in the new year.

Watch out in the new year for news to begin flowing about the **2026 Art With Heart** campaign. Early preparations will commence for this exciting national June awareness project.

Wishing all our followers a very happy and safe Christmas season.

Warm regards

Susan White MAA Chairperson



DONNA'S PASSIONFRUIT SLICE

INGREDIENTS

BASE

- 1 cup SR flour
- 1 cup coconut
- ½ cup caster sugar
- 125g butter (melted)
- ½ teaspoon vanilla extract

TOPPING

- 395g can condensed milk
- ¼ cup lemon juice
- 2 passionfruit (or tin passionfruit)

INSTRUCTIONS

- Preheat oven to 180deg
- Combine base ingredients and mix well
- Press into slice tin and bake for 15 minutes, cool.

FOR THE TOPPING

Reduce oven to 140deg and mix topping ingredients

Pour over base and bake for 10 minutes
Once coolish, place in refrigerator to set.

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



MYASTHENIA ALLIANCE AUSTRALIA

MAA UPDATE

RARE DISEASE CONNECT IN NEUROLOGY – Connecting with fellow patient organisations in Barcelona

Rare Disease Connect in Neurology (RDCN) is an annual meeting that includes both healthcare professionals and patients. I was very honoured to be invited and sponsored by UCB to attend the 5th RDCN in Barcelona on behalf of the MAA and the MG patient community in Australia.

Over 3 busy days, I engaged and spoke with MG patient organisations as well as healthcare professionals from all over the world. Fellow patients and I discussed common challenges and shared insights and ideas for how we can best support the MG community in our countries – we all agree to not reinvent the wheel when we don't need to!

Sessions for the patient organisations included updates and opportunities with MG guidelines, tackling referral challenges, the increasing role of nurses in MG care, advancing patient-centric clinical research, and the Rethinking MG project. As it was our first time attending, I gave a presentation on the MAA - who we are, what we do, and what we have achieved.

We also joined some presentations with the healthcare professionals for topics including the digital doctor and artificial intelligence (AI), late and very late onset MG, social determinants of health in MG care, and multidisciplinary teams in action.

While it was a whirlwind trip and the jet lag and physical tiredness were challenging, I was so glad to be there. The MAA will make the most of this experience, sharing the knowledge gained and fostering the connections and collaboration with fellow patient organisations. A big thank you to UCB for this opportunity to learn and to continue building our global network.

Natalie Windle MAA Secretary and MGNSW President



SUPPORT your Association by **VOLUNTEERING.**

Support ART WITH HEART



Supporting MG Awareness with "Art with Heart" 2026!

The Myasthenia Alliance Australia (MAA) is proud to continue its important work during International June MG Awareness Month 2026.

Challenge Your Friends and Family to Care

If you're wondering how you can contribute to and support the MG community, your involvement is essential. The first step in our awareness campaign is for our strong and committed Myasthenia community to reach out to family, friends, neighbours, colleagues, health professionals, government representatives, and everyone else to ask for contributions to the auction.

This event aims to strengthen our MG community by encouraging group interaction in a fun and positive atmosphere. It is also a vital opportunity to raise awareness of Myasthenia Gravis throughout the broader community.

Building Community Awareness

Help build awareness by reaching out to social groups and NGOs (Non-Government Organisations). Consider becoming a sponsor. If we hope for understanding and acknowledgment from others, including medical providers, it is important that they become familiar with our condition.

How You Can Help Make the Event Successful

- All contributions - big or small, service-based or tangible - are greatly appreciated.
- Please donate items or ask others if they would like to contribute.
- Share the news as widely as possible through focused conversation, emails, and social media platforms such as Facebook and Instagram.

MAKE A DIFFERENCE FOR PEOPLE WITH MYASTHENIA GRAVIS



operations@mgaq.com.au



1800 802 568



www.myastheniaalliance.org.au



Myasthenia
Alliance Australia

KNOW YOUR COMMITTEE

Hi all, my name is **Julie Von Grum**.

I am the newest member of the MGAQ committee having joined in August 2025.

I was diagnosed with a thymoma in 2012 with positive acetylcholine receptor antibodies. My MG is managed with fortnightly IgG infusions and Mestinon. A big part of my therapy is aerobic exercises in the water which I find helps my symptoms.

I am enjoying my role with the committee. I am a project officer alongside Sharin for "Art with Heart" and I co-ordinate the Currumbin "coffee and chats".

I am so pleased to be an active member of the MG community and hope I can play my part in the plight of building awareness of MG.



VALE SHIRLEY LANGSHAW

A Tribute to Shirley – Founding Member and Lifelong Pillar of the Brisbane Myasthenia Gravis Community



It is with deep respect and gratitude that we honour the life of Shirley, one of the founding members of the Brisbane Branch of the Myasthenia Gravis Association. Shirley's journey with Myasthenia Gravis began in 1988, at a time when the condition was still considered extremely rare. Information was limited, community awareness was minimal, and treatment options were only just emerging.

Shirley's doctor, based in Mooloolaba, was at the forefront of medical discovery in this field. Even so, navigating such an unfamiliar illness was challenging. It was in this uncertainty that Shirley discovered the Myasthenia Gravis group—a place that soon became a source of comfort, knowledge, and genuine connection. Here, she found people who understood, who listened, and who walked the same path. This sense of community gave her strength, hope, and the courage to keep moving forward.

Shirley's dedication quickly grew beyond attendance alone. She became one of the key distributors of information and newsletters, helping to spread awareness, updates, and encouragement to others living with MG. Her commitment to ensuring no one felt alone was unwavering. For 38 years, Shirley offered her time, her compassion, and her steady guiding hand to the MG community.

Her warmth was genuine, her care sincere, and her presence deeply valued. She embodied the spirit of support, advocacy, and resilience that this organisation stands for.

Shirley's legacy lives on in every member she comforted, every conversation she nurtured, and every piece of information she helped share. She leaves behind a lasting imprint on the Brisbane MG community—one built on strength, understanding, and kindness.

We thank Shirley for her extraordinary service, her courage, and her unwavering heart. She will be dearly missed but never forgotten.

**Sincere thanks for the opportunity to write this about my mum
Shirley Langshaw 11.9.1938 - 15.11.2025 ~ Debra Cooper**

PUZZLES

TEMPERATURE	PAR 2	CHANCE
HEART	COLLAR HOT	THE HEAD SAND

DEAD BODY MY	NO NO RIGHT	Ci ii
LOOKING 1111	BBBBBB	BRAIN KIDNEY HOME HEART

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

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

Find ten differences between the two pictures!



Word Change

grate
blame

Answers next page

SUPPORT your Association by **VOLUNTEERING.**

CONVERSATION CONNECTION COMPANIONSHIP

The local Coffee and Chat is a safe space to share MG experiences with others.

CAIRNS



CAIRNS - MAREEBA



SUNSHINE COAST



TOWNSVILLE



Word Change 28 Answers:
grate, grade, glade, blade, blame

Puzzle 1 Answers
1. Falling Temperature
2. Two Under Par
3. Fat Chance
4. Broken Heart
5. Hot Under the Collar
6. Head in the Sand

Puzzle 2 Answers
1. Over my Dead Body
2. Right Under the Nose
3. See Eye to Eye
4. Looking Out for Number
5. Be-Lime
6. Home is Where the Hea

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

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



The answer key.

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

COFFEE & CHAT ROUNDUP QUEENSLAND

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	

IN-PERSON COFFEE & CHAT



Gold Coast – Southport

Saturday, 10th January at 10.00am, Southport Sharks Club,
Corner Olsen & Musgrave Avenue, Southport

Gold Coast - Currumbin

Saturday, 17th January at 10.30am, Currumbin RSL, 150 Duringan Street, Currumbin

Sunshine Coast – Wurtulla

Monday, 2nd February at 10.30am, Kawana Club, 476 Nicklin Way, Wurtulla

Springwood

Sunday 8th February at 10.30am, More Cafe, Springwood Shopping Mall,
34 Fitzgerald Ave, Springwood

Townsville

Saturday, 21st February at 12 noon, Kirwan Sports Club, 159 Bamford Lane, Kirwan

*The Myasthenia Gravis Association of Queensland Inc.
Committee would like to wish everyone a*



*Merry
Christmas* and a safe
and happy
New Year!

MessaGes will take a break over January and looks forward to
resuming in February 2026.

Thank you to all contributors during 2025.