



Messages

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

JULY 2019

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.

Myasthenia Gravis Association of Queensland Inc

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PRESIDENT'S REPORT

It seems that winter has finally arrived even if it has brought the wind and damaging surf with it. I am sure everyone with Myasthenia has welcomed being able to feel comfortable and have more energy for a short time at least.

Our get-together in June was very successful, both with the number of people who attended and the quality of the guest speaker, Tracey Shaw. All financial category A members will receive a copy of the DVD in the coming weeks. Please take the time to view it as there is much useful information about the extended group of people upon whom people with Myasthenia rely. Nominations have closed for the 2019/2020 management committee.

The nominations for the AGM will be placed in next month's newsletter. We still have several vacancies and nominations for committee members will be called at the AGM. We hope that we can have a full committee as the number of projects and activities we are trying to balance and move forward continues to grow. It would be very sad if we could not continue to operate this association at such a high level because the current committee members could not cope with the enormous amount of work and projects we are currently undertaking. People do not have to be highly skilled as there are many ongoing

activities that just require someone to be responsible for making them happen regularly and within outlined timeframes. We have always prided ourselves on being a committee of volunteers and it would be a shame to have to think about employing someone to help with the workload. Please think about whether or not you can contribute to this wonderful association by becoming a committee member.

We received very welcoming news from Queensland Health that our funding has been extended for another three years with the possible option of that going to five years. We always keep this organisation informed about our key priorities and how they are being met and I am sure that the additional funding is a result of all the worthwhile work done by the association. We need to keep up this impetus over the long term.

Finally, there are exciting times ahead with the National Alliance Conference in Brisbane on 03 August. The guest speakers will be amazing and there will be breakout groups relevant to all. Those who have registered and paid will have received their information pack with preliminary information in it. It is hoped that everyone will give this wonderful opportunity careful consideration.

Thanks, Carol

Supported by



Queensland
Government

Ausenco

MYASTHENIA ALLIANCE AUSTRALIA NEWS



Now On the Home Run to the 2019 Conference!

Just a short note from the MAA this month - too exhausted for more!

We are into the pointy end of arrangements for the Conference now with Registrations closed, the Programme and Presenters confirmed. Thank you to everyone who has registered for this very informative day. The MAA Board very much looks forward to seeing everyone at the TRI Conference Facility in the grounds of the PA Hospital Brisbane on 3 August.

We offer our sincere appreciation to the Presenters and to CSL and Enjo who have offered sponsorship.

The new Website is proving to be very popular and has already enhanced the work of the Alliance.

Do register for the News posts if you have not already done so. Thank you again to Anna Wilen-Clarke for the gift of this new website.

The Alliance Board continues work in regard to other issues on the agenda. These include remaining focused on the eNID Project, progressing the potential for Rituximab to be PBS listed, supporting research, and taking a lead role as patient advocate in relation to Government policy discussions around treatment options.

Susan White - MAA President

Follow the work of the Alliance by registering at the website
www.myastheniaallianceaustralia.com.au



THE UNIVERSITY
OF QUEENSLAND
AUSTRALIA

Patient Survey Still Ongoing

**Call for your copy if you have not yet participated.
Tell your story AND help the Doctors who help us!**

In 2011, the MGAQ collaborated with the University of Q'ld (UQ) and Royal Brisbane Women's Hospital (RBWH) to undertake a patient based hard-copy survey of people with Myasthenia Gravis.

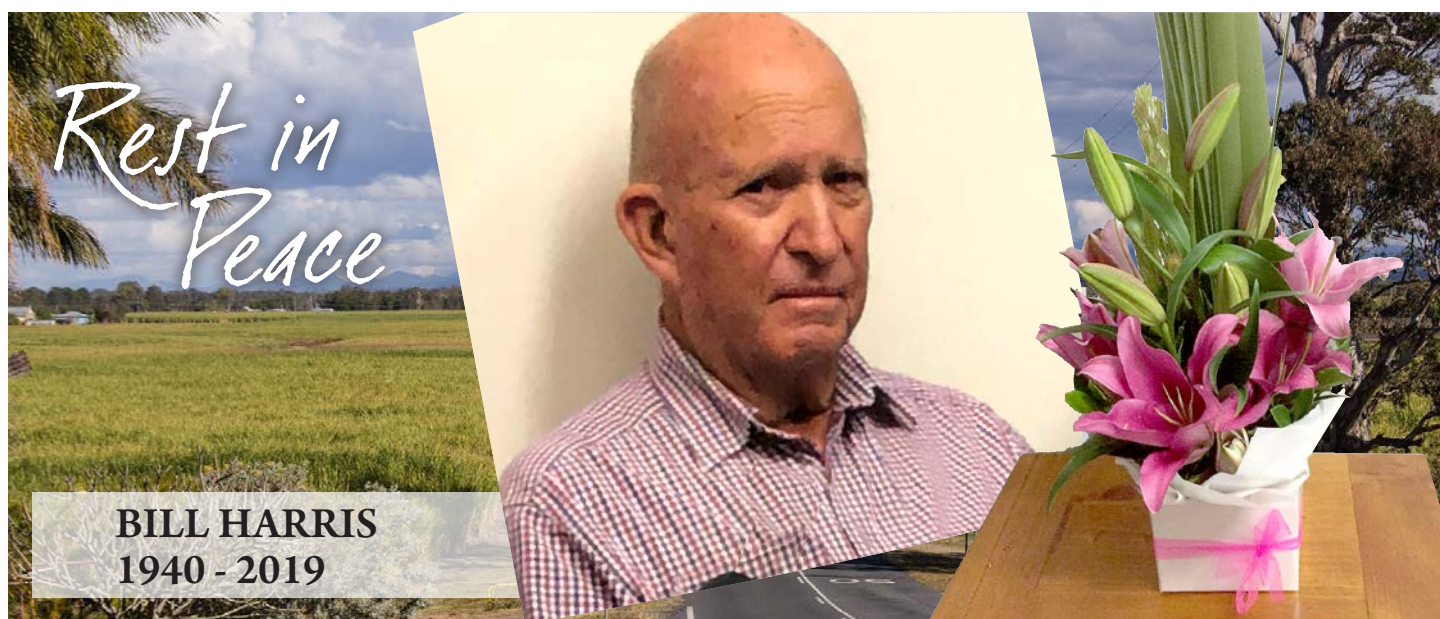
The researchers, Prof. McCombe, Dr Blum, Dr McEniery et al undertook the huge task of entering the data and interpreting the trends. A Journal Article, published 2014, showed some interesting trends.

Information is collected in reference to quality of life and community costs of this condition.

Participants are given ample opportunity to report on all aspects of their experience with this condition. The latest research looks at the written responses. The survey is ongoing and additional research is planned using the de-identified data.

Participation is still very valuable. **Please contact www.mgaq.org.au or 1800 802 568 if you can support this valuable project.**





VALE BILL HARRIS

William George Harris (Bill) was born 7th December 1940 and passed away 2nd May 2019.

Our Dad, Bill, spent the majority of his life on a cane farm at Brightley. Dad married Muriel in 1971 and had three children soon afterwards. Throughout his life, Dad had a genuine desire to continually learn – he absolutely loved learning, meeting new people and sharing his knowledge and experiences.

Dad was a very practical person he was always making things in the shed and on the farm which provided wonderful childhood experiences for us as children. We had the freedom to explore and be creative. Dad provided endless encouragement throughout our lives. He continually inspired us to accept each new opportunity to expand our horizons. Dad was a genuinely optimistic person; which guided us as children to believe that anything was possible.

Throughout Dad's life, animals have played an important role, particularly so when he was unwell, the dogs were constantly by his side. Dad was actively involved in many community organisations;

An advisor at Junior Farmers –where he met his wife.
Brightley State School P and C Association
Eton Rural Fire Brigade

The Pioneer Valley Show

The Myasthenia Gravis Association.

When Dad was diagnosed with Myasthenia Gravis, in 2003, he was willing to let doctors and medical students use his condition as a study in order to learn about the illness. In 2016 there was an article published in the Daily Mercury about Dad – he was happy to have his illness used to educate others suffering from the same disease.

Dad was the Regional Co-ordinator for the Myasthenia Gravis Association in the Mackay region, a role which he thoroughly enjoyed. He offered optimism, encouragement and support to others with Myasthenia Gravis. It did not matter who you were, Dad had the time to talk with you.

He was selfless, in giving back to the community. He was supportive, encouraging, providing unconditional love, and taught us what it meant to be a wonderful husband, father, grandfather and friend.

He gave us the courage to work hard and chase our dreams.

We are incredibly grateful and proud that Bill was our Dad.

Janet and Ian Harris

SAFE EATING FOR POOR IMMUNE FUNCTION

People with weakened immune systems are more at risk of food poisoning. This includes those undergoing chemotherapy with low neutrophils and people on immune suppressing medication. As well as the general recommended food safety guidelines, extra precautions should be taken to avoid high risk foods - Choose foods listed under the "Safer options" column.

Food Group	Safer options	High risk foods to avoid
Breads, Cereals etc	<ul style="list-style-type: none"> All breads, bagels, rolls, muffins, pancakes, waffles, crackers Cooked rice, pasta and other grains All cereals, cooked or ready to eat Potato chips, pretzels, popcorn and other snack foods 	<ul style="list-style-type: none"> Raw grain products e.g. muesli, oats (toasted grains are OK) Uncooked biscuit dough or cake batter Un-refrigerated cream or custard filled baked goods Pre-prepared rice, couscous or pasta salads from delis or salad bars
Fruit	<ul style="list-style-type: none"> Well washed raw fruit (fresh and in good condition) Canned and frozen fruit Bottled and sealed fruit or vegetable juice Dried fruit 	<ul style="list-style-type: none"> Unwashed or poor quality raw fruits Pre-cut fruit e.g. ½ serves of melons, diced fruit salads Commercial freshly squeezed fruit or vegetable juice
Vegetables	<ul style="list-style-type: none"> All cooked, frozen, canned or fresh vegetables Well washed raw vegetables & salad (fresh and in good condition) Fresh and well washed herbs. Cooked dried herbs and spices 	<ul style="list-style-type: none"> Unwashed raw vegetables or herbs All raw vegetable sprouts (alfalfa, mung beans etc) Pre-prepared salads from delicatessens, supermarkets or salad bars
Milk, yoghurt, cheese & alternatives	<ul style="list-style-type: none"> Fresh pasteurised milk, UHT milk, milk powder Yoghurt Pre-packaged processed/hard cheeses, cheese spread, cottage cheese, cream cheese Ice-cream, frozen yoghurt, iceblocks Custards, dairy desserts e.g. yogo, fruche 	<ul style="list-style-type: none"> Unpasteurised milk, cheese, yoghurt Cheese from delicatessens Soft, semisoft or surfaced ripened cheeses (pre-packaged and delicatessen) e.g. Brie, Camembert, Gorgonzola, Feta, Blue vein, ricotta Soft serve ice-cream, soft serve yoghurt and drinks containing these Commercially prepared and unpackaged smoothies or thickshakes Probiotic drinks/yoghurts
Meat, fish, poultry & alternatives	<ul style="list-style-type: none"> Commercial canned meats, poultry and fish Well cooked meat and poultry (no pink meat or juices) Freshly cooked seafood and fish Well cooked eggs (no runny yolks) Home cooked cold meats (store in fridge and use within one day of cooking) Commercial canned or cooked legumes Freshly cooked BBQ chicken that is eaten when hot 	<ul style="list-style-type: none"> Packaged/Unpackaged ready-to-eat cold meats from supermarkets, deli counters, sandwich bars etc. Raw/undercooked meat, fish, seafood Raw egg in drinks e.g. egg flips Raw egg in desserts e.g. mousse, tiramisu, cheesecakes Cold BBQ chicken from shops Cold smoked fish (e.g. salmon, cod, trout) and pickled fish Raw or ready-to-eat seafood (e.g. oysters, prawns, smoked mussels, sushi, sashimi) Pate, fish paste, liverwurst and meat spreads
Beverages	<ul style="list-style-type: none"> All canned, bottled, powdered beverages e.g. soft drinks Tap water – boiled or microfiltered Packaged fruit juices Coffee, tea, Ovaltine, Milo etc Canned/packet soups Commercial nutrition supplements - liquid and powdered e.g. Sustagen, Ensure Plus 	<ul style="list-style-type: none"> Non-carbonated bottled mineral water Water from a well, bore water or tank water. However if there are no other choices, filter and boil water before drinking. Make sure that the water is regularly tested for bacteria and found to be safe
Fats & oils	<ul style="list-style-type: none"> Butter, margarine, oil Commercial, shelf-stable mayonnaise and salad dressings (refrigerated after opening) Cooked gravy and sauces 	<ul style="list-style-type: none"> Fresh salad dressings that contain aged cheese (e.g. Blue cheese) Mayonnaise/aioli made with raw egg
Take Away Food	<ul style="list-style-type: none"> Choose foods that are freshly cooked/ cooked to order and served steaming hot 	<ul style="list-style-type: none"> Avoid food that is kept hot and not freshly cooked e.g. food in pie or food warmers/hot boxes/buffets Avoid salads, sandwiches, sushi and rice paper rolls
Other	<ul style="list-style-type: none"> Sugar, jam, syrups (refrigerated) Commercial (heat-treated) honey Roasted/packaged nuts with shell removed Commercially packaged peanut butter Mustard, tomato sauce, soy sauce etc. (refrigerate after opening) Pickles, relish, olives (refrigerated) 	<ul style="list-style-type: none"> Any outdated products Unpackaged dips Leftovers greater than one day old Raw or non-heat treated honey, honey in the comb Unpackaged raw nuts, any nuts in the shell Probiotic capsules/powders

For further information contact the Dietitian, or refer to the following:

Food Standards Australia website <http://www.foodstandards.gov.au> Australian Food Safety Information Council <http://www.foodsafety.asn.au>
 US Food Safety gateway website <http://www.foodsafety.gov> Eat For Health. Australian Dietary Guidelines <http://www.eatforhealth.gov.au>
 Dietary Guidelines for Americans 2015-2020 Food Safety Principles and Guidance <http://www.health.gov/dietaryguidelines/2-15/guidelines/appendix-14>

This is a consensus document from Dietitians/Nutritionists from the Nutrition Education Materials Online "NEMO" team

Disclaimer: <http://www.health.qld.gov.au/masters/copyright.asp>

Reviewed: August 2016. Due for Review: August 2018



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

Issues and Responses are published in the Members' Forum 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.

HOW ACTIVE ARE YOU? SEEKING PEOPLE WITH MG FOR STUDY!

A comment from Tom, a MGAQ Member who is participating in the Study

Because we are an uncommon disease getting good research information is difficult. Without good data we are going to have difficulty getting funding for new treatments. Good data requires studying as many patients as possible. Small numbers of participants doesn't produce enough information to make worthwhile interpretations.

Tahlia's study is something worthwhile and I would encourage everyone to participate. So far she has had only 4 participants in the exercise monitoring component.

It is easy to participate.

She is very friendly.

The hour session is not strenuous or uncomfortable.

Access is easy. There is a public car park within 100m of her building. A council bus stops just outside her building.

The monitoring devices are comfortable and unobtrusive.

There is a good cafe next door to her building.

Let's support those trying to help us.

Kind regards, Tom



How active are you?

We are seeking people with myasthenia gravis (MG) to help us better understand the impact of MG on levels of physical activity and sitting time.

Participation involves completing an online survey and wearing two small, lightweight activity monitors for seven consecutive days as you go about your normal day to day life, and then answering some questions about your activity levels.



For more information and to access the survey, scan the QR code with your device or go to:

www.surveymonkey.com/r/MG2019SURVEY

For more information on this study, please contact:

Tahlia Alsop (Honours student) t.alsop@uq.edu.au

Dr Sjaan Gomersall (Principal advisor) s.gomersall1@uq.edu.au or 3365 4528



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My 15 Minutes of Fame.

Honoured is the word to describe how I felt when asked if I would consider helping out in promoting in some way Myasthenia Gravis and the Association in Awareness Month. Of course, I said yes but my inner voice honestly thought someone more capable would be found. To my surprise Susan contacted me with the offer to do an Interview on ABC Brisbane Radio alongside a Neurologist.

WOW Oh my goodness, I couldn't believe my luck. I have always wanted to help bring about more awareness and education about MG but my symptoms instability in the past had always stopped me. Now with the Ritux treatment I have received I now could offer my help.

On the day my husband and I arrived an hour and half early so we could find the studio, have a coffee and generally let me

settle my 'NERVES'. Can highly recommend the café directly under the ABC Studio, yummy homemade fruit and nut toast, Yummm. We signed into reception at the appointed time and waited in the "Green Room" which was actually more orange than green and Stefan joined us shortly after. When it was our time, we were shown into the broadcast booth and introduced to Rebecca Levingston while there was a musical interlude. What was hilarious was I had left Trevor my husband in the Producer's Booth having a discussion about what the song

was and who played it. The young technician didn't know, as it was a bit old for him but ultimately Trev knew.

I found Rebecca warm and inviting. She admitted MG was an unknown for her as it would be for many of her listeners. She effortlessly bounced from Stefan and me to get a decent amount of information about Myasthenia in the limited time she had. I shouldn't have been nervous as it was a wonderful experience which inwardly, I knew I could always do and only had to overcome my diminished self-confidence which had been damaged dealing with my MG. So, as well as ticking off a life goal of doing something worth while on a media format I learnt a valuable lesson. Don't let a disease define you, 'You are still you with all your strengths and there are always people to help you be that person'.

Karen



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Reply To Gresham - From Another Aging Fart 68

Living in Uki, Northern Rivers NSW, no longer walking up Mt. Warning, but I agree whole heartedly if you can, exercise keeps one functioning much better. Even if it's very light exercise. Anything is better than nothing.

Gresham I would if you haven't done so take some pilates lessons from your wife, I only did it for a short while, due to finances, but it was a benefit. I had a hip replaced last year, waiting on an ankle replacement. If and when all things align, I'll be looking for a machine, keeping up with others in a class or affording

solo lessons not easy. So meanwhile I do daily stretching and muscle toning lessons, one friend says my routine is a little pilates like anyway. (without the machine).

I also swim 3 times a week, have to have a day off in-between, otherwise too much fatigue.

Sorry. Mate but NEVER DONE KOKODA. Hills or stairs are a no no, puts just a little to much pressure, swimming or walking along the flats only.

Cheers Trevor

GOLD COAST MG GROUP COFFEE / CHAT – GET-TOGETHER *Southport Sharks Club on Saturday, 29 June*





Welcome to our new members

Gwen, Woolloongabba QLD
 Mary, North Lakes, QLD
 Leonie, Sinnamon Park QLD
 Daryl, Murrumba Downs QLD
 Anna, Springfield Central QLD
 Hannah, Goodna QLD

June, Gleneagle QLD
 Laurence, Gleneagle QLD
 Norman, Mudgeeraba QLD
 Roy, Gladstone QLD
 Heather, Heatley QLD
 Gresham, Clifton Beach QLD
 Jody, Moree NSW



Myasthenia Gravis Friends *Western Australia* Coffee & Chat

Sunday, 11 August at 2pm - Pinnacles Restaurant
 (upstairs in Myers) **200 Murray Street, Perth**

Myasthenia Gravis Friends WA recently held a Coffee & Chat in Perth.



It was with great delight that I was recently invited to attend a Myasthenia Gravis Coffee and Chat here in Perth, first opportunity in years I believe. Since I was diagnosed with MG in December 2017, I have only met two other people, now friends, with this condition, so the chance to chat and compare treatments and journeys dealing with this somewhat rare condition was truly much appreciated.

And there is nothing like a good chat over a cuppa with others it does make one feel connected and not so isolated. Everyone was so friendly and willing to share their stories; I

really felt the relief around me from all present of finally meeting people who have been through similar situations and treatments.

Really important now that we do manage a Coffee and Chat meeting on a regular basis to provide support to each other here in Western Australia and to encourage others as well. Although we should, if may suggest, remember to ask advice from our specialist if we have any questions on our own treatment program.

Diane

Puzzlers

Puzzles by
www.thinkablepuzzles.com
www.theteacherscorner.net

Sudoku

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

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

Word Change

grate
blame

Answers

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

Commonym Answers:
 1. they are caught
 2. they are tossed
 3. they are popped
 4. they have caps
 5. they have tongues
 6. they have anchors
 7. they are magazines
 8. they have lanes
 9. they lift
 10. they have checks

Bamboozable 30
 Answers: 1. Total
 Mess; 2. Paint by
 Numbers; 3. Four Part
 Harmony; 4. Poison
 Ivy; 5. Tilt a Whirl; 6.
 Internet Site.

Word Search - Books of the Old Testament

S G N E Z R A J X S Q E
 M U K U B R P O B C C H
 A M C H M S J R A C S A
 S U T I A B E O L E E I
 H V H L T V E E B S G M
 G N M S O I S R H T D E
 B S R R O I V T S H U H
 J J P Z A J U E R E J E
 Q H P S B R Z V L R K N
 K Q T G E N E S I S A T
 W E S U D O X E Y F X S
 S Y M O N O R E T U E D

DEUTERONOMY
 ECCLESIASTES
 ESTHER
 EXODUS
 EZRA
 GENESIS
 JOB
 JOSHUA
 JUDGES
 LEVITICUS
 NEHEMIAH
 NUMBERS
 PROVERBS
 PSALMS
 RUTH

Bamboozable

MESS +MESS +MESS	paint276 paint514 paint693	ha rm on y
IpoiseV	WHIRL	teNrr net sight

Commonym (1)

What's a commonym you ask? A commonym is group of words that have a common trait in the three words/items listed. For example: the words; A car - A tree - An elephant.. they all have trunks. These will make you think!

1. A Ball - A Fish - A Cold
2. A Ball - A Salad - A Coin
3. A Cork - A Question - A Balloon
4. A Bottle - A Baseball Player - A Mushroom
5. A Bell - Mouth - A Shoe
6. A Tug of War - The Nightly News - A Boat
7. Seventeen - Time - People
8. A Basketball Court - A Highway - A Bowling Alley
9. Fog - A Jack - A Body Builder
10. A Hockey Game - A Restaurant - A Bank

NEWS FROM AROUND QUEENSLAND

News from Cairns

We will meet again on **Saturday, 21 September** and **Saturday, 7 December** at the **Cairns RSL Club, Esplanade** at **11.00am**. If you are visiting Cairns, you are most welcome to join us. For more information, please contact Donna on 0414 397 462.

News from Townsville

Townsville MG lunch - **Saturday, 17 August 2019, 12 noon** The Avenues Hotel, Kirwan. For details contact Daphne on 0400 778 637 or daphclay@gmail.com

News from Mackay

For information for the Mackay region, please contact Muriel on (07) 4954 1221.

News from Gladstone-Wide Bay Region

For local support in the Gladstone – Wide Bay region, call Garth on 0408 155 954 or (07) 973 7983.

News from the Sunshine Coast

Our next gathering will be on **Friday, 2 August** at **Kawana Bowls Club** at **10am** for a cuppa and chat. Hope to see you there.

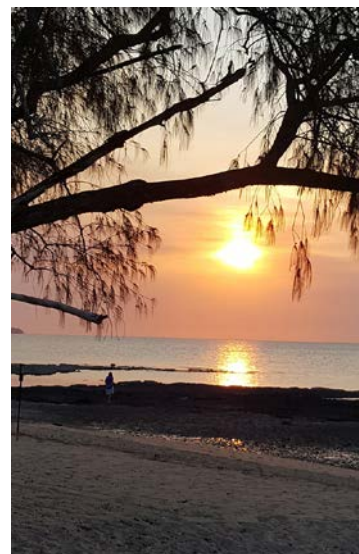
For more information about the Sunshine Coast group, call Colleen on 0409 491 789 or email colleen4551@gmail.com

News from the Gold Coast

Hi everyone. Gold Coast MG group had their regular friendly coffee-chat get-together, exchanging experiences in Southport Sharks Club on Saturday 29th of June.

Our next MG meeting will be on Saturday, 24 August, in Kurrawa Surf Club in Broadbeach. I will miss seeing you all due to overseas travel but our member Angela Brosnan (0427 752 956) will be there to greet you

I look forward to seeing you all again in the following meeting get together on **26 October** in **Southport Sharks Club**. Cheers Nader GC coordinator 0415 834 401.



News From Brisbane

Coffee & Chats are a good opportunity to connect with people in your area. All are welcome.



- Burpengary** Sunday, August 11 **at POSTPONED**
Sunday, 10 November at 2pm
The Coffee Club, 164-166 Station Road
- Cleveland** Sunday, 22 September at 2pm
Fiction Bar, 152 Shore Street West, Raby Bay
- Nundah** Sunday, 13 October at 3pm
The Royal Hotel, 1259 Sandgate Road
- Ipswich** Friday, 25 October at 10am
Queens Park Café, 10A Merle Finimore Avenue
- Wide Bay – Burnett (Hervey Bay)** Tuesday 17th September at 10.30am
The Coffee Club Stocklands, 6 Central Avenue, Pialba

For more information, Contact Anita on 0414 588 312

WHERE IN QUEENSLAND?

Let us know where you think it is:

May Edition: From Cooktown Lookout

Send to: info@mgaq.org.au or post to MGAQ, PO Box 16, Mt Gravatt, Qld, 4122

what's
coming up

What's On	When Is It	Where Is It?
MAA MYASTHENIA GRAVIS CONFERENCE 2019	SATURDAY 3 AUGUST, 2019	TRI Conference Facility within the Princess Alexandra Hospital Woolloongabba, Brisbane
MGAQ INC ANNUAL GENERAL MEETING	SUNDAY 15 SEPTEMBER, 2019	Aspley Hornets Football Club, 50 Graham Road, Carseldine