



# Messages



Myasthenia Gravis Association of Queensland Inc

**SEPTEMBER 2011**

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**

P.O. Box 16  
MT. GRAVATT QLD 4122  
NATIONAL FREE CALL:  
1800 802 568  
ABN 92 055 613 137

E-mail: [mgag@gil.com.au](mailto:mgag@gil.com.au)  
Internet: [www.mgag.org.au](http://www.mgag.org.au)

### **COMMITTEE MEMBERS**

*President*  
Anita JACKSON  
Ph. 3800 4913

*Vice-president*  
JOHN NOBLE  
Ph. 3269 5066

*Secretary and Editor*  
Graeme PETERS  
Ph. 3288 4484  
email: [graeme.peters2@bigpond.com](mailto:graeme.peters2@bigpond.com)

*Treasurer*  
Susan WHITE  
Ph: 3358 1056

*Information Officer*  
Shirley JOHNSTON  
Ph. 1800 802 568

#### *Committee*

Bill SYNNOT  
Ph. 0418196707

Carol BUCHANAN  
Ph. 4773 7122

PATRON  
Dr Cecilie LANDER  
Neurologist  
Founder Member, of Brisbane

## **PRESIDENT'S REPORT**

### *Welcome*

Well what a great day we had for the AGM at Club Pacific. We welcomed new members who had not been to anything before and we all met Dr Jean Foster from WA. Dr Foster gave us a very informative talk about 'Getting the most out of your doctor'. Many questions were asked and a good time was had by all. I would like to thank the new members for their efforts in coming to the AGM as some of them travelled quite far. I hope that they got some valuable information about MG and that they will form good friendships amongst the other members. I also like to thank Dr Jean Foster for her time in coming to Queensland for our AGM and hope that she enjoyed her visit.

The Vice President position was filled by John Noble and I would like to welcome him to the committee. I would again like to take this opportunity to personally thank Kris Klitgaard for all the support and knowledge that he has brought to the committee for many years. He will be sorely missed.

13th November 2011 we are travelling to Club Helensvale on the Gold Coast for a 'Meet the Members' meeting so looking forward to meeting our members who reside in the Coast region and anyone who would like to travel to the Gold Coast. This is a very informative and casual meeting as the committee introduce themselves and tell a story of their MG journey and then we open the discussion to the members. It is amazing what we find out about our members with their stories. We hope that someone will actually write one for the Newsletter as this helps other members, especially ones who have been newly diagnosed, to hear about your journey.

We are still looking for coordinators in the regions to look after our members by either meeting for coffee or just over to someone's home for a chat.

Take care

*Anita*

**Editor's Notes:** Shirley is back on deck at answering the 1800 phone calls. Many thanks to Carol for stepping up to the plate while Shirley was indisposed.

Supported by



**CHAT LIST:**

Each member of our Management Committee is happy to speak with you, while the following members, who include MG sufferers or their carers have offered to join our Chat List. If you have a need to have a yarn, particularly about how MG affects you, please ask if it is convenient to talk, and respect the privacy of those whom you call.

In the interests of one's privacy, we have not listed surnames. Do not be embarrassed by ringing a stranger and asking to speak to say, "Fred or Mary". If you wish to disclose your surname, that is your prerogative. Simply explain that you are a MYASTHENIC or a CARER.

Remember there is also the FREECALL telephone number for Australia manned (or is it womanned?) by Shirley and is 1800 802 568. Please do not hesitate to call if you feel the need. If the 1800 802 568 is not answering, please leave a message and Shirley will get back to you as soon as practicable. Your call is valuable to us, so please do not hang up without leaving a message.

**CHAT LIST – QUEENSLAND REGIONAL COORDINATORS**

HANNA	4054 4538	FAR NORTH QLD
CAROL	4773 7122	TOWNSVILLE
BILL	4954 1221	MACKAY
VACANT		ROCKHAMPTON
SHIRLEY	5443 1728	MAROOCHYDORE SUNSHINE COAST
JOHN / MARILYN	5532 4547	GOLD COAST
VACANT		BUNDABERG/WIDE BAY
VACANT		DARLING DOWNS

**CHAT LIST – QUEENSLAND REGIONAL MEMBERS**

JUDIE	0439 461288	AIRLIE BEACH
KELLY	4728 4913	AITKENVALE
JOHN	4783 1556	AYR
YVONNE	4783 4643	AYR
MARK	4067 1784	BABINDA
SARA	0422 109492	BLACK RIVER
HENRY	4982 6507	BLACKWATER
LYNDA	4159 2890	BARGARA
KELLY	4782 5542	BRANDON
PAMELA	4151 5499	BUNDABERG
ROBYN	5520 4242	BURLEIGH HEADS
MOYRA	5576 4979	BURLEIGH WATERS
PATRICIA	5535 0274	BURLEIGH WATERS
DENISE	4788 0798	BUSHLAND BEACH
AILSA	4055 1303	CAIRNS
DAVID	4053 2291	CAIRNS
RON / HELEN	4051 3286	CAIRNS
OWEN	4742 1190	CLONCURRY
CAROLYN	5472 0386	COOROY
BARRY	5483 1783	CURRA
GLORIA	5534 2669	CURRUMBIN
MELISSA	4662 3337	DALBY
GARTH	4973 7983	GLADSTONE
ELIZABETH	4936 2410	GLENLEE
LILLIAN	49334281	GRACEMERE
SHIRLEY	4128 3596	HERVEY BAY
ANGELA	0427752956	HOPE ISLAND
JAMES / ROSEMARY	5530 1558	HOPE ISLAND
GEOFFREY	5341 8747	LITTLE MOUNTAIN
TERRY	5494 2470	MALENY
RAY / MARY	5443 8667	MAROOCHYDORE
MAUREEN	5572 7993	MERMAID BEACH
ROBERT	5492 9754	MOOLOOLAH VALLEY
JOY	4165 4647	MUNDUBERRA
MICHAEL	5545 2802	NORTH TAMBORINE

DAVID	5474 5534	NOOSA
MARLENE	5447 4986	NOOSA HEADS
SHARON	4151 7661	NORTH BUNDABERG
TOM / SCOTIA	4693 3730	PITTSWORTH
BILL / COLLEEN	4926 2410	ROCKHAMPTON
DONALD	5563 7207	RUNAWAY BAY
KARLIENE	0432431591	SUNSHINE ACRES
HELEN	5445 4853	SUNSHINE COAST
DIANNE	4638 8447	TOOWOOMBA
HEATHER	4728 7550	TOWNSVILLE
JO	4723 8721	TOWNSVILLE
ANNE	0487305153	TRINITY BEACH
VALMA	4068 0702	TULLY
KATHLEEN	416178458	UPPER COOMERA
RAJKO	5556 0639	UPPER COOMERA
JAN	5493 4441	WURTULLA
PERLA	4939 2724	YEPPOON
IAN	4623 5169	YULEBAR

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### **Future Planned Activities**

Sunday 13 November 2011	'Meet the Members' at Club Helensvale, Gold Coast
Sunday 11 December 2011	Christmas function – Carina Leagues Club
Saturday 10 March 2012	'Meet the Members' at Mackay

More details will be published as each event becomes closer.

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### **Shirley's Recipe**

#### **PRAWN AND PEA PASTA**

#### **INGREDIENTS:**

375g spaghetti	400g raw peeled prawns
3 cloves garlic, crushed	2 tblsp olive oil
600ml thickened cream	250g punnet cherry tomatoes
1 cup frozen peas	½ bunch parsley, finely chopped

#### **METHOD:**

1. Cook pasta in salted boiling water. Drain.
2. Cook prawns and garlic with oil in a frying pan for 5 minutes, or until cooked.
3. Add cream, tomatoes and peas. Season with salt and pepper. Bring to boil.
4. Simmer for about 5 minutes, or until peas and tomatoes are tender. Stir in parsley.
5. Serve over pasta.

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### **MEMBERS' FORUM**

Bernie has another lesson to add to Bills' article on insurance claims for employment cessation because of myasthenia gravis:

Bernie's lesson is:

'Take nothing for granted and make sure the person you are dealing with has the necessary seniority, knowledge and authority. Insist on all information/advice is confirmed in writing...check it again on receipt.'

Please send in contributions to our 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 [graeme.peters2@bigpond.com](mailto:graeme.peters2@bigpond.com).

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.

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### QUOTATIONS TO PONDER

“Always forgive your enemies; nothing annoys them so much” – Oscar Wilde

“A successful man is one who makes more money than his wife can spend. A successful woman is one who can find such a man.” – Lana Turner

“A word to the wise ain't necessary - it's the stupid ones that need the advice.” – Bill Cosby

“Anyone who says he can see through women is missing a lot.” – Groucho Marx

“Between two evils, I always pick the one I never tried before.” – Mae West

“Fashions have done more harm than revolutions.” – Victor Hugo

“I am not afraid of death, I just don't want to be there when it happens.” – Woody Allen

“I don't think anyone should write their autobiography until after they're dead.” – Samuel Goldwyn

“I have never been hurt by what I have not said.” – Calvin Coolidge

“I have tried to know absolutely nothing about a great many things, and I have succeeded fairly well.” – Robert Benchley

“I spent a year in that town, one Sunday.” – George Burns

“I was born in very sorry circumstances. Both of my parents were very sorry.” – Norman Wisdom

“I would never die for my beliefs because I might be wrong.” – Bertrand Russell

“I'm an idealist. I don't know where I'm going, but I'm on my way.” – Carl Sandburg

“In Hollywood a marriage is a success if it outlasts milk.” – Rita Rudner

“My father had a profound influence on me. He was a lunatic.” – Spike Milligan

“Recession is when a neighbor loses his job. Depression is when you lose yours.” – Ronald Reagan

“The superfluous - a very necessary thing.” - Voltaire



The following is the text of the presentation by Dr Jean Foster to members at the AGM on Sunday 11 September 2011. The DVD of the presentation will be forwarded to all eligible members shortly:

## **GETTING THE MOST OUT OF YOUR DOCTOR**

*By: Dr Jean Foster General Practitioner*

It is important to understand how our health system works, in order to get the most from your Doctor. I purposely avoided a title saying how to get the most out of your *visit* to the Doctor, as I wanted to emphasise the importance of the ongoing nature of the Doctor:Patient relationship. This is particularly important in chronic diseases such as myasthenia gravis, which may go on for many years.

For most people, their most frequent contact with the medical profession is with GPs. Care from Specialists tends to be episodic, and may be one off (eg having your Gall Bladder out). For diseases such as MG, it is different, as there tends to be ongoing and possibly frequent care from a neurologist, and their role is much closer to that of the GP. However, it is important to have care from both the Specialist and the GP, as each have their own role.

The Rheumatologist or Immunologist is the person we turn to for the specialised care of this disease, as they have the detailed knowledge, kept up to date with research and contact with other specialists all over the world. Their focus is on their area of expertise, and they will refer you to other specialists if they need advice on particular aspects of your illness (eg a Dermatologist for skin problems, Renal Medicine Specialist for kidney complications, or an Orthopaedic Specialist if joint surgery becomes necessary.) These days, medicine has become so specialised that you may need to see one surgeon for your knee surgery, another for your shoulder surgery and yet another for your ankle surgery.

The increasing complexity of medical care is a double edged sword. The advantage is that we are able to do so much more than previously, with both surgery and medications. The disadvantage is that it is easy for the poor patient who is in the middle of this to get lost in the system, or become confused about what is happening with their treatment. This is where the role of the GP is so important. The GP is the Doctor who is best placed to see the big picture, and act as co-ordinator and overseer of treatment. The GP can check your medication list (which can be formidable!), explain what it was that specialist was talking about, help you navigate through the system, and act as an advocate when extra help is needed.

Seeing a GP is not just about medications and specific symptoms. It is also about having someone you can share concerns with, borrow their box of tissues when it all gets too much, or seek advice when you have a whole pile of Centrelink forms that need filling out. It is also important to have someone who is watching out for other health problems and carrying out preventive health checks. It is easy for these to be overlooked when there is a pre-existing serious illness.

The GP is the first port of call, the doorway to the rest of the health system. Even when you have ongoing specialist care, the GP can often arrange urgent appointments or discuss your care with the Specialist in case of acute flares.

Ideally, the Specialist and GP should work together to give you the best care. The specialist you are seeing may be in a Hospital Clinic, or you may see them privately in their own rooms. The Clinics are free of charge, as are the investigations that are carried out, but you may have lengthy waits, and you may see different Doctors. Seeing someone privately may be more expensive, but has the advantage that you always see the same Doctor, and it may be easier to get hold of them in an emergency. In either setting, the Specialist should keep your GP regularly informed, and if you feel you need help and are not able to get in touch with your specialist, your GP can help out.

Whilst on the topic of Hospital Clinics and Public Hospital care, an important issue is waiting lists for appointments or operations. If you are waiting to hear about an appointment, or a date for surgery, and all you get is deafening silence, it's worth checking with the Hospital or your GP, to make sure you haven't fallen off the system. If your needs have changed, and it has become urgent, your GP may be able to facilitate quicker treatment. If you are waiting for surgery at a major public hospital, it may be that the operation can be done sooner at one of the smaller public hospitals.

The following is a guide to finding and using your GP, but much of the information applies to specialists as well.

### 1. Finding a GP

Ask friends and neighbours who they like.

Make an appointment and find out if the Doctor is approachable, willing to answer questions, and gives you a clear explanation of your diagnosis, treatment and future plan of action. In General Practice, it is not always possible to make a clear-cut diagnosis. However, a good GP will explain that to you, and discuss ways in which the problem can be approached.

If the Doctor does not suit your needs, you may need to try another. Personality is also important: different patients like different doctors.

### 2. Stick to One GP

Once you have found a GP you like and trust, stick to them. It makes diagnosis and treatment very difficult if you go from one doctor to another and back again. If you feel your doctor has not addressed your problem adequately, talk to them about it. It may just be a breakdown in communication. Of course, you can seek a second opinion if you are still not satisfied, or after discussion with your GP you may both decide that a Specialist opinion is in order. You may request a referral to a Specialist at any time.

### 3. Making an Appointment.

If you are going for your first appointment, or you have a number of things to discuss, make a long appointment. Nobody enjoys the Doctor running late (least of all the Doctor!), and allowing sufficient time helps prevent this. Even with a long appointment, the Doctor may not have time to deal with all your problems adequately, and may ask you to come back for another appointment. Good quality modern medical care takes time, and a medical problem that is not clear cut may take quite a few appointments to sort out.

If you want other family members seen, make appointments for them as well, don't hope the Doctor will be able to "squeeze them in".

Ask at the time of making the appointment what the charges will be. A GP can choose to "Bulk Bill", which means that Medicare is billed directly. This costs you nothing, but means that the Doctor accepts a discounted proportion of the fee for the service. If you are privately billed you will get a rebate from Medicare, but have a gap to pay out of your own pocket. The receptionist will be able to tell you the policy on who is bulk-billed (usually Pensioners and disadvantaged people), and what the gap will be if you aren't bulk-billed. If you have a long appointment, the fee will be higher, but so is the rebate from Medicare, and in many surgeries the gap you pay tends to be much the same as for the lower fee.

It is up to you whether you take a friend or relative with you. It can be useful to have an extra pair of ears, as nobody ever remembers everything that is said in the consultation. However, don't take someone in with you if it is going to inhibit what you say to the Doctor.

### 4. What to Tell the Doctor

The Doctor will want to know the reason for your visit, and gain an understanding of what worries you the most, eg the Doctor might think you are worried about the cosmetic appearances of a mole, whereas you may not care what it looks like, but be worried it is cancer. Think about the visit beforehand to get it clear in your mind, and don't be afraid to make a list and take it with you. If there is too much to deal with in one visit, the list is a very efficient way of working out what needs to be done today, and what can be done next time.

If it is a first visit, the Doctor will want to know important past medical history, whether you smoke or drink, allergies to medications and what medications you are on now (including over the counter, herbal and homeopathic remedies). Again, a list can make things much easier and quicker. It is also useful to know about a family history of heart disease, high blood pressure, cancer, diabetes, glaucoma etc.

### 5. What to ask the Doctor

If you don't understand what the Doctor says, ask to have it explained again. We're not always very good at explaining things in plain language. If you have extra information, share it. For instance, if you belong to a support group, you will have access to plenty of good information, and there will be times when

you know more than the GP about *your* disease. Discuss it with your Doctor, as they have the training and knowledge to fit that information into the overall scheme of things. In that way your treatment becomes a partnership. The Doctor can also be a useful sounding board to discuss information you have gained from the Internet: information that can be good or bad.

#### 6. What about future visits?

Discuss with your Doctor how often they need to see you. This will depend on the illness and whether you regularly see the Specialist. You will also need to be seen for routine preventive health checks such as Pap Smears, breast checks, blood pressure, cholesterol, diabetes and skin checks. These have all been shown to be effective in preventing disease. There are other checks where the evidence is less clear cut (eg Prostate checks), and these can be discussed with the Doctor.

#### 7. Emergency Visits

Find out what the practice policy is. The ability of a practice to provide home visits when you are too ill to get into the surgery is an important part of good care. Try and give as much notice as possible that you need a home visit.

If you need an urgent appointment at the practice, you may need to see one of the other Doctors (if it is a group practice). The notes from your own Doctor should be available to the Doctor you are seeing, to ensure continuity of care.

For after hours emergencies, most GPs use the after hours emergency locum service. Some GPs do their own after hours calls for particular patients who are very ill or have very complicated medical problems. Another alternative is the After Hours GP clinics that are now available at a number of sites.

#### 8. Scripts

Try and do a stocktake before you see the Doctor, so that you know what medications you need. Most practices will do a script without seeing you, for a small fee, and only if you have been seen recently, and it is a regular medication. For instance, it is inappropriate to get an antibiotic script without being assessed: at best it is a waste if it was a viral infection, at worst a more serious condition may go undiagnosed. The Doctor will usually need 24 hrs notice to do a script, so that they can do it when they have finished seeing patients and have time to check your record.

If you regularly take medications it is very wise to stick with the same Chemist. They are a valuable source of information, and because they know what you normally take, they can alert you if the script doesn't seem correct.

One final piece of advice: If you aren't sure about something- ASK!

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### **NEWS FROM MACKAY**

Five members attended the midday lunch at the Boomerang Hotel on 14 August. All enjoyed the meal. We had a discussion about our next get-together and it was decided to hold it on Sunday 27 November at the North Mackay Bowls Club at noon for Christmas lunch.

Members had a discussion re the upcoming 'Meet the Members' in Mackay on Saturday 10 March 2012, and it was decided to check with the management of the Boomerang Hotel/Motel re cost, etc. I am waiting for their reply.

Bill Harris – Coordinator Mackay Region

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"If you talk to a man in a language he understands, that goes to his head. If you talk to him in his language, that goes to his heart." – Nelson Mandela