



MessaGes

Myasthenia Gravis Association of Queensland Inc



DECEMBER 2007

Myasthenia Gravis Asscn 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

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

E-mail mgqld@gil.com.au
Home page:
www.mg-qld.gil.com.au

COMMITTEE MEMBERS

President
Dennis JENNINGS (Townsville)
Ph: 4774 0029
0402 285520

Vice-president
Anita JACKSON
Ph. 3800 4913

Secretary and Editor
Graeme PETERS
Ph. 3288 4484
email: grapop@dodo.com.au

Treasurer
Kris KLITGAARD
Ph/Fax 3890 0115

Committee
Shirley JOHNSTON
Ph. 1800 802 568

John CHESTER
Ph. 3899 9387

Judie BARBOUR
Ph. 0439461288

PATRON
Dr Cecilie LANDER
Neurologist
Founder Member, of Brisbane

PRESIDENT'S REPORT

Hi Everyone,

I am back on deck after a short illness. Christmas is nearly here and I have not bought any presents - I hope you have as the rush is about to start.

If you are driving over the Christmas break, please do so with care and don't forget to take a break every couple of hours. I am off to Melbourne to have my 2nd Christmas with my granddaughter.

I was glad to see a great roll up to our Christmas gathering on the Gold Coast on the 9th December - it was fun so if you missed it make sure you attend next year. Thanks to John Nielson for his assistance on the day and to Mary Noble for the lucky door prize and to Judie Allison for the raffle prizes. And it was pleasing to see David Fairbrother from Far North Qld Group at the lunch.

With all the public holidays at this time of the year make sure you have all your medications up to date and not get caught trying to get some when the chemist is closed, and don't forget to take them amongst all the festivities.

Please keep articles coming in for our newsletter and also tell us about your Christmas tales.

The schedule of proposed functions for 2008 is published in this issue, and I encourage all to put the dates in your diaries and make the functions as successful as possible.

I will finish by wishing everyone a Merry Christmas and a Happy New year

Till next time

Cheers,
Dennis

PS As is the case every year, there will be no MessaGes published in January.

Shirley's Recipe

SPINACH AND PUMPKIN CURRY

Ingredients:

- | | |
|--|----------------------------|
| 2 medium onions chopped | 2 teaspoons minced garlic |
| 1 teaspoon minced ginger | ½ teaspoon minced chilli |
| 1 teaspoon ground coriander | 1 teaspoon ground cumin |
| ½ teaspoon ground tumeric | 1 teaspoon vegetable stock |
| 1 kg pumpkin, peeled and cut into small pieces | |
| 150g baby spinach, chopped coarsely | 1/3 cup fresh coriander |
| 1 tablespoon flaked almonds, toasted | 1 ½ cups water |

Method:

1. Coat a pan with cooking spray, heat and add the onion. Cook, stirring until softened. Stir in the garlic, ginger, chilli, ground coriander, cumin and tumeric. Stir for 30 seconds.
2. Add the pumpkin, water and stock. Simmer, covered, for about 15 minutes or until the pumpkin is tender. Stir in spinach and fresh coriander. Cook until spinach has just wilted.
3. Just before serving, sprinkle with the almonds.

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MEMBERS FORUM

There were no contributions for the members Forum this month.

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 grapop@dodo.com.au.

Your questions and responses may be anonymous for publication, but we will require your full name and address to be submitted to ensure genuineness. When forwarding a response, please refer to the issue or question raised so that we may correctly associate it to the issue or question.

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.

WHY WHY WHY

Why do we press harder on a remote control when we know the batteries are getting weak?

Why do they use sterilized needles for death by lethal injection?

Whose idea was it to put an "S" in the word "lisp"?

Introducing our other New Member of the Management Committee

Judie Barbour was appointed to the Management Committee at the Annual General Meeting held on August 26 2007. Judie has penned the following profile of herself so that our members will know more about her:

I was born and lived my childhood in the Flinders Ranges, South Australia. I am the 4th child in a family of 6 children.

Married at 18, I lived in Papua New Guinea with my husband and later our 2 children, for 10 years.

In 1993, I graduated as a Natural Therapist. It was at this time that I moved to Brisbane. I initially came for a 3 week holiday to celebrate my graduation, but fell in love with Brisbane and the Storey Bridge and decided to stay. Luckily I did stay, because it was in Brisbane that I met my husband Peter.

My working/career background has been predominately in the marketing field, however my personal interest has always been, and still is, natural medicine.

In 2002, my husband and I up-anchored (we live on a boat) and began what we hoped would be a life of cruising. We arrived in Airlie Beach 6 months later and I was having some health issues. Trips to doctors was frustrating to say the least. I kept being told that I was going through menopause, to take HRT and basically go away.

A trip to the dentist finally brought my symptoms to a head. Within 24 hours of a root canal treatment I was unable to speak properly and my general health was obviously deteriorating.

I finally choked and had to be rushed to hospital.

I was exposed to the regular tests and initially it was thought I had MS, however a young registrar, who had seen MG, insisted on a CT scan, which revealed a tumour of the thymus. The tumour was malignant and unencapsulated.

Having been an extremely fit and healthy person, this news was devastating. What ensued was a journey into the unknown, and one I do NOT wish to repeat.

First – plasmapheresis

Then – sternal surgery to remove the tumour and any thymic tissue

Then – back home to recover

Then – back to hospital because the drugs weren't keeping me stable. This stay in hospital lasted 8 weeks with 3 visits to ICU and being intubated.

Finally – 5 weeks of radiation

Having Myasthenia Gravis has certainly made me appreciate the worth of both allopathic and natural medicine. I still take Prednisolone and Imuran and receive 5 weekly Intragam infusions.

As well as these drugs I also take a range of natural medicines.

Ever since being diagnosed with Myasthenia it has been my goal to become more involved with the Association. Until recently, my health has been too unstable. Now 3 ½ years after my diagnosis, I feel well enough to take on new challenges.

At the recent AGM I met many lovely, warm and welcoming people. Thank you all for making my first meeting such an enjoyable experience. I thoroughly enjoyed the opportunity to chat over lunch and hear other people's stories. You are a great bunch of amazing and truly inspirational people.

Judie Barbour

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WORDS OF WISDOM

Birthdays are good for you. The more you have the longer you live.

If Woolworths is lowering prices everyday, how come nothing is free yet?

Ever notice that the people who are late are much jollier than the people who have to wait for them?

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The following article is reproduced from the website of the MGA (UK):

PSYCHOLOGICAL IMPACTS OF MYASTHENIA GRAVIS

Someone once said that life is what happens to you while you're busy making other plans. But what happens when your plans are interrupted by the diagnosis of MG? How you feel, how well you can cope, is determined by many factors such as who is around to help you (medically, physically and emotionally), such as the severity of your symptoms and how long they've been bothering you. For example, if you've had unexplained, distressing symptoms for a long time and finally found out what is causing them and what medications can alleviate your difficulties, you probably will feel somewhat relieved. For many other patients, however, the onset of illness and diagnosis of a disease that is not likely to disappear causes a great deal of anguish. How is a hard working executive looking forward to advancing his career going to feel when severe weakness slows him down. How is the mother of three young children going to cope? How is a child to feel when he can't keep up in gym and "be like other kids?"

The IMPACT PHASE

The time when myasthenia is diagnosed, is often characterised by fear and confusion and a sense of shock. "This can't be happening to me. There must be a mistake - a lab mix up, a doctor error". The doctor insists you've got MG and explains what the disease is, but your mind is a TV screen that keeps going blank. You hear the words and then they're gone. You may feel detached, as though this is all happening to someone else. Some people experience a temporary denial - they can't face the diagnosis head on all at once, so they ignore or minimise the implications of the diagnosis, forget to take medication and go "doctor shopping" to find a doctor who will tell them they are healthy. It can take a little while before the feeling of disbelief passes and reality sinks in. Now patients and families start asking "why me?" or "why us?"

Anger and resentment set in, but how do you attack a diagnosis? Some patients become angry with their doctors. Some families become angry with the patient. Both patient and family feel helpless and inadequate in the face of a powerful enemy. The diagnosis causes incredible changes. It seems like the person you were in the pre-illness days has disappeared.

You start to grieve for what you've lost. The person you'd hoped to be in the future may not come to be. Nothing seems certain any more, only the weakness which keeps reminding us that things aren't OK any more. Sadness and depression can set in.

This is the PERIOD OF TURMOIL

You know how people don't like to get dents in a new car. Well, such dents are trifles when compared to an "imperfection" in one's own body. The disease blemishes our health and reminds us of how vulnerable we are, how unpredictable life is. It may challenge our ability to remain independent and in control of our lives. We become "less than perfect" in a culture that places such an emphasis on physical perfection, health and fitness, athletic ability and independence. In addition, myasthenia is not quite like other disabling conditions such as amputations which are always obvious to others. Myasthenia is often an invisible disability. People tell you how wonderful you look and only you know how hard it is to keep your eyes open, to climb the front steps to your house or brush your hair or chew your meal. You feel different from others. Sometimes it is hard not to withdraw from people who don't have to worry about MG and who don't seem to fully understand what it is like to have MG. Other times, healthy people themselves have trouble dealing with the illness, and after their initial help and calls and flowers and cards, they withdraw. A sense of isolation sets in, and this can be more painful than the disease itself. Still, the illness won't go away. It forces changes between friends at home and at work. Yet even so, with time, most people learn to adapt. They may never accept the illness, but they learn to adjust to it and to reconstruct their lives.

RECONSTRUCTION

Means returning to the highest level of wellness you are capable of, psychologically and physically. It involves a realisation that inside one does not change because of a diagnosis. If you can only see the disease, you've become blind. Anyone with vision sees the person residing within. All has not been lost. One has to construct a satisfactory self image that incorporates the myasthenia.

The adjustment process may also involve role changes. It may require developing new skills and discovering new satisfying activities. It involves seeking relevant information from doctors, social workers, physical therapists. It involves eliciting reassurance and emotional support from family, friends and medical personnel. It involves pacing oneself and setting realistic goals. It involves identifying one's assets. More importantly, it involves the maintaining of a good sense of humour and the maintaining of hope. This doesn't mean that intermittent setbacks and depression can't or won't occur.

Any time there is a worsening of symptoms or hospitalisation, or the anniversary of the day you were diagnosed rolls around, or you visit the doctor, or you see others doing what you can no longer do - you can slip back into turmoil. Having myasthenia can be like riding an emotional roller coaster; one day you're feeling strong and your spirits are high, and shortly thereafter you are down in the dumps again. The relapses can be particularly taxing, and in periods of crisis, intense disappointment and sorrow have got to be expected. But these temporary setbacks don't mean the person has forfeited all claim to hope. What can you do to keep hope alive?

Here are what I call the 5C's - KEYS TO SURVIVAL

1. COPING ATTITUDE

Develop a positive attitude if you can and approach the disease as a challenge. Try to view yourself as a person with a problem, not as a person with troubles. People with troubles can only complain and be unhappy. People with problems can look for solutions.

2. CONTROL YOUR OWN DESTINY

Actively participate in your own care, and make decisions on your own to improve the quality of your life. If you feel a nutritionist would be a good idea, insist on a referral. You have the right to be heard and to be listened to, and the responsibility to make your needs known. Take charge of your life.

3. COMMITMENT

Commit yourself to a cause that is important to you, to something to give you value – whether it's your job, family, school, your health or a religious cause. Focus your energies on something or someone you care about.

4. CONFIDE IN OTHERS

Share the burdens of your illness, allow yourself to ask for help and accept periods of dependence when necessary. Admit when you hurt. Allow yourself to feel and know that you will heal. Vent the pent up emotions. Try to maintain a good relationship with your doctor, if possible, and with other members of your health care team. Contact fellow patients and friends. Try to preserve important relationships with relatives, in spite of all the stresses imposed on the family unit.

5. HAVE CONFIDENCE IN YOURSELF

Believe in your own abilities and inner strength. Seek all the information you can come by. Be an informed consumer. Use all the resources and knowledge available.

YOU HAVE TO BELIEVE IN YOURSELF

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KEEP YOUR BRAIN ACTIVE WITH THE TRIVIA QUIZ

Here are this month's questions for you to try. (Answers are at bottom of this page)

1. When is Queen Elizabeth II official birthday?
2. What nationality was the composer of 'Happy Birthday to you'?
3. What sign of the zodiac would you be if you were born on 1st January?
4. Amethyst is the birthstone for which month?
5. Who is the new Federal Minister for Education?
6. In which Australian state is Rameyah?
7. What is the longest word in the English language which can be typed using only the top row of letters on a standard typewriter keyboard?
8. A vexologist studies what?
9. Three shots under par in golf is called a what?
10. What is the capital of Mongolia?
11. Who won the 2007 Melbourne Cup?
12. What is the only fish that can blink with both eyes?
13. On which continent is Suriname?
14. In which classic TV show does the 'Tardis' appear?
15. In what year did Pat Cash win the mens' singles title at Wimbledon?
16. What is the floral emblem of Victoria?
17. Which bird is the bird emblem of West Australia?
18. What percentage of the area of Australia does Queensland occupy?
19. Which country is home to the 'Chrysanthemum Throne'?
20. How many feet in a fathom?

Answers: 1) 21st April; 2) American; 3) Capricorn; 4) February; 5) Julia Gillard; 6) Tasmania; 7) Typewriter; 8) Flags; 9) An albatross; 10) Ulan Bator; 11) Efficient; 12) A shark; 13) South America; 14) Dr Who; 15) 1987; 16) Common Heath; 17) Black Swan; 18) 22.5%; 19) Japan; 20) Six.



*The President and
Management Committee*

would like to wish



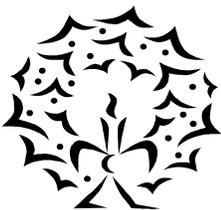
our Members,

their families and friends



*a joyous and safe Festive
Season*

and a



Happy and Healthy 2008