



Myasthenia Express

Myasthenia Gravis Manitoba Inc. March 2008

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Myasthenia Gravis Manitoba Inc.

Our next meeting will be held on March 20, 2008 at the St. Boniface Hospital in rooms AG 001 & 2 in the basement, south entrance, at 7.00 P.M. Our last meeting before summer will be held on May 15, 2008. Bring your family and friends and enjoy the evening.

We had our bake sale January 19, 2008 at Garden City Mall and it was very successful and we had a fabulous time. I would like to thank all the members who baked, worked at the sale and for those who could not attend or bake, thank you for your donations.

Presidents Report by Diane S.Kowaliuk

January 24, 2008 we had our Christmas Party at Club Regent, we started our evening with supper at the La Palmas. After supper some members played the machines and others went to listen to the free band playing. A great time was had by all.

We lost a very significant member to our executive and chapter, George Sinclair. George was very active in our chapter on the phoning committee. We would like to extend our sympathies to his family. We would

also like to thank George Sinclair family and friends for their donations made to our chapter in memory of George.

I would like to thank all members for their commitment and support they shared with one another and I would like to thank the executive for their support and commitment to this chapter.

The new year is upon us and I would like to try a new initiative, we ask each member to bring to the meetings a support person for them, which could be their family and/or friend We cannot stress how important that family and friends need to understand what a

Nutrition in Myasthenia Gravis

Alison Worwood and Kate Beamont

Alison Worwood is Senior Dietician, and Kate Beamont is Senior Speech & Language Therapist, at Kings Neurosciences Unit, Kings College Hospital

Swallowing problems (dysphagia) can be an early sign of Myasthenia Gravis and are often accompanied by ocular fatigue (drooping eyes).

Swallowing problems occur in approximately 33% of Myasthenia Gravis patients. This is a consequence of muscle fatigue associated with the disorder. Dysphagia may also occur during the treatment of Myasthenia Gravis, ie from steroid therapy.

In a study 30% of 175 persons with Myasthenia Gravis had oral, pharyngeal (throat) or laryngeal (voice) complaints.

- half of that 30% had swallowing disorders.
- 13% had dysarthria (slurring, fatiguing speech)
- 2% had dysphonia (voice disorders).

Swallowing severity can fluctuate and it is therefore important that swallow is assessed and closely monitored by a Speech and Language Therapist. In its mild form patients may experience:

- a mild sensation of food sticking in the throat whilst eating semi solids
 - liquids may be easier than solids
- coughing on dry, bitty consistencies
- difficulty with chewing
- these problems are worse with spicy foods.

Patients typically do well at the beginning of a meal but tire at the end. If swallow symptoms worsen then swallow may become too difficult and dangerous. This will be due to muscles fatiguing rapidly. Eventually patients may deteriorate to a point where there is total loss of ability to chew and swallow. As swallow fatigues food and drink may start to go the wrong way, ie into the windpipe, causing coughing and choking (aspiration), then the patient may be advised not to eat or drink at all until symptoms improve. They will be alternatively fed in accordance with the Dietician's recommendations.

Tips for easier eating and drinking

- When you experience swallowing difficulties a full assessment is advisable by the Speech and Language Therapist in your hospital. They can advise on safest consistencies, amounts and strategies.
- Exercises will not help Myasthenia Gravis sufferers as they increase fatigue. Conservation is the key point to remember and may make the difference between tube feeding and oral feeding.
- When swallowing is difficult it is advisable to take a runny puree diet.
- If swallowing is only mildly affected, take liquids and soft smooth diet. Foods best avoided are chewy, dry crumbly foods (eg toast, biscuits) spicy foods (eg curries) and foods of mixed consistencies, eg cornflakes with milk
- Alternate sips of liquid while eating. This may help prevent 'sticking' of foods. · The less you chew the better. Chewing will fatigue speech and swallowing muscles very quickly.
- Eat 'little and often' - small and frequent meals. A full meal will only cause fatigue and increase risk of coughing or cause discomfort during eating.

Signs of swallowing problems are :

- **coughing and choking on food and drink**
- **weight loss**
- **chest infections**

If you are suffering any of the above seek advice from Speech and Language Therapist and/or Dieticians via your Doctor.

Good Nutrition & Myasthenia Gravis

Eating well is important for all of us. As a result of swallowing problems, it is not uncommon to experience a loss of appetite and interest in food. This could lead to unintended weight loss and other nutritional problems. It is very important to try and maintain a good intake of food and fluids to enable the body to cope with treatments and to help recover.

Tips for maintaining your nutrition!

1. Because of the fatigue you may encounter, it is best to eat small meals and snacks 5-6 times a day.
2. When portions are small - it is necessary to make the food as nutritious as possible :
 - Include extra butter or margarine where possible, eg on vegetables, in mashed potato.
 - Avoid using 'low-fat or diet' products where possible.
 - Add sugar to deserts and cereals.
 - Use grated cheese, over vegetables, potato and pasta etc.
 - Don't worry too much about fruit and vegetables, a glass of fruit juice a day will provide enough Vitamin C.
3. Milk is a good base for snacks and meals throughout the day :
 - 'Double strength' milk can be made from using milk powder, and made with full cream milk instead of water. This can then be used for cereals, soups/sauces, milkshakes and milk puddings.
 - Be sure to drink at least one pint per day.

Advice for altering the consistency of the diet

For a soft diet

1. Keep foods moist by adding gravy, sauces to meat, or fish etc.
2. Prepare foods in a way that keeps them tender and easy to chew:
 - poached fish
 - mince or stew casserole meat
 - mashed vegetables
3. Bought or convenience foods can make good meals:
 - tinned macaroni cheese
 - frozen shepherds pie

- boil in the bag fish in sauce

Some food ideas for a soft diet:

Corned beef hash, scrambled eggs/omelettes, lasagne, ravioli, meatloaf and gravy, cottage cheese, cod in parsley sauce, cheese and potato pie. Custards, Ice cream, yoghurt, canned fruit without pips in syrup.

For a puree diet

1. There are very few foods that cannot be included in a puree diet. Regular meals can be adapted by adding extra liquid or stock. By adding liquid, the 'nutrient density' goes down, and food becomes less nutritious for the same volume : use as little additional fluid as possible.
2. All vegetables except string beans can be pureed. Remember to add butter or enriched milk.
3. Soup can be thickened with potato, yam or lentils - then pureed. Enriched milk or butter may be added also.
4. Fish in general is not suitable and should not be pureed.
5. Fish in general is not suitable and should not be pureed.
6. Variety is very important to tempt the appetite. You could try the following :
 - Use sauces such as Worcester sauce
 - Make white, cheese or parsley sauces to go with vegetables
 - Make puddings interesting by combining fruit puree with custard or yoghurt

Special dietary products

There are several good products available with or without a prescription. 'Build-Up' or 'Complan' make flavoured milk drinks. These are best used with full cream or enriched milk. They come in many different flavours and also in soup versions. There are other supplements available on prescription from your GP. These are more concentrated in their energy and protein, and have more vitamins/minerals. Examples : Fortisip, Ensure Plus, Entera. Maxijul powder may also be recommended - this adds energy to food in the form of a soluble powder, and may be added to a variety of foods such as fruit juice, milkshakes, custard, mashed potato, soup.

Tube feeding - Why is it Necessary ?

There may be times when the swallowing becomes so difficult and dangerous that it may be necessary for you not to eat, and to receive your nutrition via a small nasogastric tube. Nasogastric simply means nose-stomach. A very fine, soft tube is passed along the natural route into the stomach. A special nutritionally complete solution can be fed directly into the stomach preventing coughing and choking on food. It is possible to eat and drink with the tube in - only if this is advised by the Speech & Language Therapist. The change back to full oral diet - should be a gradual one - to make sure that all the nutritional requirements are met. If you have concerns about your diet or weight, ask to see your dietician.