COMMERCIAL IN CONFIDENCE

FINAL REPORT

The cost to patients and the community of Myasthenia Gravis

Understanding the patient experience and community wide impact

Prepared for
Myasthenia Gravis Association of Queensland, Inc

November 2013

THE CENTRE FOR INTERNATIONAL ECONOMICS
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Summary

Myasthenia Gravis (MG) has a discernible and challenging impact on the lives of those living with the disease, as well as their carers, and the wider community.

Quality of life can be severely impacted by MG. Patients incur direct financial costs due to the impact on employment and need for assistance with everyday living.

The community at large incurs direct costs also — health system costs can be extensive and workforce participation and productivity is compromised by the symptoms of sufferers.

This report seeks to promote awareness and understanding of the direct and indirect costs of MG to fill crucial information gaps and encourage greater emphasis on understanding the disease and improving the quality of care provided to those who need it.

Understanding MG — a difficult and debilitating condition

Myasthenia Gravis is a chronic neuromuscular autoimmune disease that affects the use of muscles. MG weakens the body's voluntary muscles, most commonly causing double vision, slurred speech, breathing difficulties, fatigue, and an inability to use limbs.

MG can affect anyone.

Based on the first comprehensive Australian survey of patients with MG, symptoms can occur from as young as 2 years of age, with the mean age of onset being 43.4 years for women and 53.4 years for men. Diagnosis often comes long after symptoms are experienced, reflecting widespread under-diagnosis and misdiagnosis of the disease, with the average delay in diagnosis being 3.7 years for women and 1.9 years for men.

Quality of life is severely impacted by MG with everyday activities made difficult for MG sufferers due to the weakness in muscles, especially limbs:

- over 30 per cent of patients experience very severe symptoms requiring hospitalisation and/or intensive care
- driving ability is compromised for a third of MG sufferers
- lifting and carrying heavy objects and walking stairs is severely compromised for around 70 percent of patients and 50-60 per cent of patients cannot perform basic household chores such as cleaning and hanging washing
- close to 40 per cent of patients experience depression.

Financial costs to patients and carers

The physical and emotional consequences of MG directly impact on the capacity of patients to work, leading to low workforce participation and poor work performance.

According to the survey, 59 per cent of working age patients in paid employment stopped working for a period because of MG. Assuming a conservative total population of MG sufferers and average income losses reported in the survey, annual income losses could be in the order of $19 million. This could also lead to increased welfare payments for the Commonwealth Government, depending on eligibility of MG patients to disability support payments over and above payments that would ordinarily be received.

A third of patients also have symptoms severe enough to require help with daily activities, and of these half require continuous care and half require part-time care, with a median of 21 hours a week of assistance provided by carers or families.

In addition, a third of patients require their partner or spouse to be their primary carer, as they are no longer able to care for themselves. This imposes a financial burden on carers, who also need to adjust their work patterns and lifestyle to care for those for whom they are responsible.

Costs to the community

As well as compromising the quality of life for patients, MG patients are frequent and often intensive users of the health system. According to the extensive patient survey, most sufferers (91 per cent) receive ongoing medication and treatment, including hospital admission for tests, emergency care, and treatments including drugs, thymectomy and plasma exchange.

Almost all patients (92 per cent) require regular check-ups with neurologists or specialist.

Many patients require multiple therapies including drugs (immunosuppressants or cholinesterase inhibitors), surgery, plasmapheresis and IVIg. The cost of drugs and treatments for a chronic disease is high, particularly for those with severe symptoms. The most costly treatments include IVIg, and drugs such as mycophenylate mofetil and rituximab. Close to 20 per cent also use allied health and alternative therapy to help relieve symptoms.

The treatment of chronic diseases like MG can be very expensive.

- approximately $150 million is spent annually on the two blood exchange treatments received by MG patients (IVIg and plasmapheresis), although these treatments are given to patients with a wide range of conditions, only a small proportion of which would be for MG. According to the National Blood Authority, around 6-7 per cent of IVIg issued nationally was for patients with MG, implying costs in the order of $10 million annually[1]

[1] National Blood Authority 2012, National report on the issue and use of IVIg 2010-11, http://www.blood.gov.au/sites/default/files/documents/nba-ivig-annual-report-10-11-amended-dec-2012.pdf.

- the most common drug given to MG patients is Mestinon, with an annual cost to the Pharmaceutical Benefits Scheme (PBS) of $1.1 million
- the next most commonly used pharmaceutical is Prednisone, with a total annual PBS cost of $28.8 million, although only a small proportion of which would be for MG
- the most expensive drugs include MabThera ($2 521 per script for the most common concentration) and Cellcept ($186 per script for the most common concentration, compared to $10 per script for Prednisone, which is the more common immunosuppressant prescribed)
- significant treatment costs also occur when MG patients require admission to hospital. These costs can include admission to intensive care, positive pressure ventilation, artificial feeding, physiotherapy, dietetics, speech therapy, frequent – possibly twice daily – plasma exchange, high doses of medication. Hospital admission can also result from surgery to perform a thymectomy. Three methods can be used and include an open chest procedure, key hole and robotic surgery. An additional fee of $3 000 is incurred for use of the robotic equipment. Radiotherapy treatment may be required after some thymectomies.

The main drivers of health service costs are age and co morbidities. MG is an autoimmune disease, making patients susceptible to other autoimmune diseases. Seventy-two per cent of MG patients have autoimmune (including inflammatory, osteoporotic and thyroid) and immune (infectious) related co-morbidities.

In addition to taxpayer funded health care costs, financial costs to society from MG also include productivity losses, with MG leading to an increase in sick leave (up 42 per cent for MG patients) and negative impacts on work performance (experienced by 69 per cent of patients).

MG symptoms also restrict the choice of employment for patients with 45 per cent of patients choosing employment they would not otherwise because of the need to accommodate symptoms, and a third of patients changing their occupation after diagnosis.

2 Understanding MG

This report demonstrates the scale and scope of impacts that MG has, and in doing so, raises awareness and promotes understanding of the need to undertake further research on the disease to mitigate the costs for patients, their carers, and the wider community.

Background to the report

The purpose of this report is to promote awareness and understanding about the direct and indirect costs for patients, carers, and the wider community of Myasthenia Gravis (MG) — a chronic neuromuscular autoimmune disease that affects the use of muscles.

It is widely acknowledged that there is a lack of research on the cause of MG, causes of severe symptoms, and methods to manage the condition including treatments and prevention. For example, it was only recently found that the thymus plays a role in the development of MG, however, this role itself is not clear.[2]

This report is based on the analysis of the first comprehensive Australian survey of patients with MG undertaken by the Myasthenia Gravis Association of Queensland, Inc (the 'Association') and the University of Queensland (UQ). Aside from this survey, there is no MG specific data set available in Australia, and this report fills crucial gaps in research and information about the patient experience and the costs of MG.

Table 2.1 summarises the characteristics of respondents to the survey. These characteristics have been examined to assess drivers of impact and variance. The relevant patient profile descriptors captured in the survey are set out in Appendix table A.1. Data has also been classified across a broad set of direct and indirect economic cost descriptors (table A.2) to facilitate this analysis. A summary of the data from the survey, including the number of respondents per survey question, is provided in table A.3.

2.1 Summary of respondents

Age	Female	Male	Persons
Oldest age	99	87	99
Youngest age	11	29	11
Average age	62	67	64
Total sample	**109**	**81**	**190**

Source: The CIE analysis of survey data from UQ and MGAQ, (2011), Myasthenia Gravis Survey: 2011

[2] Raica, M. Cimpean, A. M. and Ribatti, D. 2008. Myasthenia gravis and the thymus gland. A historical review. Clinical and Experimental Medicine, 8(2).

2.2 About the survey

This report is based on independent analysis by the Centre for International Economics of survey results from 190 patients that currently suffer from MG.

The Survey was distributed by the Association through various avenues. All members received a copy, the participating Specialists and other supporting Neurologists throughout Qld, NSW and WA assisted. Promotion occurred via the internet, facebook and media reports. Collection of surveys is on going with Queensland being the original target now expanded to Australia wide. Survey responses were returned to senior neurologists at the Royal Brisbane Women's Hospital and UQ who oversaw the data entry and validation of the survey results.

The Association in conjunction with Neurologists at UQ and Sydney University designed the survey. It aimed to gather information on the diagnostic process, to explore the range of treatments used and their efficacy, to capture the environmental and health factors that can influence the disease and its impact on patients, their family/friends and resultant quality of life. Socio-economic data was also collected. The survey design captured a wide range of trends and links within myasthenics with both quantitative and qualitative questions.

What is MG?

MG is a chronic neuromuscular autoimmune disease that affects the use of muscles. For patients with MG, the normal communication between the nerve and the muscle is interrupted at the neuromuscular junction (where the nerve cells connect the muscles). The body produces autoantibodies that block the regular function of the muscles and nerves. The result is muscle weakness that increases during periods of activity, and improves after periods of rest. Such symptoms are fluctuating in nature and severity.[3]

There is still much that is not known about MG with respect to the risk factors associated with developing the condition and for exacerbating the symptoms. This report draws on evidence from the patient survey on potential links with other diseases (particularly other autoimmune disorders), surgery, medical treatment and drugs to the financial, social and emotional impact of MG.

3Myasthenia Gravis Association of Queensland, Inc. Myasthenia Gravis: A comprehensive guide to living with and understanding this manageable condition. Myasthenia Gravis Association of Queensland Inc.

Symptoms include weakened voluntary muscles affecting eyesight and breathing

MG weakens the body's voluntary muscles and the types of muscle groups MG affects include ocular (eye), ocularbulbar (eye and head/neck) or generalised (limbs).[4] Individuals are affected differently and some symptoms are experienced more than others. According to the survey, 88 per cent of respondents have experienced symptoms in the past 12 months.

Those with bulbar or respiratory symptoms are at risk of a myasthenic crisis that occurs when respiratory muscles are weakened and a ventilator is required for breathing, which can be triggered by infection, fever or an adverse reaction to medication. Eight per cent of respondents in the survey have reported that they have required a ventilator in the last 12 months, 77 per cent of these patients were aged 50 or over. Overall, 19 per cent have reported that they have ever required a ventilator due to MG.

Those with ocular weakness experience weak or droopy eyelids of which 55 per cent of respondents have experienced in the last 12 months, and 45 per cent experience weakness in eye movements such as double vision. Those with bulbar or ocularbulbar weakness can have trouble talking (45 per cent), chewing (40 per cent), swallowing (40 per cent) or holding up their head (31 per cent). In generalised MG, weakness spreads from the face and neck to the upper limbs, hands and then lower limbs.

The most common symptoms experienced by respondents were general fatigue (73 per cent), followed by weak hands/arm muscles (68 per cent) and weak legs (65 per cent).

There is evidence that the thymus gland plays a role in MG as the thymus teaches the immune cells (T-cells) to recognise self from non-self. The survey data indicates that 18 per cent of the respondents had a thymoma (thymic tumour), which is in line with the rate of thymoma found in other MG patients of around 15 per cent.[5]

Co-morbidities are commonplace for MG patients due to a misbehaving immune system

Autoantibodies block receptors responsible for the normal functioning of neurotransmitters at the neuromuscular junction, this impaired function of the neurotransmitters leads to weak muscles. It is known that the thymus plays a role in the development of MG, the thymus is responsible for educating the immune system (T-cells) in distinguishing foreign substances from self. [6] The impact of this is that a single patient will often be suffering from a multitude of other illnesses at any one time.

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[4] Muscular Dystrophy Foundation: Australia, 2012. Facts about Myasthenia Gravis. Muscular Dystrophy Foundation: Australia

[5] Muscular Dystrophy Foundation: Australia, 2012. Facts about Myasthenia Gravis. Muscular Dystrophy Foundation: Australia

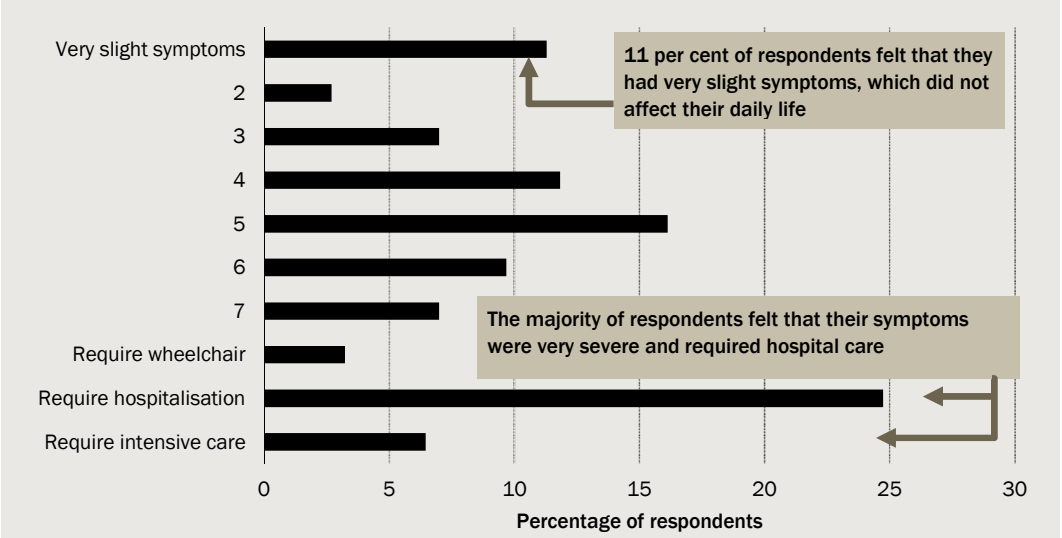
[6] Raica, M. Cimpean, A. M. and Ribatti, D. 2008. Myasthenia gravis and the thymus gland. A historical review. Clinical and Experimental Medicine, 8(2).

Symptoms at diagnosis

The severity of symptoms would fluctuate over time and even during the course of one day. For some patients, the worst period of symptoms could have been experienced many years in the past, and for others it is yet to be experienced.

The survey asked respondents how serious they felt their symptoms were when the disease was diagnosed. The severity rating was ranked from 1 to 10 with 1 meaning 'very slight symptoms (did not affect daily life), 8 meant 'require wheelchair', 9 meant 'require hospitalisation' and 10 meant 'require intensive care'. Chart 2.3 shows that a significant proportion of respondents felt that their symptoms were very severe with 31 per cent responding 9 or 10. Further, 11 per cent of respondents felt that at diagnosis, their MG symptoms did not affect daily life and 16 per cent rated the severity of their symptoms at 5.

2.3 Severity of symptoms at diagnosis as rated by respondents



Data source: The CIE analysis of survey data from UQ and MGAQ, (2011), Myasthenia Gravis Survey: 2011

Profile of the MG population

There is no definitive estimate of the number of people with MG in Australia because of the challenges associated with underdiagnoses and misdiagnosis of the condition.[7] MG is often misdiagnosed as Chronic Fatigue Syndrome and it is estimated that there are 500 people across Queensland alone that have the condition.[8]

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[7] Vincent, A. Clover, L. Buckley, C. Evans, J. G. and Rothwell, P. M. 2003, Evidence of underdiagnosis of myasthenia gravis in older people, Journal of Neurology, Neurosurgery and Psychiatry with Practical Neurology, 74.

[8] Annie Ruess, 2012, Myasthenia Gravis – a rare autoimmune disease often misdiagnosed, 612 ABC Brisbane, 13 August, accessed 6 June 2013 < http://blogs.abc.net.au/queensland/2012/08/myasthenia-gravis-a-rare-autoimmune-disease-often-misdiagnosed.html>

International research for Western countries shows that MG affects two to seven out of every 10 000 people.[9] Gattellari, M et al. (2012) estimated the annual crude prevalence rate of 1.117 per 10 000 Australians as having symptomatic MG, which based on a national prescribing database to determine the prescriptions for Pyridostigmine Bromide (a drug used to treat MG with generic name Mestinon) in 2009.[10]

This method of estimating prevalence underestimates the total number of MG sufferers, many of whom do not use Mestinon to treat their MG.

The survey found that in the last 12 months only 28 per cent of respondents used this drug. Further, the Gatteralli study only refers to patients with symptomatic MG, however, the fluctuating nature of MG means that it is possible to avoid symptoms requiring medication in a given year.

MG can affect anyone. According to the survey, the age of onset of symptoms ranged from 2 to 83 years. Fifty-seven per cent of respondents were female, and 43 per cent were male.

MG most commonly affects women under the age of 50 (66 per cent) and men over the age of 50 (67 per cent) (chart 2.4). This aligns with the literature where young adult women (under 40) and older men (over 60) are mostly affected.[11]

Table 2.5 indicates that the average years of delay of diagnosis for MG in females in 3.7 years and in males in 1.9 years. This delay between the time when MG symptoms are first experienced in an individual and when a specialist formally diagnoses it illustrates the scope for misdiagnosis and underdiagnoses of the disease.

The mean age of onset of MG symptoms in females is 43.4 years and in males is 53.4 years, below that of formal diagnosis when the mean age of diagnosis of MG in females is 47.1 years and males 55.3 years. Most people with MG can expect to have normal or near normal life expectancy and in some cases go into remission. Based on the survey, 24 per cent of the respondents are currently in remission, of these 18 per cent have been in remission for over 20 years.

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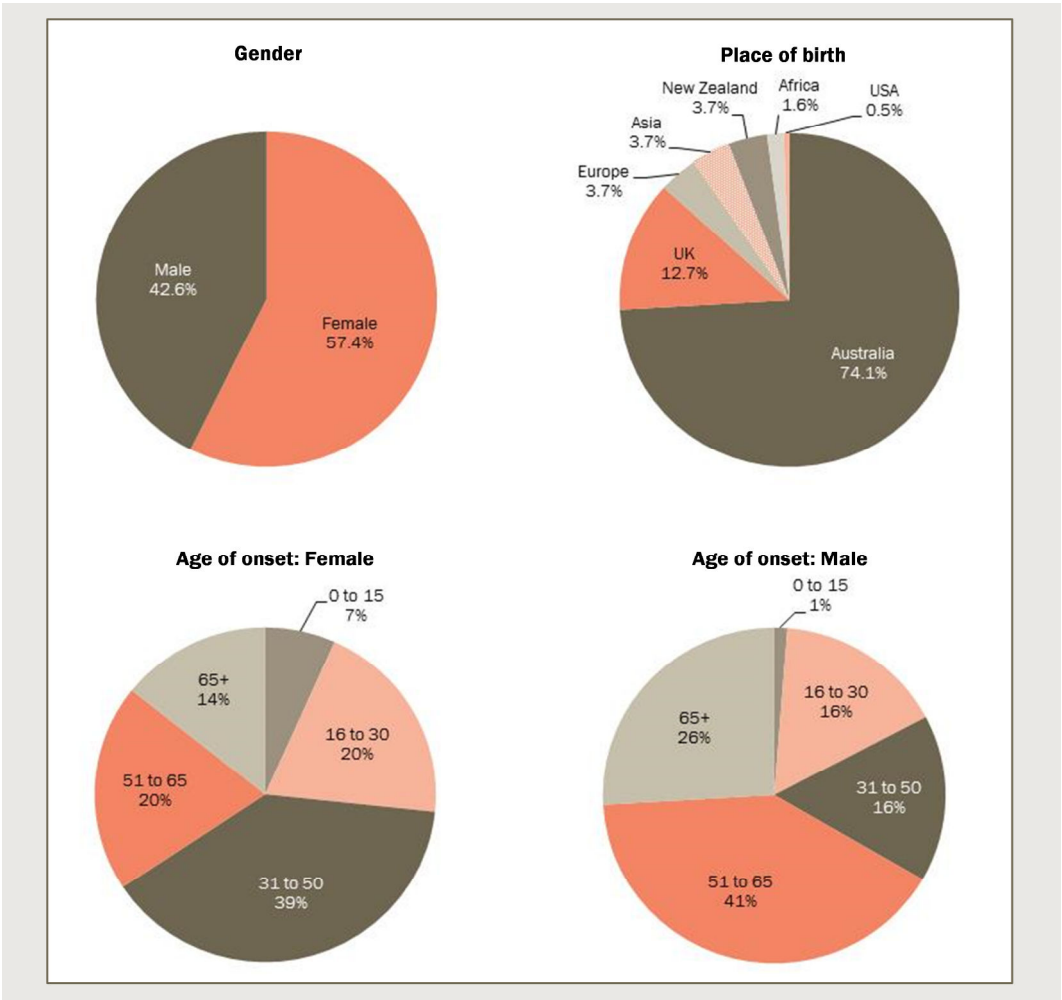
9 Muscular Dystrophy Foundation: Australia, 2012. Facts about Myasthenia Gravis. Muscular Dystrophy Foundation: Australia

10 Gattellari, M. Goumas, C. and Worthington, J. M. 2012. A national epidemiological study of Myasthenia Gravis in Australia, European Journal of Neurology, 19.

11 Myasthenia Gravis Association of Queensland, Inc. Myasthenia Gravis: A comprehensive guide to living with and understanding this manageable condition. Myasthenia Gravis Association of Queensland Inc.

2.4 Profile of the MG population



Data source: The CIE analysis of survey data from UQ and MGAQ, (2011), Myasthenia Gravis Survey: 2011

2.5 Delay in diagnosis of MG

	Female	Male
	Years	Years
Mean age of onset age of symptoms	43.4	53.4
Mean age of diagnosis	47.1	55.3
Average years of delay of diagnosis	**3.7**	**1.9**

Source: The CIE

3 Direct and indirect costs of MG

MG patients are frequent and often intensive users of the health system.

Ninety-one per cent of patients require ongoing medication and treatment. The largest financial costs result from the frequent need for emergency department care and hospital admission for tests and treatments including medication, thymectomy and possibly radiotherapy plasmapheresis and IVIg.

Most (92 per cent) of patients require regular check-ups with neurologists or specialist.

Many patients require multiple therapies including drugs (immunosuppressants or cholinesterase inhibitors), surgery, IVIg and plasma exchange. Some patients (19 per cent) also use allied health and alternative therapy to help relieve symptoms.

The main drivers of health services costs are age and co-morbidities. As MG is an autoimmune disease, patients are susceptible to other autoimmune diseases, and ageing exacerbates the impacts of symptoms and treatments.

There are numerous costs due to MG borne by the patient, their carers, their families and the community.

These costs include the direct costs such as use of health services, use of alternative treatments, financial impacts on patients and the impacts on carers and families.

Indirect costs include drivers of health care use including age and co-morbidities, societal costs and quality of life impacts.

Chart 3.1 depicts the various direct and indirect costs associated with MG.

Costs to the health system

MG patients require a range of health services, which vary depending on the severity of symptoms and the age of onset. After initial diagnosis by a neurologist, patients can be given a variety of therapies including drugs, IVIg, surgery to remove thymus (radiotherapy/chemotherapy if there is a thymoma) and plasma purification treatments. MG patients also typically require allied health services to relieve symptoms including physiotherapy and speech therapy, and alternative health therapies including massage and acupuncture.

MG is a chronic disease with symptoms, and is managed throughout the life of the patient.

3.1 Flow chart of the direct and indirect costs of MG

Data source: The CIE

Diagnosis services

Diagnosis typically involves a neurologist ordering diagnostic tests. Most patients have antibodies to AChR (Acetylocholine receptors) and others can be tested for antibodies to Muscle Specific Tyrosine Kinase (MuSK). Further, fatigue can be measured electrically using Single Fibre Electromyography (SFEMG) and CT scans to detect thymoma in the thymus.[12]

[12] Myasthenia Gravis Association of Queensland, Inc. Myasthenia Gravis: A comprehensive guide to living with and understanding this manageable condition. Myasthenia Gravis Association of Queensland Inc.

Neurologist and specialist services

Symptomatic MG patients generally visit their neurologist or specialist regularly. The majority of patients (92 per cent) have had at least one check-up within the past two years.

The average number of check-ups with a neurologist or specialist is 6.1 over two years, although 30 per cent of respondents see a neurologist or specialist between 6 to 10 times over two years.

Fees for neurological consultations vary depending on the type of consultation required, with fees listed on the MBS ranging from $109.90 to $319.65.[13]

For illustrative purposes only, the cost of specialist consultations is conservatively estimated at just over $300 000 annually, assuming 92 per cent of patients see a specialist every two years at a midpoint cost of items listed on the MBS.

Treatment costs

Patients with MG often require hospital treatment with most patients (62 per cent) requiring admission to hospital due to MG, for a myasthenic/respiratory crisis involving ventilator or feeding tube, surgery, other treatment (plasma exchange) or tests. Of the respondents who had ever been admitted due to MG, the mean number of admissions was 3 and the most visits was 50.

Most patients (91 per cent) require ongoing medication and treatment.

MG is an autoimmune disease, and one of the treatments is immunosuppressant therapy to lower the immune response and reduce symptoms. Of all the medical treatments for MG, almost half (47 per cent) of the types of treatments are immunosuppressant drugs including Prednisone, Azathioprine, Cyclosporine A, Mycophenolate mofetil and Tacrolimus. The second most common therapy was the use of cholinesterase inhibitors, including Mestinon and Neostigmine (30 per cent), these drugs help return the acetylcholine levels back to normal and boost the signals between the nerve and muscle. Other drugs made up 7 per cent of treatments used in the past 12 months.

Other treatment options, which and can feel quite invasive, are expensive, time-consuming and hold certain risks (such as blood clots forming), include:

- plasmapheresis (received by 8 per cent of patients receiving a treatment in the past 12 months) which is a blood purification procedure,
- Intravenous Immunoglobin (IVIg) (33 per cent of patients receiving a treatment in the past 12 months), which adds antibodies from a donor's plasma to the patient.

The treatment of MG can be very expensive, as shown in box 3.2.

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[13] Department of Health 2012, Medicare Benefits Schedule Book Category 2, http://www.health.gov.au/internet/mbsonline/publishing.nsf/Content/700EAEBE8BC5D5FECA257A0F0017617F/$File/201207-Cat%202.pdf

3.2 Various costs of treating MG

The treatment of chronic diseases like MG can be very expensive.

Approximately $150 million is spent annually on IVIg and plasmapheresis. For IVIg, approximately $10 million is estimated to relate specifically to treatments for MG patients each year.

Most pharmaceutical treatments received by MG patients would be listed on the Pharmaceutical Benefits Scheme (PBS). The most common drug given to MG patients is Mestinon, with an annual cost to the PBS of $1.1 million, most of which would specifically be for the treatment of MG. According to the survey, 72 per cent of patients used Mestinon in the past year.

The next most commonly used pharmaceutical is Prednisone, used by 68 per cent of MG patients in the last year, with a total annual PBS cost of $28.8 million. Only a small proportion of Prednisone use would be for MG (as would be the case with other immunosuppressant drugs), with the drug used to treat other autoimmune diseases and assist in organ transplantation.

Most other drugs used to treat MG are also be used to treat other autoimmune conditions as well as for use in chemotherapy treatments for cancer. For instance, the most expensive drugs include MabThera ($2 521 per script for the most commonly prescribed concentration), which is an antibody therapeutic used to treat cancers, and Cellcept, which has a high unit cost ($186 per script for the most commonly prescribed concentration) compared to immunosuppressants such as Prednisone ($10 per script for the most commonly prescribed concentration). The annual cost to the PBS in 2010 for Cellcept and Prednisone was $16.4 million and $28.8 million respectively.

Other treatment costs relate specifically to the hospital stay for MG patients, such as the cost of Neostigmine (Prostigmin), a cholinesterase inhibitor administered in Intensive Care Unit for very severe cases, and the procedure of thymectomy, which in some cases involves radiotherapy, although would only occur once per patient.

The average length of public hospital stay for patients with MG and other myoneural disorders is 1.8 days, or 9.2 days excluding same day separations.

Source: Drug Utilisation Sub-Committee for the Department of Health and Ageing, (2012), Australian Statistics on Medicines 2010, Canberra; AIHW (2012), Australian Hospital Statistics 2009-10; AIHW (2012), Australian Hospital Statistics 2010-11. Health services series no. 43. Cat. no. HSE 117.

Table 3.3 summarises the annual expenditure on drugs and treatments, a proportion (albeit small) of which would relate to MG.

3.3 Annual drug and treatment cost for MG patients in 2010

Drug/Treatment[a]	Annual cost (MG and other uses)	Use by MG patients	Other uses
	$'000	Per cent	
Pyridostigmine Bromide (Mestinon) (most of which would be to treat MG patients)	1 124	72	Mainly MG, orthostatic hypotension
Prednisolone (Prednisone) (only a small proportion of which would be used by MG patients)	28 792	68	Other autoimmune conditions and organ transplantation
Azathioprine (only a small proportion of which would be used by MG patients)	8 435	38	Other autoimmune conditions and organ transplantation
Mycophenolate mofetil (Cellcept) (only a small proportion of which would be used by MG patients)	16 389	18	Other autoimmune conditions (lupus) and organ transplantation
Methotrexate(only a small proportion of which would be used by MG patients)	7 658	9	Chemotherapy, autoimmune conditions
Rituximab (MabThera) (only a small proportion of which would be used by MG patients)	122 054	6	Hematological cancers (leukemia), autoimmune conditions, organ transplantation
Cyclosporine A or Cyclosporin (only a small proportion of which would be used by MG patients)	11 480	3	Other autoimmune conditions and organ transplantation
Cyclophosphamide (Cytoxan) (only a small proportion of which would be used by MG patients)	1 652	2	Chemotherapy (hematological and solid tumours), autoimmune conditions
Tacrolimus (Prograf) (only a small proportion of which would be used by MG patients)	8 728	1	Other autoimmune conditions and organ transplantation
Intravenous Immunoglobulins (IVIg, Intragam, Octagam) for all patients requiring blood exchange (around $10 million of which is expected to be attributable to MG patients)	149 000	33	Immune deficiencies (hypogammaglobulinemia), autoimmune conditions (immune thrombocytopenia), acute infections (sepsis)
Expected cost for MG patients	*9 800*		
Plasmapheresis for patients with neurological conditions	3 203	8	Other neurological autoimmune conditions

Note: Major other autoimmune conditions include rheumatism, Crohn's disease, thyroiditis, multiple sclerosis, and lupus.

Source: Drug Utilisation Sub-Committee for the Department of Health and Ageing (2012), Australian statistics on medicines 2010, Canberra. Australian Health Minister's Conference (2012), Criteria for the clinical use of intravenous immunoglobulin in Australia. Second Edition, Canberra: Commonwealth of Australia; AIHW (2012), Australian Hospital Statistics 2009-10.

Surgery can also be required to remove the thymus (thymectomy), especially for patients with thymoma. Thirty-seven per cent of patients surveyed have had a thymectomy, however, only 49 per cent of these respondents has a thymoma. A thymectomy is performed to remove a thymoma but it can also reduce the severity of symptoms, this is particularly an option for younger patients.

Most patients receiving a thymectomy for thymoma will also undergo either radiotherapy or chemotherapy to help destroy the cancer cells. Of the patients that had a thymoma and received a thymectomy, 94 per cent also received radiotherapy, 3 per cent also received chemotherapy and 3 per cent received both radiotherapy and chemotherapy.

Use of alternative treatments

In some cases, 45 per cent of patients have ever sought relief of MG symptoms from allied health therapy and alternative therapies. Only 19 per cent of patients have used any form of allied or alternative therapies in the past year.

Physiotherapy is the most common form of allied therapy (received by 45 per cent of patients receiving allied treatments), followed by a dietician (23 per cent), occupational therapy (17 per cent) and speech therapy (13 per cent).

The most common form of alternative therapy is massage (39 per cent), acupuncture (27 per cent), herbal medicines (15 per cent) and naturopathy (15 per cent).

Drivers of health costs

One of the main drivers of health costs incurred because of MG is the relatively older age of the respondent cohort. For instance, the average PBS costs for a person aged 65-74 are more than twenty times greater than for an 15-24 year old, and public hospital cost are on average five times greater for the older group.[14]

According to the MG patient survey, 56 per cent are aged 65 and over, and are therefore more susceptible to other ailments and conditions that will require them to use the health care system. Another 27 per cent of the patients were aged 50 to 64.

In 2007, there were 2.4 million Australians aged 65-84 years, this is projected to grow to 4 million by 2022. [15] This ageing population will influence the number of years patients must live with symptoms but also complicate treatment options, including thymectomy not an option and contraindications with other drugs.

While the survey only recorded MG specific use of health services, the reality is that MG symptoms are likely to be exacerbated by age and co-morbidities and therefore health system use by MG patients is well underestimated.

Co-morbidities

It is common for an MG patient to have multiple co-morbidities at once, or over the course of their lifetime. The survey asked patients if they had any of the following selected diseases, with particular focus on autoimmune, infections and osteoporotic diseases.

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[14] Treasury (2007), Intergenerational Report 2007, http://www,treasury.gov.au/igr/IGR2007.asp.

[15] ABS, Australian Social Trends, March 2009 (4102.0).

The respondents identified over 90 different co-morbidities, this indicates the challenges of having a chronic autoimmune disorder. Table 3.4 illustrates the magnitude of diseases that MG patients suffer, it is common for patients to suffer from more than one type of disease, and for example, 89 respondents suffer from 122 cases of autoimmune disorders.

It should be noted that asthma, osteoporotic diseases and thyroid diseases all have a basis as an autoimmune conditions as in the cause is a malfunctioning immune system, which attacks the self, leading to inflammation. Thus, the total percentage of autoimmune (including inflammatory, osteoporotic and thyroid) and immune (infectious) related co-morbidity cases for MG patients is 72 per cent.

Thirty four per cent of patients have been diagnosed with other autoimmune diseases (minus allergies) including thyroid diseases. This is similar to results found in other studies (19.7 per cent).[16]

3.4 Other diseases that MG patients have ever being diagnosed

Disease	Example	Total number of cases reported	Number of patients with disease	Percentage of respondents with disease
				Per cent
Auto-immune disease	Systemic lupus erythematosus (SLE), Crohn's disease, rheumatoid arthritis, allergies and type 1 diabetes	122	89	48
Infectious disease	Glandular fever, Shingles (zoster), measles (including German measles), chicken pox, mumps and rheumatic fever	477	157	84
Inflammatory	Asthma	40	37	20
Osteoporosis and other joint diseases	Osteoporosis, osteoarthritis and osteopenia	56	55	30
Thyroid disease	Grave's disease, hyperthyroidism, hyperthyroidism, thyroid eye disease and Hashimoto's disease	26	22	12
Total autoimmune and immune diseases		721		
Cancer	Breast cancer, thymoma, cervical cancer, skin cancer	40	38	20
Lifestyle disease	Type 2 diabetes, heart disease, lung disease and high blood pressure	134	119	64

[16] The difference can be due to non autoimmune causes of thyroid dysfunction as some respondents did not specify if Grave's disease or Hashimoto's disease caused their hyperthyroidism or hypothyroidism respectively. Kanazawa, M. Shimohata, T. Tanaka, K. and Nishizawa, M. 2007, Clinical features of patients with myasthenia gravis associated with autoimmune diseases, European Journal of Neurology,14:12.

Disease	Example	Total number of cases reported	Number of patients with disease	Percentage of respondents with disease
				Per cent
Mental health problems	Depression	56	56	30
Other	Vitamin B12 deficiency or supplementation required and idiopathic thrombocytopenia purpura(ITP)	54	43	23
Total		**1005**		

Note: Total number of respondents to "other diseases" question is 186.

Source: The CIE analysis of survey data from UQ and MGAQ, (2011), Myasthenia Gravis Survey: 2011. Question "Do you ever being diagnosed with any of the following diseases?"

4 Costs for patients and carers

MG causes weakness in muscles, which makes simple activities difficult for sufferers.

Regular chores such as hanging the washing and general housework are impacted by MG as are everyday activities such as walking up stair.

Weakness of muscles extends not only to limbs but also to the mouth and eyes resulting in slurred speech and double vision. Driving is compromised for a third of patients.

MG causes stress and frustration in patients, and 37 per cent experience depression.

People with MG require more daytime rest as muscle weakness improves with inactivity, leading to less time spent on recreational activities and work.

A third of patients require their partner or spouse to be their carer as they are no longer able to care for themselves.

Living with MG, making simple things difficult

The symptoms of MG and the side-effects of treatments adversely impacts on patients quality of life. The hallmark of MG is weakness in muscles, thus even simple daily activities such as driving a car or cleaning the house are difficult.MG also impacts a patient's ability to work as they find it difficult to walk, write, lift heavy objects and speak.

According to the survey, 33 per cent of patients state that MG has affects their driving ability. Those unable to drive cannot see clearly (get double vision) or are not able to hold onto the wheel due to weak arms.

The household chores/daily activities that respondents found most difficulty in performing either often or sometimes include:

- hanging the washing (58 per cent)
- lifting and carrying objects (70 per cent)
- walking up stairs (67 per cent),
- cleaning windows (58 per cent)
- cleaning bathrooms (55 per cent) and
- vacuuming (53 per cent out).

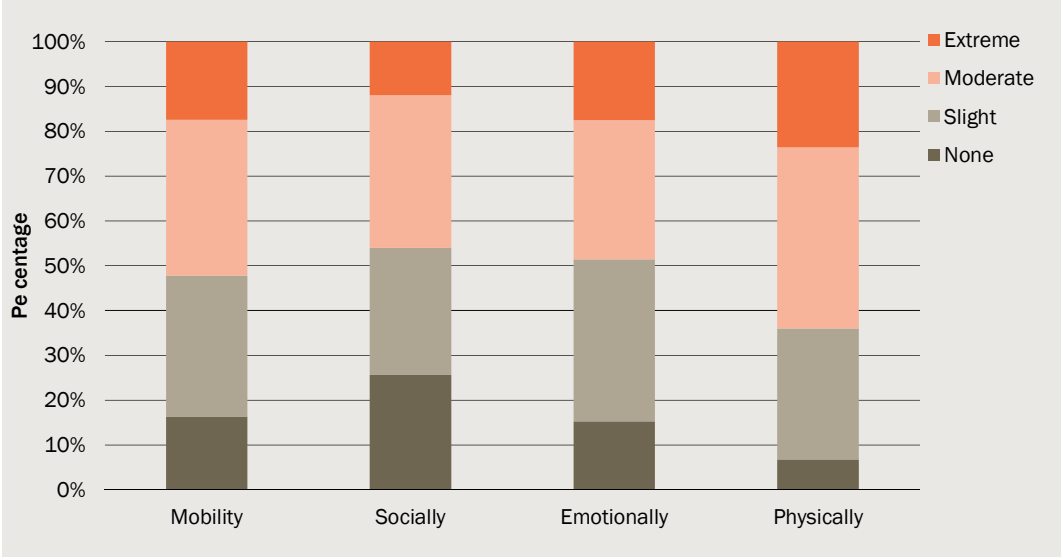
The survey asked patients if they needed someone to help with daily activities, 32 per cent of respondents (out of total 190) said they did, of these respondents, 47 per cent required continuous care and 53 per cent required part-time care. Only 36 respondents

provided detail on the hours of assistance they receive per week, a median of 21 hours a week of assistance is provided by carers or families.

MG imposes significant emotional and mental strains on a patient as a result of the frustration that patients experience. The survey asked respondents if since suffering from MG if depression had become an issue. Of the total respondents, 37 per cent have reported that depression is an issue. Feeling frustrated was a common concern of these patients with a respondent reporting that the 'unpredictability of MG symptoms causes frustration'. Of the patients that did report being diagnosed with depression, common treatments included anti-depressants, counselling and meditation.

The survey attempted to evaluate the impact of MG and its associated treatment on the lifestyle of patients. Chart 4.1 shows the categories of lifestyle including mobility, socially, emotionally and physically. Unsurprisingly the category that affected patients the most (moderate or extreme impact) was physically (64 per cent), followed by mobility (52 per cent), emotionally (49 per cent) and socially (46 per cent).

4.1 Impact on life-style of having MG and associated treatments



Data source: The CIE analysis of survey data from UQ and MGAQ, (2011), Myasthenia Gravis Survey: 2011.

Boxes 4.2 and 4.3are case studies of people living with MG, highlighting the impacts of symptoms, treatments and the effect on their families and friends.

4.2 Case study 1: Marion, Tasmania

Marion's experience of MG

'I now know about IVIg [infusion of antibodies], immunosuppressants and steroids. The latter I had been taking since 2004 for polymyalgia rheumatica [PMR], and it was when PMR resolved and the dose reduced to almost nothing that MG appeared with a vengeance. I know now that I'd had it for some years because of other mysterious symptoms unrelated to PMR, but it had been suppressed by prednisolone.

However, I digress. After 9 days of TLC and effective treatment I returned home nearly as good as new and within six months had reduced the steroid and ceased Mestinon [cholinesterase inhibitors], altogether. "No problem!" I thought, "Get it under control and life goes on as usual"…

…I managed the cold but my immune system found other things to do, and an on-call GP thought a huge dose of steroid was called for – the ambos next morning were wonderful …

Breathing with a respirator in ICU is an interesting adventure….After another week of IVIg, effective drug management and observation I went home just a little wobbly.

Still on the learning curve. Still taking Mestinon, high dose steroid and monthly IVIg to maintain equilibrium. Now considering a change of immunosuppressant, one that apparently has less than delightful other effects.'

Implications for MG patients

- Co-morbidities occurs in MG patients, Marion had polymyalgia rheumatic (PMR, an inflammatory immune disorder)
- Although Marion experienced 'mysterious symptoms' several years ago, the worst onset of MG symptoms can be rapid and severe.
- It is common for MG symptoms to fluctuate, Marion was able to 'get it under control' however her immune system was affected and had to receive emergency hospital care and is now managing her MG with treatments.
- It is common for patients to be treated with a combination of drugs (both cholinesterase inhibitors and immunosuppressant) and IVIg over the course of their life.

Source: Member Forum, MessaGes, February 2012, Myasthenia Gravis Association of Queensland, Inc.

4.3 Case study 2: Shirley Johnson, Queensland

Radio interview on 612 ABC Brisbane by Terri Begley to Shirley Johnson of the Myasthenia Gravis Association of Queensland, Inc.

Shirley's experience with MG

'..those very subtle symptoms to start off with and each time you go to the GP and present with the symptoms …for me blamed on something else. It took me 3 years to get a diagnosis…

..Well I started off with small doses of Mestinon [cholinesterase inhibitors] and … gradually increasing to more higher doses, and then I had a thymectomy, and taken off the Mestinon, had a plasmapheresis [plasma exchange] and was put on high doses of Prednisone [immunosuppressant] which I stayed on more or less for several years..

..I have been in remission totally without any medication … for 22 years'

Implications for MG patients

- It can be difficult to get a diagnosis for MG, the symptoms are misdiagnosed as other conditions such as fatigue.
- It is common for patients to be treated with a combination of drugs (both cholinesterase inhibitors and immunosuppressant) , removal of thymus and plasmapheresis for many years.
- Some patients are able to go into remission without the need to take any medication/treatment.

Source: Myasthenia Gravis – a rare autoimmune disease often misdiagnosed 13 August 2012, audio file accessed 6 June 2013< http://blogs.abc.net.au/queensland/2012/08/myasthenia-gravis-a-rare-autoimmune-disease-often-misdiagnosed.html>

The quality of life impacts imposed by MG relate to the patients being unable to do what an able-bodied individual can. Table 4.4 illustrates this by comparing the current activity load of patients to prior the onset of MG symptoms.

Respondents reported a drop in household duties of on average 5 hours a week. Recreational activities remained similar between now and prior to MG becoming a health issue. The time in daytime rest increased by an average of 7.5 hours per week, this was the only activity to have a positive change, this coincides with the fact that patients require rest or inactivity to restore the use of their muscles.

The changes can also be attributed to the advanced age of some of the respondents, this would reduce their household work hours and increase their need for rest.

This can lead to financial impacts for patients that are more likely to need to purchase cleaning and care services to assist them with everyday living.

4.4 Change in everyday life of MG patients

	Prior to symptoms of MG	Current activity load	Change in activity load
	hours/week	hours/week	hours/week
Household duties	20.6	15.4	-5.2
Recreational activities	12.1	12	-0.1
Daytime rest period	7.6	15.1	7.5
n	145	148	

Note: Mean hours/week of activities

Source: The CIE analysis of survey data from UQ and MGAQ, (2011), Myasthenia Gravis Survey: 2011. Question "What is your current activity load for a typical week?"

Given the fluctuating nature of MG symptoms, patients will often require care from another person, with a third of MG patients identifying their major carer as spouse/partner rather than themselves, and 5 per cent being primarily care for by another family member, friend or professional carer.

Box 4.5, illustrates the range of challenges that families of MG patients face.

4.5 Survey comments about family and carers

- Comments on partner or spouse:

  'My wife has health problems and is not able to cope with my health problems.'

  'Have to look after my husband (80) as well as cope with illness.'

  '[Spouse] Have to pick up house duties when not well or after plasma exchange.'

  'Caused partner considerable stress.'

  'Has to help with mobility and housework'

  'Negative when MG is at its worst.'

- Comments on Children, parents, siblings, grandchildren

  'I think they like to see I don't let it get me down and I'm not going to let MG beat me.'

  'They do not understand extent of effects of disease.'

  'MG caused change of schools [for children], financially difficulty.'

  '[Parents] scared but very supportive.'

  '[Daughters] ensuring correct medical attention.'

These comments reflect that there is still a lack of understanding of the disease and its symptoms by patient's families, in particular, the fluctuating nature of the symptoms.

Source: Patient comments from UQ and MGAQ, (2011), Myasthenia Gravis Survey: 2011

5 Impacts on workforce participation and income

More than half of working age MG patients have to stop working for a period because of their MG symptoms.

When MG patients are able to continue working, symptoms reduce working hours by an average of 5.5 hours per week. Combined with the impacts of a loss of work and reduced capacity to work, income losses of around $40 000 annually have been reported. MG also adversely affects the level of assets of patients.

The financial costs to society from MG relate to productivity losses, with MG leading to an increase in sick leave (which is up 42 per cent for MG patients because of their symptoms) and negative impacts on work performance (experienced by 69 per cent of patients).

MG symptoms also restrict the choice of employment for patients with 45 per cent of patients choosing employment they would not otherwise because of the need to accommodate symptoms, and a third of patients changing their occupation after diagnosis.

Financial strain, lost wages and reduced employment opportunity

MG often prevents patients from working. The treatment of symptoms can be very time-consuming and expensive, in particular for plasmapheresis and IVIg, which includes regular (monthly) hospital visits. Further, the side effects of the treatment options can also cause patients to stop work.

Table 5.1 shows that respondents reported a drop in work (both full-time and part-time) of almost 5 hours per week after MG symptoms appeared. These reduction in hours working will cause financial strain on patients. The number of respondents who are in paid employment (either full-time or part-time) is 35 per cent out of the total sample. The working age proportion of the sample was 43 per cent, that is, respondents aged between 15 and 65. Of the respondents within the working age group, 68 per cent are currently in paid employment (including self-employment).

5.1 Change in work load for MG patients

	Prior to symptoms of MG	Current activity load	Change in activity load
	hours/week	hours/week	hours/week
Full-time work	46.4	41.8	-4.6
Part-time work	22.7	17.8	-4.9

Note: Mean hours/week of activities

Source: The CIE analysis of survey data from UQ and MGAQ, (2011), Myasthenia Gravis Survey: 2011. Question "What is your current activity load for a typical week?

According to the survey, 59 per cent of working age patients in paid employment stopped working for a period because of MG.

Assuming a conservative total population of MG sufferers of 2 574[17] and average income losses reported in the survey ($41 505.22 per patient per year), annual income losses could be in the order of $19 million.

This could also lead to increased welfare payments for the Commonwealth Government, depending on eligibility of MG patients to disability support payments over and above payments that would ordinarily receive.[18]

Captured in this cost would be working age respondents that reported a reduction in capacity to perform work (less work rather than no work).

Hence, MG results in a reduction in working hours, a reluctance to enter higher paid professions, and an inability to advance into roles that are more senior.

Table 5.2 also highlights the average percentage reduction in income and asset levels from MG. The average reduction in income levels due to MG was 39 per cent and the average reduction in asset levels from MG was 16.4 per cent.

5.2 Reported financial impacts of MG

	Number of respondents	Sample size	Percentage
			Per cent
Respondents of working age in paid employment	55	81	67.9
Respondents that have ever stopped working due to MG	71	122	58.2
Average change in income levels from MG	61		-39
Average change in asset levels from MG	36		-16.4

Note: Sample size of respondents in paid employment refers to the number of respondents within the working age group (15 to 65 years). Some respondents to the income and asset level change question did not specify if the change was positive or negative, and only the provided the percentage, this reduced the sample size of responses.

Source: The CIE analysis of survey data from UQ and MGAQ, (2011), Myasthenia Gravis Survey: 2011. Question "Are you currently in paid employment (including self-employed)", "Have you had to stop working because if MG?" and "If possible, please indicate the impact (percentage change) of MG on your income, assets and debts?".

17 Gattellari, M. Goumas, C. and Worthington, J. M. 2012. A national epidemiological study of Myasthenia Gravis in Australia, European Journal of Neurology, 19. In 2009, 2 574 people prescribed to Pyridostigmine (Mestinon), these are symptomatic and treated MG patients. It is expected that there are more Australians with MG.

18 Maximum Disability Support Pension for a single person is $733.70 a fortnight.

Box 5.3 highlights comments by patients on their ability to carry out work.

5.3 MG impacts on ability to carry out work (paid and unpaid)

Respondents were asked about whether MG modified their ability to carry out both paid and unpaid work. The comments over affected responsibilities highlight the unique difficulties imposed on patients, including:

- 'Unable to drive long distances to go to training and conferences.'
- 'Eye strain – cannot stand for too long – muscles go weak, get tired.'
- 'Have had to cease a well-paid on call job-couldn't do night call outs. Can still do my work (as a GP) but part-time. Sold practice and now employed (less work, less stress). Due to lupus as well.'
- 'Music performance capabilities impacted due to effect on hands + breathing. Can no longer stand to lecture + electric wheelchair needed to move around building. Access is the major issue.'
- 'Unable to work, even as volunteer.'
- 'Repetitive computer use affects hands; talking for long periods affects mouth/facial muscles.'
- 'Could not use microscope while double vision present; difficult to teach.'
- 'Could not undertake a 9 to 5 job as I get too tired. Also have IVIG monthly.'

Source: Patient comments from UQ and MGAQ, (2011), Myasthenia Gravis Survey: 2011

Costs to society

Even for patients that can continue working, MG has a negative productivity impact on the economy as well as reduces the amount of income that patients can earn.

MG can influence a patient's career choice and change their careers to better suit their restrictions. Consequently, a patient may be in a career below their intellectual capabilities, missing out on a promotion or working less hours than they want to. Due to the severity of symptoms and the need for and subsequent impacts of treatments, MG can increase the amount of sick leave taken by an employee, reducing their productivity.

MG symptoms can greatly affect the work performance of patients; Table 5.4 shows that 69.1 per cent of respondents have had their performance impacted by MG. Some complaints included, "..stopping career progression", "lost my job as manager so going back to [being a] mechanic was not easy", "poor speech and sight severely hampered performance", "productivity was reduced" and "..fatigue, inability to meet deadlines".

Due to symptoms, employees are unable to progress in their careers or perform at their potential, this has resulted in respondents 'downgrading' their responsibilities and hours or leaving the work force entirely.

Another societal cost of MG is the influence it has on both the choice of an employees occupation and if it has caused them to change it. Chart 5.4 also indicates that 45.2 per cent of respondents reported that MG had influenced their job choice. Further, 33.3 per cent of respondents reported that MG had caused them to change their jobs.

Some examples of comments included:

- a 49 year old respondent who "cannot continue in chosen occupation [hairdressing] of 20 years",
- a 50 year old respondent that was "unable to have customer contact due to speech issues [at a retail bank], need low activity work load",
- a 36 year old respondent "used to be child-care worker, but couldn't pick babies up so had to redirect career" and had to move "from child-care to desk admin job",
- a 54 year old respondent had to change from a "full time to part time consultant",
- a 45 year old respondent has complained that their "sales speech has become difficult to manage" and is "in the process of moving from sales to admin role", and
- a 44 year old respondent "previously worked in financial markets/stockbroking" and has now "chosen sedentary flexible self-employed job".

MG is a chronic disease and symptoms are fluctuating, it is common for employees to require sick leave during bouts of symptoms and to recover from treatments. Forty-two per cent of working age respondents had taken sick leave in the last 12 months due to MG. Half of these respondents (50 per cent) required sick leave of 2 weeks or less, 23.5 per cent took 2 to 8 weeks and 26.5 per cent required more than 8 weeks of leave.

5.4 Productivity losses due to MG

	Number of respondents	n	Percentage
			%
Impact on work performance of working age respondents	56	81	69.1
MG influence choice of occupation	42	93	45.2
Change of occupation due to MG	34	102	33.3
Sick leave due to MG of working age respondents (last 12 months):	34	81	42
2 weeks or less	17	34	50
2 to 8 weeks	8	34	23.5
More than 8 weeks	9	34	26.5

Source: The CIE analysis of survey data from UQ and MGAQ, (2011), Myasthenia Gravis Survey: 2011. Question "Has MG impacted on your work performance", "Has MG influenced your choice of occupation?", "Have you had to change your occupation because of MG?" and "During the last 12 months have you had to take sick leave because of MG? If yes, for how long?".

A Survey data descriptors

The data of the survey respondents was analysed according to the following patient profile descriptors in table A.1.

A.1 Patient profile descriptors

Patient Profile	Descriptors
Patient Information	Gender, age, and place of birth (ethnicity)
Symptoms	Types of symptoms, age of onset of symptoms, age of diagnosis, severity of symptoms at diagnosis, remission

Source: The CIE

The survey data provided by UQ was analysed and categorised into various economic cost categories for the patient, carers, families and the community. These economic cost descriptors are listed in table A.2.

A.2 Economic cost descriptors

Cost	Type	Direct/Indirect
Check-ups by neurologist/specialist for MG in the past 2 years	Use of health services	Direct
Hospital Admissions	Use of health services	Direct
Treatment: ▪ Pharmaceuticals ▪ Surgeries (thymectomy) ▪ Radiotherapy and chemotherapy for thymoma ▪ Other treatments (IVIg and plasmapheresis)	Use of health services	Direct
Allied health therapy	Use of alternative treatments	Direct
Alternative medicine	Use of alternative treatments	Direct
Co-morbidities: ▪ Other autoimmune disorders including inflammatory diseases, osteoporotic diseases, thyroid conditions and immune diseases such as infections. Other diseases including cancer, lifestyle diseases, mental health problems and others.	Drivers of health care use	Indirect
Paid employment	Financial impacts	Direct
Percentage change of MG on income	Financial impacts	Direct
Percentage change of MG on assets	Financial impacts	Direct

Cost	Type	Direct/Indirect
Ever stopped work due to MG	Financial impacts	Direct
Percentage reduction in capacity to conduct work	Financial impacts	Direct
Loss of salary due to MG	Financial impacts	Direct
Main carer	Impacts on carers and families	Direct
Someone to assist with daily activities	Impacts on carers and families	Direct
Support: ▪ Continuous or part-time	Impacts on carers and families	Direct
Impact on family	Impacts on carers and families	Direct
Lower productivity: ▪ Impact on ability to carry out work, ▪ Impact on work performance ▪ Choice of occupation influenced by MG, ▪ Change in occupation due to MG, ▪ Increase in sick leave	Societal costs	Indirect
Lifestyle impact ▪ Mobility ▪ Socially ▪ Emotionally ▪ Physically	Quality of Life	Indirect
Impact on driving ability	Quality of Life	Indirect
Impact on performing household chores/activities ▪ Hanging washing ▪ Lifting and carrying objects ▪ Walking up stairs ▪ Cleaning windows ▪ Cleaning bathroom ▪ Vacuuming	Quality of Life	Indirect
Change in activity load after developing MG: ▪ Full-time work ▪ Part-time work ▪ Household duties ▪ Recreational activities ▪ Daytime rest	Quality of Life	Indirect
Depression	Quality of Life	Indirect

Source: The CIE

A summary of survey results including the question, number of respondents and answers is listed in table A.3.

A.3 Summary of survey results

Item	Number of respondents	Findings
Gender	190	Female 109. Male 81
Date of birth	183	Average age is 64 years. Max age is 99 years and Min age is 11 years. Number of respondents of working age is 81.
Birth details. Your place of birth	189	Australia 140, UK 24, Europe 7, Asia 7, New Zealand 7, Africa 3, USA 1.
What were the symptoms of MG that you experienced, - initially - ever experienced, ie since first symptoms - now, ie last 12 months	168	Now, ie last 12 months, number of people have experienced:Weak or droopy eyelids 92. Double vision 76. Weak hands/arm muscles 114. Weak legs 109. Weak neck 52. Weakness in face, cheeks or lips 66. Speech difficulties 76. Chewing difficulties 67. Difficulty swallowing 67. Breathing difficulties 74. General fatigue 123. Balance 70. Pelvic floor weakness 78. Difficulty with cough continence 63. Required feeding tube 4. Required ventilator 13. Required ventilator last 12 months aged 50+ is 11 (out of 13). Number of patients that ever required a ventilator 37 (out of 190).
On a scale of 1 to 10, how serious did you feel your symptoms were when the disease was diagnose? 1 = very slight symptoms (did not affect daily life), 8 = require wheelchair, 9 = require hospitalisation, 10 = require intensive care	186	1 (21). 2 (5). 3 (13). 4 (22). 5 (30). 6 (18). 7 (13). 8 (6). 9 (46). 10 (12).
How old were you when you first noticed symptoms of MG?	186. Female 105. Male 81.	Average age is 47.74 years. Max age is 83 years and Min age is 2 years. Female average age is 43.4 years. Male average age is 53.4 years.
How old were you when you were diagnosed with MG by a doctor?	189. Female 108. Male 81.	Average age is 50.6 years. Max age is 83 years and Min age is 2 years. Female average age is 47.1 years. Male average age is 55.3 years.
In the past 2 years, how often had you had check-ups with a your neurologist/specialist for MG?	181	Number of people who have had at least one visit is 167. Average number of times is 6.1. Max number of times is 25 and Min number of times is 0.
Have you had a thymectomy (ie is your thymus removed)?	190	Yes 70. No 120.
Did you have a thymoma	190	Yes 34. No 156.
If you had a thymoma, did you require extra therapy, eg - radiotherapy - chemotherapy	34	Number of thymoma patients who underwent thymectomy and radiotherapy 29. Number of thymoma patients who underwent thymectomy and chemotherapy 1. Number of thymoma patients who underwent thymectomy, radiotherapy and chemotherapy 1. Number of thymoma patients who had no therapy 3.
Are you in remission?	190	Yes 45. No 145.
Have you ever been admitted to a hospital because of MG?	190	Yes 118. No 72. Average total visits 3.
Since suffering from MG has depression become an issue?	190	Yes 70. No 120.

Item	Number of respondents	Findings
Have you ever had any of the following medicines or treatments for MG? Medical for MG: Initially. Ever. Last 12 months.	185	Number of patients who have used Medical treatments for MG 168 and the number of reported cases is 427 in the last 12 months. Last 12 months: Pyridostigmine (Mestinon) 121. Prednisolone (Prednisone) 115. Neostigmine (infusion only usually ICU) 5. Azathioprine (Imuran) 63. Cyclosporine A (Neoral) 5. Mycofenolate mofetil (Cellcept) 18. Rituximab (Mabthera) 10. Methotrexate 15. Tacrolimus (Prograf) 1. Cyclophosphamide (Cytoxan) 3. Intravenous Immunoglobulins (IVIg, Intragam, Octagam) 57. Plasmapheresis (plasma exchange) 13. Other treatments (please specify, Dexamethasone 1. Nexium 1.)
Have you ever had any of the following medicines or treatments for MG? Allied Medicines/Treatment for MG: Initially. Ever. Last 12 months.	190	Number of patients who have ever used Allied medicines/treatments is 85. The number of patients who have used Allied medicines/treatments in the last 12 months is 37 and the number of reported cases is 86. Last 12 months: Physiotherapy 24. Speech Therapy 7. Occupational Therapy 9. Dietician 12. Massage 13. Acupuncture 9. Naturopathy 5. Herbal medicines 5. Other treatments (Chiropractor 1. Hydrotherapy 1).
Do you ever being diagnosed with any of the following disease?	190	Total number of patients with other diseases 186 and 1005 reported cases. Type 1 diabetes 4. Rheumatoid arthritis and arthritis 10. Coeliac disease 6. Sytemic lupus erythamatosus (SLE) 7. Crohn's disease 4. Autoimmune hepatitis 3. Psoriasis 14. Asthma 34. Cancer 40. Allergy (includes hay fever) 52. Lung disease (not asthma) 10. Type 2 diabetes 32. Heart disease (heart failure) 19. Mental health problems (anxiety, depression) 56. High blood pressure 73. Pernicious anaemia 12. Vitamin B12 deficiency or supplementation required 24. Vitiligo 8. Osteoporosis 56. Measles 136. Mumps 99. Chicken pox 131. Shingles (zoster) 36. Glandular fever (infectious mononucleosis) 35. Cytomegalovirus 4. Toxoplasmosis2. Rheumatic fever 5. Scarlet fever 5. Others (please specify disease and/or symptoms) 62. Thyroid related diseases 26.
Who is your main carer?	184	Self 115. Spouse/partner 60. Other family members 4. Friend 1. Professional care 3. Others (Self/spouse/family 1).
Do you have someone to help with your daily activities?	190	Yes 60. No 130
Do you have someone to help with your daily activities? If yes	60	Continous Yes 28. Part Time Yes 32.
Do you have someone to help with your daily activities? If yes, Number of hours per day. Number of days per week.	36	Hours per week: Average 63.5. Median 21. Max 168. Min 1.
Has MG influenced your choice of occupation?	171	Yes 42. No 50. Not relevant 78. Don't know 1.
Have you had to change your occupation because of MG?	171	Yes 34. No 65. Not relevant 69. Don't know 3.
Have you had to stop working because of MG	122	Yes 71. No 51.

Item	Number of respondents	Findings
During the last 12 months have you had to take sick leave because of MG?	81	Findings are aged adjusted to working age (15 to 65). Yes 34.
During the last 12 months have you had to take sick leave because of MG? If yes, for how long?	34	2 weeks or less 17. 2 - 8 weeks or less 8. More than 8 weeks 9.
Are you currently in paid employment (including self-employed)?	190	Full time 31. Part time 24.
What is your current activity load for a typical week? Please specify number of days and hours)	148	No. of hours/week. Full-time work (Average 41.8, Max 84, Min 8). Part-time work (Average 17.8, Max 35, Min 1). Household duties (Average 15.4, Max 70, Min 1). Recreational activities (Average 12, Max 84, Min 2). Daytime rest period (Average 15.1, Max 168, Min 1).
What was your current activity load for a typical week before MG became a health issue? (please specify number of days and hours)	145	No. of hours/week. Full-time work (Average 46.4, Max 200, Min 25). Part-time work (Average 22.7, Max 60, Min 3). Household duties (Average 20.6, Max 119, Min 1). Recreational activities (Average 12.1, Max 84, Min 2). Daytime rest period (Average 7.6, Max 119, Min 1).
If MG has impacted on your capacity to work (both paid and unpaid), can you estimate the percentage reduction in your capacity to conduct this work? % reduction	47, 44 between 15 to 65.	Findings are aged adjusted to working age (15 to 65).Paid: Average 65.8 % reduction. Max 100 % reduction. Min 1 % reduction. Unpaid (including household chores): Average 55.1 % reduction. Max 100 % reduction. Min 5 % reduction. Excluding 100% reduction, 18 respondents out of 81 for paid work, with an average reduction of 51.94 per cent.
How much income (before tax) have you lost as a result of you having MG (please specify how many years and amount per year)?	43, 31 between 15 and 65.	Findings are aged adjusted to working age (15 to 65, total 81 respondents). Average $41 505.222 per patient per year. Max $120 000 per patient per year. Min $300 per patient per year.
Has MG impacted on your work performance?	190, 81 between 15 and 65.	Findings are aged adjusted to working age (15 to 65). Yes 56. No 25.
What has been the impact on your life-style of having MG and treatment? Mobility.	178	None 29. Slight 56. Moderate 62. Extreme 31.
What has been the impact on your life-style of having MG and treatment? Socially.	176	None 45. Slight 50. Moderate 60. Extreme 21.
What has been the impact on your life-style of having MG and treatment? Emotionally.	177	None 27. Slight 64. Moderate 55. Extreme 31.
What has been the impact on your life-style of having MG and treatment? Physically.	178	None 12. Slight 52. Moderate 72. Extreme 42.
What has been the impact on your driving ability	175	None 66. Slight 51. Moderate 28. Extreme 30.
Has MG impacted on doing household chores/activities? Hanging washing	177	Often 48. Sometimes 54. Rarely 25. Never 50.

Item	Number of respondents	Findings
Has MG impacted on doing household chores/activities? Lifting and carrying objects.	181	Often 73. Sometimes 54. Rarely 22. Never 32.
Has MG impacted on doing household chores/activities? Walking up stairs.	183	Often 62. Sometimes 60. Rarely 21. Never 40.
Has MG impacted on doing household chores/activities? Cleaning windows.	165	Often 65. Sometimes 30. Rarely 17. Never 53.
Has MG impacted on doing household chores/activities? Cleaning bathroom.	168	Often 60. Sometimes 33. Rarely 20. Never 55.
Has MG impacted on doing household chores/activities? Vacuuming.	169	Often 56. Sometimes 34. Rarely 21. Never 58.
If possible, please indicate the impact (percentage change) of MG on your income, assets and debts? Income level.	36	Excluded responses had no % change or had no direction of change. Average -39 per cent change. Max 20 per cent change. Min -100 per cent change.
If possible, please indicate the impact (percentage change) of MG on your income, assets and debts? Assets.	34	Excluded responses had no % change or had no direction of change. Average -16.4 per cent change. Max 20 per cent change. Min -100 per cent change.

Source: The CIE analysis of survey data from UQ and MGAQ, (2011), Myasthenia Gravis Survey: 2011

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