# Patient Decision Aid

## Myasthenia gravis - considering immunosuppressants

If your myasthenia gravis symptoms have become worse despite taking an acetylcholinesterase inhibitor the next step is usually to consider treatment with an immunosuppressant. There are several treatment options that may be considered, these include:

- Not taking an immunosuppressant
- Steroids (e.g. prednisolone) alone
- Azathioprine plus steroids
- Azathioprine alone
- Mycophenolate mofetil (MMF) plus steroids

### Not taking an immunosuppressant - benefits and risks

<table>
<thead>
<tr>
<th>Treatment option</th>
<th>Benefits</th>
<th>Risks or consequences</th>
</tr>
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</table>
| Not taking an immunosuppressant | No side-effects from immunosuppressants  
No need for regular blood tests or regular monitoring  
Immune system not suppressed and therefore no increased susceptibility to infections  
No need to take additional medicines to prevent side-effects such as osteoporosis | Muscle weakness may not be controlled and this may result in continuing symptoms such as muscle weakness, swallowing difficulties, or double vision  
Persistent symptoms can restrict your activities and interfere with your quality of life |

### Steroids alone - benefits and risks

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| Steroids alone | Achieves remission or good relief of symptoms in 40-80% of people  
Steroids have been used successfully for many decades to treat myasthenia gravis  
Most study evidence to support the use of steroids  
Achieves sustained improvement in symptoms and most people have a good quality of life  
Symptoms improve quickly (normally 2-4 weeks after starting treatment)  
Maximum benefit usually after 6-12 months | Treatment is usually taken long-term  
Symptoms may become worse in the first two weeks of treatment  
Long term use can have side-effects such as:  
- High blood pressure  
- Diabetes (may cause or worsen existing diabetes)  
- Osteoporosis (weak bones)  
- Cataracts  
- More likely to get infections that can be severe e.g. chicken pox/shingles  
- Weight gain  
People taking long-term steroids may need to take bisphosphonates and calcium supplements to prevent |
osteoarthritis

May need to take a medicine to prevent stomach/duodenal ulcers

Once clinical control is achieved you may be able to reduce the dose of steroids but few patients are able to come off steroids completely

Requires monitoring by your doctor e.g. blood pressure, blood glucose

Need to avoid live vaccines (e.g. rubella). However flu vaccines and Pneumovax© are not ‘live’ vaccines and are recommended

Need to carry a steroid card

Pregnancy – seek advice from your doctor if you are planning a family or become pregnant while take a steroid

### Azathioprine alone - benefits and risks

<table>
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<tr>
<th>Treatment option</th>
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<tbody>
<tr>
<td>Taking azathioprine alone</td>
<td>It has been used successfully for many decades to treat myasthenia gravis</td>
<td>Treatment is usually long-term</td>
</tr>
<tr>
<td></td>
<td>Taking azathioprine alone avoids:</td>
<td>When azathioprine is used alone it takes much longer for symptoms to improve:</td>
</tr>
<tr>
<td></td>
<td>• Steroids side-effects.</td>
<td>• Azathioprine improves symptoms 2-3 months after starting treatment. But for some people it may take up to one year to achieve maximum benefit</td>
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<tr>
<td></td>
<td>• The need to take other medicines such as bisphosphonates to prevent or treat steroids side-effects</td>
<td>• Steroids improve symptoms quickly (usually 2-4 weeks)</td>
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<td></td>
<td></td>
<td>Rare serious side effects include:</td>
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<tr>
<td></td>
<td></td>
<td>• Can lower the blood cell count</td>
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<tr>
<td></td>
<td></td>
<td>• Problems with the liver</td>
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<td></td>
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<td>• More likely to get infections (these can be severe e.g. chicken pox/shingles)</td>
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<td></td>
<td>Regular blood tests are needed to monitor blood cells and liver toxicity</td>
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<td>Need to avoid live vaccines (e.g. rubella). However flu vaccines and Pneumovax© are not 'live' vaccines and</td>
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Azathioprine plus steroids - benefits and risks

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| Azathioprine plus a steroid | When steroids are combined with azathioprine patients have rapid symptom improvement:  
- Steroids improve symptoms quickly (usually 2-4 weeks)  
- Azathioprine improves symptoms 2-3 months after starting treatment. But for some people it may take up to one year to achieve maximum benefit  

Adding azathioprine to steroid treatment allows most people to use lower doses of steroids. This minimises steroid side-effects (‘steroid sparing effect’)  

Taking azathioprine plus steroids combined has been used successfully to treat myasthenia gravis, however there is limited trial data | Treatment with azathioprine plus steroid combined is usually long-term  
For the risks and consequences of taking azathioprine see below  
Some of the consequences and risks mentioned in the section for steroids will still apply (see above)  
Pregnancy – seek advice from your doctor if you are planning a family or become pregnant while take a steroid and azathioprine combined |

Mycophenolate mofetil (MMF) plus steroids - benefits and risks

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| Mycophenolate mofetil (MMF) plus a steroid | When steroids are combined with MMF patients have rapid symptom improvement:  
- Steroids improve symptoms quickly (usually 2-4 weeks)  
- MMF improves symptoms 2-3 months after starting treatment. But for some people it may take up to one year to achieve maximum benefit  

Adding MMF to steroid treatment allows most people to use lower doses of steroids. This minimises steroid side-effects (‘steroid sparing effect’)  

Taking MMF plus steroids combined has been used successfully to treat myasthenia gravis, however there is limited trial data | Treatment with MMF plus steroid combined is usually long-term  
Rare serious side effects of MMF include:  
- Can lower the blood cell count  
- Problems with the liver  
More likely to get infections (these can be severe e.g. chicken pox/shingles)  
Small increased risk of skin cancer, therefore need to use sun cream and cover up when in the sun  
Regular blood tests are needed to monitor blood cells and liver toxicity  
Need to avoid live vaccines (e.g. |
limited trial data

However flu vaccines and Pneumovax® are not ‘live’ vaccines and are recommended.

Pregnancy – you must not become pregnant while you are taking MMF and for six weeks after stopping treatment.

Some of the consequences and risks for mentioned in the section for steroids will still apply (see above).

**Note:** occasionally other immunosuppressants have been used to treat myasthenia gravis; however the above options are suitable for the vast majority of patients.

### Some things to consider which may help with your decision

In making your decision you need to ask yourself what is important to me. You may wish to think about:

- How well are my symptoms controlled with my current medications?
- Do I want to wait a while, or am I keen to start immediately?
- Am I willing to come regularly to the hospital or the GP surgery to have my bloods monitored?
- Are the possible side-effects acceptable to me?
- Am I willing to take additional medicines to prevent the possible side-effects of immunosuppressants?
- If I take other medicines, or if I have any other medical problems will that influence my choice?
- Am I willing to take an immunosuppressant in the long term?
- Will I remember to take the additional medicines?

### For further information

- **Medicines information patient helpline:**
  Tel: 0191 2823016. Available from 9:00 to 4:00 pm. Monday to Friday (excluding bank holidays). This helpline is available for patients of the Newcastle Upon Tyne Hospitals, to answer any questions they may have regarding their medicines.

- The Patient Advice and Liaison Service (PALS) can offer on-the-spot advice and information about the NHS. You can contact them on free hone 0800 032 02 02 or e-mail northoftynepals@nhct.nhs.uk.

- If you would like further information about health conditions and treatment options, you may wish to have a look at the NHS Choices website at www.nhs.uk. On this website there is an information prescription generator www.nhs.uk/ips which brings together a wealth of approved patient information from the NHS and charity partners which you may find helpful.
References:

4. **Immunosuppressive agents for Myasthenia Gravis** (Review) Cochrane Library (search date August 2007).

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