# Appendix 1. Disease-modifying treatments for MS

**Interferon beta** is licensed for use in patients with relapsing remitting MS (characterised by at least two attacks of neurological dysfunction over the previous two or three years, followed by complete or incomplete recovery, who are able to walk 100m unaided).

- Not all patients respond.
- Interferon beta is also licensed for use in patients with secondary progressive MS but only where there are superimposed significant relapses. Interferon is **not** indicated in secondary progressive MS otherwise.
- It is given by subcutaneous or intramuscular injection. Preparations vary but can be alternate days, three times per week or weekly.
- The most commonly reported side-effect is a flu-like ague for 24 hours after the injection, which is effectively treated with ibuprofen. This lessens over time. Injection site reactions also occur, but can be minimised with good technique and rotation of sites.
- 10 years of clinical experience show a 33% relapse reduction.
- In the UK, NICE suggests interferon beta is not cost-effective.

**Glatiramer** is licensed for reducing the frequency of relapses in ambulatory patients with relapsing-remitting MS who have had at least two clinical relapses in the previous two years.

- It is designed to mimic the effects of the main proteins in myelin.
- Eight years of clinical experience show a 30% relapse reduction rate.
- It is given daily by subcutaneous injection.
- Injection site reactions are common, but these decrease over time.
- Sporadic, short-lived chest tightness and shortness of breath have been reported.
- NICE guidance does not recommend using glatiramer acetate for treatment of MS based on clinical and cost-effectiveness.

**Teriflunomide** is recommended as an option for treating adults with active relapsing remitting multiple sclerosis (normally defined as 2 clinically significant relapses in the previous 2 years).

- It is a metabolite of leflunomide which has immunomodulating and antiinflammatory properties.
- For more info see the BNF and <a href="http://www.nice.org.uk/guidance/ta303">http://www.nice.org.uk/guidance/ta303</a>

**Alemtuzumab** is an anti-lymphocyte monoclonal antibody which causes lysis of B lymphocytes. It is recommended as a possible treatment for people with active relapsing remitting MS

www.nice.org.uk/guidance/ta312

**Dimethyl fumarate** has immunomodulatory and anti-inflammatory properties and is recommended as a possible treatment for people with active relapsing-remitting multiple sclerosis that isn't highly active or rapidly evolving severe relapsing-remitting multiple sclerosis. For more information see the BNF and http://www.nice.org.uk/guidance/ta320

**Natalizumab** is recommended as a possible treatment for people with rapidly evolving severe relapsing-remitting multiple sclerosis.

- This is a recombinant humanised monoclonal antibody, produced in murine myeloma cells.
- It is given monthly by IV infusion.
- There is 68% relapse reduction.
- It is well-tolerated, but there have been rare cases of progressive multifocal leukoencephalopathy.

**Fingolimod** is recommended as an option for the treatment of highly active relapsing–remitting multiple sclerosis.

- It is the first oral therapy for MS.
- It works by preventing lymphocyte movement across the blood-brain barrier and causes a reversible lymphopenia.
- It reduces the rate of relapses by 50% compared to placebo.
- The dose is 0.5 mg/day. Possible side-effects include first dose bradycardia, macular oedema and increased risk of infection

**Mitoxantrone** is a cytotoxic immunosuppressant:

- Not currently licensed for use in MS
- It is given by monthly infusion.
- There is 70-90% reduction in very active MS relapses.
- There is a possible risk of cumulative cardiotoxicity after 2-3 years.
- There is a 1 in 400 risk of late leukaemia.

## Other treatments

Venoplasty trials have now been abandoned<sup>11,14</sup>.

Several reviews discuss the use of haematopoietic stem cell therapy for multiple sclerosis. It is not recommended as a treatment for the general population of MS patients but has been used successfully in selected cases where the disease is aggressive and there is a lack of response to standard therapies<sup>15-18</sup>.

## Appendix 2. Support for patients, and further reading for professionals

Support is very important to patients with MS, and their families, so offer people suspected of having MS information about support groups and national charities. Review information and support needs regularly, even if people with MS or their family members or carers initially appear unwilling to accept it.

## Driving

Advice about driving is important. It is a legal requirement for people with MS to inform the DVLA of their diagnosis. They should also tell their insurance company. However most patients can continue to drive normally, though some will require adapted vehicles.

The Scottish Driving Assessment Centre can undertake a driving assessment to determine medical fitness to drive after referral from any medical practitioner. Refer by letter to SMART Centre, Astley Ainslie Hospital, Grange Loan, Edinburgh, EH9 2HL 0131 537 9192. There is a mobile service for other parts of the country.

### Emotional support, and practical advice

MS can constantly cause new problems over the years, requiring help and expertise from the multidisciplinary team. Emotional support is particularly important, not just at diagnosis, but throughout the course of the disease.

Each progression in disability means a loss of function and a need to readjust. People may need psychological help to enable them to come to terms with this reality. In discussion with the person with MS, families/carers should be involved in the process as much as possible, enabling the person with MS to be empowered to make their own decisions about their care.

Advise people with MS and their family members or carers about what to do if their symptoms change significantly and the possible causes of these changes including:

- another illness such as an infection
- further relapse
- change of disease status (for example progression) or new MS symptoms.

When appropriate explain to people with MS about power of attorney and advanced care planning. There are two PBSGL modules which groups can look at to get more information on these topics, namely "End of Life Care" (2012) and "Advanced Care Planning" (2014).

### Self-help

A number of useful websites and organisations offer information and support for people with MS and their families. The MS Society can help people with and affected by MS with a range of enquiries, and offers an extensive information service, including (apart from matters already mentioned in this module):

- grants for equipment/home adaptations
- advice on benefits
- information and grants for short breaks and respite care
- specialist helpline (0808 800 8000 freephone, Monday to Friday, 9am–9pm)
- local support and services via Area Teams<sup>3</sup>

### **Further learning**

There is an excellent free on-line module on MS developed by the MS Society and the RCGP, specifically designed for primary care practitioners. <u>http://elearning.rcgp.org.uk/course/info.php?popup=0&id=94</u>.