Scottish Needs Assessment Programme

Multiple Sclerosis

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OCTOBER 2000

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EXECUTIVE SUMMARY

Multiple sclerosis (MS) is an inflammatory demyelinating condition of the central nervous system (brain and spinal cord).

MS commonly presents as a relapsing disease, characterised by episodes of neurological dysfunction (relapses or attacks), followed by partial, or complete, recovery. Over time, the individual becomes permanently disabled. The degree, and rate, of accrual of disability varies from individual to individual.

Four subtypes of MS are recognised and at least two thirds of patients present with the relapsing-remitting form of the disease.

The prevalence of MS in the United Kingdom has a north-south difference. In Scotland prevalence is 180-200 cases per 100,000 with an annual incidence of between 10 and 12 cases per 100,000. The maximum prevalence in England is less than 160 per 100,000. The total number of cases in Scotland is believed to be around 10,400. MS is commoner in females and normally presents between the ages of 16 and 60 years.

Studies indicate that life expectancy is reduced by MS and suggest a 75% 25-year survival. Other studies show that at any one time 27% of patients will have minimal impairment, 45% moderate impairment and 28% severe impairment.

The ideal MS service should:

- Allow rapid referral of suspected cases
- Provide assessment of possible diagnosis by a neurologist
- Provide assessment from a multi-disciplinary team experienced in MS management to identify individual needs and to deliver the appropriate service
- Provide ongoing and continuous follow-up at defined intervals and also to allow a rapid self-referral system at times of crisis
- Provide information and support to patients and carers

Wide variations in accessibility and quality of care exist for patients with MS. The standards of care described above are not currently being met across Scotland.

Services will be defined by local needs and national policies and may be best effected by the introduction of managed clinical networks. Rehabilitation teams form part of the network of care for treating patients with MS. If they feel it necessary they may wish to be part of a managed clinical network but they may also be self-standing.

Service planners should address the funding issues of MS services with the knowledge that current care is substantially sub-optimal, inadequately resourced and unacceptably fragmented.

Trials of therapeutic interventions are designed to focus on specific outcomes. However, these and other outcomes which attribute to the quality of life in people with MS have not been used to plan services.

Beta Interferon does provide benefits for a proportion of MS patients. The debate over whether its relatively high cost of usage is justified in terms of clinical benefit is unresolved. It is inappropriate to focus solely on beta interferon if a large number of

other needs are not being met. Health Boards should review all aspects of provision for MS and make decisions about Beta Interferon within that context and the advice of the National Institute for Clinical Excellence (NICE) and the Health Technology Board for Scotland (HTBS).

1 EPIDEMIOLOGY OF MULTIPLE SCLEROSIS

Description of Multiple Sclerosis

Multiple sclerosis (MS) is an inflammatory demyelinating condition of the central nervous system (brain and spinal cord). Pathologically, it is characterised by areas of inflammation in the white matter (myelin rich part) of the brain and spinal cord, resulting in swelling (oedema), destruction of myelin (demyelination), scarring (gliosis), and loss of axons (nerve cells). Multiple sclerosis literally means 'many scars'. Clinically, the course may result in relapsing and/or progressive symptoms. The commonest course of MS is that it follows a relapsing pattern, characterised by episodes of neurological dysfunction (relapses or attacks), with partial, or complete, recovery. Over time, the individual becomes permanently disabled. The degree, and rate, of accrual of disability varies from individual to individual. A minority of patients with MS has progressive disability from onset.

There is no objective definition of MS. The recommended set of diagnostic criteria (Poser 1983) uses four categories: clinically definite; laboratory supported definite; clinical probable; and laboratory supported probable. These were devised to ensure that only patients with definite MS would be included in therapeutic trials. Although the category of probable was devised to allow prospective evaluation of new diagnostic methods, there are no published validation studies. Thus it is possible that some patients in the probable category do not in fact have MS. It also means that because of the heterogeneity of presenting symptoms and signs, clinical diagnosis may take some time.

In the absence of an objective diagnosis and to aid clinical management, MS has been sub-divided by international consensus into different subtypes based on the pattern of attacks and progression of disability (see page 4). However, it is important to note that these sub-types are solely retrospective clinical descriptions and cannot accurately be predicted or labelled at the time of first diagnosis.

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Incidence and prevalence

The incidence of a disease is the number of new patients in a single year. The prevalence is the number of all patients with existing disease. The prevalence of MS has been the subject of many studies, using the different methods of case ascertainment.

1. Early studies in the north east of Scotland indicated a prevalence of 144 cases per 100,000 of the population. Subsequent reviews suggested a lower prevalence for England and Wales (Swingler and Compston 1986).

2. A recent study in Lothian and the Border regions (Rothwell and Charlton 1998) reported a crude annual incidence of probable, or definite, of 12.2/100,000 (95% confidence interval 10.8 to 13.7) and a prevalence of 203/100,000 (95% confidence interval 192-214). The authors concluded that the prevalence in the south east of Scotland was as high as previously shown in Orkney and Shetland (highest prevalence worldwide), suggesting that the population of Scotland as a whole had an underlying genetic susceptibility. Indeed, areas of high prevalence do appear to be associated with specific histocompatibility antigen profiles (Francis DA et al, 1987).

3. Recently Forbes and Swingler (1999) estimated the prevalence of Multiple Sclerosis in the United Kingdom by using capture/re-capture methodology.

They confirmed the higher MS prevalence in Scotland was not an artefact of ascertainment. The same group (Forbes, Wilson and Swingler 1999) felt it unlikely that there was a gradient across the UK but rather Scotland and Northern Ireland for genetic reasons had a higher prevalence than southern UK. This emphasises that the distribution of MS is not uniform, and is consistent with the hypothesis that populations with higher prevalence have an underlying genetic predisposition.

Therefore it is reasonable to assume for the population of Scotland a prevalence of 203/100,000, with an annual incidence of 10 to 12/100,000. An annual incidence figure also gives an indication of the number of patients requiring investigation as "possible MS". It has been suggested that the number of possible cases referred exceed the number of confirmed cases by a factor of 5 (However, tertiary referral centres with established MS expertise report lower figures). **This is an unresearched area, but clearly has implications in relation to the availability of diagnostic facilities for a far larger number of individuals than is evidenced by the annual incidence figures alone (Hopkins et al, 1989).**

What is known about the natural history of the condition itself? Longitudinal studies are confined to a few centres and are heavily influenced by the fact that such centres have an established MS "expertise" and do not necessarily recruit "the average patient". Despite these limitations, the following observations can be drawn from available published data:

Sex ratio
Female prevalence exceeds male by a ratio of 2 to 1, though this varies. Males are more likely to suffer the progressive form of disease. Females are more likely to be of early age onset (Ebers 1986).

Age of onset
MS normally presents in young adults, onset before the age of 16 years unusual - 2.7% of cases (Duquette et al, 1987). It rarely presents after the age of 60 years (Noseworthy et al, 1983). A recent symptom management survey carried out by the Multiple Sclerosis Society suggested that approximately 50% of patients with established disease lay between the ages of 36 and 50, but this did not address the age of disease onset.

Table 1 Absolute Numbers of Patients with MS in Scottish Health Boards
(Based on a prevalence of 203/100,000 (Rothwell & Charlton 1998) and calculated from June 1998 Health Board Population)

Population, June 1998, by sex and health board				SCOTTISH MS PREVALENCE = 190-220/100,000					
				Patient Numbers			Standards of healthcare phases – Patient numbers		
Health Board Areas	All sexes	Males	Females	All	Males	Females	Minimal	Moderate (see table 2)	Severe
Argyll & Clyde	426,900	206,775	220,125	867	276	591	234	390	243
Ayrshire & Arran	375,400	180,457	194,943	762	240	522	206	343	213
Borders	106,300	51,238	55,062	216	68	148	58	97	60
Dumfries & Galloway	147,300	71,612	75,688	299	96	203	81	135	84
Fife	348,900	169,069	179,831	708	226	482	191	319	198
Forth Valley	275,800	133,825	141,975	560	179	381	151	252	157
Grampian	525,200	259,885	265,315	1066	350	716	288	480	299
Greater Glasgow	911,200	436,596	474,604	1850	589	1286	499	832	518
Highland	208,300	102,357	105,943	423	137	286	114	190	118
Lanarkshire	560,800	272,846	287,954	1138	364	774	307	512	319
Lothian	773,700	376,650	397,050	1571	503	1068	424	707	440
Orkney	19,550	9,695	9,855	40	13	27	11	18	11
Shetland	22,910	11,576	11,334	47	16	30	13	21	13
Tayside	389,800	187,983	201,817	791	251	540	214	356	222
Western Isles	27,940	13,837	14,103	57	19	38	15	26	16
TOTAL	**5,120,000**	**2,484,401**	**2,635,599**	**10394**	**3327**	**7092**	**2806**	**4677**	**2910**

M:F = 1:2

Minimal impairment	23 – 31% (27)
Moderate impairment	39 – 51 % (45)
Severe impairment (see table 2)	24 – 29 % (28)

2 PATHWAY OF THE DISEASE

Disease duration

Early studies in MS found a high mortality rate. An Edinburgh study (Bramwell 1917) showed a mean duration of illness to death of 12 years. Bronnum-Hansen and colleagues (1994) looked at survival in patients from Denmark diagnosed in the late 1940s. They found the median survival in men to be 28 years (40 in the control population) and 33 years in women (46 years in the control population). Studies from two large MS clinics have suggested that in 50% of patients death is due directly to a complication of MS, such as pneumonia or urinary infection rather than to the disease itself. The suicide rate in patients with MS is four times that of an age-adjusted control population (Sadovnick et al, 1991).

Disease Subtype

Studies have addressed the type of MS at onset. Weinshanker et al (1989) in a total population study showed that 65.8% of patients had relapsing and remitting disease, 14.8% progressive with a relapsing component and 18.7% progressive from onset without relapse, with unavailable data in 0.9%. When they studied a small subgroup prospectively from the disease onset 85% were relapsing and remitting and 15% progressive. They acknowledged that within their total population study, data was retrospective and that the prospective subgroup probably reflected referral bias. Other studies have however come to similar findings, the probability being that at least two thirds (and possibly up to 80%) of patients with MS present initially with relapsing and remitting disease.

The recognised clinical sub-types are:

1. **Relapsing-remitting multiple sclerosis (RRMS).** This is the most frequent onset of MS (approximately 80% of patients) . It is characterised by acute attacks of neurological dysfunction, usually followed by partial or complete recovery occasionally taking up to 3 - 6 months. The frequency and severity of these attacks varies both within and between individuals . The average frequency of attacks within the first five years is one per year, falling to one every two years thereafter. Over time, with incomplete recovery from repeated attacks, there is an accrual of disability.
2. **Primary progressive multiple sclerosis (PPMS).** Some patients (c. 10-15%) present with insidious progression of disability from onset without remission. In general this category is characterised by progressive spasticity (stiffness) with weakness of the legs, and bladder and bowel dysfunction. It tends to spare the head, neck, and upper body. The rate of progression varies.
3. **Progressive relapsing multiple sclerosis (PRMS).** This recently described, and less common, sub-type of MS is characterised by progression from onset with subsequent relapses.
4. **Secondary progressive multiple sclerosis (SPMS).** Approximately 50% of patients who have relapsing-remitting MS progress to this phase of the disease within 10-14 years of onset . This sub-type is again characterised by progressive disability, with or without superimposed relapses. Overall, this is the most prevalent form of MS.

Outwith this sub-type classification, other descriptive terms are used:

1. **'Benign' multiple sclerosis**. This is a sub-type of relapsing-remitting MS and is characterised by few and non-disabling, predominantly sensory, attacks, without the accrual of significant disability over time. This is a retrospective diagnosis.
2. **"Malignant" multiple sclerosis.** Usually, these patients have a progressive course from onset but may have devastating relapses with poor recovery, such that they are wheelchair bound within two years.
3. **Transitional multiple sclerosis.** This describes the phase during which patients progress from relapsing-remitting MS to secondary progressive MS with significant change.

Further terms include:

- **Impairment.** Lack of normal biological function, e.g. head movement.
- **Disability.** The lack of normal functional ability – whether psychological or physical – resulting from interaction between an individual and their environment.
- **Handicap.** The loss of expected social function as a consequence of impairment or disability.
- **Relapses or attacks.** These refer to clearly defined episodes of neurological dysfunction. These may be exacerbations of previous symptoms or new symptoms, lasting more than 24 - 48 hours, for which there is no better explanation. (Pseudo-relapse = worsening of symptoms related to inter-current infection or other).
- **Plaques.** This refers to the pathological or radiological appearance of lesions in the brain or spinal cord on neuro-imaging. Pathologically MS is characterised by multiple areas of inflammation (plaques) within the brain and spinal cord, normally in a particular distribution involving the white matter.

Temporal course of illness

Predicting the clinical course of disease is difficult. Attack rate, duration of first inter-attack interval and rate at which disability develops in early years of disease do give some indication of prognosis and are indicators of when mobility may be lost, as well as when relapsing and remitting may transform into secondary progressive disease. The Extended Disability Status Score (EDSS) has been used as a measure of disability in most longitudinal studies. Weinshenker's group studied the time from onset of MS to reaching selected levels of disability as defined by the EDSS. They reported that 50% reached an EDSS of 3 (impaired not disabled) within approximately 8 years and an EDSS of 6 (requiring one stick to walk) at approximately 15 years.

Cross sectional analysis of disability

Data derived from the London Ontario MS Clinic showed the "point prevalence" of EDSS levels within a total MS population, 42% having an EDSS of 3 or less, 28% an EDSS between 4 and 6, and 30% an EDSS of 7 to 10. This study assessed individuals attending an MS clinic and therefore unsurprisingly underestimates the percentage of persons with severe disability. The "MS Symptom Management Survey" (Appendix 1) carried out in October 1997 identified 275 MS Society members who had attended recent Society meetings and were asked to complete a postal questionnaire in total 223 surveys were returned (80% response rate). Individuals were asked to grade the severity of their disease, 5% stating that it was very mild, 18% mild, 51% moderate, 23% severe and 1% very severe. Whilst this information is of interest it is difficult to draw useful conclusions from it in relation to the MS population at large as the method of ascertainment, namely being a member

of the Society and having attended a recent meeting, clearly would introduce bias. It can be assumed in this study that patients with very mild and very severe disease were underrepresented.

Table 2 - Progression of Multiple Sclerosis with respect to disability and duration

This table uses data from Weinshenker et al, and the MS Society Symptom Management Survey, to estimate the percentage of patients within disability category as quantified by the extended disability status score (EDSS) (Kurtzke 1983), and the average duration at each stage of the EDSS.

Importantly it shows that at any one time 27% of patients will have minimal impairment, 45% moderate impairment and 28% severe impairment. This breakdown is important because it dictates the level and nature of service provision required.

Table 2 - Progression of Multiple Sclerosis with respect to disability and duration

EDSS (Extended Disability Status Score)	**0-1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10** (Dead)	MS Clinic London Ontario
Time at DSS step (years ± sem)	4.1 ±0.2	2.8 ±0.1	2.0 ±0.1	1.2 ±0.1	1.3 ±0.1	3.1 ±0.2	3.8 ±0.3	2.4 ±0.4	2.5 ±0.6		
Weinshenker* *(n = 1,099)*	17%	14%	11%	6%	3%	19%	18%	8%	2%	*1% ?*	
'Standards of Healthcare' phases (*applying figures above and below to set ranges for these phases)	Minimal impairment 23 – 31%		Moderate impairment 39 – 51%				Severe impairment 24 – 29%				Minimal ~ 27% Moderate ~ 45% Severe ~ 28%
MS Society Symptom Management Survey* *(n = 223)*	Very mild 5%	Mild 18%	Moderate disability 51%				Severe disability 23%	V. severe disability 1%			MS Society

3 SERVICE PROVISION

This section is based on a document produced by the MS Society and the MS Research Trust in July 1999, and describes a notional 'ideal' service which is used as a benchmark within this report. The key message is that service requirements change as the disease progresses and a wide spectrum of services are necessary to cope with the multiplicity of problems the patients encounter. Scotland needs to address models of service delivery which address the challenges presented by its geography (rural population and poor transport infrastructure).

PRESENTATION AT PRIMARY CARE LEVEL

MS may present as a variety of neurological symptoms. These vary over time and in severity and duration. The suspicion of possible MS in primary care represents a considerable diagnostic challenge. The index of suspicion that the symptoms may be MS should be raised in the presence of:

- Particular symptoms such as visual disturbance, paraesthaesia and weakness.
- Apparent neurological signs such as hyper reflexia, ataxia and sensory loss.
- Repeated consultations with multiple neurological complaints.
- Relapsing and remitting symptoms.

DIAGNOSIS AT SECONDARY CARE LEVEL

A GP may suspect MS or refer for assessment of unexplained neurological symptoms. Referral should be to a neurologist. It is inappropriate to refer to a general physician with no specialist knowledge of the differential diagnosis and evaluation of neurological conditions.

A referral for suspected MS should allow for three hospital appointments:

- The initial consultation - for obtaining a detailed history, examination, and ordering of investigations (preferably "one-stop").
- A second appointment to discuss the results of the investigations, to introduce the person with MS to liaison or other specialist staff and to provide contact details for source(s) of help in the community.
- A third, follow up appointment, to review the situation and to ensure that the person with MS has received appropriate information and support.

Accuracy in diagnosis (using recognised criteria (Poser 1983)). Compassionate imparting of that diagnosis and communication of its full meaning and implications must be the aims of this phase.

ONGOING SUPPORT AND REHABILITATION

Following diagnosis, people with MS will need ongoing access to specialists working as a team to help maximise their potential and minimise their disability and its impact (See Box 1). The MS charities play an important role in providing education, information and support. A flexible network of support and advice is necessary to deal with specific issues as they arise.

BOX 1

Multidisciplinary teams of specialists include:

- Neurologists
- Rehabilitation physicians
- Specialist nurses
- Physiotherapists
- Occupational therapists
- Speech and language therapists
- Continence specialists
- Orthoptists
- Psychologists
- Dieticians
- Social workers
- Counsellors

It is essential that individuals with MS have a constant point of contact whether this is their GP, an MS nurse or other specialist. As the patient's advocate, the general practitioner should ensure continuity of service provision for each patient.

The MS Society publishes a wide range of information leaflets and fact-sheets on many aspects of MS, which are produced with professional advice, regularly updated and freely available. There is also a free telephone helpline (0808 800 8000) staffed by trained personnel.

Rehabilitation (expanded in Appendix 8)

Evidence of objective benefit from rehabilitation is patchy and it is not clear which patients are most likely to benefit. Rigorous evaluation is needed. Several studies - focused upon assessments of impairment, disability or handicap - have demonstrated short term benefit from inpatient, multidisciplinary rehabilitation (Solavi et al 1999, Freeman et al 1997, Fuller et al 1996), although there is doubt as to whether this is sustained over a prolonged period (Freeman et al 1999). Studies focusing on symptom relief have perhaps demonstrated greater benefit (Di Fabio et al 1998, Welham 1995). There is evidence that both physiotherapy and occupational therapy approaches can be helpful in fatigue (Di Fabio et al 1998, Welham 1995).

Nonetheless it is logical to suggest that a multidisciplinary team approach is necessary, rather than for example physiotherapy alone, if disability and handicap are to be minimised. Periodic courses of rehabilitation (say every 9-12 months) are usually necessary to preserve functional gains achieved at initial rehabilitation. Because of the multifaceted symptomatology associated with the condition, many different variables may influence rehabilitation outcome, particularly the cognitive state of the patient, verbal intelligence and cerebellar function - areas which have been neglected in the approach to MS management.

Information (expanded in Appendix 7)

It has been shown repeatedly that people with long term disabling conditions and their families need and want more and better information about the condition, about therapeutic options and about sources of help and support (Holman et al 2000, Coulter 1999, Berwick 1998). Sometimes this is because the information is not available. More often however it is because those who need the information are unable to access it.

Recent developments in information technology mean that some patients or carers can access information and often more up-to-date knowledge than their general practitioners. The danger is that many users will be unable to assess its quality and not all have access.

There is therefore a need to develop systems for the production and dissemination of information for patients and families that ensure a high standard of accuracy targeted to requirements at different stages of an illness or disability, and which can be readily accessed by people not only with different needs but with widely diverse levels of intellectual and social functioning. Suggestions for possible ways forward are given in Appendix 7. The potential benefits of providing patients with the information they would like to have are as follows:

- Improved patient/client satisfaction, minimising their much repeated and clearly documented dissatisfaction regarding access to information.

- Patients/clients encouraged to participate more fully in the management of their own care, thus reducing their reliance on health services.

- Facilitating movements of patients/clients between services, thus minimising delays within the system of care, reducing the risk of people failing to receive necessary services and encouraging equity of access to care.

Once again, however, evaluation of the impact of information is essential.

Pharmacological treatment

1. **Symptom Management**
   A wide range of drug treatments are available for symptom management but the evidence base for many is limited. **Fatigue** is one of the most common and disabling symptoms of MS. People with MS need to learn to pace their lifestyle. In some cases, drugs such as amantadine may be helpful, although only moderate success has been seen in trials compared with placebo (Canadian MS Research Group 1987). **Pain** can often be managed with simple analgesics, such as paracetamol, but neuropathic pain may require more specific treatment such as carbamazepine and amitriptyline and others.
   Spasticity may be treated with physiotherapy and pharmacologically with a number of drugs, including baclofen, tizanidine, dantrolene, or local therapies. Many drugs have been tried to treat **tremor** but with limited beneficial effects. Most merely dampen down the tremor and tolerance often develops or side effects become unacceptable.

   Anticholergenic drugs may be helpful to control **passing urine** often. **Impotence** can be helped by sildenafil and by intracorporeal injections of the prostaglandin, alprostadil. Various mechanical devices, including vacuum

pumps may also be considered. Some female sexual dysfunction can also be treated.

Incontinence and other bladder symptoms such as frequency, urgency and nocturia are often distressing and disabling but much can be done to help retain control. Advice about fluid intake, pelvic floor exercises, intermittent self-catheterisation and continence aids can be extremely helpful. **Depression** is commonly associated with MS and can be managed through cognitive behavioural therapy, counselling and the use, where necessary, of antidepressants.

2. Management of acute attacks

Corticosteroids Formatted

Corticosteroids are frequently prescribed for acute exacerbations of MS as high dose intravenous injections for 3-5 days in order to shorten/lessen the relapse. Intravenous methyl prednisilone is the drug of choice in terms of published evidence though recent studies support the use of high dose oral steroids (Sellebjerg et al 1998). Corticosteroids have no proven effect on the long term course of MS.

3. Disease Modifying Drugs Formatted

Beta Interferon

In many respects the catalyst for a needs assessment into MS was the concern regarding the potential demand for Beta Interferon and the fact that not all health boards have an existing budget for such treatment. The cost effectiveness of Beta Interferon has been debated in both the medical and popular press. This report argues that discussion on costly disease-modifying treatments cannot take place outwith a comprehensive needs assessment covering all phases of the disease process. If as seems to be the case a large number of patient needs are not currently being met it is clearly inappropriate to focus solely on Beta Interferon (see Appendix 3, 4 and 5). Conversely, the fact that the "Interferon question" has highlighted these deficiencies cannot be used to deny patients such treatment. Therefore it is recommended that health boards should review all aspects of provision of care for MS sufferers and make decisions about the availability of Beta Interferon within that context and in light of forthcoming advice from the National Institute of Clinical Excellence (NICE) and the Health Technology Board for Scotland (HTBS), both of whom are currently undertaking an appraisal of the clinical and cost effectiveness of Beta Interferon and glatiramer.

Evidence from published trials of Beta Interferon as well as emerging evidence awaiting publication, demonstrates that Beta Interferon will reduce the number of exacerbations experience by MS patients with relapsing and remitting disease (Appendix 10). In addition there is evidence to support a slight but statistically significant effect upon disease progression. There are several available forms of Interferon and the differences in efficacy between each probably reflects no more that the study design of each particular trial. Adverse effects including flu-like symptoms and injection site reactions are not uncommon but only infrequently are of such severity that treatment by mutual consent is withdrawn. A further difficulty in arriving at decisions regarding the usage of Beta Interferon arises from the fact that clinical trials have tended to address as a primary end point a reduction in relapse rate. However, MS patients and their carers are concerned with a wider range of

issues that relate to quality of life. Some of these can be addressed by other approaches described elsewhere in this document but it is clear that although the Interferons provide benefit they leave many of the important outcomes for MS unknown and unexplored.

Despite these uncertainties the consensus seems to be that some patients with active relapsing and remitting disease run the chance of deriving some benefit from this treatment. Of all eligible patients with active relapsing and remitting disease (10-20% of the MS population) it is the experience in practice that approximately one third will decline therapy on the basis of potential side effects, unknown long term effects or spontaneous reduction in disease activity. Of those who go on to treatment, only between 5 and 10% will withdraw on account of side effects or disease progression within the ensuing 2-3 years. Not all patients with relapsing and remitting disease derive benefit (numbers needed to treat=6 [95% CI 4 –13]) (Association of British Neurologists 1999).

The role of Beta Interferon in secondary progressive disease is less certain, though published and presented data would appear to infer that whilst those with secondary progression still experiencing exacerbations may derive some gain (numbers needed to treat 12), those without exacerbations do not.

Glatiramer acetate has been shown to reduce relapse rate and MR disease activity similar to Beta-Interferon and at comparable cost (Johnson et al 1995).

The National Institute of Clinical Excellence (NICE) and the Health Technology Board for Scotland (HTBS) are examining the whole issue of Beta Interferon and glatiramer acetate in MS with the probability of NICE announcing their recommendations in the Autumn 2000. In the meantime it would seem wise for health boards to offer Beta Interferon to those groups of patients who may derive benefit in terms of exacerbation reduction. However, these decisions must be seen within the context of all demands made on health board budgets to meet the many needs of MS patients identified in this document as well as other neurological diseases and conditions outwith neurological disease. The difficulties involved in understanding and assessing therapeutic outcomes in MS are discussed in Appendix 6.

COMPLEMENTARY THERAPIES

It is important that ‘complementary’ therapies are included as therapeutic options. There is no doubt that people with MS seek therapies such as aromatherapy, reflexology and hyperbaric oxygen, and having experienced them once often return for further treatment. Such user satisfaction is probably in part attributable to the chosen therapy or therapies, but part is also likely to be due to general factors such as self-motivation and the additional patient support offered and the environment in which such treatment is provided. Complementary practitioners usually base their treatment on the way patients experience and manifest their disease, including their psychological state and response to illness. For example, patients’ personalities and emotions play an important part, and they are encouraged to participate actively in the treatment process; and when touch is involved this facilitates communication and the development of rapport with the practitioners (NMAC 1996).

The National Medical Advisory Committee on Complementary Medicine and the national Health Service (Scottish Office Department of Health, Nov 1996) recommended a controlled exploration of the costs and benefits of integrating complementary medicine with conventional medicine; establishing audit and evaluation procedures with active consumer input; and observational studies, controlled trials and randomised controlled trials (including placebo-controlled trials, where appropriate) for the rigorous testing of complementary therapies.

4 PERSPECTIVES ON NEEDS AND SERVICE PROVISION

Without undertaking a thorough audit of services for MS throughout Scotland, it would be impossible to identify the patients' needs and the strengths and weaknesses of current service provision as they are manifested in the various Health Boards throughout Scotland. Nonetheless a picture does emerge from three sources of information: the views of people with MS, the views of general practitioners and perspectives from Health Boards.

The Views of People with Multiple Sclerosis

Figure 1 overleaf is an attempt to summarise the principle findings of a survey of people with MS, informal carers and professionals involved in the care of people with MS (Brunel MS Research Unit 1996 and 1998). These have been grouped under five headings: the person with MS, professionals, carers, the wider public and the environment. Recommendations which derive from these findings are listed in Appendix 3, and these deserve detailed study. The main points include:

- Needs assessments need to be carried out from the perspective of people with MS and not channelled through the, sometimes distorting, perspective of professionals.

- People with MS are often disappointed with the level of understanding and expertise of health care professionals who deal with their problems.

- Insufficient information is provided to people with MS at key points in their "patient journey".

- People with MS want a positive outlook from the professionals that focuses on what they can achieve rather than concerning themselves exclusively with the problems associated with MS.

- Employment issues and the needs of carers require to be addressed.

- The perspective and needs of carers should be addressed.

Appendix 7 develops the theme of information needs in people with MS. The advantages of an effective information strategy is that it improves patient satisfaction, encourages participation and reduces the risks of patients failing to receive necessary services. The appendix makes a number of recommendations about how information needs could be more effectively channelled. Attention should be drawn to the checklist for action.

In addition to the findings of the two qualitative studies cited above, the Multiple Sclerosis Society, Scotland has recently completed a quantitative study of the experiences of people with MS in Scotland (Appendix 11). This study is the largest survey of people with MS ever conducted. The questions in the survey form were based on the Society's "Standards of Healthcare for People with MS", on which other sections of this report draw heavily. The Standards document itself is a consensus report which has gained wide currency in the two years since its publication. 1,688 people with MS in Scotland responded to the survey representing 16% of the estimated 10,400 people with MS in Scotland.

The overall view of the MS community in Scotland is clear: the present service offered to patients often falls short of the service set out in the Society's "Standards of Healthcare for People with MS". The perceived shortcomings fall into two main categories: service and information.

- ***Services***

Only 16% of patients felt that they had received adequate support from the health service around the crucial time of diagnosis. People experienced ongoing difficulties in accessing the other services they needed subsequently.

- ***Information***

Provision of information was viewed less positively than provision of services. Amongst the more important points which emerge from the survey: 17% reported discussion about the implications of the diagnosis, 2% had been put in touch with a specialist clinic/team after diagnosis, and 19% given the number of an MS organisation. 11% reported that their local health services had informed them about the range of services it offered, and 27% thought they knew how to make a complaint or ask for a service to be changed if they were not happy.

Notes on the survey methodology and full findings of the survey are in Appendix 11.

The Primary Care Perspective

Appendix 4 reports a survey based on interviews with 20 GPs throughout Scotland, undertaken for the purposes of this SNAP report. It shows what GPs perceive to be available for their patients, rather than measuring what is actually available. Despite the small sample size, this survey demonstrates that there are wide variations in accessibility and quality of care available for patients with MS. It is clear that the standard of care described in the previous section is not being fully met.

The Health Board Perspective

In January 2000 a questionnaire was sent to Directors of Public Health asking for information on services and perceived shortfalls in services through each of the phases of MS. Eight of 15 Boards responded to the questionnaire. The main problems identified related to access: to neurologists, diagnostic facilities, to other specialists (e.g. urologists, psychologists, physiotherapists and specialist nurses), to respite care and to social work services. Other problems were difficulties in obtaining wheelchairs, lack of knowledge among general practitioners, difficulties specific to rural areas, deficiencies in co-ordination and team-working and the unsuitability of nursing home accommodation. The important role of voluntary organisations in providing information, advice, therapies and in resolving communication difficulties was mentioned by several respondents. These results are summarised in Appendix 5 and could form a baseline for the development of a strategy to achieve improved services.

Managed Clinical Networks

The management of a patient with MS from pre-diagnosis onwards with appropriate care and treatment, requires the involvement of many different professionals, from various agencies and in multiple locations. The aim should be to ensure that a patient experiences co-ordinated care, and is not aware of professional and

administrative boundaries. It is likely that managed clinical networks can produce this co-ordination.

Managed clinical networks (MCN) have been defined as: “linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a co-ordinated manner, unconstrained by existing professional and health board boundaries, to ensure equitable provision of high quality, clinically effective services”. An MCN for MS should include other statutory agencies, such as social work, voluntary organisations, people with MS and their carers.

The necessary components and extent of the network for any patient will vary according to location and also over time according to the needs of the patient. NHS MEL (1999)10 lays out the core principles for networks, although it is intended to develop these based on experience emerging from pilot sites. Core principles include the identification of a lead clinician, a clearly defined structure, management input, a quality assurance framework based on evidence and audit; and information for and empowerment of the patient.

The advantages for MS patients of such an approach would be clear, integrated pathways for diagnosis and care; quality assured clinical management based on available evidence, and equity of treatment within any network area. There may be particular issues surrounding a network for chronic disease management that would make establishing networks in more than one area desirable, to identify key determinants for success.

5 RESOURCE ISSUES

Accurate costings are not available; either of current expenditure on MS, in all facets of the health service, or on the appropriate level of spend based on the estimate of need. Therefore, what follows must be treated with caution and requires careful interpretation. However, we do have some information from published work and other surveys to indicate some of the levels of expenditure within the overall picture.

1. Estimated current spend on multiple sclerosis

Published MS costing studies to estimate the costs associated with MS from both health service and societal perspectives have been examined and listed at the end of this section. Estimates of the costs of MS, to the NHS, and to society as a whole, vary considerably and no data is available on expenditure in Scotland. Studies are performed in different financial years, use different definitions and methodologies and vary in the level of costing detail reported. Nevertheless, in the absence of more accurate information, they can be used to provide a rough estimate of the current spend on MS.

a) Cost per MS patient - breakdown by level of disability

Published costing studies demonstrate clear variation in the costs associated with MS according to the level of disability. The study by Holmes, Madgwick & Bates (1995) is the most recent UK work that examines the costs of MS by level of disability although the cost structure in Scotland cannot necessarily be regarded as comparable. . This study was used to examine the breakdown of NHS and societal costs for three stages of MS:

- A – able to walk unaided for an unlimited distance,
- B – able to walk unaided but only over a limited distance or with the aid of a walking stick,
- C – need to use a wheelchair on most days/every day.

This analysis suggests that the annual NHS cost per patient in 1998 was £365 for type A, £686 for type B and £4,637 for type C. The 1998 societal cost per patient, including transfer payments, is estimated to be £4,789 for type A, £14,339 for type B and £19,944 for type C.

b) Estimated cost of multiple sclerosis in Scotland and by health board area

By applying the Holmes, Madgwick and Bates study results to the Scottish MS population an estimate of the current spend on MS in Scotland has been obtained. This suggests that approximately £18m was spent on MS related health care in Scotland in 1998. The corresponding cost to society, including transfer payments, was approximately £140m. Table 1 shows this best estimate of the amount spent on MS in Scotland and in each of the health boards.

We know, however, that some of the expenditure items that go to make up table 1 are underestimates. Most obvious of these is the amount allocated for drug treatments which, by today's standards, is certainly low. Beta Interferon is not included in these figures. Therefore, the expenditure presented in table 1 is almost certainly an underestimate. Caution must be noted in applying Holmes (1995) data that assume a certain service provision and cannot necessarily be applied in Scotland.

c) Scotland compared to other countries

Table 2 shows indicative international costings, extrapolated from the existing literature to identify any differences in MS spend between the UK and other countries. Definitions and costs ranged widely. For example, low estimates of under £500 for the annual health care costs associated with mild MS were obtained from Belgium and the UK. High estimates of over £20,000 for the annual societal costs associated with severe disease were reported from Canada and the USA.

2. Estimated cost of an ideal multiple sclerosis service in Scotland

a) Diagnosis

The components of resource use associated with best practice in the diagnosis of MS, as stated in "Standards of healthcare for people with MS" (1997), and summarised as:

- GP recognition of symptoms (training/ awareness),
- Speedy specialist referral – three appointments,
- Prompt access to MRI scan and other investigations.
- Ready access to a specialist nurse
- Counselling support and access to written information

We estimate that 2,750 individuals in Scotland are tested for MS each year. This is based on an annual MS incidence rate of 10-12 per 100,000 population, with five individuals examined and tested for every one diagnosed as having MS.

A very rough estimate of the cost of ideal diagnosis is £1,000 per patient, or **£3m** in Scotland per year. This estimate does not include other critical aspects of best practice – speed of referral, speed of investigation, and access to a specialist nurse and counselling.

b) Rehabilitation

An estimate of the ideal resources required for ongoing support and rehabilitation was obtained from Ayrshire and Arran, where there is an established rehabilitation unit which cares for MS patients but also other neurological disabilities. This service is considered to meet the standards recommended by the Multiple Sclerosis Society and it received an award for the highest standard of MS service in the United Kingdom in 1999. The Ayrshire and Arran unit cares for 900 regular follow-up MS patients and has dedicated staffing as shown in box 1. The total annual revenue cost for the service is approximately £750,000. This suggests that the annual cost of a similar service throughout Scotland, where there are 10,500 MS patients, would be **£9m**. The cost per MS patient of this ideal rehabilitation and support service is around £850 per year. These costings however are "hospital based" and cannot be regarded as an accurate estimate of direct costs (these exclude primary care, community non-hospital cost and regional specialist services amongst others). Also, this estimate does not cover the whole population of patients with MS in Ayrshire but deals with a referred or selected population. Extrapolation to the Scottish population would underestimate the true cost and would not address service delivery to rural communities.

Box 1. Estimated NHS resources required for ideal MS rehabilitation service

Type of staff	Number A&A 900 MS patients	Estimated number Scotland 10,500 MS patients
Consultant Physician	1	12
MS Nurse Specialist	1	12
Physiotherapist	5	60
Occupational Therapist	5	60
Speech Therapist	1	12
Dietitian	0.5	6
Clinical Psychologist	2.5	30
Social Worker (funded by LA)	1	12
Inpatient Ward Nurse Manager	1	12
Inpatient Ward Staffing	32.5	390
Estimated annual NHS cost	£0.75m	£9m
Estimated NHS cost per MS patient	£850	£850

Source: Dr Paul Mattison, Consultant Physician, Ayrshire Central Hospital

This box refers only to clinical staff and does not include secretarial, records, building maintenance staff, transport, heating and training etc.

c) Non rehabilitation, including primary care

There are likely to be some aspects of service provision for MS patients that do not fit into the categories of diagnosis and rehabilitation. These will include primary care input. We do not have accurate figures for these costs but we suggest an annual Scottish figure of **£1m**. Again the provision of specialist equipment (e.g. pressure relieving mattresses) need to be costed.

d) Beta Interferon

Beta Interferon is a recent addition to the costs of providing care to MS patients. We present the evidence for using this drug elsewhere in the document. The best estimate of numbers is that 10% of MS patients may benefit from Beta Interferon and one third of these will refuse treatment. This gives us approximately 700 patients receiving treatment in Scotland at an annual cost of around **£7m**. Emerging evidence on the value of Beta Interferon following first symptomatic presentation (Jacobs 2000) indicates that the indications for use will widen and this figure will also be an underestimation but is probably a useful “yardstick” for the short-term.

e) Total estimate of the cost of an ideal service in Scotland

The total estimate of the cost of an ideal MS health service for Scotland is **£20m**. We present an estimate of the total expenditure that each health board would have to make to deliver the ideal MS service in table 3. This is an important table because it illustrates the additional expenditure that may be required to provide Beta Interferon for approximately 10% (minimum figure) of the MS population.

3. How does current spend match that of the ideal service?

According to literature sources, Scotland does not spend as much as some other countries on MS care. However, a survey conducted recently in Greater Glasgow has revealed that, for the needs of patients to be met, the emphasis should be on higher quality and better co-ordination of input and a more patient centred approach to service delivery (Penrice 2000).

Some resources may currently be used inappropriately. For example, ineffective treatments may be used due to the perception that doing something is better than doing nothing for this debilitating disease. It is possible that some of these resources could be redirected towards the other aspects of MS though such monies will probably be negligible.

Quantifying the resources required for a model service requires detailed investigation and planning. Given the inadequacies of current provision revealed in Chapter 5 the Multiple Sclerosis Society considers it is unlikely that a service measuring up to its Standards document can be provided on the basis of the current level of resourcing. It is of course likely that some aspects of current service provision can be improved through reorganisation, better co-ordination and more patient centred delivery. However, some cost which might *a priori* be expected to exceed current expenditure are:

- Provision of sufficient neurologists both to reduce referral times and to permit appropriate ongoing follow up (the ongoing follow-up had an impact on the new:return ratio of outpatient neurology services and therefore increases waiting times for an initial appointment for diagnosis). ***(The median waiting time in Scotland for a new outpatient neurology appointment at March 1998 was 70 days – longer than for all other acute medical and surgical specialities apart from clinical genetics, anaesthetics and homoepathy[*] – approaching twice the median wait for all acute specialities and two and a half times the MS Society's standards.)***

- Extension of specialist MS nursing provision (there are currently estimated to be only 7 specialist MS nurses in Scotland and some of this provision is funded by the Multiple Sclerosis Society, Scotland.)

- Increased MRI capacity for diagnosis.

- Capital costs (and subsequent depreciation costs) of purpose built rehabilitation centres comparable to that accommodating the service in Ayrshire and Arran.

- Programmes of professional education.

[*] ISD Hospital and Clinical Activity 1998

- Supporting managed clinical networks.
- Tailoring services to meet the needs of dispersed rural populations remote from the four neurology centres.
- Improving access to the other components of the multidisciplinary team.

Table 1 **Estimated annual costs of MS (excluding Beta Interferon)**
Scotland by health board (1998)
(£000s to nearest £1,000)

Health Board Area	Minimal		Moderate		Severe		Total	
	NHS	Society	NHS	**Society**	NHS	Society	NHS	Society
Argyll and Clyde	85	1,121	268	**5,592**	1,127	4,846	1,280	11,559
Ayrshire and Arran	75	987	235	**4,918**	988	4,248	1,298	10,153
Borders	21	278	67	**1,391**	278	1,197	366	2,865
Dumfries and Galloway	30	388	93	**1,936**	390	1,675	512	3,999
Fife	70	915	219	**4,574**	918	3,949	1,207	9,438
Forth Valley	55	723	173	**3,613**	728	3,131	956	7,468
Grampian	105	1,379	329	**6,883**	1,386	5,963	1,821	14,225
Greater Glasgow	182	2,390	571	**11,930**	2,402	10,331	3,155	24,651
Highland	42	546	130	**2,724**	547	2,353	719	5,624
Lanarkshire	112	1,470	351	**7,342**	1,479	6,362	1,942	15,174
Lothian	155	2,031	485	**10,138**	2,040	8,775	2,680	20,944
Orkney	15	53	12	**258**	51	219	78	530
Shetland	5	62	14	**301**	60	259	79	623
Tayside	78	1,025	244	**5,105**	1,029	4,428	1,352	10,557
Western Isles	5	72	18	**373**	74	319	98	764
Scotland	1,035	13,438	3,209	67,078	13,498	58,057	17,742	138,573

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Sources: Holmes, Madgwick & Bates (1995), adjusted to £1998
Estimated MS prevalence Scotland 1998

Table 2. Estimated annual cost (£1998) per MS patient – indicative comparison between countries

Country	Literature source	Type of cost	Mild MS	Moderate MS	Severe MS	Average cost
USA	Stolp-Smith 1998	Health	£1723	£3312	£4550	£2420
USA	Whetten-Goldstein 1998	Health Society				£10235 £23082
USA	Harvey 1995	Society	£9218		£16514	
Canada	Auty 1998	Health Society	£1051 £7859	£793 £11742	£4668 £20036	£16556
Canada	Asche 1997	Health Society				£3982 £10621
Belgium	Carton 1998	Health Society	£305 £323	£686/ £1439 £817/ £1992	£1353 £1574	
France Germany UK	Murphy 1998	Health Society Health Society Health Society	£799 £1265 £1336 £1819 £514 £3363	£1525 £2586 £674 £1349 £591 £4348	£1148 £3726 £1682 £3741 £1940 £9417	
UK	Parkin 1998	Health	Remission £531	Relapse £2654		
UK	Blumhardt 1996	Health Society				£882 £14049
UK	Holmes 1995	Health Society	£365 £4789	£686 £14339	£4637 £19944	
UK	O'Brien 1987	Health				£753 £5192

Sources: Literature as referenced, adjusted to £1998

Table 3 Estimated annual NHS costs associated with an ideal MS Scotland by health board (1998), (£000s to nearest £1,000)

Health Board Area	Diagnosis	Rehabilitation	Other, including primary care	*Beta Interferon* (10% MS popn., 1/3 decline treatment)	Total NHS
Argyll and Clyde	236	737	70	581	1,624
Ayrshire and Arran	207	750	70	510	1,435
Borders	58	184	20	145	407
Dumfries and Galloway	81	254	30	200	565
Fife	192	602	60	474	1,328
Forth Valley	152	476	50	375	1,053
Grampian	291	906	100	714	2,011
Greater Glasgow	498	1,572	170	1,240	3,480
Highland	115	359	40	283	797
Lanarkshire	309	967	100	762	2,138
Lothian	425	1,335	140	1,052	2,952
Orkney	11	34	4	27	76
Shetland	13	40	4	32	89
Tayside	216	672	70	530	1,488
Western Isles	15	48	5	38	106
Scotland	3,000	9,000	1,000	7,000	20,000

Sources: Holmes, Madgwick & Bates (1995), adjusted to £1998
Estimated MS prevalence Scotland 1998
Standards of healthcare for people with MS (1997) - diagnosis requirements
Dr Paul Mattison, Consultant Physician, Ayrshire Central Hospital - rehabilitation requirements
Professor Ian Bone, Consultant Neurologist, Southern General Hospital - Beta Interferon requirements

6 CONCLUSION

The summary section of this document has an obvious conclusion. People with MS and their professional and lay carers have a clear understanding of the needs which arise in people with this chronic but progressive condition. In essence, a variety of inputs are necessary but these vary from individual to individual and change throughout the course of the disease. Consequently what is required is a sophisticated mechanism for co-ordinating assessments and input.

It is clear from the GP and Health Board summaries and from the publications of organisations representing people with MS that this ideal is not being achieved.

Within this context, there is a sub-debate about the role of drug therapy (particularly Beta Interferon). However, the authors of this report would argue strongly for all the needs of people with MS to be addressed in their full complexity rather than focus on a narrow debate about drug therapy.

There is an urgent need to develop properly resourced services in MS care. Services will be defined by local needs and national policies and may be best effected by the introduction of managed clinical networks. Rehabilitation teams form part of the network of care for treating patients with MS. If they feel it necessary they may wish to be part of a managed clinical network but they may also be self-standing. Service planners should address the funding issues of MS services with the knowledge that current care is substantially sub-optimal, inadequately resourced and unacceptably fragmented. Health boards should urgently develop strategies for the achievement of the good practice outlined in the MS Society's Standards document. Consideration must be given to service provision in geographically remote areas and a national strategy for MS care developed.

The available literature and methods of "costing" MS services are poor and probably reflect an underestimation. Managed clinical networks offer the opportunity to estimate more accurately what is currently being spent and what further would be required to achieve the standards and quality aimed for in this report. Networks could also identify inappropriate expenditure that could be better used though this is expected to be small.

The appendices of this document expand these key themes.

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Appendix 1

MS Society Symptom Survey

The MS Symptom Survey, despite its methodological flaws, addressed symptoms that patients with Multiple Sclerosis most commonly experienced, those causing them the greatest amount of stress, the impact upon their quality of life, and the drug treatments made available to them. In this selected group of patients:

- 85% saw their general practitioner
- 66% Neurologist
- 45% Physiotherapist or Occupational Therapist
- 15% Complementary or alternative therapist
- 13% MS or Neurology specialist nurse
- 8% specialists in rehabilitation.

The drugs most commonly prescribed were those for spasticity, depression, bladder symptoms and pain. The most active problems being:

Fatigue	86%
Balance problems	73%
Muscle weakness	69%
Bladder or bowel problems	66%
Numbness and tingling	64%
Muscle stiffness	64%
Pain	54%
Muscle spasm	51%
Symptoms diminished ability to travel freely from their home	43%
Problems attending work or education	40%
Bladder problems disruptive	40%
Impaired sleep	24%
Impaired sexual function	23%

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While not necessarily supported by other studies, the aforementioned symptoms are common to all MS sufferers at some time or another during the course of their illness. Psychological symptoms were probably under represented in the MS survey, occurring between 25% and 55% of patients, particularly in early disease (Jouvent et al 1989). **Mood changes** and cognitive impairment are also common, the latter under reported by patients (Grant et al 1984) and not necessarily related to disease course (Rao et al 1985). **Fatigue**, though the commonest symptoms of Multiple Sclerosis affecting at least 75% of patients, has typical characteristics, but as yet are not understood in terms of pathophysiology, and does not have affective specific therapy**. Bladder dysfunction** in MS is often complex being a combination of the commoner frequency/urgency problems with failure to empty, and often requires specialist assessment (Betts et al 1992). **Bowel dysfunction** occurs in up to 70% of people with MS, 40% experiencing constipation, 50% episodes of faecal incontinence (Heinds 1990). **Sexual disturbance** in male patients with MS, characterised by

erectile dysfunction and impotence is experienced at some time by up to 90% of patients, and is an ongoing problem in up to 60% of patients (Betts et al 1994). Little is known about problems of sexual dysfunction in women though postal surveys suggest as many as 50% experience some degree of sexual dysfunction as a consequence of disease. **Spasticity** is encountered in 90% of patients with MS at some time during the course of their illness. This symptom may be managed by physiotherapy, oral medications, peripheral nerve blocks, reversible invasive procedures such as using intrathecal baclofen, or non-reversible procedures. **Tremor** occurs in 30% to 40% of patients and is generally poorly responsive to drug treatment although recently and with increasing frequency, thalamic surgery (ablative or stimulatory) is considered (Speelman et al 1984). **Paroxysmal symptoms** such as abnormal movements, transient pain or even seizures occur in a small proportion of patients and are generally well managed (Thomson et al 1993). Pain occurs in 30% to 65% of patients sometime during their disease course. Indeed 50% of patients with progressive MS will suffer chronic pain (Moulin et al 1988).

Appendix 2

MANAGEMENT STRATEGIES

Introduction

Multiple Sclerosis is the most common neurological cause of disability in young adults in Scotland. Its clinical course is variable and unpredictable. The range of impairments and disabilities that may arise from the condition require input from a variety of different professionals if they are to be managed ultimately with the aim of reducing handicap within any individual trial to an individual. The aim is to restore the highest level of physical, cognitive and social function.

The Multiple Sclerosis Society's Standards of Health Care document divided Multiple Sclerosis into four phases: diagnostic, minimal impairment, moderate impairment and severe disability. But in many instances these divisions are somewhat arbitrary and can overlap to a significant degree.

Multiple Sclerosis is a lifetime illness and life expectancy following diagnosis is in excess of 35 years in the majority of cases. The patient's situation can change unpredictably and requirements in terms of input from the Health Service will change over time. It is logical to suggest that services should be organised to provide a continuous level of overall supervision for patients with this condition by appropriately skilled multi-disciplinary teams.

Diagnosis

There are still major issues with the length of time that arriving at an actual diagnosis can take. In some instances it may not be possible to reach a conclusive diagnosis even following proper examination and investigation but in the majority of cases the diagnosis can be arrived at if the patient is given access to appropriate examination and investigation.

Diagnosis should be confirmed by a Consultant Neurologist or Physician with extensive experience in dealing with neurological conditions and the diagnostic process should be completed within a reasonable space of time.

Equally important at this stage is appropriate explanation of the outcome of investigations and detailed discussion with the patient and his/her family regarding the nature of Multiple Sclerosis and current knowledge in relation to research. Emphasis should be placed on an optimistic prediction since the majority of patients with Multiple Sclerosis will not proceed to very severe disability. Opportunity should be given for patients to have any questions that they may have fully answered.

The emphasis should be placed on an on going contact with an established Multiple Sclerosis Team inbuilt into which is regular review, as well as access to professionals with appropriate skills and counselling.

Minimal Impairment Phase

All patients diagnosed with Multiple Sclerosis should have a full functional assessment including assessment of medical problems which may respond to intervention as well as assessment from physiotherapists, occupational therapists,

speech and language therapist and clinical psychologists where problems are identified within these particular areas.

Help must be readily available at times of exacerbation, e.g. contact numbers and self-referral to clinics in the event of exacerbations which may require treatment with steroids.

Regular follow up should be offered in order to review the patients situation and also for further exchange of information in allowing the patient opportunity to raise questions or issues that may have arisen.

Moderate Impairment Phase

Continued assessment from the multi-professional team is required, opportunities to access physiotherapy, occupational therapy as well as wheelchair assessment if required. Assessment of bladder function including ultrasound scan and flow studies with seamless access thereafter to special urology services if these are indicated following initial assessment. Assessment and management of sexual dysfunction should also be available and should be freely discussed with patients.

Severe Disability Phase

Ongoing physio and OT assessments should be provided with a range of aids and adaptations provided as appropriate for each patient within their own home. This does require a good working relationship with local Social Work and Community Occupational Therapy Departments. Respite care facilities should be available in an appropriate atmosphere and setting and a policy should be in place with respect to provision of terminal care in the event of this becoming required.

Organisational Issues

Since Multiple Sclerosis may affect many different aspects of the patients life it is important that there is an overall co-ordinator of a multi-disciplinary team approach. This may be a specialist in neurology who has interest in ongoing management of Multiple Sclerosis and who has access to an appropriate multi-disciplinary team or within a Neurological Rehabilitation Service with wide experience of management of patients with neurological disability.

The core team should consist of a number of different professionals all of whom have wide experience of management of the condition. Physiotherapy, occupational therapy, speech and language therapy, clinical psychology, orthotics and wheelchair assessment together with a dedicated social worker are the minimum requirements for such a team to operate flexibly.

The team should work in an inter-disciplinary way forming a relationship of trust with the patient.

Regular follow up at defined intervals should be provided as well as an emergency contact system by which a patient is referred for assessment at times of crisis. A key member of this particular service is the Multiple Sclerosis Nurse Specialist who may co-ordinate and advocate services for individual patients across the whole spectrum of the multi-disciplinary team.

Part of the remit of the team would be to identify patients who might benefit from disease modifying therapies and to set up an assessment service and operational

service within that in order to deliver new therapies where they are felt to be appropriate for the patient. Part of this service is a full explanation of the pros and cons in an objective way, so that the patient is involved in the decision making process.

Where no established framework exists eg where there is no Neurological Rehabilitation Unit, there is an opportunity for visiting Neurologists to liaise with Consultant colleagues to develop services along the managed clinical guideline network system.

Multiple Sclerosis is a multi-faceted condition. It is a life long condition during the course of which a patients needs are likely to change significantly over the passage of time. Any system which is designed to meet these needs would provide therefore a continuance of care using the multi-professional approach from Healthcare Professionals who have knowledge and experience of management of the condition.

This system needs to be flexible enough to react at times of crisis and knowledgeable enough to identify specialist needs for patients including the ability to identify the patients who may require or may benefit from other therapies.

It would seem appropriate that where services are established that they should also be involved in clinical applied research to fill many of the gaps in terms of an evidence base for intervention in Multiple Sclerosis.

Appendix 3

IMPROVING SERVICES FOR PEOPLE WITH MS

1. Recommendations derived from the surveys by the MS Society/Brunel MS Research Unit (Reports 1996 and 1998).

IMPROVING RELATIONSHIPS BETWEEN PROFESSIONALS AND PEOPLE WITH MS

- Improve understanding amongst professionals about what people with MS (and their carers) see as their major concerns and needs.
- Foster partnership between professionals and people with MS in the management of their condition. Improve communication between all services and with people with MS.
- Give people with MS as much control over their own lives as possible, with professionals applying realistic criteria of risk (e.g. in relation to the use of mobility aids).
- Minimise the extent to which general practitioners attribute extraneous signs and symptoms to MS without appropriate exploration of other possibilities.

HELPING PEOPLE WITH MS TO RETAIN CONTROL OVER THEIR LIVES

- Help people with MS (and their carers) to acquire as much technical expertise as they wish and are capable of for managing their own condition; help professionals to understand and recognise the relevance of this; and tailor service provision and other forms of support accordingly.
- Provide a range of therapies and services and other forms of support for people with MS to use as and when they wish - on a preventive as well as a therapeutic basis.
- People with MS to play the central role in assessing the effectiveness of therapies.
- Ensure that people with MS (and their carers/families) are able to access appropriate information when they need it – possibly by creating “a centralised system of information on all aspects of MS to enhance their choices and capacity to manage MS”.
- Find ways to help people with MS overcome any problems relating to body image, sexual performance and general physical fitness.
- Help people with MS in making decisions about whether to have children.

IMPROVING PUBLIC PERCEPTIONS OF PEOPLE WITH MS

- Improve public awareness of MS, with particular emphasis on the portrayal of positive aspects: what people can do rather than their disabilities.

CREATING A MORE FAVOURABLE ENVIRONMENT

- Provide a system of advocacy to help people 'cut their way' through bureaucratic problems and to provide special expertise in relation to health, social services and financial problems.

- Helping people with MS to gain relevant information to help with the difficult process of managing their financial affairs.

- Explore possible ways of "incorporating the symptomatic patterns of people with MS in a working situation to enable them to continue if they wish". Also to provide support for family members who may otherwise have to alter their career plans or give up their job to provide care.

- Quantify the extent to which environmental difficulties (eg lack of seats, kerbs, availability of wheelchairs/mobility aids, public transport) disabled toilets restrict mobility and access, and promote necessary change.

- Establish a friendship/dating agency for finding others with common interests.

- Ensure that the special needs of younger people and of minority groups such as ethnic minorities and those with different sexual orientation are identified and as far as possible met.

HELPING FAMILY CARERS

- Quantify the need for respite care for people with MS and their carers, and endeavour to meet this "in a sensitive and appropriate way".

- Ensure that people with MS and their families are able to "take time away from each other for leisure purposes".

- Support children who are involved in substantial caring activity.

2. Measured steps: extracts from proceedings of a conference jointly organised by the NHS Executive and the MS Society – 2nd September 1997.

- There is evidence of poor resource use: services not well thought through or well organised.

- Assessment of needs must take account of patients' life goals as much as physical handicaps. Meeting those needs is more a matter of building bridges to help them to go where they want than simply providing specific aids, alterations or therapies.

- Improved communication between patients and professionals and within professionals is a prerequisite to improving services and satisfying patient aspirations. (Sheila Adam)

- The only common characteristic of people with MS, is that they have the disease. Otherwise people are very different in age, background and interests. The emphasis should be more on the person than the disease.

- There must be better health service provision for the majority of people with MS – not just the minority who might be eligible for certain of the new drugs, who are often the least disabled patients.
- A service for the majority of MS patients will involve much more than neurologists and MS specialist nurses. It involves therapists, social workers and others. Therefore a scheme for a multidisciplinary approach has to be tackled productively. Duplication has to be avoided and gaps in the service filled.

- Build in training and education systems both for professionals and for lay carers.

Appendix 4

A Primary Care Perspective on MS Services

A series of semi-structured phone interviews were held with a random group of GPs representing all mainland Health Boards in Scotland: They were asked about their perception of the services available. The questioning followed the structure of the "Standards of Health Care for People with MS" document, dividing the illness into four stages:

1. The Diagnostic Phase

The MS Society document calls for a short referral time of 4 weeks before seeing a neurologist, comprehensive investigation within 4 weeks and communication of the results within a further 2 - 4 weeks, supported by written information, MS nurses, telephone helplines, expert counselling and early review appointments.

20% of the GPs were unable to access a neurologist, (or would choose not to because of the wait involved): the average wait to see a neurologist was 24 weeks (range 6 - 32 weeks).

The average wait for an MRI scan was 4 - 8 weeks, with a delay of 4 - 8 weeks before the patient was informed of the result. Some patients had their diagnosis confirmed on the basis of a L.P. which is not a totally reliable method of confirming the diagnosis.

Only 2 of the GPs were aware of MS nurses in their area, and none were aware of written information being given to patients.

2. The Minimal Impairment Phase

"Standards of Care" calls for continuity in service provision, access to support and informed advice (relating to personal relationships, employment, housing, finances, and the appropriate treatment options - including access to treatments for illness unrelated to MS).

Generally it was felt that the continuity was given by the G.P., but most felt uneasy about giving any prognostic advice, or advice about employment, finances and housing. Some gave advice on sexual dysfunction and family planning.

There was no evidence of structured care for patients, and most care and treatment seemed to be episode based, rather than proactive and structured.

The GPs interviewed had not attended any specific educational meetings or courses about MS, and some had clearly deficient knowledge about current management.

Steroid usage at times of relapse was not universally mentioned: Where it was, there was a wide variation in how it was delivered - either in a Neurology Unit, a general Medical Ward, Cottage Hospitals or in the home.

70% of GPs did not know if Interferon was available in their Health Board area, and most seemed uncertain about the most appropriate patients for its use.

3. The Moderate Disability Phase/4. The Severe Disability Stage

The MS Society calls for integrated, multidisciplinary care to reduce disability, the key issues being responsiveness of services, convenience of access and location, expertise, communication and co-ordination, and patient-centred care.

50% of GPs had access to a local multidisciplinary, consultant-led Rehabilitation Service, though not all provided a community-based service, and care was still felt to be episodic, rather than on-going.

All had access to paramedical staff –e.g. Physiotherapists, OTs, Speech Therapists, Counsellors, though waiting times and local accessibility varied significantly.

Social Work referral was considered to be straightforward and much easier than formally, though the time taken to assess clients needs was considered by some to be excessive.

Significant variations were noted in ease with which a GP might order a wheelchair for a patient, with some GPs unable to access this without a consultant signature, some obtaining a wheelchair promptly, and some experiencing a wait of over 6 months.

District Nurses provided consistently high standards of care and generally were the Healthcare Professional most in contact with the patient. Some variation in what nurses were allowed to do was noted (e.g. catheterising male patients, changing supra-pubic catheters).

Respite Care was considered to be the most deficient area of care. It was felt that most Respite Care was difficult to organise, and the setting varied greatly - from Community Hospitals, GP beds in DGHs, General Medical or Geriatric Wards, specialised places in Young Chronic Sick units to Social Work provided Respite Care in various settings, often Nursing homes. Many GPs felt that the settings were inappropriate, especially for the younger patients, and were difficult to arrange promptly, especially when the main carer was taken ill suddenly.

Several GPs noted that Respite Care often “undid” some of what the patient and the carer had achieved in term of overcoming disability, and patients were more at risk of developing infections, pressure sores and other complications during periods of Respite Care - a feeling that was a strong testament to the ability of patients and carers to manage their problems.

Urological problems are a major cause of morbidity in MS patients, and it was noticeable that few patients were seen by urologists unless they were felt to need supra-pubic catheters. This was surprising in view of the fact that several GPs felt less than confident in dealing with the urological problems presented.

Throughout the severely disabled stage of MS, the critical determinant of the type of care received (and thus the cost to the NHS) was the availability of a competent and committed relative/carer, and the need to support these carers was noted, both for the sake of the patient, and for the economic cost to the Health Service.

Several noted that the provision of extra services, such as evening “tuck-in” services were invaluable for their patients, but 2 expressed concern about the lack of availability of these services at Public Holidays.

There was agreement that moderately and severely disabled patients did not always have the optimum care for other unrelated conditions. For example, disabled patients were less likely to receive breast and cervical screening, and patients with co-existing diabetes were less likely to have structured regular reviews of their diabetes.

Conclusions

The standards of care document from the MS Society paints a picture of patients receiving prompt, supportive, structured and pro-active care from easily accessed, multi-disciplinary teams throughout their illness. It is implicit that standards of care will be equitable throughout the service.

The survey is based on 20 interviews with GPs throughout Scotland, and is therefore a small picture of the services available. The responses also reveal what GPs believe is available for their patients, rather than measuring accurately what is actually available, but if a GP is unaware of a local service, or believes it to be inadequate, then patients are unlikely to be referred.

Despite the small sample size, the survey demonstrated that there are wide variations in the accessibility and quality of care available for patients with MS.

Appendix 5

THE HEALTH BOARD PERSPECTIVE

A questionnaire was sent to Directors of Public Health in January 2000 asking for information on services and shortfalls in services in each of the phases of multiple sclerosis. Information was sought on services delivered by primary care, by secondary care (non specialist services), by secondary care specialist services and by voluntary organisations. Eight replied out of a possible 15. The replies have been summarised as key themes emerging under the different phases. Many themes were common throughout the course of the disease, and thus there is some repetition.

1. *The diagnostic phase*

The key role of the general practitioner in this phase was identified by all. Some noted that there was a variability in their knowledge of the disease which can be important in speedy referral.

Access to neurology was seen as important here, with great variation in waiting times for first consultation. This was sometimes compounded by difficulty in accessing diagnostic tests. One reported this as being severely restricted. Access in rural areas presents a particular problem.

The importance of a specialist with a knowledge of multiple sclerosis and a specialist trained nurse were seen as important, again with variation in availability.

2. *Minimal impairment*

During this phase the primary care team was seen to play an important part, but concern was expressed about appropriate knowledge and skills base.

The MS Society consistently was cited as having an important role, at this stage mainly for advice, support and communication.

Wide variations exist across Scotland in the funding of beta interferon, ranging from none at all to funding (according to clinical protocol).

Access to specialists was again highlighted here as a difficulty. Long waiting times for neurology were reported in some areas with “access restricted”. There was also variation in specialist nurse input.

3. *Moderate disability*

Access to rehabilitation services varied considerably, from none to excellent.

Access to key professionals in the professions allied to medicine was almost universally seen as insufficient, with lack of sufficient resources being highlighted. The MS Society again featured largely in this section, as in all.

The impact on carers was a factor common in all areas, with financial support and respite care being particular issues of concern.

The need for integrated access to other specialties such as urology and psychology was important and their involvement in the team variable.

Co-ordinated team working was seen as important but variable.

4. *Severe disability*

In this section the input from social services ranged from “none” to “good”, with a desire for them to be part of the team or network.

Respite care was variable and generally poor. PAMs access was again variable with a particular lack of inpatient and outpatient physiotherapy. Wheelchair access and the waiting times for them was common. Day respite care was variable, especially for the under 65s.

The community hospitals played a vital role in remote areas, with the primary care team again important.

The general organisation and provision services for younger physically disabled people was stated as an indicator of how good the services were for MS sufferers.

Voluntary centres were important (e.g. the MS Therapy Centre) but travel to the centres could be a problem.

Nursing Home places vary and there were shortages in some areas.

The use of environmental control equipment was mentioned in one area.

Outreach services to a hospital near the patients home was seen as desirable and variable. In some DGHs there was seen to be a danger of lack of co-ordination as varying physicians looked after MS patients.

Finally, the funding of the national and local MS Society from a variety of sources was seen as potentially a problem, especially as the appeared to play such an important role in routine service provision.

Appendix 6

CLINICAL APPROPRIATENESS: assessing therapeutic outcomes in multiple sclerosis *(extracts from Freeman et al (2000)[1] and other papers)*

Numerous clinical trails have been undertaken in the past decade to determine the effectiveness of a range of interventions in multiple sclerosis. These trials have usually evaluated outcome on the basis of clinical end points (for example, relapse rate) and physiological parameters (for example, lesion load on MRI). In recent years there has been a gradual broadening of the outcomes measured to include aspects of health status. The choice of outcome measure(s) is crucial to the successful design of a clinical trial. An informed decision is reliant on knowledge of the scientific (reliability, validity, and responsiveness) and clinical (feasibility, appropriateness to the study sample, respondent burden) properties of available measures.

People with MS often regard criteria which are not directly related to neurological impairment or disability as being more important to their general health status[2]. These include general well-being, social and psychological function and vitality. It follows therefore that outcome from the patient's perspective should be central to evaluation of treatment for MS. This approach would also facilitate assessment of the overall balance between the benefit derived from treatment and the harm caused by side effects and the constraints of treatment. Although these measures of outcome or 'quality of life' are largely subjective, it is preferable to have measures which are valid, reproducible and important to patients than more 'exact' measures which only partly reflect the concerns of patients[3].

The symptoms which people with MS experience vary considerably from day to day, and even from hour to hour. The condition is progressive, although the rate of decline may be gradual or intermittent. It is therefore very difficult (and expensive) to assess what benefits derive from any particular form of treatment. This means that only therapies which are likely to achieve commercial gain (ie medication) are likely to be subject to rigorous evaluation - and even then the outcome measures will be chosen by the companies and professionals concerned rather than by people with the condition.

The SF-36 is generally considered as the 'gold standard' generic measure of health status. The SF-36 was constructed to compare functional health and wellbeing across patient and general populations, and to evaluate and compare the benefits of alternative treatments. Although proved to be reliable and valid in a range of patient groups relatively few studies have investigated its use in multiple sclerosis.

Freeman and his colleagues conducted a prospective study in which 150 adults with moderate or severe disability due to multiple sclerosis completed a battery of questionnaires evaluating generic health status, disability, handicap, and emotional wellbeing. These included the SF-36, Functional Independence Measure (FIM), London Handicap scale (LHS) and General Household Questionnaire (GHS). Comparison of the SF-36 with the other three measures demonstrated internal consistency reliability and validity of the SF-36 as a measure of health status in multiple sclerosis. Floor to ceiling effects were acceptable for four of the eight SF-36 dimensions: emotional wellbeing, social function, vitality and energy, and general health perception. However there were large floor and ceiling effects in the remaining four: physical function, physical and emotional role limitation and pain. This indicates that the range of health status measured is unlikely to represent the range

experienced by this population, and demonstrates limitations in the ability of the SF-36 to discriminate between individual patients in these dimensions.

The floor and ceiling effects did not apply only to patients at the extremes of the disease severity range; moderately disabled patients also exhibited significant floor effects in three dimensions. Concerns as to the appropriateness of the SF-36 in multiple sclerosis were heightened when the population was subdivided into groups according to disease severity. This is very important as the selection criteria of most clinical trials will inevitably narrow the range of disease severity of the study sample, sometimes markedly. No floor or ceiling effects however occurred in the SF-36 mental and physical summary scales, suggesting that these scales may be more appropriate than the individual dimensions for discriminating between individual patients at a single point in time. A disadvantage of these summary scales however, is that it is impossible to know in which dimensions changes have occurred.

Forty four patients with moderate or severe disability participated in a programme of inpatient rehabilitation for an average of 20 days. Of the eight dimensions of the SF-36, only pain and physical function demonstrated a statistically significant change in scores between admission and discharge. By contrast statistically significant differences were demonstrated between scores on admission and discharge for the FIM (measuring physical function), the GHQ (measuring emotional health), and the LHS (measuring handicap). The poor responsiveness of the SF-36 may, in part, be explained by the fact that it measures broad issues of both function and wellbeing, which taken together may not give a clear effect. By contrast, the FIM, LHS and GHQ measure more specific health constructs.

Scores on the FIM, LHS, and the global rating scale of QoL span virtually the entire scale range; the mean scores were near the midpoint; and the floor and ceiling effects were minimal. This indicated that the scales were appropriate for the total study sample. When patients were subgrouped according to EDSS score the appropriateness of these instruments, while not ideal, remained satisfactory.

The clustering of scores at either end(s) of the scale, found in half of the SF-36 dimensions, suggests that the range of the scale is too limited to enable small but possibly clinically significant changes to be recorded; thereby limiting responsiveness. However, the responsiveness data in this study is restricted to patients with moderate to severe disability undergoing rehabilitation and the SF-36 has not been assessed in of the less disabled patients who are included in most multiple sclerosis trials.

The development of disease specific measures for multiple sclerosis has been undertaken either by adapting current measures (for example, the functional assessment measure or the multiple sclerosis QoL-54); by gathering together a wide range of symptom specific measures (for example, the QoL inventory); or by identifying key areas and then weighting them according to how important the patient thinks these areas are to their lifestyle (for example, the disability and impact profile). All of these measures are in the early stages of evaluation. It is suggested that trials evaluating health status in multiple sclerosis should supplement the use of the SF-36 with other relevant and scientifically sound instruments to maximise the validity of health measurement.

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Appendix 7

Information for People with MS: requirements and solutions

Research suggests that the provision of information to patients should be patient-centred and evidence based.[1] When establishing a new information network for people with MS, then, the control for the flow of information should be in the hands of the consumers, rather than the suppliers.[2]

Different people exhibit different information-seeking behaviour and much work has been done in trying to categorise it.[3] Simply, at any one time people are either information-seekers or they are not - although the amount of information and depth of detail are variable. However, information-seeking behaviour is a dynamic process, and those who were initially non-information seekers may change over time as they adjust to their diagnosis and its impact on their life and on those around them. For this reason it is important not to label people as one or the other.

Requirements

1. To put into place an information system for people with MS that is patient-centred and evidence-based.

2. Every patient diagnosed with MS should be provided with the means to access information and this should be officially documented.

3. To design a system that is flexible enough in presentation, availability and content to accommodate varying information-seeking behaviours: People who want as much information as possible should have easy access to it and those who want little or no information should not have it forced upon them.

4. The information needs of patients change over time - they require different information according to where they are in the diagnosis and subsequent illness progression. For this reason, there needs to be in place a system that allows people the freedom to get information, take time to assimilate it, then return for more as and when they need it. People typically formulate questions *after* the consultation.

5. Thought needs to be given to equality of access issues. All people in the target group must have equal access to the information in spite of differences in intellectual ability, literacy levels, language, culture, sensory capabilities, sex, age etc. These issues should be dealt with when implementing the different solutions outlined below.

6. It must accommodate people with various degrees of physical and cognitive impairment. In particular, people with MS often suffer from memory disturbance, attention deficit and an impaired ability to process information – even in the mild stages of the disease.[9] This suggests that verbal information sessions will not be sufficient in themselves and should be backed up with a hard copy (whether it is audiotapes, leaflets, videos etc).[10,11]

7. The system must be objective. At all times the people who want the information should be in control of the flow of information. At no time should their requirements be overridden. In other words, at no time should information that is asked for be withheld for fear of upsetting the patient. Similarly, information

should not be forced on people who do not want it. Studies involving people with long term or life-threatening illnesses have shown that patients prefer an honest response to their questions even though it may temporarily increase feelings of depression or anxiety.

Solutions

The plan is to look at information provision in the short term followed by long-term developments. Short-term solutions need to be implemented in order to provide immediate support for existing and newly diagnosed pwMS. However, the development of a system of information needs to be viewed as a long term and evolutionary process.

Short -term Solutions

1. **a) Supply contact details of voluntary organisations**
   As there is already a very effective support and information service provided by the various voluntary organisations (MS Therapy Centre, MS Society, MS Research Trust), to supply people with MS, their families and/or carers with a contact number for these at the outset should be prioritised. A leaflet should be produced and handed to each newly diagnosed patient; and cards with the contact details should be available in health and community sites.

   b) Supply information on health & social services
   All people with MS should be given information detailing what health and social services are available to them and how to gain access to them. (Details to be available in leaflet (a) above, and on the Internet.)

2. **Summary of key consultations**
   Offer people with MS the opportunity to have a tape-recording or printed summary of key consultations e.g. the diagnosis consultation, advice sessions with specialist nurses etc.[13, 14,15,16,17]

3. **Commission development of an MS Information Website**
   Current estimates of public access to the Internet vary from 7% to as much as 40%. With the emergence of new technologies it can be expected that within a few years, home Internet access will be the norm for the majority of the UK population. Web-based information is therefore one of the most effective and economical ways of disseminating information to a large number of people.[18, 27]

Long-term Solutions

1. **Conduct a needs assessment survey**
   Involve the consumers in the design of the system.[19, 20] The opinions of people with MS should be sought, or, if that's not possible, the opinions of their families/carers. A needs assessment survey should be conducted using a variety of methods including focus groups, questionnaires, and interviews.

2. **Further develop the MS Information Website**
   For those without home Internet access, community-based, touch-screen computers could be used using kiosk software to prevent "surfing" if required.

3. **An information consultation** [21]
   Offer all people newly diagnosed with MS an information consultation with a specialist in MS. This should be an "opt-out" consultation: i.e. patients should be offered it and given the option to refuse rather than having to motivate it themselves. A tape-recording of the consultation should be supplied if wanted.

4. **Educate primary care practitioners**
   A common complaint of people with long-term neurological conditions is that, after diagnosis, they are discharged into the care of their GP but that their GP lacks sufficient knowledge about the condition to provide a useful service. Therefore, educating those who work in primary care to have a greater understanding of MS, its impact on the patients and their families, its management and about sources of help (e.g. voluntary organisations) is a priority.[22, 23]

5. **Improve information exchange between consultants and GPs**
   An additional way of increasing knowledge amongst GPs is to improve information exchange between consultants and family doctors. In particular, consultants should be encouraged to review their discharge letters. Family doctors want information regarding the proposed treatment, expected outcomes, and psychosocial factors, yet this is often omitted.

6. **Re-educate the Information Providers**[2,24,25,26]
   Information giving tends to be haphazard in nature and is often dependent on the sentiments of the person giving the information and how they perceive the patient to be. Despite the time and resources that have been spent researching patient information needs (e.g. information-seeking behaviours, coping styles, patient's perceptions, knowledge-deficit etc.) and dissatisfaction with information etc, little is known among the providers of information about the theory behind it.

   There is a need to educate information that information provision should be patient-centred and evidence-based (i.e. the patient should be in control of the information gathering process and the information content should be targeted to satisfy the stated needs of patients not the providers' perceptions of patients' needs.)

7. **Information should be widely disseminated**
   Information should be available in a variety of places including health care settings and community sites e.g. health centres, GPs surgeries, hospital clinics and tea bars, DSS offices, libraries, shopping centres, the Internet etc.[2, 20]

8. **Information formats**
   Information should be available in as many formats as possible including written, verbal, computer-based (either specially written programs or Internet), videos, and any other media identified by consumers as being useful.[19, 20]

9. **Audit information provision**
   There needs to be a regular audit of information provision. A sample of people with MS should be tracked through the system.2, 19,20

10. Incorporate information into Integrated Care Pathways

The inclusion of information provision into ICPs is important. Research suggests that different professions within the health services give information within the confines of their professional roles. Assumptions are made about what information other professions are giving without any system in place for checking this. Therefore, the fact that a patient has been given certain key information should be documented and a record retained by the patient.

11. Produce an information directory

Each service involved in the care and support of people with MS should produce a list of approved sources of information pertaining to their particular specialty. These should be collated to form an MS information directory, and each person with MS should be given a copy. It should also be available on the Internet.

12. Electronic Patient Records (EPRs)

Supporting the development of EPRs is probably one of the most fundamental long term requirements in establishing a realistic information system for *all* patients, not just those with MS. An EPR would facilitate the sharing of patient information between *all* services.

Everyone involved in a patient's care (including the patient) could have access to their EPR and could contribute to it. The system should be designed to work for the benefit of the patients without compromising their rights to confidentiality and privacy. There is no need for everyone involved in patient care to have access to *all* the details in a patient's record.

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Appendix 8

REHABILITATION IN MULTIPLE SCLEROSIS

INTRODUCTION

The European Charcot Foundations 1998 Nice Declaration set out as a basic goal for the management of Multiple Sclerosis to be the prevention and reduction of disablement and social economic loss with full maintenance of daily life activities and social participation. This particular goal is analogous to Mairis 1972 definition of rehabilitation as being restoration of a patient to the fullest possible physical, social and economic level of function.

It follows therefore that a rehabilitation approach and its principles should underpin the management of a lifetime progressive illness, such as Multiple Sclerosis.

The evidence for the effectiveness of a multidisciplinary rehabilitation approach is however somewhat patchy and based largely upon accepted practice rather than evidence based.

The conclusion has to be that there is a pressing need for large scale extended studies of multidisciplinary team management of Multiple Sclerosis to demonstrate effectiveness of interventions and likewise to indicate current interventions which may be ineffective.

The situation presently within the United Kingdom is that there are few organised multidisciplinary teams dealing with Multiple Sclerosis patients.

Where team exist the composition is very variable. Generally within neuro-rehabilitation it would be recognised that physiotherapy, occupational therapy, speech and language therapy and clinical psychology would be core members of any such team, together with social work input and support from Bo-engineering and wheelchair services.

PRESENT EVIDENCE

There is evidence that patients as a group feel that physiotherapy intervention is helpful in improving their mobility, although this is very difficult to quantify since assessment is to a large extent dependent upon subjective rather than objective measures [1] .

There are however several small studies which demonstrate short term benefit from in-patient, multidisciplinary rehabilitation [2, 3, 4].

However there is some doubt as to whether this is sustained over any prolonged periods of time [5].

These small studies have focused upon methods of assessment which are global measure of impairment, disability or handicap.

Studies which are focused upon symptoms relief have perhaps demonstrated greater benefit. There is evidence that both physiotherapy and occupational therapy approaches can be helpful in fatigue, which is a frequent symptom in Multiple Sclerosis patients [6, 7].

Considerable caution must be adopted however in the outcome of any of these studies, since the numbers involved are very small and follow-up periods of relatively short.

Patient perception however plays a major role in outcome of any intervention in Multiple Sclerosis and there is evidence to support the view that patients who are seen within dedicated Multiple Sclerosis centres are more likely to have a comprehensive care plan formulated and delivered, as well as more likely to be considered for disease modifying treatments [8].

Because of the multifaceted symptomatology associated with the condition, many different variables may influence rehabilitation outcome. Not least of which is the cognitive state of the patients and Langdon and Thomson's recent paper concluded that the rehabilitation outcome may be determined by verbal intelligence and cerebellar function as the most potent factors in predicting the response to rehabilitation and this is an area that has long been neglected in the approach to Multiple Sclerosis management [9].

Separate from the physical rehabilitation aspects, the organisation of a multidisciplinary team approach to assessment may well lead to improved quality of life and therefore reduced handicap in MS patients. Provision of appropriate aids to daily living or housing adaptations may significantly reduce handicap and unless these are assessed within the context of patients overall function an opportunity may be missed to contribute significantly to quality of life.

Similarly appropriate investigation and management of bladder and bowel continence, utilising relatively simple bedside investigation can significantly reduce symptoms which are often distressing and embarrassing for patients [10].

Symptom management of the individual symptoms may also respond better to a collaborative approach from different professionals, for example physiotherapy and clinical psychology approach to pain in association with muscle spasm.

SUMMARY

Multiple Sclerosis is a complicated life-long disorder. The variety of symptoms associated with the condition mean that no single professional is likely to be expert in the management of all of the difficulties associated with the condition. The organisation of a comprehensive multidisciplinary approach would seem to be a logical step with multi-professional assessment and access to more specialised services, for example neurosurgery where it is appropriate to deal with specific problems or urological surgery in relation some difficulties with bladder control.

Whilst this approach may seem common sense, the evidence of its effectiveness is somewhat sparse and patchy and the requirement is for firmer evidence on which to base future practice.

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Appendix 9

The use of Beta Interferons in Multiple Sclerosis

In May of 1999 the Association of British Neurologists produced guidelines for the use of Beta Interferon in Multiple Sclerosis. They outlined the four large randomised double blind placebo controlled trials that had been conducted to date, emphasising that three of these had been performed in relapsing and remitting disease and one in secondary progressive Multiple Sclerosis. Three bands of Beta Interferon are available. Beta Interferon 1b (Beta-feron) produced in a bacterial system and differing slightly from natural human Beta Interferon and Beta Interferon 1a (Avonex and Rebif) produced in mammalian cells.

The three trials in relapsing and remitting disease were performed using Beta-interferon 1b (Betaferon) 1.6 million units and 8 million units subcutaneously on alternate days. Beta-interferon 1a (Avonex) 6 million units inter-muscularly once per week and Beta-interferon 1a (Rebif) 6 million units and 12 million units subcutaneously three times per week. In all studies patients were ambulant without assistance and had to have experienced two relapses within the preceding two years. They were also required to have a disability status score (EDSS) at entry of 5.5 in the Betaferon study, 5.5 in the Rebif study and 3.5 in the Avonex study. Each of these studies were associated with the significant reduction in the frequency and severity of relapse over a two year period and both the Rebif and Avonex studies indicated a slowing in the accumulation of neurological impairment or disability. The Betaferon and Rebif studies were associated with significantly fewer periods of hospitalisation or courses of steroids.

A single study had been carried out of Beta Interferon 1b (Betaferon) in secondary progressive Multiple Sclerosis. At entry patients were required to be able to walk 10 metres with bilateral assistance and to have shown evidence of disease progression. This study was associated with a significant reduction in relapse rate, fewer periods of hospitalisation, or necessity for courses of steroids. In the treatment group a smaller proportion of patients over the time of the study became wheelchair bound.

T2 lesion volume on MRI was measured in all four studies with only Avonex showing no significant effect on total lesion volume accumulation from base line over a two year period. Betaferon and Rebif being associated with approximately 70% reduction in the number of gadolinium enhancing lesions on T2, Avonex with a 50% reduction.

The beta interferons are associated with significant side-effects such as flu like symptoms, myalgia and fever frequently occurring during the first few weeks or months of treatment and responding symptomatically to non-steroidal anti-inflammatories. The subcutaneous preparations (Betaferon and Rebif) are associated with injection site reactions, and in rare cases skin narcrosis. The intramuscular injection of Avonex is generally well tolerated. Minor changes in white cell count and liver function have been noted and require to be monitored but have rarely been of significant severity to result in discontinuation of therapy. The long term side-effects of the interferons remain as yet unknown. They are contra-indicated in pregnancy and should not be used when breast feeding.

Neutralising antibodies to the interferons occur in a varying proportion of patients. The assay technique used varying in each of the clinical trials. It still remains uncertain as to whether the presence of neutralising antibodies has a detrimental effect upon drug response and clinical course.

On the basis of this evidence the Association of British Neurologists made the following recommendations:

1. Commencement of treatment

a. Relapsing and remitting Multiple Sclerosis

Beta Interferon should be considered in suitable patients with relapsing and remitting Multiple Sclerosis fulfilling all of the following features:

1. Able to walk at least 10 metres with or without assistance.
2. At least two relapses in the last two years, which were possible, can be confirmed by neurological examination or by an independent source.
3. The patient should be of 18 years or older, as no recommendations are possible in a paediatric age group, since trials have not been performed in this patient group. The Association of British Neurologists recommend that any of the three available Beta Interferon preparations licensed for relapsing and remitting disease could be used.

b. ***It was felt on the basis of one reported clinical trial that until further evidence came to light, whilst Beta Interferon 1b could be considered it suitable patient with secondary progressive disease fulfilling all of the following features:***

1. ***Able to walk at least 10 metres with or without assistance.***
2. ***A gradual increase in disability, sustained for a minimum of 6 months.***
3. ***Disease being active in terms of either progression or two relapses within the last 2 years.***
4. ***Adult age group, as again no recommendations are possible in patients under the age of 18 on the basis of currently available trial data. It was felt that currently only Beta Interferon could be considered in this patient group and the guidelines might well need to be adapted depending upon the results of other trials.***

2. Stopping Drug Treatment

In some patients the Interferons require to be stopped because of unacceptable side-effects, or in the context of a planned pregnancy. The decision to withdraw treatment should be made on an individual basis after full discussion and with full agreement between the patient and their neurologist. Cessation of drug treatment should be considered when there is no decrease in the frequency or severity of relapses, in relapsing and remitting disease, and when there is continuing progression in secondary progressive disease.

It was felt that treatment should be initiated by a Consultant Neurologist and that follow-up should be supervised closely by such an individual. Follow-ups should be performed three monthly for the first year and six monthly thereafter. It was felt that the availability of an MS specialist nurse was of paramount importance in acting as an information resource and giving reassurance to patients during their frequent attendance to hospital.

The Association of British Neurologists concluded by stating that there remained areas of uncertainty in relation to the use of Beta Interferons in Multiple Sclerosis in terms of:

- Long term efficacy and potential risks

- Optimum dosage
- The effect of therapy in primary progressive and more advanced Multiple Sclerosis
- The role of neutralising antibodies on clinical course
- The discrepancy between a modest treatment effect and more evident MRI improvement
- The cost effectiveness of treatment

Appendix 10
Survey Methodology and Findings
Methodology

Survey data was gathered using a fully structured questionnaire designed, developed and piloted with the full involvement of people with multiple sclerosis. **1688** people with MS completed all or part of the survey, and returned it by 10th November 1999. The questions in the survey form were based on the report 'Standards of Healthcare for People with MS'. The sample was obtained from the MS Society database of around 4000 people in Scotland, out of a UK total of 45000. The Society believes that two-thirds of these are people who have MS. People with MS who are not members of the MS Society were targeted through primary and secondary care settings using a comprehensive database of NHS services likely to be used by people with MS. The questionnaire was also available on the Society's web site.

Findings

Unless otherwise stated, all percentages are based on the total sample of 1688.

Background information

Questions 31 & 32 – Time since diagnosis and appearance of symptoms

	Q31 Time since symptoms first appeared		***Q32 Time since diagnosis***	
	No.	**%**	**No.**	**%**
More than 30 years	194	11%	86	5%
20 – 30 years	292	17%	199	12%
15 – 20 years	257	15%	200	12%
10 – 15 years	271	16%	291	17%
5 – 10 years	281	17%	353	21%
0 – 5 years	213	13%	386	23%
Not stated	180	11%	173	10%

This shows a differential between the appearance of symptoms and diagnosis, with the distribution of time since diagnosis being skewed further towards more recent dates when compared with time since symptoms appeared.

(Assumptions: 1. The present is taken as Nov 1999; 2. If respondents have given a number less than 20 in the "year" column, this is assumed to be no. of years since diagnosis, not the actual year – e.g. "10" is assumed to mean 10 years ago, not 1910: 3. "0-5" years includes up to and including 5 years ago exactly, "5-10 years" includes anything over 5 years up to 10 years exactly, and so on for the other time bands – e.g. 5 years and 6 months would be placed in "5-10 years".)

Q35 Gender

	No.	**%**
Female	1187	70%
Male	440	26%
Not stated	61	4%

Q36 Age

	No.	**%**

0-18	1	0%
18-25	15	1%
26-35	175	10%
36-45	395	23%
46-55	541	32%
56-65	312	18%
65+	207	12%
Not stated	42	2%

Q33 Type of MS

	No.	%
I have attacks which come and go	463	27%
My MS has got progressively worse	867	51%
Neither of the above	238	14%
Both*	56	3%
Not stated	64	4%

* Although respondents were not given this as an option, some chose to tick both types

Q34 Severity of MS

	No.	%
Mild	349	21%
Mild/Moderate*	19	1%
Moderate	892	53%
Moderate/Severe*	28	2%
Severe	349	21%
Not stated	51	3%

* Although respondents were not given these as options, some chose to tick two boxes

About Diagnosis

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Q1 & 2 - Investigations and Results:

	Q1 Did neurologist complete investigations into symptoms within one month?		***Q2 When investigations complete, were results given within one month?***	
	No.	**%**	**No.**	**%**
Yes	658	39%	832	49%
No	749	44%	672	40%
Unsure	188	11%	108	6%
Other/not stated	93	6%	76	5%

Q3 – Discussion of Implications:

When you received your diagnosis, did any of the staff at the clinic talk through the implications of having MS with you?		
	No.	**%**
Yes	291	17%
No	1280	76%
Unsure	53	3%
Other/not stated	64	5%

Based on the 291 who said “yes” they had talked to staff:

If YES, how helpful was this to you at the time?		
	No.	**% (n=291)**
Very Helpful	7	2%
Fairly Helpful	20	7%
Moderately Helpful	21	7%
Poor	5	2%
Very Poor	1	0%
Not applicable	0	
Not stated	237	81%

Although only a minority of those who had received advice answered this question, it seems that most of those who did had found the advice at least moderately helpful.
Although respondents were only asked for their opinion if they *had* had a discussion with staff, 111 others still replied. Of these, 65 ticked "not applicable", but 36 (of the 46 who expressed an opinion) ticked "poor" or "very poor", suggesting dissatisfaction with the *lack* of discussion.

Q4 – Provision of written information:

When you received your diagnosis, did anyone give you written information about MS to take away and read?		
	No.	**%**
Yes	197	12%
No	1403	83%
Unsure	28	2%
Other/not stated	60	4%

Based on the 197 who said "yes" they had been given written information:

If YES, how helpful was this to you at the time?		
	No.	**% (n=197)**
Very Helpful	51	26%
Fairly Helpful	66	34%
Moderately Helpful	62	31%
Poor	8	4%
Very Poor	4	2%
Not applicable	3	2%
Not stated	3	2%

In contrast to Q4, almost all those who recalled being given written information, expressed an opinion about how helpful the information had been, and the vast majority of these felt the information was at least moderately helpful.
Once again, there was a group (498) who had *not* answered "yes" to Q3, but still responded to the 2nd part of the question. 347 of these ticked "not applicable", but 130 (of the 151 who expressed an opinion) ticked "poor" or "very poor" suggesting they were disappointed with this lack of information.

Questions 5 to 10 – Support at the time of diagnosis:

The results of these questions are shown in the table below:

Key to abbreviations in the table:
Q5: *Given by neurol.*: When you received your diagnosis, was it given to you by a consultant neurologist?
Q6: *Meet neurol.*: Were you able to meet the neurologist in the month following your diagnosis to discuss any concerns or questions you had?
Q7: *Meet MS nurse*: Were you able to meet a specialist MS nurse or other support worker for further support in the first month following diagnosis?
Q8: *Clinic/team*: After your diagnosis were you put in touch with a specialist MS clinic or team?
Q9 *Support*: Do you feel that you received adequate support from the health service around the time you were diagnosed?
Q10: *Contact no.*: At the time you were diagnosed were you offered the contact number of an MS organisation?

	Q5 Given by neurol.		Q6 Meet neurol.		Q7 Meet MS nurse		Q8 Clinic/team		Q9 Support		Q10 Contact no.	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Yes	849	50 %	329	19 %	137	8%	30	2%	265	16 %	327	19 %
No	653	39 %	1123	67 %	1371	81 %	222	13 %	1162	69 %	1156	68 %
Unsure	70	4%	111	7%	34	2%	7	0%	128	8%	72	4%
N/A					33	2%						
Other/NS	116	7%	125	7%	113	7%	1429	85 %	133	8%	133	8%

Support and Information

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Q11 Have you been invited to information sessions organised for people with MS?		
	No.	**%**
Yes	930	55%
No	562	33%
Unsure	54	3%
Other/not stated	142	8%

Q12 Have you attended a local support group organised by any of the following?:		
	No.	**%**
MS Society	1005	60%
Health professional	53	3%
Other	191	11%

The data shown in the above table for Q12 represents the *total* numbers who had attended each type of support group. This breaks down as follows:

MS Society only	920 (55%)
Health professional only	23 (1%)
Other only	122 (7%)
MS Society + Health professional	18 (1%)
Health professional + other	2 (0%)
MS Society + other	57 (3%)
All 3	10 (1%)
None stated*	536 (32%)

* Does not necessarily imply that this number had *not* attended a support session.

Q13 During time since diagnosis have you been offered written booklets that explain common problems experienced by PWMS?		
	No.	**%**
Yes	1230	73%
No	373	22%
Unsure	32	2%
Other/not stated	53	3%

Based on the 1230 who said "yes" they been given booklets:

If YES, who produced these materials?		
	No.	**% (n=1230)**
MS Society	1156	94%
Health Service	111	9%
Other	137	11%

The data shown in the above table for Q13 represents the *total* numbers who said they had received booklets from each source. This breaks down as follows:

MS Society only	992 (59%)
Health service only	30 (2%)
Other only	35 (2%)
MS Society + Health service	65 (4%)
Health service + other	3 (0%)
MS Society + other	86 (5%)
All 3	13 (1%)
None stated*	6 (0%)

A further 60 people answered the second part of the question (sources of materials), despite not having responded to the first part of the question. Of these, a total of 52 ticked "MS Society"; 46 ticked "MS Society" *only*, further substantiating the view that the MS Society is by far the most important source of written booklets.

Q14 & 16 – Information about treatment/care:

	Q14 Received enough information to make decisions about whether to accept treatment/care offered in last year?	***Q2 Like more information about the range of treatments available to PWMS?***

	No.	%	No.	%
Yes	650	39%	1315	78%
No	707	42%	202	12%
Unsure	230	14%	110	7%
Other/NS	101	6%	61	4%

Q16 Need for services and ease of obtaining them

The following numbers said that they had needed to use each of the following services in the last year:

	No.	%
Physiotherapy	822	49%
Occupational Therapy	547	32%
Speech Therapy	106	6%
Dietetics	168	10%
MS Nurse	281	17%
Neurologist	537	32%
Counselling	138	8%
Continence advice	493	29%

Based on those who said they had needed to use each service, the ease of obtaining each service was rated as shown in the table overleaf:
(A number of respondents gave an opinion about availability of services despite *not* having indicated that they had needed the service in question.
The analysis of availability is based only on those who said they had needed to use each service in the last year).

	Easy		Average		Difficult		Service not available		Not stated	
	No.	%	No.	%	No.	%	No.	%	No.	%
Physiotherapy (Base: 822)	348	42 %	231	28 %	118	14 %	28	3%	97	12 %
Occ. Therapy (Base: 547)	229	42 %	163	30 %	76	14 %	7	1%	72	13 %
Speech Therapy (Base: 106)	53	50 %	20	19 %	10	9%	4	4%	19	18 %
Dietetics (Base: 168)	90	54 %	41	24 %	17	10 %	1	1%	19	11 %
MS Nurse (Base: 281)	142	51 %	52	19 %	33	12 %	17	6%	37	13 %
Neurologist (Base: 537)	162	30 %	187	35 %	110	20 %	5	1%	73	14 %
Counselling (Base: 138)	62	45 %	29	21 %	18	13 %	7	5%	22	16 %
Continence adv. (Base: 493)	217	44 %	130	26 %	47	10 %	8	2%	91	18 %

Clearly both the individual's *need* for each service, and the *availability* of the service are based on the subjective view of the respondent. but this question does give an indication of how readily services were available for the individuals in question.
Clearly it does *not* give information about the *general* availability of a service in a given area, as the question was phrased: "how easy was it <u>for you</u> to receive the services".

Q17 Have you received advice on how to manage day-to-day activities, to reduce impact on your symptoms?		
	No.	**%**
Yes	446	26%
No	1015	60%
Unsure	114	7%
Other/not stated	113	7%

Assessment

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Q18 Are you aware of having an assessment/review from any of the following in the last 12 months?:		
	No.	**%**
GP	540	32%
Other	197	12%
MS Nurse	130	8%
Neurologist	494	29%
Neurological Nurse	35	2%

The table above shows simply the *totals* who had had a review from each health care professional.

Appendix 2 gives the complete breakdown for each *combination* of professionals seen.
712 (42%) did not indicate that they had had a review from *anyone* in the last year; however, this may be just because they failed to answer the question.
285 (17%) had seen *only* a GP (for review), and a further 140 (8%) had *not* seen an MS Nurse, Neurologist, *or* Neurological nurse (These 8% had ticked either "GP + other" or "other" only; without knowing what may be included under "other" we cannot necessarily say this group had not seen an MS specialist of some kind)

Q19 If you receive an annual review from your GP, does (s)he discuss any changes in symptoms with you?

This question has been analysed in two ways:
1. The group who had said (at Q18) that "yes" they had had a review from their GP in the last year
2. The remainder (respondents were *not* instructed to answer this question *only* if they'd ticked "GP" at Q18)

Looking at the responses, it is probably more meaningful to consider group 1.
The relatively high number of "No" responses in the second group suggests that many may be answering "no" symptoms were not discussed, when in fact the reason for this was that no review had taken place.

	1. Yes to "GP" at Q18 (n=540)		***2. Did not tick Yes to "GP" at Q18 (n=1148)***	
	No.	**%**	**No.**	**%**
Yes	352	65%	89	8%
No	110	20%	423	37%
Unsure	35	6%	57	5%
Other/NS	43	8%	579	50%

Beta Interferon

Q20 Do you currently receive beta interferon?

	No.	**%**
Yes	71	4%
No	1558	92%
Unsure	8	0%
Other/not stated	51	3%

Q21 Has your consultant neurologist told you that you are suitable for beta interferon but that it is not available, for any reason?

This question appears to have caused a high degree of confusion, with a much larger number of anomalous responses (more than one box ticked) than for any other part of the questionnaire.
(see Appendix 1 for listing of these responses)

Those who answered "no" to this question, may have either (a) been assessed and told they are not suitable for beta interferon, or (b) not been assessed.

	No.	%
Yes	132*	8%
No	858	51%
Unsure	71	4%
Not applicable	372	22%
Other/not stated	255	15%

* Of the 132 who said yes, they had been positively assessed but told beta interferon was not available, 6 had actually said that they were taking the drug (Q20)

Q21 – 2nd part: If YES, have you been placed on a waiting list for beta interferon?

Based on the 126 who answered YES to Q21 *and* were not already taking the drug according to their response to Q20:

	No.	% (n=126)
Yes	21	17%
No	75	60%
Unsure	23	18%
Other/not stated	7	6%

A further 10 people said they were on a waiting list, despite the fact that they had not, to their knowledge, been assessed. (However, one of these was already taking the drug).

Thus a total of 21+9 = 30 people, (2% of the total sample) believed they were on a waiting list for beta interferon.

Q22 Whether or not you have been assessed for beta interferon, do you think you would benefit from the drug?

	No.	%
Yes	335	20%
No	322	19%
Unsure	863	51%
Not applicable	74	4%
Other/not stated	94	6%

Looking at the 335 who said "yes" they thought they would benefit:

- 27(8%) were already taking the drug
- 15(4%) believed they were on a waiting list
- 30(9%) had been assessed as suitable but *not* put on a waiting list
- 12(4%) had been assessed as suitable but were *not sure* if they were on a waiting list
- 172(51%) had either not been assessed or had been assessed but told they are unsuitable (i.e. answered NO to Q21)
- Most of the remaining 79(24%) had ticked "unsure", "not applicable" or had not answered Q21 – i.e. these may or may not have been assessed.

Respite and Other Care

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Q23 Have you ever used respite care facilities?		
	No.	**%**
Yes	290	17%
No	1343	80%
Unsure	18	1%
Other/not stated	37	2%

Based on the 290 who said "yes" they had used respite care facilities:

If YES, were the facilities available when you needed them?		
	No.	**% (n=290)**
Yes	231	80%
No	22	8%
Unsure	8	3%
Other/not stated	29	10%

Clearly, most of those who have used respite care, were able to access the facilities when they needed them. But this question does *not* tell us whether there are others who may have *needed or wanted* to use this service, but could not access it.
Although respondents were only asked for their opinion if they *had* used respite care facilities, 275 others still replied. Of these, 84 (31%) said facilities were not available, and 132 (48%) were not sure, suggesting that there may indeed be some people who are denied these services.

Q24 If you have used respite care facilities, were you directly involved in making the decision about what facilities you used?		
	No.	**% (n=290 who have used)**
Yes	187	64%
No	61	21%
Unsure	12	4%
Other/not stated	30	10%

Again, there were a group (187) of respondents who replied, despite not having used respite care, and of these 124 (66%) said they had not been involved in the decision (suggesting they are referring to lack of involvement in a decision *not* to offer them the facility)

Other Issues

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Questions 25 to 30

Key to abbreviations in the table:

Q25: *Decisions*: When decisions are made about your care, do you feel that your views are taken into account?
Q26: *Named*: Is there a named professional who you have been told is responsible for co-ordinating your treatment or care?
Q27: *Emergency*: Do you feel confident that you would be able to get access to services you use if an emergency happened because of your MS?
Q28: *Opinions*: Has your local health service asked you for your opinions to help them develop services for people with MS?
Q29: *Informed*: Has your local health service informed you about the range of services it can offer you?
Q30: *Complaints*: If you were not happy with the health services provided would you know how to make a complaint or ask for that service to be changed?

	Q25 Decisions		Q26 Named		Q27 Emergency		Q28 Opinions		Q29 Informed		Q30 Complaints	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Yes	841	50%	420	25%	739	44%	69	4%	181	11%	448	27%
No	242	14%	866	51%	356	21%	1452	86%	1295	77%	800	47%
Unsure	217	13%	165	10%	415	25%	39	2%	80	5%	285	17%
Other/NS	388	23%	237	14%	178	11%	128	8%	132	8%	155	9%